

CHAPTER 13

Living with Multiple Sclerosis: The Connection to Spirituality

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WHAT IS SPIRITUALITY?

This chapter will ask you to consider the influence of spirituality in your life and what, if anything, it has to do with multiple sclerosis (MS). Specifically, we will discuss definitions of spirituality within a health-care context and the importance of spirituality in maintaining well-being. We will present the personal spiritual journey of someone who has MS, and we'll offer tools to bring you closer to your spiritual nature.

Spirituality is a very complex concept. It's hard to study and difficult to describe. One reason for this difficulty is that nearly everyone has had unique experiences that helped form his or her own understanding of spirituality. Also, as you move through life experiencing different events, spirituality takes on different meanings. A diagnosis of MS is a major life event that can and often does change the person's view of spirituality. For example, many people have reported that the diagnosis caused them to reexamine their life values and how they relate to the world around them.

Health researchers have tried to understand the spiritual dimensions of chronic illnesses. It has been widely accepted, but not well-understood, that spirituality plays an important, positive role in maintaining health for people with MS. Some healthcare professionals have defined spirituality as a set of religious beliefs. Although religious practices certainly can be included in a definition of spirituality, this type of description may be too narrow and doesn't address other approaches to spirituality.

A religious definition of spirituality ignores that segment of the population that may hold nonreligious spiritual beliefs. Healthcare researchers have also proposed broader views of spirituality that include religious and nonreligious practices. Spirituality can be defined as "our need and capacity for

relationships to whatever or whoever gives meaning, purpose, and direction to our lives” (McCurdy 1998, p.82). The values that Elkins refers to include the belief that life is sacred, has meaning, and the realization that everyone and everything in the world is connected in some fashion. This broader definition of spirituality recognizes that no one size fits all approaches to spirituality.

THE CONNECTION BETWEEN SPIRITUALITY AND WELL-BEING

When we talk about MS and well-being, people tend to be surprised. Many people assume that once someone has a chronic illness like MS, that person can never be in a state of well-being. However, one of the common goals for people with MS is to achieve the highest standard of well-being possible within the context of MS. “Well-being,” as it is used here, does not denote a state of perfect physical or cognitive functioning. Instead, it refers to living the best and healthiest life possible with MS. People with MS report that the ability to live well comes from a combination of three factors: competent medical care, support, and spiritual practice.

Spirituality has been identified as a health-promoting activity. It has been acknowledged that it can play a major role in the way people cope with the consequences of MS. Research has shown that spirituality can have a positive impact on the quality of life, health, and life satisfaction. A study was conducted that examined two groups of people with MS. One group reported strong spiritual practices, both religious and nonreligious. The other group reported that they did not believe or engage in spiritual activities. Measurements of general health, coping, and changes in health status were taken. Those in the group who reported strong spiritual connections demonstrated the fewest changes in health status and above-average life satisfaction and coping abilities (Sullivan 2005). Many other studies have also been done examining the connection between well-being and spirituality with similar results (McNulty et al. 2004). Generally, it has become clear that spirituality is another available tool to help people cope with the challenges of living with MS.

MAUREEN’S SPIRITUAL JOURNEY WITH MS

Maureen Manley, a world class cyclist, was at the top of her game in the early 1990s. She had spent many years training and was moving up the ladder in the cycling world. In 1994, she was better prepared than she had ever been. While cycling in a race that was going so well that Maureen thought she might be on her way to another victory, Maureen suddenly lost her vision and veered off the course. She had no idea what was happening to her.

Maureen was forced to withdraw from the race. After some rest, however, her eyesight returned. Maureen continued to cycle and she also sought medical advice about her sudden loss of eyesight and some other symptoms that she had begun to experience. Finally, a diagnosis was made. It was MS. Maureen knew that MS affected physical functioning and it had already interfered with her career goals. What could she do? How could a world-class athlete cope with MS?

That was eleven years ago! Since that time, Maureen obtained her master’s degree in counseling and began working in Seattle, promoting wellness for people with MS. She has also returned to cycling.

Maureen had to redefine who she was to herself, others, and the world. She began a long spiritual journey and channeled her energies into developing the tools she needed to live well with MS, and still take part in the activities she loved. Her friendly, outgoing nature encouraged her to share her story and

new identity with others who have MS. As part of Maureen's outreach to others with MS, during her lectures she often discusses the different phases of the journey that brought her to where she is today: living well with MS. She describes five distinct stages she experienced as she came to terms with MS. They were desire, acceptance, awareness, choice, and action. During the writing of this book, Maureen discussed these five stages with Dr. Klassner. The following text is based on those discussions.

Desire

Desire is the place of beginning. You've got to want to move forward to live beyond the problems that life has presented to you, while still being challenged by those problems. The desire to do that doesn't have to be a monumental occurrence; it can simply be a stirring in your soul that sparks an interest to try something new, something different, and expand your knowledge. Ultimately, it is a desire to move forward into your life.

Acceptance

Acceptance is not a place of resignation. It is the beginning. It is the place that life springs from. To be accepting means to make peace with what is, so that a greater peace may be known.

Awareness

It's so easy to be aware of what you don't want; to resist and refuse to engage with people or ideas that don't appeal to you. It's much harder to be aware of what you do want. But, if you are going to get what you want from life, you need to ask yourself how you can become aware of what you do want. One good way to start is to ask yourself these questions: "How aware am I about what I want in life?" "What do I do to make the things I want to happen actually happen?" "What do I love?" "What do I value?" "What gives meaning and purpose to my life?" "How and where are the things that give meaning and purpose to my life?" "Am I living a life that I desire, or is my life made up of reactions to the things I don't want?"

Choice

When you become aware of what you want in life, you can look at the choices you are making that create your life. Do your choices bring you more life, love, and fulfillment? How would different choices create more of what you want for yourself and those around you? How often do you repeat old choices that have predictable outcomes because you are so used to doing things the same old way? When you slow down and take a long, clear look at your life, you can try on new ideas and attitudes, and you can develop new thoughts about people, circumstances, and viewpoints about everything that has been difficult in the past.

Action

What are the actions that you are taking to create the life you desire? Ask yourself, "Does this action bring me more joy, peace, vitality, and fulfillment?" "Is this action not harmful to anyone?" If you answer yes to these questions, then your spirit is in action creating the life you yearn to live. You are living your life intentionally.

HOW YOU CAN TAKE YOUR OWN SPIRITUAL JOURNEY

Incorporating spirituality into your daily routines as a tool to live well with MS makes sense. It involves living your life with a sense of purpose. However, it isn't always easy to get started. The following section offers a number of ways to get started incorporating spiritual practices into your life as a powerful tool to use toward living the best life possible with MS.

Developing the Right Attitude

Spirituality has often been defined as a form of optimism. People who have positive life attitudes tend to live longer than those who hold more pessimistic views about life (Dello Buono, Urciu, and DeLeo 1998). So, the first thing you need to ask yourself is this: "How can I feel more content with my life? How can I explain my having MS in a way that fits in with my view of the world?" At first, these questions may seem purely philosophical in nature. But they are not. They are extremely practical. However, to understand why they are practical, you need to decide what will help you maintain a positive attitude toward your life with MS. To get started, you can use the following worksheets to determine what would help you to establish and maintain a positive attitude.

Worksheet 27 asks you to list five things that you are sure would add more happiness to your life. The things you choose must be both realistic and attainable. For example, listing a life without MS is desirable but not attainable; so, listing it wouldn't help you maintain a positive attitude. When you've figured out five things that would make your life happier, then write short notes about how you might go about getting those things. For example, you may have always wanted to learn a foreign language, but never had the time. Now, perhaps you can make this a priority and develop a plan to make it happen. You can decide on the language you want to learn and then contact community centers in your area that may provide foreign language classes. The key is to start small so that you can make changes and see your progress.

WORKSHEET 27: LOOKING ON THE BRIGHT SIDE

Things that would make me happier

How do I do it?

- | | |
|----------|-------|
| 1. _____ | _____ |
| 2. _____ | _____ |
| 3. _____ | _____ |
| 4. _____ | _____ |
| 5. _____ | _____ |

Setting Your Goals

Making sense of your MS is a fairly difficult task. Initially, it is perfectly reasonable to feel sad and overwhelmed. In order to live well, however, you need to come to terms with the diagnosis. This may require you to set new goals or think of new ways to achieve already established goals. You have to decide how MS is going to fit into your life. You cannot change MS, but you can change your attitude and behavior toward the disease and how you think about it. You need to consider MS as you make plans to reach your desired goals. This doesn't mean giving up; on the contrary, it means looking at your goals "head-on" and using your creativity and problem-solving skills to achieve those goals.

For example, suppose you've set a goal to take a yearly trip; now you need to plan your travels with your disability in mind. You can still achieve your goal, but it's likely that you'll have to take a different path to get there. Spouses, significant others, friends, counselors, medical professionals, and others may be of help in making realistic modifications or accommodations due to your MS.

In addition to making sure that your goals are attainable, you will also have to make sure your goals are manageable. An unmanageable goal, for example, might be to achieve a fully developed sense of "spiritual awareness" or "oneness" with the world. This is certainly a commendable goal, but it may be very hard to achieve. A more manageable goal might be to read an article or book about spirituality and follow its advice on how to make some positive changes in your life. Filling out worksheet 28 below would be a good first step in setting some realistic goals for yourself.

WORKSHEET 28: SETTING REALISTIC GOALS

My immediate goals required because of MS

Goal modifications that may be

1. _____	_____
2. _____	_____
3. _____	_____
4. _____	_____
5. _____	_____

Control

Many people with MS have reported that the sense of loss of control that comes with the diagnosis is one of the hardest issues to bear and to live with. People think about control in two different ways. Some people have an *internal locus of control*, meaning they feel they can make change happen. Others have an *external locus of control*, meaning they believe things happen to them as a result of external forces. Those who have an internal locus of control are better able to handle change in their lives and make the necessary adjustments to cope with the changes.

It's true that you cannot control everything and MS certainly can cause feelings of uncertainty and unpredictability. However, you do have control over the choices you make and how you react to your circumstances. Now, take a few minutes and list several things that you feel you can control about your life. Save this list. Some time in the future, it may come in handy to remind you that you have the ability, skills, and intelligence to make things happen. When you finish making this list, you may be surprised and realize that you have more control over the events in your life than you previously thought you had.

WORKSHEET 29: THINGS I CAN CONTROL IN MY LIFE

1. _____
2. _____
3. _____
4. _____
5. _____

HOW TO GET IN TOUCH WITH YOUR SENSE OF SPIRITUALITY

Once you've established some goals and made some decisions about what is really important to you, you need to start working on achieving your new goals. There are several resources and methods that can help you along your spiritual journey.

Your "Tool Box"

The following is a list of concrete suggestions to help you get started on your road to living well with MS. Some of these may be just what you are looking for and others may not be suitable for you at all. Use the ones you think will work and enjoy the ride!

Counseling

A diagnosis of MS is difficult to hear, and even harder to get used to. It will take you some time to adjust and move on. You may want to seek individual counseling to help you start accepting the changes in your life that having MS causes. Counseling is one way to become aware of all of your concerns and feelings and to address them. You may choose to meet with a counselor about a specific issue like your relationship with your spouse since you were diagnosed, or you may want to seek help about broader issues. Finding the right person is discussed in detail in chapter 3.

Some counselors are trained in specific techniques such as problem solving. This is a highly effective way to help people deal with chronic illness. It requires you to look at your illness and to change the way

you see it to make it more tolerable. For example, you may experience a new MS symptom. Instead of immediately assuming that the disease is progressing, you can learn how to “reframe” your thoughts, and by doing that, you may realize that a new symptom is not equivalent to progression of disease. You can then take the logical step necessary to get the new treatment you may need.

Counseling can help you draw a road map and start on your journey. In the same vein, many people find that support groups, peer counselors, telephone or Web networks, and so forth are very helpful. Sharing your feelings with people who are going through similar experiences in a group or network is a good way to connect to others and the world around you. It can help you put your worries and concerns into a broader perspective when you realize there are people who understand what you are going through and are willing to help. You need to decide whether this tool is something you want to utilize.

Mind-Body Techniques

The following offers some suggestions that may help you to feel more in control of your life in small ways. Once you learn these techniques (from reading self-help books, through your therapist, etc.), you “own” them and you can call them into action at any time. One frequently used technique is called “progressive muscle relaxation.”

If you are able, this method requires you to tense and relax different parts of your body, until you achieve a complete overall sense of relaxation. You tackle each part of your body separately—tensing and then relaxing the muscles of separate parts of your body, for example, your shoulders—until you’ve accomplished what you set out to do. If you are able to tense and relax only certain muscle groups, then concentrate on those and don’t think about the areas to which you cannot apply this method.

Deep breathing is another way to get focused and promote relaxation. This is a simple technique that can be applied anywhere, anytime you think it will be of benefit. Deep breathing basically requires you to take deep breaths and hold them for progressively longer periods of time. Be aware of your physical limitations in this exercise (e.g., overexertion, spasticity issues), however; deep breathing can be used to feel calm and in control as can simply slowing your breathing.

Meditation is a very successful method for concentrating your attention totally within yourself. Meditation requires you to think only of the present moment and of your body, focusing on your breathing. You may want to use a special word or image to help you achieve a relaxed feeling. If this is something that appeals to you, practice it frequently to obtain a new sense of calm. Some people view prayer as a form of meditation.

One variation of meditation is called “guided imagery.” This works especially well when you need to be distracted from an unpleasant situation. In a guided imagery meditation, you are asked to focus on an image that you associate with peace, relaxation, and control. This is particularly effective for people who must self-administer medication by injection. The individuals who practice this technique “transport” themselves to a peaceful place while they are giving themselves the injection. The injection then becomes less difficult.

Some people may need a form of guidance to learn relaxation techniques. Hypnosis has been very helpful in such situations. Hypnosis has been used successfully by many people with MS. It allows them to reach a deep state of relaxation while gaining control over mild anxiety and pain. Hypnosis doesn’t cause you to feel out of control, rather it allows you to take control and concentrate on the things that you want to change. Of course, it’s important to check with your physician before starting any program, and this is as true for hypnosis as it is for other mind-body techniques. Contact your local area psychological or counseling association to find board-certified hypnotists. For any of the approaches discussed above, the self-help

section of a bookstore or library can be a great resource. The Internet also can provide useful guides for mind-body techniques that can teach you how to relax and thus to live more comfortably with MS.

Freeing Your Creative Energies

Some people find it quite difficult to express themselves with words. But there are many ways to express yourself. Different forms of art, writing, or music can be used as ways to explore your innermost thoughts and feelings and get in touch with your spirit. Find your unique form of self-expression and use it to make positive changes in your life. When you begin to express your creativity, you can often tap into the spiritual dimension in your life.

Conclusion

MS is a serious medical condition that changes the lives of the people who are diagnosed with it and those around them. Having MS may not be the life you imagined for yourself before your diagnosis, but you still retain the ability to take control and make the choices that will give your life purpose and meaning. For some of you, the necessity to deal with this disease sometimes results in deeper explorations of your inner life and spiritual nature than you would have undertaken if you did not have MS. Such explorations can give your life greater meaning and richness.