

Rare Disease & Chronic Illness Medical Binder Checklist

Stay organized, informed, and prepared for every appointment.

Managing a rare disease or chronic illness often means keeping track of many records, medications, test results, and healthcare providers. A medical binder helps keep everything in one place so you can easily access important information and share it with healthcare professionals when needed.

Use this checklist to organize your personal medical binder.

Section 1: Personal Information

- Full Name
- Date of Birth
- Emergency Contact Information
- Insurance Information
- Primary Care Physician Contact Information
- Pharmacy Contact Information
- Allergies List
- Blood Type (if known)

Notes:

Section 2: Medical Conditions

- List of diagnosed conditions
- Date of diagnosis for each condition
- Treating specialists for each condition
- Important symptoms to monitor
- Known triggers or flare indicators

Notes:

Section 3: Medication List

- Current medications
- Dosage information
- Medication schedule
- Prescribing doctor
- Known side effects
- Previous medications that did not work

Notes:

Section 4: Medical Appointments

- Upcoming appointments calendar
- Appointment preparation worksheets
- Questions for doctors
- Notes from previous appointments
- Follow-up instructions

Notes:

Section 5: Test Results & Medical Records

- Lab results
- Imaging reports (X-rays, CT scans, MRIs)
- Genetic testing results
- Hospital discharge summaries
- Specialist reports
- Surgical records

Notes:

Section 6: Insurance & Financial Documents

- Insurance cards
- Prior authorization paperwork
- Insurance appeals or denial letters
- Explanation of Benefits (EOB)
- Medical bills and payment records

Notes:

Section 8: Emergency Information

- Emergency contact list
- Current medication list
- Allergies and reactions
- Primary diagnosis summary
- Doctor contact information

Notes:

A Gentle Reminder

Staying organized can make medical appointments less stressful and help ensure healthcare providers have the information they need to provide the best care possible.

You deserve to feel informed, prepared, and confident in your healthcare journey.

Alpha Health Alliance

www.alphahealthalliance.org

This resource is provided to support individuals and families navigating rare diseases, genetic disorders, and chronic illnesses.

This document is for personal organization only and does not replace professional medical advice.