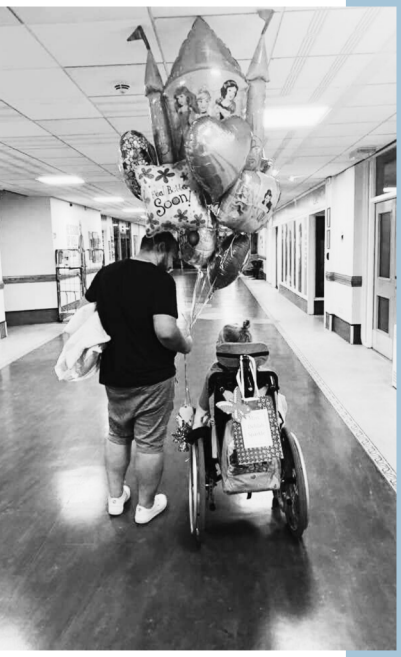
Choice
WELLBEING SERVICE

After a Diagnosis

Whether You're Waiting for Answers or Have a Diagnosis

Contents



Introduction

Your new born baby has just arrived and after months of being asked whether you had preference on gender, and your response was possibly... Any as long as it is healthy!

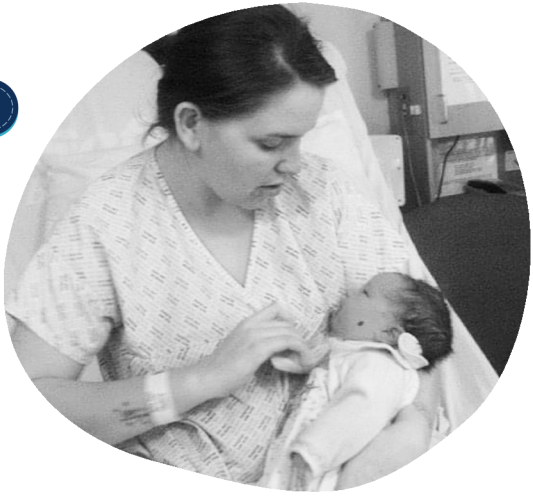
You may find yourself with a child that maybe healthy, but have additional needs. They may have already been given a diagnosis or they maybe undergoing some further investigation towards a diagnosis.

This guide was lovingly written for you by another parent carer, who I can guarantee has been exactly where you are, right now.

Because it was me, exactly 13 years ago.

Purpose of This Booklet

- Help you understand your emotions
- Understand the impact on wider family
- Look at how others can support your family



Delilah & Delilah's mam, Tracey (me)

Understanding the Rollercoaster of Emotions

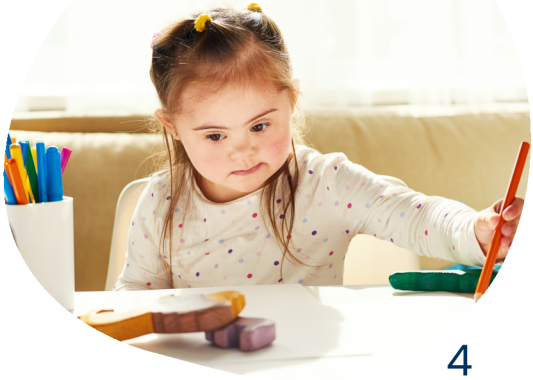
After the initial shock
- What does this diagnosis mean?
- What can I expect?
- Is it okay to feel the way I feel?
- How do I deal with it?

After your child's diagnosis, you may find yourself searching for answers, understanding, and support. This is a completely natural response.

This guide can provide essential information, practical steps, and, most importantly, reassures you that as a parent, you are not navigating this alone. If you've recently learned your child has a disability or chronic illness, you're beginning a significant and often emotional journey. This new world can feel overwhelming, filled with unfamiliar medical practitioners, therapies, and procedures. To help you find your footing, it's beneficial to learn as much as possible about the condition that makes your child - and your life - uniquely special.

Some parents don't remember anything about the appointment after the diagnosis. But there are also parents who experience relief because, after years of diagnostic searching, they finally receive an answer to their question. Some parents do not experience any of the above. They are not sad, their world is not collapsing, but they have received confirmation of something they have had an (indefinable) feeling about for a long time.

"Don't waste too much time worrying about the future, it comes soon enough."



In essence, your experience of receiving your child's diagnosis will be unique to you. However, it's reassuring to know that many helpful resources exist to support you through this period. Finding comfort in the understanding that you are not alone in this experience can be a source of strength. Therefore, we will explore the varied ways parents react and provide practical tips and advice to offer guidance based on what others have learned. Keep in mind that every child and every parent is different, so what you read here may not exactly refer to your situation.

Though it may be hard to imagine, there will come a time when the first thing you notice when you look at your child, is the amazing and unique individual, and not the diagnosis or disability. When I look at my daughter now, I see the sassy, funny, inspirational kid she is.

Not the undiagnosed bundle of complexities that her paperwork would allow you to believe.

Rollercoaster of emotions

There you are, either leaving the appointment, in the car on the way home, or sat on busy public transport with words echoing in your head. Maybe you expected it, maybe you didn't. Maybe, you never saw this day coming... Maybe you are in shock.

When that shock subsides, the big question comes. How do you deal with this, how do you get your head around it, and how do you relay this information to others?

So many emotions...

After your child's diagnosis, you might feel deeply protective and loving, wanting to hide away a little while, but also understandably angry about the situation.
You might react by trying to act as if nothing has changed, or you might feel emotionally drained, not up for speaking to others. All of these feelings are perfectly normal.

It can take time - weeks, months, or even years - to fully integrate your child's disability or chronic illness into your life. However, parents often find that the initial pain lessens over the years. You will experience good days and challenging days, but the majority will likely become ordinary, just like in any other family. It may not get any easier, just slightly different year on year.

It is very normal to have feelings of:
Confusion
Powerless
Disappointment
Rejection
Guilt
Denial

Confusion

You may not know what has happened and what is going to happen. You don't know what the specialist or paediatrician is talking about, you don't know who the people are who your child now has appointments with and you may struggle to make decisions.

Powerless

Your child now has additional needs and you cannot do anything about it, except incorporate it into your life and adjust your life moving forward. There will be elements of uncontrollable situations and that can be scary.

Grief

Parents of children with disabilities can experience a range of grief-related emotions, including sadness, anger, and disappointment, as they navigate the challenges of their child's condition and mourn the loss of the future they envisioned for their child. It can be difficult to accept the idea that it could be grief, but it is okay to not be okay, whatever that looks like for you.

Disappointment

Of course you may be disappointed. You have spent at least 9 month of your life envisioning the day you had your child. The days out, the getting ready for school, the introducing them to family... and in a single moment it could all change.

Rejection

Although you may not reject your child, others might. Individuals who maybe don't understand your child and have determined that they will leave them out of things 'just in case'. This would make it hard not to feel rejected.

Guilt

It is hard isn't it? To not feel guilty. You maybe asking yourself, is this my fault? or what if I am not capable of looking after them as well as others expect me to? What if I drop the ball? All natural normal questions and concerns to have, lot's of parent carers express similar questions and feelings.

Denial

What if they got it wrong? What if they got the wrong child? what if, what if, what if...

How do you deal with these emotions?

Everyone deals with things differently. We all find different ways to learn to cope with the changes that a diagnosis of additional needs can bring. You will attempt numerous ways to cope and adapt, it is all trial and error, but know there is no wrong or right way, just whatever way works for you and your family.

Here are some suggestions to help you begin:

Talk

Talk to friends, family, or a practitioner you trust. Seek other parents who also have children with additional needs too, this can help you process the diagnosis.

Cry

Lot's of people will feel they should suppress their emotions as being visibly upset can be a sign of weakness. Don't be afraid to show your emotion, don't be afraid to cry. However, if you are finding yourself unable to control your emotions after a long period of time, please reach out to someone for support.

Read

You probably have 100's of questions, collecting information about your child's diagnosis, and their future is a great source of comfort as long as you do it at your own pace. It will be hard to avoid googling it all, but if you are going to google, make sure you are reading the right information.

When you are done researching everything you can possibly think of, check out some podcasts by parent carers. Some offer invaluable information, some offer support, and some just simply can make you laugh.

Connecting with your partner

Keep talking to each other. Over the years it appears that many parents do not talk about their feelings. Sometimes they make themselves appear stronger than they are (especially towards each other). But if you can communicate in more difficult times like this, the greater strength you will have between you to tackle the future.

Relationships

It can be increasingly difficult to keep your relationship afloat when you have a child with a disability. Numerous parents have highlighted that sometimes it can truly 'make or break' a relationship. The key is not to forget who you were as a couple before. If you can't do date nights now, do date days. When possible carve out time during the day when they maybe at school or out with family and friends to reconnect. Ban discussions about your child's needs and focus on nonsense, just for a little while.

Connect with others

Connecting with parents of older children who share a similar diagnosis can be incredibly helpful. They can offer insights into their early experiences and how they navigated practical and emotional challenges. Consider finding a "mentor" parent to support you through difficult times. Simply talking things through or getting encouragement over coffee or a call can make a significant difference.

This support doesn't have to come from someone whose child has the exact same condition. Parents of children with different disabilities or illnesses often face similar caregiving, emotional, and practical hurdles. They can understand your experience in a way that close friends or family members might not fully grasp, as they have likely been in a similar position. Additionally, parent support groups are a valuable resource for connecting with other parents.

Check on social media for local parent carer coffee mornings or groups that you gravitate to and try them out

Ask any of your child's practitioners if they would advise any particular support group or organisation in the area

If you do go along to any take a friend or family member, they will never mind you taking a extra person for support!

Still Waiting for Answers?

Waiting for answers?

Not every child receives a diagnosis straight away. Some children wait months, some wait years, and some may never receive a diagnosis at all. That doesn't make your concerns any less valid, and it doesn't mean your child doesn't need support.

A diagnosis can help explain why something is happening, but it doesn't change what your child needs today. Your child is still your child, whether the paperwork has a label on it or not.

The waiting can be one of the hardest parts

Waiting for answers can be exhausting.
You know something isn't quite right. You see your child's struggles every single day. You know they are finding things harder than other children, yet you don't have the words to explain why. Instead, you find yourself caught in limbo.

One appointment leads to another. One test comes back normal, so another is arranged. You wait weeks for letters, months for referrals, and sometimes years for someone to join all the dots together.

Meanwhile, life carries on.
School still expects attendance.

Family still ask questions. Friends compare milestones. You are expected to continue parenting whilst quietly carrying the weight of not knowing. That uncertainty can feel incredibly lonely.

It can make you question yourself

One of the hardest parts of not having a diagnosis is that it can make you doubt your own instincts. You may wonder if you're imagining things. You may worry that other people think you're exaggerating.

You may hear comments like:
"They'll grow out of it."
"Every child develops differently."
"Let's just wait and see."

Whilst those comments are often well intentioned, they can leave you feeling unheard when every instinct you have is telling you that your child needs more support.

Trust yourself.
Nobody knows your child the way you do.

The frustration is real

It's frustrating when you know your child needs help, but every service seems to ask for a diagnosis first. I'm still not quite sure when we stopped putting the human first and started waiting for a label before offering support.

It's frustrating having to tell your child's story over and over again to different practitioners. Starting right back at conception, through pregnancy, birth, every milestone, every worry, every appointment. You relive the same story so many times that it almost stops feeling like your own. Sometimes it feels as though your dignity is left at the door of another clinic room, while your life is reduced to a timeline on somebody else's paperwork.

It's frustrating watching your child work twice as hard as everyone else, whilst you continue waiting for answers that never seem to come.

It's heartbreaking to watch your child undergo test after test, hoping this will finally be the appointment that gives you an answer. You celebrate when results come back clear because you don't want anything serious to be wrong, yet at the same time you feel disappointed because you're still no closer to understanding why your child is struggling. It can leave you feeling guilty for wanting an answer, even though all you really want is to know how best to help your child.

And perhaps most frustrating of all...

You can begin to feel like you have to prove your child is struggling enough to deserve support.
No parent should have to feel like that.

A diagnosis isn't the finish line

When you're waiting for answers, it's easy to believe that everything will somehow fall into place once somebody finally gives your child a diagnosis.

I know I certainly did.

I imagined someone would finally explain everything. That practitioners would suddenly understand my daughter, support would become easier to access, and life would somehow become less complicated.

Sometimes, that does happen.

For some families, a diagnosis provides relief. It can answer questions that have been hanging over your family for years. It can help explain why your child experiences the world differently and, in some cases, open doors to support, services and communities who truly understand.

But sometimes, a diagnosis simply gives a name to what you've already been living with.

Your child wakes up the next morning exactly the same person they were the day before. They still laugh at the same silly jokes, still have the same likes and dislikes, the same personality, the same strengths, and the same things they find difficult.

The only thing that has really changed is that someone has finally found a word to describe part of their journey.

That word doesn't define your child.

It doesn't define your family either. One thing I wish someone had told me is that a diagnosis isn't the end of the journey; in many ways, it's the beginning of a different one. There will still be appointments, forms, questions and decisions. There will still be days where you wonder if you're doing enough and days where you celebrate achievements that nobody else quite understands.

The diagnosis doesn't suddenly make everything easier.

What it can do is help other people understand what you've known all along.

And if that diagnosis never comes?

Your child is no less deserving of support, understanding or opportunities.

Whether your child has a diagnosis, is still waiting for answers, or may never receive one at all, they are still the same incredible little person you tucked into bed last night.

A diagnosis may explain part of their story.

It should never become their whole story.

From me to you...

My daughter still doesn't have a diagnosis.

For years, I thought everything would get easier once somebody finally gave us an answer.

I imagined for years there would be a moment where all the practitioners would suddenly understand, support would appear, and everything would finally make sense.

We would have a breakthrough.

What I eventually learnt was that I couldn't put our lives on hold whilst we waited for a label. I already knew what she struggled with. I already knew what she needed. I didn't need permission to start advocating for her.

Waiting for answers doesn't make you any less of a parent carer. It doesn't make your child's needs any less real. Some of the strongest advocates I know are still waiting for someone to tell them why.

So if you're still waiting, please don't think you have to wait before asking for help. Your child is worthy of support today—not just after a diagnosis.

Are you a parent carer?

Am I a parent carer?

I mean, technically, yes.

The internet defines a parent carers as:

"A parent carer is an adult who provides care for a disabled child for whom they have parental responsibility, encompassing practical or emotional support, and is entitled to a Parent Carer's Needs Assessment under the Children and Families Act 2014."

Whether or not you define yourself as a parent carer, that is your choice.

A large amount of individuals who have children with additional needs struggle with the concept of being defined by the care of their child and see themselves as simply 'just' parenting.

As I said previously, it is your choice how you define yourself. Theres is equally no shame in accepting yourself as a parent carer or not.

As a carer, one of your most significant responsibilities will be that of Advocate. You will act as your child's voice, being present to ensure that all relevant parties are informed when their needs change or are not being fulfilled. This is often the time when individuals begin to accept the carer title, as it goes beyond the role of being a parent.

Charmolypi (Greek)

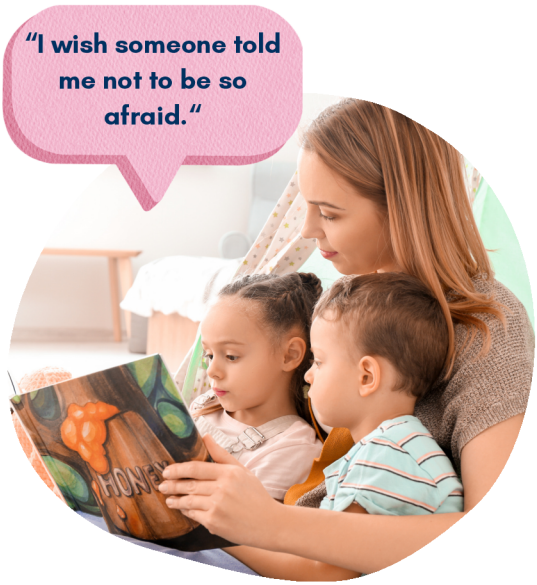
Charmolypi (*khar-moh-LUE- pee*) represents a state where joy and sadness coexist and are not simply mixed, but rather integrated. It's a feeling that cannot exist without both sorrow and joy, with each emotion giving rise to the other. I feel this sums up being a parent carer, and accepting the title of carer. It's the beauty of being a parent with the tough job of being a carer.

Telling Family & Friends

Your first reaction to the diagnosis will likely be sadness. However, those close to you often share similar emotions: sorrow, fear, confusion, and disappointment, and may even feel more anxious than you at times. Therefore, sharing the news with family and friends and guiding them through this process can be difficult. You might encounter unexpected reactions from your parents, siblings, or close friends, such as reluctance to provide childcare due to their own fears.

While this can be upsetting, it's a dynamic that can arise in any family. These reactions can be part of your loved ones' own process of coming to terms with the news, potentially involving denial and anger. The most constructive approach is to clearly explain your child's condition and your plans for their care. For example, you could say, "He might reach milestones at a different rate and may face certain challenges, but our love for him is unwavering, and we will raise him with the same care and expectations as our other children.

Share photos of your child just as you would with any other child. Let your photos and interactions show your pride and joy in your child. This will help shape the perceptions and behaviours of those around you.
If you are initially struggling to come to terms with your child's limitations, be honest about it. Explain that you are still processing these emotions. Regardless, be clear about how you would like others to interact with your child and your family.



Looking After Yourself

Single Parenting After a Diagnosis

Being told your child has additional needs can feel overwhelming for any parent. If you are navigating this journey as a single parent, it can sometimes feel as though the weight of the world has landed on your shoulders.

You may be the one attending every appointment, making every decision, remembering every medication, completing every form, comforting your child after difficult days, and somehow still trying to keep the household running.

That can feel incredibly lonely.
The truth is, you were never meant to carry everything by yourself.

Being a single parent doesn't mean you have to do everything alone. It simply means you may need to build your own support network, even if it looks different to someone else's.

Allow yourself some time

Everyone copes differently with a child's diagnosis. Some may find comfort in crying, while others may laugh, talk, or pray.

It's important to remember that there is no single "right" way to process these emotions. Your partner, for example, might react in a completely different way than you do. It's crucial to be patient with yourself and allow time to find coping strategies that work best for you. Accepting that this process takes time, sometimes years, is essential.

Once your child's development or appearance differs from the norm, you may find yourself in the position of having to interact with strangers who may ask intrusive questions. Even seemingly simple inquiries like "What's wrong with your child?" can be upsetting on certain days. You might also encounter more insensitive remarks such as, "Well, it could be worse," or "You were given the child you can manage."

It's helpful to remember that while people often intend well, they may lack understanding of your specific experience. They may not grasp that while things could be different, you are currently navigating a reality that you wish were better.

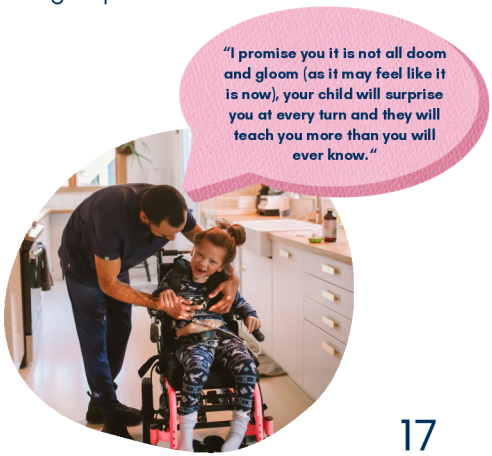
They may not know your own uncertainties about coping, and they may not realise the urge you sometimes feel to withdraw from such interactions.

How you respond to the question "What does your child have?" is entirely your prerogative. It depends on the moment, your available time, and your willingness to share. You are not obligated to answer every question and have the right to politely decline and move on.

It's understandable that you may be deeply affected by how people respond to you or your child. However, many reactions to significant challenges stem from a lack of awareness or apprehension towards the unfamiliar.

Many individuals are unsure how to interact with a child who has a visible or audible disability or uses visible aids, and their nervousness can sometimes lead to awkward or insensitive remarks. While you cannot control how others react, you can decide how you respond to their glances or questions.

Try not to dwell on those who struggle to react in the ways you might hope. As your child's parent, your energy is best focused elsewhere. Regardless of how you choose to respond in any given situation, remember that you are **not** obligated to educate everyone about your child's condition. Their diagnosis is simply one aspect of who they are, much like their eye or hair colour. It does not define their entire being or potential.



Be as active as you can

Engaging in physical activity offers significant benefits for mental well-being. When you move your body, it triggers the release of endorphins, natural mood boosters that can alleviate feelings of stress, anxiety, and even symptoms of depression. Regular exercise can also improve sleep quality, reduce mental fatigue, and enhance focus and cognitive function, contributing to a greater sense of calm and overall mental resilience. Being active doesn't mean instantly signing up to a gym membership or taking up running, it can be going for a stroll with your music on, walking to the shops instead of taking the car, and making time for you.

Parent carers looking after themselves is crucial as it enables them to maintain the physical and emotional stamina needed to provide high-quality care, benefiting both themselves and the person they care for.

Take a rest when you can

Rest isn't just about sleep; it encompasses various forms of recovery for your mind and body, including quiet reflection, engaging in relaxing hobbies, and simply taking breaks from mental and physical exertion. Can't sleep on a night? That's okay, but don't be tempted to pick up your phone! Instead, lay down and watch a series you enjoy that is feel good, or journal your thoughts.

Remember to eat

Amidst busy appointments and demanding responsibilities, it's crucial to remember to nourish your body with regular meals. Taking the time to eat isn't just about physical sustenance; it provides essential fuel for your brain, impacting concentration, mood, and overall energy levels. Prioritising eating, even if your grabbing another supermarket sandwich, packet of crisps and a bit of fruit. It is important to remember to eat, once you begin to miss meals, it will begin impact your caring role.

Burnout Doesn't Happen Overnight

Burnout doesn't happen overnight

Burnout isn't something that suddenly appears one morning. It usually creeps in so slowly that you don't even realise it's happening.

As parent carers, we're very good at putting one foot in front of the other. We tell ourselves we'll rest after the next appointment, after the next assessment, after the next school meeting, after the next hospital stay.

Except there is always a next one.

Days become weeks. Weeks become months. Before long, years have passed and you've spent so much time surviving that you've forgotten what it feels like not to be running on empty.

The difficult thing about burnout is that it doesn't always look like falling apart. Sometimes it looks like becoming numb. Sometimes it looks like forgetting simple things, losing your patience more easily, struggling to make decisions or finding yourself irritated by things that would never usually bother you.

Sometimes it looks like cancelling plans because you're simply too exhausted to explain your child's needs to someone else again. Sometimes it looks like sitting in your car after an appointment for ten minutes because you don't have the energy to drive home just yet.

Burnout isn't a sign that you're failing.

More often than not, it's a sign that you've been carrying too much, for too long, with too little support.

As parent carers, we often wear burnout like a badge of honour. We tell ourselves that we're just tired, that everyone is busy, and that we'll be okay once life settles down.

The truth is, for many parent carers, life doesn't settle down.

The appointments continue. The paperwork continues. The advocating continues. The worrying continues.

Which is exactly why looking after yourself can't always wait until things get easier. Sometimes, looking after yourself is what helps you get through the difficult bits.

You don't need a weekend away or a luxury spa day to begin looking after yourself. Sometimes it's accepting help when it's offered. Sometimes it's eating lunch before three o'clock. Sometimes it's sitting in the garden with a cup of tea for ten minutes before going back inside.

Those small moments aren't selfish. They're maintenance.

Just like your phone needs charging to keep working, so do you. You are one of the most important people in your child's life.

Looking after yourself isn't taking anything away from them.
It's helping make sure you can continue being there for them tomorrow, next week, and years from now.

Signs you might be burning out

You may be experiencing burnout if you are:

- *Constantly exhausted, even after sleeping.*
- *Feeling emotionally numb or detached.*
- *Forgetting things more often.*
- *Becoming easily overwhelmed by small tasks.*
- *Feeling guilty whenever you take time for yourself.*
- *Running on autopilot most days.*
- *Thinking, "I can't keep doing this," but carrying on anyway.*

Professional Support

If you find yourself deeply troubled by the diagnosis or struggling to manage daily tasks like work or caring for your family, it may indicate a need for more than just support from loved ones. It's important to remember that practitioner help is available. At the back of this guide you will find local organisations that can help and support you and your family.

Whole family Impact

Your child's diagnosis affects everyone at home. As parents, you'll need to find a new balance as a couple. If you have other children, the whole family will adjust. Thankfully, most families find a good rhythm again in time.

You understandably want to fully support your child's development and might feel the urge to give everything. However, focusing all your energy on one person can leave little for others, including you. Try and create a loving and supportive home where everyone, including yourself, gets the attention and care they need. Difficult to remember and do at times, but you only need to get it right 50% of the time.

How do you get through it together?

If you and your partner have different reactions to the diagnosis, it can cause tension. If one is more emotional and the other more practical, give each other space and keep communicating your feelings and your desire to talk.

It's also important to accept each other's way of processing the news. Avoid getting upset if your partner cries or researches extensively. Work together to decide how to best care for your child and family. Be clear about what you expect from each other and continue to enjoy activities together, even without the children. This will help you become a strong team.

How do you explain it to your other children?

Whether you are bringing a new baby home, or returning home with your child, your other children might sense that something is different and may be worried to learn that their new sibling has a disability or need. How do you talk to them about this?
While every parent will find their own way, here are a few tips that might be useful:

Be honest
Be clear
Toddlers
School-aged children
Siblings

Be honest

Answer your children's questions as simple and honest as possible. Don't know the answer? Then just say that. Children pick up everything that happens around them, so shielding them is not always a good idea. If you do not explain why you are sad, children will become more concerned, think they have done something wrong or think something terrible is going to happen.

Be clear

Don't know where to start explaining? Then keep the following set-up:

1. A "this is it" statement: "Your brother's kidneys are not working so well and that is why I feel sad and worried."

2. Explanation of what is going to happen: "She is not sick, but she does need help to learn things and that is why we go to the doctor so often."

Toddlers

Children's ages influence how they react to a sibling with a disability or illness. Toddlers, whose world revolves around themselves, might be more interested in their toys. As a parent, you'll often know when to leave your toddler and will need to explain things simply.

School-aged children

Children who are older can react differently, depending on the your children, especially if they are older, they can become very protective of their sibling. They may want to be more hands on, help without being asked, and watch over them.

Siblings

The more normal you can deal with the
situation, the less traumatic it can be for them. It is understandable that you cannot always be cheerful, you are only human. And you certainly don't have to pretend. Just try the best you can and help your children to live the most pleasant life they can.

Supporting Your Whole Family

Undivided attention

Give your children your undivided attention. If you's often walk the dog together before, do that still. Did you often have them tell you about their day after school? Keep up that time together. It is vital for you and your other children to continue to have that time together.

Be flexible

Balance the need of your child with additional needs, with your other children. Engage in as many activities as you can together, even if those activities are therapies, i.e, swimming, physio, or reading etc.

Let them help

Involve your other children with the care of your child with additional needs. This will support your children's empathy and bond they will have growing up.

Involve other adults

Where you can, ask family to support you, whether it's taking the other children out when you have appointments etc.

"Be realistic. Try to accept life as it is. Recognise that there are a number of things that you can change and some things that you cannot change. The trick is to learn which things you can change and then only do something about these things. You can let go of the rest."

When trauma becomes part of everyday life

As parents, we never expect to become familiar with hospital wards, medical equipment, emergency appointments or difficult conversations about our children's future.

Yet for many parent carers, these experiences become part of everyday life. The repeated hospital admissions. Watching painful procedures. Holding your child whilst they are frightened. Waiting for test results. Receiving unexpected phone calls. Watching your child struggle. Having to make decisions no parent ever imagined making.

One difficult event is hard enough. But when these experiences happen over and over again, they can begin to affect us too.

It's okay if appointments affect you

People often assume that because you've been doing this for years, you've somehow become used to it. That the appointments no longer bother you, the hospital corridors don't make your stomach turn, and hearing words like MRI, biopsy or surgery have somehow become easier to hear.

The truth is, they often don't.
You simply become incredibly good at carrying it.

You know which entrance to use because it's quicker with a wheelchair. You know which café does the best coffee after a long appointment. You know which bag to pack, where the toilets are, and exactly how long it takes to walk from one department to another. You know how to distract your child during blood tests, how to smile when they're frightened, and how to hold yourself together until you're back in the car.

To the outside world, it can look like you've got used to it.

In reality, you've just learnt how to function whilst carrying an incredibly heavy load.

That doesn't mean it hurts any less to watch your child go through another procedure. It doesn't mean you stop worrying whilst waiting for results, or that you no longer hold your breath every time the phone rings from an unfamiliar number.

You've simply become experienced at surviving situations that no parent ever imagined would become part of everyday life.

If you still feel anxious before appointments, if hospitals make your heart race, or if certain memories unexpectedly come flooding back, please know there is nothing wrong with you. Your brain is responding to experiences that have been stressful, frightening and emotionally exhausting.

You are not overreacting.

You are responding like any parent would after walking beside their child through some of the hardest moments of their life.

Give yourself permission to acknowledge it

As parent carers, we become very good at putting ourselves to one side. After all, it's our child going through the tests, the procedures, the operations, the appointments and the endless poking and prodding.

Compared to what they are facing, it can feel wrong to even acknowledge how it has affected us.

I spent years telling myself exactly that.
"It's not happening to me."
"I'm not the one having the blood test."
"I'm not the one having the surgery."
But the truth is, we are there too.

We're the ones holding their hand whilst they cry. We're the ones trying to stay calm when we're anything but. We're the ones sleeping in uncomfortable hospital chairs, making impossible decisions, remembering every medication, every appointment and every conversation. We become the safe place our children need, often whilst quietly carrying our own fear in the background.

People often see the child receiving the treatment, but they don't always see the parent living every single moment alongside them.

Watching someone you love suffer can leave its own mark.

It can change the way you think. It can change how your body responds. You may notice your heart racing every time the hospital number flashes up on your phone, or find yourself feeling anxious before an appointment you've attended dozens of times before. You might replay conversations with consultants over and over again, wondering if you asked the right questions or missed something important.

None of that makes you weak.

It makes you human.

Acknowledging that these experiences have affected you doesn't take anything away from your child's journey. It doesn't make you selfish, and it certainly doesn't mean you're making it about yourself. It simply recognises something that often gets forgotten.

You were there too.

If you find yourself constantly on edge, struggling to switch off, avoiding certain places, feeling emotionally numb or overwhelmed, or simply feeling like you've been surviving rather than living for a long time, please don't ignore it.

Speak to someone you trust. Talk to your GP.

Reach out to an organisation that understands parent carers.

You deserve support too.

Because the healthier you are, both physically and emotionally, the better placed you'll be to keep doing the one thing you've done all along...

Standing beside your child.

Moving Forward

After the diagnosis, life will largely carry on. Your child will still need your attention, love, and care, and may require more support than other children their age. You will learn the best ways to provide this care over time, with guidance from doctors, support teams, and therapists.

Your child is more than their diagnosis

Treat your child as normally as you can. They could experience the same emotions as other children their age. Be careful not to only focus on their medical condition; they are a unique individual with their own personality, talents, and interests.

Playing is learning

Interact with your child as normally as possible. Encourage them to move, play, and explore. Play with them as you would with any other child. Everyday activities like brushing teeth, washing dishes-bubble play, cooking-trying new foods if able, or walking the dog can also be fun learning opportunities.

Enjoy your child

The fact that your child is different from other children does not make your child less special. Your child is a unique individual, so enjoy the love you share for each other as well as spending quality time together.

"At first playing with my child was difficult, I didn't quite know how much they were taking in. Turns out way more than i thought!
It definitely got easier, they are still kid's"

How to work with Practitioners

At times, it might feel like there are many practitioners involved in your child's care, which can be overwhelming initially. You might even feel out of control, but remember that you are central to your child's well-being. Ensure you are happy with what's happening and have the information you need to care for your child at home.
Communication between practitioners can sometimes be unclear. When working with a team, it's vital that everyone knows their role and communicates clearly about how to support you and your child.

Try to:

Keeping control
Clear communication
Educate yourself
Help on hand
Let them guide you
Don't forget to raise your child
Learn the terminology
Don't feel intimidated

Keeping control

You may begin to feel you have lost control over your child's care, and that everyone all of a sudden has a say in their care. This will happen periodically throughout their lives, but you still have control over their care. You are their parent and entitled to a say in how your child is supported.

Clear communication

Ask for clear communication when talking with different practitioners. Each practitioner will be used to speaking their own jargon to one another using acronyms. Never feel like you can't ask what they mean, and if they can consider their language they use in their letters to you. This will make communication between you better and transparent.

Acronyms

Make sure when they are talking in acronyms you ask what they mean if you don't know. Practitioners aren't always aware they are doing it!

Educate yourself

To be well-prepared for consultations, proactively gather as much information as possible regarding your child's disability or condition. Understand the challenges they may encounter and the rights they are entitled to.

Help on hand

Nowadays it is no longer the case that doctors and therapists just decide everything for you and your child. practitioners and parents work together as much as possible.

Let them guide you

Ask practitioners for clear instructions on how to support your child's development. Even if they aren't natural coaches, this knowledge will help you feel more in control and confident in managing your child's care. Knowing how to stimulate and address your child's needs will mean you won't need to rely on others as often and will strengthen your connection with your child.

Have you been told ***NOT*** to google yet?

Yea, we were told not to, too. However, I didn't listen. This is my child, and I needed to know what was going on, and I learnt a lot I wanted to know, and much more that I didn't from Google.

We advise that you ***always*** try to speak to a healthcare practitioner first as they will want to answer any questions you may have around your child's diagnosis. However, if you are going to search for answers, please consider using only reputable sites. Sites with research, a .org title and are well known, are the ones most likely to have the most reliable information.

Don’t forget to raise your child!

If you're a parent of a child with a disorder or chronic illness, you might find yourself doing too much and expecting too little. Instead, actively work towards making your child as independent as possible.

From an early age, avoid over-protecting them; It's natural to feel very protective of a child with a disability or chronic illness. Despite this, actively encourage your child to be as independent as possible. Let them make mistakes and learn from them.

Learn the terminology

If someone uses a word that you don’t understand, stop the conversation for a moment and ask that person to explain it. Especially in conversations with doctors you can, may and must do this. Above all, don’t feel “stupid” because practitioners are often hard to understand for everyone

Don’t feel intimidated

It's natural for parents to sometimes feel insecure around doctors and therapists because of their qualifications and practitioner style. But you don't need to feel intimidated by their knowledge. practitioners want you to leave feeling good and with clear answers, and you are ultimately your child's expert.

“Remember diagnosis is just a word -it doesn't define who they are. Their personality and character do that”

Help from Family and Friends

This section is for family and friends to read.

Many close friends might feel awkward asking about your child's development or illness and may not know how to help. If you notice a friend struggling to connect or offer support, consider sharing this with them.

For those supporting a family with a child needing extra care, the best approach is: don't be afraid to ask about the child's disability or illness. Be open about wanting to learn more. Stay informed about the child's progress with the parents. Remember their time for fun is likely less.

Avoid comparing your children to the child with a disability or illness. Offer emotional and practical support when possible, and make a habit of regular "hello" calls.

How you can help:

Emotional support

Listening is important. Be available, take the time and listen actively (so ask open questions, reflect and summarise) and be attentive.

Practical Support

You can offer reliable support, even if you feel a bit like a 'loose end' at times. The help you could offer could be:

- Picking up bits from the shop
- Offer to watch their other children if they have them when they have to go to appointments
- Just 'be there' to step in, in an emergency for the other children
- Visit or call at a certain time every week, just to chat through their day or week
- Encourage them out for a walk at a local beauty spot
- Offer to walk the dog

Every family needs a different kind of help depending on the situation. If you don't know what the parents need from you, just ask them.

“One friend in particular really helped me go back out into the world. It became to easy to shield myself, and them, from others. She came and told me we were going out, didn’t ask, just picked me up and said we were going out. I’ll never forget it.”

Empathy

Parents don’t want sympathy! What they want is empathy and it takes quite some effort from you to understand how they feel and what they go through. Therefore try to “walk in the parents’ or the child’s shoes” for a while.

Don’t deny the disability or illness

Saying things like "Don't worry, it's nothing" or "He'll grow out of it" can really hurt parents. Even if you mean well, you're minimising the seriousness of the diagnosis they've just received. Even "Everything can be fixed these days" can feel dismissive. It's also possible that you yourself are finding it hard to accept the seriousness, and that's okay. First, try to deal with your own feelings. Or connect with others who understand, like other family members or friends of families with a child who has a disability or chronic illness.

Criticise parents choices

Because parents often face the unknown with their child's disability or illness, practitioner advice is very important to them. They might also consider new or alternative treatments. As a family member or friend, it's crucial to support the advice and efforts of practitioners the parents trust, even if you disagree. Your acceptance and support are necessary and valuable for these families.

Express fears out loud

After a diagnosis, a common and overwhelming fear is what the future holds. Parents often worry about their child's life at different ages and what will happen if the parents are no longer there. They also question their child's ability to learn, go to school, experience love and happiness, and achieve their dreams. The uncertainty of the diagnosis itself can also be a major fear. This fear can be paralyzing. So, it's important not to add to these worries. Listen to their fears, say you understand, but don't join in with predicting or talking about the worst possible outcomes.

Finally

Raising a child with a chronic illness or disability brings stress, sadness, and fatigue, but parents also experience happiness and fulfillment. Friends and relatives should understand this reality and offer support through continued communication, practical help, and consistent love and friendship.

Be yourself

You don't suddenly have to act differently because your friends' or family's child has a disorder or chronic illness. If you're the friend who makes jokes, don't suddenly become overly serious. If you're the caring type, don't suddenly become tough. Find your own way to help the parents. Instead of thinking "How should I act?", think "How do I want to act?"

Show how you feel

Real love and friendship mean sharing happiness and feeling pain alongside each other. Showing your true emotions about the diagnosis or their child's struggles can deeply touch and strengthen the parents. While you shouldn't burden them with your sorrow or expect them to comfort you, you also don't need to hold back your tears. Letting your emotions show demonstrates that you understand some of what they're going through and that you have a lot of sympathy.

Say something

Parents of children with additional needs can become so stressed that they push themselves too hard without realising it.

As a friend or family member, you can often see this from the outside. Remember that their situation might be much tougher than they say. If you notice they're doing too much, are exhausted, or rarely smile, talk to them about getting extra help, whether that's more babysitting or speaking with a GP.

What not to do

Don't avoid the subject - You don't have to avoid the subject of the child and their additional needs, but sometimes, parents don't always want to talk about either. Ask them what they want to talk about instead.

Don't forget the invite - Parent carers with children with need are less likely to take up invites to nights out, meals etc. Still invite them, the invite sometimes can be all they need.

Don't avoid them - don't not invite them to your children's parties or events. Just because their child may not be able to join in, it can hurt a lot more to see their child excluded.

Be yourself

You don't suddenly have to act differently because your friends' or family's child has a disorder or chronic illness. If you're the friend who makes jokes, don't suddenly become overly serious. If you're the caring type, don't suddenly become tough. Find your own way to help the parents. Instead of thinking "How should I act?", think "How do I want to act?"

Imagine...

Imagine if it was you, what would you want or need. That is always a good place to start... you can only offer as much as you can and anything is better than nothing.

To you, from others like you

We had a post natal diagnosis of Down Syndrome. My son was born via emergency c-section and I didn't get to see him for 10 hours or so, not one nurse or dr asked if I wanted to go see my baby. I saw him for 5 minutes before he was whisked to a hospital 70 miles away. I wasn't sure if he'd survive the night and I hadn't even got to hold him! Open heart surgery at 21 weeks old, a pacemaker at 22 weeks old. A teratoma tumour removed at 12 months.

If I could go back 7 years I would tell myself that being a mum is tough, being a mum of a child who is classed as disabled with additional needs is tough but it will be ok. Watching your son being wheeled away for numerous surgeries is tough, no feeling like it but it will be ok. People's perception of your son will change the way you think, you'll be the advocate for your son, his voice in the world but it will be ok. He will reach his milestones just like a typical child but in his own time and that is ok. Everything will be ok even on your darkest days.

Another parent carer

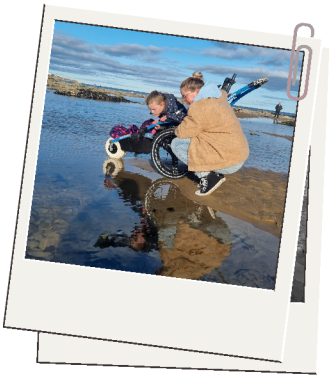
I could think long and hard about what I would say to myself back then, but I don't think I would really do it justice.
What I can say is for all that it feels so incredibly difficult now, it won't always feel this way.
I don't think I ever felt an experience like that day ever since...
I suppose, in a way... that is a good thing.
That nothing ever got any worse, I mean tiring, yes. Complicated? yes. Frustrating at times? yes. But nothing close to do the day it felt our world had been blown up. And I suppose that, is all I can ask for. Better days are ahead.

Another parent carer

We had a similar experience when my boy was diagnosed. My usual script back then if anyone asked how things were was, "we're okay. Taking a day at a time."

So what would I say to myself?
I'd say, "Tell everyone that you're not okay. Be angry, be upset, throw things and let it all out. Don't feel ashamed to be grieving for the baby you thought you were having. Your boy will be your biggest joy, but also your biggest heartbreak. Being angry and sad doesn't make you a bad mum, it makes you human."

Another parent carer



To you, from others just like you

My mental health has suffered for various reasons over the years, but the diagnosis of my son proved to be the biggest challenge I've ever faced. To try and process and adapt to this new way of life with no support in sight, news that although not life threatening, was life changing.

I always compare being a parent carer to receiving a cancer diagnosis. When you are diagnosed with cancer you are given a treatment plan, it's explained to you, there are people to help with finances if you cannot work, macmillan nurses will visit your home to make adaptions and there are people to talk to if you need mental health and wellbeing support.

As a parent carer, you are given the diagnosis (which is not even always face to face) and then you are sent off on your merry way. That little brown piece of paper you receive containing the diagnosis might also have a couple of support links on which are often defunct or outdated. You have to navigate the SEND world, a totally alien planet, to find the right support and advice, all while processing how you and your child's world has been completely and utterly turned upside down.

George was (and is!) my entire world, this gorgeous human being who was struggling and post diagnosis I felt no more able to support him and his needs than I did before.

One of the biggest challenges for me was feeling comfortable enough to talk to those around me, ask for help when I needed it and understand that it's okay not to be okay. Sometimes admitting you're struggling and need help, feels like admitting you're failing your child. How can a mother possibly not know what their child needs?

That brown bit of paper in the post, also contained so many abbreviations and terms - ASD, GDD, SPD, Pica, SALT, OT. It sent my mind into a tailspin. What did all of them mean? What did I need to do next?

Now, looking back on that moment, I felt like an absolute failure. I had no idea how to help my child and I was completely lost, stranded on a desert island madly waving my arms for help and watching ships pass by.

It all seems wrong to me now, that when your child receives a diagnosis, there is no one there to guide or support you, to help you to understand that this world is not always as scary as you think. So I set out to learn everything I possibly could to help my child.

I built up my own knowledge, researching and learning everything I could to build the best future as possible for my child. But when you're struggling to process your child's differences, you might not be coping well and might not have the capacity for that.

The biggest lesson I've learnt post diagnosis is: trust your gut when it comes to your child, learn as much as you can about the systems around you and empower yourself as much as you can.

This wonderful, terrifying, exhausting, beautiful, fun, difficult roller coaster of a SEND journey that I never asked to get on, yet I'm riding that ride anyway! Sometimes I'm closing her eyes and gripping bar white knuckled and sometimes I'm laughing and loving every second of it.

Another parent carer

I wrote this a couple of days ago on the 'I met my younger self' trend my son has Mowat Wilson syndrome diagnosed at 6 after genetic testing.

I met my younger self for coffee, well a cup of tea actually, neither of us like coffee. She smiles but looks sad, I ask her if everything is ok. She says she's fine just a bit worried, her little boy is about to turn 2. He has a heart condition and has had surgery but she thinks there's something else wrong. He's so delayed compared to her friend's children he isn't walking or talking yet and she just knows something isn't right.

She tells me how tired she is he wakes up frequently and her day starts really, really early, she feels like she is only just holding it all together with work and caring for him. She's so scared of the future and worried no one will love or accept her son or want to include him in things. He is so difficult around people he doesn't know, he is ill often and it feels like he cries constantly. She is obsessively searching the internet for clues of what might be wrong.

I tell her to try to be kind to herself and spend time getting to know her son for who he is not who she thinks he should be.

I tell her he is perfect the way he is and not to worry in time he will grow to love all the people in his life and they will love him too and he will become known as one of the happiest most beautiful souls most people know.

I tell her the years will go too quickly and one day he will be about to be 18 and she would give anything to have him nearly 2 and be able to do it all over again, even the hard bits.

I tell her she is stronger than she thinks, that she is so lucky to have the most amazing husband, family and friends and that even though there will be more tough times to come their love and support will help her through.

I also tell her that she will find the answers to her questions and when she does it will open up a whole other support network of other families with children like hers.

We both have a little cry and say goodbye. I tell her it'll all be okay and she's going to have so many good times with her son but she will always be tired and feel like she's only just holding it all together!!!

I would tell myself 'don't feel guilty in loving yourself, everyone needs a bit a love. So after a long day of appointments, meltdowns, lashing outs being a human punch bag and just hanging on enough to get through to the end of the day, it's OK to sit in the 'crap cupboard' under the stairs drinking gin from a tin and eating a well deserved freddo while the kids are finally asleep. Don't ever feel guilty.

Before You Close This Guide...

If you've made it this far, I want to say thank you.
Not for reading my guide, but for giving yourself the time to stop for a little while. If you're anything like I was, you've probably spent weeks, months, or maybe even years, focusing on everyone else. Your child. Your family. The appointments. The phone calls. The paperwork. The endless list of things that suddenly became your new normal.

I know how easy it is to lose yourself in all of that.

It might not feel like it today. You may still be overwhelmed, exhausted, or wondering what the future holds. I know that feeling, because I've been there too.

When Delilah's journey began, I thought I was waiting for someone to fix everything. Instead, we learnt, we adapted, and slowly, without even noticing, this became our normal.

Not because it became easy, but because we continued to overcome things we never thought we would have to.

If there is one thing I hope you take away from this guide, it's that your child is so much more than a diagnosis, a report or a list of needs. They are still the same little person you loved before any practitioner wrote a label on a piece of paper.

There will be difficult days, but there will also be incredible ones. There will be laughter, achievements that nobody else quite understands, and moments that remind you just how amazing your child really is.

So don't forget to make memories alongside the appointments. Read the stories, take the photos, celebrate the little wins, and enjoy your child.

From one parent carer to another, thank you for letting me be part of your journey.

You are not alone.

With love,
Tracey Huggins

Parent Carer first. Everything else came afterwards.

Support in the Community

Within your local community there is most likely a multitude of support on hand, most of which can be found on your local offer website. This support can be in the form of support groups, therapeutic care, groups for children where you can also meet other parents, and lot's of choice for you and your family to explore.

This guide was brought to you by Choice Wellbeing Service, a parent carer specific mental health and wellbeing organisation.

Choice WELLBEING SERVICE

RAINBOW Guide
One Stop Guide to SEND Support By Parent Carers for Parent Carers

To use the QR codes above, open your camera and hover over the codes until a link appears. Follow the link by clicking on it.

Written by Tracey Huggins
Founder of Choice Wellbeing Service and parent carer.

Your Child, Your Choice

Because one size doesn't fit all

Find our website here: