A PRACTICAL DIGITAL TOOLKIT

The Family Autism Crisis Toolkit

Words, structure and confidence for families when the system is confusing.

£10 · one-time payment · digital download

Written by a psychologist with UK NHS and inpatient experience

Before anything else, an honest boundary

This toolkit is a practical resource: scripts, checklists and plain-English explanations.

It is **NOT therapy**. It is **NOT a diagnosis tool**. It is **NOT emergency advice**.

If you or the person you care for is in immediate danger, call **999** now.

How to use this toolkit

You don’t need to read this front to back. Read the page you need before the thing you’re about to do.

Who this is for

Parents and carers of autistic teens and adults in the UK who have meetings and appointments coming up that they don’t feel prepared for. It assumes you know the person you care for better than any professional — and that what you need is *words* and *structure*, not more theory.

How the toolkit is organised

Ten sections, each starting on its own page. Use them in any order:

Section	What it’s for	Use it
1	Meeting scripts	The night before a school, NHS or social-care meeting.
2	Email scripts	When you need to ask, chase or raise something in writing.
3	Describing distress	When you need to explain a difficult situation and be taken seriously.
4	Tracking sheet	The week before an appointment or review.
5	Meltdown/shutdown explainer	When you need other people to understand what happens.
6	Reasonable adjustments	When you need to ask for changes at school, work or in hospital.
7	Hospital prep	If an inpatient admission is possible or happening.
8	Carer burnout plan	When you notice you’re the one running on empty.
9	Plain-English glossary	When a professional uses a term you don’t recognise.
10	Red flags	When you’re not sure whether something is urgent.

A note on how professionals read

Most professionals meet many families. They take notes, then write them up into reports, referrals and care plans later. The families that get listened to are rarely the loudest — they are the ones whose *observations are easy to copy down*. Sections 1, 3 and 4 are built around that idea.

What this toolkit is and isn’t

It is a practical resource: scripts, checklists and plain-English explanations. It is a starting point for conversations — not a replacement for them.

It is **NOT therapy**. It is **NOT a diagnosis tool**. It is **NOT emergency advice**.

If you or the person you care for is in immediate danger, call **999** now.

Disclaimer. This toolkit does not replace professional advice, assessment or treatment. It is written to help you prepare for conversations with professionals — it does not tell you what decision to make, and it does not diagnose anyone. Crisis numbers and escalation guidance are here to help you find the right help, not to stand in for it. If you are unsure whether something is urgent, use Section 10 and, when in doubt, contact a professional.

SECTION 1

What to say in school, NHS and social-care meetings

The questions professionals ask sound simple, but they aren't. "How does he present at home?", "Tell me about the behaviour", "What would you like us to do?" — each one is doing a job. The person asking is gathering information they will turn into a report, a referral, a plan, or a decision about whether you get help. This section gives you frameworks for answering those questions in a way that is easy to write down and hard to ignore.

The one idea that changes everything

Professionals don't need your summary of what things *mean*. They need what things *look like*. Your job in a meeting is to translate your lived experience into observations they can put in a file:

- What you **see and hear** (the behaviour itself, described plainly)
- When it **happens** (context, timing, triggers)
- What **helps** (what you've tried, what worked)

If you only do one thing at the next meeting, do this: answer every vague question with those three parts.

Framework 1 — The three-part answer

> **Part 1: What I/we see → Part 2: When it happens → Part 3: What helps**
>
> You can answer almost any "how is things at home?"-type question this way. It gives the professional a fact, a context and a way forward — everything they need to write something useful.

Example. The professional asks: *"How is Alex at home at the moment?"*

Weak answer: "He's fine at home, it's only at school that's a problem." *(Too vague to write down, and it invites the next question about school instead of helping anyone.)*

Strong answer: "At home Alex is mostly calm. Three things we see regularly: he paces in the kitchen when the washing machine is on; he needs about 20 minutes alone after school before he can talk; and loud phone notifications make him cover his ears. What helps is warning him before noise and giving him quiet time after school." *(Three observations, each with context and what helps — the professional can copy that straight into a report.)*

Framework 2 — If the question is vague, ask what they mean

It is completely reasonable to pin down a question before answering it. You look more, not less, competent when you do:

SCRIPT — CLARIFYING A VAGUE QUESTION

"Can I check what you mean by 'present' — do you mean what he does day to day at home, or how his mood seems to me?"

"When you say 'behaviour', do you mean things we can see, like hitting or shouting, or do you mean how he's feeling inside?"

“I want to make sure I answer the right thing — are you asking about last week, or overall?”

Framework 3 — The “so what” test

Before you offer a detail, ask yourself: *why does this matter to the decision?* If you can’t say why a detail matters, either drop it or say why it matters. Details with no point get you tuned out; details with a point get you taken seriously.

> **Example.** “He only eats beige food” becomes “He eats a very narrow range of foods — about six things — and the school canteen can’t offer any of them, so he’s not eating during the school day. That matters because he comes home starving and it’s making the after-school meltdowns worse.”

The questions professionals actually ask — and what they’re really asking

You’ll hear	What they’re really doing	How to answer
“How does X present at home?”	Gathering behaviour observations for a report, assessment or care plan.	Three-part answer: what you see, when it happens, what helps. Stick to observable behaviour.
“Is it attention-seeking?”	Deciding how to interpret the behaviour, and whether to refer on.	Describe the trigger and the timing first, then reframe calmly: “When he needs something and can’t put it into words, we see X. It seems to be a way of communicating, rather than for attention.”
“What do you want us to do?”	They want a specific ask, not general worry. Vague concerns are hard to action.	Name one concrete outcome: an adjustment, a referral, a reassessment, a written plan. If you’re not sure, say so and ask what the options are.
“On a scale of 1–10, how bad is it?”	Triage — they need a sense of severity and urgency.	Answer with frequency, duration and impact: “About four times a week, each episode lasting an hour, and it means he can’t go to school that day.” Then give your number if it helps.
“Has anything been tried before?”	Checking history, avoiding repeating failed approaches.	Say what was tried, what happened, and what lasted. You don’t need a full timeline — a few examples is enough.

Scripts for the meeting itself

OPENING — SETTING THE FRAME

“Thank you for meeting us. Before we start, I’d like to make sure we cover three things: what’s been happening, what’s already been tried, and what happens next. Is that okay?”

Why it works: it makes the meeting predictable, and it makes sure the next steps don’t get forgotten.

WHEN YOU FEEL UNHEARD OR MISUNDERSTOOD

“I want to make sure I’ve been understood. What I said was [repeat it]. What I’m asking for is [name it]. Could we make sure that’s written down?”

Why it works: it doesn’t accuse anyone. It treats the meeting as a shared record, which is exactly what it is.

WHEN IT’S GOING TOO FAST

“This is important to us, and I don’t want to lose it. Could we slow down for a moment so I can note it down?”

Why it works: meetings move at the pace of whoever leads them. Slowing down is a legitimate move, and most professionals respect it.

CLOSING — PIN DOWN NEXT STEPS

“Before we finish, can we confirm: what happens next, who is responsible for it, and when we should hear back? And what should we do if we don’t hear by then?”

Why it works: the meeting that doesn’t end with actions is the meeting that never happened. Writing them down in the room beats chasing afterwards.

Rules of thumb for any meeting

- Write down your **three most important points** before you go in. If the meeting goes sideways, those three points are your floor.
- Take someone with you if you can — a partner, friend or advocate. An extra pair of ears changes everything.
- Ask **who makes the decision** you need, and what they need from you to make it.
- Ask for things to be **put in writing** — you are not being difficult, you are creating a record.
- After the meeting, send a short email summarising what was agreed. (Template in Section 2, Email 4.)

Your three points — fill this in before the meeting

Five minutes of this beats an hour of worrying. Write your three points in the form that makes them easy to say out loud and easy for a professional to write down.

Point	Your answer
Point 1 — the fact. What is happening, observably? (Section 3)	
Point 2 — the context. When does it happen, and what has been tried?	
Point 3 — the ask. What do I want to happen after this meeting?	

SECTION 2

Scripts for emails

Email is where most of the system actually runs. A clear, calm, well-structured email gets answered; a long emotional one gets skimmed and dropped. The scripts below are templates — replace the bits in [square brackets], keep the structure. One ask per email, always.

The structure that works every time

1. **Subject line** that says what the email is about and who it's from: *"Re: [child's name] — requesting a follow-up meeting"*.
2. **One line** reminding them who you are: "I'm the parent of [name], [number] student in [class/year]."
3. **The ask** — one sentence. "I'd like a 20-minute phone call to discuss [X]."
4. **The reason** — one or two sentences, factual.
5. **A deadline** — "Please let me know by [date]." This is the line that stops your email being forgotten.
6. **A thank-you** and a simple sign-off.

Keep every email under about 200 words. If it's longer, you're trying to do two asks in one email — split them.

EMAIL 1 — ASKING FOR A MEETING

Subject: Re: [name] — requesting a meeting to discuss [school support / care plan / treatment]

Dear [Name],

I'm [name]'s [parent/carer], [class/year] at [school], or under [team/GP]. I'd like to arrange a meeting to discuss [one thing: e.g. the support in place, the recent incidents, the referral that hasn't moved].

I have [school/nursery/hospital] on [dates], or I'm happy to come in at a time that suits you. Could you let me know by [date]?

Thank you,
[Your name] · [phone number]

EMAIL 2 — CHASING A REFERRAL THAT HASN'T MOVED

Subject: Re: [name] — follow-up on [team/service] referral sent [date]

Dear [Name],

I'm writing to follow up on the referral to [service] that was sent on [date]. I haven't heard anything and I want to check it was received and whether anything else is needed from us.

[Name]'s situation hasn't improved — [one factual sentence]. If the referral hasn't been accepted, could you let me know why and what the next step is? If it has, could you confirm the expected waiting time?

Please could you update me by [date]. Thank you,
[Your name] · [phone]

EMAIL 3 — RAISING A CONCERN CALMLY

Subject: [name] — a concern I'd like to raise about [area]

Dear [Name],

I'm writing to raise a concern about [specific thing: e.g. restraint incidents at school, what happens at break, pain reported after [event]].

On [date], [one factual description of what happened, using Section 3's language: what was seen, when, what helped]. This is happening [frequency]. I'm asking for [one ask: a meeting, a plan, a review].

I want to work with you on this, and I'm happy to provide more detail. Please could you reply by [date] to arrange a conversation.

Thank you,
[Your name] · [phone]

EMAIL 4 — AFTER A MEETING: THE SUMMARY (SEND THIS AFTER EVERY IMPORTANT MEETING)

Subject: Summary of our meeting on [date] — [name]

Dear [Name],

Thank you for meeting us on [date]. To make sure we're all working from the same page, here's my understanding of what was agreed:

- [Action 1 — who is doing it, by when]
- [Action 2 — who is doing it, by when]
- [Next review date]

Please let me know if anything here is wrong or missing.

Thank you,
[Your name]

EMAIL 5 — REQUESTING A COPY OF RECORDS

Subject: Subject access request — records for [name]

Dear [Records/Data Protection team],

I'm writing to make a subject access request under the UK GDPR / Data Protection Act 2018 for a copy of [name]'s records held by [organisation], covering [date range or service].

I'm [name]'s [parent/carer]. I understand you'll need me to verify my identity, and I'm happy to provide whatever you need. Please let me know if you require any further information.

Thank you,
[Your name] · [phone]

EMAIL 6 — ESCALATING WHEN YOU'VE BEEN IGNORED

Subject: [name] — second follow-up, [date of original email]

Dear [Name],

I wrote on [date] and followed up on [date] about [X], and I haven't had a reply. I understand you're busy, so I'm writing once more.

I'm asking for [repeat the one ask]. If I don't hear from you by [date], I'll [raise it with [manager] / make a formal complaint / contact [body]]. I'd rather not have to.

Thank you,
[Your name] · [phone]

Keep a log

When things get complicated, the family with a simple log wins. A table like this — one row per contact — takes minutes and is worth its weight at every review meeting:

Date	Who (name & role)	What happened / what was asked	Outcome / next step

SECTION 3

How to describe distress without sounding “dramatic”

Professionals hear emotional language all day. It is not that they don’t care — it is that emotional language is hard to write down, hard to compare, and hard to act on. Descriptions of what you actually *saw and heard* are the opposite: they are easy to write down, and they get acted on.

This is not about suppressing your feelings. You can feel everything you feel *and* describe what happened factually. One is for you; the other is for the professional’s notes. This section is about the second one.

The core distinction: observable behaviour vs interpretation

Observable behaviour is anything a camera could film or a sound recorder could catch: “he hit the wall three times”, “she stopped speaking for two hours”, “he left the room and sat under the table”.

Interpretation is the meaning you add: “he was aggressive”, “she’s shutting down”, “he was being naughty”.

Interpretation has its place — but when you lead with it, professionals have to translate it back into facts before they can use it, and translation loses information. Lead with the observable. Add your interpretation *after*, clearly labelled as yours, if at all.

Rule 1 — Describe what you can see, hear or count

> **Interpretation first:** “He was really aggressive this week.”
>
> **Observable first:** “This week, on three occasions, he hit his own head with his fist, and twice he threw a cup across the kitchen. Each time lasted under a minute.”
>
> *Same event. Different usefulness.*

Rule 2 — Give frequency, duration, intensity and impact

Professionals triage on numbers. The four numbers that matter are:

- **How often** — “about four times a week” beats “all the time”.
- **How long** — “each episode lasts 20–40 minutes”.
- **How intense** — “the last one ended with him banging his head on the floor” (again, observable).
- **What it stops** — “it means he misses school that day”, “I can’t leave the house”. This is the one that signals severity.

Rule 3 — Add context: when, where, what helped

The same behaviour means different things at school, at home and at 3am. One sentence of context and one sentence of what helped turns a complaint into a working observation:

THE PATTERN IN ONE BREATH

"[When] it happens, [where], [observable behaviour], and [what helps / what we've tried]."

"When there's an unexpected change to the timetable at school, he walks out of class and sits in the corridor with his headphones on. He comes back if a staff member sits nearby without talking to him."

Before and after — real examples

Instead of saying…	Try saying…	Why it lands
"He was really aggressive."	"He hit the wall three times with his fist, then left the room."	Observable, countable, filmable.
"She's so depressed."	"She's stayed in her room for three days, speaking in single words, and is eating noticeably less."	Gives the professional something to assess.
"He's anxious all the time."	"About four times a week he says he 'can't do it' and won't leave the car. Each episode lasts about an hour."	Frequency and duration — triage-ready.
"She's attention-seeking."	"When she's overwhelmed she bites her hand. It happens mainly at transition times — coming in, leaving, changing tasks."	Describes the trigger; invites help rather than judgement.
"He completely lost it."	"He shouted and threw a chair in the classroom, then went quiet and wouldn't move for 30 minutes."	Two observable phases instead of one vague summary.
"She won't eat."	"In the last week she's eaten two small meals a day, only from a plate she chooses herself. She refuses offered food from anyone else."	Specific enough to flag a real concern.
"He's not coping."	"He's missing school two days a week, and on the days he goes he comes home and needs two hours alone before he can speak."	Impact on daily life — the detail that signals severity.
"It's all too much."	"Since [event], [name] has been awake until 2am most nights and has started refusing to leave the house."	Anchor to a date and a change — easy to track from there.

Words that tend to get you dismissed — and what to say instead

Word that raises walls	Why	Say instead
"naughty", "manipulative", "dramatic"	Judges the person, not the situation. Professionals immediately wonder about the reporter.	Describe the behaviour: "he refused to leave the shop and shouted for 10 minutes".

Word that raises walls	Why	Say instead
“attention-seeking”	Reads as blame. It also names a motive you can’t see.	“When he needs something and can’t say it, we see [behaviour]. It happens most when [trigger].”
“always”, “never”, “constantly”	Absolute words get discounted. No one is “always” anything.	Give a number: “most days”, “about three times this week”.
“can’t cope” (about yourself)	Vague and hard to action.	“I’m struggling with [specific situation] and I need help with [one thing].”

Practice — rewrite these so a professional could act on them

1. “She’s been awful lately.” → *Your version:* _____
2. “He flips out at school all the time.” → *Your version:* _____
3. “I can’t cope anymore.” → *Your version:* _____

Tip: answer out loud, then write down what you said. Most people find the spoken version is closer to the observable truth than the written one they were drafting in their heads.

SECTION 4

What to track before appointments

You do not need to track everything, forever. One week before a review or appointment is enough — and it turns a vague conversation into one where you hold the evidence. This section is a fill-in sheet you can bring to the appointment and hand over, or simply refer to while you talk.

Why track at all

- Memory under stress is unreliable. The week before a review is usually the most stressful week of all.
- Professionals ask “how often?” and “what helps?” — a week of entries answers both without you having to guess.
- A filled-in sheet signals that you are a person worth listening to. It also gives the professional something they can photocopy into their file, which is exactly what you want.

What each column is for

Column	What to put in it
Sleep	Approximate time to sleep and waking, and rough quality (“woke 3× ”). Don’t get obsessed with exact hours — rough is fine.
Food	Roughly what and when was eaten. The point is to spot patterns (e.g. nothing eaten before school), not to judge.
Distress events	Anything that stands out: a meltdown, a shutdown, refusal, self-injury, panic. One line is enough — use Section 3 language (what was seen, when, how long).
Triggers	What seemed to set it off, or was different about that day: change of routine, noise, demand, illness, exam, a missed meal.
What helped	What actually worked — even a little: quiet time, headphones, being left alone, a specific person, going outside. This column is gold; it shows you’ve already tried things.

How to track without it becoming another job

- Fill it in **once a day**, at the same time (evening is easiest). Don’t carry it around and fill it in live — that’s a burden and it will stop.
- One or two words per cell is fine. The sheet doesn’t need to be beautiful.
- If a day gets missed, **leave it blank** rather than trying to remember it later. A blank day is honest and fine.
- One person fills it in consistently, even if several people care for the person.

Example — one filled-in row

Day	Sleep	Food	Distress events	Triggers	What helped
Monday	11pm–6am, woke once	Toast for breakfast, nothing at school, ate dinner	Shouted in car on the way home, ~10 mins	Unexpected fire alarm at school	20 mins alone in room after getting home

Your blank week — print this page (or photocopy it for more weeks)

Day	Sleep	Food	Distress events	Triggers	What helped
Monday					
Tuesday					
Wednesday					
Thursday					
Friday					
Saturday					
Sunday					

Track the week before your appointment, then bring this page with you. You don't need to hand it over — but you'll be glad you have it.

If a professional asks "why are you tracking that?"

SCRIPT

"We wanted to bring real information about what's happening day to day, rather than trying to remember it under pressure. It's helped us spot what the triggers are."

No one has ever argued with that.

Your appointment one-pager — copy this onto one page and bring it

This is the page that keeps the appointment on track. Fill it in before you go; you can even hand it over.

What is happening? (2–3 observable lines, Section 3 style)	

What has been tried? (and what helped / didn’t)	
What I’m asking for today (one ask, if possible)	
Next steps agreed (who, what, by when)	
If I don’t hear back (plan a date and a way to chase)	

SECTION 5

Meltdowns and shutdowns — a plain-English explanation sheet

This section is written so you can print it and hand it to someone who needs to understand: a teacher, a support worker, a relative, a new professional. It explains in plain English what a meltdown and a shutdown are, what helps, and what doesn't. It is a shared-language document — the kind of thing that saves everyone a lot of re-explaining.

What a meltdown is (and isn't)

A meltdown is an overwhelming response to too much stress, sensory input, or demand. The person has reached a limit and, in that moment, has lost the ability to process, to choose, or to communicate calmly. It is a response to overwhelm.

A meltdown is **not** a tantrum. A tantrum is a strategy to get something — it usually stops when the goal is achieved or ignored. A meltdown is not chosen and is not aimed at an outcome. The person is not in control of it, and neither, really, is anyone else in the room. It is also not "naughty" or "dramatic" — it is what overwhelm looks like from the outside.

What a shutdown is

A shutdown is the quieter version of the same overload. Instead of erupting, the person withdraws: goes quiet, goes blank, stops responding, loses speech, or seems to "disappear". It can look like calmness or even sulking from the outside, but internally it is just as overwhelming. The same causes, the same limit — a different way of running out of battery.

Some people have only meltdowns, some only shutdowns, some both at different times. Both are responses to overload, not choices.

What commonly causes them

There is rarely one cause — usually a build-up. Common contributors include:

- **Sensory overload:** noise, lights, smells, crowds, being touched, too much going on at once.
- **Unexpected change:** a change of plan, a different person, a surprise, a cancelled routine.
- **Demands:** being asked to do, decide, speak or perform — especially when already at capacity.
- **Communication pressure:** not being understood, being interrupted, having to explain over and over.
- **Body basics:** tired, hungry, thirsty, ill, in pain, or recovering from a big event.
- **Social demands:** masking (putting on a "normal" face) for a long time, then running out of fuel.

What helps during a meltdown or shutdown

Helps	Why
Reduce demands — stop asking questions, stop asking for speech	Talking demands processing, which is what has run out.

Helps	Why
Reduce sensory input — dim lights, lower voices, clear the room	Overload is the fuel; removing it lets the fire burn down.
Give time and space — don’t crowd, don’t stare, don’t touch without invitation	Recovery can’t be rushed; being watched extends it.
Stay calm and quiet — your calm is the calmest thing in the room	Pressure and panic are contagious; calm is too.
Keep the person safe — move hazards, stay nearby but not on top of them	Safety first; intervention second.

What doesn’t help (and can make it worse)

Doesn’t help	Why
Reasoning, explaining or “teaching a lesson” during the event	The person cannot process it in that moment. It becomes more noise.
Punishing, threatening, or using it against them later	A meltdown isn’t a choice, so punishment teaches nothing except fear.
Insisting on eye contact, a calm-down, or an apology before they’re ready	All of these are demands, and demands are the problem.
Questioning afterwards (“why did you do that?” over and over)	They may genuinely not know, or not be able to say. Interrogation closes the door.
Multiple people talking, crowding, or grabbing	Adds sensory and social load at the worst moment.

After the event

- Recovery takes time — sometimes hours. Don’t expect a return to normal quickly.
- When the person is ready, a short, non-judgemental debrief can help — but only if they want it. “That looked really hard. Is there anything we could do differently next time?” beats “What were you thinking?”
- Regret and shame often follow a meltdown. The person may be feeling terrible already. Recovery is helped more by matter-of-fact kindness than by anything else.
- Make a note of what helped (add it to the Section 4 sheet) so next time is a little easier.

If you’re a professional writing about this

Describe what you observed, not what you assumed. “X became distressed, shouted and left the room; staff gave space and he returned after 20 minutes” is useful. “X had a meltdown to get attention” is an interpretation, and it will be read as one. If you believe there is a pattern, describe the pattern: what came before, what happened, what helped.

> **A note for families**

> You don’t need to have the right words for every moment. Handing this sheet to someone is not a failure — it is the most efficient way to get them on the same page. You can use it exactly as it is.

SECTION 6

Reasonable adjustments checklist

In the UK, under the Equality Act 2010, service providers and employers have a duty to make **reasonable adjustments** so that a disabled person is not at a substantial disadvantage compared with someone who is not disabled. “Disabled” is a wide category — an autistic person will usually meet it, with or without a formal diagnosis in some cases. This is not legal advice, but it is a plain-English explanation of a real right.

What counts as *reasonable* depends on the setting, the size of the organisation and the cost or disruption involved. The point is: **you can ask**, and asking is normal. Most good organisations would rather adjust than struggle.

> **What “reasonable” usually means in practice**
>
> In plain terms, a request is more likely to be seen as reasonable if it: **meets a real need** (grounded in observable difficulties, not preference), **won’t fundamentally change** what the organisation is for, and **isn’t disproportionately expensive or disruptive** for a body of that size. You don’t need to win this argument in the abstract — you need to make a clear request and see what they say. A refusal has to be explained, and a written refusal is something you can work with.

How to ask — the one-paragraph method

SCRIPT — ASKING FOR ADJUSTMENTS

“[Name] is autistic. In our experience, [one or two things that help, from Section 3 or 4]. Could we arrange [the specific adjustment]? For example, [concrete version of what you’re asking].”

Example: “Aisha finds bright lights and sudden noise very difficult. Could she sit near the back, and could we arrange a quiet place to go if she feels overwhelmed? For example, the library corner.”

School and college

- ☐ A named person Aisha/your young person knows they can go to when things get hard.
- ☐ A quiet, predictable place to go during breaks and when overwhelmed.
- ☐ A warning before fire alarms and other planned loud events (drills, assemblies).
- ☐ Permission to wear headphones / ear defenders when needed.
- ☐ Adjustments to uniform if sensory (e.g. softer fabric, no ties) — where this doesn’t change the school’s core rules unfairly.
- ☐ Exam arrangements: extra time, separate room, rest breaks, a reader or scribe.
- ☐ Homework: reduced or adjusted where the demand is the problem, not the ability.
- ☐ Planned, supported transitions between lessons, rooms and key stages.
- ☐ Communication adjustments: written instructions, one instruction at a time, no surprise verbal tests.
- ☐ Meetings with you at a time that works, with written notes after (see Section 2, Email 4).

Work

- ☐ Clear, written expectations and instructions rather than verbal-only.
- ☐ A consistent line manager / named contact.
- ☐ Flexible start/finish times to manage sensory and routine needs.
- ☐ Adjustments to the physical environment: quieter desk, away from high-traffic areas, adjustable lighting.
- ☐ Permission to use headphones, take breaks, or work from home where the role allows.
- ☐ Adjustments to meetings: agendas in advance, no surprise questions, notes afterwards.
- ☐ A workplace “reasonable adjustments passport” if the employer offers one — it travels with the person through role changes.

Hospital and healthcare

- ☐ Double-length appointments, or two appointments booked together.
- ☐ Quiet waiting: a side room, a booked time, or a call when the clinician is ready.
- ☐ Adjustments to letters and forms: larger print, plain English, or a phone call instead of a letter.
- ☐ Information about procedures in advance, in an accessible format.
- ☐ A flag on the person’s record noting communication needs and what helps (ask how this is done locally).
- ☐ Being allowed to bring a supporter to appointments.
- ☐ Medication information given in writing, not just verbally.
- ☐ Reasonable notice of any changes to appointments, and to be called if there are long delays.

If an adjustment is refused

1. Ask for the refusal **in writing**, with the reason.
2. Ask what would make it reasonable — sometimes the refusal is about the specific version, not the principle.
3. Escalate: to the head teacher / SENCO, the employer’s HR, or the organisation’s patient experience / complaints team.
4. If you need support, disability organisations and advocacy services can help you word it (see notes in Section 9 for where to find them).

SECTION 7

Hospital and inpatient admission prep checklist

If an inpatient admission is possible or already happening, preparation reduces chaos. It won't make it easy — no toolkit should pretend that — but it will mean fewer lost items, fewer unanswered questions and a clearer record of what was decided. Work through this with the ward or unit if you can, and ask every question out loud. You are allowed to ask questions in a hospital.

Before admission — questions to ask

- ☐ Who is the responsible clinician (the consultant) and who is the named nurse / key worker?
- ☐ How do we contact the ward, and when is the best time to phone for updates?
- ☐ What are the visiting rules — hours, who can visit, and how will we know if they change?
- ☐ Can the person keep a phone / tablet, and is there Wi-Fi?
- ☐ What happens to the person's belongings — is there a locker, and what shouldn't be brought?
- ☐ What is the plan for the first 24 hours, and who will explain it to the person in a way they can understand?
- ☐ When is the first review / ward round, and can we attend or call in?

What to pack

- ☐ Comfortable clothes — several days' worth, no drawstrings or cords where the ward has rules about them.
- ☐ Toiletries (check what the ward allows — some items may be restricted).
- ☐ Phone charger and (if allowed) a long cable, with the person's name on everything.
- ☐ Comfort and fidget items: headphones, ear defenders, a familiar blanket, a book, sensory objects.
- ☐ A current list of all medication, with doses and timings, plus a list of known allergies.
- ☐ This toolkit's tracking sheet (Section 4) filled in for the last week.
- ☐ A one-page "what helps / what doesn't help" sheet — use Section 5's format. This is the single most useful page to hand to a new team.
- ☐ Details of known triggers and communication needs (how does this person communicate best, and what do staff need to know?).

During admission — who to speak to

Role	What they do
Ward manager / matron	Runs the day-to-day ward. The person to speak to about practical issues.
Named nurse / key worker	Your main day-to-day contact. Ask for their name on day one and keep it.
Consultant / responsible clinician	Makes the medical decisions. You may need to ask when they review and how to get questions to them.

Role	What they do
Care coordinator / social worker	Pulls together the plan across services — especially for discharge.
Advocate	Someone whose job is to represent the person's views. Ask the ward whether an independent advocate is available — this is a right in some settings, not a favour.

Keep a log while on the ward

Use a simple page for each day: who you spoke to, what was said, what was decided, what you're waiting for. It feels like admin; it is actually the most powerful thing you can do. It lets you walk into a review meeting with facts rather than impressions. (You can use the log table in Section 2 for this.)

At review meetings

- ☐ Ask who is at the meeting and what each person's role is.
- ☐ Ask what decisions will be made today — and what decisions won't be.
- ☐ Ask the person themselves how they want to be involved, and respect it. Their voice matters more than any checklist.
- ☐ Ask for decisions in writing, or write down what you heard and send it around (Section 2, Email 4).
- ☐ Ask: "What should we do if things get worse after we leave?" — always get a crisis answer before discharge.

On discharge — before you leave, confirm

- ☐ The discharge plan on paper, with dates and who is responsible.
- ☐ Follow-up appointments booked (not "you'll get a letter" — ask when).
- ☐ Medication: what's changed, how much to take, who to contact about side effects, and enough supply to get there.
- ☐ A crisis plan: who to call, at what point, and what to say. Write the numbers down before you leave.

SECTION 8

Carer burnout plan

This section is not a lecture about self-care, and it is not a demand that you add “look after yourself” to your to-do list. It is a blunt instrument for noticing when you are running on empty, and a simple plan for when you are. If you are reading this in a quiet moment, good — use it then. If you are reading it in a loud one, start at the self-assessment and skip the rest.

Self-assessment — how many of these are true this month?

- ☐ I’m sleeping badly — can’t get to sleep, waking early, or exhausted but wired.
- ☐ I feel irritable or snappy with the people I care about most.
- ☐ I dread appointments, phone calls and meetings.
- ☐ I’ve put off my own healthcare — dentist, GP, a check-up I need.
- ☐ I can’t remember the last time I did something just for me.
- ☐ I feel like I’m the only one holding everything together.
- ☐ I’m doing more and more, and it still doesn’t feel like enough.
- ☐ I feel guilty when I rest, and guilty when I don’t.

If three or more are true, treat this like a warning light, not a personality trait. It is information about the situation you are in, not a verdict on you.

What burnout actually looks like in a carer

- Running on autopilot — days blur together, and you can’t remember what you did.
- Short fuse with professionals — you snap at the person who is actually trying to help.
- Giving up on things that used to matter to you, because there’s no room.
- Physical signs: constant tiredness, headaches, more illness, tense shoulders.
- A sense that nothing you do changes anything.

The one sentence that gets you help

SCRIPT — ASKING FOR HELP, TO A GP OR ANOTHER PROFESSIONAL

“I’m the main carer for [name], who is autistic and has [brief context]. I’m struggling to keep going. I need [one specific thing: a carer’s assessment, a short-breaks referral, a conversation about support, a GP appointment for myself].”

Why this works: it names the role, the situation and the specific ask. “I’m struggling” on its own is easy to nod at and move on from.

Your simple plan — fill this in, it takes five minutes

Keep the plan small. A plan you keep is a plan that works.

Question	Your answer
What genuinely fills me up — even 20 minutes of it?	
One small thing I'll do this week (not a lifestyle overhaul — a single thing)?	
Who could I actually ask for help — and what would I ask for?	
What am I doing that I could stop, or do less of?	
Who needs to know I'm struggling — and what's the first sentence I'll say?	

What counts as rest (it's not what you think)

Rest is not "doing nothing productive" — it is the thing that returns energy to you. For one person that's a walk, for another it's twenty minutes with headphones, for another it's a long bath or an hour of a comfort show. If the "rest" you're taking isn't returning energy, it isn't rest — it's just a different kind of doing. Choose the thing that actually fills you back up, and treat it as part of the job of caring, not a reward for it.

> **Permission, stated plainly**
>
> Asking for help is not failing. You are the most important resource in this person's life, and looking after that resource is caring, not selfishness. Professionals know this — that is why the scripts in this section are here.

Where to get help with caring, in plain English

- **Carer's assessment:** adult social care can assess your needs as a carer. Ask your GP or local council how to request one. This is a real thing you can ask for.
- **Short breaks / respite:** ask at reviews — the wording differs by area, but the ask is the same: "Is there any support for short breaks for our family?"
- **Carer's Allowance:** a benefit for carers who care for someone at least 35 hours a week. Check current eligibility criteria before relying on it.
- **Your GP:** for yourself. You can see a GP about your own health, even if you spend all your energy on someone else's.

SECTION 9

“What professionals mean” — a plain-English glossary

The system runs on acronyms. When a professional says “we’ll consider an EHCP review within the SEND process”, they are not trying to confuse you — it is simply their working language. This glossary translates the terms you’ll meet most often. Each entry gives the plain meaning, when you’re likely to meet it, and one useful question you can ask. Definitions are deliberately short and honest — this is a phrasebook, not a textbook.

One rule for any term not in this list: say “Could you tell me what that means, in plain English? I want to make sure I understand.” Anyone who won’t explain their own acronym is not someone you need to be quiet for.

ASC / Autism Spectrum Condition

The current term most UK services use for autism. (“Autism Spectrum Disorder” — ASD — is still used in some diagnostic wording.) It describes a different way of processing the world, affecting communication, sensory experience and routine.

You’ll meet it: in assessments, letters and meetings.

Ask: “Are you using ASC and ASD interchangeably, or is there a difference in this service?”

CAMHS

Child and Adolescent Mental Health Services — the NHS mental health service for young people, usually up to age 18. The adult equivalent is sometimes called AMHS (Adult Mental Health Services).

You’ll meet it: when a young person is referred for mental health support.

Ask: “What happens at 18 — is there a transition to adult services, and who manages it?”

Care Act assessment

An assessment by adult social care (your local council) of what care and support an adult needs, or of a carer’s own support needs. It is something you can request — you don’t need to be referred by a professional.

You’ll meet it: when looking at care and support at home, or as a carer yourself.

Ask: “How do we request a Care Act assessment, and what happens after it?”

Care plan

A written document describing what support someone should get, from whom, and what to do if things change. A good care plan is specific and reviewed.

You’ll meet it: in almost any ongoing service.

Ask: “Can we have a copy of the care plan, and when is it next reviewed?” — then write the answer down (Section 2, Email 4).

Care coordinator

A named person (often a nurse or social worker) who organises and connects the different parts of someone's care, and is your main point of contact.

You'll meet it: in mental health services where several teams are involved.

Ask: "Who is the care coordinator, and how do we reach them directly?"

CPA — Care Programme Approach

The framework mental health services use for people with more complex needs. In practice it means: a named care coordinator, a written care plan, and regular review meetings you should be invited to.

You'll meet it: when someone is under a mental health team.

Ask: "Are we on CPA, and when is the next review meeting?"

Crisis team / Home Treatment Team (CRHT)

A short-term mental health team that supports people in crisis at home, as an alternative to hospital admission. They typically work intensely for a few weeks, then step back.

You'll meet it: when things get urgent but not an emergency.

Ask: "How do we contact the crisis team outside office hours, and what should we say when we call?"

DLA — Disability Living Allowance

A benefit for children under 16 with care and/or mobility needs. For most people aged 16 and over, Personal Independence Payment (PIP) has taken its place. Rules change — check current guidance.

You'll meet it: when applying for disability benefits for a child.

Ask: "Is this the right benefit for our situation, or should we be looking at PIP?"

DoLS — Deprivation of Liberty Safeguards

A legal framework for making sure that if someone is deprived of their liberty (for example kept in a care home or hospital), it is done lawfully and reviewed. The system is being replaced gradually by the Liberty Protection Safeguards (LPS) — the practical point for families is: if someone can't consent to their care, ask whether a DoLS/LPS authorisation is in place.

You'll meet it: in care homes and hospitals when someone lacks capacity to decide about their care.

Ask: "Is there a DoLS authorisation in place, and who is the supervisory body?"

EHCP — Education, Health and Care Plan

A legal document for a child or young person (up to age 25) with special educational needs, describing the support they need and who provides it. Having one means the support is legally specified — it is not just good practice.

You'll meet it: in schools and when support is in dispute.

Ask: "What's in the plan, what isn't, and how do we get it reviewed or changed?"

Equality Act 2010

The UK law that protects people from discrimination and requires employers and service providers to make reasonable adjustments so disabled people aren't substantially disadvantaged. Autism usually counts as a disability under this law.

You'll meet it: when asking for adjustments (Section 6).

Ask: "Can we put that in writing under the reasonable adjustments duty?"

Learning disability

A lifelong condition that affects understanding, learning and day-to-day independence. It is different from autism, though many people have both. "Learning disability" is not the same as "learning difficulty" (like dyslexia).

You'll meet it: in health and social care, especially where support needs are high.

Ask: "How does the service describe this person's needs — as a learning disability, autism, or both?"

Mental Capacity Act

The law governing decisions for people who may lack the ability to make a specific decision at a specific time. Capacity is decision-specific and must be assumed unless evidence says otherwise. The Act has a legal framework that professionals must follow.

You'll meet it: whenever someone struggles with decisions and professionals mention capacity.

Ask: "Has a capacity assessment been done for this specific decision, and can we see how it was done?"

Mental Health Act / being "sectioned"

The legal framework that can allow someone to be detained in hospital for assessment or treatment. Common sections: section 2 (short assessment, days), section 3 (treatment, months), and section 136 (a police power to take someone to a place of safety if in immediate need of care). Exact rules matter — always ask the hospital to explain the section in plain English and what it means for you.

You'll meet it: in a mental health crisis when admission is being considered or happening.

Ask: "What section is this, what does it mean in practice, and what are our rights to appeal?"

OT — Occupational Therapist

A professional who helps people do the everyday things that matter to them — washing, eating, working, going out. In autism services OTs often work on sensory processing and daily living skills.

You'll meet it: in education, health and social care teams.

Ask: "Can an OT do a sensory or daily-living assessment?"

PBS — Positive Behaviour Support

A framework for understanding "behaviour that challenges" as communication. It focuses on improving quality of life and changing the environment, rather than punishing or suppressing behaviour.

You'll meet it: in learning disability and some autism services.

Ask: "Is the team trained in PBS, and is there a PBS plan we can see?"

PIP — Personal Independence Payment

A benefit for adults (16 and over) with daily living and/or mobility needs, assessed on how the condition affects day-to-day life. It is not means-tested.

You'll meet it: when applying for disability benefits for a young person or adult.

Ask: "What evidence will the assessment want, and can we use the tracking sheet (Section 4)?"

Reasonable adjustments

Changes an organisation must make so a disabled person isn't at a substantial disadvantage — quiet waiting, written instructions, longer appointments. "Reasonable" balances the person's needs with what the organisation can do. See Section 6.

You'll meet it: in schools, workplaces, hospitals and public services.

Ask: "Can I request reasonable adjustments? What's the process?"

Referral

A formal request from one professional or service to another for assessment, treatment or support. Things get lost in referrals — which is why chasing (Section 2, Email 2) exists.

You'll meet it: constantly.

Ask: "When was the referral sent, to whom, and what happens next?"

Respite / short breaks

Arrangements that give the family a break and/or give the person a positive time away — clubs, overnight care, holiday schemes. Wording varies by area; the ask is always the same.

You'll meet it: in social care reviews and care plans.

Ask: "Is there any short-breaks support available, and how do we access it?"

SALT — Speech and Language Therapist

A professional who works on communication (speech, understanding, alternative communication like PECS or AAC) and, in some settings, eating and drinking.

You'll meet it: in education and health teams.

Ask: "Is SALT involved, and are we up to date with their recommendations?"

Seclusion

A term used in inpatient settings for placing someone alone in a room, under observation, often as a last resort in a crisis. It has strict rules around how and when it can happen. If it's ever used for the person you care for, you should be told, and you can ask about the review that must follow.

You'll meet it: in inpatient settings.

Ask: "Can you explain the policy on seclusion, and when would it be used?"

SEND — Special Educational Needs and Disabilities

The umbrella term used in education for children and young people with additional needs. The SEND system covers school support and the EHCP process.

You'll meet it: in schools and local authorities.

Ask: "What SEND support is in place, and who is the SENCO?" (SENCO = the school's special educational needs coordinator.)

Transition (children's to adult services)

The process of moving from children's services (school, CAMHS, children's social care) to adult services. It is a place where support often falls apart, so it needs to be planned, written down and chased.

You'll meet it: around age 16–18.

Ask: "What's the transition plan, who is coordinating it, and what happens if there's a gap between services?"

SECTION 10

Red flags: when to escalate and ask for urgent help

Most situations can be handled in working hours, at reviews and in planned appointments. Some cannot wait, and knowing which is which is one of the hardest parts of caring. This section is a plain-English triage guide: what to do now, what to do today, and what to bring up this week. When in doubt, phone someone — Section 1's script works on the phone too.

Tier 1 — Call 999 now. Do not wait.

Call 999 when there is immediate danger to life or safety

- The person is trying to harm themselves seriously, right now.
- Someone is unable to keep themselves or others safe in the next few minutes — for example severe self-injury that won't stop.
- There is a medical emergency — unconscious, fitting, severe injury, severe overdose.
- You believe staying where you are is not safe.

Say it plainly on the call: "This is an emergency. I need an ambulance because [what is happening right now]." Stay on the line. You don't need the right words — you need to be clear about danger and location.

Tier 2 — Urgent but not an emergency. Contact help now, today.

Contact the Crisis Team, NHS 111, or A&E now — don't wait for a planned appointment

- A sudden, severe worsening — in a few days or hours — not a gradual decline.
- The person is talking about not wanting to live, or about harming themselves, even if you think it won't happen. Always take this seriously, every time.
- Extreme agitation or distress that has lasted hours and isn't settling with what normally helps.
- A long shutdown where the person is not eating or drinking, or you cannot reach them at all.
- Behaviour that is becoming unsafe to manage at home and you feel at the edge of what you can cope with.
- Any sudden physical symptoms alongside distress — don't assume it's "just" mental health.

How to contact: NHS 111 (free, 24/7) — they can connect you to urgent services and the local crisis team. If the person is already under a mental health team, use the crisis number you were given; if you don't have one, NHS 111 can find it. A&E is appropriate if you need to be seen now and you believe the risk is immediate.

Tier 3 — Escalate this week (don't keep it to yourself)

Contact the GP, care coordinator, or lead professional within a few days

- A pattern that is clearly getting worse week on week.

- The person has stopped eating or drinking consistently over several days.
- Sleep has collapsed — a clear change from their usual pattern, lasting more than a few days.
- Marked withdrawal — not leaving the room, not speaking, no longer doing things they enjoyed.
- New or increased self-harm, even if each incident is minor on its own.
- Medication concerns — side effects you're worried about, or they've stopped taking it.

Use the three-part answer from Section 1 on the phone or in an email (Section 2): what you see, when it happens, what helps. Ask for a specific next step and a date.

Tier 4 — Bring up at the next review (don't let it slide)

- Quality-of-life changes: fewer interests, less contact with friends, more time in bed.
- Repeated problems with a specific setting (school, work, a service) that you've raised before.
- You, the carer, are burning out (see Section 8) — that belongs on the agenda, not in the margins.
- Anything from the tracking sheet (Section 4) that shows a pattern worth discussing.

What to say when you call a crisis or triage line

PHONE SCRIPT — KEEP IT TO FACTS

"My name is [name]. I'm calling about [person's name], who is [age], and is autistic / under [service]. Right now [one line: what is happening]. This has been going on [duration]. What normally helps is [one thing], and it isn't working. I need to know what to do next."

Why it works: name, situation, one line of now, one line of duration, what's been tried, one ask. The person on the other end is triaging; give them what they can act on.

Keep a record of red-flag events

If you ever need to escalate further — to a complaint, to the GP, to a review — the family with dates wins. Log: date and time, what happened, who you spoke to, what they said, what happened after. One row per event, five minutes. (The log table in Section 2 works for this.)

Numbers to keep somewhere you can see them

999 — in an emergency, immediate danger. Call now, don't wait.

NHS 111 — urgent medical advice, 24/7, free.

116 123 — Samaritans, free, 24/7, confidential.

Crisis Team / Home Treatment Team — via your GP, NHS 111, or A&E. If the person is under a mental health team, use the number they gave you.

This toolkit is not emergency advice. When in doubt, phone. You are not wasting anyone's time — asking is what services are for.