

AUTISM MUM SUPPORT

The Fear of What Happens When I'm Not Here

When you are the person who knows every detail, the thought of somebody else having to understand your child can feel enormous.

Many mums carry a future question that is difficult to say aloud: what happens if I am ill, unavailable, getting older, or one day no longer here? It can arrive in the middle of the night, after a difficult appointment, when your child refuses support from somebody else, or when you realise that you are the only person who knows exactly what a particular sound, look or movement means.

This fear is not a prediction that something bad is about to happen. It is often a sign of how much knowledge and responsibility has become concentrated in one person. The answer is not to force independence quickly. It is to begin spreading understanding, relationships and practical information so your child is not dependent on one person's memory alone.

You may be carrying knowledge nobody can see

You may know which cup is acceptable, how food must be presented, what 'I'm fine' actually sounds like when your child is not fine, which clothing causes distress, how much warning is needed before leaving, what happens before shutdown, how pain is communicated, what helps after school and which apparently tiny change can derail an entire day.

This knowledge has often been built through years of observation. It matters. But if it only exists inside Mum's head, it can also become a source of fear.

Planning is not giving up control

Future planning can feel as though you are preparing to hand your child over. That is not the aim. A good plan protects what you know and makes it easier for other people to support your child respectfully. It can also reduce the pressure on you to remain available every minute.

Think of planning as building a wider circle around your child while you are still there to guide it.

Start with the next absence, not the distant future

You do not have to solve adulthood, ageing, housing and long-term care in one sitting. Begin with something smaller: if you were unwell for one day, what would another trusted adult need to know? If you were delayed for three hours, who could step in? What information would prevent avoidable distress?

Small practical planning can make the distant future feel less like one enormous unknown.

The first page of a support record

My child communicates distress by: _____

The quickest ways to help them feel safe are: _____

Things that must not be forced: _____

Important health/food/sensory information: _____

People my child already trusts: _____

BUILDING A WIDER CIRCLE OF PEOPLE WHO KNOW

One trusted person is a beginning

A wider support network does not have to mean a large group. For some children, one additional adult who understands them well is a significant step. This could be a partner, adult sibling, grandparent, friend, support worker or another consistent person.

The relationship matters more than the title. A relative who rarely sees your child may know less than a trusted support worker who has spent time learning their communication.

Let somebody learn while you are still available

It can be tempting to step in immediately when another person does something differently. Sometimes that is necessary for safety. But where the stakes are lower, allow the other adult to learn your child's signals and allow your child to learn that support can come from more than one person.

Start with shared experiences: the other person joins you for a familiar activity, then takes responsibility for one part, then perhaps spends a short period with your child while you remain nearby. The pace should reflect your child's needs, not an arbitrary expectation of independence.

Write down the things you automatically know

Information becomes useful when it is specific. 'He doesn't like change' is less helpful than 'Tell him the plan the night before, show it visually in the morning and give ten- and five-minute warnings before leaving.' 'She is fussy with food' is less helpful than a current list of safe foods, presentation requirements, allergies, intolerances and signs that eating is becoming difficult.

Include what helps, not only what is difficult. A support record should tell somebody how to create safety, connection and enjoyment.

What another person needs to know

AREA	USEFUL DETAIL TO RECORD
Communication	How yes/no, pain, fear, refusal and overload are shown
Sensory	Sound, light, touch, clothing, movement and useful supports
Food	Safe foods, presentation, allergies, risks and what not to pressure
Routine	Important anchors, transition warnings and flexible areas
Health	Medication, conditions, pain signs, clinicians and emergency information
Regulation	Early warning signs, calming strategies and what makes things worse

Keep the record alive

A support record is not something to write once and file away for ten years. Children change. Safe foods change. Communication grows. Medication changes. New fears and new strengths appear. Put a review date on it and update it after important changes.

If your child can contribute, include their own words, preferences, symbols, photographs or communication. The record should increasingly belong to them, not only describe them.

INDEPENDENCE WITHOUT FORCING INDEPENDENCE

Independence is not doing everything alone

For autistic people, independence may include knowing how to ask for support, using technology, relying on routines, living with assistance, using visual prompts or having somebody help with particular tasks. Interdependence is part of ordinary human life. The goal is not to remove support to prove capability.

A more useful question is: what can my child understand, communicate, choose or participate in with the right support?

Build participation into everyday life

Future skills can grow through ordinary routines: choosing between two foods, helping pack a familiar bag, recognising a medication box, knowing their address where appropriate, using a communication card, identifying a trusted adult, practising a small purchase or learning what to do if Mum is late.

Break skills into steps. A child who cannot independently make a meal may still learn to choose a safe food, retrieve it, use one appliance safely or tell another person what preparation they need.

Do not make fear the teacher

Parents sometimes feel pressure to push independence because they are frightened about the future. Children can sense that urgency. Repeated overwhelm can make the skill itself feel unsafe. Aim for supported practice that stretches capacity without repeatedly flooding the nervous system.

If a skill is not developing, ask whether the barrier is motor, sensory, cognitive, communication, anxiety, executive function, lack of motivation or the way the task is being taught. Different barriers need different support.

Siblings are not automatic future carers

It is understandable to hope siblings will remain involved, but a brother or sister should not silently inherit a lifelong caring role. Talk openly and age-appropriately about hopes, practicalities and choices. A sibling may want a close relationship without becoming the primary carer.

Future planning is stronger when it does not depend on one sibling making a promise they may not be able to keep.

What can we build now?

Something my child can already do with support: _____

One part they could participate in more: _____

A communication skill that would increase safety: _____

A trusted person who could practise alongside us: _____

One skill I am pushing because I am frightened about the future: _____

How could I make that skill smaller and safer? _____

Decision-making matters too

Where possible, involve your child in decisions about their life. Choice may be spoken, signed, typed, selected from pictures, communicated through behaviour or supported in another way. Future planning should not become a plan that everybody creates around the autistic person without them.

As your child grows, seek appropriate advice about decision-making, capacity, advocacy and support relevant to their age and circumstances rather than assuming childhood arrangements automatically continue into adulthood.

PRACTICAL PLANNING FOR THE UNEXPECTED

If Mum is suddenly unavailable

An emergency plan is different from a long-term future plan. It answers immediate questions: who should be contacted, where essential information is kept, who can collect your child, what medication or health information matters, what will reduce distress and what routines should be protected first.

Keep emergency information somewhere a trusted person can actually access it. A perfect folder that nobody knows exists will not help.

Create a simple priority order

In an unexpected situation, another adult does not need to recreate every detail of family life. Identify the essentials. For example: medication and medical safety first; safe food and hydration; communication; sensory regulation; sleep; then ordinary routines. This reduces pressure on the person stepping in and can protect your child from too many changes at once.

Important documents and contacts

Depending on your child's age and circumstances, useful information may include health contacts, medication lists, allergies, education or care contacts, benefits or service information, communication plans, emergency contacts and details of people who know your child well. Keep sensitive information secure and share it only with appropriate people.

For legal, financial, guardianship, wills, trusts, deputyship, appointeeship or adult social-care planning, get current specialist advice for your part of the UK. These areas depend on age, capacity, finances and jurisdiction, and they should not be based on a generic checklist.

Do not let paperwork replace relationships

A folder can explain that your child needs quiet, but it cannot replace a person who has spent time learning how they communicate. Build the paperwork and the people together.

Where possible, let future supporters experience ordinary, positive time with your child rather than only being called during crises. Familiarity is built through shared routines, humour, interests and trust.

Emergency plan worksheet

If I am unavailable, contact first: _____

Second contact: _____

Where essential information is kept: _____

Medication/health priorities: _____

Food/hydration priorities: _____

What helps my child regulate: _____

What must people avoid doing: _____

Practise the plan gently

You do not need to stage frightening emergencies. Instead, practise ordinary versions: another adult does pickup, prepares a safe meal, handles bedtime, attends an appointment with you or learns where information is stored. Each successful transfer of knowledge makes the system less dependent on one person.

Your plan can grow with your child

The future at age seven is not the future at seventeen or thirty. Review what your child can do, what support they need, who is in their network and what services are relevant. Planning is a process, not a single decision.

PLANNING FOR A FUTURE THAT STILL BELONGS TO YOUR CHILD

Move from 'Who will look after them?' to a wider set of questions

Who understands them? Who do they trust? How do they communicate choice? What makes a home feel safe? What support enables them to participate? Which relationships matter? What gives them enjoyment? What would a good day look like from their perspective? These questions keep the person at the centre of planning.

UK support starting points

National Autistic Society: autism information and resources across different life stages.

Contact: information for families with disabled children, including practical and financial topics.

Carers UK/local carers services: support for unpaid carers and information about carers assessments.

Local authority children's or adult social care: information about assessments, transition and support available locally.

SENDIASS: education-related information and advice for children and young people with SEND in England.

Citizens Advice or an appropriately qualified legal/financial professional: for individual advice where benefits, wills, trusts, decision-making or financial planning are involved.

Law, eligibility and service arrangements vary across the UK and can change. Check current information for your nation, local authority and individual circumstances.

A future-planning check-in

Who knows my child well besides me? _____

Who could know them better? _____

What information exists only in my head? _____

What should I write down this month? _____

What relationship could we strengthen? _____

What is one future worry that needs specialist advice rather than more worrying?

Planning should create more life, not more fear

You are unlikely to remove every uncertainty. Nobody can. The aim is to reduce avoidable vulnerability: more than one person knows, important information is recorded, your child has opportunities to communicate preferences, support is not concentrated in one exhausted parent, and professional advice is sought where legal or financial planning is needed.

When the fear returns, come back to the next useful step rather than trying to solve the next forty years in one night.

Message from Maggie

There is a particular fear that can come with knowing your child so deeply. You know the tiny signs other people miss. You know which 'no' means no, which silence means overwhelm, which food must be exactly right and what happens when somebody tries to rush them. It can make you wonder how anybody could ever do this without you.

I do not think the answer is to tell a mum not to worry. I think the answer is to help that knowledge travel. Write it down. Let another trusted person learn. Let your child build a relationship with somebody while you are still beside them. Practise small pieces of support being shared. Get proper advice for the legal and financial things that cannot be solved with a checklist.

You do not have to prepare your child for a world without you by suddenly making them cope without you. You can prepare by making sure the world around them contains more people who understand, more information that is not locked inside your head, and more ways for your child's own voice to be heard. That is not stepping away. It is building something around them that can remain strong.