

SPECTRUM UNLOCKED

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# The First 48 Hours Post-Diagnosis

A Calm, Step-by-Step Guide for Parents

You just received an autism diagnosis for your child. Take a breath. This guide will walk you through the first two days with clear, practical steps so you don't have to figure it out alone.

*"The diagnosis doesn't change who your child is. It gives you better tools to support who they've always been."*

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# First, Breathe

Before we get into action steps, here is what you need to hear right now:

- **Your child is the same person they were before the diagnosis.** Nothing has changed about who they are. What has changed is that you now have a roadmap for how to help them.
- **You are not to blame.** Autism is a neurodevelopmental condition. It is not caused by anything you did or didn't do.
- **This is not a tragedy.** It may feel overwhelming right now, and that is valid. But autistic people live full, meaningful, joyful lives. Your child will too.
- **You do not have to figure everything out today.** The internet will try to convince you that you are already behind. You are not. Take this one step at a time.
- **It is okay to grieve.** Many parents feel a sense of loss for the future they imagined. That grief is normal and does not mean you love your child any less.

## A note on Googling

*Resist the urge to spend hours searching tonight. The internet is full of conflicting information and fear-based content. This guide gives you everything you need for the first 48 hours. Deeper research can wait until you have a clear head and a plan.*

# Hours 0–12: The Day of the Diagnosis

## What to do right now

- **Give yourself permission to feel whatever you feel.** Relief, grief, fear, numbness, anger, hope. All of it is valid.
- **Tell one trusted person.** Call your partner, a close friend, or family member. Just say: “We got the diagnosis today. I need someone to talk to.”
- **Do something normal with your child tonight.** Read a book together. Watch their favorite show. Eat dinner. Remind yourself that today changes nothing about your love.
- **Write down three things you love about your child.** On the hard days ahead, you will come back to this list.
- **Put the evaluation report somewhere safe.** Do not try to read the whole thing tonight. Just file it or photograph every page with your phone.

## What NOT to do right now

- Do not announce it on social media until you have had time to process.
- Do not start researching therapies and treatments tonight.
- Do not let anyone tell you how to feel about this.
- Do not compare your child to other autistic children. The spectrum is enormous.
- Do not make any major decisions about school, therapy, or treatment tonight.

## Hours 12–24: The Next Morning

Today is about taking three concrete actions that set you up for everything that comes next.

### Action 1: Read the evaluation summary

Find the evaluation report. Look for these key sections:

- **Diagnosis and severity level** (Level 1, 2, or 3 support needs)
- **Strengths identified** (these matter as much as the challenges)
- **Areas of concern** (communication, behavior, sensory, social, motor)
- **Recommendations** (the most actionable section — tells you what to do next)

#### Understanding support levels

*Level 1 = “requiring support.” Level 2 = “requiring substantial support.” Level 3 = “requiring very substantial support.” These are not fixed forever. They describe current needs, not your child’s potential.*

### Action 2: Call your pediatrician

Let them know about the diagnosis and ask:

- Can you send a referral for a developmental pediatrician?
- What therapy referrals can you make right now (speech, OT, behavioral)?
- Are there any medical screenings we should schedule?
- Can you help connect us with early intervention (if child is under 3)?

### Action 3: Contact your school district

If your child is 3 or older, call your local school district’s special education department and request an evaluation for services under IDEA.

#### Script you can use

*“Hi, my child was recently diagnosed with autism spectrum disorder. I would like to request an evaluation for special education services under IDEA. Can you tell me how to submit that request in writing?” Then follow up with an email confirming your verbal request. Written requests trigger legal timelines.*

## Hours 24–48: Getting Organized

Day two is about creating the foundation everything else will build on.

### Create your autism binder

Every parent of an autistic child needs one central place where all documents live:

- **Evaluations and Diagnoses:** The diagnostic report, developmental screenings
- **Medical Records:** Pediatrician notes, specialist referrals, prescriptions
- **School and IEP:** Anything from the school district
- **Therapy Reports:** Notes from speech, OT, behavioral therapy
- **Insurance and Financial:** Insurance cards, authorization letters, receipts
- **Communication Log:** Every call, email, and meeting — date, who, what was discussed

### Research your insurance coverage

Call the number on your insurance card and ask:

- Is ABA therapy covered? How many hours per week?
- Is speech therapy covered? How many sessions per year?
- Is occupational therapy covered? How many sessions per year?
- Do I need a referral or prior authorization?
- Are there in-network autism therapy providers near me?

#### Important

*Most states have autism insurance mandates requiring coverage for autism-related therapies. If your insurance denies coverage, do not accept the first no. Appeal it and look up your state's autism insurance mandate for the specific law to cite.*

### Start building your support network

- Search Facebook for autism parent groups in your area
- Visit [autism-society.org](http://autism-society.org) to find your local chapter
- Ask your diagnosing provider about local parent support groups
- Visit [spectrumunlocked.com/community](http://spectrumunlocked.com/community) for our resource directory

## After 48 Hours: What Comes Next

The first 48 hours are about stabilizing. Here is what the next few weeks look like:

Timeframe	Focus
Week 1–2	Get on waitlists for therapy providers. Waitlists can be months long, so call early.
Week 2–4	Schedule your IEP evaluation with the school district. Learn about your rights under IDEA.
Month 1–2	Begin therapy as openings become available. Start building daily routines at home.
Month 2–3	Attend your first IEP meeting. Use our free IEP Checklist to walk in prepared.
Ongoing	Connect with other parents. Learn from autistic adults. Celebrate progress. Take care of yourself.

### Essential free resources

Resource	What you'll find
<a href="https://spectrumunlocked.com">spectrumunlocked.com</a>	Free guides, tools, IEP resources, and parent community
<a href="https://autism-society.org">autism-society.org</a>	Local chapters, support groups, and resource navigation
<a href="https://wrightslaw.com">wrightslaw.com</a>	Special education law and IEP advocacy information
<a href="https://parentcenterhub.org">parentcenterhub.org</a>	Find your state's free Parent Training and Information Center
<a href="https://autisticadvocacy.org">autisticadvocacy.org</a>	Resources from autistic self-advocates

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## You Are Your Child's Greatest Advocate

Right now, everything feels new and uncertain. That is normal. But here is what will happen: day by day, you will learn more. You will find the right therapists. You will learn to navigate the school system. You will connect with other parents who understand. You will watch your child grow in ways that surprise and inspire you.

*And on the hard days, you will come back to what you already know: your child is extraordinary, and they have you in their corner.*

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