Choice
WELLBEING SERVICE

Caring for Youself

A Parent Carer's Guide to Wellbeing, Support and Self-Care

Practical Support for Parent Carers Navigating the SEND Journey

Looking After You

Being a parent carer is incredibly demanding, and prioritising self-care is essential for both your well-being and your ability to provide effective care.

Here's a breakdown of how as a parent carer, you can look after yourself:

Acknowledge Your Needs:

- Recognise your limits: Understand that you can't pour from an empty cup. It's not selfish to prioritise your own needs.
- Identify your stressors: Pay attention to what triggers stress and anxiety, and find ways to mitigate them.

Prioritise Physical Health:

- Sleep: Aim for adequate sleep, even if it's in short bursts.
- Nutrition: Eat healthy, balanced meals, even when time is limited.
- Exercise: Incorporate physical activity into your routine, even if it's just a short walk.
- Medical Check-ups: Don't neglect your own health. Schedule regular medical appointments.

GP Carers Register

If your GP's surgery has a carers register, you could ask to be added. If your GP knows you're a carer, they can keep an eye on your health with you.

Mental Health & Well-being

Seek Support:

- Connect with other parent carers through support groups or online communities.
- Talk to a therapist or counsellor to process your emotions.
- Lean on trusted friends and family members.

Practice Relaxation Techniques:

- Try mindfulness, meditation, or deep breathing exercises.
- Engage in activities you enjoy, such as reading, listening to music, or taking a bath.

"Me Time":

- Schedule regular breaks, even if they're short.
- Pursue hobbies and interests that bring you joy.

Set Boundaries:

- Learn to say "no" to requests that overwhelm you.
- Delegate tasks when possible.

Seek Practical Support

Short Break Care:

- Explore short break care options to give yourself a break from caregiving responsibilities.

Ask for Help:

- Don't hesitate to ask for help from family, friends, or community resources.
- Accept offers of assistance with household chores, errands, or childcare.

Parent Carer Burnout: When Surviving Becomes the Goal

Being a parent carer is often described as a marathon, not a sprint. However, when you are navigating appointments, therapies, paperwork, sleepless nights, caring responsibilities, and everyday family life, it can sometimes feel like you're running a marathon every single day.

Many parent carers become so focused on meeting everyone else's needs that they stop noticing their own. What starts as tiredness can gradually become exhaustion. What starts as stress can become burnout.

Burnout is not a sign that you are failing. In fact, it often happens because you have been coping for too long, with too little support.

What does parent carer burnout look like?

Burnout can affect everyone differently, but common signs include:

- Feeling physically and emotionally exhausted most of the time.
- Struggling to enjoy things you once enjoyed.
- Feeling irritable, overwhelmed, or tearful.
- Becoming forgetful or finding it difficult to concentrate.
- Feeling numb or disconnected from others.
- Resenting tasks you previously managed.
- Withdrawing from friends, family, or support networks.
- Feeling like you are simply surviving rather than living.

Some parent carers describe burnout as feeling like they are constantly running on empty, whilst others say they feel like they have nothing left to give.

Why does burnout happen?

Parent carers often juggle multiple roles every day. You may be a parent, advocate, nurse, therapist, chauffeur, administrator, teacher, and care coordinator all at once.

Unlike many jobs, caring responsibilities do not always stop at the end of the day. There are no guaranteed breaks, weekends, or annual leave. Over time, this constant demand can take a toll on both your physical and emotional wellbeing.

What can help?

Acknowledge how you are feeling
Many parent carers minimise their own struggles because someone else always seems to have it harder. Your feelings matter too.
Recognising that you are struggling is not weakness—it's self-awareness.

Accept support
If help is available, try to accept it. Whether it's a short break, a friend collecting prescriptions, a family member helping with meals, or someone listening over a cuppa, support is there to be used.

Lower the bar
Not every meal has to be homemade. Not every email needs answering immediately. Not every task needs to be completed today.
Sometimes "good enough" really is good enough.

Connect with others
Speaking to people who understand can reduce feelings of isolation and remind you that you are not alone in your experiences.

Speak to your GP
If you are feeling persistently low, overwhelmed, anxious, or exhausted, please seek professional support. Looking after your own health is an important part of looking after your family.

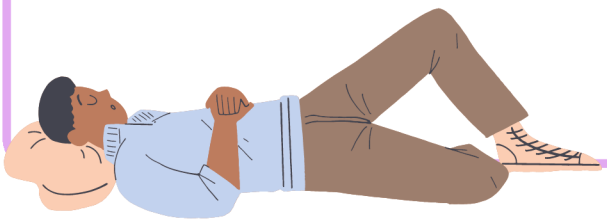
Remember
You do not have to earn rest.

You do not have to reach breaking point before asking for help.

You do not have to carry everything alone.

Looking after yourself is not taking away from your child. It is helping ensure that you can continue to care for them in a sustainable way.

Sometimes the bravest thing a parent carer can do is admit that they need support too.



Your Right to a Carer's Assessment

When caring for a child with additional needs, it can often feel as though all the focus is on your child's needs. However, parent carers have needs too, and you have the right to ask for support in your own role as a carer.

A Carer's Assessment is an opportunity to talk about how caring affects your day-to-day life and what support may help you continue caring whilst maintaining your own wellbeing. Importantly, a Carer's Assessment is about you, not whether you are a good parent or whether your child needs support.

What is a Carer's Assessment?

A Carer's Assessment is carried out by your local authority and looks at how your caring responsibilities affect different areas of your life, including:

- Your physical health
- Your mental wellbeing
- Employment, education, or training
- Relationships and family life
- Social activities and hobbies
- Your ability to take breaks and rest
- Future plans and aspirations

The assessment helps identify what support may be available to help you in your caring role.

Who Can Request One?

Any parent carer who provides regular care for a child with additional needs can request a Carer's Assessment.
You do not need to be receiving benefits and your child does not need to have a diagnosis for you to ask for an assessment.

What Support Could Be Available?

Every family's situation is different, but a Carer's Assessment may help identify support such as:

- Information and advice
- Emotional support services
- Parent carer support groups
- Short break opportunities
- Training and learning opportunities
- Equipment and adaptations
- Support with accessing community activities
- Help to maintain your own health and wellbeing

Not all assessments result in funded support, but they can still be valuable in identifying your needs and ensuring they are recognised.

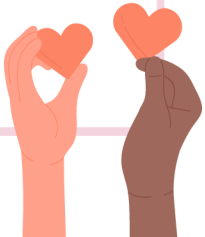
Preparing for Your Assessment

Before your assessment, it can be helpful to think about:

- What does a typical week look like?
- What caring tasks do you undertake?
- How does caring affect your health?
- When was the last time you had a proper break?
- What would make the biggest difference to your family's daily life?

Many parent carers are so used to coping that they find it difficult to talk about their own struggles. Try to be honest about the challenges you face, even if they have become your "normal."

Remember, You matter too.



How do I speak to my friends and family about my child?

Sharing your child's disability or diagnosis with friends and family is a deeply personal decision, and how you approach it can significantly impact your support system and you. Start by considering who in your circle is most supportive and understanding, and begin with them. Be honest and straightforward, but tailor the information to their level of understanding.

Provide clear, honest information about the diagnosis, focusing on your child's strengths and needs. Be prepared to answer questions, address misconceptions, and offer resources for further learning. Emphasise that your child is still the same person they've always been, and that your family's love and support remain essential.

Talking to family about your child's disability or diagnosis can be a delicate process, demanding patience and understanding. It's important to recognise that everyone processes information differently, and some family members may need time to adjust.

What if communication breaks down and you don't get the response you expected?

Their response is often influenced by their own understanding, experiences and worries. While this can be upsetting, it does not mean you have done anything wrong.

Finding a Support Network

Parent carer support groups are vital lifelines for those navigating the unique challenges of raising a child with disabilities or complex needs. These groups provide a crucial space for shared understanding and emotional support, where parents can connect with others who truly understand their experiences.

They can offer a sense of community, reducing feelings of isolation and validating the often overwhelming emotions that accompany caregiving. Beyond emotional support, these groups offer practical advice, information on available resources, and advocacy opportunities, empowering parents to navigate the complex systems and challenges they face.

Ultimately, parent carer support groups foster resilience and provide a sense of belonging, reminding parents that they are not alone in their journey.

So how do you find the right group for you?

Think about your needs. Would you like:

- Emotional support or practical support?
- Practitioner run or Parent led?
- National Organisation or Local ones?
- Face to face or Online?

No matter what you need, remember, **you are not alone**. There is likely someone out there just like you, looking for the same safe space.

How do I know what information about my child's diagnosis is reliable?

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, even 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 the suggestions below.

General search engines such as Google are also popular when searching for information on the internet, and it is ok to use them as long as you bear the following in mind.

Is it a reputable site?
Assess the information they are sharing, is it backed up by evidence.

Analyse the Website:
Is the design well done and professional looking?

Be aware of potential bias:
Be aware of your own biases and avoid seeking out information that only confirms your existing beliefs.

Trusted Sources:

- National Autistic Society
- Cerebra
- Contact
- Scope
- NHS
- GOV.UK

Moving & Handling

Safe moving and handling for parent carers

As a parent carer if you are in any doubt of how to move and handle your child safely, discuss your issues with your child's Physiotherapist or Occupational Therapist.

They will be able to discuss what techniques and equipment that may help you move and handle your child more safely. If you do not have access to a Physiotherapist or Occupational Therapist, then speak with your GP or your child's Paediatrician.

Good moving and handling is all centred on using safer positions for your body to move, if you get this right this helps the muscles work more efficiently and enables them to be less tired.

Before considering lifting or handling your child, ensure that you get everything ready beforehand. This includes the chairs, or equipment that you maybe placing your child in or on. Make sure there is enough room to lift and that you can bend your knees without hurting yourself or your child.

When you have to hold a smaller child, you should avoid placing them on one hip. This will cause strain on one side of the back causing issues that can be lifelong.

Use the appropriate equipment to help support both you and your child. Good support for your child is as equally as important looking after yourself during the process.

Most importantly, if they are too heavy... **DO NOT lift them!**

1

Keep your child close to you when you are lifting, or hoisting them, this means that they are safer and it encourages your body to be in a better position.

2

Adopt a Step Standing position, with slightly bent knees, this position helps if you are rolling your child on the bed for personal care.

3

Maintain an upright (natural standing position) posture, try to avoid over bending, overreaching or twisting when lifting or moving your child.
Think about how long you hold a bending posture for, for example when fastening them into supportive seating, try not to maintain a static bending position for more than about 20 seconds, as this tires the muscles in your back more quickly.

4

Get a good hold of your child, try to avoid gripping under the armpits to lift them out of their seating systems or bed use your hands in a curved CARING position and your arms to lift them. The saying is PAWS not CLAWS. Use the Hoist when you can.

5

Communication, talk to your child and tell them what you are doing and encourage them to help you and join in when possible.

Advocating for You and Your Child

To effectively advocate for a child with SEND, understand your child's rights, build a supportive network, engage with schools and practitioners, document everything, and consider getting involved in your local parent carer forum.
If you have questions that need to be answered in a legal manner reach out to your local SENDIASS or specialist solicitors like Irwin Mitchell for support.

If all of that sounds a bit too much, let's be honest... that's a bit much for anyone!

Then let's start here with our top tips:

Step 1: Understand your child's needs

There is no one who is more of an expert in your child, than you. So believe it! You are the expert by experience already and will continue to be that throughout their lives. Those that work with your child are considered practitioners, as they are practising a skillset, i.e. practicing medicine, etc.

Step 2: Create a support network

Use your support network to keep you going. Whether it's other parent carers in coffee mornings, local support groups, or social media groups online, reach out when you feel you are struggling to keep up. However - please remember, not all the information on social media is correct. Unless they have experience in whichever role in SEND, take it with a pinch of salt and seek further confirmation.

Step 3: Building Bridges with clear communication

We understand working with practitioners can be difficult, especially when nothing seems to be going right, but bridges are sometimes better built than burning. By maintaining good relationships with practitioners, communication, and problem solving, can be tackled head on and together. Clearly articulate your child's needs and concerns to teachers, practitioners, and decision-makers. Try and maintain a positive, collaborative approach, even when disagreements come. Be honest and open to talking things through, and listening to their points of view too.

Step 4: Keep a timeline

Keeping a timeline from day 1 is a good diary or guide to have. You are most likely going to be asked on multiple occasions about your child's birth etc. Keeping a timeline, plus any letters in one place can help you answer questions effectively. Keep copies of your child's medical reports, school assessments, and communication with practitioners. When making calls with practitioners, ask for an email address that you can send confirmation emails of discussions to. This will help you keep a 'paper trail' of communications incase you ever need to refer back to it. Regularly check their progress and make sure their needs are being met.

Step 5: Don't Give up

Advocating for a child with SEND can be challenging, so stay persistent and don't give up when faced with obstacles. Remember that the goal is to ensure your child receives the support they need to thrive. Acknowledge and celebrate your child's achievements and progress,
but also your own.

Read more on the Disabled Children's Partnership here:

Emergency Planning: What Happens If You're Not There?

It's a thought many parent carers have at some point, but one that can feel difficult to talk about:

What would happen if I became ill, had an accident, or was suddenly unable to care for my child?
For many parent carers, they are the person who knows everything. They know medication routines, communication methods, sensory triggers, likes and dislikes, appointments, support needs, and all the little details that help their child feel safe and understood.
Whilst it can feel uncomfortable to think about, having an emergency plan in place can provide reassurance for both you and your family.

Why is Emergency Planning Important?

Emergencies can happen unexpectedly.

Having a plan can:

- Reduce stress during a crisis.
- Ensure your child receives consistent care.
- Help professionals and family members understand your child's needs.
- Prevent important information being forgotten.
- Give you peace of mind.

Planning ahead isn't expecting something bad to happen—it's simply being prepared, just in case.

What Information Should You Record?

Consider creating an emergency information folder containing:

Essential Information

- Your child's full name and date of birth.
- NHS number (if known).
- GP details.
- Hospital consultants and specialist teams.
- Emergency contact details.

Medical Information

- Diagnoses and health conditions.
- Current medications and dosages.
- Allergies.
- Equipment used.
- Feeding requirements.
- Mobility needs.

Communication and Behaviour Support

Include information about:

- How your child communicates.
- Things they enjoy.
- Things they dislike.
- Sensory needs.
- Strategies that help if they become anxious or distressed.
- Any behaviours that others should be aware of.

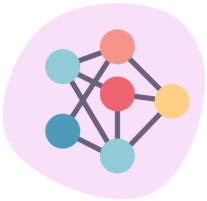
Daily Routines

Children often feel safest when routines remain consistent.
You may wish to include:

- Morning and bedtime routines.
- Food preferences.
- Personal care requirements.
- School arrangements.
- Activities they enjoy.

Identify Your Emergency Support Network

Think about who could help in an emergency.
This might include:



- Family members.
- Friends.
- Neighbours.
- Other parent carers.
- Paid carers or support workers.

Speak to those people in advance where possible so they understand what support may be needed.

Keep Information Up to Date

Review your emergency plan regularly, particularly if:

- Medications change.
- Support needs change.
- Contact details change.
- Your child starts using new equipment or services.

A plan is only helpful if the information is current.

Remember

Many parent carers carry the responsibility for their child's care every day. Having an emergency plan is not pessimistic or negative—it is simply another way of caring for your child.
Preparing for the unexpected is just as important as preparing for meetings etc. Hopefully, you'll never need to use your emergency plan. But if you do, you'll be glad it's there.

What is Short Breaks?

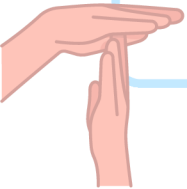
Short break care for parent carers is essentially a planned break from the intense and often round-the-clock responsibilities of looking after a child with disabilities or complex needs. It allows parent carers to take time for themselves, recharge, and attend to their own well-being.

Purpose of short break Care:

- Prevent Burnout: Caregiving is demanding, and short break care helps prevent physical and emotional exhaustion.
- Maintain Well-being: It allows parent carers to focus on their own health, relationships, and personal needs.
- Reduce Stress: Taking a break can significantly reduce stress levels and improve overall quality of life.
- Maintain Family Balance: short break care can help maintain a healthy balance within the family, allowing other family members to also have their needs met.
- Prevent Crisis: By providing regular breaks, short break care can help prevent crises that may arise from caregiver burnout.

Types of short break Care:

- In-Home short break: A caregiver comes to the family's home to provide care for the child.
- Out-of-Home short break: The child stays in a short break care facility, with a host family, or attends a day program.
- Planned short break: Regularly scheduled breaks to provide consistent support.
- Overnight short break: Care provided overnight, allowing parent carers to get a full night's sleep.



Accessing short break Care:

- Local Authorities: Social services departments within local councils are often responsible for assessing and providing short break care.
- Charities and Non-Profit Organisations: Many charities and organisations offer short break care services for families with children with disabilities.
- Private short break Care Providers: There are private agencies that provide short break care services.

Who is entitled to Direct Payments?

- A parent carer of a child with SEN and disabilities
- A young person with SEN and disabilities aged 16 to 17 years old (up to age 25 where an EHC Plan is in place)
- A young carer aged 16 - 17
- A person nominated in writing by the child's parent or the young person to receive Direct Payments on their behalf

What is a Personal Budget?

A Personal Budget may help you to find alternative solutions that you may feel supports your child/young person better. This can be by purchasing existing services or by developing new and imaginative ways of using the money.

Instead of a family being provided with a service, a budget is identified and work takes place to plan how this can best be used to meet the child or family's needs. A parent/carer of a child, young person or adult up to 25 years old with an EHC plan can request a personal budget.

There are 4 ways that a personal budget can be delivered:

- Managed Budget - where the local authority, school or college holds your Personal Budget and buys the support identified in the assessment;
- Direct Payment - Money is paid directly to the young person/family and they pay for their agreed support where this funding has been identified in the plan
- Third party arrangement - A third party organisation, trust or nominated person holds the money and pays for agreed services on behalf of the young person
- A combination of the above

Personal budgets are optional and parents and carers or the child or young person can continue to have services provided in the current way.

You can find more information here:

Helpful Organisations and Resources

Being a parent carer can sometimes feel like navigating a maze. Thankfully, there are organisations dedicated to supporting families of children and young people with additional needs. Whether you're looking for information, emotional support, financial advice, or practical guidance, these organisations can help.

Parent Carer Support

Contact
A national charity supporting families with disabled children. They provide information, advice, listening support, and resources on education, benefits, and family life.

Scope
Offers practical advice, disability information, emotional support, and online communities for disabled people and their families.

Family Fund
Provides grants to families raising disabled or seriously ill children and young people. Grants may help with household items, technology, family breaks, and equipment.

Carers UK
Offers information, advice, and support for unpaid carers, including guidance on benefits, employment rights, and looking after your own wellbeing.

Organising yourself and them

Organising and storing your child's appointments, letters and documents is crucial for efficient management of their care, and let's be honest, your sanity!

Storing documents you could consider:

- Binders
- Folders & expanding files
- Filing cabinets
- Plastic storage boxes
- Lever arch files
- Scanning onto a PC
- Cloud Storage
- Secure folders on hard drives

Once storage is selected, you could consider:

- Categorise by theme, i.e hospital letters, therapy, etc
- Chronological order
- Label everything
- Regular review and purge!

Appointment Planning

Before the appointment: think about questions you want to ask, write them down alongside any points you may have that you want to discuss.

During the Appointment

Don't hesitate to ask questions, make notes, clarify any instructions, and be honest and open. This will build better relationships.

After the Appointment

Review your notes, follow up on anything you were expected to do, organise your information, and document any changes to medications etc.

Your Child, Your Choice

Because one size doesn't fit all

Find our website here: