

Organize your medical records



Start 2015 off right by resolving to take control of your health information.

by Sarah Markel

About two-thirds of Americans make New Year's resolutions. After weight loss, the second most popular resolution is getting organized. Organizing medical information, in particular, can help people with multiple sclerosis improve their healthcare by reducing the risks of medical mistakes, test duplication and potential hassles with insurance, tax and disability claims.

Even so, tackling years of paperwork can be daunting. According to J. Tamar Kalina, an occupational therapist who directs the rehabilitation and research program at New York University's Comprehensive MS Clinical Care Center, the fatigue, depression and mobility issues that often accompany MS can make any kind of organizing difficult. Breaking the process into smaller steps can make it more manageable.

Going digital



Try out a tablet.

Electronic “organizers” and personal health record systems can help reduce clutter. For help selecting one, visit the American Health Information Management Association’s searchable database at myphr.com/resources/choose.aspx.

To learn more about the Microsoft HealthVault, visit healthvault.com.

For information about using Blue Button to aggregate your health records, visit healthit.gov/patients-families/blue-button/about-blue-button.

For information about My MS Manager, visit mysaa.org/manage-your-ms/mobile, or download it from the Apple Store or Google Play.

Gather the right information

The first step is to prioritize and compile the most important records. This includes copies of the tests and lab work—biopsies, lumbar punctures, MRIs—that led to an MS diagnosis. Next: gather any records related to surgeries, immunizations and ongoing health conditions, including those not obviously related to MS. Having these high-priority records organized and easily accessible can be extremely helpful if you move, seek a second opinion or otherwise change providers, as requested records arrive at a new office in time for the appointment.

To obtain these records, you may have to request copies from healthcare providers, sign a release form and pay a fee. However, Medicare beneficiaries, military personnel and participants in more than 30 private-sector insurance plans can download their health information at no cost using Blue Button, a government-sponsored initiative designed to increase patient access to medical information. Currently, about half of all U.S. consumers have access to Blue Button, and the federal government plans to make it universal by 2024. (See “Going digital,” right)

Lydia Washington, senior director of Health Information Practice Excellence at the American Health Information Management Association (AHIMA), says there is no industry standard for how long an individual should keep medical information. However, she recommends keeping key records, such as medical diagnoses, surgical procedures, and the names and contact information for doctors or clinics where files may be located, indefinitely. Other information, such as routine lab work and the results of health screenings, can be discarded every few

years or when your physician recommends it. Meanwhile, according to the IRS, medical receipts used for tax purposes can be discarded three years after filing a claim.

Once you have shredded and discarded any files that are no longer needed and have compiled the records you want to organize, you'll need to decide whether you are more comfortable with old-fashioned paper filing or prefer electronic storage systems. Either way, using a bit of insider knowledge can help make the organization process less painful.

Call in the organizing experts

Occupational therapists can teach clients strategies to manage paperwork, such as setting up "in-boxes," and placing easy-to-forget items, such as insurance cards, within arm's reach. Call an MS Navigator at 1-800-344-4867 for a referral to an OT in your area. Check with your insurance plan to see if an OT's help is covered.

While not covered by insurance, a professional organizer can set up personalized systems for tracking and sorting records, which can ultimately save money by preventing duplicated tests and tracking tax deductions. To find a certified professional organizer, check out the National Association of Professional Organizers' member directory at napo.net/publicdirectory.



File it
away.

Paper pals

Hang it all. For people who prefer paper systems, a hanging file in a file cabinet is better than a binder, Kalina says. Many people with MS have complicated medical histories involving lots of paper, and binders can get heavy quickly, which can cause difficulties for people with muscle weakness or numbness. "It's easier on the body to pull out a drawer than to pick up a binder," Kalina adds.



Count on color.

Use color. Color-coding hanging files can help people with memory issues recall what's filed where. The trick is to use only two high-contrast colors for folders. Everything related to finances—insurance forms, referrals, bills—goes into green folders (think money!). Meanwhile, everything related to the body—tests, health journals, physician's reports—goes into orange folders (think MS awareness!).



Be bold.

If low vision is an issue, Kalina says it is important to choose bright colors. “You don’t want anything washed out,” she says. Using boldface 14- or 16-point type makes it easy to scan labels quickly. And studies show that sans serif fonts, such as Arial and Verdana, are easier to read.



Store
data in
the
cloud.



Health to
go.

Digital devotees

Reach for the cloud. Those who prefer a digital approach can find a range of personal health record (PHR) programs online. Some of these programs can be particularly beneficial for people who see multiple providers because the programs can integrate information from different sources such as doctors, pharmacies and labs, says Washington. **Some PHRs can even aggregate information from popular third-party health apps that track things like heart rate and blood pressure.** With cloud-based PHRs, data is stored remotely and can be viewed from mobile devices and shared with loved ones who live far away, or in some

cases, with healthcare practitioners.

One such example is Microsoft's HealthVault. This PHR allows users to securely upload health information, including MRI scans and other imaging files, as well as more routine health data such as allergies, blood pressure or weight. You can log in to your account from your computer or mobile device, and can also authorize third parties—hospitals, labs, even medical and fitness apps you already use—to send information directly to your HealthVault record. You can choose to share some or all of your HealthVault file with your doctors, nurses or family members.

Finding the right PHR may take some research. AHIMA streamlines the process by offering a searchable database of several dozen PHRs (see "Going digital," above. Washington recommends selecting a PHR that uses the Blue Button. "This allows you to download information, so you don't have to do a lot of manual scanning and transferring information," she says. Washington also suggests that people choose PHRs that allow them to easily share information—perhaps via a link or a password—with their healthcare providers. "Think about how you get the information in and how you get it out."

While they may not link to PHRs, some MS-specific mobile apps that help users track symptoms can make it easier to manage MS-related information. The Multiple Sclerosis Association of America offers My MS Manager, a mobile app that functions a lot like a PHR because it stores health information while also enabling users to track medications, relapses and symptoms. This app, which stores information on a mobile device and can be backed up to the cloud, is available at no cost to users. Other apps track single aspects of MS management, such as injection sites.

Washington cautions that when using mobile apps, consumers should carefully read user agreements to find out how much of their data is shared with third parties. "You want to understand exactly how they are going to use your information," she says. It's also wise to understand the benefits and limitations of any PHR or app, so be sure to check out user reviews, and contact the developer directly if you have any questions.



Lock it
up.

Keep it private. All electronic tools come with security risks. Medical identity theft—when someone else uses your insurance number or personal information to get healthcare—is a growing problem. "You should protect your [medical information] the same way you protect your financial information online," says Washington, who recommends only using programs

that encrypt your data, and changing passwords frequently. She adds that while she has not heard of any medical identity theft scams specifically related to PHRs, consumers should carefully read the privacy policies of any PHR or mobile app they select. “If you don’t see a policy or you don’t understand their policy, you should steer away it.” (See “[Protecting your privacy](#).”)

How long should I keep my medical information?

Indefinitely

- medical diagnoses
- surgical procedures
- names and contact information for doctors or clinics where records may be located

Three years

- medical receipts used for tax purposes, after filling a claim

Short-term (ask your doctor on your next visit)

- routine lab work
- health screenings

Put it on one page

Regardless of whether you use a paper or electronic system, the most important step—and the one that can really make a difference when it comes to quality of care—is to create a short one- to two-page medical summary, says Patty Ribera, a certified professional organizer who specializes in medical records.

“I have my clients do their summaries in a chronological order,” Ribera says. “It becomes a brief statement of what happened. It can mark the milestones in their progress with MS,” along with allergies, current medications, immunizations, recent test results, diagnoses, procedures and hospital visit notes, if available. “You don’t need everything, just the highlights,” Ribera warns. For example, a person with MS who has a history of optic neuritis may include the date and results of his or her most recent ophthalmology exam, while someone without any history of visual symptoms can leave off details of routine eye exams.

The summary should be updated regularly to reflect new medications and changes in health. This can help prevent duplicated tests and procedures when transitioning between providers. A 2014 study published in the *Applied Clinical Informatics Journal* showed that a significant number of diagnostic tests and procedures—particularly blood work and radiology—could be avoided if clinicians exchanged health information. The summary bridges those types of gaps. It can also provide critical information during an emergency if kept in a place where

you can access it quickly.

According to Dr. Heidi Crayton, medical director of the MS Center of Greater Washington, in Vienna, Virginia, a summary can also enable people with MS to set the agenda when visiting their neurologists. She encourages her patients to think about which symptoms are most affecting their lives and include that information in their summary. “Really try to break those things down into digestible elements,” Dr. Crayton says. “I can’t treat a symptom unless I know it is a problem.”

Make it a habit

As with any New Year’s resolution, the key to staying organized is to commit a specific amount of time every week or month to scanning documents, downloading files and updating the short overview. And even though the goal of organizing medical records is better health, Kalina says that it is important that the process also be pleasurable. So play your favorite music while working on your medical records and reward yourself in some way after you’re done.

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