



Are You Talking?

Issues to Consider Around *Disclosure,* *Chronic Illness,* *and Work*

*ideas for the highly motivated to consider around
if, when, and how
to get the conversation flowing*

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Introduction

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, we will explore the communication issues fundamental to navigating your career and your health while living with chronic health challenges.

Names and details have been changed to protect client privacy.



I. ARE YOU TALKING ABOUT ILLNESS AT WORK?

This chapter explores how illness can demand we change the way we behave in the world, and the value in maximizing your communication skills.

Achieving the success you desire when you live with a debilitating chronic illness often requires you to make changes in the most unexpected places. In my experience, those who can meet these challenges are more likely to thrive, not just survive.

One key element for thriving with illness is the ability to communicate effectively. This is particularly important because most symptoms from illness are invisible. This means that other people have no idea what you are experiencing unless you tell them. And even when a symptom is visible, it is often unclear how this impacts you.

That means that the burden rests on you to be in charge of the necessary communication.

Here is one example of this. Jim has lived with Crohn's disease for a decade. Over the past two years, the symptoms of disease have become progressively worse. Now he is finding that Crohn's is impacting his performance at work.

Jim is a VP in the finance department of a multi-national firm. He continues to receive high marks from his clients. But recently some on his team have made comments about his unpredictable absences and missed deadlines.

Jim describes himself as a "can do" person who is known to be someone who can turn a challenge into success. He describes himself as a private person who doesn't need to talk about his feelings or his needs. He hasn't told anyone at work

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that he lives with a disease. *"I've always been a man of few words and it's never been a problem before,"* he told me.

But living with chronic illness is presenting challenges that Jim hadn't encountered before. As he explored the situation at work, he was struck by how much he relied on frequent collaboration with his team. He could see how his health challenges were impacting overall 'team' performance. This gave him the motivation to find the possibilities. He looked at his firmly held beliefs and behavior patterns and could identify those that were useful and those that were getting in his way. He could identify some "workarounds" that would enable him to be more reliable and to meet expectations. But he was still overwhelmed by the idea of talking about this and even worse, asking for what he needed. He needed a framework that he could apply in a variety of settings.

We developed 4 guiding principles:

1. Craft a message that is

simple -- *stay clear of jargon and say only as much information necessary to make your point*

clear -- *know your facts and share only what will minimize confusion and maximize comfort*

unemotional -- *keep your feelings to yourself and focus on making it clear that you are in charge of your situation*

2. Focus on how the health challenge impacts what you can or cannot do rather than naming or explaining the disease.

"I live with a condition that makes it difficult for me to stand for more than 10 minutes."

"I live with an autoimmune disease that requires frequent medical appointments."

"Health problems make it significantly difficult for me to walk flights of stairs or long distances."

3. **It is on you to keep people informed.** There are days when you look the same but your body and/or mind might be on fire or asleep. Invisible symptoms typically mean that others don't know what you are experiencing unless you tell them. You might encounter surprise or even disbelief that makes you uncomfortable. But I've seen that in most situations, it is in your best interest to speak up rather than leaving it up to their imagination why your performance has changed.
4. **Consider this:**
- Make it clear that the symptoms change unpredictably and frequently or infrequently, whichever is the case.
 - Focus on how the symptoms impact what you can and cannot do, rather than a detailed explanation of the nature of the disease.
 - Stay away from complicated medical terms and vague explanations that might increase confusion and lead to more questions.

When you recognize what you need to achieve personal success and capitalize on the challenges, you are stretching new muscles that will help you grow more resilient. Adapt any of these ideas to your situation and play with them. It's easier than you think. Living with chronic illness can offer the opportunity to grow and change. Most likely, you would not have chosen that illness be a catalyst for personal growth. But here it is.

II. TO DISCLOSE OR NOT IN THE JOB INTERVIEW?

This chapter explores a key issue that comes up for people seeking employment while living with a chronic illness. And offers ideas to consider so you can make a thoughtful, decision.

Why would you disclose in the interview phase? There is no reason that you must disclose that you live with a chronic illness in the interview process. But if chronic illness impacts the way you do the job or your level of performance, it's likely that at some point you will *have to choose to disclose or lose your job*.

Prevailing *wisdom* says that you almost certainly will not get the job if you disclose a chronic illness before you are hired. Unfortunately, too often this is the case. This is a position based on fear. You might ask yourself if this belief allows you to feel confident in what you have to offer and why you are the right choice?

The following three questions come up frequently asked around this issue. When you consider these carefully, you will be more likely to make an effective decision based on clear intention and strength.

1. Is there a situation where it is best to disclose that you live with a chronic illness to a prospective employer?

- If chronic illness impacts *how* you do your job (e.g., you can't do the job the same way that everyone else does), sooner or later you will have to disclose to get the “workaround” that you need. Although employers cannot ask you about a disability in the hiring process, it is not illegal or unethical for you to bring it up.

2. What information should you tell a prospective employer?

- Be as *public* as you *need* to be and as *private* as you *want* to be.
- Keep it simple. Don't confuse people with jargon. Give them only as much information as they need to know.

- Keep it clear. Know your facts. Deliver to maximize comfort and minimize confusion.
- Keep it unemotional. No one wants a sob story. A prospective employer wants assurance that this will not become their problem.

3. When should a prospective employer be told? It is not the first thing people *need* to know about you. But it does not have to be the very last.

- **A computer security analyst disclosed that he lives with diabetes when he received the job offer.** He used the initial interviews to show what he could contribute and brought up the nature of the illness when he was negotiating his package. He made it clear that he had lived with diabetes for many years, had no problems managing it, and it would not prevent him from doing his job.
- **An I.S. administrator with multiple sclerosis chose to talk about her illness early in the process.** Initially, she did not bring it up because it is not one of the top three messages about herself that she wanted to communicate. However, because she knows that there are times when symptoms impact her work, she wanted to know how people would respond to the information. She chose to discuss it when she was offered the job.
- **A corporate lawyer with lupus disclosed the illness a week after she was hired.** The disease does not currently impact her, but she did not want people to think she was hiding it if it does become an issue.

Finally consider this: *If you believe that you were not hired because you disclosed, is this a job you want?* You might think this is your dream job or you have no other choices. But if chronic illness impacts you at work, how long will you be able to continue *without talking about it*? If you want to work as long as you possibly can, working in a truly employee- friendly environment (not just one that says it in their mission statement must be a top priority. **An organizational culture that values teamwork and honesty should view carefully crafted disclosure as a point in your favor.**

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III. WHEN IS IT THE *RIGHT TIME*?

This chapter explores the issues concerning timing in talking about your illness at work. When you have a thoughtful plan to communicate as effectively as possible about this complicated subject, you are more likely to create a productive working environment.

Sue had been diagnosed with ankylosing spondylitis (AS) over one year ago and now she was in a bad flare. After several days of struggling to get to the office, she told her boss about her health problems, and asked to switch to a virtual schedule so she could continue to work from home.

Sue was a VP in a large healthcare facility and a lot of her job could be easily be done virtually. Her boss told everyone that Sue would be working virtually and, at her request, gave no other details.

After one month, the *flare* calmed down enough for Sue to return to the office. She had been able to maintain her work output, and her lack of physical presence did not seem to have impacted the team performance. Sue assumed all would slide back into place once she was at her desk again.

But not long after she entered the building, Sue felt something was wrong. For the first time in the 10 years she'd been working there, she felt like an outcast. She decided to speak with her closest friend on the team, Dave. He told her that she had been tense and withdrawn for weeks before she went virtual. When she stopped coming to the office, people were relieved that she wasn't around but upset that they had no idea what was going on. This was a team where the work pattern relied on-in person communication and things had slipped through cracks that she wasn't aware of. Now that she is back, people want an explanation.

Sue was surprised and then upset. She didn't understand why she should have to explain herself to anyone other than her boss. But on reflection, she could

see that this was about more than hurt feelings. She realized that she was facing a situation in which her desire to maintain her privacy was preventing her from achieving her work goals.

Sue felt frustrated when she thought about what it would require to repair the damage that had occurred during her absence. What made it worse, is that she would have to stretch herself emotionally at a time when she was already stretched thin from dealing with this illness. As she thought about it, she realized that if her top current priority is to maintain her high level of performance at her job, she had to take *strategic* steps.

She would restore these relationships with the following actions:

- Build on her strength in creating meaningful relationships with individuals, rather than in a group. She would have a 1:1 with each member of the team.
- Identify the current problem. She would explain her health, why she had to work from home, why the information had come from her boss, and what she had experienced since her return.
- Apologize at an appropriate time to any individuals impacted by errors that she had made.
- Ask what she might do now that would allow her get “back on the team.”

No doubt, there will be times when you lack either the awareness or the motivation to take care of both your health and your relationships. But when you do notice that there is a problem that you must address, evaluate your capacity and do the best you can with the resources you have available

IV. ARE YOU PREPARED TO ASK FOR WHAT YOU NEED?

This chapter explores what happens when you can no longer do the job as expected. It offers suggestions to think about, such as what and when to communicate, and finally introduces a strategic model to help you frame the communication process.

Patty lives with chronic migraines and an immune deficiency. She has been working as a legal assistant for the last 20 years. Whenever she has started a new job, she told her boss and the co-workers who needed to know that she lives with chronic health problems. And always adds that this won't present a problem for anyone. She's been comfortable disclosing because she saw it as being transparent and a team player. And her health had never become an issue at work.

Over the past year, however, the debilitating symptoms have become increasingly frequent. This has led to frequent healthcare appointments and unexpected absences from work.

Patty is growing anxious that her health challenges are impacting her work life and her work life is impacting her health. She is taking about two days off each month. When she returns, all the work from the previous days have piled up and must be done before she can focus on that day's tasks.

Recently she was hospitalized and put on bed rest when she got home. Worried about the growing pile of work waiting for her, she returned to work as soon as she could get around.

As expected, she was bombarded with problems that had come up when she was out as soon as she sat down. The amount of email was out of control. Everyone seemed to assume she would just plow through the massive material until it was back in order.

By mid-morning, she was exhausted, overwhelmed by what faced her and had no idea what to do about it. She worried that the tension would set off a migraine. She left early, saying that she still felt sick, knowing that the work would still be there tomorrow.

Reviewing the situation, Patty spoke about her long-standing belief that it is fine to talk about a personal difficulty at work, once. But if you bring it up frequently, you become a burden to others. She sees that this idea isn't working for her but cannot see any alternatives. She feels stuck.

When you feel *resource-less*, unable to think about a difficult situation differently, try this.

Ask yourself,

- ***What do I want to be different?*** *I can take time off from work and know that the work will get done.*
- ***What purpose will this serve me?*** *I can take care of my job and my health confident that I can take the time I need to heal and return in a way that supports my healing.*
- ***What obstacles might get in the way?*** *Pushback from those who are worried this will be a problem for them. Some might not listen carefully or misunderstand my proposal. Some might worry that this will hurt rather than help the team.*
- ***What do I need to do to achieve my desired outcome?*** *To identify how the current way of doing things is harming the team production. A workflow plan workflow to continue when anyone on the team is absent. will continue to get done. This will include why this is so important to an individual and the team. It would include what, who, when. I will identify who needs to know about this and prepare what I will say to shine a light on what is working well and minimizes confusion, resentment or concerns. I will also include a check in for myself to see how I'm doing with the on-going conversations that need to happen.*



- *What actions will show me I have **succeeded**? When I take unexpected but necessary absence from work, I will return to work and face only the current workload.*

The bottom line? When facing a situation where you feel resourceless, apply a strategic approach that helps you maximize your strengths and achieve what you need.

V. ARE YOU MAINTAINING THE ONGOING CONVERSATION?

This chapter focuses on the challenges that come up when you are in ongoing conversations about your difficult and unpredictable health.

Judy is in the third "flare" of Hashimoto's disease within 5 years, and on her second short-term disability leave. She told me that she can't stop worrying about being marginalized in her job and thinking about the reasons why she should stop working altogether.

A health care executive, Judy is proud of her excellent track record with the same company for 20 years. You wouldn't think that she would worry about losing her job, even after two extended sick leaves. Nor would you suspect that she would want to leave her job at this point in her career. But both are true.

When Judy reflected on her desire to stop working, however, she realized that it's not the fear of losing her job or the difficulties around being able to do the job when she isn't well. This disease has turned her life upside down and most of all, she hates the unpredictable quality to all of it. She's tapped out from managing her own emotions around this and can't muster the energy to manage other people's response or lack of response to her challenges.

When Judy first became ill five years ago and took a three month leave, she disclosed the illness to her team and her direct supervisor. No one asked any questions or challenged anything she said and she assumed all was fine. She also assumed that she wouldn't have to talk about it anymore. She thought the issue was over. But then, she couldn't predict that her health would continue to be such a large factor in her life.

Nothing Judy had done before in her life prepared her for what she was facing now. Judy had always been confident in her ability to build positive work relationships and communicate effectively with people. But since the disease onset, even the simplest exchange about her health leaves her feeling worse about herself and her situation. She was overwhelmed.

As she talked, it became clear that each situation felt new and she felt totally

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unprepared. Her homework was to journal daily any incident that provoked a negative response. After one week, she looked at what she wrote and saw themes. This is what she wrote.

1. On days when I have to leave work early for a healthcare appointment or do a meeting virtually instead of in person because I'm so tired, I wonder, *"Do they think I'm a slacker because I'm leaving early for a medical appointment or missing a meeting? Do they resent my medical leaves that means more work for them?"*
2. When a colleague asks how I'm doing and I say I'm not doing well, I get a blank stare or they look away without responding. I wonder, *"Should I have said that I'm fine? Does an honest answer make them uncomfortable or not know what to say?"*
3. When someone peppers me with questions about what I am or I'm not doing to get better and then offers advice, I feel angry and think, *"Why can't you leave me alone and let me do my work? Can you see I don't want to talk about this?"*
4. On days when just getting to work feels like I ran a marathon but everyone around me seems oblivious to how I feel, I wonder, *"Why can't they see I don't feel well? Do I need to scream in pain or faint so someone notices?"*

Judy felt less overwhelmed when she recognized what happens and seeing the patterns. She could see patterns yet recognize there is no pat response. She needed a strategic frame that she could use that is flexible and adaptable to the situation she is facing.

Consider this when you talk about living with illness:

- Clarify in your own mind what you want your words to achieve.
- Keep the message simple. Stay away from jargon. Focus on the symptoms you are experiencing right now and their impact on what you can do.
- Keep your words and tone unemotional. No one *wants* to listen to a sob story when there's work to be done.

Bottom Line? Be as public as you need to be and as private as you want to be



VI. ARE YOU SETTING THE BOUNDARIES YOU NEED?

This chapter focuses on how and why establishing boundaries around the topic of your illness will allow you to maintain your own comfort and your effectiveness.

Sarah was out of work for two days because of illness. When she got back, her supervisor, Nancy, took her aside and said, “*You told me that you have multiple sclerosis. You’ve been sick a lot. Are you taking care of yourself?*”

Sarah stayed quiet but she was distraught. Since starting this job one year ago, Sarah has been out of work twice. The first time, one month after she started, she took a day off for the doctor’s appointment where she was told she had multiple sclerosis (MS). The symptoms were relatively mild and the medication that was prescribed seemed to be working.

Her recent absence was due to a respiratory virus that was making the rounds in her office.

That day, Sarah kept going back to that interaction with Nancy and became increasingly depressed. When we talked about it, she said that since the diagnosis, everyone seems to think that she isn’t capable of taking care of herself. She did not want anyone to think that chronic illness gave them permission to tell her how to live her life but couldn’t see how she could prevent that.

Probing deeper into what might have prompted Nancy, Sarah realized her unexpected absence meant more work for Nancy who was already under a lot of pressure. Sarah had always valued her independence but also welcomed input from others.

She didn’t want anyone to think that chronic illness gave them permission to
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© Robert Howell to live her life but couldn’t see how to prevent that. Staying



silent was not working for her but a defensive reaction would not be helpful either. Sarah wants to be comfortable in steering unexpected and undesirable advice in the direction she wanted. This would require strengthening the communication muscles that would help her use her voice.

We developed a strategy that she believed would be easy for her to tap into when needed and adaptable to whatever she encounters.

When someone tells her what to do to take care of herself, she will:

- rely on a quick and simple breathing practice. She would silently count to 3 as she takes an 'in-breath' and release. This slows her down to collect herself.
- look directly at the person and focus on what prompted the remark, rather than launching into a defense.
- try to address the person's underlying concerns and direct the conversation toward that.
- if the above don't apply, briefly acknowledge what was said without agreeing or disagreeing and steer the conversation to another topic.

Regardless of *why* someone gives you unwanted advice or tells you how to take care of yourself, you can set boundaries that maintain your self-esteem. Just because your health is a challenge, it does not mean that other people have a free pass to tell you how to live your life.



VII. ARE YOU STUCK IN CHECKMATE CONVERSATION?

This chapter explores the idea that sometimes it is not what you say, but what you do not say, that can have a negative impact on communication with people at work. It is important to take responsibility for making clear and reasonable suggestions for the changes and accommodations that you need in order to be successful at work.

Does a chronic health condition overwhelm you to the point that dealing with other people feels like a burden that *you just cannot carry*?

Sadly, it is not unusual to get to the point when your chronic health condition overwhelms your already stressed system and you can't see any options.

For many of us, meeting resistance, lack of cooperation, or resentment from a boss or co-workers makes work a toxic environment. Your resilience is low and you can feel that you've done what you can and there are no moves left to play. It's checkmate.

Sam used that expression when we first met. He works in a position of responsibility and reward in a highly technical field. But when he started experiencing intermittent severe fatigue a year ago, he tested positive for chronic fatigue syndrome (CFS). "I was literally floored to hear that. I had barely been sick a day in my life and had no experience with not being 110%"

For the ten years he had worked at this firm, he had always been the highest performer on the team. The first thing he did was make an appointment with his direct supervisor, Joe. He described how he'd been feeling and told him the diagnosis. Sam told Joe that he although he most likely couldn't get as much done, he could still meet the group performance levels since his output had always exceeded the others. Joe thanked him for letting him know.

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Yet Joe continued to give Sam the same number of projects. Since Sam was working more slowly, he was continually behind his production quota. Joe didn't say anything directly but he was checking in frequently to see what Sam was doing and looking for updates on deliverables. Sam felt micro-managed.

"Doesn't he understand that I'm doing the best I can?" he asked me. "I am exhausted all the time and doing the best I can. But even though my output is slower I'm still producing at the rate of most of the team."

When I asked what he needed to continue working at this job, Sam was very clear. He wanted his workload reduced to be in line with the production output of the rest of the team and he wanted to be left alone to manage his time.

Sam was surprised when I asked if he had said this to Joe. He told me that he didn't think it was his responsibility to tell his manager how to do his job. Nor did he want to sound like a complainer.

But in our next meeting, Sam was worried about losing his job. A colleague told him that people were saying that Sam was falling behind and wondering if he'd lost interest or was looking for another job. Sam had assumed Joe had told the team about his health. And he couldn't understand why Joe continued to give him the highest volume of cases when Joe knew he wasn't well. Sam felt trapped and he couldn't see any options. He was out of moves.

The problem was not what Sam had said. Rather, it's what he didn't say. Yes, he made a statement about his current health. But without a clear request, he had left it to his supervisor to fill in the blanks.



A declarative statement, such as, “*This illness makes me tired,*” might be how you feel but it lacks any detail. But when followed by a brief explanation of *how* this impacts your performance, and what you believe would be helpful to achieving the goals, you’re not burdening others to figure out what you need. You might not get what you want but you will know that you did what you could.

When it feels like you are in checkmate with no moves , ask yourself: *what have I done and what might be left to do?*



About the Author



Rosalind Joffe, M.Ed., ACC 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, and resources 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. For information about her coaching services, www.ciCoach.com.

She is co author of **Women, Work and Auto Immune Disease: Keep Working Girlfriend!** She publishes a widely read blog, [Working with Chronic Illness](http://WorkingwithChronicIllness.com).

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 career development and job search strategies, [The Keep Working with Chronic Illness Workbook](http://TheKeepWorkingwithChronicIllnessWorkbook.com).

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