

NOTES FROM A ONCE-ILL, NOW-WELL, COULD- GET-ILL-AGAIN PERSON

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Serious illness is a consuming job that comes when you are scared and have limited energy. There are no courses, no apprentice programs, no mentors and no job descriptions. You don't even know you have a job to do until you're faced with it.

The overarching nature of the job - the dialectic of illness - is moving between surrender and action

I learned this myself over the course of several episodes of Meniere's Disease that spanned 15 years. Meniere's Disease is a syndrome of the inner ear that includes hearing loss, pressure in the head, and attacks of severe dizziness and vertigo. During an attack you can't think, can't move and are literally helpless. Attacks come without warning. They can be managed with medication, but there is no known cure. Sometimes, there is spontaneous remission that can last several years. I am presently enjoying the 18 month anniversary since my last episode which lasted 7 months.

Coping with Meniere's meant dealing with profound feelings of fear, helplessness and loss. Also, I learned as much as I could about what actually happens in the inner ear and the various available treatments. I did everything I could on a daily basis to reduce the frequency and severity of attacks. I had to figure out how to adapt my work to this erratic illness, to accept help from others, to relinquish control and give up doing a lot of things.

I get teary and sad remembering, am grateful for all I learned, grateful I'm not there today, scared I could be again. I take comfort in knowing that each time I had an episode of Meniere's, I further developed my ill-person job skills. Today I am much better prepared for that job.

In this article, I have attempted to identify the essential elements of the ill-person's job description. My hope is that my thoughts will spark more questions, and that those questions will live in you until they grow into answers. If we share our questions and answers, we might just develop a course and become mentors to each other and to those who follow us.

The overarching nature of the job - the dialectic of illness - is moving between surrender and action. Surrendering to your illness is not an abstract idea. It is raw, real, moment-by-moment acceptance. Acceptance is a process. It means going through denying, railing, pleading, resenting and bargaining until you've had enough of that and you know that acceptance is all that is real. It's the only thing that will actually help you make it through. If you're like me, acceptance has to be done many times a day. Just (what a word), sink into the exact reality of your condition. No making it bigger, no making it littler than it is - just moment-by-moment feeling it, being it. Dizziness, with the world spinning around me, unable to stand or move, was my greatest challenge. When I could accept dizziness, moment by difficult moment, I found peace. Learn to follow the breath, use a mantra, a prayer, a psalm. Turn your illness/plight over to God as you know and name Him (or Her).



Action involves looking for all the things you can do to help yourself heal. Then step-by-step, one day at a time, do them. I remember being amazed at how much information I found related to my illness; and how many different ways there are to approaching, understanding and treating illness. I found hope and inspiration in learning and in applying new understandings to my own situation.

The table on the next page outlines the skills I've found essential for the job:

Don't	Do
Get <u>stuck</u> in denying, railing against, pleading or bargaining	Go through the moment-by-moment process of acceptance of your illness.
Decide that there is nothing that can be done; or that healing is outside your control.	Look for all the things you can do to heal and do them.
Expect your doctor to have all the answers and heal you.	<p>Consider your doctor a consultant – a knowledgeable resource & supporter; and get your mind around the idea that you are the primary treating agent</p> <p>Get several opinions from M.D.s; explore and consider Naturopathic, Chinese & Chiropractic Medicine.</p> <p>Investigate your illness via written word, & the World Wide Web.</p> <p>Investigate alternative approaches to healing, e.g Bernie Siegel, Larry Dossey, Caroline Myss, Andrew Weil, Jon Kabot Zinn, Barbara Brennan, Yoga, Tai Chi, Gi Gong.</p>
Abdicate to others' advice whether they be doctors, relatives, friends or counselors/coaches	Find people who will be a sounding board, helping you sort through all the information possible while affirming your right and ability to decide what's best for you.
Squash your feelings.	Make room for the tears, rage and fear. Learn how to stay grounded while you are feeling. Express your feelings with emotionally savvy relatives and friends. Express your feelings through writing (try writing with your non dominant hand), music, art, etc.
Deny the soulful questions	<p>Once you're grounded in your feelings, allow those soulful questions to emerge, e. g. Has my life been worthwhile? What do I regret doing or not doing? What do I still want time for? Do I matter? Is there a God? An afterlife? What unfinished business gnaws at me?</p> <p>Find an objective and emotionally present coach, counselor, or minister to walk with you while you answer these questions.</p>

Don't	Do
Isolate	<p>Talk with emotionally savvy relatives and friends about your thoughts & feelings.</p> <p>Join a support group, email list serve or chat room (facilitated and knowledgeable about your illness).</p>
Do it all yourself	<p>Come to understand that you can ask others to help you. People generally like to help. Find others who can help with:</p> <ul style="list-style-type: none"> Meals Doctor visits Reading to you Taking you for a drive Researching on the Web Housecleaning
Do more than you have energy for	<p>Say no to nonessential tasks.</p> <p>Ask others to fill in for you.</p>
Follow the "shoulds"	<p>Do exactly what you really need to do in order to take the best care of yourself possible even if it seems extreme.</p>

These skills help me where I live and are my touchstone when I coach people with chronic illness.

In Fellowship,

Jill Richmond-Covey

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