

Managing a job and a chronic illness

Shannon's story

In the fall of 2002, Shannon Young noticed a bumpy red rash on her wrist. It persisted, didn't really itch, and the cream her doctor prescribed didn't help it go away. Of much greater concern to the doctor was an infection in all Shannon's cuticles. A dermatologist took one look and diagnosed dermatomyositis. By that time, Shannon who works as a news anchorwoman for channel 7 in Roanoke, Virginia also felt tired and achy. The young woman spent New Year's Eve on the couch, completely wiped out.



Shannon Young,
Television Anchorwoman

Shannon's DM affected her appearance, a particular concern because of her work on camera, and soon after treatment began she experienced facial swelling from prednisone. Makeup didn't make her look completely normal: My employers deserve all kinds of credit for being understanding and flexible, she said. They kept me on the air and never mentioned doing otherwise despite my prednisone-induced facial swelling and obviously altered appearance. They gave her extra time off when she needed to rest and a light workload while continuing to make her feel part of the team. I'm lucky to have not had my work schedule interrupted too much, she

said. Aside from doctor's appointments and the occasional sick day, I've worked pretty consistently. Most of the discomfort has been as a result of the medication. That discomfort included the emotional side effects of prednisone, as well as the more obvious facial swelling. Shannon's fingers bothered her when she typed, but she found that light, stretchy gloves help cushion the impact of the computer keys.

Shannon also says that exercise, family support and some insights she got from Eugenia Zuckerman's *Coping with Prednisone* helped her stay in the workforce. Her disease course was fairly mild, and her work situation was just about ideal: her employers worked with her to help her continue in her profession. Not everyone is so lucky. Depending on the degree of disease, the type of work, the financial situation and the possibilities for both accommodation and further training, myositis patients face a variety of choices about their employment as well as their health.

Tom's account

Like many myositis patients, Tom Stuart knows the very moment that he realized something was terribly wrong. It hit him like a freight train as he was running, then in the weeks to come he felt like a man who had taken poison. Tom is the director of manufacturing engineering for a start-up company called Crossbeam Systems in Concord, Massachusetts.

It's a demanding job, Tom says, and would be a difficult one under any conditions. In all, Tom only missed about three weeks of work during the initial flare of his disease and two weeks of that were before the diagnosis, then one week as the prednisone kicked in. By the Monday after he'd been treated for a week, Tom said he was on a euphoric high from the prednisone. This was the most energy I had since the previous summer, Tom said. I was high to the point of being spacey. But, like Shannon, Tom soon became familiar with the other side of the drug. After two weeks of working tirelessly, he crashed, collapsed, and spent the next four months on disability, with his muscles deteriorating to the point where he had trouble walking around the block. By January, he started to feel better and in February he went into physical therapy.

With increased, monitored activity and the inflammation under control, Tom went back to work. Meanwhile, he was struggling with prednisone reduction, and it really was a struggle: There would be times that I would reduce it, say from 40 mg/day to 30 mg/day, and for a few days all would be well, and then all of a sudden I would be in misery. This might come on so suddenly that I would be at work when it happened and I would worry about how I was going to get home. I'd go out to my car and try to sleep in preparation for the drive. There were a number of times that I would sleep in my car for an hour or

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Dear Friend,

This issue of *The Outlook* focuses on maintaining your life and career despite having myositis. This is not easy to do, but you will find within this issue examples of how to maintain a career and the emotional state of mind necessary to persevere.

Included in this is being able to laugh at yourself and not being too hard on yourself. Managing the disease, treatment and drug side effects is not easy and will inevitably lead to times where you feel overwhelmed, out of control and no longer "on top of your game." We hope this issue will help you to accept this and focus on all the things you are able to do and how much you have achieved despite the devastating impact of myositis.

This theme of celebrating life and focusing on the positive will be evident at TMA's Annual Conference in Las Vegas, where we will seek to emphasize abilities not disabilities. And we will provide a setting and environment that will encourage you to appreciate how much fun and excitement in life remains for you, your family and your friends.

For those unable to attend the Annual Conference, the issue of *The Outlook* following the Conference will provide you with the substance of the Conference and will also give you a feel for some of the fun and excitement that makes Las Vegas the liveliest city in the world.

We want all of you to appreciate what life holds for you. Enjoy this issue of *The Outlook*!

A handwritten signature in black ink, appearing to read "Bob Goldberg".

Bob Goldberg
Executive Director

Working, Cont'd from front cover

more, just to get myself prepared for the drive. One solution for Tom during this period was to work part-time, three days at work, one day at home, and the fifth day to rest. Tom had several flares, and each time he reduced his work schedule. He's now been off medication for five months and works full-time at his demanding job. What helped Tom, a former serious runner? Yoga, he said. I think yoga is the perfect exercise for myositis patients because it can be modified to very simple doable positions to accommodate your poor muscle strength, and also because a good instructor makes sure that all of your muscles get attention, especially your back. If your back is weak, the rest of you doesn't have a chance.

Step-by-step suggestions

It's no secret that much of our self-esteem and self-worth are tied to our work. (See our Messages page, where we've included some short comments by members on this subject.) This is a subject addressed by Gayle Backstrom in *I'd Rather be Working*. More than 60 million Americans of working age have a chronic illness or a disability that makes getting or keeping a job a daily struggle. Most of them would rather be working than unemployed or underemployed. Working would not only help them financially; it would also contribute to their sense of community, value and contribution.

Backstrom, who is chronically ill herself, subtitled her book, *A Step-by-Step Guide to Financial Self-Support for People With Chronic Illness*. It's a guide for anyone considering the search for paid employment. She suggests that you first evaluate yourself, asking these tough questions:

- Where am I?
- Where am I going?
- What can I do?

- What do I know?
- Where do I want to go?
- What do I want to do?

Self-assessment will help you decide what is realistic for you. Then you may want to make use of some of the public resources designed to help people with chronic illness. Resources are listed below. You may also want to consider self-employment, which may allow you to work at a pace that's compatible with your energy and strength.

Not all the factors for success in holding on to your job are practical or logistical, Shannon Young says. When she faced the challenge of juggling DM and her job on the air, she found that stressing out about it and agonizing over what could happen did not help. I'm learning to be proactive rather than reactive, she says. Her advice, to keep your energy and optimism up:

Learn to live in the moment and appreciate what you CAN do.

Take control of the things you can, like your attitude and healthy habits, to balance out the things you can't.

Decide to enjoy life, regardless.

Resources

The Job Accommodation Network

This free consulting service provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities to both employers and job seekers. It offers hundreds of resources for people who are disabled and want to return to work. Its web site includes samples of letters to employers, interview techniques, a full list of reasonable accommodations, and information about dozens of job banks designed to connect employers with the disabled work force. There are also resources for working at home, with a long list of further resources. West Virginia University, PO Box 6080,

Morgantown WV 26506-6080; Toll-Free: (800) 526-7234; TTY: (800) 526-7234; Fax: (304) 293-5407; jan@jan.wvu.edu; www.jan.wvu.edu.

JobAccess

The goal of JobAccess is to enable people with disabilities to enhance their professional lives by providing a dedicated system for finding employment. JobAccess, 1001 W 17th St., Costa Mesa CA 92627; Phone: (949) 854-8700; Fax: (949) 548-5966; www.jobaccess.org/contact.htm.

Small Business and Self-Employment Service (SBSES)

The SBSES is a service of the Department of Labor's Office of Disability Employment Policy providing comprehensive information, counseling, and referrals about self-employment opportunities for people with disabilities. For more information, contact the Job Accommodation Network (JAN) at 1-800-526-7234; www.jan.wvu.edu/sbSES/index.htm.

Small Business Administration

The Small Business Administration (SBA) can provide assistance for starting a small business. For a local SBA office, look in the telephone directory under Government Listings or access www.sbaonline.sba.gov.

Office of Disability Employment Policy

ODEP is an agency within the U. S. Department of Labor. ODEP provides national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment. ODEP, 200 Constitution Avenue NW, Room S-1303, Washington, DC 20210; Direct: (202) 693-7880; TTY: (202) 693-7881; Fax: (202) 693-7888; infoODEP@dol.gov; www.dol.gov/odep/welcome.html.

Editor's note: Ms. Young will be presenting at TMA's 2004 Annual Conference and will be available for further discussion.

DEPRESSION AND CHRONIC ILLNESS: MOVING TOWARD FREEDOM

It seems to be a cycle: you're depressed because you're sick, in pain, isolated and weak; or you're at such a low point emotionally that you just can't get well. It's a complex dance, with each illness—myositis and depression—taking the lead at times. Add to that the side effects of multiple medicines and it becomes nearly a hopeless tangle. We know that any illness can lead to depression, and that the severity of the depression mirrors the severity of the illness. In the mainstream population, men have a risk of 5-12 percent of becoming depressed at some point in their lives; women have a greater risk at 10-25 percent. In the population of those with chronic illness, there's a much greater risk—between 25 and 33 percent for both men and women. Depression caused by chronic illness prolongs the illness, makes pain worse, aggravates the loss of energy that's a concern with any chronic disease, stresses relationships and causes isolation, all problems associated with longer recovery periods. Although studies show that autoimmune activity measures higher in people who describe themselves as anxious or depressed, it's hard to design a study that could prove whether the depression followed the disease activity or the other way around.

Many people are unaware that they need treatment for depression, often accepting it as a normal part of aging or disability. According to a public opinion poll, nearly 93% of adults think that depression is normal in people suffering from a serious medical condition. A study at the University of Washington in Seattle has shown that it is safe and effective to treat depression in patients with complex patterns of physical and mental disorders. And research conducted at the National Institute of Mental Health suggests that treatment for depression

can reduce disability and result in improved physical functioning.

Other research, from the University of North Carolina School of Public Health, showed that the cause-and-effect relationship between physical illness and depression can reverse course. Illness can bring on bouts of depression, which, in turn, can lead to a run-down physical condition that impedes recovery, according to study investigator Elizabeth J. Mutran. Her research team looked at the role of social support and depression in older women's physical recovery following hip fracture surgery. This longitudinal study found that women who were depressed or had inadequate social support directly after surgery showed less improvement in their ability to walk two months later. After six months, however, cause and effect were reversed: Low improvement in walking ability led to increased levels of depression.

The journey to successful coping

Participants in a Gerontological Society of America symposium said that medical illness is the most consistently identified factor associated with the presence of late-life depression and is the most powerful predictor of poor depressive outcome. Certainly, it's not hard to understand why people with chronic illness are depressed. They're experiencing losses in independence, relationships, even in their own feelings of worth and usefulness, and a sense of sadness seems natural. It's part of the process, says Laury Goolsby. Goolsby was a founding medical advisor of TMA and is a clinical psychologist at James Madison University. She has lectured often about depression and chronic disease—myositis in particular. The normal negative reaction to events that will change our lives and make them harder is the first step on

our path, Goolsby says.

The problems increase when we can't move along from one step to another. Goolsby describes the steps:

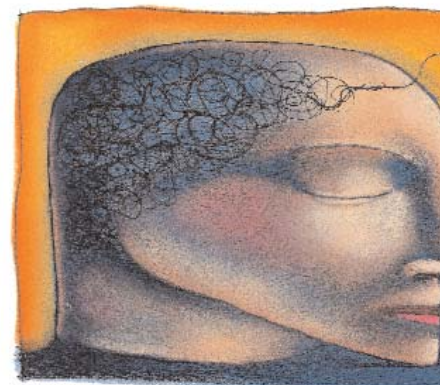
Acknowledge the reality of your situation, trying to look at the facts. Describe the situation in objective terms to yourself, as though you were describing someone else.

Express your feelings, as honestly as you can, to yourself and those around you. You need to let yourself feel your feelings, Goolsby says:

Simply experiencing them without constantly willing them to go away will actually get you through more quickly. Don't feel that you've failed if you are revisited with intense emotions again and again, she said. Your experience of loss and grief will come back at unexpected times. Anyone who has experienced the death of someone close, or divorce, or the betrayal of a friend or colleague will have experienced these kinds of flashbacks, where the sadness, shock or injustice of an event suddenly comes back as sharply as the very moment it happened.

Move into action. What can I do about this? It is what it is, Goolsby says, and your feelings are what they are. Now, it's time to act in a way that is helpful.

Don't put yourself on a timetable, although you may feel pushed to move faster along the path by yourself or others. The steps on the journey are important themselves, full of meaning and purpose. Another roadblock to successful coping is the issue of control. Enormous energy goes into attempting to exert control over





people and events over which there is no possibility of control. What you CAN control is how you react, how you relate to those around you, how you take care of yourself in other ways. It may take a long time to come to

an understanding of what you can and cannot control, Goolsby says. But eventually you will want to focus your energy on those things that are changeable and controllable.

Goolsby encourages those with myositis to examine the beliefs and fears that stall their progress. You may believe that you've done something to deserve your condition, or fear that you are being punished for something lacking in your character. Examining and dispelling these fears is easier said than done, especially if they're ingrained by family or religious beliefs, but these fears may disable you as much as the disease.

In an address to myositis patients at an Annual Conference, Goolsby quoted from *The Prophet* by Kahlil Gibran: *You shall be free indeed when days are not without a care or your nights without a want and a grief. But rather when these things girdle your life and yet you rise above them naked and unbound.* Like Gibran, Goolsby asks, Who is free? Is there anyone on earth whose days are without a care? No one with responsibilities, physical limitations or emotional ties is free: thinking so is an illusion. After the initial shock of being diagnosed with a chronic disease, most of us want to rise above it emotionally, but we sometimes get stuck, unable to find the skills to do so.

That's where professional help comes in. Depression in the elderly and chronically ill is getting more attention as it becomes more of a public health problem: Depressed adults with chronic disease are among the most frequent and costly users of

healthcare resources, according to a study by the National Institute of Mental Health. With treatment that ranges from exposure to emotional peer support like that found in a KIT member support group to professional therapy and medication more than 80 percent of cases of depression, including those related to chronic illness, can be cured, said Ira R. Katz, professor of psychiatry at the University of Pennsylvania Medical Center in Philadelphia, co-chairman of a study looking at depression in older adults. A more recent study, conducted last year at Johns Hopkins University, found that spirituality of any kind predicted victory over depression in a third of the 77 adults with rheumatoid arthritis.

Researchers found that the degree of disease activity was definitely associated with pain and depression, not surprising considering what other researchers have found. But the

Baltimore researchers also found that the one-third of the group who reported positive spiritual outlets were more likely to be happy and have a hopeful attitude towards

their illness, regardless of the amount of disease activity. Researchers concluded that spirituality may help patients with pain and disability adjust emotionally, experience more hopeful feelings and focus on the positive elements of their lives.

What to do if you or someone you love is severely depressed

If depression persists or is accompanied by references to suicide, it's important to get help immediately. An article in May's issue of the *American Family Physician* suggests that both short-term therapy and medication help depressed patients. Allan Abbas and Dave Gardner, a psy-

chotherapist and pharmacist respectively, say that in most patients with depression of mild to moderate severity, psychotherapy and antidepressants appear equally effective. In severe cases, antidepressants may provide greater relief of the severe symptoms.

They also found that psychotherapy is usually preferred by patients, and they may accept it more readily. Comparative studies have demonstrated lower dropout rates with brief psychotherapies than with drugs. This greater acceptance may be partly related to drug side effects, which are a common reason for discontinuing treatment. Adverse effects are not a factor with psychotherapy. Some studies also have shown that psychotherapy reduces the risk of relapse and recurrence after treatment has been terminated: 20 percent versus 50 percent relapse at two years for psychotherapy and use of antidepressants, respectively. The researchers

suggest that a combination of psychotherapy and antidepressant medications may have an added effect in certain patients. The writers question why the rates of psychotherapy use

have decreased while the prescribing of antidepressant medications has increased, and conclude that the effective marketing of pharmaceutical companies has made a generation of physicians well versed in the prescription of antidepressants, while perhaps unaware of the effectiveness, acceptability, and preferences for psychotherapy. If you prefer a combination of drug and psychotherapy for depression, don't be afraid to discuss both options with your doctor, particularly if you are on multiple medications.

Editor's note: Ms. Goolsby will be presenting at TMA's 2004 Annual Conference and will be available for further discussion.

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A NEW ERA OF SUN PREVENTION

As with most other aspects of myositis, how each person with myositis reacts to the sun is different. Dry, hot climates have allowed some to taper off medicines completely, while others seem better suited for cooler climates. Whatever your preference, it's important to take precautions when exposed to sunlight and heat.

Just about any doctor or specialist will recommend that everyone stay out of the sun and heat during the peak hours of the day—between 10 am and 4 pm. That's not always possible, but there are steps you can take to protect yourself from both the intense sun and heat of summertime.

Protection from the sun's rays

With the threat of skin cancer increased with sun exposure, everyone is advised to protect his or her skin. Simply using sunscreen may not be enough. If you have skin involvement with dermatomyositis (DM), it is especially important to heed these warnings. But these same tips apply to everyone with myositis as exposure to the sun can exacerbate your symptoms.

Choosing the right sunscreen

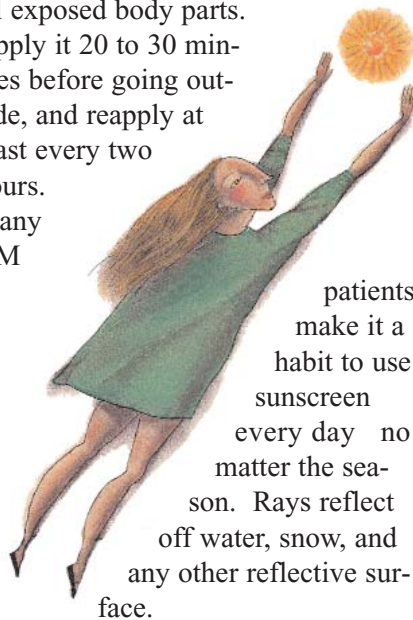
Sun lotions are an essential first step in sun protection. If you use the wrong type, though, the benefits don't apply. Be sure your sunscreen is broad spectrum, which filters out both UVA and UVB rays. The Sun Protection Factor, or SPF, refers only to UVB protection. This number tells you the level of protection, so SPF 30 blocks about 96 percent of the sun's damaging rays whereas SPF 15 blocks 92 percent. These figures stem from lab testing, and most people don't apply the same amounts of sunscreen in real-life situations.

Therefore, when a photosensitive patient uses a SPF 30 sunscreen in real life, says TMA Medical Advisor Richard Sontheimer, MD, they in

reality often get a SPF of about 15 or less, which is the minimum necessary for adequate protection for dermatomyositis patients.

Applying it correctly

Once you've chosen the right sunscreen, be sure to use it properly. An average adult needs at least one ounce of lotion to sufficiently cover all exposed body parts. Apply it 20 to 30 minutes before going outside, and reapply at least every two hours. Many DM



patients make it a habit to use sunscreen every day, no matter the season. Rays reflect off water, snow, and any other reflective surface.

Cover all parts of your body that may be exposed—including your ears, around your eyes, and lips. Dr. Sontheimer suggests stick-type sunscreens that are easier to apply to some of these areas. Zinc oxide and titanium oxide provide the most effective blockage of UVA rays, though their opaque appearance may limit more popular use.

Clothing as a sun accessory

There are many companies that now sell sun protective clothing and accessories, and Rit Dye offers Sun Guard, a detergent that washes sun protection into the clothes you already own. The UPF rating on clothes represents the ultraviolet protection factor, or the amount of the sun's rays absorbed by the fabric itself. UPF of 15 to 24 is good protection, meaning that the fabric is reducing your exposure by 15 to 24 times. A UPF of 40 to 50 is considered excellent protection.

In the absence of sun protective clothing, Dr. Sontheimer offers these pointers:

Consider weave tightness—the tighter the weave, the better the protection. When stretched, fabrics offer less effective protection.

Choose darker colored clothing, which provide more photoprotection than lighter colors.

Wear hats with brims of four inches or more to provide greater protection for your cheek, nose, neck and chin. (Some companies also offer hats with sun-protective flaps to cover your neck.)

Don't forget sunglasses, too. The American Cancer Society web site recommends wrap-around glasses for more complete protection and urges people to carefully read the labels to make sure they provide adequate UV protection.

If you can't take the heat

The sun's harmful rays aren't the only issue you confront with the coming of summer. The intense heat and humidity can also aggravate your symptoms. This doesn't mean you need to give up all outdoor activities, just be sensible about them.

Stay in the shade. Drink plenty of water or other liquids (preferably without sugar or caffeine) to replenish your body's needs. Rest, especially if you're actively working or playing outside. Wear loose-fitting, comfortable clothing. Most importantly, if you start feeling overheated, find a cool place and relax.

Enjoy your summer!

For more information on sun protection, email TMA@myositis.org or call 1-800-821-7356 to receive a copy of Relief from Dry Skin: Prevention Through Sun Protection from the Summer 2003 Outlook Extra Products Issue.

MESSAGES FROM MEMBERS



Setting the record straight

Mark Roberts recently emailed us about the article *Experts and members share recipes for health* from the Spring 2004 *OutLook* to clarify one aspect of his story. He writes:

Thank you for mentioning my story and emphasizing the dramatic effect a disciplined, specific diet has had on my life. It's the most important message I would like to get out to my fellow myositis patients. However, I have not been on prednisone for over 18 months now and have been completely med-free for a year on April 1st. I also feel it is important that others know I am MED-FREE as a direct result of my dietary, supplement, rest, exercise, and positive attitude regimen.

Myositis and working

Employment is a critical issue for patients with chronic disease, as you can see by the messages below. Please see cover story for more on this subject.

Lynne was diagnosed with polymyositis two years ago and will soon graduate from college after student teaching: What I really need is a career that will be flexible around my disease. I find waking up early in the mornings incredibly difficult. So I need a job that starts later than 7:30 am. Does anyone have any advice or suggestions? I can handle this disease, I only wish it could have come when I was 29, not 19.

It must be very frustrating for you to have accomplished your dream of an education and then not be able to use it in the career of your choice. You are fortunate that you are still in college, because every college has a Career Center. In the Career Center are computer programs that will direct you in different paths depend-

ing on your interests and abilities. I wish you every success in finding a career that is compatible with PM. Kay

You could start up a home-based business. I love the days I work from home. Stay in my jammies if I want, take a nap when I'm tired, and if I can't hold the hairdryer long enough, who cares what my hair looks like. Sometimes I'm up for a ten-hour day, and some days I can only work a couple of hours. Peggy/DM

I personally enjoy what I do and can't imagine not working. Working is what keeps me going! I can do this because I have a great career that allows me to work from home most of the time. I think the key is finding a flexible company that will work with you. Lenor/PM

I would go to the college employment office and tell them you have a challenge for them. A different place to ask for help will be similar to where my wife works Disability Resource Center. They provide support for all forms of handicappers. This is a private nonprofit organization. The name will be different but you should be able to find one locally. Greg/DM

What did you forget?

Shirley, a devoted Bulletin Board regular, introduced a bit of humor to the Boards recently, and others graciously added their own stories:

We have all been there, done that sort of thing. Thought we might take a lighter look at what meds do to all of us. I ran the dishwasher the full cycle and forgot to put the soap in.

Other examples of forgetfulness from the BB: I went to the doctor in my slippers. I told her I was having some

difficulty walking, maybe I was getting worse? She never said, but I got outside and saw slippers on my feet, not shoes...I blame the prednisone.

I forgot to put up the garage door backed right through it! My husband was still at home and when I walked back inside, all he said was having a little trouble with the door?

ANNOUNCEMENTS:

Because of the Annual Conference at the end of August, we've scheduled our fall edition of *The OutLook* for publication in early August. Look for last-minute Conference information, information on the progress of myositis research and more. The Conference proceedings will be covered in the December *OutLook* and the fall *OutLook Extra* treatment review.

We are compiling the second article on long-term care for the fall *OutLook*. If you have had any success in becoming insured for long-term care, please email tma@myositis.org. Many thanks for your help.

The Juvenile Programs section of the web site has expanded! The Parents' pages now include more on myositis, answers from experts, social and practical issues, current research and clinical trials, and news from the recent JM Conference. You'll find JM Conference presentations, speaker summaries and photos of the children from this well-attended event. Keep checking back for the latest updates and additions.



2004 Annual Conference

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