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Julia's Dilemma

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Julia, a professional woman in her mid-thirties, has had relapsing-remitting multiple sclerosis as a part of her life for the last five years. Now she must decide whether to disclose her hidden illness at work. Julia disclosed her illness to her manager in a prior employment, when her MS was first diagnosed, and experienced a supportive response. But she was always mindful that her performance would likely be carefully scrutinized since she was in a job that required strict deadlines. Julia made a career change about a year ago, and did not tell anyone in her new organization that she had MS. She avoided the issue during the hiring process, and deliberately refrained from informing her manager during her probationary period. She made lifestyle and workplace accommodations on her own to compensate for her disability. She was concerned about confidentiality and others' perceptions of her as a person with a disability. Julia's current decision was precipitated by changes in her health care coverage. Access to expensive drugs was a key factor in managing her illness, and she needed information in order to make her decision. This impending decision made her think again about whether she should disclose her illness, and to whom. Others who will be immediately impacted by her decision include her manager, coworkers and friends at work, human resource professionals, and her husband.

Julia's Dilemma

"Anyone can run into a medical condition at any time. Maybe it's a personal health crisis, maybe it's a family member or parent, maybe it's a co-worker or if you are a manager, one of your employees may get ill. I have learned lessons at 33 that most people don't have to deal with until they are in their 70's and an illness strikes." This was how Julia articulated her personal growth over the past four years. But this growth also presented a dilemma since her chronic illness was invisible. So far Julia had not disclosed her illness to anyone at her current workplace. But now she needed to change her health care plan, and realized that she faced an immediate decision: should she disclose her disability, and, if so, to whom?

Julia's personal and professional history

Julia was a professional in her mid thirties who described herself as career minded and serious about her job. She knew she was an overachiever and tended to push herself to meet deadlines and goals. Julia's previous employer was a small firm where she worked for ten years. She was well known, respected, and was in a specialized role where she could not be easily replaced in her job. She acted as staff support to an engineering team responsible for design, documentation, and regulation of customized mechanical equipment for the aerospace industry. She was the technical writer responsible for compiling operating and maintenance manuals - these were generally several hundred pages long, filled with complex diagrams and detailed descriptions. Since the manual was the last item produced before shipping the equipment and realizing revenue, extreme pressure was put on Julia to have the manual ready - and error free - even though design and production invariably ran late. In addition, Julia was responsible for reviewing standards and documenting compliance with FAA regulations. Her work involved interactions with many different people, intense periods of solo development of her portion of the equipment, and stringent customer-imposed deadlines.

Julia enjoyed a high level of mutual trust with her long-term manager, and felt he understood her desire to increase her job responsibilities. Her manager was experienced and often took the time to ask Julia how she was doing. She sensed his concern for her. "He would always stop what he was doing and give me his attention; many times employees have to work at getting their manager's attention but I never did."

Julia had always enjoyed excellent health until about four years ago when, over a period of several months, she had difficulty moving, concentrating, and even writing her name. "I've kept a copy of my signature from that time," she said, "it looked as if I was 80 years old!" She remembered that at first she thought she had the flu, and then continued to blame a virus while seeking medical attention and being subjected to a series of tests. Julia told her manager she would need an MRI and he was caring and concerned about her results. Even though she trusted her manager, she did not reveal the diagnosis until it was confirmed and she knew enough about the condition to educate others about multiple sclerosis and reassure them she would be OK.

About multiple sclerosis

(This section was compiled from www.nationalmssociety.org)
Multiple sclerosis, or MS, is considered to be an autoimmune disease: a chronic, unpredictable neurological illness that affects the central nervous system (i.e., the brain, spinal cord, and the optic nerves). It is not contagious nor considered to be a fatal disease. There is no cure for MS yet, but drugs can help slow the course and/or symptoms in some patients. The exact cause of the disease is unknown, since scientists do not know what triggers the immune system to attack its own tissue. Anyone may develop MS, but there are some patterns: most people with MS are diagnosed between the ages of 20 and 50, and two to three times as many women as men have MS. Approximately 333,000 Americans acknowledge having MS, and every week about 200 people are diagnosed. Worldwide, MS may affect 2.5 million individuals.

People with MS can expect one of four clinical courses of the disease, but 85% of those initially diagnosed have the relapsing-remitting form. These people experience clearly defined flare-ups (also called relapses or exacerbations) that are episodes of acute worsening of neurological function, followed by partial or complete recovery periods (remissions). Others may have more continuously progressive forms of the disease. The majority of people with MS do not become severely disabled.

Symptoms of MS are unpredictable and vary from person to person and from time to time in the same person. For example, one person may experience abnormal fatigue, while another might have severe vision problems. A person with MS could have loss of balance and muscle coordination making walking difficult; another person with MS could have slurred speech, tremors, stiffness, and bladder problems. Even severe symptoms may disappear completely and the person will regain lost functions. People who have "invisible" MS symptoms have a unique set of problems, since others may assume that the person doesn't really have a disease.

Disclosure at her previous workplace

Julia's manager gave her a hug after she disclosed the fact that she had multiple sclerosis and asked her what he could do to help. He set the tone by responding to the diagnosis with a reassuring comment, "I'm not going to talk about this." Julia felt secure that her confidentiality would be maintained and that only those on a need-to-know basis would have knowledge of her condition until such time that she elected to inform others. The HR department and upper management at the company knew about her diagnosis since Julia had to disclose her condition in order to qualify for medical coverage for state-of-the-art drugs that can cost $1000 per month. Her employer was self-insured and therefore required the diagnosis in order to make a special case that her drugs be covered.

A short time later, as her confidence in herself returned, Julia started to tell others. She gave her colleagues a booklet from the MS Society that outlined the condition to educate them and allay fears or doubts about her capabilities. "I started by showing this booklet to the department secretary who always seemed to know what was going around on the company grapevine, so she would be sure to get the "correct" rumor going!"

Julia experienced a different reaction when she was at her dentist and had to adjust her medical file. The receptionist looked at her, "… as if I had AIDS and as if she was going to cry. I try to not feel sorry for myself when I get this type of reaction to MS, and I tell myself I will beat this disease."

The worst case for Julia as a working professional would be the loss of job responsibility or work assignments. Although her boss expressed support for her personally, Julia wondered whether he would be scrutinizing her performance more carefully and looking for opportunities to give her less challenging assignments. "At one point I thought I might need a lawyer to ensure that my job stayed intact," she recalled. "I eventually realized that there was no perceptible change in my job assignments. The deadlines did not disappear!"

Once her initial exacerbation had passed, Julia's work life resumed much as before. That is, she maintained her previous pace at work, meeting all deadlines, even when experiencing symptoms of the disease, while scheduling few activities for the weekends so that she could rest. She answered her co-workers' direct questions of concern, attended a support group for the newly-diagnosed, and educated herself as much as possible about the disease. "Sometime after the first anniversary of my diagnosis, I suddenly realized that I was comfortable with my identity as a professional woman with MS."

A career change

Julia and her husband both decided to make a career move, and, after some searching, relocated to a different city on the west coast. Julia looked for, and found, a "dream position." The work was self-paced, yet challenging, and drew on both her professional skills and personal interests.

As a public relations specialist for a large service-oriented organization she was responsible for liaison among divisions, keeping each part of the organization informed about relevant operations in the other parts, and ensuring that the organization spoke with a single voice to outside constituents. Her work involved meetings at the different locations and participation in conferences with her counterparts in similar organizations.

With her MS in remission, and her personal health regimen well established, Julia had no need to divulge her condition to her new employer. Her husband suggested that her health insurance be carried under his plan since Julia wanted to ensure that her performance was being perceived as excellent even though she was on a learning curve for her new position. She didn't want anything to stand in the way during her probationary period.

Julia had no need to disclose her illness during the job application process. There were no questions on the application or during interviews that caused her to even stop and think about how she might answer. But several days after being hired, the HR coordinator for her department came to her office with a large index card containing a series of questions of a personal nature: Who should be notified in an emergency? Who was her next of kin? And so on.

Julia vividly remembers that one question had a box that she needed to check if she had a disability status, and a space for providing an explanation. She left it blank, rationalizing that her MS was in remission, so at present she did <u>not</u> have a disability. "But I wondered if this would ever come back to haunt me." Part of her reluctance to confide was due to the HR coordinator's position within her department. Even though Julia had been a part of the organization for a short while, she knew that this coordinator, who handled payroll and general benefits, had a close relationship with her manager. Later Julia became friends with Carol, a benefits specialist in the main HR department, and realized that the HR department was extremely well-run and professional. "We met at a social gathering, and later had lunch together once or twice a month. Carol never talked about other employees, even though we both knew that she was responsible for administering benefits in my department."

Lifestyle and work accommodations

Every time Julia thought about whether to disclose her hidden illness, she remembered how proactive she was as she started her new position. "I held myself accountable for what I needed to do as I walked the fine line between coping with my illness and not disclosing any disability to my current employer," she said. She believed that the fear of a "trigger event" that would cause a relapse (a period of time where every movement was difficult, fatigue was acute, and vision was impaired) could be worse than the event itself. Since the fear factor could be worse than the actual symptoms of the disease, the moderation of temperature, food and other variables within her control were critical. "When I expressed my fear of loss of cognitive ability to my neurologist, she replied that lack of sleep could influence <u>anyone's</u> ability to think clearly." Julia has made lifestyle friendly adjustments since her body was not as forgiving as it was prior to MS.

Julia made her own adjustments to her work practices and schedules in order to accommodate her disability. Steering clear of high heat environments, maintaining a low fat diet, and avoiding fatigue were three simple ways through which many people who lived with MS ensured that they could function at optimal levels for their stage of the disease. For example, since prolonged exposure to high temperatures could impair her ability to "think on her feet," she dressed in layers so she could always remove a jacket or sweater if the room was hot. Last summer, when an energy crisis precipitated an organization policy that air-conditioning thermostats be set five degrees higher, she did not comply, and actually set her office controls slightly lower, hoping that her boss would not discover that she was breaking the rule. Whenever a group of employees went out for lunch, or when traveling with colleagues, Julia forcefully insisted that they not eat in certain restaurants where she knew there would not be low-fat choices available. "I jokingly referred to 'my diet,'" she noted, "and even though I was skinny, everyone just thought I was a fanatic and shrugged it off."

Julia's new employer was an organization with buildings spread out over a large area. She saved steps where she could and planned her route carefully when she navigated the physical plant and attended meetings in other buildings. She balanced busy appointment days with a less busy day in order to control exhaustion and fatigue. Business travel assignments stretched Julia physically. She might take a vacation day to travel a day early, using the ploy of "wanting to sight-see" in order to be ready for important assignments. Once at her destination she would work in her hotel room. She often took vacation time for her doctor's appointments so that her manager would not become curious about her time off. One of the benefits of her current job was that she worked alone for the most part and so had some control of her own schedule.

In her previous job Julia worked as part of a team and needed to attend many mandatory meetings. "I had to switch from sobbing in a doctor's office over bad news to joining a team meeting at work within a 45 minute time span. I was pushed into my professional role rather than indulging in self-pity for a longer period of time." She recognized that work was a safety net since the routine and stability of work grounded her and distracted her from the uncertainties of the disease.

"I have a personal rule that I do not take a sick day – even if I'm feeling sick I go to work. I want to be known as the person who is never out, so in case I need four days off someday I will not have a problem taking them. I know I am rigorous and hard on myself in proving MS has not beaten me. I remember one day when I was working on a project and had to walk to a meeting during a difficult episode. I felt like I was walking through mud in slow motion and had trouble keeping my balance. My coworker saw me grab a table in order to avoid falling and I know he probably thought I was drunk. I didn't go home or take a sick day because I need the continuity that work provides. I'm trying to keep my MS in a box but I can't always control it."

Family and friends outside of work provided a support network. Although her parents lived several thousand miles away, Julia kept in close contact through emails and phone calls. "I allow myself a 15 minute complaint session every so often when I vent about my condition to my Mom and Dad or to my sister." She called this "my indulgence," and often apologized afterwards for her self-pity. After a year, she was able to joke about "shooting up," referring to her regimen of self-injection of the powerful drug that would keep the MS in remission and keep her active. Fortunately she only needed a single injection a day, so this part of her life could stay outside the office, and side effects – nausea, swelling at the injection site, and muscle stiffness, for example – usually passed before she went to work. Even so, she never took her medication on a business trip for fear of needing to explain herself publicly within earshot of colleagues at an airline security check (medical syringes are permitted in hand baggage). The routine of medication administration could be debilitating and difficult to maintain without support. Julia knew that every time she convinced herself that a business trip was an excuse to escape the daily regime of injections, she was neglecting a painful procedure that had little apparent current effect during the remission stage, but should postpone the onset of the next episode and help her function in the long term.

Rethinking her decision not to disclose

When Julia took her current position she was advised by legal experts at the local chapter of the National MS Society not to disclose her disability for at least six months, or until after her probationary period. Now a year has gone by, and she has still not confided in her manager or colleagues.

"In my new job I do not know my manager that well, and he has little history of my work since I have only been here a year. Not knowing is the most difficult aspect to deal with. I don't want to be marginalized or replaced in my job. By that I mean I don't want to be passed over either overtly or subtly. I don't want things removed from my job or not to hit my desk before I have a chance to see them. I've seen this happen when someone resigns from a company – they are left out even though they still have work to do and are fully committed to completing it. I don't want anyone making a presupposition about what I can or cannot handle."

Julia asked her boss for a flextime arrangement so she could take a course at a local university. He eventually agreed, but only after a long meeting in which he questioned her need for higher education, and pretended that he would not grant her request. "He's such a clever debater," Julia reflected, "that he'll bring up some facts and give others the silent treatment, so the issue doesn't get fair representation. He always wants someone else to take the fall."

But a recent interaction with another woman with a disability caused Julia to reflect on her own situation. This woman represented a supplier and made frequent visits to the organization. She was known "to have had a brain injury about ten years ago" and this was understood to be the reason why she used a wheel chair. Julia sensed the woman thought that Julia had no understanding of her disability and had no desire to accommodate her. As Julia confided to her husband that evening, "Nothing was further from the truth. I wanted to say to her, 'I have a brain disability too, I have lesions in my brain and I can relate to what you deal with every day.' It may have helped our relationship had I been open with her."

Now there was a more urgent reason for disclosure. Julia had to think through her medical insurance coverage. Recent changes in her husband's policy made it necessary for her to carry her own coverage. Her husband would use an HMO with cost savings, while she needed a plan with access to preferred providers.

"When I looked on my organization's website, the information about access to drugs made no sense. All non-insulin formularies were grouped together – my drug was listed with Viagra and a host of other drugs related to improving 'long-term functioning.' I couldn't figure out if the co-pay was $20 or 20% a month. For the cost of my drug, 20% would be close to $200 a month! I needed to get the facts straight, but I didn't want to go to an open meeting – even if it was part of a support group for employees with special medical needs."

Julia's husband encouraged her to think about how she wanted others to see her – and how she saw herself. Maybe it was time to tell her manager and coworkers. At first she replied, "People are dealing with me as I am, not their perception of me as a person with MS." But then she thought about it some more – "Who am I, a person with MS, or a person who hides her identity? Maybe I should disclose."

Student Resources

Check the following websites to increase your understanding (URL's current as of April 2004)

For Information about Multiple Sclerosis

The National Multiple Sclerosis Society www.nationalmssociety.org.
Use to locate local chapters, information about volunteerism and fund-raising (MS Walk and MS Bike Ride), on-line chat rooms www.nationalmssociety.org/Chat.asp, webcasts with doctors, as well as information about the disease

The Multiple Sclerosis Foundation www.msfacts.org.
This site has support and educational programs for those coping with MS, including a multimedia library in English and Spanish.

Videos with information about the disease can be viewed on www.medicalview.com (choose multiple sclerosis from the list of topics on the left hand side).

The Multiple Sclerosis International Federation www.msif.org.
This is a comprehensive site with international portals and worldwide medical research results and well as information about the disease, symptoms and treatments.

MS ActiveSource www.msactivesource.com.
A site maintained by one of the three major drug companies that make therapies for MS. Use this site to explore the way people with MS live with MS.

ADA and MS www.nationalmssociety.org/%5CIMSFa01-ShrewdMoves.asp.
This links to an online article about an individual's rights under ADA: Cooper, L., Law, N., and Sarnoff, J. (n.d.) "ADA and people with MS: A guarantee of full participation in society."

Disclosing MS www.nationalmssociety.org/Brochures-Disclosing.asp.
For issues and hints related to disclosing MS to others.

For Information about Relevant Employment Laws

Americans with Disabilities Act of 1990 (ADA) www.usdoj.gov/crt/ada/pubs/ada.txt.
This links to a full text of statute.

ADA homepage www.usdoj.gov/crt/ada/adahom1.htm.
    This government site contains a lot of information, mainly about visible physical disabilities and accommodations.
ADA Primer for Small Businesses www.eeoc.gov/ada/adahandbook.html.
    Clear, concise overview of application of ADA to businesses.

Federal government-related resources for people with disabilities www.disabilityInfo.gov.

Family Medical Leave Act of 1993 (FMLA) www.dol.gov/esa/regs/statutes/whd/fmla.htm.

Family and medical leave practices in other countries
http://www.familyleavesurvey.homestead.com/FMLANonUS.html.

Instructor's Resources: The instructors' resources begin with a detailed overview of the case linked to the subheadings used in the student version. Information follows about the research basis for the case and learning objectives, teaching options and the authors' experiences using the case in undergraduate and MBA classes. A list of questions for class discussion is followed by suggested responses and teaching points. The Epilogue details Julia's decision with her reasoning, and is followed by Julia's tips for managers for sensitivity towards the needs of employees who may have invisible illnesses or hidden disabilities.

Instructor's Resources available upon request from Jill Woodilla at woodillaj@sacredheart.edu.

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