

# AUTISM MUM SUPPORT

## Losing Yourself in the Caring Role

**When so much of life is organised around caring that it becomes difficult to remember where Mum ends and you begin.**

Caring for an autistic child can involve far more than the visible parts of parenting. You may be the person who remembers appointments, notices sensory overload, manages school communication, plans food, anticipates transitions, researches support, protects routines, explains needs to relatives and keeps track of everybody else's emotional temperature. Over time, your own preferences can become the easiest thing to postpone.

Losing yourself does not necessarily happen dramatically. It can happen in hundreds of small exchanges: choosing the restaurant everybody else can manage, declining another invitation because planning feels impossible, putting your appointment off, abandoning a hobby, changing work, wearing whatever is quickest, or realising that almost every conversation you have is about your child.

## Loving your child and missing yourself can coexist

Some mums feel guilty even admitting that they miss parts of their old life. Missing spontaneity, work, friendships, quiet, travel, creativity or simply being able to leave the house without planning does not mean wishing your child were different. It means recognising that caring has changed your life too.

You are allowed to hold two truths at once: **I love my child deeply, and some parts of this are hard for me.** One does not cancel the other.

## When your identity becomes a job description

Ask yourself how you introduce yourself in your own mind. Are you Mum, carer, advocate, organiser, taxi, researcher, appointment keeper and crisis manager before you are anything else? Those roles may be important, but they are roles you perform. They are not the complete definition of you.

Identity also lives in preferences, values, humour, interests, relationships, skills, ambitions, sensory needs, beliefs, creativity, sexuality, work, learning and the things that make you curious. Some of these may have been quiet for years rather than gone.

## The question 'What do you want?'

When you have spent a long time responding to other people's needs, being asked what you want can feel surprisingly difficult. You may automatically calculate what is practical for everyone else before noticing your own preference. Start smaller than major life decisions: Which drink do I actually want? What music would I choose? Do I want company or quiet? What would I wear if comfort and my own taste were the only considerations?

## A first identity check

Three things I used to enjoy: \_\_\_\_\_

Something I still enjoy when I get the chance: \_\_\_\_\_

Something I am curious about now: \_\_\_\_\_

Something that belongs to me, not my caring role: \_\_\_\_\_

# HOW CARING CAN QUIETLY SHRINK YOUR WORLD

## Friendships can change

Friends may stop inviting you because you often cannot attend, or you may stop accepting because every plan requires too much preparation. Some people understand cancellations; others take them personally. You may also find that ordinary conversation feels difficult when your head is full of assessments, school problems or sleep.

Connection does not have to look the way it did before. A voice note, short walk, coffee at home, predictable monthly date or friend who is comfortable with last-minute changes may fit your life better now. The aim is not to maintain every old friendship. It is to notice whether you still have relationships in which somebody asks about you, not only your child.

## Work, ambition and financial identity

Caring can affect hours, career progression, training and confidence. You may have turned down opportunities because the family could not absorb another demand, or chosen flexibility over progression. That can bring grief, especially if work once gave you independence, competence, adult conversation or a strong sense of identity.

Your career story is not necessarily finished because it has changed pace. Skills developed through caring - organisation, advocacy, research, communication, negotiation and persistence - are real skills, although you should not have to turn caring into productivity in order for your experience to have value.

## Your body can disappear from the list

Mums often become excellent at noticing everybody else's sleep, food, medication, sensory load and appointments while ignoring their own. You may realise you have delayed the dentist, GP, eye test, meal, rest or prescription because there was always something more urgent.

Try treating your own basic needs as household infrastructure rather than a reward. Eating, sleeping, attending healthcare and having recovery time support the whole system because you are part of that system.

## When everything becomes functional

Clothes become whatever is quick. Meals become whatever can be eaten while standing. Your phone becomes school messages and appointments. The house becomes regulation equipment and laundry. Even rest becomes preparation for tomorrow. Function matters, but a life made entirely of function can become emotionally flat.

Look for one thing that exists because you like it: a scent, colour, book, programme, lipstick, game, garden pot, playlist, craft, photograph or chair by the window. Pleasure does not need to justify itself by improving anybody else's outcome.

## What has become smaller?

| AREA          | WHAT HAS CHANGED?                       | ONE SMALL WAY BACK                          |
|---------------|-----------------------------------------|---------------------------------------------|
| Friendships   | Who do I rarely see now?                | A message, call or short predictable plan   |
| Interests     | What did I stop doing?                  | Ten minutes or a smaller version            |
| Work/learning | What ambition went quiet?               | Read, enquire or explore without committing |
| Body          | What need do I postpone?                | Book or protect one basic need              |
| Fun           | When did I last do something pointless? | Choose something simply because I like it   |

# FINDING YOUR WAY BACK WITHOUT ADDING ANOTHER JOB

## Do not turn identity into another self-improvement project

When somebody feels lost, advice can quickly become another list: exercise, journal, socialise, meditate, join a class, date your partner, start a hobby. If your capacity is already low, this can feel like proof that you are failing at looking after yourself too. Reconnection should reduce pressure, not add another performance.

Begin with noticing rather than fixing. What catches your attention? What makes you laugh? What do you miss? What do you actively dislike? Preference itself is part of identity.

## Use fragments, not perfect conditions

You may not have an uninterrupted afternoon for painting, but perhaps you can sketch for ten minutes. You may not be able to return to a weekly class, but you can watch a tutorial. You may not manage dinner with friends, but you can sit with one friend for half an hour. Smaller does not mean meaningless.

Fragments can keep a pathway open until life has more room. They remind your brain that you are still connected to a wider self.

## When Mum is neurodivergent too

If you are autistic, ADHD or otherwise neurodivergent, caring may interact with your own sensory, executive-function and social needs. You may require more recovery after appointments, struggle with constant interruption, hyperfocus on researching your child's needs, forget your own meals, or find traditional social 'self-care' exhausting rather than restorative.

Choose reconnection that fits your nervous system. Solitude may be connection to self. Repetition may be comforting. A special interest may restore you. Movement, headphones, dim light, parallel company or a visual plan may be more useful than a generic wellness routine.

## Relationships can become administration

Partners can gradually become co-managers: Who is collecting? Who emailed school? Did you order the prescription? Who is awake tonight? Practical communication is essential, but if every exchange is logistical, the relationship can lose its other language.

Connection may need to be intentionally tiny: sit together for ten minutes without discussing appointments, send something funny, watch one programme, remember a shared story, or ask a question unrelated to parenting. If there is significant conflict or disconnection, relationship counselling or individual support may be useful.

## The permission list

### I am allowed to...

have an interest nobody else in my family shares.  
spend some money on myself within what our finances allow.  
say that caring is hard without saying my child is a burden.  
want adult conversation.  
change my mind about who I am.  
rest without using the time to research autism.  
have needs that inconvenience other people sometimes.  
enjoy something even when my child is having a difficult period.

## Try an identity shelf

Imagine a shelf containing pieces of you. Some are active, some dusty, some new. Put five things on it: a value, an interest, a relationship, a skill and something you want to explore. You do not have to act on all five. The exercise is simply evidence that your identity contains more than caring.

# GUILT, GRIEF AND THE PERSON YOU WERE

## You may grieve parts of your old life

Grief does not only follow bereavement. You may grieve a career path, friendships, freedom, sleep, spontaneity, a relationship dynamic or the version of motherhood you expected. Naming this can feel dangerous because you do not want grief to be interpreted as grief about your child.

Be specific: 'I miss travelling without weeks of planning.' 'I miss feeling confident at work.' 'I miss seeing my friend every Friday.' Specific grief is easier to understand than the frightening global thought, 'I miss my old life.'

## Do you want the old you back?

Sometimes the answer is no. You may have changed in ways you value. Caring may have clarified what matters, altered friendships, developed your confidence or helped you understand your own neurodivergence. Reconnection is not necessarily restoration. You are allowed to build a new identity rather than recover an old one.

## Guilt when you choose yourself

The first time you protect something for yourself, guilt may become louder rather than quieter. That does not automatically mean the choice is wrong. Your family system may be accustomed to you being endlessly available. A new boundary can feel uncomfortable before it feels normal.

Ask whether the choice is unsafe or neglectful, or simply unfamiliar. Going for a walk while another trusted adult cares for your child is different from abandoning a need. Attending your appointment is not selfish. Having a conversation that is not about autism is not disloyal.

## When other people only see you as Mum

Friends, relatives and professionals may unintentionally reinforce the caring identity by always asking about your child first. You can redirect: 'They're okay - but tell me about something else; I need a break from autism talk today.' You are allowed to protect spaces where you are not giving updates.

## Identity rebuilding page

I am more than... \_\_\_\_\_

I feel most like myself when... \_\_\_\_\_

I miss... \_\_\_\_\_

I do not actually want to return to... \_\_\_\_\_

A part of me I would like to strengthen is... \_\_\_\_\_

One boundary that would create room for me is... \_\_\_\_\_

## When loss of self feels deeper

Sometimes feeling lost is part of burnout, anxiety, depression, trauma, prolonged sleep deprivation or an unsustainable level of caring. If you feel persistently numb, hopeless, unable to enjoy anything, unable to function, or significantly unlike yourself for a prolonged period, consider speaking with your GP or an appropriate mental-health professional.

Support should not reduce every difficulty to mindset. If there is genuinely no room for your needs because the caring load is too high, practical and structural support matters too.

# MAKING ROOM FOR YOU IN THE FAMILY

## Move from 'time off' to shared responsibility

If everything remains your responsibility until somebody temporarily 'gives you a break', you are still the default manager. Where possible, move whole responsibilities rather than individual tasks. Another adult can own a school run, prescription, activity, meal, form or regular bedtime rather than waiting to be instructed each time.

This is not possible in every family, particularly for lone parents or where a child accepts care from very few people. In those situations, outside support, gradual relationship-building with another trusted adult, carers services or practical help may matter even more.

## Let your children know you are a person

Children can benefit from seeing that Mum has interests, friends, work, boundaries and needs. This does not burden them when it is age-appropriate. Saying, 'I'm going to read for twenty minutes because I enjoy it,' models that every family member is allowed a self.

Your autistic child also deserves a future in which their own identity is larger than being cared for. Modelling mutual personhood can support that message.

## UK support starting points

**Carers UK:** information about unpaid caring, rights, work and carers assessments.

**Local authority/carers services:** ask about a carer's assessment and local practical or peer support.

**Contact:** information and support for families with disabled children.

**National Autistic Society:** autism information and family resources.

**Your GP:** a starting point if caring is affecting your physical or emotional health.

**Local peer support:** parent-carer forums and carers groups can sometimes provide connection with people who understand the practical realities.

Services, eligibility and provision vary across the UK and can change. Check current information directly with the relevant service or local authority.

## Your next seven days - not a transformation plan

One thing I will do because I like it: \_\_\_\_\_

One need I will stop postponing: \_\_\_\_\_

One person I will speak to about me, not only my child: \_\_\_\_\_

One responsibility I can ask somebody else to own: \_\_\_\_\_

One sentence I want to remember: \_\_\_\_\_

## A sentence to keep

**You do not have to disappear in order to be a devoted mum.** Your child's needs can matter enormously without becoming the only needs in the household. Reclaiming part of yourself is not stepping away from your child; it is making room for both of you to exist as whole people.

## Message from Maggie

Sometimes you can become so good at knowing everybody else's needs that you stop hearing your own. You know the safe food, the appointment date, the school trigger, the sensory warning sign and the exact moment somebody else is reaching their limit - but if somebody asks what you want, your mind goes blank.

I do not want to tell you to 'find yourself' as though you have vanished or as though this is another task you need to complete. I want you to notice the pieces that are still there. The music you turn up when nobody complains. The friend who makes you laugh. The subject you still want to learn about. The clothes that feel like you. The quiet you crave. The future idea you have not completely let go of. You are Mum, and that can be one of the biggest parts of your life. But it does not have to be the only word left to describe you.