Acromegaly Medical Notebook

Plan for Assembling a Medical Notebook

Obviously, much of what is described here can be done and stored electronically. It is simply a matter of how you like to do it. The important thing is having the information at your fingertips wherever you are. You can make tabs/files with these bold headings. Be sure to take your notebook with you to every appointment. Also, be sure at least one person in your household knows where you store the notebook in case of emergency.

Buy a notebook and index sheets and make these sub-groups:

- Grab and Go
- Calendar
- History
- Meds List
- Updates
- Insurance

- Medical Caregiver
- Data
- Acro Community
- Records
- Financial

The notebook can be compiled in whatever order you like.

Grab and Go

This is a list to be kept in the very front of your notebook. In case of emergency you or a family member will know what materials to take to the hospital, etc. Mine includes things like: your driver's license and insurance card , phone charger cord, sweater (hospitals are always cold), your routine medications, toothbrush, assistive devices- such as canes, glasses or contacts, hearing aids, walkers, ,and C-Pap machines), glasses or contact lens case, reading material, address book or planner, snacks. Place house key in outside hidden location or at a neighbor's house. The hidden key is to provide a way for a friend to get into your house for you if you are stuck at the hospital, etc.

Calendar

Pick one with enough room to write appointments in. (Just tear apart and hole-punch a freebie.)

History

- List of surgeries by date, including surgeon's name and condition treated.
- List of past and current medical issues
- List of tests done- by date, place, prescribing dr., reason, summary of results

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- List /Documents of immunizations with dates (be specific)

    Ex.   "Shingles Zoster 12-2-09   Shingex 8/20/18 and 2/20/18"

- Family medical history - often you can print these from your doctor's pre-visit questionnaires

Meds List

Page 1: Pharmacy Names & Numbers
Enter the names and phone numbers of the pharmacies (local and / or mail order) that you use.

Include your list of "Allergies" on Page 1. List drugs or materials (ex. latex) you are allergic to.

Page 2: Medication Lists
The second page will start your list of medications. Add the date when you printed the list at the top of the list. Most pharmacies allow you to download a list of your medications with pertinent information. You can also download your medication list from your patient portal. Store these print-outs behind the "Meds" tab.

Be sure to update this list every time you make a change. This is also a good place to store a master copy of your Meds Schedule. Each time your update your medications, print out a new list and add the date the list was updated.

For each medication, include the following information:

- Brand name & generic name
- Condition treated
- Dosing, frequency, time of day you take the medicine (labels on the bottle don't always specify) and how taken
- Prescribing doctor's name
- Allergic reactions or side effects?

For example:

- **Brand Name:** Montelukast Sodium
- **Generic Name**: Singulair
- **Condition Treated**: Allergic Rhinitis
- **Date Started**: 02/01/16
- **Dosage Amount**: 10mg
- **Frequency**: Daily
- **Time of Day Taken**: AM

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- **How Taken**: Pills (or topical, occasional/PRN)
- **Prescribing Doctor**: Dr. George
- **Allergic Reaction**:2010 anaphylactic reaction
- **Side effects**: Causes migraines
- **Still taking?** (Yes or No)

Or you can create a spreadsheet:

Brand Name	Generic Name	Condition Treated	Date Started	Dosage Amount	Frequency	Time of Day Taken	How taken	Prescribing Doctor
Montelukast Sodium	Singulair	Allergic Rhinitis	02/01/16	10mg	Daily	AM	Pills	Dr. George

One of our patients prints this list out at a reduced print size and keeps this list in her wallet next to her driver's license and insurance card. You could add emergency contact names and phone numbers on this copy.

In your binder you might want to keep the Medication Info Sheets the pharmacy always includes with your meds.

Be sure to notice the Med's Schedule sample at the end of this document.

Meds Schedule

Create this in Microsoft Excel, etc.

This is a sample piece of a personalized spreadsheet I made for my family to use. Make masters of these forms in advance of surgery or other times when you have multiple medications to keep track of. I used a clipboard and a pencil on a cord and just hung it up next to my box of meds. You could also attach a small digital clock. (Look for kitchen timers.) You can tell at a glance which meds have been taken for the day, and it helps your medical team and caregivers to monitor your needs. Just fill in the times and dates when you take the medicine or record blood pressure.

Fill in date below day of the week. Write time taken in white box.

allegra 24 hr.	synthroid .75mg	hydrocod aceta 10-325	prometh	cycloben flexiril	patanol drops	nasacort spray	other	Blood pressure	Time
allergy long pink 1 in AM	thyroid round gray 1 hr before brk	back pain white round 1-2 ev 4-6hr	nausea blue tab 1 ev 8 hrs	musc rlx 1 3xday	dry eyes 2 x day	allergy 2 x day			

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										9:00AM
Sun. 8/1/2018	7:00	6:00	7:15 AM 1:00 PM	7:00AM 3:00PM					118/68	
Mon.										
Tues.										

Updates

This is a record of your on-going care. This may be the most valuable part of your medical binder. With multiple doctors at multiple locations it can be difficult to keep up with all of your doctors and their instructions. After every appointment (or email, or phone contact) take a minute to note date, which doctor, and summarize the visit as succinctly as possible.

> Example: "10/18/17 Dr. ***- I reported 3 recent bouts of chest pain radiating to lower jaw. He felt we should follow-up with referral to cardio for a stress test at *** hospital to rule out cardiac disease before Dec. surgery. He did EKG which showed no concerns. Heart lab will call me to schedule ".

Note from Patient: I keep this as a single (ever-expanding!) document. Since my general practitioner was not part of the medical institution where I was receiving my specialty care, I would occasionally print off the most recent page and drop it by his office. He appreciated my keeping him "in the loop."

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Records

Visit Summaries: Many doctors either hand out or post on your patient portal a summary of your visit, including instructions.

Tests: Always ask for print-outs of test results. When getting MRIs, you can also get a burned copy on a CD. Many group practices make these available online, but some only post them for a limited time Sometimes you may have to wait until the medical professional completes the results and can send it to you later. If you don't have copies of past ones, contact the provider's "Medical Records" dept. and complete the request forms. You may have to pay a small fee.

Operative Reports: These contain information that the surgeon might not have bothered to mention, or told you when you were too drugged in Recovery to remember. These are not routinely included in Patient's history, but you do have a legal right to them. Sometimes you can get them from the hospital and other times you have to request them from your surgeon. (Be aware that they may not be released immediately.) The anesthesiologist will probably have a separate report. In a teaching hospital there may be a report from the surgeon's Fellow and one from the Supervising surgeon. If you need access to information about your care while you were in the hospital, you will need to contact the hospital's Medical Records Dept. and complete Request and Release forms. Sometimes there is a charge for this.

Medical Team

This section contains info on all the doctors and other professionals involved in your care. Much of it is easy to find online or even on the business cards in their offices. Be sure to include Teledocs. If possible, include a photo of the provider. It should include the caregiver's name, specialty, location, office hours, phone numbers, names of nurse or PA they also use, and name and phone number of their "scheduler", note regarding "in/out of network" status. Download a map or instructions for how to get to their location.   Add any specific info you want to remember about this professional or office.

Dr. xxxxxxxxxxxxxx MD PhD   professor cardio-thoracic surgery

UTSW University Hospital Hematology Med. & Surg. Oncology Clinic

2201 Inwood Rd. 3rd. floor, Suite 500 Dallas 214-645-4673

 ***** nurse   ***** scheduler   **In**-network

Simmons Cancer Center off of Harry Hines Blvd.   parking garage behind

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I also list the most vital info for labs and hospitals you frequent. "**** Hospital patient in yellow gown can't get up independently. Good cafeteria on second floor 6 AM to 9 PM. Only East door stays open 24 hrs. Kroger and McDonalds are 1 street to east.

Data

With a new diagnosis it is easy to get overloaded with the volume of new information you receive. Use this section to store reference data you collect. It can be hand-outs from your doctor, info you found online, or links to references to which you may wish to return, and Instructions from physical therapy

Financial

Hole-punch a large envelope. You can store bills and receipts here. Remember that charges like parking garage fees can be included on taxes if you have receipts.

Insurance

Use to store "Explanations of Benefits" or other insurance-related info. Make a copy of your insurance card to store here. Include contact information for your insurance or hospital-assigned case manager if you have one.

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Names and contact info of your support people. Names and email addresses, or phone numbers of people who will want prompt notification after you had surgery. Names and phone numbers for people who may be available for back-up babysitting so family can get some rest. Also include the name and phone number of someone available to care for your pets in case you are hospitalized.