

AUTISM MUM SUPPORT

Who Is Looking After Mum?

When so much of your energy goes into supporting someone else, your needs matter too.

Being the mum of an autistic child can contain enormous love, pride, humour, connection and a deep understanding of a child who experiences the world in their own way. It can also involve a level of responsibility that other people rarely see. You may be thinking about communication, sensory needs, food, sleep, school, appointments, transitions, safety, siblings, work, finances and the emotional temperature of the whole household - often all at once.

This resource is deliberately about **you**. It is not another list of things you should be doing better for your child. Autism is not a parenting failure, and an autistic child is not a problem to be fixed. The pressure often comes from trying to meet genuine needs inside systems, environments and expectations that are not designed around your family.

The work nobody sees

A great deal of caring happens before anything visible occurs. You may scan a room before your child enters it, remember which clothes are tolerable, anticipate a change in routine, prepare explanations for relatives, check menus, rehearse an appointment, email school, chase referrals and notice the first signs that your child is becoming overloaded. This constant anticipating can become so normal that you stop recognising it as work.

There can also be an emotional role: staying regulated when somebody else is distressed, absorbing criticism, making difficult decisions and being the person who continues to advocate when you are already exhausted. A mum can look capable from the outside while internally running on almost nothing.

When your nervous system never really stands down

Some mums describe feeling permanently 'on'. Even during quieter moments, part of the mind may still be listening for movement, worrying about tomorrow or mentally working through the next problem. Long periods of high demand can affect sleep, concentration, patience, memory and the ability to make decisions. You may become tearful, irritable, numb, forgetful or unusually sensitive to noise and interruption.

These signs do not automatically mean that you are doing something wrong. They can be useful information that the demands around you have become greater than the recovery available to you. Support should not begin only when somebody reaches crisis.

WHEN MUM IS RUNNING ON EMPTY

Signs worth noticing

You might notice...	What may be underneath it
Feeling irritated by tiny things	Overload, interrupted recovery, too many demands
Crying once everyone is settled	Holding emotion in throughout the day
Forgetting appointments or simple tasks	Cognitive load and exhaustion
Avoiding messages or calls	No capacity left for another demand
Feeling guilty whenever you rest	A belief that caring means always being available
Feeling invisible	Attention repeatedly centred on the child's needs rather than yours

Guilt can make support harder to accept

Guilt often appears in contradictory forms: guilt for working, guilt for not working, guilt for needing time alone, guilt about siblings, guilt about losing patience, guilt about enjoying something without your child, or guilt because another family appears to be coping differently. Comparison rarely shows the whole picture. Two autistic children can have very different needs, and two families can have completely different resources, finances, support networks and pressures.

Rest is not something that has to be earned by reaching complete exhaustion. Neither does looking after yourself mean withdrawing love or support from your child. Sustainable caring requires some space for the carer to remain a person.

A five-minute check-in

- 1. What am I carrying today?** Name the practical and emotional load without minimising it.
- 2. What is urgent, and what only feels urgent?** Not every problem needs solving tonight.
- 3. What can be shared?** Think specifically: a school email, an appointment, shopping, a sibling activity, paperwork or simply somebody listening.
- 4. What does my body need?** Food, water, medication, quiet, movement, warmth, sleep or five minutes without conversation can matter.
- 5. Who knows how I am really doing?** If the answer is nobody, that is useful information rather than a criticism.

Small support still counts. A realistic support plan may be ten quiet minutes in the car, somebody else making one phone call, cancelling a non-essential commitment, using headphones, asking for information in writing, or telling somebody: 'I don't need you to solve this; I need you to hear me.'

SUPPORTING MUM, NOT JUST THE SYSTEM

Advocacy fatigue

Repeatedly explaining your child's needs can be exhausting, particularly when you feel you must prove difficulties before support is considered. Keep important information together where possible: key reports, useful wording, names, dates and copies of correspondence. After meetings, a short written summary of what was agreed can reduce the burden of remembering everything later. Where appropriate, take another person with you so you are not simultaneously listening, processing, remembering and advocating.

You are also allowed to say that a meeting time is unsuitable, ask for an agenda, request written information, ask for clarification or take time before agreeing to something. Needing information presented accessibly is not being difficult.

When Mum is neurodivergent too

Some mothers recognise their own autism, ADHD or other neurodivergence while supporting their child. That can bring relief, grief, recognition and practical complications all at once. The same environments that overload your child may overload you. Executive-function demands, telephone calls, forms, unpredictable appointments, noise and rapid changes can be difficult for both of you. Supporting the family may therefore mean reducing demands and creating predictability for more than one person.

Your needs do not become less important because your child's needs are more visible. A household can contain several nervous systems with different needs; support works better when this is acknowledged rather than expecting one person to absorb everything.

Build a support map

Draw three circles. In the first, write the people who can offer **practical help**. In the second, those who can offer **emotional support without judgement**. In the third, write **professional or community support**. Do not worry if the circles are small. The purpose is to see what exists and where the gaps are.

Then choose one gap. Instead of the broad question 'How do I get more support?', make the next step concrete: 'Who could collect one afternoon?', 'Who can sit with me while I complete this form?', 'Can I ask the school for one named contact?', or 'Where can I speak to another parent who understands?'

When you need more than self-care

A bath, a cup of tea or a walk can be pleasant, but they cannot repair an unsustainable caring load on their own. Sometimes the answer is practical change: respite, reasonable adjustments, financial or carers advice, school support, help from family, peer support, counselling or a review of how responsibilities are shared. If your wellbeing is deteriorating, speak with your GP or another appropriate health professional. If you or someone else is in immediate danger, use emergency services.

A PAGE FOR YOU

What I wish somebody would notice

Finish these sentences privately, or use them to begin a conversation:

The part people do not see is...

I am tired of having to explain...

Something I am proud of myself for is...

The thing I most need help with this week is...

I feel most like myself when...

One thing I can stop carrying alone is...

Permission slips

I am allowed to be tired.

I am allowed to enjoy time away from caring.

I am allowed to have needs that have nothing to do with parenting.

I am allowed to ask people to be specific when they offer help.

I am allowed to change a plan that is not working.

I am allowed to love my child deeply and still find parts of caring extremely hard.

I am allowed to want support before I reach breaking point.

UK places to start

NHS: Your GP can be a starting point if your own physical or emotional wellbeing is being affected. NHS information also signposts support for autistic people and families.

Your local authority: Unpaid carers may be able to request a carer's assessment to look at the impact caring has on their wellbeing and what support may help.

National Autistic Society: Provides autism information and resources for families and carers. Local services and peer groups vary by area.

Carers UK: Provides information for unpaid carers about rights, assessments, work, benefits and practical support.

Contact: Offers information and support for families with disabled children, including benefits, education and family life.

Services, eligibility and availability can change. Check the organisation or local authority directly for current information.

Message from Maggie

So much attention can naturally go towards the child - what they need, what happened at school, the next appointment, the next form, the next difficult day. Mum can slowly disappear behind all of that. I want this page to bring you back into the picture. You matter as a whole person, not simply because other people rely on you. You do not have to wait until you cannot carry any more before your needs count. Sometimes support begins with one person finally asking the question: **who is looking after you?**

Space to Breathe Therapy

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