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HELPING THOSE WHO HELP OTHERS

Electronic Gizmos and Even Paper

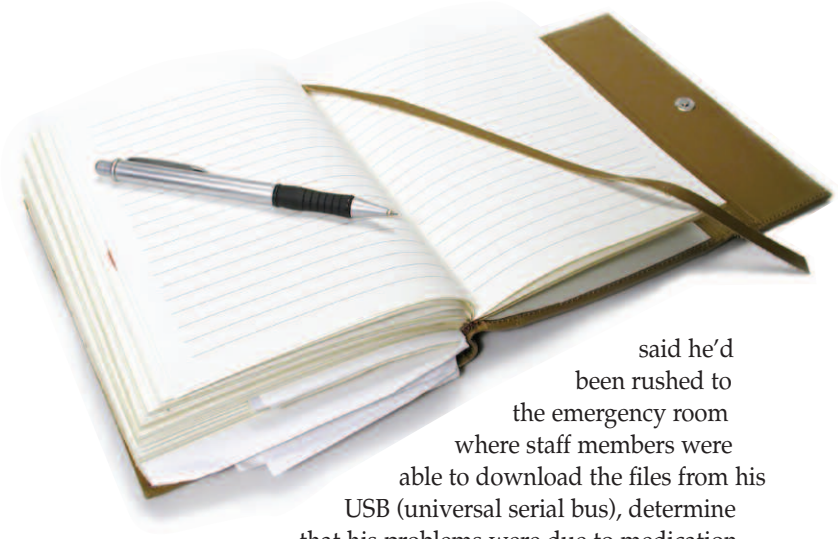
Personal Health Records Benefit Everyone

By Paula S. McCarron

"It all started with Harold," says Dr. David Kibbe, director of The Center of Health Information Technology, part of the American Association of Family Physicians. The year was 2003, and Kibbe was speaking at a professional healthcare conference on the feasibility of using electronic health records to send patient information from a hospital to a primary physician whenever a patient is discharged.

That's when Harold, a non-medical member of the audience, stood and related how he had created his own computerized personal health record and then saved the file onto his portable USB drive, a thumb-sized device that can then be plugged into almost any newer computer in order to retrieve the information.

What intrigued the assembled doctors about Harold's story was what he said next. Harold



said he'd been rushed to the emergency room where staff members were able to download the files from his USB (universal serial bus), determine that his problems were due to medication interactions, and then take the quick and needed action to save his life. Basically, Harold's electronic gizmo played a role in saving his life, Kibbe recounted.

Harold's experience is a great example of two trends that are currently directing the evolution of voluminous, hand-scribbled, paper healthcare records into interactive tools that can be used by consumers and doctors alike.

First, the personal health record is indeed a *personal* document. It is not a medical file kept onsite at a hospital or a chart kept in a physician's office; rather, it is a tool being used, maintained, and shared between healthcare providers, patients, and authorized individuals such as family members. ▶

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The personal health record is indeed a *personal* document. It is not a medical file kept onsite at a hospital or a chart kept in a physician's office.

Personal Health Records *Continued from page 1*

Second, PHRs, as they are called, are increasingly taking advantage of available technology so information can be recorded, transmitted, and shared in ways that are either limited or impossible with paper records.

When it comes to creating a PHR, four basic options are currently available:

Paper Filing Systems. For many family caregivers, keeping a paper record of their loved one's health information has become a routine part of the caregiving journey. According to a 2004 Harris Interactive poll of the 42% of Americans who maintain personal health records, 82% keep them on paper.

Paper PHRs have their advantages. For example, they don't require special equipment or passwords. But unless one is carrying the paper record, or has immediate access to it, a paper PHR is not of much benefit.

Yet for those not comfortable with computers, the paper PHR is as valid a tool as ever for tracking health information. After all, it is far better to have some information available rather than none at all. And for those who are concerned about placing confidential information online, the paper PHR does give a degree of control over access to information, if the paper PHR is filed in a safe and secure place.

Provider Driven Digital Summary. Some healthcare groups, physicians, and insurance companies offer patients website access where they can access their own health information by using an assigned password. These PHRs are "read only" files, meaning patients can read what has been entered into their files, but they cannot enter or change the data.

Some of these websites offer "value-added" features such as secure messaging, making appointment requests, submission of medication renewal requests, and obtaining lab results.

The Internet-based, or web portal servers, allow for an even greater exchange of information since all one needs is a password to open the online PHR. Such accessibility to records can be immensely useful for long distance caregivers, traveling elders, and managing multiple healthcare providers by keeping them informed of a patient's condition, medications or treatment.

Patient-Owned Software. By using software, patients or their family members can create their own personal health record. The information can be simply printed out, or it can be downloaded from a computer onto a CD disc for portability, or it can be sent anywhere via email attachment, or—as Harold did—it can be stored onto a USB drive and carried on a key ring.

"We're offering software that can be used to create a personal health record at no cost to anyone who requests it, even if they live outside of our service area," says Carmhiel Brown, senior vice president of marketing and communications with Thomas Jefferson University Hospital in Philadelphia. The software developed by TJU Hospital includes friendly prompts to guide users as well as the option to graphically track changes in blood pressure and weight.

Portable Digital Files. Of course, the value of having any type of PHR is in large part based on one's ability and commitment to manage, retrieve, and share the information. That's why many healthcare consumers are moving toward the use of electronic devices such as cell phones, personal digital assistants, and USB drives. These devices offer certain advantages, including ease of transmission and portability. This flexibility allows for a greater exchange of information, particularly the exchange of clinical files saved in data formats.

Other uses of these devices may include the use of sound and video to observe changes in a patient's condition or to observe symptoms. The possibilities are ever-changing, as is the technology.

Given both the speed with which new PHR options are being introduced, it can seem overwhelming or confusing to determine just which PHR best suits one's needs. To help narrow the choices, here are a few guidelines:

Before starting out, be sure to find out if your loved one's physician, healthcare organization or insurer offers or uses a particular PHR format. If so, it might be best to use that format to ensure ease of transmitting information and technological compatibility. The Veteran's Administration is offering a PHR (see www.myhealth.va.gov), and The Centers for Medicare and Medicaid is considering the development of a PHR system for Medicare beneficiaries.

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The Sneezin' Season

Coping with Your Loved One's Seasonal Allergies

By Kelly D. Morris

About 35 million of us are spending the summer sneezing, wheezing and coughing our way through what should be the most relaxing season of the year. Runny noses and dry eyes are everywhere among us. The culprit: seasonal allergies, which can be especially hard on the elderly.

According to the American Academy of Allergy, Asthma, and Immunology, while seasonal allergies are merely annoying for some, they can sometimes impact the quality of life in others, making it difficult to even leave the house or participate in outdoor activities.

Beth Crawford of Knoxville, Tennessee, is one who can attest to this. She says her severe allergies caused her to even stop singing in the church choir. She couldn't get through a song without sneezing.

Dr. William Storms, an allergy specialist and professor of medicine at the University of Colorado Health Sciences Center, hears stories like Beth's all the time. And he notes that seasonal allergies can lead to secondary conditions, such as ear infections, sinus infections, and asthma.

Be Alert to Allergy Dangers

Allergies are not to be ignored. Dr. Storms emphasizes that for some, allergies can cause life-threatening breathing problems.

Allergic reactions occur when the body is overly sensitive to particles in the environment. Allergy problems are common in the spring because of all the newly-blossomed plants and weeds. In the fall, other plants and leaf mold contribute to seasonal allergies.

In addition, people with seasonal allergies often have other allergies as well, such as dust mites (microscopic insects that feed on human skin cells), animal dander (tiny skin flakes shed by animals), and molds, all of which can be found indoors during any season.

Mild allergic reactions often mimic the common cold. Symptoms may include sneezing, a runny nose, and red or itchy eyes. A cold usually runs its course in 7 to 10 days, however, while allergy problems can last for weeks or even months. Allergic reactions may also include itchy or inflamed skin, hives, wheezing, and difficulty breathing. In extreme cases, an allergic reaction can cause anaphylactic shock, a life-threatening condition in which a person's airway swells shut and they can't breathe.

Caregivers: Frontline Defense

Allergies often worsen with age, because the more one is exposed to allergens, the more sensitive one becomes. In addition, the elderly may suffer from other health conditions that will worsen with allergic reactions. That's where you come in; as a caregiver, you can become the first line of defense for your loved one.

The first step in dealing with seasonal allergies is to keep the culprits out of the house. For many allergy sufferers, this will take care of the problem.

Start by keeping windows closed. Keep furniture dusted, and reduce clutter as much as possible, especially things like knickknacks and bric-a-brac, because they easily collect dust and pollen.

Vacuum carpets regularly. If your elderly's allergies are severe, consider removing carpets and installing wood, tile, or vinyl floors instead. Keep in mind that elderly people may need help in keeping their environment truly clean in order to prevent allergic reactions.

Weather conditions affect the amount of pollen and mold in the air. Allergy symptoms are often minimal on rainy, cloudy, or windless days, while hot, dry, and windy weather can quickly whip up symptoms. Keep your loved one indoors as much as possible during times their symptoms are likely to be worse. If they are outdoors on a day their allergies are bothering them a lot, have them change their clothes and take off their shoes as soon as possible when they come inside. Ask them to shower and wash their hair as soon as possible to remove pollen and other allergens. Clothes and body hair can act like magnets in attracting allergens.

When to Consider Medication

If keeping the environment as allergen-free as possible doesn't do the trick, it's time to consider medication. If your loved one is on any prescription drugs or has any other medical problems, be sure to check with a doctor or pharmacist before

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Senior-Proofing Your Home

By James D. Capozzi, M.D.

We are all familiar with child-proofing our homes. Covering electrical outlets, using protective furniture corners and placing harmful household products in unreachable locations are precautions we all take to safeguard our children from significant harm. But how do we senior-proof our homes to protect our older loved-ones from serious injury?

As an orthopedic surgeon in New York City, specializing in fracture care of the elderly, I see a large number of serious injuries in our aged population. Each year, more than 1.8 million seniors over age 65 are treated in U.S. hospital emergency rooms for fall related injuries. More than half of those injuries are associated with stairs, bath tubs, carpeting and other ordinary household items. Approximately 400,000 fall-related fractures occur each year involving the hips, wrists, pelvis and spine. A large percentage of those fractures occur, not on icy sidewalks, but right in the home.

Here are 12 tips for caregivers to help keep homes safe for their elderly loved ones:

A Dozen Caregiver Tips

1. Remove or secure any loose throw rugs. Seniors often slip on loose rugs, especially those placed over polished floors. They can also trip over curled rug edges, frayed carpets or uneven flooring. Fix any loose or raised floor boards, tiles or carpets. Keep all tile, marble or concrete floors carpeted or covered with softer, well-fixed surface materials. Use light colored floors to help your loved one to more easily see stair edges, loose objects, or pieces of furniture.

2. Relocate any exposed extension cords. Electrical cords are often strung across floors or between pieces of furniture. I am amazed at the number of fractures I see from seniors tripping over phone and electrical wires. Secure cords along baseboards or behind large pieces furniture.

3. Showers and tubs can be very dangerous places. Install grab bars in all showers and tubs. Place slip-resistant mats or adhesive strips on tub and shower bottoms.

4. Many elderly have difficulty rising from toilet seats. Weakened lower body strength is common among older patients. Use elevated toilet seats or over-the-toilet commodes with armrests to assist in getting off of the toilet. Grab bars next to the toilet can be very helpful.

5. Make sure there is adequate lighting throughout the home. Light switches should be easily accessible, especially when located near stairways. Consider installing illuminated switches, or even motion sensitive automatic lighting. Don't skimp on electricity with your loved one's safety at risk!

6. Pets are a tremendous source of comfort for the elderly, but they also pose significant fracture risks. Patients often trip over small pets or become entangled in their leashes. Larger pets can be stronger and more energetic than their owners, pulling them to the ground. The elderly should be very careful when walking their pets. Consider a dog-walking service if their pet is difficult to handle. Also, make sure there is plenty of pet food on hand. We often see fractures in patients who run out of pet food and try to venture out in snowy or icy conditions to purchase more food. Grandma will allow herself to go without food for several days but she would never permit Whiskers to go hungry. Help her out.

7. Many seniors have impaired vision. Make sure eyeglass prescriptions are up-to-date. Also, if possible, keep several pair of glasses in various locations throughout the house. Ironically, many seniors fall while stumbling around the house in search of their glasses.

8. Night time can be especially dangerous for seniors. The elderly often become disoriented at night. Couple that with fatigue and darkened rooms, and falls become much more likely. Keep water and medications at the bedside so seniors don't have to wander in the night looking for them. Consider a bedside bedpan or urine bottle, if patients frequently need to use the facilities at night. A bedroom night light is helpful to both improve visualization and to decrease disorientation.

9. Every year I see scores of seniors who fall from significant heights. What they are doing up there is beyond me. But you can help by moving frequently used objects to lower shelves or cabinets. If your loved one must climb to reach overhead objects, they should use a stable folding step ladder with a grab bar. Keep one handy. They should not stand on chairs, stools or boxes.

10. Keep all medications up-to-date and well marked. Our elderly too often overdose, under-dose or simply take the wrong medications. Any of these errors can lead to an altered state of perception, balance or alertness. Make sure Mom or Dad are very clear about their medications, dosages and schedules. Consider a laminated, easy to read wall chart listing medications and times. Commercially manufactured medication timers or reminder systems also are available and work well.

11. Remove any clutter from floors. This is especially important in high traffic areas. Common clutter includes boxes, plants, pet food bowls and shopping bags. Be especially mindful of "new clutter" that your senior may not be used to, such as visiting grandchildren's toys or guest's suitcases or pocketbooks.

12. When all else fail, call for help. Despite all of these precautions, accidents do happen and seniors still fall. Because of significant pain and an inability to move their legs, a loved one with a fracture hip can remain on the floor, sometimes for days. Consider some type of patient alert system to notify neighbors, relatives or the police if a fall should occur.

Following these tips as a general guideline will help keep your elderly out of a hospital emergency room and give you greater peace of mind. There's a little effort involved, of course, along with periodic checks to make sure things remain the way they should be, but the effort will be well worth it. ■

James D. Capozzi *is an associate clinical professor of orthopedic surgery at the Mount Sinai School of Medicine in New York City, where he specializes in the care of elderly patients with fractures and is a board certified orthopedic surgeon with specialty training in joint replacement surgery. Dr. Capozzi also has published a book of reflections on the Psalms entitled Beside Quiet Waters. He can be reached at capoz5@aol.com.*

Personal Health Records
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So, how does one choose wisely from among all these choices?

Dr. Cedric J. Priebe, III, chief medical information officer for Care New England Health Systems, offers this advice: "Consumers should consider first why they wish to maintain a PHR for themselves or their family members. Do they simply want to use the PHR as a record keeping tool for easy entry and easy access of personal health information? Or do they want to utilize any value-added services within the PHR such as links to informational content or communication with their healthcare provider?"

Priebe also suggests that family caregivers who want to create a PHR for an aging loved one confirm whether a particular PHR allows a user to create records for multiple family members, such as siblings, under one user account.

You can comparison shop PHRs at the American Health Information Management Association website located at www.myphr.com. The website offers visitors a chance to compare a variety of PHR products, some of which are free. The AHIMA site also includes a number of informative articles about how to create an effective PHR for oneself or a family member.

Jill Burrington Brown, manager of practice resources for AHIMA, emphasizes that some key questions should be addressed before choosing a PHR product or even a format. Some of these questions include:

- Who owns the data once it is entered into the PHR?
- Who can access the information?
- How is information added to the file? Who can delete information?
- Is any of the information ever sold and to whom?
- What confidentiality and privacy assurances are provided?
- For web-based PHRs, are specific web browsers or operating systems required in order to access the information?

"We have the ability to gather and transmit the information, but what isn't clear yet is how to make the information routinely useful," says Kibbe. "It's not only a matter of creating the information but using it."

Kibbe says the time is coming when a request for a patient's personal health record will be a standard part of health practice in a physician's office, hospital or upon emergency room admission. And, in his words: "I can't think of a group of people who could benefit more by the availability of a personal health record than elders and their family caregivers. It's an idea whose time has come." ■

Paula S. McCarron *has more than 20 years of experience in healthcare, including nursing homes and hospice. She lives in Chelmsford, Massachusetts, and can be reached at paulamccarron@gmail.com.*

LEARNING MORE ABOUT PHRS

- My Personal Health Record **www.phr.com** is operated by the American Health Information Management Association. It highlights a "shopping and evaluation tool" that helps consumers evaluate paper-based, Internet and PC software PHR formats, available either at cost or no cost.
- Care New England, at **www.carenewengland.org,** offers a free, confidential Internet-based PHR that lets individuals track their own and their family's health information.
- Thomas Jefferson University Hospital offers a free Personal Health Manager CD-ROM. Phone **1-800-JEFF-NOW** or complete the request form found at **www.jeffersonhospital.org/jeffnow/article11759.html**.
- Free forms for use in compiling a paper PHR can be found at Merck Source, **www.mercksource.com**.
- The Veteran's Administration has rolled out its own PHR system at **www.myhealth.va.gov**.
- Body Journal can be found at **www.bodyjournal.com**. This system tracks up to 10 individual records, making it ideal for family use.
- Records for Living **www.recordsforliving.com** is a software-based PHR available for a fee. It has features specially designed to benefit those living with chronic illness.

A Most-Common 'Prescription'

Are Laxatives and the Elderly a Necessary Evil?

By Sharon Palmer, RD

Laxative use and aging seem to go hand in hand. An estimated 75% of elderly residing in hospitals or nursing homes use laxatives to regulate bowel function.

And the high level of laxative use in the elderly population isn't limited to healthcare facilities: in a survey of more than 4,000 elderly by Duke University, laxative use was found to be common in the home and was related to specific factors concerning family practices, health status, and access to health care.

It shouldn't be any surprise that elders and their caregivers turn to laxatives for a solution to constipation. And, as a result, business is booming. There are approximately 700 commercially available products touted to relieve the symptoms of constipation, many of which are regularly advertised in the media. But health experts are concerned that elderly dependence on laxatives has turned into laxative abuse rather than use.

Recent studies also have raised concern that the elderly population too frequently receives inappropriate medical care and drugs that are not supported by a clear need. Sometimes, according to these studies, it may be that a physician turning to a prescription pad to order laxatives might be the easiest solution to treating constipation.

Chronic use of laxatives has been associated with many problems, such as diarrhea, fecal soiling, hypoalbuminemia, and high serum levels of magnesium and phosphorus. The *Nutrition Health Review* reported that the heavy use of laxatives has created long-term laxative abuse, a condition that might lead to nutrient deficiencies, metabolic disorders, and potentially severe damage to the gastrointestinal tract.

Chronic laxative use also can injure the nerves and muscles of the colon, leading to a condition known as megacolon, where the colon becomes flabby and unable to push along fecal material.

Defining Constipation

The elderly often turn to laxatives without fully understanding constipation, which is defined as a condition in which stools are too small, too hard, too difficult to pass, or are infrequent (less than three per week). Researchers have identified these risk factors for constipation: older age, African-American, female, poor socio-economic status, less exercise, less education, and low calorie intake. But contrary to popular opinion, constipation does not have to be an automatic consequence of aging.

Constipation is frequently caused by inadequate dietary fiber or fluids, medication side effects, emotional or physical stress, lack of activity, certain medical conditions, or simply a poor understanding of normal bowel habits.

Medications that can cause constipation include antacids, anticholinergics, antidiarrheals, antiparkinsons, antidepressants, antihypertensives, antiarrhythmics, metals (bismuth, iron, heavy metals), opioids, NSAIDs, and sympathomimetics. Medical conditions that might have side effects of constipation include colon cancer, underactive thyroid, overactive parathyroid, depression, dehydration, scleroderma, Parkinsonism, stroke, and diabetes.

Constipation can also happen when patients are hospitalized due to extended bed rest, lack of exercise, and change in food and fluid intake.

Non-Laxative Solutions for Constipation

Before you turn to over-the-counter laxatives to solve a constipation problem in an elder, try alternative methods. Start by scheduling an appointment to discuss constipation with the doctor. Pain, fever, urinary or fecal incontinence, diarrhea, or delirium may occur with prolonged constipation or fecal impaction, so it is best to deal with constipation head on rather than ignoring it.

Also, it may help to keep a journal of bowel habits, including stool frequency, consistency and straining. If an acute episode of constipation occurs, you may need to see a physician immediately. For battling chronic constipation, many solutions may prove effective. But searching out the root of constipation, from medications to medical conditions, is an important first step.

Eating to Avoid Constipation

Changing diet to increase fiber and fluids is also a very effective method of combating constipation. Strong epidemiologic evidence has shown that greater amounts of dietary fiber are associated with a lower prevalence of constipation and other gastrointestinal disorders, including diverticular disease and colorectal cancer. Fiber appears to do its work by increasing stool bulk and weight and by speeding intestinal transit time. Current recommendations suggest that adults consume 20–35 grams of dietary fiber per day, but the average American eats only 14–15 grams of dietary fiber a day. Fiber supplements in the diet, such as added bran, can further increase fiber intake.

In addition, it is important to increase the intake of fluid along with fiber. The recommended daily requirement for water or non-caffeinated fluids is eight 8-oz glasses, assuming that the individual has no cardiac or renal problems that may prohibit this amount of fluid. Try to make sure meals are eaten on a regular basis and that foods are chewed well.

Encourage your loved one to have regular bowel movements, taking advantage of particular times of the day, such as immediately after breakfast, when the body has a natural gastrocolic reflex

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***Sharon Palmer** is a registered dietician with 16 years experience managing healthcare food and nutrition departments. Her career has included clinical nutritional care for a broad spectrum of patients, from eating disorders to elderly. She also has managed the food and environmental services departments in several acute care hospitals. Ms. Palmer lives in Southern California and can be reached at spalmer952@earthlink.net.*

10 TIPS FOR INCREASING DIETARY FIBER

By adding the proper amount of fiber to our diets and that of our elderly, we can create a natural laxative in our bodies, avoiding the need for more harsh and sometimes dangerous laxatives—both prescription and over-the-counter—to combat constipation. Here are 10 tips on using fiber to naturally balance your elimination schedule:

- Switch to bran cereal for breakfast.
- Sprinkle bran in soups, casseroles, and salads.
- Substitute whole grain flour for about half of the all purpose flour in your favorite recipes.
- Look for the first ingredient to be whole grain when shopping for bread, crackers, cereals, and pasta.
- Switch from white rice to brown rice.
- Try out whole grains for dinner, such as bulgur, barley, buckwheat, quinoa, or millet.
- Instead of fruit juice, offer fresh fruit.
- Include vegetables with each meal.
- Offer a handful of nuts and dried fruit for a snack.
- Include more dried beans and legumes in your menu.

for elimination.

Also, encourage your senior to never resist or postpone the body's urge to have a bowel movement. And don't forget to include regular exercise in their daily routine.

Sometimes, when all attempts to solve the constipation problem have failed, it may be necessary to turn to laxatives as a last resort. But rather than self-medicating your loved one, create a plan with your healthcare provider that combines complimentary care through diet and exercise along with a laxative program, takes into consideration possible side effects of laxative medications, and implements a long term plan to resolve constipation. Your loved one will be healthier and happier for it. ■

Coping with Your Loved One's Seasonal Allergies *Continued from page 3*

taking any over-the-counter allergy medication. Over-the-counter allergy remedies can exacerbate many health conditions and can also interact with many common prescription medications. This can be of particular concern to the elderly, who are often already taking a number of prescription medications.

Common over-the-counter medications usually contain antihistamines, which should not be used by anyone with breathing problems such as emphysema or bronchitis, anyone with glaucoma, anyone taking sedatives or tranquilizers, or anyone with difficulty urinating, unless directed by their doctors. Antihistamines have a number of side effects, as well, including drowsiness, dryness of the mouth and eyes, and blurred vision.

Many over-the-counter medications also contain decongestants, which can raise blood pressure. Decongestants should not be taken by anyone with heart disease, thyroid disease, or diabetes unless a doctor says it's OK. Decongestants should also not be taken with certain antidepressants. Always check with a doctor or pharmacist first.

If over-the-counter medications aren't enough, there are also a number of prescription medications available. These include oral medications and nasal sprays. Make sure the doctor prescribing an allergy medication knows about all other medication your loved one takes, including over-the-counter drugs. Watch your elderly closely, and let the doctor know if they experience any side effects. The medication should be taken exactly as prescribed by the doctor. Don't let them take extra medication to try to further reduce symptoms.

Simple Reminder Tools Help

You can help your loved one remember to take the correct dose of medication by purchasing a medi-set, one of those inexpensive plastic boxes with sections for each day, or day part, of the week.

If allergies continue to plague your loved one after trying a number of medications, or if allergies are particularly severe, their doctor may recommend a skin test to determine the exact source of their allergies. For this test, the doctor pricks the skin with a number of possible allergens. If one is allergic to a substance, a small raised red spot will appear.

Once the doctor determines exactly what allergies are at work in the body, they will administer allergy shots designed specifically for the situation. Each shot contains small amounts of the active allergens. The idea is that over time, one becomes desensitized to these substances, after a few years, the shots are no longer needed.

"I am more productive, less irritable, and less fatigued since taking allergy shots," says Beth Crawford. She is now able to participate fully in life, and has resumed singing in her church choir.

While it may take a while to find lasting relief, Dr. Storms encourages allergy sufferers to aggressively seek treatment. Help is available, even if it takes some time to find what will work best. But left untreated, allergies rarely get better and often get worse. ■

Kelly D. Morris is a former social worker and home health and hospice worker whose writing has appeared in a number of journals. She lives in Mansfield, Ohio, and can be reached at multihearts@hotmail.com.

COMING UP IN AUGUST

- **Parish nurses.** Have you ever heard of them? They may be the best-kept secret in elder-caregiving. We'll tell you why.
- **When partners become patients—** renegotiating the spousal contract to honor "what is" and keep the love alive.
- **Bathing the elderly—**dealing with resistance and modesty. Always a delicate topic, and more delicate if you must attend to your loved one's bathing needs yourself. A look at tub bathing, sponge baths and other alternatives that ease stress and promote elderly hygiene.
- **Don't get burned!** We look at the dangers lurking in our aging loved ones' kitchens and what caregivers can do to minimize potential hazards in this most-familiar setting.

Irritable Bowel Syndrome Clustered Strongly in Families

A new Mayo Clinic study finds that irritable bowel syndrome often runs in the same families, hinting at a genetic link in the condition that affects nearly 20% of the adult U.S. population.

"Because we don't understand the causes for the symptoms of IBS, it is difficult to identify a definitive therapy," says Dr. Yuri Saito, Mayo Clinic gastroenterologist and the study's lead investigator. "This study was one of the first steps in getting at the root of the problem and determining whether there could be a genetic basis for the disorder."

IBS affects nearly one in five American adults, and the disorder accounts for more than one of every 10 doctor visits in the United States. It is characterized by abdominal pain or cramping and changes in bowel function, including bloating, gas, diarrhea and constipation.

The study population included 50 patients with irritable bowel syndrome who were seen in gastroenterology clinics, as well as a control group of 53 age-, gender-, and race-matched patients seen at general medicine clinics in 2004 and 2005. Surveys asking about gastrointestinal symptoms were then mailed to more than 400 of their first-degree relatives. Family comparisons of the relatives showed that 70% of patients with IBS had at least one affected family member. In contrast, only 43% of the control group families had an affected family member.

"While it is too early to say that there is a genetic cause for IBS, this research is a step in the right direction and gives us the foundation to analyze genetic patterns," says Saito. The next step in her team's research is to identify 500 families affected by IBS, as well as 500 control families, and develop in-depth family modeling to determine whether genetic and/or environmental patterns exist. The ultimate goal of the research is to identify a molecular base of the abnormality in order to develop more definitive treatment programs for patients with IBS.

Saito points out that the study also identified the importance of gathering IBS symptom data directly from family members, as patients typically underestimated the frequency of IBS-type symptoms in their relatives.

Individuals with IBS estimated that 20% of their first-degree relatives had IBS, while those relatives who participated in the study self-reported that 46% were actually affected by the disorder. Likewise, the control group estimated that 4% of their first-degree relatives had IBS, but when the relatives themselves were surveyed, 25% were affected.

"It is not surprising that individuals underestimated the frequency of IBS in their relatives, since gastrointestinal symptoms are not something that many people feel comfortable discussing," says Saito. "This simply emphasizes the need for direct data collection from family members in any family study of IBS."■