Your Health Records: Why and How to Access, Organize and Use Them

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As a neuropathy patient, you probably have seen multiple physicians and other care providers. Whenever you have an appointment, you are asked to provide information, and the provider's findings and conclusions, as well as new test results, are added to your growing medical records. You may well have multiple sets of records, one for each hospital system or provider group. While the task may seem daunting, you may want to consider obtaining your records and putting the information into a format that will be very helpful in getting you the best medical care as efficiently and cost effectively as possible.

Why should you do this? If you know what is in your medical record, you will be able to understand your health history and be your own best advocate. You'll be able to ask better questions, and work better with your providers to make decisions. You can track your lab results and medications. Each healthcare provider you see wants to know your medical history, but does not have time to read through hundreds of pages of medical notes and lab test results. They rely on you to summarize what you know about your medical condition(s), what testing has been done, test results and the conclusions of other providers you have seen. Few people can accurately recall the details of their medical visits and testing, and frequently the provider only shares part of his or her thoughts and concerns with each patient. In the few minutes allotted for the initial patient-doctor conversation, some material may be misunderstood or entered in your record inaccurately. The only way for you to be sure that your providers know your past medical history, so they can partner with you to give you the best care, is for you to get your records, check them for accuracy, organize the contents into a usable format, and share this summary with your medical care team. Your efforts will be welcomed by your team of providers, especially new ones trying to get up to speed.

What does this involve? First, you need to get the complete record from each of your providers and hospital systems. You have the right, under the Health Insurance Portability and Accountability Act, or "HIPAA", to see and get copies of all your health records. While some providers have website portals where you can access some of your test results and certain other materials, these almost never include all the information that is in

your full medical record. Typically you need to request your records in writing. Most providers will give you a records release form either by request or available on their websites. You will need to complete the release forms, designating yourself as the one to whom the records should go, and mail or fax it back. The release form will ask the purpose for which you want your records. Since you are using the information to provide to your care team, you should mark the reason as being for medical care; this often will incur no charge for the records. Be sure to request your entire medical record, including providers' notes about visits, discharge summaries, reports on labs, operations, pathology, radiology, genetic screening and mental health care reports. You can also request information on your account and billing history. The law requires that you be provided with your medical records even if you may still owe medical bills.   You will usually be able to choose the format in which you get your records. If you request your records in paper form, there may be a per page fee. The fee is typically less, or even free, if you request that your records be provided electronically by secure download. There may be an additional fee if you want copies of photographs or x-rays along with your records.   The provider has 30 days to send you your records, but often will provide them in less time.

Now that you have your records, what next? You might want to get sets of file folders, and separate the records into sections, such as for visit notes, hospital inpatient stays and discharge reports, lab tests, radiology/imaging reports, cardiology, pathology, microbiology and other tests (like neurophysiology testing such as nerve conduction velocity or autonomic function testing).   The records will typically be in chronological order.   As you go through the records, be sure to note if you think there is an error.   You would then ask your provider to correct the record. Even if the provider disagrees with you, you have a right to have the facts of the problematic material put into your medical record.

Now the work starts. The goal is to extract the information from your record, and put it into a concise form that is useful for you and for your care team. I have my records, which total about 1500 pages from the last 12 years of a complicated health history, condensed into a 4 page document. As noted below, the information in some of the sections are organized in tables. It is helpful if you mark abnormal results by shading those lines of the tables.

These are the sections of my report:

1. Name, birth date and medical record numbers for my providers' institutions.
2. Brief summary statement of age, family and work status, and overall statement about my health.
3. List of the conditions with which I've been diagnosed, including date of onset, status and treatment received.
4. Conditions for which I have family history. For each condition, I give the relative and age of onset.
5. Surgical history table, with columns for surgery type and date.
6. Pathology table, with columns for tissue, what is being tested for, and results. Include normal results. As an example, one line might read Skin punch biopsy/ small fiber nerve density/5% normal on 12/2011
7. Table for electrophysiology and autonomic testing, with columns for test, date(s) and results. Make the tables as concise and possible. For example, if you had 4 EKGs, all normal, list the dates in one row in the middle column, with the right column entry marked "normal". Include in this table electromyography and nerve conduction velocity tests (EMGs and NCVs), hearing tests, autonomic function testing, qualitative sensory testing, Holter monitoring, electrocardiograms and blood pressure.
8. Genetic testing - columns for test, date and results.
9. Lab results. Again, make this as concise as possible, using one line per test or test group. The first column is for test, and the second for date and result. For example, one line might read "Hematocrit,

serum iron, ferritin / normal all dates.   Next line: Lyme, HIV, Parvovirus, Celiac / Negative/Normal. Another: White blood cells / Generally low, 2008-2018

10. Imaging, with columns for test and body part, date, and result. Include MRIs, x-rays, CT scans, PET scans, fluoroscopy, ultrasounds, echocardiograms, and bone density tests,
11. Allergies – list
12. Immunizations – table of type and dates.

Once your summary report is done, share it with your providers.   Every year or so, it is recommended to request your records from the past year, and go through them and update your summary. The records release form lets you specify the dates for which you want your records.   I have found this to be very helpful for making my medical history information accessible, so my providers and I can use it effectively. It eliminates the need to repeat some tests, since we can immediately see what has already been done and when. It is a powerful tool in helping get the best medical care.