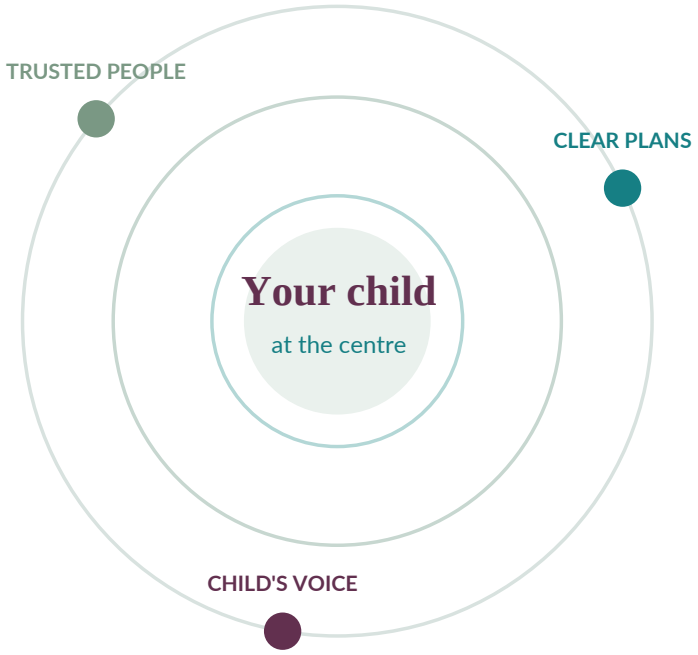
AUTISM MUM SUPPORT

The Fear of What Happens When I'm Not Here

Understanding the worry. Sharing the knowledge.
Building a future circle of care.



For the parent who carries so much invisible knowledge. This guide helps you turn worries about absence, illness and the future into shared understanding, practical arrangements and relationships that can grow over time.

There is no expectation to complete everything at once. Start with one person, one page, or one conversation.

The knowledge only you may hold

For some families, Mum is the person who interprets the smallest changes: a different breathing pattern, a pause before a meltdown, the meaning of a gesture, or the exact way to make a transition feel safe. The worry is often not simply “Who will care?” but “Will they understand?”

What may sit underneath this fear

- **Communication**
  Your child may use speech, AAC, gestures, behaviour or a combination. A new caregiver needs to know how to listen and respond.
- **Regulation and sensory safety**
  Someone needs to recognise overload early, know what helps and avoid responses that increase distress.
- **Trust and relationships**
  Knowing a routine on paper is different from becoming a safe, familiar person through repeated positive experiences.

A useful way to organise what you know



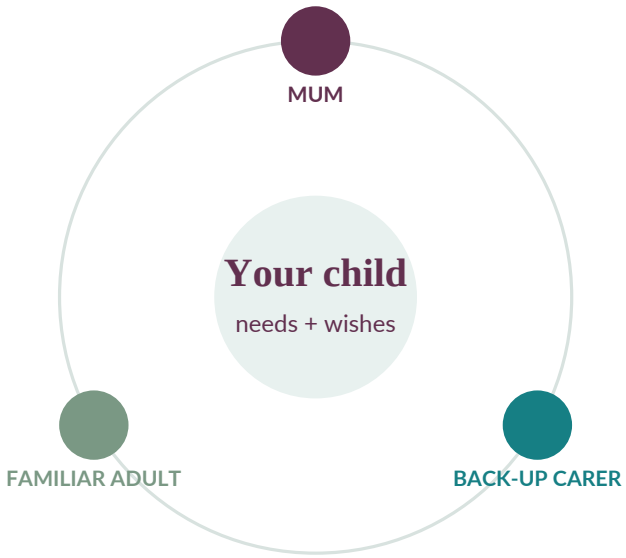
Example: “When she goes quiet and rubs her sleeves, she may be overloaded. Reduce language, move somewhere quieter, offer her headphones and allow recovery time. Do not insist on eye contact or an immediate explanation.”

A starting reflection

What is one thing you understand about your child that another person might easily misread?

From one person to a circle of support

A future-care plan is strongest when it is more than a folder. It combines trusted relationships, accessible information and practice. Your child should be involved in ways that suit their communication, understanding and preferences.



A gentle handover: four stages

01 **Connect**
Low-pressure shared activities while Mum remains available.

02 **Learn**
Other adults observe communication, routines and regulation support.

03 **Practise**
Short, agreed periods of support; review what felt safe or difficult.

04 **Maintain**
Keep contact regular and update the plan as needs change.

Important distinction

A handover is not a test of independence. Pause or adapt if distress is escalating. The aim is additional safe relationships, not withdrawal of essential support.

A practical care profile

Complete this page with your child wherever possible. Use their own words, symbols or AAC preferences. Share it securely with people who genuinely need it, and review it whenever circumstances change.

My child's preferred name and how they communicate

Speech, gestures, AAC, processing time, what "yes" and "no" look like.

Signs of stress or overload

Early signals, common triggers, signs of pain or illness that may be missed.

What helps them feel safe

People, sensory supports, routines, comforting activities, helpful language.

What makes things harder

Approaches to avoid, demands to reduce, environmental considerations.

Essential routines and practical care

Food, sleep, personal care, school, mobility, medication information location.

My child's preferences and choices

Who they trust, what matters to them, what they want others to know.

Keep sensitive information safe

Store medical details and contact information in a secure, up-to-date document. Only share what each caregiver needs; include where to find the current version.

Your next steps, on one page

You do not need to solve the whole future today. A workable plan identifies who can act, where information lives and which decisions need professional advice. Review it with your child and trusted people.

If I were unexpectedly unavailable

The first person to contact is:

If they cannot help, contact:

The current care profile and emergency information are stored:

The most important thing a caregiver must do first:

Three manageable actions for the next month

1

2

3

Longer-term arrangements to explore

Consider who could provide care, how decisions would be made, financial provision and what support services may be available. In England and Wales, wills, guardianship, trusts, benefits and decision-making rights require individual advice; arrangements differ with your child's age and capacity. A solicitor experienced in disability planning and relevant local services can help.

When the fear feels too big

It is understandable to feel grief, exhaustion or uncertainty. You deserve support too.
Speak with someone you trust, a therapist or your GP if worry affects daily life.
Planning can be paced; your wellbeing matters alongside your child·s future.