

Are You Talking?

Issues You Must Consider About Disclosure *Chronic Illness* And Work

*stories for the highly motivated who want to know
if, when, and how
to get the conversation flowing*

2nd Edition

Rosalind Joffe, M.Ed.

Table of Contents

Introduction	3
I. <i>Are You Talking About Illness At Work? communication as opportunity</i>	4
II. <i>To Disclose Or Not To Disclose In The Job Interview? make this a thoughtful decision</i>	7
III. <i>When Is It The Right Time? have a plan</i>	10
IV. <i>Are You Prepared For Complicated Conversation? framing the conversation</i>	12
V. <i>Can You Maintain The Ongoing Conversation? ideas for talking about it</i>	15
VI. <i>Are you Setting Your Boundaries? knowing why and how</i>	18
VII. <i>How High Is Your Performance Bar? getting real with yourself</i>	20
VIII. <i>Are You Stuck In A Checkmate Conversation? waiting for others to bring up illness</i>	22
IX. <i>Are You Dodging Difficult Comments? responding when you would prefer to remain silent</i>	25
X. <i>When Is An Apology In Your Best Interest? acknowledging mistakes</i>	29
About the Author	32

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, like you, who feel that illness might someday hurt their career.

My own experiences working within organizations large and small, and for myself while living with debilitating chronic illness, have taught me about the unique set of pressures you face every day. Your goal is to manage unpredictable health while staying at the top of your game.

This booklet focuses on the communication topics that influence success when you are navigating career while living with chronic health challenges.

Chapter 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.

(Names and details have been changed to protect client privacy.)

Achieving the success you desire when you live with a debilitating chronic illness can require change in the most unexpected places. In my experience, those of us who can meet the 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 some symptoms are visible, others cannot understand how this impacts you, unless you tell them.

Therefore, the burden is on you to describe your experience of debilitating symptoms as they impact your life.

Jim lives with Crohn's disease. The disease has been getting progressively worse over the past ten years and he is working at an increasingly uneven pace. Although he has always done well at his job (as a senior accountant in a *Big 10* Firm), his colleagues and his supervisor frequently express frustration about what is not getting done or getting done late.

Jim has not told anyone at work that he lives with a disease. He doesn't see why he should have to tell, since it's nobody's business. But he has become increasingly angry with his colleagues. They often seem annoyed by his absences, or missed deadlines, as he's struggling to manage difficult and painful symptoms. He has thought about leaving his job and taking advantage of the company's private disability policy. But it won't be enough for his family to live on and he worries that he would be bored if he doesn't work.

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

Jim realizes that he is stuck, and needs to do something to pull himself out of this place. He describes himself as a private person who does not talk easily about his feelings or his needs. "I've always been a man of few words and it's never been a problem before," he told me. This style is not working for him now, but he does not see what he might do differently.

Chronic illness is creating problems that require Jim to stretch his comfort zone and develop new skills. When he was able to explore his situation, he discovered he had options. Once he recognized what kinds of changes and accommodations he needed at work, Jim could see the opportunities rather than just focusing on the obstacles. He was struck by how much he relied on his colleagues and they relied on him. This motivated him to develop his capacity to discuss his situation sufficiently with others, so he would be able to manage work more successfully. But Jim still felt completely unsure about what and how much to say.

Together we developed these three ideas to guide him:

1. **When you name the particular health challenge with which you live,** you can find that people are uninformed or misinformed. Your words and behavior impact how others respond. Create a message that is:
 - **SIMPLE.** Stay clear of jargon. Say only as much information necessary to make your point.
 - **CLEAR.** Know your facts. The information should minimize confusion and maximize comfort.
 - **UNEMOTIONAL.** No one wants a sob story. You will increase the other person's comfort level when you show that you are comfortable, yourself, with the situation.

2. **If you choose not to name the disease,** focus your language on how this health challenge impacts what you can or cannot do. For example:

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

or

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

3. Symptoms of most chronic health challenges are frequently invisible.

You can look just like you did yesterday and feel completely different.

Invisible symptoms mean that others don't know what you are experiencing unless you tell them. And since you look the same, they are typically surprised (at best) and even disbelieving (at worst).

Unfortunately, the responsibility rests with you to explain the changes, so you are not leaving this up to their imagination. Some ideas to consider are:

- Make it clear that the symptoms change unpredictably and frequently or infrequently, whichever is the case.
- Focus on what you can and cannot do because of these symptoms, rather than offering an exhaustive explanation of the nature of the disease.
- Stay clear of medical terms and vague explanations that might create confusion. For example:

"Even though this wasn't a problem last week, I cannot make it to today's meeting, in another building. The medical condition with which I live, multiple sclerosis, is making it very painful and tiring to walk this distance."

Adapt these ideas to your situation and play with them. It is 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 the catalyst for personal growth. But here it is. **When you recognize what it takes to achieve personal success and capitalize on the challenges, you are stretching your muscles so you can be more resilient.**

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

Chapter II

TO DISCLOSE OR NOT TO DISCLOSE IN THE JOB INTERVIEW?

This chapter explores a key issue that comes up for people seeking employment while living with a chronic illness. It offers some tips for making a thoughtful decision.

(Names and details have been changed to protect client privacy.)

Prevailing *wisdom* says that if you disclose a chronic illness before you are hired, you almost certainly will not get the job. Given the biases and stereotypes that prevail around chronic health conditions, there is no arguing that this might be the case. But, do you think that operating from fear puts you in a position of strength? Do you think that you are more likely to get a job if you show up feeling confident in yourself, what you have to offer, and why they should hire you?

There is no reason that you *should* disclose that you live with a chronic illness, unless chronic illness factors into your performance (or unless it matters to you for some other reason). If that is the case, then it seems likely that you are going to either *choose* to disclose, or *have* to disclose at some point.

What follows are three commonly asked questions (at least these are the questions that reporters ask me) about disclosure before getting the job:

1. In what situation is it best to disclose that you live with a chronic illness to a prospective employer?

- If this health problem impacts your schedule (e.g. you need a flexible or virtual work day, or time off for healthcare appointments) and will do so as soon as you start working, then by choosing to disclose before you are on the job, you have taken charge of the situation. You get to set the timing and the message. Because there are no surprises, you

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

establish from the outset that you are a team player. You get to state this in a way that shows that you know how to handle things so it will not be a problem for your employer.

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

2. What 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 them in a way that minimizes confusion and maximizes comfort.
- Keep it unemotional. No one wants a sob story. A prospective employer wants assurance that this won't become his or her problem.

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

- **A computer security analyst disclosed that he has diabetes once he had gotten the job offer.** He used the initial interviews to show the value he could bring, and discussed 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

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

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 asked back for a second round of interviews.

- **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 in the event that it does become an issue.

If you are not hired because you have disclosed, do you really want this job? It is easy to feel that you *have to* take this job and you don't have a choice.

But consider this: If chronic illness impacts you at work, you can only continue to work for so long without talking about it. Also, if your plan is to be able to work for as long as you possibly can and want to, then working in a truly employee-friendly environment (not just one that says it in their mission statement) should be one of your top priorities. **The organizational culture that values teamwork and honesty will view your carefully crafted disclosure as a point in your favor.**

Chapter 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.

(Names and details have been changed to protect client privacy.)

Sue was in a bad flare with ankylosing spondylitis (AS). After several weeks of struggling to get to the office, she told her boss about her health problems, and asked to switch to a virtual schedule that allowed her to work from home. Luckily, she had a job that she could do *virtually*. Her boss told everyone that Sue was unwell, and would return in the office full-time when she was better.

Within a month, the *flare* calmed down, and Sue returned to her regular office schedule. Her work output had stayed the same, and her lack of physical presence did not seem to have made any difference in team performance. Sue did not think there would be a problem going back to her old schedule.

But when Sue returned to the office, she felt that her colleagues were treating her differently. For the first time in her life she felt like an outcast. She decided to speak with her closest friend on the team, Dave. Dave told her that even before she went *virtual*, she had been tense and withdrawn for weeks. Then when she stopped showing up, people seemed relieved that she wasn't around. But it did not help that she had not explained to anyone what was going on or why she was working from home. Furthermore, when she returned, she had not bothered to explain what had happened. Other people thought that she acted like nothing had happened and they resented this behavior.

Sue was relieved that she was not imagining the bad feelings. But she was hurt because she did not think she should have to explain herself to anyone. She thought her health was a private matter, and that they should understand this.

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?
© Rosalind Joffe, www.cicoach.com, 2014

After acknowledging her hurt feelings, I asked her how her behavior was working for her. Since she returned, had she been meeting her own performance expectations? As she considered her current effectiveness at work, she saw that the situation involved more than hurt feelings. That is when she realized that, although her style had not been a problem for her before, she now faced a situation in which her desire to keep things to herself was preventing her from achieving her work goals.

Sue was frustrated thinking about what it would require to repair the damage that had occurred during her absence. She was even more upset that she would have to stretch herself emotionally, at a time when she already felt stretched thin. As she evaluated her options, she realized that her tendency to maintain her privacy, and keep to herself, had led her to the current spot. She understood that it was up to her to improve the situation.

She decided that she would rebuild her team relationships by doing the following:

- √ Build on her strength in creating meaningful relationships with individuals, rather than in a group. She would speak with each member of the team.

- √ Identify what she saw as the current problem. Then she would explain what had happened regarding 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.

- √ At an appropriate time, apologize for errors that she had made.

- √ Ask what she might do differently now that would allow her to get “back on the team.”

There are going to be those times when you have neither the awareness nor the motivation to take care of both your health and your relationships. **Notice, however, that the longer you wait, the harder it can be to properly nurture and sustain those relationships that are critical to your productivity.**

Chapter IV

ARE YOU PREPARED FOR THE COMPLICATED CONVERSATIONS?

This chapter explores what it takes to manage the ongoing conversation around your health challenges and their impact on your workplace performance. This includes what and when to communicate and introduces a strategic model that will help you facilitate the communication process.

(Names and details have been changed to protect client privacy.)

Patty struggles with communicating about her health challenges at work – both disclosure and ongoing communication. She lives with chronic migraines and an immune deficiency. Over the past six years, she has been experiencing increasingly debilitating symptoms. Patty gets stuck figuring out the appropriate time to:

- Disclose her health problems for the first time.
- What to say when she does disclose.
- When to refer to this with the people to whom she has disclosed.

Recently, this has become a major concern. Patty has spoken of her health problems only once to her boss. He never brought it up again, even after she was hospitalized and missed work for two weeks. She believes that she was protecting her job by not referring to her health problems again. And, she thought she was not burdening others by talking about it.

But she finds herself constantly worried about what people might be thinking and not saying to her, particularly on her bad days. This worry is creating a high degree of tension and making her less productive.

Patty explained that she wanted a checklist to refer to when she was debating whether to discuss her health problems. But every time she thought she had a *formula* for what to say and when, she found that there were too many variables in the equation. As we discussed the situation over weeks, she began to see that this issue is more complicated than she had first realized.

Patty was surprised that this was not more straightforward and simple and it would require a more strategic and thoughtful approach. I am not surprised, though. I have never found that there is a simple solution to a complex situation. Have you?

I think the best way to explain this is from a personal example. I was having difficulty training our new rescue dog not to poop in the house. I thought it would be relatively simple to break this habit since I had trained many dogs. But this dog responded differently from previous experiences and I became frustrated. With this less predictable dog, each situation had too many variables. Therefore, I was unable to rely on the checklist of steps that had always worked before. Seeing I needed to do something different, I let go of the notion that this training should follow a series of clearly defined steps. Instead, each time she pooped inside, I took a mental step back to allow myself the space to analyze the situation and figure out what actions would most likely achieve my goals.

Whether you are training a dog or discussing your health challenges and their impact, consider tackling this with a strategic approach. You are more likely to achieve the outcomes you seek when you adapt this model:

1. ***Start at the end: What do I want to be different?*** (e.g., *I want my supervisor to trust me to do my job, and not resent when my pace may be different from others.*)
2. ***Say this in action terms: What are the actions that will show me I have succeeded?*** (e.g., *He will show his trust by giving me the bigger projects, and not micromanage me as he has started to do recently.*)

3. **Ask yourself: What do I need to say or do to achieve my desired outcomes?** (e.g., He needs enough information to feel confident that I am taking care of my responsibilities, but not too much information or emotion that makes him think he has to take care of me.)
4. **Ask yourself: What challenges or obstacles might get in the way of achieving what I want?** (e.g., My boss worries about everything, he doesn't like when anyone else's problem becomes his problem, and he doesn't like to be surprised.)
5. **Ask yourself: Where are the opportunities to overcome the challenges that I have identified?** (e.g., I can assure him that I am competent in taking care of my health, and my job, because I've been living with this for many years and know how to be a successful worker, even with this. I will let him know that I will keep him as informed as he needs to be so he is never surprised or embarrassed.)

The bottom line? **When facing a complex situation, you are likely to achieve the changes you seek when you adapt a strategic approach that starts with your desired result.**

Chapter V

CAN YOU MAINTAIN THE ONGOING CONVERSATION?

This chapter focuses on what happens after you disclose, and the challenges in managing the conversation and expectations after you have disclosed.

(Names and details have been changed to protect privacy.)

Judy is in the third "flare" of Hashimoto's disease in five years, and on her second short term disability leave. She said that she was unable to sleep at night because she could not stop worrying that she was going to lose her job. However, she was also thinking about the reasons why she should quit.

A health care executive, Judy is proud of her excellent track record with the same company for 20 years. You would not think that she would worry about losing her job just because she has taken two sick leaves. Or that she would want to leave her job. But both are true. When Judy reflected on her situation, she realized that it is neither the disease nor the job that makes her want to leave the workforce. "The thing I struggle with most is the need to keep explaining my body's problems to other people."

Judy feels:

- Uncomfortable with how others respond when she brings up her debilitating symptoms.
- Resentful about the ongoing need for explanation.

Sound familiar?

Judy acknowledges that her self-esteem is woven into her sense of her own success at work. But she is unclear how this affects her difficulty in discussing her health issues.

When she first became ill, five years ago, she disclosed to her team and her supervisor. That seemed to go well and she breathed a sigh of relief thinking that this issue was taken care of. She had always been confident in her positive

work relationships and her ability to communicate effectively with people. But since she developed Hashimoto's disease, her confidence eroded significantly. On those days when she feels sapped of energy, she finds herself obsessively concerned about what people think of her. She wonders, "Do they think that I'm a slacker because I'm leaving early for a medical appointment, or missing the meeting? Do people resent the medical leaves that I have taken?"

She feels angry when she thinks about those who ask her how she is doing, and then look away without a response when she replies that she is not feeling well. She finds herself wondering: *do they really want to hear the truth?*

Then there are those who ask too many questions about her health and even offer advice. *Why can't they leave me alone when I need to work, and clearly do not want to talk about it?*

Finally, she grows infuriated on days when just getting to work feels like an accomplishment. On those days, everyone around her seems oblivious to how she feels. They pepper her with questions and pile on the work.

Judy noticed how much better she felt, and how much calmer her mind seemed when she allowed these thoughts to surface, and said them aloud. They no longer overwhelmed her. She was ready to consider what issues to address, and where she wants to make improvements.

Here are three things to consider when you talk about illness, either for the first time or the tenth:

- **Keep it simple.** Do not confuse people with jargon. Give them only as much information as they need to know.
- **Keep it clear.** Know your facts, and deliver them in a way that minimizes confusion and maximizes comfort.
- **Keep it unemotional.** No one wants a sob story. A prospective employer wants assurance that this will not become his or her problem.
- **Be as public** as you need to be and as private as you want to be.

There is no simple way to make this easy for yourself or others. Even those colleagues, friends and even loved ones with the best of intentions often do not "get it right." In fact, as our state of health and symptoms change, we are often as clueless as anyone about what we want and need.

But when you acknowledge the difficulties, even if it is just to yourself, you have taken the first step in taking charge of your own obsessive worry. This frees you for the second step in which you can create clear intention, that leads to thoughtful action, that leads to the outcomes you seek.

For many people, the challenges in talking about illness at work seem to be the most pressing and difficult issue that they face. Even for those who disclose with "positive" results, the inevitable ongoing conversation can feel demanding and create anxiety. Because chronic illness is both unpredictable and invisible, it is up to you to be aware of what needs to be said and done. Not an easy charge. But when you are feeling like you just cannot do it anymore, ask yourself this: *what is my alternative?*

Chapter VI

ARE YOU SETTING YOUR BOUNDARIES?

This chapter focuses on creating boundaries that allow you to maintain your comfort level and continue to be effective at work. By identifying boundaries, you can ensure that small issues do not become larger issues that affect your success at work.

(Names and details have been changed to protect client privacy.)

When Sarah returned to work after missing two days, her supervisor, Nancy, took her aside. Nancy told Sarah that she had, "... been sick a lot recently and she needs to take better care of herself in light of her chronic disease." Sarah was furious.

Since starting this job one year ago, Sarah had been out of work twice. The first time, shortly after she started, she had taken one day off for the doctor's appointment during which she had gotten the diagnosis of multiple sclerosis (MS). Her recent absence was due to a virus that was literally making the rounds in her office.

Sarah spent that day thinking of all the things she wanted to say to Nancy to defend herself. She was angry and ready to quit. But as she described what happened when we spoke, she realized that it was not the first time that a co-worker, boss, or even a friend, had given her advice about what she should do to take care of herself.

Sarah was silent as she thought about this. Then she angrily said that since she had gotten this chronic illness, it seems like everyone around her thinks that she needs them to tell her how to live her life.

Sarah clearly needed to vent a little before she could sort out what was really going on. When I asked her if she was aware of how her recent absence might

have impacted Nancy directly, she replied that Nancy had filled in for her at two important events. Sarah went on to say that Nancy had been under pressure from her boss, and Sarah's absence could have put her behind. As Sarah considered that this might have provoked Nancy's comment, she grew calmer.

But she also realized that although she understood that her absence might have been a burden on Nancy, she was still offended that Nancy would tell her how to take care of herself. She did not want people to think that chronic illness gave them permission to tell her how to live her life. She also recognized that in some relationships, particularly professional ones, she would be better off if she steered the conversation in the direction she wanted. Becoming reactive or defensive would not be helpful. Sarah decided to have a conversation with Nancy that would:

- **Acknowledge** Nancy – by telling her that she realized her absence had meant Nancy fell behind in her own work.
- **Express** apology – for the fact that this happened.
- **Ask** for input – concerning help she could give Nancy now.

Sarah had developed a plan to address her immediate concern. The next step for her was to consider a strategy that would help her be prepared for this type of interaction. She decided that when someone told her how to take care of herself, she would stop to ask herself if her unpredictable health had been a problem for the other person, and might have caused the other person to make this kind of remark. If yes, then she would focus her energy on what prompted the remark, rather than trying to try to defend herself. When someone tells her how or what to do to take better care of herself, Sarah would matter-of-factly state that she does not think this is relevant to the discussion. She will bring the conversation back to goal-oriented specifics, such as what she can and will do to ensure the work gets done.

Regardless of why someone makes a remark that implies she should be living her life differently, Sarah will be prepared. **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.**

Chapter VII

HOW HIGH IS YOUR PERFORMANCE BAR?

This chapter explores the challenges in setting expectations, your own and others, so that you can create success rather than failure.

(Names and details have been changed to protect client privacy.)

I have lived with chronic illness for decades, yet I can still ignore my limitations in my desire to please others and meet expectations (mine and theirs). Recently, a colleague and I had to travel across the city to a meeting. It was a lovely day and she suggested we walk to our destination which she thought would take about 30 minutes. Not wanting to seem difficult or 'wimpy', I agreed. But, 10 minutes into the walk, I regretted this decision as the alarm signals were firing in my body. I have lived with heat intolerance and an incontinent bladder for almost 30 years (due to multiple sclerosis) and the symptoms that were bubbling up were no surprise. Yet I had ignored this when I agreed to the walk.

Now, however, I had to pay attention to my symptoms. Fortunately, my colleague was understanding. I found a cab easily. She continued her walk and I arrived at our destination in good shape. Later that day, I made a mental note to self: Do not ignore what you know in an effort to please others. It creates unnecessary problems.

I thought about this a few days later when my client, Don, who lives with lupus, described his dilemma. Six months earlier, Don had a bad flare (meaning the disease had gotten worse for a period of time), and he took a short leave of absence for three weeks. This led him to miss several deadlines and although he was able to catch up, he was extremely uncomfortable about this. He did not want it to happen again. He could see two options and neither felt good:

- Reduce his projected deliverables to lower expectations. This would give him the room to take a leave if he became ill again, without missing deadlines. But, he feared he would be perceived as unenthusiastic or disinterested if he requested lowering his performance bar.

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

- Keep expectations the same, ignore what happened, and hope that he would stay healthy and be able to work to capacity. He had always been a high energy person who outperformed everyone else on the team. He is proud of this idea of himself, and resists giving it up. But, he feared that he could lose his good standing or his position.

Don felt depressed and stuck, thinking about these options. He was sure there must be a move that is 'right'. When Don asked me what I thought he should do, I suggested that he have this conversation with the person who would be most impacted by his behavior. His boss knew he lived with this disease, and had seen Don manage his work successfully. He and Don also had a relationship that was based on mutual trust. These were all good reasons to think that they could come up with a plan.

Don met with his boss, and they came up with a formula for setting and re-setting expectations that met both their needs. He was surprised by how easy this was.

On the other hand, if you worry that asking directly is not a good idea, try a different approach. Imagine yourself as the manager and your employee was experiencing these difficulties.

Now ask yourself:

- What would I think of a direct report who does not meet deliverables?
- What would I expect this employee to do?
- Which would I prefer: an employee who reaches beyond capacity but does not get the job done, or a realistic employee whom I can count on?

When you cannot do things that you want to do (or once did) due to the limitations caused by symptoms, it is very tempting to deny or ignore an unpleasant reality. But ask yourself, *what does that achieve for me?* **When you put your focus on what you can and cannot do, rather than on what others think of you, you are more likely to know what you need to do and say to satisfy all concerned.**

Chapter VIII

ARE YOU STUCK IN A 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 learn how to take responsibility for making clear and reasonable suggestions for the changes and accommodations that you need in order to be successful at work.

(Names and details have been changed to protect client privacy.)

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

I often hear people tell me that they cannot get what they need from the people with whom they work. From their point of view, the lack of cooperation that they get from others makes it hard to keep working. It is as if they are stuck in *checkmate* and they feel that they have no moves left to play.

Sam told me that although he has not been meeting his deadlines, he thinks that his supervisor, Joe, needs him too much to fire him. But lately, Joe has been constantly checking up on what he is doing, and dropping hints that Sam is working too slowly. This is driving Sam crazy, but he has no idea what to do about it. He is wondering if he should look for another job or stop working altogether for a while until he feels better.

"Doesn't he understand that I'm doing the best I can?" he asked me. "I am exhausted all the time. But I can't take the breaks that I need with Joe breathing down my neck waiting for work that was due two days ago."

Sam has a highly technical job creating complex software. His problems in this job started a year ago when he developed severe fatigue. Within a few months, he had tested positive for chronic fatigue syndrome (CFS). He thought that he

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

had done the right thing by telling Joe his diagnosis. Sam was happy to have a reason for how he felt and he thought that Joe would understand that things had changed. Sam explained that he would not be able to maintain his previous production pace. For the ten years he worked at this firm, he had always been ahead of schedule, and exceeded expectations. He told Jim that although he would be working at a slower pace, he could meet the performance levels set for the group.

Sam thought that conversation should have been enough. But he was still being given the same number of projects. Everyone, including Joe, behaved as if nothing had changed. He just wanted his workload reduced to be in line with the production output of the rest of the team. He also wanted to be trusted, and left alone to get it done.

When I asked if he had discussed this with Joe, Sam sounded surprised by the question. He told me that it was not his responsibility to say all this. That was his manager's job. He certainly did not want to sound like a complainer.

But in our next call, Sam was concerned that he might lose his job. A friend had told him that there were complaints that Sam was falling behind. Sam realized he did not want to lose his job, but he felt trapped. He was sick and tired and did not have the energy to fight this. Sam needed a different move, a move that would not drain his energy (as a difficult confrontation might), but he could not figure out what it was.

In this situation, the problem was not about what Sam had said. Rather, it was what he had not said. His conversation with his supervisor, Joe, had been too limited. Sam had made a statement without any clear requests. Also, he expected his supervisor to fill in the blanks.

We started by exploring what would allow him to work as efficiently as possible with his health changes. With that information, he was ready to consider what he thought were reasonable requests. In fact, it was easy for Sam to identify what he needed from his supervisor to continue to do a good job. He just had not thought that it was *his* responsibility to ask for it. Nor had he recognized that

regardless of what he thought about whose responsibility it was, it was his job in jeopardy.

I suggested that a declarative statement, such as, “This illness makes me more tired,” is rarely enough detail to achieve any substantive change. Too often, people do not know what to do with this information. Rather than ask why, they ignore it. But when you follow this with clear suggestions regarding how this impacts your performance, and what you think would make a difference, you have clarified why you are sharing this information. You are also offering your ideas for solving the problem you have presented. This kind of message gives the other person something to work with.

When it feels like you are in checkmate, ask yourself: *what have I failed to say, or what requests have I not made?*

*To learn more about the language of making requests, refer to, **You Are What You Say**, by Matthew Budd and Larry Rothstein. I particularly like their 10 Linguistic Viruses.*

Chapter IX

ARE YOU DODGING DIFFICULT COMMENTS?

It can be difficult to respond to comments made by people who do not understand your illness or what it is like to live with illness. This chapter offers some ideas for effective ways to communicate with others about your health. By educating others, you can decrease your frustration and feel more comfortable in your work environment.

(Names and details have been changed to protect client privacy.)

Julie was describing how isolated she feels. Periodically and with no clear trigger, she becomes incapacitated by severe asthma. Additionally, she has to juggle medications that can have significant side effects. Compounding the stress she experiences from living with unpredictable and debilitating illness, she faces comments people make regarding her symptoms, and how she takes care of herself. The typical comment goes something like this:

"Oh, you've got asthma? It's related to stress. You should try relaxation techniques."

or

"Really? My brother has that but it's not a big deal for him."

Comments like these can leave you frustrated and intimidated. They can feed your own concerns that you are less than the person you used to be because of this chronic health condition. It is easy to understand how this could lead a person to prefer not to talk about difficult symptoms or illness with anyone.

But here is the thing: When invisible symptoms wax and wane in severity, people cannot realize how you feel *unless you tell them*. If you find that the silence is not working for you, ***consider these three ideas:***

1. Focus your message so it achieves your desired outcome.

Often people do not realize what they do not know, nor do they realize how hurtful their comments can be to you. Put your energy toward crafting a message that will best achieve your *desired outcome*.

When you have to explain that you cannot do something, focus your message on how the disease affects you, rather than on the disease itself.

How does this sound?

"I can't hike today because symptoms from Crohn's disease mean that I have to be near a bathroom at all times."

or

"I can't go to the meeting because I have debilitating pain in my legs today due to rheumatoid arthritis, a chronic illness that I live with."

You might choose to not name the disease because of the incorrect associations people commonly make. In that case, focus on the *impact this symptom creates* on what you cannot do:

"I need to sit in a chair when I'm presenting at the meeting because I live with a medical condition that makes it difficult for me to stand for very long."

or

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

2. Chronic illnesses are frequently invisible.

You can feel very different than you did yesterday, yet you look the same.

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

This can create a disconnect for those around you. Here are three things to keep in mind:

- Stay away from medical terms and vague explanations.
- Focus on what you can and cannot do, tie it to a specific medical reason that is simple for others to understand.
- Make it easy to grasp that change comes frequently and because the symptoms are invisible, others are not aware of the change unless you tell them.

Which do you think is more effective?

"I can't attend the meeting because I'm having an MS flare."

or

"I can't walk the distance to the meeting because MS symptoms of extreme fatigue make it impossible for me to walk a long distance, today."

Try playing with these ideas and adapt them to your situation. It is easier than you think!

3. Unfortunately, even the most thoughtful people can speak without thinking and say hurtful comments.

When you explain that you cannot participate in an activity, or accomplish a task because dizziness (or pain, fatigue, etc.) leaves you feeling poorly, you probably hope for an empathic or at least an accepting response.

But what happens to you when you hear, "Oh, yeah, that happens to me but I push through it."

Do you find that the best response to this kind of remark is no response? It might be true in certain situations. But if this continues to occur within an ongoing relationship, it is bound to create resentment, and therefore, increase your problems. Keep in mind that most people have no clue about your experience and your silence will not increase their insight.

Ask yourself this:

Would I help someone understand my world better so I feel less isolated, even if it means taking a risk that I might hear something that is not pleasant?

If your answer is YES, the next time someone says, "I don't see why this stops you," try something like this:

"Yes, back pain makes it difficult for me to sit at my desk today. But, I've found ways to keep my life going, meet my commitments, and minimize the triggers that increase the pain."

For most of us, these are not easy messages to deliver, and they do not roll off the tongue. But, I have found that if you practice this (try saying it aloud to yourself while you look in the mirror), it not only becomes easier, but you might actually grow comfortable with it.

The next time someone offers a response that feels uncomfortable, you will take a step toward decreasing your isolation with your thoughtful response. You will also go some distance toward educating people about what it is like to live with chronic illness.

Chapter X

WHEN IS AN APOLOGY IN YOUR BEST INTEREST?

This chapter explores how to respond when you have made a mistake. Living with illness means living with the unpredictable. You do not have to apologize for what you cannot change. But when you acknowledge and apologize for your mistake, you open the road for conversation and learning.

(Names and details have been changed to protect client privacy.)

It was a bad morning for Carol. Her allergy symptoms had been horrible since she had gotten out of bed, and the fibromyalgia pain was searing. Only able to pay attention to how badly she felt, she made a quick decision, and emailed her supervisor that she would not be at work that day. She had never done this before, but she did not think twice. She knew she could not get into the office. Carol went back to bed.

When Carol woke up feeling a little better a few hours later, she read her email messages. Her manager had written back to remind her that she and Mark, her teammate, were making a major presentation to a client that morning. Carol now realized that without her part of the report, Mark could not make the presentation. She realized too late that he must have had to reschedule with the clients.

When Carol called Mark (who knew about her health challenges), he was very angry. He said that he needed to be able to depend on her and he could not work with someone who is unreliable. Carol did not respond to his comments. She got off the call feeling miserable. She thought he was saying that he did not want to work with someone who got sick. She berated herself for not going into work that day, and for *giving in to the illness*. She could not stop from thinking that her unpredictable illness could mean the loss of an account, and maybe even her job.

When she returned to work the next day, Mark was cold. He made comments implying that he might ask to work with someone else. She liked working with Mark, and loved her job, but now she considered quitting. She could not take the stress of other people's anger, and she felt helpless to do anything about it. How did Carol go from taking a sick day to thinking that she would either lose or voluntarily leave her job, so fast?

I do not think that Carol's error was in missing work that day. Nor is it a mistake to work while living with an unpredictable illness. What follows are three actions that would have led to fewer problems:

- When confronted with Mark's anger that she had let him down, it is best to acknowledge her mistake in not preparing them both for her unpredictable health.
- Once she felt satisfied that Mark heard this, she could apologize for the problems that her lack of preparation had created and she would not let it happen again.
- Finally, she could engage Mark in brainstorming what she can do to improve the current situation, and what she can do to ensure it does not happen again.

Once she thought about it, Carol realized that it was not too late to acknowledge and apologize. She would ask for Mark's help in putting the pieces in place that were necessary to ensure that an unexpected absence did not jeopardize their work.

Can she be sure that if similar events happen in the future, it will unfold as she would like? No, but she can do her best. Carol does not have to apologize for living with an illness that is unpredictable, and often debilitating. But she can apologize for her very human error.

Mistakes and errors are a fact of life. No matter how we try to create systems to

eliminate errors, they are inevitable. Saying you are sorry might not regain a lost client. **But, acknowledging that you made a mistake allows others to feel validated and heard. Acknowledging the results of your mistake opens the conversation for learning. Having a conversation that creates the opportunity for change enhances the likelihood that a conflict such as this will not happen again.**

About the Author

WHEN IS AN APOLOGY IN YOUR BEST INTEREST?



Rosalind Joffe, M.Ed., ACC

For more than thirty years, Rosalind has made decisions from a unique perspective: *living with chronic illness does not preclude living a full life and workplace success.*

Rosalind Joffe founded her business, ciCoach.com, 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. As a highly seasoned and well-trained coach, she has worked with hundreds of people to develop the competencies they need to stay at work and in their jobs, find new jobs, or create new careers.

As 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*, as well as numerous regional and national media outlets.

For more information about coaching, products and services, please visit:

www.cicoach.com.

Contact Rosalind directly: Rosalind@cicoach.com

To read more on the subject of working and chronic illness, visit and sign up for her

blog: *WorkingWithChronicIllness* <link to this page:

<http://www.WorkingWithChronicIllness.com> >

For more specialized, career development and job search strategies, read about my *Keep Working with Chronic Illness* <link to this page:

<http://www.cicoach.com/workbookpromo.html> > workbook.

The Guidebook Series: **CAREER THRIVE When You Live With Chronic Illness**
Are You Talking?

© Rosalind Joffe, www.cicoach.com, 2014

