AUTISM MUM SUPPORT

When You're Constantly Fighting for Your Child

The emotional, physical and mental toll of advocating, chasing and fighting for your child's needs.

Many mums never expected parenting to involve becoming an advocate, case coordinator, researcher, record keeper and persistent voice inside systems that can be difficult to navigate. You may find yourself chasing school, health services, assessments, referrals, support plans or reasonable adjustments while also caring for the child those systems are discussing.

Advocacy can be necessary and powerful. But when every piece of support appears to require another email, another explanation or another round of evidence, the parent can become exhausted by the process itself. This resource is about recognising that cost and finding ways to protect your capacity without silencing your child's needs.

When support has to be repeatedly proved

One of the hardest experiences can be knowing your child well, seeing what is happening at home, and then feeling that you must repeatedly demonstrate that the difficulty is real. A child may mask in school, recover only after returning home, communicate distress differently or cope until demands accumulate. A short observation in one environment cannot always show the whole picture.

Keep descriptions concrete. Rather than only saying 'school is overwhelming', record what happens before, during and after: sleep changes, physical symptoms, shutdowns, meltdowns, refusal, recovery time, eating, communication or changes in daily functioning. Patterns can communicate impact more clearly than repeatedly trying to find stronger words.

The cost of staying in fight mode

When you expect resistance, your nervous system may prepare for every meeting as though it is a battle. You rehearse arguments, gather documents, worry about being dismissed and replay conversations afterwards. Over time this can affect sleep, concentration, confidence and relationships. Some mums become hyper-alert to every email because experience has taught them that missing one detail may matter.

Being assertive does not require you to be permanently activated. Where possible, build processes that allow the evidence and written record to carry some of the load.

ADVOCATING WITHOUT CARRYING EVERYTHING IN YOUR HEAD

Create one evidence trail

Keep a simple chronology with dates, who you contacted, what was discussed, what was agreed and the next expected action. Save important emails and reports together. After a significant telephone call or meeting, consider sending a short factual email confirming your understanding of what was agreed. This is not about creating conflict; it reduces confusion and gives everyone a shared record.

When writing, separate **facts**, **impact** and **request**. For example: 'There have been four early collections in two weeks. Afterwards he needs several hours in a dark room and cannot manage dinner. Please can we meet to review the current support and identify what is happening before he reaches this point?'

BEFORE A MEETING	TAKE WITH YOU
What are the 1-3 main issues?	A short written list
What evidence shows the impact?	Relevant examples, dates or reports
What does your child communicate?	Their words, behaviour or preferred communication
What outcome are you asking for?	A clear, realistic request
What was previously agreed?	The relevant email/plan
What happens next?	Names, actions and dates

You do not have to say everything in one meeting

When you have been waiting a long time, it can feel as though one meeting must contain the entire history. That can leave you exhausted and make the central request harder to hear. Bring a fuller written chronology if it is relevant, but decide beforehand which points need discussion today.

You can also ask for an agenda, request information in writing, take notes, bring another person, ask what a term means, request time to consider a proposal and ask for the agreed actions to be recorded.

When you are described as 'difficult'

Parents who persist can sometimes worry that challenging a decision will damage relationships. It is possible to be respectful and still disagree. Keep communication focused on the child's needs, the evidence and the action requested. You are allowed to ask why a decision was made, what evidence informed it, what alternative is being offered and how a decision can be reviewed.

You do not need to become smaller to make a system more comfortable. Equally, protecting your energy may sometimes mean choosing which issue needs your attention now and which can wait.

SCHOOL, SEND AND SERVICE PRESSURE

When home and school see different children

A difference between home and school observations does not automatically mean either account is false. Context matters. Structure, sensory environment, social demands, predictability, masking and the effort required to cope can all influence what is visible. Ask for curiosity rather than a contest over whose version is correct: what is different between the environments, and what can that difference teach everyone?

Where appropriate, ask school to look beyond incidents alone. Patterns around particular lessons, transitions, unstructured time, noise, communication demands, hunger, fatigue or unexpected change may be more useful than simply counting behaviour.

SEND processes can become another job

Families may encounter SEN Support, EHCP processes, health referrals and multiple professionals. Keep a master folder and a short 'current position' page containing the child's key needs, current support, unresolved concerns, important contacts and next dates. This can prevent you having to reconstruct the story every time somebody new becomes involved.

For formal education decisions in England, use current official SEND guidance and specialist advice rather than relying solely on social-media information. Processes differ across the UK, so families in Scotland, Wales and Northern Ireland should use the relevant national and local systems.

Waiting lists and the space between referrals

Waiting can be particularly difficult when your child still needs support now. A diagnosis can be important, but practical support should be based on current needs wherever possible. Ask what can be put in place while assessment is pending, what service is responsible for current difficulties, what you should do if needs escalate, and whether there are interim resources or local services.

Keep a note of referral dates and expected contact points, but try not to make checking the system a daily task. Choose a sensible follow-up date and put it in your calendar so your brain does not have to hold it continuously.

A boundary for advocacy

I can care deeply without dealing with every issue today.
I can send the email tomorrow.
I can ask somebody to read it before I send it.
I can stop researching at a set time.
I can ask another adult to attend.
I can say, 'I need this in writing.'
I can take time before responding.
I can rest after a difficult meeting.

LOOKING AFTER THE ADVOCATE

After a difficult meeting

Do not expect yourself to move instantly into the next demand. Your body may still be carrying adrenaline even when the meeting has ended. If possible, leave a small recovery gap. Drink, eat, move, sit somewhere quiet, write down only the essential next actions and postpone detailed analysis until your nervous system has settled.

If you are replaying the conversation, ask: **Is there an action I need to take, or is my mind trying to resolve something that has already happened?** If there is an action, write it down. If there is not, give yourself permission to stop preparing a defence.

Your advocacy support plan

The issue I am dealing with: _____

The outcome I am asking for: _____

The evidence I actually need: _____

The next action and date: _____

Who can support me with this? _____

What can I stop doing until then? _____

UK information and support

GOV.UK / Department for Education: current SEND information and statutory guidance for England.

IPSEA: independent information about special educational needs and disability law in England.

SENDIASS: local information, advice and support services for children and young people with SEND and their parents/carers in England.

National Autistic Society: autism information and family resources.

Contact: support and information for families with disabled children.

Carers UK: information about support and rights for unpaid carers.

This resource provides general support, not legal advice. Education and social-care rules vary across the UK and can change. Check the current official guidance and appropriate specialist service for your nation and circumstances.

Message from Maggie

When you have had to fight repeatedly, it can become difficult to believe that anybody will listen unless you arrive ready for battle. I want you to remember that advocacy is something you do; it does not have to become your whole identity. Keep the evidence. Ask the questions. Challenge what needs challenging. But protect the person doing all of that as well. You are still allowed to laugh, rest, work, have interests, switch your phone off and have moments in which nobody needs an explanation from you. Supporting your child matters. So does making sure the fight does not take all of you.