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Make it Happen!
The who, how and what when Chronic Illness stops you from getting your job done

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Introduction

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Chronic illness is a challenge that you can meet…

I am here to tell you that living with a chronic illness and succeeding in your career are not mutually exclusive. I have coached hundreds of people, perhaps like you, who feel that illness might someday, or maybe now, hurt their career.

My own experience living with debilitating chronic illness while working both within large and small organizations and for myself have taught me about the unique set of pressures many of us face every day. There is no single answer, no simple solution. But there are strategies that can help you take charge, *where you can*, so you can deliver, *to the best of your capacity,* while living with unpredictable and debilitating health.

In this booklet, I have pulled from my blog posts, *Working with Chronic Illness*, to identify and explore strategies you can use to achieve what you want and need.

I. 10 *Things I Want You to Know About Living with a Chronic Illness & Working*

Please share this with friends and colleagues whom you believe need a better understanding of what your experience is so they can give you the support you want and need.

1. **For most people, health, like the weather, is relatively unpredictable, and there's an element of luck**. But living with chronic illness means that I face unpredictable health daily. It can change as quickly as the weather, often without warning. I find this difficult, constantly challenging, and sometimes demoralizing, but I do my best not to let this get in my way of doing the best job I can.

2. **When I have to slow down or I don't show up because of chronic illness symptoms, it can mean that others have to pick up the pieces to keep things going.** I understand that this can be frustrating for you. It is for me, too. Let's just make sure we discuss what I can do to prevent my illness from becoming a burden to anyone.

3. **I'm not looking for your pity, or even your sympathy.** I don't feel sorry for myself, and I don't want you to feel sorry for me, either. But I do welcome empathy, such as, "I understand this is tough." And once in a while, it's really great to hear your words of encouragement, such as, "You're doing a great job with *this.*" (But please only say it if you mean it).

4. **I know it doesn't seem to make sense, but I can feel terrible and look fine.** When most people have the flu or even just a cold, they look sick. My symptoms, which are sometimes disabling, are usually invisible. I know it's hard for others to understand this, especially when I look the same through it all. That's why I'm often nervous about what others believe about me and my health. It might sound odd, but when I hear, "You look so good," I find myself wondering if you think I'm exaggerating my experience.

5. **You probably think you're being helpful when you tell me what I could do to get better.** Your Aunt Gertrude, who went into remission with that special diet, or your friend, Phil, who got better when he stopped working – they're not me. I promise you, if I want advice, I will ask for it. Just because I'm not healthy, it doesn't mean I'm incapable of managing my life.

6. **When I mention my chronic illness, please don't "skip" over it and look away**. When you avoid the subject, it doesn't feel polite or respectful. Instead, it feels as if you're avoiding the topic. The fact is, I appreciate questions that show genuine interest in my experience, such as, *"What does this mean for you?"* In return, I'll try my best to be respectful of you by not overly focusing on the subject.

7. **Have you ever noticed how people pass you in the office halls with the greeting "How ya' doing?"** . . . and then keep walking? I know, it's just a greeting, but when I don't feel well, I don't have a quick answer. Funny thing is, I'm still responding to the question five minutes later -- in my head. In fact, there are times when it's difficult to carry on simple, normal office banter when I don't feel "normal" and my life doesn't fit into a sound bite. So if you ask, be prepared for more than you might have bargained for.

8. **Healthy people can work (or play) too hard, but they can catch up after pushing their bodies too far without too much wear and tear.** Part of the problem with this chronic illness, however, is that my limits can vary greatly. I can't ever be sure how hard I can push without hurting myself. Some days, walking upstairs to the water cooler feels like I'm running a marathon. Sometimes it can take days or even weeks

to feel “normal” after working just a few late nights and weekends. And, yet, at other times, I can do any of this without a problem. Go figure.

9. **People in the office (particularly management) will tell me, “Take care of yourself - that’s what’s most important.”** But how should I interpret this message when working 10 hour days for 6 days a week is considered virtuous? I want to have high standards for my performance and be respected for what I do, just like everyone else. But the crazy schedule that we work doesn’t allow time for doctors’ appointments or time to recoup. I find that there’s a bit of a contradiction here.

10. **Please don’t assume that because I live with a chronic illness, I can’t do my job or take on new responsibilities.** If I say I can do something, I will. I don’t want to be protected from work demands, and I want to be held to the same high standards as everyone else. I might have to ask for help at times, but that’s my responsibility. Please don’t discount me without checking with me first.

II. *Chopping Down the Decision Tree*

This article focuses on how and why even seemingly simple decisions can feel overwhelming and offers suggestions for simplifying decision-making regarding your chronic illness and work.

My daughter was stuck trying to make a decision: should she accept a smaller role than she wanted acting in the school play, or should she play a much bigger role on the costume design team? Neither was her first choice, since what she really wanted was to have a big part acting in the play. When the time came to make a decision, and she still couldn't decide, she asked me what I thought. Being the logical person I am, I suggested she make a plus/minus list for each option and see which had the highest tally. When she looked at it for herself, it became clear on paper, at least (she chose the costume design team). Whew! Another close parenting call!

Obviously decision-making is easy when there is one preferable option over the other. But, when there are no "good" choices, only unpleasant alternatives, it can feel like you're stuck in quicksand. When you live with a chronic illness that unpredictably upsets the "constants" most of us rely on, you're often facing unattractive alternatives. If you can't make relatively quick decisions, you're going to stay stuck in that quicksand. Let's look at what might happen.

Symptoms start to flare and, in the beginning, you most likely ignore them, thinking and hoping that they'll get better rather than worse. And they might. But when things don't improve, you're wading into in the muddy water.

How do you know when it's the right time to do something different? You can easily lose focus as you become immersed in the internal debates (e.g., *should I go to the doctor, leave work early, or not go into work today?*). It can paralyze you. Unfortunately, there isn't an easy fix to this. You're not going to find a "one size fits all" response to each situation.

Anyone with a chronic illness knows that activities that feel perfectly fine one day can be unmanageable another.

But you can manage the unpredictable with a mental model that helps you focus and eases the decision making process. The next time you have to decide if you can do something or not, try these 3 steps:

1. **Locate** an identifiable point in your symptoms**.** Don't get stuck on how it's always different. Instead, find the similarities within your experiences.

2. **Evaluate** based on your experience, whether you would feel better or worse (emotionally and physically) with each alternative. Rate this on your experience.

3. **Be honest** with yourself about what option makes the most sense, and then act on it. This is tough because it's easy to ignore what you don't want to know and stay stuck in the debate.

This isn't rocket science. But, in my experience, living with chronic illness can make even the most high-achieving person dysfunctional. The fear that we're going to make ourselves sicker if we keep going, that others will judge us poorly, or that we'll disappoint ourselves if we stop, all drain our precious resources and can prevent us from moving at all.

Approach making decisions about your chronic illness as you do other business decisions, big and small. You can't ever be 100 percent sure that what you do will yield the result you want. Most importantly, don't beat yourself up if you go home instead of going to that meeting and find that you're feeling better before you even reach your front door.

III. *Action Isn't Always Louder Than Words*

This chapter focuses on misunderstandings that arise when disabilities are invisible and offers concrete suggestions about the things you can say so that others understand and support your efforts.

Think about the expression, "*Actions speak louder than words.*" Although there's a lot of truth there, you can't ignore the power of words. How often do you find that your actions cannot support your intention *because of chronic illness*?

People often tell me, *"I hate to use illness as an excuse when I can't get my work done on time."* I think that's bunk. An *excuse* isn't just another word for an *explanation.* Without an adequate explanation, the other person has no idea why you haven't met expectations and is less likely to cut you any slack.

But, as in all conversation, what you don't say is just as important as what you say. And an explanation must have enough information to achieve its purpose.

Now imagine this scenario: you're unable to prepare some documents because your multiple sclerosis (MS) is flaring and your hands are too numb to use a keyboard. What should you say? At the minimum, explain how the symptoms are affecting you, and what you intend to do about it. You might or might not name the disease, depending on whether it helps to clarify the situation.

One response might be: *"I'm sorry, but I can't work on the documents this morning. Today, my hands are numb from a chronic condition and I can't use the keyboard. I know how important this is to the team, and if the problem doesn't improve by this afternoon, I'll find someone who can do it for me. I'll be sure to review it before it goes out. Please, let me know if there's anything that I haven't thought of."*

With this, you’ve done three things to prevent a misunderstanding and preserve your relationship.

1. You’ve explained what has happened and acknowledged the issue, showing that you recognize this is a problem.
2. You’ve offered a recommendation for how to prevent any possible damage, showing your commitment to your position.
3. You’ve asked for input regarding the situation, showing your openness to other ideas.

Words and actions are equally important. Sometimes, words are all you've got to communicate your body's inaction. A thoughtful explanation plus follow-up action makes an unbeatable combination.

IV. *Embracing Plan B*

This chapter focuses on what happens when disease flares unpredictably and you can't do what you need or want to do. Read about resilience and being ready to easily adopt Plan B!

It looked like we might have to cancel our summer vacation when my chronic back pain flared again. It was another reminder that living with a chronic condition means being ready to adapt to the unpredictable. Let's face it, a backup plan makes sense, chronic illness or not. Anyone who leads a military campaign, rolls out new products, or organizes family vacations knows this.

But chronic illness makes the unexpected even more likely. You have to be prepared with alternatives, and be comfortable with change on a moment's notice. My husband and I started working on our summer vacation last winter. With two teenage daughters, this meant getting everyone's input and careful planning.

When my back went into severe spasm the day before we were to leave, we had to shift gears quickly. The girls did the laundry and my husband packed while I directed. We left the now unnecessary golf clubs home so I could lie on ice packs in the back seat of the car. And with hourly stretch stops, which made the trip longer, I arrived at least no worse than when we'd departed. Plan B was in play and working.

Who would have predicted that this would turn out to be one of our best family vacations? I learned to adapt and be comfortable with backup plans on the job from living with several chronic illnesses that would act up when I least expected.

Turn what looks like a disaster into a manageable event by being prepared for the unexpected:

- **Make sure everyone on your team has realistic expectations.** Be matter-of-fact when you discuss your disease, and be honest about its unpredictability.

- **Cross-train your staff so they can share your responsibilities when you're unavailable (or unable).** It’s not always supported in organizations but there are creative ways to be sure it gets done.
- **Craft a plan, in case you need a medical leave, which allows you to re-enter at a comfortable pace**. You can contribute fully where you're essential, and temporarily reduce your workload in other areas.

I don't have any experience planning military operations, but I've read that great generals recognize that flexibility and planning for the unpredictable are key factors in success. **Preparing for the unexpected allows you to enjoy your summer vacation, thrive at your job, or take the enemy's hill.**

V. When You Have to Explain, *"I Can't*"

This chapter focuses on an inevitable aspect of living with unpredictable disease: there are times we just can't do what others expect us to do. But when you offer a full explanation, you'll go a long way toward keeping the good will and loyalty of those around you.

Yesterday, my suit (that I'd wanted to wear for a special speaking engagement) materialized three weeks after it was sent to the dry cleaners. I got these responses to my repeated calls: "It will be delivered by the end of the day. Don't worry, this happens. "*We're sure, it will show up eventually." "Fabrics are tricky and some things just take longer to clean."*

Excuses and rationalizations. When the suit finally came, I called to close my account.

Later that day, the manager called. When I told her what had happened, she apologized for the "poor service". And, she explained, their new computer system had caused many delivery problems that have since been straightened out.

Ah hah! A reason that made sense. Why hadn't I heard this before? She went on to say that she felt horrible about this. (I'm feeling better with every word.) What could she do to repair the relationship? I was so surprised that I didn't have any ideas. And then the kicker, I wouldn't have to pay for cleaning the suit, and my next service would be free! With that, she'd regained a loyal customer.

You see, it was bad enough that they hadn't met my expectations and my suit wasn't ready when it should have been. They lost my good will with poor *excuses and rationalizations*. What I wanted was a *reason* that explained the situation. And just as importantly, to be reassured that they were taking care of things so that this wouldn't happen again.

According to Merriam Webster Dictionary Online:

- *An excuse:* something offered as justification
- *A rationalization*: to bring into accord with reason or cause something to seem reasonable
- *A reason*: the thing that makes some fact intelligible

Think about this the next time you miss a meeting, a deadline, or an important event because your internal health system goes “off.” **Give a *reason that is easy to understand* and you make the situation intelligible and easier to accept.**

Let's say that you're scheduled to attend a meeting that's a two-hour drive from the office. But for the past few days, your hands and feet have been very stiff, making driving difficult. You might tell your boss that you're not going because your car isn't working (an excuse). You could tell your boss you're not going because you don't think the content warrants the time (a rationalization). Or, you could tell your boss that you're not going because you're having trouble with your hands and feet, making driving long distances difficult (a reason), but you'll call for the handouts and find out when it will be scheduled again.

Let’s face it, when symptoms prevent you from doing what’s expected, nothing can change the fact that you can’t do it. But your reason, the truth, makes the situation intelligible to others and helps you maintain loyalty.

Your co-workers probably won’t understand your experience unless they live with chronic illness. But they can be comfortable that you’re not making up an excuse or trying to avoid something. This is true whether it’s the computer system or your body that is messing things up and not working as you wish it would.

VI. You Can’t Always Get What You Want

This chapter focuses on the challenges you face when chronic illness makes it difficult for you to do your job. It also offers a strategic approach with specific tactics that you can use to improve the situation.

This past week, we adopted a nine week old puppy. After walking him four times in two hours in the biting, cold rain, cleaning up after his frequent “accidents,” and playing interminable “fetch” so he wouldn’t howl, I found myself relieved to leave him in his crate and crawl back to my office.

I'd forgotten how much physical energy it takes to raise a dog … never mind a family. It brought back those years when my daughters (now 19 and 16 years old) were infants, and then toddlers, and so physically demanding. Many people talk about work challenges -- but living with debilitating, fatiguing chronic illness can make even typical "parenting work" (with all its physical demands) a draining and demoralizing experience.

Work was the safe haven when my brain soared from my aching body. Staying employed was my mantra. And, it is my message to you, dear reader.

I frequently get emails from people who fear that they're going to lose their jobs, and ask about their "rights." That's when I explain that I'm a coach not a lawyer. But I’ll tell you what I think: the ADA (American Disabilities Act) was created to protect the rights of the physically and visibly disabled. Chronic illness is not necessarily included. Furthermore, to invoke the ADA can be similar to waving a red flag at a bull.

It’s no doubt true that there are situations in which it can be your only option. But be sure you’ve explored other options first. Waving the ADA flag puts you in a highly adversarial position with your employer.

If you fear that you could lose your job because of chronic illness, I suggest that you consider taking the following three steps first:

1. **Identify what you need to enable you to do your job successfully.**

    - List what you can’t do because of chronic illness and develop alternative solutions that could be helpful.
    - Rate each (1 being lowest to 7 being highest) regarding how easy this change would be for your colleagues and employer.
    - Rate each item, same scale, regarding how effective this change would be toward enabling you to do your job.
    - Determine the top two changes which satisfies these criteria: it would be easy on others and it would make it possible for you to get the work done.

2. **Meet with the decision maker.**

- State in clear terms your current health status.
- Describe with concrete specifics how this impacts your job performance.
- Identify and describe the changes you seek with the options you've developed and your plan for how it could happen. You might even include your rating system.

With this, you've demonstrated sincere interest in meeting everyone's needs to accomplish the group goals. You might not get what you want, but you gave it your best.

3. **If there are no options that would allow you to maintain your current position, explore alternatives**. **Ask yourself:**

- Are there other jobs within this organization that I could do?

- Can I look for a similar job outside this company that would be more amenable to my health?
- How much of a pay cut, title demotion, or job retraining am I willing to take to stay in my current organization? To get a job in a different organization?

  Remember that your current employer will be more likely to find another placement for you in the organization if you continue to behave as a team player.

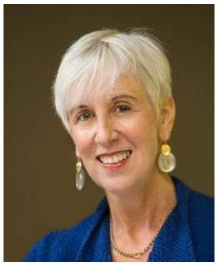
4. **If nothing comes from pursuing #1 or #2, it's likely that you will consider making this an adversarial issue.** But, remember that once you start talking about "your rights," you've turned this into an "us vs. them" situation and you'll no longer be seen as a valued employee, a member of the team. So, before you go down that path, consider why you're doing this, what will you gain, and what will it cost.

Finally, ask yourself:

- Are you doing this to make a point about the rights of the chronically ill?
- Are you trying to force your employer to keep you employed?
- Are you willing to work in a hostile environment?
- Were you angry with your employer for other reasons, and this is the straw that broke your back?

At the end of the day, an adversarial approach might be the only way to achieve your goals, if you are willing to go that route. But know what you want and what you're getting into before you leap. I think this is true: ***You can't always get what you [think] you want. But if you try, you just might get what you need.***

About the Author



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For more than forty years, Rosalind has guided her life by this perspective*: living with chronic illness does not preclude living a full life and workplace success.*

Rosalind founded her business, ciCoach, based on the knowledge and experience that comes from living with several autoimmune diseases, and facing the challenges of staying in the workforce. She is dedicated to giving the guidance, support, andresources necessary to create success even while living with chronic health challenges. A highly seasoned and well-trained coach, she has worked with hundreds of people to develop what they need to stay at work and in their jobs, find new jobs, or create new careers. A recognized national expert on the challenges people with chronic health conditions face in the workplace, Rosalind has been quoted in *The New York Times, The Wall Street Journal, The Washington Post, The Boston Globe, ABC Radio, Fast Company, msnbc.com*, to name a few.

For information about her coaching services, www.ciCoach.com.

She is co author of **Women, Work and Auto Immune Disease: *Keep Working Girlfriend!***

Sign up for her widely read blog, *Working with Chronic Illness*.

For career development and job search strategies, ***The Keep Working with Chronic Illness Workbook***.