After the Diagnosis

A guide for parents through the first months after an autism diagnosis

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FREE GUIDE

A word before we begin

If you are reading these lines, it is probably because your child has just received an autism diagnosis. Or because you are waiting for that diagnosis. Or because you have doubts, because something is worrying you, and you are looking for clear answers.

This guide was written for you. It is free. It is not selling you anything. Its only goal is to give you the right information at the right time, in plain language, so that you feel less alone and know where to begin.

My name is Valentine. My son Sasha was diagnosed with autism at 19 months, in November 2015. Today, he leads an ordinary life, goes to school, and has friends. I am not telling you this to promise you the same thing: every child is different. But to tell you that there is a path, and that we can walk it together.

This guide follows the official recommendations of the major international health and research authorities — including the World Health Organization (WHO) and national public-health and research bodies. It does not promote any miracle method. It helps you understand, take action, and breathe.

Take your time. You do not have to read everything at once. Come back to it whenever you need to.

VALENTINE'S TESTIMONY — The day of the diagnosis

I remember very clearly the day the neuropaediatrician said the word. Sasha was playing on the floor with a block. I did not cry in the moment. I took notes, as if I were a journalist. It was in the car, on the way home, that everything hit me.

If I could speak to the Valentine of that day, I would tell her: you are going to be afraid, you are going to cry, and that is normal. But tomorrow morning, you will get up, and you will start taking action. And that is exactly what you need to do.

— Valentine, Sasha's mum

Part 1 — Understanding

Before acting, understand. This first part gives you the current scientific basics about autism, in plain language. We dismantle the false ideas, we look at the numbers, and we talk about the emotional shock of the diagnosis.

What is autism?

Autism, or more precisely “autism spectrum disorder” (ASD), is a developmental condition of the brain. It begins very early, before the age of 3, even if it is sometimes spotted later. It lasts a lifetime.

According to the official international definition set out in the DSM-5 diagnostic manual, autism affects two main areas.

- **Communication and social interaction:** difficulty understanding others, using eye contact, gestures and emotions, playing or interacting with other children.
- **Repetitive behaviours and restricted interests:** repeated movements, a need for very precise routines, intense interests in certain subjects, and a particular sensitivity to sounds, lights, textures and smells.

We speak of a “spectrum” because autism is not a single condition with a single face. It is a very wide range of profiles. Some children speak very well and shine at school. Others do not speak and need help with everyday tasks. Many are somewhere in between.

The word “neurodiversity” is used more and more. It says one simple thing: an autistic brain works differently. Not worse, not better. Differently. This concept does not say that nothing should be done; it says that we must understand how this brain works in order to support it well.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

The medical diagnosis remains essential

Recognising neurodiversity does not replace having a genuine diagnosis made by a specialised team. On the contrary: it is the diagnosis that opens up rights, support and services. If you have doubts, talk about it with your doctor, your paediatrician, or contact your national autism association, which can point you to the diagnostic pathway in your country.

What autism is NOT

Many false ideas circulate about autism. Some come from old theories abandoned by science. Others come from the internet, from family, or even from poorly informed professionals. Here are the main ones, to throw out right away.

“Autism is caused by vaccines.” FALSE. This is the best-known false idea. It comes from a 1998 study published by a British doctor, Andrew Wakefield. That study was shown to be fraudulent, retracted by the journal that had published it, and the author was struck off. Since then, more than twenty large international studies covering millions of children have confirmed it: there is no link between vaccines (notably the MMR:

measles-mumps-rubella) and autism. The WHO and national health authorities are unequivocal.

"Autism comes from a cold mother." FALSE. This theory, known as the "refrigerator mother" theory, was invented in the 1940s by the psychoanalyst Bruno Bettelheim. It is completely false. Autism originates mostly in genetics and in the development of the brain before birth. No way of raising a child causes autism. If anyone has ever made you feel guilty, know that science is on your side: it is not your fault.

"They will grow out of it." FALSE. Autism is a developmental condition that lasts a lifetime. However, with early and appropriate support, many children make enormous progress. Some, like Sasha, end up leading a completely ordinary life. Others will keep some support in place. But "waiting for it to pass" is never a good strategy.

"It's just their personality." FALSE. Autism is not shyness, daydreaming, or a "strong character." It is a different way the nervous system works, identifiable by a trained team. A shy child looks you in the eye, understands jokes, and plays pretend. An autistic child often has difficulty with these things, even when they are very intelligent.

"Autistic people have no emotions." FALSE. Autistic people feel as many — and sometimes more — emotions than others. They simply have more difficulty expressing them or decoding them in others. Never confuse difficulty in showing with absence of feeling.

The numbers: how many? where? why?

Knowing the numbers helps you understand that you are not alone. Autism is much more common than was thought twenty years ago.

Source	Prevalence	Year
US public-health surveillance	About 1 child in 36	2023
World Health Organization (global)	About 1 child in 100	2022
National research estimates (varies by country)	Around 1 child in 100	2024
National health authorities (range across studies)	0.9% to 1.2% of births	2018–2025

Worldwide, autism is now estimated to affect roughly 1 in 100 people. Boys are diagnosed three to four times more often than girls, partly because autism in girls goes more unnoticed (they "mask" it more).

These numbers have been rising for twenty years. That does not mean there are more autistic people: it mainly means we diagnose them better, earlier, and that the definition has broadened to include less "visible" profiles.

Why diagnosis is sometimes late

Many parents discover their child's autism late: at age 3, 5, 8, sometimes in adolescence. Why?

- Lack of training among frontline professionals (family doctors, paediatricians, nurseries, preschools).
- Long waiting lists in specialist diagnostic services: from 6 months to 2 years depending on where you live.
- Confusion with other conditions (language disorders, ADHD, specific learning disorders, high ability).
- The persistent belief in "let's wait a little" before age 3.
- For girls: less visible symptoms and social masking, leading to later identification.

And yet, health guidelines are very clear: if there is a doubt, act quickly. The first interventions can begin even before the diagnosis is fully confirmed. This is what is called early intervention.

> **VALENTINE'S TESTIMONY — One month between doubt and action**
>
> When I understood that something was wrong with Sasha, I called everyone. The paediatrician, the ENT specialist, the neuropaediatrician, the early-intervention service. Many told me: "he's little, wait." Only one told me: "we lose nothing by taking a look." That is the one I listened to. Sasha was 18 months old.
>
> If you have doubts, do not let anyone tell you to wait. Ask for a specialist opinion. The worst that can happen is that you are reassured. The best is that you act in time.
>
> *— Valentine, Sasha's mum*

The warning signs that should prompt a consultation

Not all children develop at the same pace. But certain signs, especially when they add up, should prompt you to seek a specialist opinion. Here are the main ones, based on international guidelines (most recently updated 2025) and public-health surveillance.

Before 12 months

- Baby does not respond consistently to their name.
- No babbling at 9 months (repeated "ba," "ma," "pa").
- No smile in return, few shared glances.
- No pointing gestures, no gesture to say "bye-bye."
- Unusual posture (stiff or very floppy body) that persists.

Between 12 and 24 months

- No real word at 16 months (other than generic "mama/papa").
- No two-word combinations at 24 months.
- Loss of words or gestures already acquired (regression).
- Little interest in other children.

- Very repetitive play (lining things up, opening/closing, spinning).
- Strong intolerance to changes in routine.

Between 2 and 4 years

- Difficulty imitating (waving, playing pretend, dancing along).
- Absence of pretend play (feeding a doll, driving a truck while making the sound).
- Language absent, echolalic (repeats what they hear), or very formal.
- Hypersensitivity (noise, light, textures) or, on the contrary, indifference to pain.
- Difficulty with eye contact, or an avoidant gaze.

At any age

- Sudden regression in a behaviour, in language or in sociability.
- Marked motor stereotypies (hand-flapping, rocking).
- Very intense interests in narrow subjects (signs, dinosaurs, numbers).

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

A single sign means nothing

Many children show one or two signs without being autistic. It is the ACCUMULATION, the PERSISTENCE and the INTENSITY that should raise concern. If you have doubts, the M-CHAT-R screening tool (for 16–30 months) is freely available online and can be a first indicator. But ONLY a trained professional can make or rule out a diagnosis.

What we know about the causes (and what we don’t)

One question always comes back: why? Science has advanced a great deal but does not yet give a simple answer. Here is the state of knowledge in 2026.

The genetic factor

Autism is very largely genetic: it is estimated that 80 to 90% of the risk comes from the genes. But it is not “one gene”; it is hundreds, which interact. Twin studies show that if one identical twin is autistic, the other is too in 60 to 90% of cases. For non-identical twins, it is around 30%.

The early developmental factor

Certain factors linked to pregnancy slightly increase the risk: advanced age of the parents, prematurity, certain serious infections during pregnancy, exposure to certain medications (notably sodium valproate). But these factors explain only a small part of cases.

What does NOT cause autism

- Vaccines. None, ever. Proven across millions of children.
- Upbringing, the quality of attachment, the “coldness” of parents.

- Screens. They can worsen certain behaviours, but they do not cause autism. It is wise to limit screen time before age 3, but that is not the origin.
- Sugar, milk, gluten. No evidence.
- The mother's stress during pregnancy. Not shown to be a causal factor.

What research is still looking into

Researchers are working on the interaction between genes and the early environment. Research institutes around the world have dedicated teams. You can follow their progress through your national health and research authorities.

Grieving the dreamed-of child

When you learn that your child is autistic, something very particular happens inside you. Psychologists speak of "grieving the imagined child" or "dreamed-of child."

Before birth, and even after, you built in your mind an image of what your child would be. How they would walk, talk, hug you, draw you pictures, tell you about their day. The diagnosis is the announcement that this imagined child will not be exactly that one. It is a loss. The loss of a child who never existed, but a loss all the same.

This pain is NORMAL. It does not make you a bad parent. On the contrary, it speaks to the intensity of your love.

The five stages (often out of order)

The model of Elisabeth Kübler-Ross, created for grief, often applies to the diagnosis. But beware: these stages are never gone through in order, and you can go backwards.

- **Denial:** "The doctor is wrong. There is nothing wrong with my child."
- **Anger:** "Why me? Why them? Why us?"
- **Bargaining:** "If I do this diet, this method, this prayer…"
- **Sadness:** an often long phase, which can resemble depression.
- **Acceptance:** "This is my child. They are who they are. We are going to help them."

Acceptance does not mean you are happy. It means you stop fighting against reality, and you use your energy to act.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

If sadness lasts and paralyses you

If after several weeks you no longer sleep, no longer eat, can no longer take care of your child or of yourself, this is not "a phase." Go and see your doctor. Parental depression after a diagnosis is common and can be treated. Taking care of yourself is also taking care of your child.

Part 2 — Acting right now

This part is practical. It tells you what to do in the days and weeks that follow the diagnosis. We talk about actions, contacts, administrative steps and financial support. Keep it close at hand.

The first 10 steps after the diagnosis

Here, in order, is what experience and best practice recommend in the first 30 days.

1. **Ask for a written copy of the diagnosis.** This dated, signed document is what will open up all your rights afterwards. Keep it in a dedicated binder.
2. **Start an "Autism" binder** with sections: diagnosis, appointments, assessments, disability paperwork, school, invoices. You will need it for years.
3. **Contact the diagnostic and support pathway in your country**, even if there is a waiting list. Your national autism association can tell you the exact entry point for a full evaluation and follow-up.
4. **Talk to your primary care doctor** about any health coverage or long-term-condition status that may reduce the cost of care where you live.
5. **Identify an early-intervention service** (often available before school age) to begin the first therapies without waiting for the full diagnosis to be confirmed.
6. **Open a disability-support file with the relevant authority in your country.** These processes can take several months — so start straight away.
7. **Inform the school or nursery, asking for a meeting.** Bring the diagnosis. Ask for an individual education/support plan if your child is enrolled.
8. **Join one or two local and national associations** (see Part 6). Peer support is just as important as medical care.
9. **Make appointments with a speech-and-language therapist and an occupational/psychomotor therapist** (the two most useful forms of support in the great majority of cases).
10. **Rest. Really.** An evening, a weekend. You cannot run a marathon if you start by sprinting.

VALENTINE'S TESTIMONY — My first binder

I bought a big red binder, with dividers. Everything went into it: the neuropaediatrician's report, the first assessments, the prescriptions, the invoices. Five years later, that binder was thirty centimetres thick. And every time someone asked me for a document, I found it in two minutes.

It is a silly little detail. But the day an administration asks you for a document from 2017, you will be glad to have it.

— Valentine, Sasha's mum

Finding the right services

A few types of service come up everywhere. Names and structures vary from country to country, but the functions are similar. Your national autism association can give you the exact local equivalents.

The specialist diagnostic centre

In most countries there is a specialist service (sometimes regional) that makes or confirms the diagnosis, gives guidance, and trains and informs families. It does not usually provide regular follow-up. To find it: ask your national autism association, or search online for “autism diagnostic centre” plus your region.

Early-intervention services (early years)

For young children, multidisciplinary teams (paediatrician, psychomotor/occupational therapist, psychologist, speech therapist, educator) provide early support. In many countries these services are free or subsidised. To find them: ask your primary care doctor, your local child-health service, or your national autism association.

Ongoing support services (school years)

For older children, similar multidisciplinary teams provide continuing support. Ask your national autism association or your child’s school for the services available where you live.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

Waiting times are long: you can apply in several places at once

Specialist services often have 6 to 18 months of waiting. Apply EVERYWHERE at the same time, and begin in parallel, privately if you can, with a speech-and-language therapist and a psychomotor/occupational therapist trained in autism. You can always stop when a place opens up.

The disability-support file: step by step

In most countries, an administration or agency assesses your child’s needs and opens up your rights: financial support, help at school, and guidance on services. The file is often heavy but accessible. Ask your national autism association for the exact forms and the office that handles them where you live.

The documents to gather

- The official application form(s) for disability support in your country.
- A medical certificate, completed by a doctor (often your primary care doctor or the doctor at the diagnostic centre).
- **The “life plan” or needs statement:** a free-text document where you describe your child, their difficulties and your needs. This is THE most important document. Take your time over it.
- A copy of the diagnosis and the assessments.
- Proof of identity, proof of address, and any health-coverage documents required.
- School reports or nursery reports, if relevant.

The main forms of support

The exact benefits and amounts vary widely from country to country. As a general principle, you can usually apply for the following kinds of help. Ask a social worker, your early-intervention service, or your national autism association which ones exist where you live and how much they are worth.

Type of support	Who it is for	What it provides
Basic disability allowance for a child	Any child with a recognised disability	A monthly financial allowance
Increased allowance / supplement	Depending on costs and constraints	A higher allowance based on need
Compensation for disability-related costs	Depending on human/material needs	Variable, often a monthly amount
Support worker at school	If enrolled in school	Hours of in-class assistance

In some systems you have to CHOOSE between an allowance supplement and a separate compensation benefit. Before deciding, ask a social worker, your early-intervention service, or a parents' association. The right choice depends on your particular file.

Realistic timelines

- **Submitting a complete file:** allow about 1 month to gather the documents.
- **Assessment by the authority:** several months on average, and longer in some areas.
- **The official decision letter:** follows the assessment.
- **First payment:** usually one to two months after the decision.

Plan B if the delays drag on

- Call the office regularly: do not be shy, some files move forward thanks to a phone call.
- Ask for a written acknowledgement of receipt as soon as you submit.
- In case of refusal or disagreement, you usually have the right to appeal — ask about the deadline and procedure where you live.
- While you wait, some support may be backdated. What you pay today may be reimbursed later.

Financial support to know about

Beyond the main disability allowances, several other forms of help often exist. Many parents do not claim them simply because they do not know about them. Ask your national autism association which of these apply in your country.

- **Health-coverage status for a long-term condition:** can reduce or remove the cost of autism-related care. Ask your primary care doctor.

- **Coordinated early-intervention funding:** in some countries, a public scheme covers an assessment and therapy pathway (psychomotor therapist, occupational therapist, psychologist) without you having to pay up front.
- **Parental presence allowance:** if you reduce or stop work to care for your child.
- **Mobility / inclusion card:** parking, priority access, and sometimes a disability status.
- **Tax credits or deductions** for home-care and support services.
- **Local and regional support:** highly variable. Contact your local social-services office.
- **Private health insurance:** some policies cover psychomotor therapy and psychology. Check your contract.

GOING FURTHER

Coordinated early-intervention schemes

A growing number of countries now run coordinated schemes for young children with neurodevelopmental conditions. They give access to assessments and sessions that are covered or subsidised, privately, often without you having to pay up front.

To access them: ask your primary care doctor or paediatrician how to be referred, or contact your national autism association.

Part 3 — Supporting your child day to day

The diagnosis has been made, the paperwork is under way. Now, life goes on: meals, sleep, shopping, meltdowns. This part gives you concrete, validated tools for everyday life.

Communication: alternatives to speech

Many autistic children do not (yet) speak, or speak little. This does not mean they do not want to communicate. It means we need to give them other channels. Best practice strongly recommends using these tools as early as possible, without waiting.

PECS (Picture Exchange Communication System)

This is a system of exchange through pictures. The child hands a picture (for example, one of a biscuit) to an adult in order to obtain the item. There are 6 progressive levels. Very widely used and scientifically validated. To be set up with a trained speech-and-language therapist.

Makaton

A combination of simplified signs, pictograms and speech. Developed in the United Kingdom. Widely used for children with language difficulties. Learned through a short course (often over a weekend).

Pictograms (PCS, ARASAAC)

Simple little images that represent a word or an action. The ARASAAC set can be downloaded for free online. They are used for routines, choices and emotions.

AAC apps (augmentative and alternative communication)

On a tablet: apps such as Proloquo2Go, Mind Express and similar tools allow the child to build sentences by touching images. Very useful from about 4–5 years. Some are paid for but may be reimbursable through your local disability support.

> **IMPORTANT — A PROFESSIONAL OPINION IS NEEDED**
>
> **Communicating with pictures NEVER delays speech**
>
> Many parents (and some poorly trained professionals) fear that pictograms or sign language will “block” speech. The opposite is true. All the studies show that these tools actually speed up the arrival of language in children who are ready to talk. And for those who will not talk, they remain an essential channel. The scientific consensus is unanimous.

Visual routines

An autistic child often needs to anticipate what is going to happen. Not knowing is distressing. Visual routines answer this need.

The morning schedule

On a strip of card, stick pictures in order: wake up, use the toilet, get dressed, have breakfast, brush teeth, put on shoes, leave for school. As each step is done, the child turns over or removes the picture.

The visual timer

A timer that shows time passing (for example, a Time Timer with a red disc) helps enormously. The child sees how long an activity lasts, and understands when it will end. This reduces transition meltdowns.

The “before / after” board

Two boxes side by side: on the left, what we are doing now. On the right, what comes next. Very effective for children who resist stopping a pleasant activity: they see that it is not the end of the world, just a change.

Social stories

A short written and illustrated story that describes an upcoming situation: “Today I am going to the dentist. First we go in. Then we sit down. The dentist is going to look at my teeth.” Scientifically validated (Carol Gray, 1991), it heads off the anxiety of new situations.

> **VALENTINE’S TESTIMONY — Mornings in our house**
>
> For two years, I had a laminated schedule at child height in the hallway. Seven pictures: pyjamas off, clothes on, toilet, teeth, shoes, coat, door. When we removed a picture, we clipped it into the “done” box. Sasha did not speak. But he looked at the schedule, and he knew.
>
> The morning he handed me a picture himself (the coat) because I had forgotten it, I understood that we had gained something.
>
> — *Valentine, Sasha’s mum*

Sensory meltdowns: understand, prevent, manage

An autistic child often has senses that are “tuned” differently. Too strong, too sensitive, or on the contrary not enough. The noise of the hand-dryer in the toilets, the label on a T-shirt, the supermarket lighting can trigger a meltdown.

What we call a sensory meltdown

It is NOT a tantrum for effect. It is NOT bad parenting. It is the brain’s response to overload: too much information at the same time, and the system short-circuits. It is also called a “meltdown.”

Spotting the warning signs

- The child covers their ears, closes their eyes, hides.
- They start rocking, or doing stereotypies more strongly than usual.
- They move away from the situation, or on the contrary become hyperactive.
- They go silent when they were speaking, or shout when they were calm.

Preventing

- Avoid the shops at peak times. Prefer quiet hours.
- Spot the clothes that are scratchy. Cut off labels.
- Always keep noise-cancelling ear defenders in the bag (child models exist from age 3).
- Prepare the child for any new situation with a social story or a photo.

Managing during the meltdown

- First, get the child out of the triggering environment. Right away.
- Do not talk too much. As few words as possible. Low voice.
- Offer a reassuring object (comforter, ear defenders, weighted blanket).
- NEVER punish a sensory meltdown. You would be punishing the child for something they cannot control.
- Once the meltdown has passed, calmly, you can later talk again about what happened.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

Sensory meltdown or tantrum: telling them apart

A tantrum has a goal: to obtain something. It stops if you give in. A sensory meltdown has no goal: it is a neurological overflow, and it does NOT stop when you give in. If you have doubts, talk about it with your psychomotor therapist or an occupational therapist trained in sensory integration.

Sleep: validated protocols

60 to 80% of autistic children have sleep difficulties. It is one of the most exhausting problems for families. Fortunately, there are solutions.

The basics of good sleep hygiene

- Bedtime at the same hour every evening, weekends included.
- A short and always identical ritual: bath, pyjamas, story, lights off.
- No screens 1 hour before bed.
- A dark, cool (18–19 °C), quiet bedroom (or steady white noise).
- No very exciting play in the hour beforehand.

Melatonin

In many countries, prolonged-release melatonin can be prescribed for an autistic child in cases of persistent sleep difficulties, on the prescription of a paediatrician or neuropaediatrician only.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

Sleep medication: a medical opinion is MANDATORY

NEVER give over-the-counter melatonin without a prescription, nor any "sleep" food supplement, without speaking to a doctor. The doses, the duration and the combinations must be supervised by a professional. The right first contact: a paediatrician or neuropaediatrician.

Selective eating

Many autistic children eat only 5, 10 or 15 foods. For them, the texture, the colour, the brand and the plate matter as much as the taste. This is very common and is linked to oral hypersensitivity.

What to do

- Keep mealtimes regular.
- Regularly offer a new food, alongside those the child already eats. Without forcing.
- Let them touch, smell, lick before eating. These are steps.
- Praise every small advance. Do not make a drama of refusals.
- Ask for an oral-motor assessment with a speech-and-language therapist if the selectivity is extreme.
- Check weight, height, and blood work (iron, vitamin D) at least once a year.

What NOT to do

- Force the child to eat. This creates a lasting aversion and can be traumatic.
- Hide foods inside others. The child almost always detects it and loses trust.
- Put the child on a gluten-free / casein-free diet without medical advice: health authorities do NOT recommend these diets as a treatment for autism. On the contrary, they can cause deficiencies.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

Alternative diets: caution

No dietary regimen has shown, in serious studies, any effect on the symptoms of autism. The major health authorities agree. If someone promises you a "cure through food," walk away. And if your child has a genuine digestive problem (constipation, diarrhoea), talk to a paediatric gastroenterologist.

Toilet training: realistic ages, methods

Toilet training often comes later in the autistic child: 4, 5, 6 years, sometimes more. This is linked to a delay in body awareness, to routines, and sometimes to sensory difficulties.

When to start?

- Not before the child sits up solidly and walks.

- Not before they can stay dry for 1 to 2 hours.
- Not before they can understand a simple instruction (word or pictogram).

If these conditions are not met, we wait. Forcing does not work.

The gradual visual method

1. **Step 1 — familiarise.** The child goes into the bathroom, looks, touches the potty. We read a book about the toilet.
2. **Step 2 — sit clothed.** A few minutes a day, without pressure.
3. **Step 3 — sit undressed**, at fixed times (after meals, on waking).
4. **Step 4 — praise every success**, do not dramatise the misses.
5. **Step 5 — remove the nappy during the day.** Keep it for the night.
6. **Step 6 — night dryness**, much later, sometimes well after age 6.

> **VALENTINE'S TESTIMONY — Sasha and toilet training**
>
> Sasha was toilet-trained at four and a half. For months, I believed it would never come. And then one day, it was there, almost without transition. As if his brain had finally connected the dots.
>
> Do not compare yourself to the neighbourhood children. Your child has their own pace. Follow it.
>
> *— Valentine, Sasha's mum*

Support methods: what the evidence says

Health authorities have published, and regularly update, recommendations on interventions for autistic children. They classify approaches into several categories according to the level of scientific evidence.

Recommended approaches (graded A or B)

- Early developmental and behavioural interventions (ESDM and derived models).
- Applied behaviour analysis (ABA) in its contemporary, respectful form, supervised by a trained professional.
- The TEACCH programme (structuring of the environment).
- Specialised speech-and-language therapy (including PECS and AAC).
- Psychomotor therapy with a sensory-integration approach.
- Occupational therapy for sensory-motor difficulties.

Approaches that are NOT recommended

Health authorities are very clear: certain practices, sometimes still offered, are not recommended because they lack evidence of effectiveness, or because they can delay access to useful support.

- Methods with no evidence of effectiveness (such as the "3i" method or the Son-Rise programme).
- Packing (cold wet wraps): banned in several countries, advised against.

- Restrictive diets presented as a “cure” (gluten-free/casein-free, paleo).
- Chelation (“cleansing” heavy metals), which is dangerous and useless.
- Hyperbaric oxygen therapy as a treatment for autism.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

Beware of promises of a cure

No method “cures” autism. Anyone who promises you that, in exchange for hundreds or thousands of euros, is taking advantage of your distress. ALWAYS ask for the level of scientific evidence. ALWAYS ask what the official health authorities say. If you have doubts, contact your national autism association before committing any money.

Play: why it is essential

Play is the means by which children learn. For an autistic child, playing does not come naturally. Imitation play, symbolic play (pretending) and turn-taking play are often difficult. Yet play is a powerful lever for progress.

Three levels of play to offer

1. **Sensory play:** water, sand, modelling clay, shaving foam. Stimulates the senses, puts the child at ease.
2. **Functional play:** using an object for its purpose (pushing a car, brushing a doll).
3. **Symbolic play:** pretending (feeding the doll, playing doctor).

How to guide without forcing

- Follow the child’s interest: if they line up blocks, join in before suggesting something else.
- Imitate their movements: this is the basis for them eventually imitating yours.
- Start with 5 minutes, increase gradually. No marathon.
- ALWAYS end on a success, however small.

Challenging behaviours: understand before punishing

A difficult behaviour (biting, self-harm, throwing objects, shouting) is NOT naughtiness. It is communication. The child is telling you: “I don’t know how to say what’s wrong any other way.”

The 4 main functions

- **OBTAINING** something (an object, attention, contact).
- **ESCAPING** from something (a demand, a noise, a presence).
- **SENSORY STIMULATION** (seeking a sensation).
- **A PHYSICAL NEED** (pain, hunger, tiredness, infection).

The reflex: observe before reacting

The ABC method, used by trained professionals: A = Antecedent (what happened just before?), B = Behaviour (the behaviour itself), C = Consequence (what happened after?). By noting 5 to 10 episodes, you spot patterns and you can act on the triggers.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

A silent pain to rule out first

Always check first that there is no physical pain: an ear infection, toothache, constipation, a urinary infection. An autistic child who does not have the words can express pain through violent behaviours. Any sudden change in behaviour justifies a prompt medical consultation.

Everyday safety

Some autistic children have little sense of danger: the road, water, fire, heights. Others, on the contrary, have an intense fear of them. A few golden rules.

- An identity bracelet (first name, parent’s phone number, a note such as “ASD”) as soon as the child moves around alone. Available in pharmacies or online.
- For outings: a recent photo on your phone, ready to show if your child gets lost.
- At home: high locks on outside doors, window safety catches, a protected stove.
- At the pool, at the seaside: armbands or a life jacket ALWAYS, even if the child can swim. Drowning is the leading cause of accidental death in autistic children.
- Inform the neighbourhood and local authorities: knowing there is a child who might wander off helps in case of need.

Part 4 — Schooling

School is a subject that causes a lot of anxiety for parents. Which setting? What pace? What to do if the school refuses? This part explains the general principles, which hold in most countries. For the exact rules and rights where you live, ask your national autism association.

Early years: the options

In most countries, education becomes compulsory at a young age. For an autistic child, several options exist. The names differ from country to country, but they generally fall into the following categories.

Setting	Description	Who it is for
Mainstream class	An ordinary class, with or without a support worker	Mild to moderate profiles
Specialist unit within a mainstream school	A specialised class inside an ordinary school	Moderate profiles
Specialist school	A full-time specialised setting	Profiles needing more support
Intensive autism teaching unit	A dedicated, structured unit	Profiles needing an intensive framework
Support service into the home/school	A service that supports the child alongside their setting	A complement to the other settings

Best practice recommends mainstream schooling whenever it is possible, with the necessary support. An inclusive school is better than an overly closed setting — unless the child is genuinely not happy there.

The school support worker

A school support worker is an adult who helps the child in class. They do not teach: they accompany, translate, reassure, prevent meltdowns and help the child follow instructions.

How to obtain one

1. Have the need recognised by the authority that assesses disability support in your country (in your file, explicitly request a support worker).
2. The authority states the need: “support worker, X hours per week.”
3. The school education service then allocates an available support worker.
4. Waiting time: from a few weeks to several months depending on where you live. This is one of the weak points of many systems.

How to make good use of one

- Meet the support worker on the first day. Introduce your child: what they like, what they avoid, their warning signals.
- Give them the visual schedule, the tools, the social stories you use at home.
- Ask for a 5-minute weekly check-in at pick-up. It will be precious.
- The support worker does not replace the teacher: they assist them. Stay in contact with the teacher too.

The individual education/support plan

An individual education plan is an official document that says: here are this child's needs at school, here are the adjustments to put in place.

It defines: the class, the amount of schooling time, the human support (a support worker), the material support (tablet, ear defenders), the teaching adaptations (simple instructions, extra time) and the yearly objectives.

It is reviewed each year in a meeting that brings together the family and the school team — a meeting you take part in, by right.

> **VALENTINE'S TESTIMONY — Our first review meeting**
>
> At the first school review meeting, I was alone facing 8 adults: the teacher, the support worker, the head, the school psychologist, the special-needs co-ordinator, the school doctor, two from the support service. I didn't dare say anything.
>
> Today, I would give you two pieces of advice. One: prepare in writing, list your 3 priority subjects. Two: ask to be accompanied by an association or a person you trust. You have the right. And no one should be alone in that room.
>
> *— Valentine, Sasha's mum*

What to do if the school says no

It happens. Some schools, especially private ones, do not want to take in an autistic child, or refuse a support worker, or ask for part-time schooling "just in case."

Your rights

In most countries, a public school cannot refuse to enrol a child because of their disability — that is the law. Private schools that receive public funding usually have to take in any child, except for a genuine, written educational reason. And any reduction in schooling time should be justified by the assessing authority, not by the school alone. Ask your national autism association for the exact rules where you live.

What to do concretely

1. Ask for everything in writing (email). Note the name of the person, the date, what is said.

2. Contact the special-needs coordinator or the mediator between families and schools in your area.
3. Contact the regional education service that handles inclusive schooling.
4. Contact a parents' association to support you.
5. If nothing moves, escalate to the education ombudsman or a rights-defence body in your country.

Specific cases: nursery, private school, home education

Nursery before school age

The same right to be taken in as any other child, with an individual reception plan signed by a doctor. You can request a support worker for certain times. Find out from your local authority.

Private school

With public funding: rights close to those of public schools, but cooperation varies. Fully private: no obligation, and the fees may not be covered by disability support. To be considered case by case.

Home education

In many countries, home education is possible and a child's disability is one of the recognised grounds. It is a demanding option (one parent dedicates their day to it) but sometimes the best one when school does not keep up. Find out from your national home-education and autism associations.

The transition to primary school

The move from the last preschool year to primary school is one of the most delicate moments for an autistic child. A new teacher, new classmates, new demands (staying seated, following long instructions, writing). It needs to be prepared.

- From several months ahead, ask for a meeting with the new class or school, even if the child stays in the same school: a new team, often a new building.
- Visit the premises several times over the summer (with the agreement of the management).
- Build a presentation booklet about your child for the new teacher: photo, what they like, their warning signs, their tools.
- Keep the support worker if there was one. If they change, ask for a handover.
- Anticipate reading-and-writing difficulties: pre-writing practised the year before, sounds worked on at home or in speech therapy.

Secondary school: another universe

The move to secondary school frightens many parents. More teachers, more subjects, more noise, more social pressure. It is manageable, provided you prepare.

- Ask for an updated education plan in the final year of primary: precise adjustments for secondary school.
- Visit the secondary school several times before the start of the year.
- Ask for an introduction to the teaching team at the start of the year (each teacher should know your child).
- Specialist support units within secondary schools exist in some systems: they can be an intermediate solution. Worth discussing.
- Keep up speech and psychomotor follow-up if necessary, even if progress seems to be there.

VALENTINE’S TESTIMONY — Starting primary school

The year Sasha started primary, I prepared a little 4-page booklet for the teacher. On the first page, a photo of Sasha smiling. Then: his strengths, his difficulties, his signals when things are going wrong, and the 5 tools that worked at home. Laminated. I handed it over in person at the end of August.

The teacher told me, in December: “I’m keeping this document for all future pupils like him.” If you make this little booklet, make it for yourself too. You will feel less alone facing the school.

— Valentine, Sasha’s mum

Part 5 — The family and you

The diagnosis does not affect only the child. It affects the couple, the siblings, the grandparents, and you first of all. This part is devoted to ALL the others, and above all to you.

The couple in the face of autism

The figures are frightening: according to several international studies (including one from a US university in 2010), the separation rate among parents of autistic children is higher than average. But this does NOT mean it is inevitable.

The classic traps

- One of the two parents throws themselves in completely, the other feels excluded or useless.
- The whole conversation revolves around the child. No more couple time.
- Sleep is fragmented: exhaustion wears everything down.
- You avoid talking about the things that cause friction (methods, school, money).
- You never do anything just the two of you anymore.

What helps

- One decision a week made together, written down, dated. This stops one person carrying the choices alone.
- One dinner a month without talking about the child. It is hard. And it is precious.
- Couples therapy, before the tensions become unmanageable. Not a sign of failure: a sign of wisdom.
- Outside support: grandparents, a trained babysitter, respite care. So you can breathe.

GOING FURTHER

Respite and temporary care

Many areas offer temporary-care services for children with a disability: a few hours, a weekend, a week. This allows parents to catch their breath.

Find out from your early-intervention service or your national autism association.

Siblings: growing up alongside an autistic brother or sister

Brothers and sisters live through something very particular. They love, they protect, and sometimes they resent. They need to be seen too.

What they often feel

- Immense pride when their brother/sister makes progress.
- A hidden jealousy: “they get more attention than me.”
- A responsibility that is too heavy: “I have to protect them at school.”

- Shame, sometimes, in public, followed by guilt.
- An early maturity, which can hide tiredness.

How to help them

- Time just for THEM, alone with each parent. At least once a week.
- True words, adapted to their age, about autism: neither hiding it, nor overdoing it.
- The right to say that they have had enough, without being told off.
- An activity that is entirely their own (sport, music, dance), completely unrelated to the disability.
- “Sibling” groups: they exist through associations. They can change their lives.

> **VALENTINE’S TESTIMONY — If you have several children**
>
> Sasha is my first. When I tell our story, I also think of all the siblings I have met. Those children who share the everyday and whom we sometimes forget.
>
> If you have several children, always keep in mind: the brother or sister of the autistic child also has the right to all of your presence. Not in equal parts (life does not work like that), but in fair parts.
>
> *— Valentine, Sasha’s mum*

Grandparents: a treasure to inform

Grandparents are often the first to see a difference, and the last to accept it. Many come to the diagnosis with their own history, their beliefs, their fears.

How to talk to them

- Announce the diagnosis face to face, calmly. Not by phone, unless distance requires it.
- Give them simple words and an official leaflet (national autism associations publish them, often free).
- Allow them to cry, to doubt, to ask “silly” questions. They too are grieving.
- Avoid long debates about the causes. On the “why,” science is young and no one knows everything.

How to involve them

- Ask them for a concrete gesture: looking after the child for 2 hours, going with you to an appointment, doing the shopping.
- Teach them the tools you use: pictograms, the visual schedule.
- Warn them about the situations to avoid (loud sounds, surprises, crowds).
- Thank them. Often. Grandparent burnout exists too.

Your OWN wellbeing: the warning signs of parental burnout

Caring for an autistic child takes incredible energy. Studies (notably from a Belgian university in 2018) show that parents of children with special needs are 2 to 3 times more at risk of parental burnout.

The signs not to ignore

- You can no longer sleep, even when the child is asleep.
- You cry over nothing, or on the contrary you feel nothing anymore.
- You feel distant from your child: you act “on autopilot.”
- You no longer want to see anyone, even your close friends.
- You have dark thoughts about yourself, about the future.
- You feel constantly guilty, whatever you do.

What to do

- Talk. To your doctor, to a psychologist, to a trusted friend.
- Ask for concrete help: home help, respite care, occasional overnight childcare.
- Cut out some activities. Not everything is mandatory.
- Move. Walk 20 minutes a day. Science is unanimous: it is as effective as many antidepressants for mild depression.

IMPORTANT — A PROFESSIONAL OPINION IS NEEDED

If the dark thoughts come back

If you have dark thoughts, urges to give up everything, or if you wonder whether you are worth anything: call. A suicide-prevention helpline in your country — see findahelpline.com — is free, available, and confidential. Tiredness and parental burnout can be treated. You deserve this help, and your child needs you alive.

Finding a support network

You should not do this alone. No parent manages alone. Here are the doors to push open.

- A local association: atmosphere, advice, shared outings.
- A large national association.
- A closed Facebook group between parents (moderated, serious): precious for everyday questions.
- A psychologist used to families with an autistic child.
- A national autism helpline: free, confidential, with trained professionals to listen. Your national autism association can give you the number where you live.

Getting organised: a typical yearly calendar

When you start out, you feel as though you are running all the time. Here is a yearly structure that helps you breathe.

Period	Key tasks
January–February	Possible renewal of assessments (speech, psychomotor therapy). Review your health insurance.

Period	Key tasks
March–April	Prepare the school review meeting if not yet done. Think about the next school level.
May–June	Check the support worker for the coming school year. Plan summer activities or respite care.
July–August	Rest as much as possible. Visit the new setting if there is a change. Prepare the welcome booklet.
September	Start of the school year. Introduction to the team. Resumption of therapies.
October–November	First review meeting. Interim assessments.
December	Take stock as a family. Prepare the files for the new year (taxes, disability paperwork if needed).

Print this table and stick it on your fridge. It becomes a useful reference point.

Preserving your social life and friendships

Many parents withdraw into themselves after the diagnosis. The declined invitations, the friends you no longer see, the weekends at home just trying to hold on. In the long run, this is dangerous for you.

- Keep at least one friendship, even a fragile one. A person to whom you can say "things are bad" without having to explain why.
- Accept short invitations (1 hour, an afternoon snack), even if your child needs to leave.
- Invite people back to your home, where it is easier to manage.
- Do not say no to every outing just for yourself. A dinner without the child is not a betrayal.
- The friendships that cannot tolerate your child: let them go, without feeling guilty.

VALENTINE'S TESTIMONY — The phone call that saved me

One evening, I was at the end of my rope. I had not slept for three nights. I called a friend who knew nothing about autism. I just told her: "I need someone to listen to me cry." She did it, without a word. For 45 minutes.

The next day, I felt better. Sometimes you do not need someone to give you advice. You just need someone to be there. Ask, without shame.

— Valentine, Sasha's mum

Part 6 — Resources

Here are reliable resources, organised by category. Because exact organisations and titles differ from country to country, this part focuses on the types of resource to look for. Your national autism association is the best starting point for the specific names where you live.

Useful associations

National associations

In most countries there is at least one large national autism federation that provides information, support and advocacy, as well as a national autism helpline. There are also broader disability organisations that cover autism among other conditions, and rights-focused associations that specialise in schooling. To find them, search online for "national autism association" plus your country, or ask your primary care doctor or your child's diagnostic team.

Finding an association by region

The simplest method: type "autism association" plus the name of your region or town into a search engine, or contact your national autism helpline, which will redirect you.

Recommended reading

Level 1 — Testimonies

- *Breaking the Codes* by Valentine Lecêtre. The story of supporting Sasha, without jargon, with the concrete tools used.
- Personal accounts by autistic adults are invaluable for understanding the autistic experience from the inside — look for well-regarded memoirs by autistic writers.

Level 2 — Methods and tools

- Practical, fact-sheet-style guides for supporting an autistic child at home.
- Books written to explain autism to the extended family and to non-autistic relatives.
- Survival guides written for autistic adults and pre-teens.

Level 3 — For professionals (also useful for motivated parents)

- University reference works on autism from childhood to adulthood.
- The official clinical-practice recommendations on autism spectrum disorder published by health authorities. These are usually downloadable for free from your national health authority's website.

Relevant podcasts

- Podcasts gathering testimonies from autistic people and families, in a journalistic style.

- Podcasts with a professional approach and an accessible tone, often produced by autism organisations.
- Science-communication programmes on neurodiversity from public radio and media.
- Independent podcasts specifically on adolescence and entry into adulthood.

Reliable websites

- Your national health authority's website: official recommendations.
- National health-research institutes: autism dossiers, research, plain-language explanations.
- Government disability portals: all the administrative rights.
- comprendrelautisme.com: plain-language explanations by professionals.
- sortirdelautisme.fr: Valentine's site, articles, testimonies, free tools.

Emergency and helpline numbers

Service	Number
National autism helpline	Ask your national autism association
Parental-crisis / family helpline	A family support line in your country
Emotional-support / befriending line	A listening line in your country
Suicide prevention	A helpline in your country — see findahelpline.com
Disability and schooling helpline	Your national education or disability service
Medical emergency	Your local emergency number

Glossary: key terms explained

The world of autism and disability has its own jargon. Here are the most common international terms.

Term	Meaning
ASD	Autism spectrum disorder
AAC	Augmentative and alternative communication
ABA	Applied behaviour analysis
ADHD	Attention-deficit/hyperactivity disorder
ADOS-2	Autism Diagnostic Observation Schedule (a standardised observation tool)
ADI-R	Autism Diagnostic Interview – Revised (a structured parent interview)
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
ESDM	Early Start Denver Model (early developmental intervention)

Term	Meaning
M-CHAT-R	Modified Checklist for Autism in Toddlers, Revised (a screening tool)
MMR	Measles-mumps-rubella vaccine
PECS	Picture Exchange Communication System
TEACCH	Treatment and Education of Autistic and related Communication-handicapped Children
WHO	World Health Organization
WISC	Wechsler Intelligence Scale for Children
WPPSI	Wechsler Preschool and Primary Scale of Intelligence

Practical appendices

Here are four ready-to-use tools, to print or copy and paste: a checklist for the first appointment with the neuropaediatrician, two letter templates, and a repertoire of phrases to respond to tiresome remarks.

Appendix 1 — Checklist: first appointment with the neuropaediatrician

Print this checklist and bring it. You can tick it off during the appointment, or give it to the professional.

To bring

- The child's health record / vaccination booklet.
- A list of developmental milestones (smile, first words, first steps, walking, word combinations).
- Short videos (30 sec) showing what worries you.
- Assessments already done (speech therapy, ENT, vision, hearing).
- A list of any medications.
- Your questions, written down, in order of priority.

Questions to ask

1. In your view, what warning signs does our child show?
2. Do you think a full evaluation at a specialist centre is necessary? If so, how do we arrange it?
3. Can we start therapies right now, without waiting for the full diagnosis?
4. Which specialists should we consult first (speech therapy, psychomotor therapy, occupational therapy)?
5. Should we apply for long-term-condition health coverage straight away?
6. What additional assessments do you recommend (hearing, vision, genetics, EEG)?
7. Can you give us a written report of the consultation?
8. Which associations do you recommend?
9. How often should we see you again?
10. Are there any warning signals that should make us seek urgent advice again?

Appendix 2 — Template letter to the disability-support authority

To adapt to your situation. To send by registered post with acknowledgement of receipt, or to hand over in person against a receipt.

> [Your surname, first name]
>
> [Address]
>
> [Phone, email]
>
> [Town, date]
>
> To the attention of the Director of [the disability-support authority]
>
> [Address of the authority]

Subject: Submission of file — Application for disability support for [Child’s first name]

Dear Sir or Madam,

I am writing to submit an application for disability support for my child [First name Surname], born on [date], who has an autism spectrum disorder diagnosed on [date] by [name of the professional and the service].

Please find enclosed all the required documents: the duly completed application form, the medical certificate, our child’s needs statement, as well as the recent medical and paramedical assessments.

Our child requires significant daily support, regular multidisciplinary therapies, and adjustments at school. I therefore ask for your kind attention in examining this file.

I remain at your disposal for any further information and thank you in advance for the attention you will give to our request.

Yours faithfully,

[Signature]

[Surname and first name]

Appendix 3 — Template letter to the school

To request a meeting, flag a need, or ask for an individual education plan to be put in place.

[Your surname, first name]

[Address]

[Phone, email]

[Town, date]

To the attention of the Head Teacher

[Name of the school]

[Address]

Subject: Request for a meeting — Setting up an individual education plan for [First name]

Dear Sir or Madam,

My child [First name Surname], born on [date], enrolled in [class/year], is being supported for an autism spectrum disorder, officially diagnosed on [date].

In order to organise their schooling as well as possible and to put in place the necessary adjustments, I am requesting a meeting with you, the class teacher, and if possible the special-needs coordinator for the area.

This meeting will allow us to consider together the setting up or updating of an individual education plan, in line with the law and with current best-practice recommendations.

Thank you for proposing several possible time slots in the coming weeks. You can reach me on [phone] or by email at [email].

Yours faithfully,

[Signature]

[Surname and first name]

Appendix 4 — Ready-made responses to tiresome remarks

You are going to hear a lot of them. At the bakery, at the family meal, at the park. Here are some calm and firm responses. No one has the right to judge you. And no one has the right to judge your child.

“He’s just shy.” “No, he has a medical diagnosis. Shyness is something else. Please respect that.”

“In my day, this didn’t exist.” “It did exist, but it was called something else. Today we diagnose it better, that’s all.”

“It’s because he watches too many screens.” “No. Autism is a neurological condition present since before birth. All the studies confirm it.”

“You should just give him a smack.” “You don’t correct a neurological condition with violence. And hitting a child is not the answer — it harms, it does not help.”

“My cousin tried such-and-such a miracle method, it fixed everything.” “Thank you, but we follow recommendations based on evidence, with a team of trained professionals. Every child is different.”

“You should put him in a special setting.” “The choice of schooling is our decision, made with our team. Please respect it.”

“You’re overdoing it.” “I am doing what is needed for my child. If one day you want to understand how, I will be happy to explain.”

“He’ll end up talking on his own.” “Maybe, maybe not. In the meantime, we are giving him all the tools. That is what science recommends.”

“It’s hard for you, isn’t it?” “Yes, it is hard. But it is also beautiful. My child teaches me a great deal.”

And the universal phrase

When you do not feel like replying, you can always say, with a smile: “Thank you for your interest. Have a good day.” And go on your way. You have NOTHING to justify.

A final word

If you have read this far, it is because you are an extraordinary parent. Not perfect — no one is. But deeply committed. And that is exactly what your child needs.

Remember:

- You did not cause your child's autism. The science is clear.
- You are not alone. Tens of thousands of parents are moving forward, and millions around the world.
- There is no one right way to do this. There is your way, which adjusts every day.
- The outlook is always better than it seems at the beginning. The plasticity of the brain is immense.
- Taking care of yourself is taking care of your child. You are not indispensable to them only in theory: you are indispensable to them ALIVE and WELL.

I wish you courage, patience, and joy. Lots of joy. Because yes, despite everything, there will be some. More than you believe on the day of the diagnosis.

VALENTINE'S TESTIMONY — Sasha today

Today, Sasha goes to school like the others. He laughs, he plays, he has friends. I do not forget the little girl — me — sitting in the car in November 2015. I would like to tell her: hold on. It will be hard, it will be long. And one day, you will be at the school gate, your son running towards you, telling you about his day.

I wish that for you, you who are reading me. And I am here, on sortirdelautisme.fr, if you need.

— Valentine, Sasha's mum

Going further

sortirdelautisme.fr

Articles, testimonies, and free resources for parents and professionals.