



# PREPARING YOUR MEDICAL HISTORY

A toolkit to help you prepare for your doctor or specialist visit





# How to Use This Toolkit

This toolkit helps you gather your medical history, symptoms, and questions in one clear place. You can fill out this toolkit yourself or for your child or family member.

## **You can complete it:**

- On your own
- With help from a family member, caregiver, or advocate

## **Once finished, you can:**

- Print it and bring it to your appointment.
- Scan it and save it to share through a patient portal or email, if available.

You do not need to have all the answers. Do the best you can with the information you have. It's ok if some details are missing.





# Why This Toolkit Can Help

Many people with rare, ultra-rare, and undiagnosed conditions see multiple doctors over time. Medical records can become spread out across different doctors' offices, hospitals, labs, and healthcare systems.

Doctors often have limited time to review long medical records. When information is hard to find, people may miss important details.

This toolkit helps you share a simple but comprehensive picture of your experience of your medical history. By highlighting what matters most to you, including key symptoms, changes over time, and key test results, you can help your healthcare provider focus on critical information.

For people with rare or undiagnosed conditions, this organized summary can help toward getting answers and effective care.

This toolkit cannot guarantee a diagnosis. However, clear and organized information can support the conversations you have and help doctors make more informed decisions.





# You Are Part of Your Care Team

You are an important part of your care team. You know your symptoms, your history, and how your condition affects daily life better than anyone else.

Medical records and test results matter, but they don't always show the full picture. Your experiences, patterns you've noticed, and concerns help doctors understand what those records mean.

Sharing your perspective helps your doctor or specialist understand what you're experiencing. Working together with your doctor helps you both make more informed decisions about your care.

This toolkit gives you a clear way to highlight what feels most important to you. If something feels relevant, include it, even if it does not appear in your medical records.





# How to Share This With Your Doctor or Specialist

1. Bring a printed copy to your appointment, or save a digital copy to share through your patient portal or email if available.
2. Ask your doctor or specialist to review it during your visit or before making next-step decisions.
3. Use this toolkit to guide the conversation and make sure your main concerns and questions are addressed.

## **Disclaimer**

*This toolkit is for informational and organizational purposes only. It is not a medical record, does not provide medical advice, and cannot diagnose or treat any condition. This toolkit is meant to support communication with healthcare providers and should not replace medical advice and care. Always follow your healthcare providers' guidance when making medical decisions.*



# My Medical Summary

**Name:**

**Date of Birth:**

**Age or Date of First Symptoms:**

**Short Summary of Symptoms/Medical History:** This section is for a short, brief summary. List the current diagnosis in the box below.

*For example: I have muscle weakness in my legs, fatigue, and joint pain. This started when I was a child and has gotten worse. Current diagnoses: ataxia; arthritis.*

**Current Diagnosis List:**


**List of All Symptoms:** Include current and past symptoms.

List one symptom per box.


**Have symptoms changed over time?**

Do you have new symptoms? Have some symptoms gotten worse or better? Do you have symptoms that come and go?

### Abnormal Blood Tests

List significant abnormal test results, if known. Include test name and date if possible. List in order of oldest to newest.

Date	Test Name	Above or Below Normal	Actual Result if Known

### Other Testing Results

Include imaging and other tests, such as MRIs, CT scans, x-rays, biopsies, genetic testing, etc. List in order of oldest to newest.

Date	Test Name	Results

### My Notes for Labs, Photos, Other Testing, and Hospitalizations

Use this space to add notes that explain your records. Include:

- Date
- Test or event
- What was happening at the time

**For example:**

**1/5/2023 MRI:** *I had pain in my lower back and could not walk. I woke up with this pain the week before the MRI and couldn't get out of bed without help. My mom had to help me get dressed because it hurt to raise my arms.*

Date	Test or Event	What was happening at the time

**Are there triggers or patterns?**

Did something happen before your condition started? Or are there triggers for symptom flare-ups? Does something happen to make your symptoms worse or better? Triggers for symptoms may include illnesses or infections, injuries, stress or lack of sleep, foods, activity, weather, etc. If there are no clear triggers, then write "no triggers."

**Medications Tried:**

List medications you have tried. Did each medication help or not help? What symptoms did the treatment help or not help?

Medication Name	Date(s) when taken	Did it help your symptoms? (yes, no, some)	What symptoms did it help?	What symptoms did it not help?

**Specialists Seen:**

List the doctors and/or specialists you have seen.

Specialty	Doctor Name	Location

**Current Concerns and Questions:**

*What are your main concerns right now? What questions do you want answered?*

**How my undiagnosed disease affects me, my child, or loved one, and how it affects our family:**

*Describe how symptoms are affecting daily activities, school, work, social life, and/or family life.*

**Family History:**

*Do other family members have similar symptoms? Do other family members have a chronic illness diagnosis or unusual conditions?*



# Tips for Putting Together Your Medical Summary

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## This Summary Is Your Perspective

This summary is from your point of view. You know your symptoms, or your child or loved one's symptoms, best. Some important details may not appear in medical records, and that's okay.

If something feels important to you, include it.

## When in Doubt, Include It

If you are unsure whether to list a symptom, trigger, or concern, include it. Small details can help doctors see patterns.

You do not need to decide what is medically important. Share what is important to you and what you are unsure about. This helps your doctor see the whole picture and guide your medical care.

## Think About Change Over Time

Try to describe:

- What was life like before symptoms started?
- What has changed since then? What is your new normal?
- Which symptoms are new, worse, better, or come and go?

This helps doctors understand how your condition has progressed.





# Tips for Putting Together Your Medical Summary

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Add notes to photos, imaging, and labs.

When including copies of photos, MRIs, blood tests, and other test results, include your notes about what was happening in the photo or the day of the test.

For example, did you have pain or swelling in a joint at the time of an MRI? When you had a blood test, what symptoms did you have at the time of that test? Or were you feeling good that day?

If you can't write directly on a lab report or photo, use the My Notes for Labs, Photos, Other Testing, and Hospitalizations section in this toolkit to make it easy for the doctors to match your notes to the medical records.

## Use What You Have to Remember Details

Exact dates are helpful, but not required.

If you need help remembering:

- Check text messages or emails
- Look at calendars, photos, or social media posts

Approximate dates, or years, are okay.





# Tips for Putting Together Your Medical Summary

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## Consider Family and Shared Exposures

Family history can be important.

Include:

- Family members with similar symptoms.
- Family history of autoimmune, chronic conditions, symptoms that seem to start younger than is expected, etc.

Also, think about shared environments:

- Schools, workplaces, or communities.
- Exposure to environmental toxins! or substances.

If several people you know have similar symptoms, include that information.

## Think About Possible Triggers

Consider whether anything happened:

- Before symptoms first started
- Before symptom flare-ups

Examples include:

- Illness or infection (such as COVID, flu, or mono)
- Injury or surgery
- Travel
- Big events like a birthday party or school finals
- Certain foods
- Stress or lack of sleep

If symptoms are constant and you do not notice triggers, that is important to note too.



# Resources

These resources can help you gather family medical history, talk with relatives, and organize information to share with your care team.

## **Global Genes: Make a Plan: How to Talk to Your Family**

Tips for talking with your family to create a family medical history.

<https://globalgenes.org/blog/make-a-plan-how-to-talk-to-your-family/>

## **AMA: Collecting a family history**

<https://www.ama-assn.org/delivering-care/precision-medicine/collecting-family-history>

[https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/genetics/family\\_history02\\_0.pdf](https://www.ama-assn.org/sites/ama-assn.org/files/corp/media-browser/public/genetics/family_history02_0.pdf)

## **My Family Health Portrait**

Online family tree/pedigree builder that can be printed or saved to pdf.

<https://cbiit.github.io/FHH/html/index.html>



# Need Help?

We're here to support you every step of the way.

Reach out to us at [support@udnf.org](mailto:support@udnf.org)

