

This is the section I use most in my MEDICAL NOTEBOOK. It is nothing more than a few pages of 3-hole punched, lined paper inserted after a divider labeled QUES & NS. On these pages I gather all my medical questions, worries, observations, triumphs, confusion, and actions needed—notes made useful by being in one place instead of on scattered scraps that scatter me. Your careful observations matter to clinicians, guiding their decisions about your care.

Your notes should include your emotional health, but these pages are not a diary. They will eventually become *your agenda*—your Report from the Front—for your next appointment. What if a doctor calls you at home to follow up? Rather than being flummoxed, your concerns are at your fingertips in your notebook. Thus, I decided to label this section QUESTIONS & NEXT STEPS, instead of the vague “Notes,” to remind me that the purpose of my words is to drive progress on my case—to increase my knowledge and understanding during every medical conversation, as well as to ensure that my clinicians and I know our action steps and deadlines.

Think about it. Why do we tend to prepare more thoroughly for a budget meeting than a meeting about our most important business, our health? Clinicians greet us with their medical agendas and little time. You know how it goes: a myriad of checks and questions, confusing information, new vocabulary to grasp, an interruption or two, and the added distraction of computer entries required of doctors during our precious time with them. The patient’s agenda is easily lost in all that bustling. But now your MEDICAL NOTEBOOK is open to QUES & NS to ensure that your concerns are heard and your needs met. Insist on participating because *together* you and your medical team become experts on your body, not alone. My clinicians know not to escape before discussing my Report from the Front, earning me a few laughs but also respect. And results.

Tips for your Report from the Front of Cardiac Land

1. Number your concerns and keep the next couple of lines empty for writing in the response.
2. I like to begin with a headline including the anticipated date/season/month and doctor for my next medical discussion. Example: *Fall 2020 appt. w/Bill C.* Or, in a list of issues, I might jot the name of the doc—cardiologist, PCP, specialist? Examples: 2. *Suz: confirm inoculation history.* 3. *GI: Impact of vagus nerve on recent issues?*
3. Refer to data in other sections of your MEDICAL NOTEBOOK and your reading/research. For example: 1) *Blood pressure all over the place. See Vitals.* 2) *See Lipids: Normal?* 3) *Prevention questions. See encl. article from Harvard Heart Letter.*
4. Before writing down your concerns—certainly before organizing them into your Report from the Front—check your past QUES & NS to see if the issue has already been addressed or needs follow-up. I keep a years’ notes in my notebook for this purpose. They may offer immediate reassurance and are a wonderful self-teaching tool.

No medical discussion is complete without a “Clinical Closing Ceremony”

In the quiet of my home, I review my notes, place action items on my calendar, and schedule follow-up appointments. I might even begin my next collection of QUES & NS inspired by what I just learned during a clinic. Once satisfied that I am on top of what happened and what is yet to be done, I put my MEDICAL NOTEBOOK away, a little ceremoniously, to honor the border between the hospital and the rest of my lucky life. Compartmentalizing relieves stress.

An example from one month after my heart transplant

For almost 3 months post-transplant, my husband and I rented an apartment in Boston to be near Mass. General Hospital for countless check-ups and tests, almost every day.

9/19/06 MGH w/Marc

1. Rehab yet? *Intro scheduled 9/26, 10 am, at MGH, later in Maine.*
2. Don't drink mineral water?! Bottled water or Maine well water? *Well water contains unfiltered bacteria; bottled is safe bec. processed/filtered.*
3. Ate piece of cucumber. OK? *Too little to matter. (At the time, raw fruit and vegetables were forbidden to recent heart transplants for 3 months because of bacteria.)*
4. Flash in my eye sometimes? *Will go. (It did)*
5. Resume osteopathy? *OK in 3 mos.*
6. Flu shot? *Early Dec. @ MGH Transplant Clinic this time.*
7. Tingling in feet and hands? *Observe & report. (It disappeared.)*

NS:

1. Biopsy next week. Monitor: Clinic will call tomorrow to schedule.
2. Exchange portable blood pressure machine; this one isn't working.

YOUR NEXT STEPS HAVING READ THIS SECTION

1. Create your MEDICAL NOTEBOOK in a 1-2", 3-ring binder.
2. Insert colorful (for easy identification) section dividers and label them as recommended on deborahdawheffernan.com.
3. In each section, insert 3 or so copies of the worksheets provided on my website and give them a try. Customize and improve my models to work for you!
4. Prepare your QUES & NS section by inserting a few pages of 3-hole-punched, lined paper. What do you want to discuss at your next appointment?

Be joyful, though you have considered all the facts.

— Wendell Berry