

The First 30 Days

A practical starting point after a diagnosis - built by a rare-disease dad. Use what helps. Ignore what doesn't.

Start here

You don't have to solve the next ten years this week. Capture the essentials, protect your energy, and choose the next useful move.

TODAY

- ☐ Write the diagnosis or working diagnosis exactly as the care team gave it to you.
- ☐ Ask who your main point of contact is and how to reach that office after hours.
- ☐ Request copies of the visit summary, test results, and current care plan.
- ☐ Put medications, allergies, and urgent warning signs on one page.
- ☐ Tell one trusted person what would actually help this week.
- ☐ Write down the next appointment before leaving the building.

THE NEXT 7 DAYS

- ☐ Start one binder or digital folder. Don't build a perfect system - build one place to look.
- ☐ List the three questions that keep circling in your head.
- ☐ Confirm referrals, prior authorizations, and any testing instructions.
- ☐ Ask for a plain-language explanation of unfamiliar terms.
- ☐ Write down who handles insurance, school, work leave, and family updates.
- ☐ Choose one person who can sit in on appointments and take notes.

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Page 2 - Build a working family system

THE NEXT 30 DAYS

- [] Create a one-page About My Child sheet for providers, school staff, and emergency care.
- [] Make a running question list instead of relying on memory.
- [] Review insurance deadlines and keep a log of every call, reference number, and name.
- [] Ask the school or early-intervention team what supports can begin now.
- [] Identify the disease-specific organization or registry, if one exists.
- [] Ask which information is urgent, which is useful, and which can wait.
- [] Schedule time with your partner to compare notes without trying to fix everything.
- [] Check in with yourself: sleep, anger, isolation, work pressure, and the support you have.

Questions for the care team

Names and numbers I need

NAME / ROLE	PHONE / PORTAL
NAME / ROLE	PHONE / PORTAL
NAME / ROLE	PHONE / PORTAL
NAME / ROLE	PHONE / PORTAL
NAME / ROLE	PHONE / PORTAL

Peer support and education only. This worksheet doesn't replace your child's medical team, school professionals, insurer, attorney, or emergency services.