

For Managing Life in Cardiac Land Instead of It Managing You

You just arrived home from a devastating medical appointment or, as happened to me, an emergency hospitalization. In an instant you went from great health to disastrous health. Your brain is stuck in an echo chamber of, “What now?” Cry your eyes out, lie in bed staring at the ceiling, wander the house a zombie. I’ve been there. Falling apart is part of the process, but it can only get you so far. Here is your way out of the abyss: While in shock and useless for any deep thinking, get organized. Doing something practical to save your life right now will make you feel more in control, safer, calmer. Just follow the suggestions below and eventually “What now?” will become clear and you will become a pro who thrives with heart disease. Promise.

1. Assemble your **MEDICAL NOTEBOOK** immediately—your foundation for self-care

Pulling medical paperwork, test results, and notes all together in one, portable place—an ordinary 3-ring binder with interior pockets and dividers—is a proven life-saver and anxiety reducer. I enter medical data and notes in my notebook every day. It comes with me to all clinical meetings, hospitalizations, and dashes to the emergency room. Even clinicians have come to rely on my notes when electronic records are down or unclear. I have helped friends and family create their **MEDICAL NOTEBOOKs** for a lung transplant, various cancers, and normal aging, all of which require frequent, confusing medical care. Everyone reports immediate reduced anxiety and increased confidence, and all it took was a little organization. Try the following sections for starters (examples you can print are at deborahdawheffernan.com):

1. **Docs & History**—1-page summary of your medical history, including emergency contact information for key doctors and family/friends, and all major hospitalizations. Check-in is lots easier in combination with your 1-page Medications sheet (below).
2. **Medications**—1-page list of meds, dosages, timing, allergies. Ditto for easy check-in, becoming an efficient, 2-page case history with your Docs & History sheet (above).
3. **Vitals**—Chart for recording your blood pressure, heart rate, and weight, whether at home or a medical appointment.
4. **Lipids**—Chart of your cholesterol and triglyceride levels over time.
5. **Tests**—A page each for categories of tests, procedures, operations, imaging; for example EKG/echo, lots of blood work, biopsies, inoculations, x-rays, mammograms, dental work. You’ll be glad to find all that data in one place.
6. **Questions & Next Steps (NS)**—My **MEDICAL NOTEBOOK** began from notes I took in hospital and in shock. As you use this section more, you will be glad to have all your notes—including next action steps for you and your clinicians—in one place, whether you scribble them at home or during check-ups and hospital stays.

2. Create and post an Emergency Call List at home and at work.

Worried beloveds want to help. Here is an example of something any caring person can do for you. A laminated, mini-directory of people to call in an emergency, my list is the size of an index card and includes:

- 1 to 3 key doctors and their pager numbers
- 1 to 3 personal contacts (family/friends on my core team of intimates)
- the local hospital/ambulance service.

Post your Emergency Call List by every home phone and by your phone at work, whether that's in a truck or at a desk. Carry a copy with you and give copies to your personal emergency contacts. You will feel much calmer and in control knowing that no one will have to scramble for these numbers in an emergency.

3. Set up your home “Control Central” for managing your health.

A dedicated cupboard or drawer in your kitchen works, but a private, peaceful space is best. You will need the following:

- small table/surface for ordering, sorting, and consuming your medications, as well as for working in your MEDICAL NOTEBOOK before and after every appointment
- a drawer or tray for storing your meds in an organized system. I use alphabetical order.
- comfortable, straight-backed seat for taking blood pressure readings
- pill cutter and weekly pill organizer(s)—both available at your drugstore
- home blood pressure machine (ask your doctor for recommendations)
- quality digital scale for monitoring your weight.

Keep your special place neat, clean, and *cheery*. We patients confront our mortality every time we load up on meds or take our blood pressure. Some days I just toss the pills and liquids down my throat and get on with it. Other days I sit among the bottles and wonder, “How can this be my life?” My cozy spot offers quiet and privacy in which occasional despair can move through me. For perspective, I keep a small vase of flowers on my table to remind me that yucky meds, too, are life. Consider what motivates you and makes you happy, perhaps a picture or a talisman.

4. Immediately purchase a Medic Alert emblem on a bracelet or necklace.

The Medic Alert Foundation (www.medicalert.org, 1-800-432-5378) provides you with a wearable medical emblem, as a sporty piece of jewelry, that is universally recognized by EMTs and medical professionals the world over. Embossed on the emblem is one phone number for an emergency responder to call for your diagnosis, medications, allergies, and key doctors. If you are ever unable to speak for yourself, a wearable Medic Alert emblem assures you of quick, correct assistance. My tiny bracelet gave me confidence to venture beyond my property, a key step in a patient's return to life, enhancing full recovery.

5. Housebound for awhile? Consider purchasing a home Medical Alert System.

In one press of a button on either a lanyard or a wrist band, EMT's are on the way to save you at home! There are a number of choices, both wireless and waterproof. Go on-line to research which system and options are right for you; for example, consider coverage range if your home is huge, or you frequently visit another apartment in your building, or you like to spend time outside. Also consult with your local alarm or ambulance company for their preferences and models that work well in your area.

Without what I affectionately called my "alarm watch," I doubt I would have dared to open the door and walk into the garden during my most acute years. I was terrified, rightfully, of another v-tach episode that would knock me unconscious and invisible beneath the hostas or blueberry bushes. Some systems can even sense a sudden fall and send the EMTs to you automatically!

In addition to giving me courage, my little "alarm watch" liberated me from needing in-person, round-the-clock supervision—restoring my privacy while also giving Jack and other beloveds peace of mind. My Medical Alert System was the sole reason that Jack could return to work and begin his own reach toward normalcy and healing.

After installing your system, consider asking your monitoring service for a trial run so the EMTs can see where you typically wander in your house, apartment building, and outside. Get to know the people who may save your life. I blow kisses to my EMTs in the grocery store.

6. Subscribe soon to the *Harvard Heart Letter* (www.health.harvard.edu/newsletters/harvard_heart_letter), the *Cleveland Clinic Heart Advisor* (www.heart-advisor.com) or any of the other fine newsletters published by major cardiac centers. They all do a terrific job providing the latest cardiovascular information in layman's language. A lack of knowledge can stoke unnecessary panic in patients and their families—or the dangerous opposite, apathy, which can lead to neglecting vital medical protocols or missing symptoms that should be concerning. So, keep yourself up-to-date and motivated. Your doctors will respect you more for your effort.

7. Sign-up for a cardiac rehab program when your doctor gives you permission.

I am a 3-time graduate of rehab and each time I have benefited hugely. You will gain strength and confidence much faster and more solidly than if you avoid this step in your return to LIFE. Make sure your rehab program emphasizes mind/body training based on the work of Herbert Benson, MD. Most do, these days.

As part of your cardiac rehab, **schedule time with a good psychotherapist**. This step toward full recovery is often overlooked by doctors, which puzzles me. Every patient is emotionally affected by a cardiac event, no matter how small. Increased anxiety is entirely normal, for example. While it's important to discuss your feelings with your loved ones, they may only be able to help you so much for a variety of reasons; for example, they, too, may be experiencing

trauma from the event and also need a little psycho-therapeutic support. So I urge you and your family to seek good coaching from professionals trained to help us heal our minds and spirits—while you are also learning to walk again with a spring in your step. Therapy made a huge difference in my recovery—and in my husband’s.

8. Settle your Living Will/Advance Health Care Directive and Power of Attorney.

I know. No one wants to do this and neither did I. But you must. You will feel so unburdened once it is done. Knowing your wishes, your loved ones will suffer less. Free, downloadable forms are available on-line. I also suggest consulting a lawyer to be sure your documents are compatible with state law; for example, I live in one state and am treated in two. Put five or so signed original copies of them in your home files. Finally, *keep a signed copy of these documents in your Medical Notebook*, because they are needed at every hospitalization. Ask administrators to make a copy and return the original to you, if possible.

9. Put YOU on your schedule first.

This single change in how I manage my life has been transformative. Here is how it works: Every 3 to 6 months, I schedule all medical and complementary care (massage, osteopathy, reflexology, PT, even a facial) appointments *well before* any thing else goes on the calendar. I stick to a set time for dedicated exercise every day. All other obligations and fun fit in around my primary commitment to health. And guess what, all you folks who feel indispensable at home and on the job? No one has even noticed! Since having learned to “place the oxygen over my own face first, before assisting others,” as I wrote in *An Arrow Through the Heart*, I feel more available and effective as a wife, friend, sister, colleague, step-parent to five, and step-grandparent to 17!

10. Just move. Move your body a lot—every day.

In hospital and rehab, you will be given a lot of instruction on a heart-healthy diet and exercise. But I find that clinicians and patients overlook the importance and ease of making little movements all day long. Jiggle a leg, rise up and down on your toes while you wait in line. Before rising in the morning and falling asleep at night, put your legs in the air and flex your ankles, twirl your feet. When you walk along streets, hallways, and grocery store aisles, let your whole body unfurl as you press through your entire foot and lift your chest high, shoulders gently relaxed down and back. Open your heart with your whole body, every minute of every day. Kitchen counter downward-dog yoga pose while waiting for the toast to pop, anyone? As Mary Chapin Carpenter sings it, “We’ve got two lives—one we’re given and one we make.”

Hope this helps. xox Deborah