

# Preserve the Balance of Your Family

*Wellbeing for parents and couples living with autism*

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[sortirdelautisme.fr](http://sortirdelautisme.fr)

2026 Edition — free to share

FREE GUIDE

# Wellbeing for parents and couples living with autism

*You are not alone. You are not crazy. You are not a bad mother.*

*A guide to breathe, to recognise yourself, to rise again.*

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## Before we begin

If you are reading this guide, it is because a part of you is still searching. Searching for air. Searching for meaning. Searching to stop feeling so alone, so exhausted, so guilty. That part of you, I want to honour first. It is precious. It is what keeps you standing.

My name is Valentine Lecêtre. I am the mother of an autistic child and the founder of [sortirdelautisme.fr](http://sortirdelautisme.fr). For years, I believed that holding on was the only thing I could do. No one had told me that parents of autistic children carry a risk of burnout three times higher than average, a risk of depression doubled, a risk of separation twice as high. No one had told me that what I was feeling — the tiredness that never lifts, the anger that flares up, the marriage crumbling, the friends who no longer understand — was NORMAL.

I wrote this guide for the woman I was ten years ago. For the one who cried in her car in the speech therapist's car park. For the one who screamed at her child and then hated herself for it. For the one who no longer knew how to talk to her partner without it ending in reproach.

You will find figures here (because they ease guilt), exercises (because words alone are not enough), exact phrases for the conversations that frighten you, and reliable resources. Everything is free. Everything is printable. Everything is yours.

One last thing before you turn the page. Taking care of yourself is not selfishness. It is the very condition for being able to keep caring for your child. A drained parent saves no one. A parent who breathes does.

*Valentine*

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## Part 1 — You are not alone

*“What you are living through is not an exception. It is a massive statistical reality that no one tells you about.”*

### The figures no one tells you

Before we talk about feelings, let us talk about figures. Because a figure eases guilt. When you know that your exhaustion is not a personal weakness but a predictable consequence of an extreme situation, something loosens.

#### Parental burnout

- In the general population, around 5% of parents meet the criteria for parental burnout (research by Mikolajczak & Roskam, 2018–2022).
- Among parents of autistic children, international studies converge around 15 to 20%, that is a risk multiplied by three to four.
- Among single mothers of autistic children, some studies (Hayes & Watson, 2013; Padden & James, 2017) rise as high as 30–40% of clinically significant symptoms.

#### Depression and anxiety

- Mothers of autistic children show a risk of major depression multiplied by 2 compared with mothers of neurotypical children (meta-analysis by Yorke et al., 2018, *Journal of Autism and Developmental Disorders*).
- 60 to 70% report clinically significant anxiety symptoms (vs 20–25% in the general population).
- Fathers are not spared: their depression risk is multiplied by around 1.5, but they seek help three times less often.

#### Couple and separation

- The separation rate among parents of autistic children is estimated at 23–25% (Hartley et al., 2010, *Journal of Family Psychology*), against 13–14% among couples with neurotypical children — almost double.
- The risk increases sharply after the autistic child reaches adolescence (cumulative load plus social isolation).
- Couples who “hold on” share three characteristics: they have time together without the child, they have sought help at least once, and they have accepted that they do not experience things at the same pace.

#### Physical health

- 80% of caregiving mothers report chronic sleep disturbances (international studies suggest).
- Life expectancy reduced by 8 to 17 years for long-term caregivers (World Health Organization report on caregiver health, 2017).
- A doubling of the risk of autoimmune and cardiovascular disease after 10 years of intensive caregiving.

## **TO REMEMBER**

You are neither fragile, nor a bad mother, nor “not up to it”. You are within the statistical average of an objectively extreme situation. The figures above exist in every country studied. It is not you. It is the situation.

## **The exhausted-expert-parent syndrome**

You probably know by heart the addresses of five speech therapists, the diagnostic criteria for autism spectrum disorder, the difference between the various classroom support roles, the average waiting time for a disability assessment, picture-communication symbols, and the latest clinical recommendations. You have become, without meaning to, an expert. And that expertise is exhausting you.

The exhausted-expert-parent syndrome is not an official diagnosis, but a reality described by many clinicians. It combines:

- A permanent hyper-vigilance: watching for regressions, sensory issues, transitions, special diets.
- A colossal mental load: appointments, administrative paperwork, tracking progress, coordinating professionals.
- A cognitive loneliness: no one around you understands the terms, the stakes, the emergencies.
- A defensive perfectionism: “if I don’t do everything perfectly, my child will regress”.
- A chronic guilt: “I could have done better / sooner / differently”.

This syndrome is not a flaw. It is a coping strategy in a situation where the system around you (school, medical, social) is NOT adapted. You are compensating. And compensating wears you down.

## **A LITTLE MIRROR**

Tick in your mind, without judgement:

- I know more about autism than most general doctors I come across.
- I can no longer read a book that isn’t about autism.
- I check my child’s things three times before leaving the house.
- I find it hard to delegate, even to a caring relative.
- I feel responsible for every gain AND every setback.

## **The 5 stages of grieving the imagined child**

The word “grief” may shock you: your child is alive, they are here, you love them. And yet it is the right word. You are grieving a child imagined during pregnancy, a fantasised family life, projections of the future. That grief, like all grief, follows the stages described by the psychiatrist Elisabeth Kübler-Ross in the 1960s. Here is their adaptation to autistic parenthood.

## 1. Denial

“He will end up talking.” “It’s just a delay.” “There’s nothing autistic about him.” Denial is not stupidity: it is a mechanism of psychological protection against unacceptable information. It can last months, sometimes longer. You are not “wasting time”: your mind is adapting.

## 2. Anger

Against the doctors (“they took three years to diagnose”), against the school (“they do nothing”), against your partner (“he doesn’t get involved”), against yourself (“I should have seen it sooner”), sometimes against the child himself (and that is terribly guilt-inducing). This anger is healthy. It says that you refuse the situation as it is imposed on you.

## 3. Bargaining

“If I do 4 hours of therapy a day, he will talk.” “If I cut out gluten, he will sleep.” “If I stop working, everything will be better.” You are looking for the magic lever. You pay dearly (in money, time, health) for everything that promises a result. It is a stage of over-investment that empties you.

## 4. Sadness / depression

The moment when the evidence settles in: your child will remain autistic. They will have their own life, one that will not resemble the one you imagined. This sadness is not depressive in the pathological sense: it is a legitimate sorrow. Crying here is not a failure, it is psychological work.

## 5. Acceptance

Be careful, acceptance does NOT mean resignation. It is: “My child is who they are. I love them as they are. I keep supporting them, but without an inner war.” It is the stage where energy returns for something other than the fight.

### WHAT YOU SHOULD KNOW

These stages are NOT linear. You can return to anger after acceptance, fall back into sadness at each of your child’s transitions (starting school, puberty, end of a support programme). It is a spiral movement, not a staircase. You have failed at nothing if you cross a stage again — you cross it differently.

## Why you can’t cry (or why you cry all the time)

Two profiles I encounter constantly in support groups:

### The “blocked” profile

You haven’t cried since the diagnosis. Or for years. You tell yourself “if I start, I won’t be able to stop”. Your brain has set up what we call protective dissociation: in order

to keep functioning (managing school, appointments, work), it has anaesthetised the emotion. It's not that you feel nothing. It's that you have put a lid on it.

The risk: emotions that go uncried do not disappear, they accumulate and resurface as physical symptoms (pain, insomnia, eczema, back pain) or as sudden explosions (shouting at the child, at the partner, at the cashier).

### **The “flooded” profile**

Conversely, you cry over everything. An advert, a song, a misplaced word from a relative. You feel as if your tears are never far away. This is not weakness: it is a saturated nervous system. Your internal alarms ring constantly because they have rung for too long.

#### **EXERCISE — Recognise your profile and respond to it**

If you are “blocked”: Choose a moment alone. Put on music that used to move you (not during the crisis). Look at an old photo of yourself pregnant, or of yourself as a teenager. The goal is not to “provoke” tears, but to gently lift the lid a little, in a setting that YOU choose.

If you are “flooded”: Work on breathing through cardiac coherence (see Part 3). Limit stimuli (social media, news, long conversations). Ask yourself this question three times a day: “Right now, am I in danger?” If not, say it out loud: “I am not in danger.” The nervous system needs to hear that sentence.

### **The 12 emotions you feel you're not allowed to feel (and that are normal)**

No one will tell you, but here is the list of “taboo” emotions that are in fact shared by almost all parents of autistic children. Naming them is the start of defusing them.

1. **The urge to run away** — Imagining taking the car and never coming back, just for a day. This urge does not mean you don't love your child. It means you are out of resources.
2. **Jealousy of other parents** — When you see a neurotypical child make progress “all on their own”. This jealousy is the expression of grief, not of meanness.
3. **Relief when the child is at school / with the other parent** — Feeling better when the child is not there is not rejection. It's your nervous system finally getting a pause.
4. **Social shame** — No longer daring to invite people over, no longer daring to go to a restaurant, lowering your eyes in supermarkets. This shame comes from others' gaze, not from you.
5. **Anger at the child** — When they have the same meltdown for the 14th time. This anger does not make you a bad mother. It says you have no reserves left.
6. **Guilt over loving the siblings more / less** — Loving differently is human. Loving the one who demands less is understandable. You are not a monster.
7. **Wishing they didn't exist** — One of the most taboo emotions. It crosses the mind of a majority of parents at least once. It speaks of exhaustion, not of rejecting the child.
8. **Resentment towards your partner** — When he comes home from work and “sits down”. When he doesn't see. When he sleeps through the night. This resentment

says: "I am alone."

9. **Fear of the future** — What will happen when I am no longer here? This fear is legitimate. It deserves to be addressed, not repressed.
10. **Nostalgia for your former life** — The carefree days, the spontaneous outings, the easy friendships. Grieving your former life is not betraying your child.
11. **The urge to walk away from everything** — The job, the relationship, sometimes parenthood. This urge is an alarm signal, not a decision. It says: "I need help NOW."
12. **Indifference** — Feeling nothing anymore, neither joy nor sorrow. This is the sign of a deep dissociation. This is the moment to seek help.

### TO REMEMBER

None of these 12 emotions makes you a bad mother. They make you a human being in an extreme situation. The only danger is keeping them to yourself. The name of an emotion, said out loud (to a therapist, a friend, a group), loses 50% of its destructive power. This is neurobiological (Lieberman, UCLA, 2007).

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## Part 2 — Recognising exhaustion

*"We only heal well what we name."*

Parental burnout is still poorly understood. It was scientifically defined by the researchers Isabelle Roskam and Moïra Mikolajczak from 2017 onwards. It is distinct from depression: it is confined to the parental role. You can be exhausted as a mother without being exhausted at work, and vice versa.

It has 4 dimensions:

- **Exhaustion:** you are drained by the parental role.
- **Emotional distancing:** you go through the motions but without pleasure, without tenderness, on autopilot.
- **Loss of effectiveness:** you feel you are no longer a good mother, that you can no longer manage anything.
- **Contrast:** "I used to be a good mother, now I don't recognise myself."

### Self-assessment: am I in parental burnout?

This questionnaire is inspired by the PBA (Parental Burnout Assessment) by Roskam & Mikolajczak (2018). It is not a diagnosis — only a professional can make a diagnosis — but it gives you a reliable indicator and a starting point.

Answer each item with a number from 0 to 4:

- 0 = never / 1 = a few times a year / 2 = a few times a month / 3 = every week / 4 = every day

*To print and fill in with a pencil:*

No.	Statement	0 to 4
1	I feel completely exhausted by my role as a parent.	
2	I feel I have lost all patience with my child.	
3	I do things “out of duty”, with no pleasure left.	
4	I hear myself shouting when I had sworn never to do it again.	
5	I no longer recognise myself in the mother I have become.	
6	I dream of leaving, just to catch my breath.	
7	I feel indifference when my child is sad or happy.	
8	I feel constant guilt about being a bad mother.	
9	In the morning, I dread the day ahead.	
10	I have sleep problems I didn’t have before.	
11	I have gained or lost weight without meaning to.	
12	I isolate myself from my friends, I no longer want to see anyone.	
13	I have no more drive, no plans, no desires for myself.	
14	I cry easily OR I can no longer cry at all.	
15	I feel incompetent in the face of my child.	
16	I consume more alcohol, tobacco, sugar or medication than before.	
17	I have intrusive thoughts (imagined catastrophes, dark thoughts).	
18	My relationship is suffering: we talk little, touch little, blame each other.	
19	I no longer know what would do me good.	
20	I sometimes think my family would be better off without me.	

**How to interpret your score**

- **0 to 20: Green alert.** You are holding on, but don’t drop your guard. Keep up breathing and sleep rituals.
- **21 to 40: Yellow alert.** First signs of exhaustion. Put 2-3 tools from Part 3 in place this week.
- **41 to 60: Orange alert.** Parental burnout is likely. Consult your primary care doctor and talk to a psychologist.
- **61 to 80: Red alert.** Severe burnout. Seek help urgently. If you work, you have the right to take medical leave. You have the right to help.

**Important:** question 20 (“my family would be better off without me”) counts DOUBLE. If you answered 3 or 4, seek help without waiting for the other answers. It is a warning

signal that alone justifies a consultation.

## The 8 physical signs of parental burnout

The body speaks when the mind no longer listens. Here are the eight signals your body sends you.

1. **Degraded sleep** — Difficulty falling asleep, night-time waking, non-restorative sleep, night eating.
2. **Chronic pain** — Back, neck, jaw (teeth grinding), stomach, migraines. The body carries the tension we don't put down.
3. **Falling immunity** — Recurrent colds, cold sores, fungal infections, worsening allergies: chronic cortisol exhausts the defences.
4. **Digestive problems** — Irritable bowel, heartburn, bloating, morning nausea. The gut is the "second brain".
5. **Weight changes** — Rapid gain or loss. Sugar overeating (comfort) or loss of appetite (anxiety).
6. **Skin problems** — Eczema, psoriasis, hives, hair loss, brittle nails. The skin expresses stress.
7. **Cycle / libido disturbances** — Irregular cycles, painful periods, a marked drop in sexual desire.
8. **Underlying exhaustion** — Fatigue present from the moment you wake. Coffee no longer helps. Weekends no longer rest you.

## The 8 psychological signs

1. **Loss of vital drive** — Nothing makes you want anything anymore. Things that used to bring you pleasure leave you indifferent.
2. **Intrusive thoughts** — Catastrophic scenarios that loop, sometimes at night, sometimes in broad daylight.
3. **Explosive irritability** — You shout over a spilled glass, you slam a door, you silently curse the cashier.
4. **Anhedonia** — Inability to feel pleasure. You eat without tasting, you make love without feeling, you laugh without laughing.
5. **Cognitive fog** — You search for your words, you forget appointments, you reread the same sentence three times.
6. **Hyper-vigilance** — You jump at the slightest noise. You anticipate the meltdown before it happens. You sleep with one eye open.
7. **Feeling of unreality** — You watch yourself live from the outside. You function like an automaton. Depersonalisation is a serious signal.
8. **Dark thoughts** — Thoughts that life no longer has meaning, that everything would be simpler without you. RED SIGNAL — seek help.

## The 8 relational signs

1. **Social isolation** — You decline invitations, you no longer reply to texts, you pick up the phone less.
2. **Conflicts in the relationship** — Reproaches, silence, physical distance, taboo subjects piling up.

3. **Parental disengagement** — You go through the motions but without tenderness. You respond mechanically to the child’s requests.
4. **Cynicism towards professionals** — “They’re useless anyway.” You criticise everything, you no longer trust.
5. **Feeling of being misunderstood** — “No one can understand.” You stop explaining, you cut yourself off.
6. **Envious comparison** — You hate the social-media posts of “perfect” parents. You envy your sister who has neurotypical children.
7. **Hostility towards the siblings** — Without meaning to, you are harder on the autistic child’s brother/sister. You ask too much of them.
8. **Breakdown with your family of origin** — “They understand nothing.” Conflicts with parents, in-laws, brothers and sisters.

### When to seek help urgently: the red signals

#### **WARNING SIGNALS — You must seek help NOW**

If you recognise EVEN ONE of these signals, contact your primary care doctor today, or call a suicide-prevention helpline in your country (see [findahelpline.com](http://findahelpline.com)), available free and around the clock.

- Suicidal thoughts, even fleeting ones (“if I no longer existed”).
- Thoughts of harming your child or yourself (slapping, shaking, hurting).
- Total insomnia (less than 3h of sleep) for more than 5 days.
- Prolonged sensation of unreality (you no longer recognise yourself in the mirror).
- Rapid increase in your use of alcohol, medication, drugs.
- Uncontrollable crying that lasts several days.
- A sense of physically breaking down (constant dizziness, palpitations).
- Thoughts that “my family would be better off without me”.

Asking for help is not a failure. It is precisely what a responsible parent does to protect their family.

#### **EMERGENCY CONTACTS — TO SAVE IN YOUR PHONE**

- A suicide-prevention helpline in your country (free, confidential, 24/7) — find it at [findahelpline.com](http://findahelpline.com)
- Your local emergency number (for a life-threatening emergency)
- Your national autism association’s helpline (information and support)
- A domestic-violence helpline in your country (if the family situation becomes unsafe)
- An emotional-support / listening line in your country (anonymous)

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## Part 3 — The anti-collapse toolkit

*“You cannot pour water from an empty jug.”*

This part is the most practical of the guide. You will find 10 tools that have been tested,

clinically validated, and can be applied TODAY. You don't have to do everything. Choose 2 or 3 to begin with. Consistency is a thousand times better than perfection.

## **Tool 1 — Cardiac coherence**

Cardiac coherence is a breathing technique that has been scientifically validated (meta-analyses 2014–2020). In 5 minutes, it lowers cortisol (the stress hormone) by 20 to 25% and raises DHEA (the youth hormone). It improves sleep, blood pressure, mood, and concentration.

### **Protocol 365 (the simplest)**

- 3 times a day
- 6 breaths per minute (= 5 seconds in / 5 seconds out)
- For 5 minutes

### **Protocol 4-7-8 (for falling asleep)**

- Breathe in through the nose for 4 seconds
- Hold the breath for 7 seconds
- Breathe out slowly through the mouth for 8 seconds
- Repeat at least 4 times. Do this lying down, lights off.

### **Protocol 4-6 (for acute anxiety)**

- Breathe in for 4 seconds
- Breathe out for 6 seconds (a longer out-breath than in-breath activates the parasympathetic system)
- For at least 3 minutes, in the car, in the bathroom, anywhere.

### **EXERCISE — Guided cardiac coherence**

Sit down, feet on the floor, back straight. Put one hand on your belly. For 5 minutes:

- Breathe in through the nose, expanding the belly — count mentally 1-2-3-4-5
- Breathe out through the mouth, deflating the belly — count 1-2-3-4-5

If you lose track, start again. It doesn't matter. Many free apps offer guided cardiac-coherence sessions; choose one that is ad-free.

## **Tool 2 — The morning check-in in 3 questions**

Five minutes in the morning, before the child, before the phone. Ask yourself these three questions quietly or in writing in a notebook.

1. How am I physically this morning, out of 10? (energy, pain, sleep)
2. How am I emotionally, out of 10? (joy, calm, sadness, anger?)
3. What can I do TODAY, even something tiny, that would do ME good?

Why it works: naming your starting state lets you adjust your expectations. If you are at 3/10 physically, you won't ask the same of yourself as if you were at 8/10. You stop judging yourself on a scale that isn't your scale for the day.

### Tool 3 — The micro-victory gratitude journal

Not "Instagram" gratitude. Not "I am grateful for the sun." Concrete PARENTAL gratitude. Every evening, write 3 lines:

- One thing you managed today (even tiny: "I had my shower").
- One thing your child managed ("he looked at his sister for 2 seconds").
- One thing for which you tell yourself well done ("I didn't shout at 4pm when I could have").

A validated study (Emmons & McCullough, 2003): 3 weeks of practice = a measurable drop in depressive symptoms, improved sleep, increased perceived patience.

#### EXERCISE — My journal for the week

Print this page and use it for 7 days. Don't judge yourself if you skip a day. Pick it up again the next day.

MONDAY: \_\_\_\_\_  
TUESDAY: \_\_\_\_\_  
WEDNESDAY: \_\_\_\_\_  
THURSDAY: \_\_\_\_\_  
FRIDAY: \_\_\_\_\_ SATUR-  
DAY: \_\_\_\_\_ SUNDAY:  
\_\_\_\_\_

### Tool 4 — The 2-minute micro-pause

You don't have 30 minutes. You have 2 minutes. Those 2 minutes are enough to slow your heart rate, get out of "emergency mode" and reconnect with yourself. Do it in the bathroom, in the car, in the kitchen while the dough is baking.

#### 2-MINUTE MEDITATION (to print)

Minute 1 — The body Close your eyes. Place both feet flat on the floor. Feel the contact of your feet with the ground. Move up mentally: calves, thighs, pelvis, belly, back, shoulders, jaw. At each area, ask: "Is this tense?" If so, breathe out into it.

Minute 2 — The breath Count 5 full breaths. On the in-breath, say in your head: "I welcome." On the out-breath, say: "I release." At the end, open your eyes. You are back.

### Tool 5 — Self-compassion (Kristin Neff)

Kristin Neff, an American researcher, has shown that self-compassion protects against burnout better than self-esteem. Three pillars: kindness towards oneself, recognition of shared humanity, mindful awareness of emotions.

### **Exercise 1 – Hand on the heart**

When you feel a difficult emotion rising, physically place your right hand on your heart or belly. Say quietly to yourself: “This is a hard moment. Many mothers go through this. May I be gentle with myself.” This gesture activates oxytocin (the attachment hormone) in 30 seconds.

### **Exercise 2 – The letter to yourself**

Write a letter to yourself as if you were writing to your best friend who is going through exactly the same thing as you. What would you say to her? You would be infinitely gentler with her than with yourself. Read this letter out loud. What you offer to others, you can offer to yourself.

### **Exercise 3 – The self-compassion break**

Three sentences to say in hard moments:

- “This is a moment of suffering.” (mindfulness)
- “Suffering is part of life.” (shared humanity)
- “May I be gentle with myself right now.” (kindness)

### **Tool 6 – Unplugging toxic thoughts (CBT method)**

Cognitive behavioural therapy (CBT) has shown that our emotions do not come from events, but from what we TELL ourselves about events. Changing our thoughts changes our emotions.

Here are 5 frequent toxic thoughts in parents of autistic children, and their reframes:

Toxic thought	Reframe
“If I don’t do everything, my child will regress.”	“I do what I can. No parent does everything. My child also has their own resources.”
“I am a bad mother because I shouted.”	“I shouted because I was exhausted. Shouting does not make me a bad mother; it says I need help.”
“No one can understand.”	“Many mothers go through this. I can find my group, my friend, my therapist.”
“I have no right to be tired, others have it worse.”	“My suffering is legitimate, regardless of others’. Comparing relieves no one.”
“If I take time for myself, I am selfish.”	“Taking time for myself makes me available for my child. It’s not a luxury, it’s a necessity.”

## Tool 7 — The liberating “no”

You are probably an expert at “yes”. Yes to extra appointments, yes to the exhausting family party, yes to friends asking a favour, yes to the school’s requests. Saying no is not unkind. It is the most protective act you can perform.

### What you can say no to without guilt

- Social invitations that cost you more than they give.
- Too many medical or therapy appointments in one week — spreading them out is better than stopping.
- Unsolicited advice from your mother-in-law, the neighbour, the colleague.
- Toxic group chats (competing parents, a stressful school, a conflict-ridden association).
- Non-negotiable professional demands if they are finishing you off.
- The idea that “everything must be perfect” for Christmas, the birthday, the holidays.

#### PHRASES FOR SAYING NO WITHOUT APOLOGISING

“I can’t, I’m sorry.” “It’s not possible for me this week.” “I’d rather decline, but thank you for thinking of me.” “I need to preserve my energy right now.” “No, not this time.”

You don’t have to justify yourself. “No” is a complete sentence.

## Tool 8 — Building your personal mantra

A mantra is a short sentence, in the first person, present tense, that you repeat to yourself in hard moments. It acts as an anchor in the storm. Not an empty new-age affirmation: a truth you CHOOSE to remind your brain of.

### Method in 4 steps

1. Identify your main fear (e.g. “I won’t make it”).
2. Flip it into strength (e.g. “I have already been through far worse”).
3. Make it concrete (e.g. “I have already held on for 5 years, I can hold on today”).
4. Reduce it to 5-7 words (e.g. “I hold on, one day at a time”).

Examples that work (tested in parent groups):

- “I am doing my best. It is enough.”
- “My child does not need a perfect mother, they need a present mother.”
- “One meltdown is not a whole life.”
- “Today, I breathe. Tomorrow, we’ll see.”
- “I am exactly the mother they need.”

## Tool 9 — The weekly 30-minute ritual just for you

Thirty minutes a week. Non-negotiable. Blocked in your diary like a medical appointment. Not for the house, not for the shopping, not for paperwork: for YOU.

## Rules of the ritual

- The same day, the same time, every week (the brain loves rituals).
- If possible, away from home (café, park, bookshop, gym).
- Phone on airplane mode or left at home.
- An activity that you CHOOSE, not one imposed on you.
- If an emergency cancels it, reschedule it within 48 hours, not the following week.

## 30 ritual ideas (draw from the list)

Walk alone · read a novel at a café · have a cup of tea with a friend · do yoga · draw · keep a journal · go to the hairdresser · take a long bath · listen to a podcast not related to autism · photograph flowers · swim · meditate · pray (if you believe) · cook for pleasure (not for the family) · go to a concert · visit a museum · garden · sing · dance in the living room · buy a plant · do a puzzle · knit · embroider · go to the library · do a facial · go for a walk in the forest · write to an old friend · tidy one drawer (and only one!) · listen to a whole album without interruption · do nothing.

## Tool 10 — The apps that really help

Wellbeing apps do not replace human support, but they help out at 3am when no one is reachable.

### RECOMMENDED APPS (free or freemium)

- **Insight Timer** — The world's largest FREE library of meditations. Search "parent burnout" or "self-compassion".
- **Guided-breathing apps** — Look for a free, ad-free cardiac-coherence app. Essential.
- **Calm** — Bedtime stories read by soothing voices (also useful for the child).
- **Mood-tracking apps (e.g. Daylio)** — An ultra-quick mood journal (10 seconds a day). Spots patterns over the month.
- **General meditation apps** — Many offer dedicated programmes for parenting, anxiety and sleep, often with a few free sessions before any subscription.

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## Part 4 — The couple

*"The couple is not the victim of autism. It is the victim of the things left unsaid around autism."*

An autism diagnosis is a shockwave that runs through the couple. You are not alone in noticing that your relationship is suffering: the figures are clear (separation rate x2). This part will not tell you "everything will be fine". It will give you precise tools to UNDERSTAND and to TALK.

## **The 5 mistakes that kill the couple facing autism**

### **Mistake 1 – Becoming co-therapists instead of staying lovers**

You talk about therapy methods, paperwork, speech therapy and regressions at breakfast, at dinner, in the car, in bed. The child has colonised the couple's space. You are no longer two adults in love, you are two tired teammates. Solution: set up AUTISM-FREE TIME (see Mistake 5).

### **Mistake 2 – Keeping an invisible scorecard**

"I did 3 appointments this week, he did none." "I handled the meltdown last night, your turn tonight." The scorecard kills. It turns the couple into permanent arbitration. No one wins. Solution: get out of the scorecard through an honest conversation (see Conversation 3 below).

### **Mistake 3 – Believing the other should guess**

"If he really loved me, he would see that I'm exhausted." No. He won't see. He too is in cognitive overload. Asking explicitly is not a weakness, it's a relational skill. Solution: say what you expect, in a short sentence, in the present.

### **Mistake 4 – Never touching each other anymore (and confusing cuddles with sex)**

Non-sexual physical contact collapses: no more hand on the back in the kitchen, no more morning kiss, no more cuddle while watching a film. Tender touch maintains oxytocin. Without it, bodies become strangers. Solution: at least 6 non-sexual touches a day (hand, shoulder, forehead, kiss).

### **Mistake 5 – Postponing the couple until "things get better"**

"We'll go out when he sleeps through the night." "We'll go away for a weekend when he's in school." Spoiler: things won't get "better" in the sense you mean. They will evolve, differently. If you wait, in 5 years there will be no couple left to save. Solution: act NOW, even imperfectly.

## **Why you don't react the same way**

This difference is one of the most painful shocks for the atypical parental couple. One cries, the other hides in work. One seeks a diagnosis, the other refuses it. One joins groups, the other withdraws. It is not a lack of love. It is neurobiology.

## **The figures**

- Mothers seek professional help 3 times more often than fathers for a child's disorder (international studies suggest).
- Mothers spend on average 2.5 times more time in direct care of the autistic child.
- Fathers take on average 18 months longer than mothers to accept the diagnosis (Pelchat & Lefebvre, 2004).

## **The neurobiology (very simplified)**

Under chronic stress, the female brain (on average, with enormous individual variation) tends to activate the “tend-and-befriend” response (caring, gathering, talking). The male brain tends to activate the “fight-or-flight” response (fighting or fleeing). That is why you want to talk and he wants to “not talk about it right now”.

Neither strategy is better. They are complementary. But they can be experienced as a mutual abandonment if we don’t name them.

### **TO SHARE WITH YOUR PARTNER**

“I am not asking you to react like me. I am asking that we accept that we don’t react the same way — and that we turn it into a strength, not a wall.”

## **The 4th wheel: the diagnosis that invites itself into the couple**

In a classic parental couple, there are three entities: you, him, the child. With autism, a 4th wheel appears: THE DIAGNOSIS. It takes a seat in the couple’s car. It weighs. It steers the conversations, the holidays, the weekends, the friendships, the finances.

Naming it out loud is the beginning of putting it back in its place. The diagnosis is a reality of your life. It is not THE reality of the couple. You also exist outside of it.

### **COUPLE EXERCISE — Uninviting the 4th wheel**

In the living room, sit facing each other for 30 minutes. On a sheet of paper draw a circle (you), another circle (the child), another (the diagnosis).

Question 1: Where is the diagnosis in our current life? At the centre? To the side? Question 2: Where would we like it to be in 6 months? Question 3: What concrete steps this week to move it a few centimetres?

## **The 5 conversations to HAVE (exact phrases)**

Here are the five hardest conversations, with the exact phrases that work. Adapt them to your voice, but keep the structure: emotion in “I”, a concrete request, an opening.

### **Conversation 1 — “I can’t take it anymore”**

The trap: starting with “YOU” (“you don’t help me”, “you see nothing”). The other shuts down.

#### **SAY INSTEAD**

“I need to talk to you about something important. I’m not blaming you for anything, I just need you to listen to me for 10 minutes without replying.”  
“I’ve reached a point where I can’t take it anymore. Not of you. Not of our child. Of the sheer amount of things I’m being asked to carry.” “I don’t want a solution right now. I want you to know that it’s serious. And for us to set aside a moment this week to talk about it again.”

## **Conversation 2 – “I feel alone”**

The trap: the other takes it as an attack (“but I’m here!”).

### **SAY INSTEAD**

“When I say I feel alone, I’m not saying you’re not there. I’m saying that in my head, in my fears, in my tiredness, I am alone.” “What would help me is for you to ask me this question once a week: how are YOU? — not how is the child, not how is the house. How am I.” “And for you to listen to the answer, even if it’s long, even if I cry.”

## **Conversation 3 – “You do less than me” (without falling into the scorecard)**

The trap: listing what you do vs what he does. You end up competing.

### **SAY INSTEAD**

“I don’t want us to keep score. Keeping score moves nothing forward. But I need us to look together, over a typical week, at who carries what.” “Not to blame you. So we can reorganise. Because the current split — I can’t hold up under it.” “Which regular appointment will you take? Which paperwork will you handle? Which evening alone with the child so I can go out? We write it down, we sign it, we try for 1 month.”

## **Conversation 4 – “We don’t do anything together anymore”**

The trap: nostalgia + reproach (“we used to…”). It paralyzes.

### **SAY INSTEAD**

“I’m not asking you to resurrect our former life. I know it no longer exists.” “I’m asking us to invent a new one. ONE thing a week that we do just the two of us. Even 1 hour. Even a coffee.” “You choose this week, I choose next week. We try for 1 month. If after 1 month it hasn’t worked, we talk about it again.”

## **Conversation 5 – “And us, in all of this?”**

The most important conversation. To have at least twice a year. Not in the bedroom. Not after a meltdown. Outside, in a neutral café, no phones.

### **SAY INSTEAD**

“We’re going to spend an hour talking about US. Not about the child. Not about the diagnosis. About the two of us, as a couple.” “3 questions each, in turn: What do you still love about us? What do you miss? What do you want us to try in the next 6 months?” “We don’t judge the other’s answer. We listen. And afterwards we decide ONE thing together.”

## **The 1-outing-per-month calendar (minimum)**

One couple outing per month, away from home, without the child. Non-negotiable. It is the DIFFERENCE between couples who hold on and those who break.

## How to organise it concretely

- Block 12 dates in the year, starting in January, in your shared calendar.
- Find a stable childcare solution: grandparents, a babysitter trained in supporting autistic children (family-support associations often offer this), respite care.
- If no solution: go out after the child is asleep (2 quiet hours at a bar or restaurant at 9pm).
- Vary it: restaurant, walk, cinema, concert, a simple coffee — what matters is not the luxury, it's the regularity.
- Golden rule: during this outing, talking about the child is FORBIDDEN for the first 30 minutes.

### RESPITE AND RELIEF CARE

Many countries offer respite support to family carers — ask your national autism association or the disability/carer support available in your country.

Local autism associations often provide trained babysitting.

Some areas offer at-home respite schemes that let a trained carer take over for a few hours.

Depending on where you live, respite care may be included in a personalised support or care plan — check what is available in your country.

## Sexuality: what you should know

The taboo subject par excellence. And yet it is one of the most reliable barometers of a couple's health. The figures:

- In couples who are parents of autistic children, the rate of sexual avoidance (more than 3 months without an unwanted abstinence) is around 50-60% (vs 15-20% in the general population, meta-analysis Hartley 2010-2018).
- The main causes: exhaustion (no. 1), loss of desire (no. 2), unresolved conflicts (no. 3), a body inhabited by the child 24/7 (no. 4).
- The risk: confusing a drop in desire with the end of love. They are two different things.

## How to rekindle it (without turning it into an obligation)

The "3 zones" rule, to be respected in this order:

1. **ZONE 1 — Non-sexual contact:** touching in the kitchen, sleeping skin to skin, holding hands at the cinema. Rebuild the bridge.
2. **ZONE 2 — Sensory intimacy:** massages, showers together, prolonged eye contact, kisses (with no expectation).
3. **ZONE 3 — Sexuality:** only when zones 1 and 2 are rebuilt. Not before. Otherwise = obligation = it makes things worse.

If the drop in desire persists for more than 6 months and causes you distress: couple sex therapy is very effective (60-70% improvement in 8-10 sessions). Look for a qualified sex therapist or couple therapist in your area.

## When to seek couple therapy

### SIGNS THAT IT'S TIME TO SEEK HELP

- You haven't had a conversation UNRELATED to the child in more than a month.
- You no longer sleep in the same room (apart from nights with the child).
- You avoid being alone together.
- The conflicts always centre on the SAME subjects, for months.
- One of you is considering leaving / an affair has happened / verbal abuse is setting in.
- You function like flatmates, no longer like a couple.

### How to choose a couple therapist

- Prefer a clinical psychologist with recognised training (Gottman, EFT, systemic).
- Ideally trained in parenting children with special needs (so you don't have to explain everything).
- The first session tests the "connection": if either of you doesn't feel at ease after 2 sessions, change.
- Check what couple-therapy or counselling support may be partly covered by the health or carer support available in your country.

### If the other parent is absent, in denial, or angry

Three very common situations, and what they really say.

#### The ABSENT other parent

He works too much, he often goes out "to see friends", he escapes into screens. It is not necessarily a lack of love: it is often an avoidance strategy in the face of a reality he doesn't know how to confront. What to do?

- Name it factually: "you're not home 4 evenings out of 7 this week." No accusation, just figures.
- Ask him: "what's going on for you right now?"
- Offer him a PRECISE and SINGLE responsibility (1 appointment, 1 evening of child-care, 1 piece of paperwork).
- If nothing changes within 3 months: couple therapy is mandatory before making any decision.

#### The other parent in DENIAL

"He's not really autistic." "It's a phase." "You're overdoing it." Denial is a mechanism of psychological protection. It can last years. What to do?

- Do NOT force him to accept: it creates counter-denial.
- Share ONE single document at a time (not 50 articles).
- Invite him to ONE single appointment (with the specialist, not an activist).

- Keep going with the steps yourself without waiting for him. He can join when he is ready.
- If the denial puts the child in danger (refusing care, refusing suitable schooling): family mediation, or even legal proceedings.

### **The other parent in ANGER**

Anger at the doctors, at the school, at society, sometimes at the child himself. Anger is often grief that has found no other way out. What to do?

- Don't argue in the heat of anger: "we'll talk again when you're calm."
- Suggest a sport, a physical activity (anger needs to be housed in the body).
- If there is verbal or physical violence: contact a domestic-violence helpline in your country and seek immediate help.
- Steer him towards a therapist (anger-management groups exist in many places).

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## **Part 5 — Brothers and sisters**

*"The brothers and sisters of autistic children are not spectators. They are co-actors in a story they did not choose."*

Siblings are often the forgotten ones of the family system. Adult too soon, too well-behaved, too responsible, sometimes too quiet. This part gives you markers to protect them without sacrificing them, and to love them without confusing them with a second helper.

### **The "parent" brother / sister: how to avoid it**

The phenomenon is well known: a brother or sister of an autistic child sometimes develops a "para-parental" stance. He/she:

- Watches over their autistic brother/sister without being asked.
- Anticipates their meltdowns, their needs, their emotions.
- Makes themselves "invisible" so as not to overload the parents.
- Succeeds (too well) at school, is (too) well-behaved, is (too) sensible for their age.

On the surface, it's wonderful. In reality, it's a warning signal. The child has given up part of their own childhood. Studies (Mascha & Boucher, 2006; Cuskelly, 2016) show an increased risk of depression and anxiety in adolescence for these "parentified" children.

### **What you can do starting today**

- Say explicitly: "YOU are not responsible for your brother / sister. That is OUR role, mum and dad's."
- Politely forbid them from playing the supervisor ("thank you, but that's my job").
- Ask them regularly: "And you, are you okay? Don't answer quickly, take your time."
- Reserve exclusive time for them (see below).

- Don't systematically rely on their adult-like qualities ("thank goodness you're here").

## **The 7 topics to discuss with siblings (by age)**

Here are seven topics to address, adapted by age. Not talking about them doesn't make them disappear: they stay in the child's head, in silence.

### **1. What is autism? (ages 3-6)**

In simple words: "His brain works differently. He finds it hard to understand words, to cope with noise, to say what he feels."

### **2. Why does he have meltdowns? (ages 5-8)**

"It's not anger against you. It's as if there were a storm in his brain. He doesn't do it on purpose."

### **3. Is it my fault? (ages 5-10)**

To be addressed EXPLICITLY, even if he/she doesn't ask the question: "It's not your fault. You didn't do anything. You can't cure anything."

### **4. Will I become autistic too? (ages 6-12)**

"No. It has been with him since he was very small. If you're not autistic now, you won't become it."

### **5. Why do you take care of him more? (ages 7-13)**

"Because he needs more help with things that are easy for you. It's not that we love you less. It's that he needs help where you don't."

### **6. How do I explain it to my friends? (ages 8-15)**

Give concrete phrases: "My brother is autistic, it means he thinks differently. If you have questions, you can ask me."

### **7. Will I have to look after him later on? (ages 12 and up)**

The CRUCIAL question of adolescence. Answer: "You can help him if you want. You are NOT obliged to. Dad and I are preparing his future with other people. You will have your own life."

## **Support groups for siblings**

Siblings need to meet other siblings. To normalise, to not feel alone, to share. It is just as effective as it is for parents.

## RESOURCES FOR SIBLINGS

- Many countries run “young carers” organisations offering camps, peer groups and resources for children supporting a sibling — ask your national autism association.
- Local autism associations often run sibling workshops in various regions.
- There are excellent picture books and young-reader novels written specifically for the siblings of autistic children — your library or national autism association can recommend age-appropriate titles.

### Exclusive time: why it’s non-negotiable

The brother or sister needs time ALONE with a parent. Not half your attention while you cook. EXCLUSIVE time: 100% for them, where they decide the activity.

### The bare minimum

- Once a week, at least 30 minutes, chosen by the child.
- Once a month, an “exclusive outing” (cinema, restaurant, walk) — 2 hours without the brother/sister.
- Once a year, a weekend or day just with them, without the autistic child.

This may seem unreachable. And yet it is the no. 1 PREVENTION against the “invisible child syndrome” that often appears in adolescence.

### EXERCISE — The special hour

Announce to your non-autistic child: “Every [fixed day], from [time] to [time], it’s OUR hour. You decide what we do. I don’t answer the phone. I don’t leave if your brother/sister cries. It’s our time.” This announcement, by itself, changes the place the child holds in the family.

### When to consult a therapist for the sibling

#### WARNING SIGNALS IN THE BROTHER/SISTER

- Persistent sleep disturbance (nightmares, insomnia).
- Regression (bedwetting, thumb-sucking, withdrawal).
- Repeated physical complaints (stomach aches, headaches).
- A drop in school performance OR, conversely, anxious over-investment in school.
- Social isolation (no longer brings friends home).
- Phrases like: “I’m useless”, “no one sees me”, “everyone only cares about him”.
- In adolescence: risky behaviour, running away, dark thoughts.

Who to turn to? A child psychiatrist or psychologist, or a psychotherapist specialising in childhood and adolescence. The sibling of an autistic child is NOT a special case for most therapists — general supportive follow-up is usually enough. Ask your primary

care doctor or your national autism association for referrals, and check what support is covered in your country.

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## Part 6 — Building your network

*“You don’t survive autism alone. You survive by surrounding yourself with the right people at the right time.”*

You have probably noticed: since the diagnosis, some friendships have dried up, others have deepened. This section helps you rebuild a network that carries you instead of weighing you down.

### The 5 concentric circles of help

Picture yourself at the centre, and around you, 5 circles. Each circle has a different function. You don’t need to fill every circle with the same people.

#### **Circle 1 — The absolute confidant(s)**

1 to 2 people max. The ones you can tell “I can’t take it anymore” at 11pm. They don’t have to understand autism. They have to love you unconditionally. Often: a childhood friend, a sister, sometimes your mother.

#### **Circle 2 — The peers (other parents of autistic children)**

Indispensable. They understand without you having to explain. Places to meet them: local associations, moderated online groups, conferences, the diagnostic pathway.

#### **Circle 3 — The professionals (doctor, therapist, association)**

Your primary care doctor, a psychologist (your own), a psychiatrist if needed, a social worker, an association contact person. Keep their numbers clearly accessible in your phone.

#### **Circle 4 — The “light” friendships**

The friends you go for a drink with without talking about autism. Indispensable too: they remind you that you exist outside the role of mother. Don’t cut yourself off from them, even if they “don’t understand”.

#### **Circle 5 — The practical contacts**

A neighbour for emergencies, a babysitter, a classroom assistant, school parents. No need for depth, but a need for reliability.

## The friend who understands / the friend who doesn't

### The friend who understands

She asks how YOU are before asking how the child is. She doesn't say "you should try...". She says "it's hard. I'm here." She doesn't judge you when you break down. She doesn't give you unsolicited advice. Those friends, keep them like treasure.

### The friend who doesn't understand

She tells you "my son has a difficult personality too". She minimises ("it's a phase"). She compares ("my neighbour has an autistic child, and he..."). She advises ("have you tried essential oils?").

What to do? THREE options depending on your energy at the moment:

1. **Patient education:** "Actually, what I'm living through has nothing to do with a difficult personality. If you want, I can explain it to you."
2. **Polite distancing:** don't cut her off, but space things out. You don't have the energy to educate everyone.
3. **Owned cut-off:** if the friendship costs you more than it gives. You have the right. It's not a failure.

### Reliable online groups (moderated)

The internet is a resource AND a trap. Unmoderated groups quickly become battlefields (methods, schools, diet, vaccines). Prefer groups that are:

- Actively moderated (the admins remove conflicts).
- Affiliated with a recognised association.
- Of a human scale (fewer than 5,000 members, otherwise it becomes unmanageable).
- With a "no proselytising about methods" rule.

#### RECOMMENDED GROUPS & FORUMS

- The official Facebook group of Sortir de l'autisme (moderated by Valentine).
- Local groups run by your national autism association's branches.
- The forum of your national autism information service (anonymous, moderated by professionals).
- Large but strictly moderated parent groups (e.g. "parents of autistic children").
- Discord and dedicated servers (increasingly, younger parents are migrating there).

### In-person association meetings

Nothing replaces a real-life meeting. Seeing another parent in the flesh say "yes, me too" is a thousand times more powerful than a Facebook message.

## **How to find an association near you**

- National directory: your national autism association's website.
- The regional autism resource centre in your area: they hold the list of local associations.
- The disability/carer support service in your country: they often list associations.
- The [sortirdelautisme.fr](http://sortirdelautisme.fr) site also lists a directory.

## **What you can find there**

- Monthly support groups (most often free).
- Parent cafés (informal, in bars and cafés).
- Conferences with professionals.
- Practical workshops (structured teaching, picture-based communication, and so on).
- Activities for the children (which frees up time for you!).

## **Individual therapy: finding the right therapist**

Individual therapy for you (not for the child, for YOU) is probably the best investment you can make. Here is how to find the right professional.

### **The profiles to prefer**

- A clinical psychologist (university degree) or a psychiatrist (a medical doctor).
- Approach: CBT (effective on burnout), EMDR (effective on the trauma of the diagnosis), systemic therapy (effective for couple/family problems), mindfulness (MBSR/MBCT).
- If possible: aware of atypical parenting (so you don't have to explain everything).

### **The signals that this is the RIGHT therapist**

- You feel in trust by the 2nd session.
- He/she doesn't give advice, but asks you questions.
- You come out tired but lighter, not crushed.
- You do NOT feel judged.
- He/she agrees to set a clear objective with you.

### **The signals that this is NOT the right one**

- He/she talks more than you.
- He/she judges you ("but you should have...").
- He/she knows nothing about autism and takes no interest in it.
- You feel worse than before after 4-5 sessions.
- He/she insists on keeping you in therapy with no clear objective.

## **How to fund it**

- Check whether your country's public health system covers a number of psychology sessions per year, sometimes with a referral from your primary care doctor.

- Private health insurance: many policies reimburse a few sessions a year. Check your contract.
- Public mental-health services: often free, but with long waiting times.
- Associations: some offer psychological support at a reduced rate.

## A recap of the contacts to save

### TO SAVE IN YOUR PHONE — NOW

- Your national autism association's helpline (information and support)
- A suicide-prevention helpline in your country (free, 24/7) — find it at find-ahelpline.com
- Your local emergency number (for a life-threatening emergency)
- A domestic-violence helpline in your country (anonymous and free)
- An emotional-support / listening line in your country (24/7, anonymous)
- A child-protection helpline in your country (for a child in danger)
- A carer-support listening line, if one exists in your country

## Appendix — Sources and resources

### Main scientific sources

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- Hartley S. et al. (2010). *The Relative Risk and Timing of Divorce in Families of Children With an ASD*. Journal of Family Psychology.
- Yorke I. et al. (2018). *The Association Between Emotional and Behavioral Problems in Children With ASD and Psychological Distress in Their Parents*. JADD.
- Padden C., James J. (2017). *Stress among parents of children with and without ASD*. JADD.
- Neff K. (2011). *Self-Compassion: The Proven Power of Being Kind to Yourself*. HarperCollins.
- World Health Organization (2017). Report on the mental health of family caregivers.
- Lieberman M. D. et al. (2007). *Putting feelings into words*. Psychological Science.

### Recommended books

- Isabelle Roskam & Moïra Mikolajczak — *Parental Burnout* (Odile Jacob, 2017).
- Kristin Neff — *Self-Compassion* (2011).
- Brené Brown — *The Power of Vulnerability* (2012).
- Christophe André — books on mindfulness and serenity.
- Valentine Lecêtre — *Breaking the Codes* (sortirdelautisme.fr).

## Useful websites

- Your national autism association's website — national federation.
  - Your country's official clinical-guidelines body — official recommendations on autism.
  - Your regional autism resource centres.
  - Your national autism information platform.
  - Your government's disability information site.
  - [www.sortirdelautisme.fr](http://www.sortirdelautisme.fr) — Valentine Lecêtre's resources.
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## To close

If you have made it this far, it is because you are searching. It is because you are not giving up. It is because something in you knows that you deserve better than exhaustion.

You deserve to be well. Not "less bad". Well.

You deserve conversations that don't revolve around the diagnosis. You deserve to have dreams that are not all for your child. You deserve a full night's sleep, a present friend, a hand in yours in the evening, silence sometimes, and a great deal of gentleness.

If this guide has helped you, share it. A friend, a cousin, a school mum. Somewhere, another woman is crying as she reads these lines, and she will feel less alone.

If you want to go further, find me at [sortirdelautisme.fr](http://sortirdelautisme.fr). Everything is free. Everything is for you.

*With all my tenderness,*

*Valentine Lecêtre*

*[sortirdelautisme.fr](http://sortirdelautisme.fr)*