



School-Ready with a Rare Diagnosis

A CHECKLIST FOR PARENTS SENDING A CHRONICALLY ILL KID BACK INTO THE BUILDING

Nobody hands you a manual for this. You get a diagnosis, a discharge folder, and a vague sense that school starts again whether you're ready or not. So we made the manual. **This isn't about wrapping your kid in bubble wrap** — it's about walking in with a plan instead of a prayer.

THE PAPER TRAIL

- Lock in the **504, IEP, or Individualized Healthcare Plan** before day one — not after the first bad day forces it.
- Get a **one-page medical summary and emergency action plan** from your specialist the school can keep on file.
- Request a sit-down with the **principal, nurse, and counselor** — not a hallway conversation on the first morning.
- Brief the **school nurse** specifically: what a flare looks like, what triggers it, what to do.
- Give every **teacher** a plain-language, non-scary summary — what to watch for, what to do, who to call.
- Write down the **emergency response chain**: who's called first, second, third, and what happens before you arrive.
- Pack and deliver a **labeled bin of meds/enzymes/supplies** to the health office, with dosing and timing clearly attached.
- Make a **quick-reference sheet for substitutes** — written for someone who's never met your kid before.
- Loop in **food services** early if there are dietary restrictions, supplements, or meal timing needs.
- Get **physical accommodations** (locker location, bathroom access, elevator pass) written into the plan — not left to chance.

SETTING UP YOUR KID — NOT JUST THE PAPERWORK

- Give your child **simple, age-appropriate words** for their condition — language that's theirs to use, or not, on their own terms.
- Identify **one safe adult and a check-in spot** that doesn't turn into a whole production.
- Pack your kid a small **"go bag"** they carry themselves, so they're not relying on memory alone.
- Have a quiet word with the counselor about possible **teasing or "why do you get to leave class"** questions — before they come up.
- Give **siblings or close friends** at the school a simple heads-up on what to do if something happens.

THE LOGISTICS NOBODY WARNS YOU ABOUT

- Set up a **home-school communication log** so updates don't depend on a kid accurately relaying medical details.
- Get **medical absences explicitly exempted** from "excessive absence" policies — in writing, before they pile up.
- Know exactly how **makeup work and grading** will work before the first missed day.
- Decide **bus vs. pickup rules** for symptom days, and who has authority to make that call mid-day.
- Build a separate mini-plan for **field trips and after-school activities** — standard accommodations don't always transfer automatically.
- Build your own **decision tree**: what means "stay home," what means "go but flag the nurse," what means "pick up now." Decide before the panic, not during it.

STAYING THE COURSE

- Put your **504/IHP renewal date** on the calendar somewhere you'll actually see it.
- Schedule a deliberate **first-week and first-month check-in** — don't wait for a crisis to ask "is this working?"
- Keep a running log of **what worked and what didn't**, so next year doesn't start from zero.
- Name your **own anxiety** as part of the plan. Managing your fear at drop-off is logistics too — not a lesser problem to handle quietly on your own.

You don't have to do all 25 perfectly. You just have to do the next one.

You're early. Not behind. That's the whole point of this list.

This checklist is for general informational purposes and does not replace medical, legal, or educational advice from your child's care team or school district. Every diagnosis and every district is different — use this as a starting point, not a substitute for your own team's guidance.



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