A PARENT'S GUIDE

While You Wait

Supporting your child's mental health when help is slow to arrive

What to do, who to ask and how to get through the wait, with sheets to fill in so you are ready when someone does answer.

Neurodivergent Minds

www.neurodivergentminds.com

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This guide is a practical tool. It is not therapy or medical advice. If you are ever worried about your child's safety, go straight to Part 7.

Start here

If you are reading this, you are probably worried about your child, and you may have been worried for a while. You might be waiting for a first appointment with children's mental health services (often called CAMHS), waiting to hear whether a referral was accepted, or waiting for a diagnosis assessment that will not come for a long time. You might have been told your child does not meet the threshold, and been left wondering what happens now.

First, some things that are true:

- **Waiting is not your fault, and it is not a sign that your child does not deserve help.** Children's mental health services are under huge pressure in many parts of the UK, and that is a problem with the system, not with you or your child.
- **You do not need a diagnosis for any of this.** Many neurodivergent children and young people are never formally assessed, or wait years to be. If you recognise your child as autistic, ADHD or both, your observations count, and everything in this guide works with or without a label. The same is true of a young person who recognises themselves.
- **Your child is not broken.** A neurodivergent child living in a world built for other minds can be worn down by it. Struggling is often a sign of a mismatch between the child and their environment, not a flaw in the child.

What this guide is not. It is not therapy, medical advice or an assessment, and it cannot tell you what is happening for your child or replace a doctor or clinician. It is a practical tool: a way to use the waiting time well, to be heard when you do get an appointment, and to look after your child and yourself in the meantime. If you are ever worried about your child's safety, skip to **Part 7, "If you are worried about safety"**, and use the numbers there. You do not need to read anything else first.

How to use it. Read it once when you have a quiet half hour. Then fill in the sheets at the end, because they are what you will actually use. The "In a hard moment" page is short enough to read while things are happening.

PART 1

Understanding the wait

What CAMHS is, and why it can feel like a closed door

CAMHS stands for child and adolescent mental health services. It is the NHS service for children and young people whose mental health needs more than a GP or school can provide. How it works, what it is called and how long you wait vary a great deal from one area to another, so this guide does not try to give you a map. What it can do is help you ask the right questions locally.

Some honest things that families often find out the hard way:

- **Referrals can be made by different people**, usually a GP or a school, and in some areas by a parent or the young person directly. It is worth asking your GP whether your area accepts self-referral.
- **A referral can be turned down, or you may be told your child "does not meet the threshold".** This is about service capacity and criteria, not a verdict on how much your child is struggling. It does not mean you were wrong to ask and it does not mean you cannot ask again if things change or explore private diagnosis.
- **Waiting times can be long, and a child's situation can change while they wait.** That is why keeping a record and telling people when things get worse matters.
- **Services often have separate routes for autism and ADHD assessment and for mental health support.** One does not always unlock the other. You can ask about both.

None of this is a criticism of the individual people working in the service, who are often stretched themselves. It is simply useful to know before you start.

Three different kinds of help, and what to ask for

When help feels out of reach, it can feel as if there is only one kind. There are usually several, and the wait for one does not have to be the wait for all of them:

1. **Help that does not need a referral.** Your child's school, your GP, local charities and some online services. This is where most of the support during a wait comes from.
2. **Help that needs a referral.** CAMHS, assessment services, specialist teams. This is where the waiting list is.
3. **Help you give at home.** This is not second best. It is often the most consistent support a child gets, and it is the part this guide spends most time on.

PART 2

Your first step: write down what you are seeing

Before any appointment, and before you contact the school, take twenty minutes to write the picture down. It is the single most useful thing you can do, for three reasons: it helps you see patterns you may not have noticed, it makes an appointment shorter and less stressful, and it means you can say the same clear thing to different people instead of starting from scratch every time.

You do not need to write well. Short phrases and dates are fine. You will find the **"One-page picture"** sheet at the end of this guide.

What to include:

- **What you are seeing.** Describe what happens, not what you think it means. "Refuses to go to school most mornings, cries, says her tummy hurts" is more useful than "school anxiety".
- **When it started, and how often.** Even a rough idea. "About six weeks, most school days."
- **What it is affecting.** Sleep, eating, school, friendships, family life, things your child used to enjoy.
- **What helps, and what makes it worse.** Include small things. A particular snack, a quiet half hour after school, a certain person.
- **What your child says**, in their own words if you can. Some children cannot or will not talk about it, and that is worth writing down too.
- **Anything about your child's neurodivergence that affects how they cope**: sensory needs, communication differences, how they handle change, what they need in order to talk.
- **Anything that worries you about safety.** See Part 7.

Keep it somewhere you can find it, and add a line when something changes. Each time you tell someone new, you are not repeating yourself: you are handing them the page.

PART 3

Asking for help while you wait

At the GP

A GP appointment is often short, so it helps to start with one clear sentence and to ask for something specific. You are not being pushy. You are making it easy for them to help.

Some ways to open:

- "I am worried about my child's mental health. It has been going on for [how long] and it is affecting [school, sleep, eating or family life]."
- "I have written down what I am seeing. Can I give you this?"

Things you can ask:

- What support is available locally **while we wait**, and who can I contact if things get worse?
- Is a referral being made, who is it going to, and how will I find out what happens?
- Does our area accept self-referral to children's mental health services?
- In England, can we use the NHS Right to Choose for an assessment?
- Is there a local service, charity or school-based team that supports neurodivergent children and families?
- If things change, what should I do, and who should I contact first?
- Can you note in my child's record what we have discussed today?

If your child is neurodivergent, say so, and say what helps them in appointments (a quiet room, extra time, written questions, a parent present or not present). You can ask for these things.

If you leave without what you hoped for, you can say so, and you can ask again when things change. A single appointment does not use up your chance.

The sheet **"What I want to say at the GP"** at the end gives you a page to fill in and take with you.

At school

School is the place a child spends most of their week, and in many areas it is the quickest source of practical support. It does not have to wait for a referral or a diagnosis. Some things you can ask for, in writing if that is easier for you:

- **A named adult** your child can go to, and who knows what helps them.
- **A conversation with the SENCO** (the special educational needs coordinator) and, where there is one, the pastoral lead or mental health lead. Ask what support the school can put in place now.

- **Whether the school has a counsellor, a mental health support team or other in-school help.** Some schools do and some do not, and you can ask.
- **Practical adjustments**: a quiet place to go, a way to leave a lesson without a fuss, fewer demands on the hardest days, a gentler way back after time off.
- **Sharing what you have written.** Handing over the one-page picture helps staff understand what you see at home that they may not see at school.

Many children hold everything together in school and fall apart at home. If that sounds like your child, say so. It is often a sign of how much effort the school day takes (sometimes called masking), not a sign that school is fine. The school may see a calm child, and both pictures are true.

For anything to do with your child's legal entitlements or formal plans, SENDIASS (your local special educational needs and disabilities information, advice and support service) and Contact (a charity for families with disabled children) give free, impartial advice. This guide does not give legal advice, because rules differ and change, and they are better placed to help.

Other places to ask

- **Local charities and neurodivergent family groups.** Search for your area plus "autism", "ADHD" or "SEND parent support". Many run groups, drop-ins and helplines.
- **Free online or text services for young people.** Some areas fund these and some do not. Ask your GP or school what is available locally. Childline (0800 1111) and Shout (text SHOUT to 85258) are free and always there.
- **Other parents.** Parent groups, online or local, can tell you what actually works in your area faster than any website.

PART 4

Looking at it through different lenses

When a child is struggling, we all want to know why. There is usually not one answer, and what fits one child can be wrong for another. Here are some lenses you can try on, not as a diagnosis, but to open up ideas for what might help. You can hold several at once.

- **The nervous system.** Is my child running on empty? Neurodivergent children often spend far more energy on ordinary things: noise, change, social rules, long days. When the tank is empty, feelings get bigger and recovery slows. *What could be taken away or softened?*
- **The environment.** Is something in their day, at school or at home, a bad fit? A noisy classroom, an unpredictable routine, a hard lesson, a friendship problem. *What would change if the environment changed?*
- **An unmet need.** Is the behaviour a message? A meltdown, a refusal, a silence or an outburst is often communication: "this is too much", "I do not understand", "I need you to stop". *What might they be telling me?*

- **Strengths and interests.** What is going right? What does my child love, and when are they most like themselves? Time with interests is not a waste. For many children it is how they recharge. *How can I protect it?*
- **Development and stage.** Is this a phase, a transition or a big change (a new school, a new sibling, puberty)? *Does the timing tell me something?*
- **Our family's values and capacity.** What can we actually manage right now? You are allowed to choose the smallest next step. *What is one thing, not ten?*

Try one lens for a week, notice what you see, and write it on your sheet. You are collecting information, not searching for the one right answer.

PART 5

At home while you wait

Nothing here is treatment, and none of it will make waiting easy. These are things many families find lower the load and keep the connection going. Take what fits, ignore what does not.

Lower the load first

If a child is running on empty, adding new strategies rarely helps. Before you teach a skill, ask what can come off. Fewer plans, fewer transitions, less noise, a quieter evening, a day with nothing in it. Rest is not giving up.

Make the day more predictable

Many neurodivergent children feel safer when they know what is coming. A simple visual routine, a warning before a change, the same order each morning. Small and steady beats ambitious and short-lived.

Protect sleep, food and movement where you can

These three affect everything else, and each is worth a gentle look, not a battle. If sleep is the main struggle, our Sleep guide goes into it in more depth. If you are worried about your child's eating or growth, that is one for the GP.

Time together with no demands

Ten minutes a day of being with your child doing what they choose, with no teaching, no questions and no correcting, can be one of the most protective things in a day. Sit alongside rather than opposite. Some children talk more when you are doing something side by side: in the car, on a walk, drawing, building, playing a game.

Do not push your child to “talk about it”

Many neurodivergent children find it hard to put feelings into words, or find direct questions unbearable. Other ways in include drawing, a feelings scale from one to five, a list of faces to point to, a message on paper, or simply saying “I’m here when you want to”. Our Little Minds wellbeing packs are built around this idea, if you would like something printable. They are practical tools, not therapy.

Name feelings together when things are calm

“That looked like it felt really big.” “I wonder if your body was telling you it was too loud.” Not in the middle of a hard moment. Afterwards, when it has passed.

Say what is good about how your child’s mind works

Children who struggle often hear a steady stream of corrections. Specific, true praise (“you noticed the small detail nobody else did”) counters it. Strengths are not a prize for good behaviour. They are a fact about your child.

What tends not to help

- Telling a child to “calm down” or “just relax”
- Punishing a meltdown, or taking away comfort items as a consequence
- Asking for an explanation or an apology in the middle of a big feeling
- Comparing your child with siblings or classmates
- Putting too much weight on one tool or one plan, so that when it does not work you feel you have failed. If something does not help, that is information about the tool, not about you or your child.

PART 6

In a hard moment

Keep this page where you can find it. It is meant to be read in about a minute.

1. **Safety first.** Is anyone in danger? If yes, get help (see the next section). If not, carry on.
2. **Lower everything.** Less noise, less talking, fewer people, dimmer light. Fewer words from you, and a calm, low voice.
3. **Do not problem-solve now.** Reasoning, bargaining and teaching come later.
4. **Offer, do not demand.** “I’m here.” “Do you want water or quiet?” Accept “no”.
5. **Stay close but give space.** Be near enough to be a calm presence.
6. **Look after the basics afterwards.** Drink, snack, rest, a favourite thing.
7. **Talk about it later, if at all.** Keep it short and kind, and do not turn it into a lesson.
8. **Then look after yourself.** Hard moments are hard on the grown-up too.

If hard moments are frequent, our Meltdowns and Shutdowns guide goes into this in much more depth.

PART 7

If you are worried about safety

Some things are not for waiting out. Please take these seriously, even if your child seems fine a few minutes later:

- Your child talks about wanting to hurt themselves, wanting to die, or not wanting to be here.
- Your child has hurt themselves, or you find signs they might have.
- Your child talks about hurting someone else.
- Something has changed suddenly and you are frightened about it.

You do not have to decide how serious it is. You can ask for help and let someone else assess it.

If someone is in immediate danger, call 999.

For other situations, get help the same day:

- Call **NHS 111**, or use 111 online, for urgent health advice.
- Contact your **GP surgery** and say it is about your child's mental health and safety. You can ask for an urgent appointment.
- Tell the **school's safeguarding lead**, who can often act quickly.
- Children and young people can call **Childline on 0800 1111** or text **SHOUT to 85258**, any time.
- You can call the **YoungMinds Parents Helpline on 0808 802 5544**. It is open on weekdays, so check youngminds.org.uk for current hours.
- **Samaritans on 116 123** is free at any time, for anyone, including you.

What to do in the moment. Stay calm, listen and take what they say seriously. It is okay to ask directly and gently whether they are thinking about hurting themselves or ending their life. Asking calmly does not put the idea in a child's head. Do not promise to keep it secret, and do not leave a child alone if you think they might act. Then get help the same day.

PART 8

Looking after yourself

"You cannot pour from an empty cup" is a cliché because it is true. Parenting a struggling child, often while fighting for support, is real work and it is allowed to wear you out. Some things that help:

- **Tell someone.** A friend, a family member, another parent who understands. You are not meant to carry it alone.
- **Lower your own load too.** What can you drop this week?
- **Small recoveries count.** Ten quiet minutes, a walk, a hot drink, an early night.
- **Support for you.** The YoungMinds Parents Helpline (0808 802 5544), Samaritans (116 123) and Carers UK (carersuk.org) are all there for you, not only for your child. If you are struggling, your own GP is a good first step.
- **Brothers and sisters.** Siblings notice everything. A few minutes of one-to-one time and an honest, age-appropriate explanation ("your brother's brain finds some things really hard") often helps.

You do not have to be calm all the time. You have to be there, and you already are.

PART 9

Keeping going: records, chasing and when things change

Keep a short log

Every time you speak to someone about your child's mental health (GP, school, a service, a charity), add a line to the **"Who I have spoken to"** sheet: the date, who, what was said and what happens next. It stops things getting lost and lets you chase politely and clearly.

Chasing

Waiting lists go quiet. It is fine to ask where things are. A short email or phone call is enough:

"I am following up on the referral for [child's name], made on [date]. Could you tell me where it is up to, and what we should do if things get worse while we wait?"

When things change

If things get worse, say so again, even if you have said it before. A change in sleep, eating, school attendance or mood, or anything that makes you more worried, is worth telling the GP and school. Do not assume you have used up your chance.

If you have a concern about a service

You can ask the service how to give feedback or raise a concern, and the NHS also has a Patient Advice and Liaison Service (PALS) that can help in many areas. If you are not sure what to do, SENDIASS and Contact can point you in the right direction.

PART 10

When your appointment comes

When a first appointment arrives, a few things help it go well:

- **Bring your one-page picture** and any notes from school.
- **Tell them your child is neurodivergent** and what helps in a room: sensory needs, how they communicate, how long they need to settle, whether they would rather talk alone, with you or in writing.
- **Ask for adjustments.** A quieter room, extra time, written questions, a break.
- **Ask your child what they would like said**, and make sure they know what will happen. Surprises can make a hard day harder.
- **Ask what the plan is**, what happens next and who to contact if things get worse.
- **Write down what you were told** straight afterwards. It is hard to take it all in.

You are an expert in your own child. A good clinician will want to hear what you know.

The sheets

Print these, or copy the headings onto paper.

Sheet 1 One-page picture

Sheet 2 What I want to say at the GP

Sheet 3 My bad day plan

Sheet 4 Who I have spoken to

SHEET 1

One-page picture

Child's name and age:

What I am seeing (what happens, in plain words):

When it started, and how often:

What it is affecting (tick or note): sleep / eating / school / friendships / family life / things they used to enjoy / other:

What helps:

What makes it worse:

What my child says (their own words, if any):

Things about their neurodivergence that matter (sensory needs, communication, change, what helps them talk):

Anything that worries me about safety:

Last updated:

SHEET 2

What I want to say at the GP

My opening sentence: "I am worried about my child's mental health. It has been going on for _____ and it is affecting _____."

I have brought: the one-page picture / notes from school / other:

Questions I want to ask:

1. What support is available locally while we wait?
2. Is a referral being made, to whom, and how will I find out what happens?
3. Does our area accept self-referral?
4. Is there a local service or charity for neurodivergent children and families?
5. What should I do if things get worse, and who do I contact first?
6. Can you note today's conversation in my child's record?

What helps my child in appointments:

What was said, and what happens next (fill in afterwards):

SHEET 3

My bad day plan

Early signs I see that a day is getting hard:

What I can lower or take away straight away:

Three things that usually help my child:

1.
2.
3.

Things that make it worse (what I will not do in the moment):

Who I can call or text for support (name and number):

Where the helplines are (999, NHS 111, Childline 0800 1111, YoungMinds Parents Helpline 0808 802 5544, Samaritans 116 123):

What I will do for myself afterwards:

SHEET 4

Who I have spoken to

Date	Who (GP, school, service, charity)	What was said	What happens next / when I will chase

If you need more help

This guide is a practical tool. It is not therapy or medical advice, and it cannot replace support from a professional. If your child's distress is lasting, getting worse or affecting daily life, please talk to your GP or your child's school SENCO, and say it again if things get worse.

Helplines (free)

- Emergency, or if someone is in danger: **999**
- Urgent health advice: **NHS 111**
- Childline, for children and young people: **0800 1111**
- Shout, free text support, any time: text **SHOUT to 85258**
- YoungMinds Parents Helpline, for parents and carers: **0808 802 5544**
- Samaritans, for anyone, at any time: **116 123**
- Contact, support for families with disabled children: **0808 808 3555**
- More places to turn: **neurodivergentminds.com/help.html**

Phone numbers and opening times change. Please check each organisation's own website for the latest details. We checked the Childline, Shout, YoungMinds and Contact details against their own sites on 4 October 2026.

This guide is for general information. Neurodivergent Minds is not a clinical, crisis or advice service, and we do not diagnose or treat anyone. Nothing here is a substitute for personalised medical, psychological, therapeutic or legal advice.