

Life with MS: Mastering Intimacy



MASTERING



Multiple Sclerosis

Essential Information About MS

Multiple sclerosis (MS) is a disease that attacks the central nervous system (CNS). MS usually progresses over time, but early diagnosis and treatment may help slow disease progression. It is important that people recognize the symptoms of MS as early as possible. Research has found that starting treatment after the first clinical attack suggestive of MS could slow disease progression and delay disabilities. People with MS who begin treatment after their diagnosis can also benefit from long-term, consistent treatment.

For more information about MS, visit:

<http://www.ms-gateway.ie>

Mastering MS

Mastering MS is a global awareness campaign designed to illustrate how MS can affect a person's personal relationships and work life, whether as a spouse, parent, child, friend or coworker. The campaign shows that with the right tools, people with MS can continue to lead physically and emotionally fulfilling lives. The campaign offers resources to help people with MS manage their condition, as well as to better cope with changes that may occur in their personal and professional relationships.

Dear Friends,

The physical and emotional closeness created through intimacy is an important part of every romantic relationship. It forms the special bond that a couple shares. Intimacy can be expressed both physically and emotionally. It's developed through sharing our true thoughts and feelings, as well as through sexual interactions and other loving gestures.

Every romantic relationship will experience a natural ebb and flow of intimacy over time. Having children, stress from work and other lifestyle changes can all contribute to a lull in intimacy. This is also true of coping with a chronic illness, such as MS.

Oftentimes, people feel like their lives are turned upside down after an MS diagnosis. Suddenly they may be overwhelmed with doctors appointments, therapist visits and a new medicine regime. During this time, it's especially important to do things that keep intimacy alive.

Your relationship can provide immense comfort and support when you are coping with MS. In this brochure, you will find some tips and advice to help couples facing MS keep the intimacy alive and strong. With the right steps, you can continue to enjoy a meaningful and fulfilling relationship during these challenging times.

I wish you all the best in your journey toward health and happiness.

Devin Knack

MS and Intimacy

MS can cause physical symptoms that change sexual response. It also may make some activities more difficult than before. If you are worried about being less attractive to your partner, or feeling a dip in your sex drive, you are not alone. According to a global survey, the majority (71%) of people with MS who were married or dating at the time of their diagnosis feared the disease would negatively impact their relationships.

Among those surveyed who were in relationships when they learned they had MS, about one in four respondents believed their sex life would suffer. An equal number believed they wouldn't be able to maintain intimate relationships (24%), or even that their diagnosis would end their relationships (26%).

Despite widespread concerns, the people surveyed maintained strong relationships after their diagnosis: Seven in ten are either married or dating; and more than half (55%) felt their partners were their most important source of support since their diagnosis.

“When I was first diagnosed with MS, I was afraid my husband wouldn't find me attractive anymore, and that I would become a burden. But he has been wonderful and I have found my greatest support in him. He helped me look for therapy options and he took care of the children when I couldn't do it myself.” - Lidia, Poland

Emotional Intimacy and MS

Our relationships are usually where we feel the most accepted, appreciated and understood. It is where we draw comfort and support to help us face the challenges life brings. When facing a chronic condition such as MS, maintaining this emotional bond with your partner is more important than ever.

Emotional intimacy is the closeness created through sharing your deepest thoughts and feelings. It is what enables you to truly understand each other.

An MS diagnosis can add stress to a relationship. It is likely to bring up emotions for both partners, such as sadness, fear, shock or uncertainty about the future. This is a particularly important time for both partners to verbalize what they are experiencing. When both partners express their feelings, their desires and their needs openly and honestly, emotional intimacy stays strong. Unspoken feelings can lead to misunderstandings, hurt feelings and can lead to a sense of distance in a relationship.

How to Discuss Your Feelings with Your Partner

If you want to be understood, you must help your spouse understand you. Here are some useful tips to help you talk openly about MS with your partner.

- **Be sensitive**

When talking with your partner, be considerate of your partner's feelings. It's important to talk about how you are feeling and what you are experiencing, without placing blame. Remember, your partner is also coping with the stress of MS.

- **Help your partner learn about MS**

Bring your partner some literature or refer them to an online resource to read more about MS. The more informed they are about MS, the easier it will be for them to understand your needs and be sensitive to what you are going through.

- **Write it down**

Sometimes it helps to write down our thoughts before we say them out loud. Journaling can help you sort through your feelings before you talk to your partner. Writing a letter can also be a useful way to express what's on your mind. Then ask your partner if you can read it out loud.

- **Be a good listener**

Emotional intimacy requires two types of communication: talking and listening. Your job is not only to share how you are feeling with your partner, but also to understand what they are going through so you can provide good support to them as well.

Physical Intimacy and MS

During the course of a relationship, we become familiar with our partner's body. Whether it's a back rub, a foot massage or more intimate touch, your partner probably knows what feels good to you. But as MS progresses, there may be sensory changes that affect the way you respond to touch. This doesn't mean you won't be able to continue having a fulfilling physical relationship. Staying aware of these changes and communicating them to your partner will help you take steps to keep the intimacy alive.

Having MS does not mean you have to resign yourself to a life without sex or intimacy.

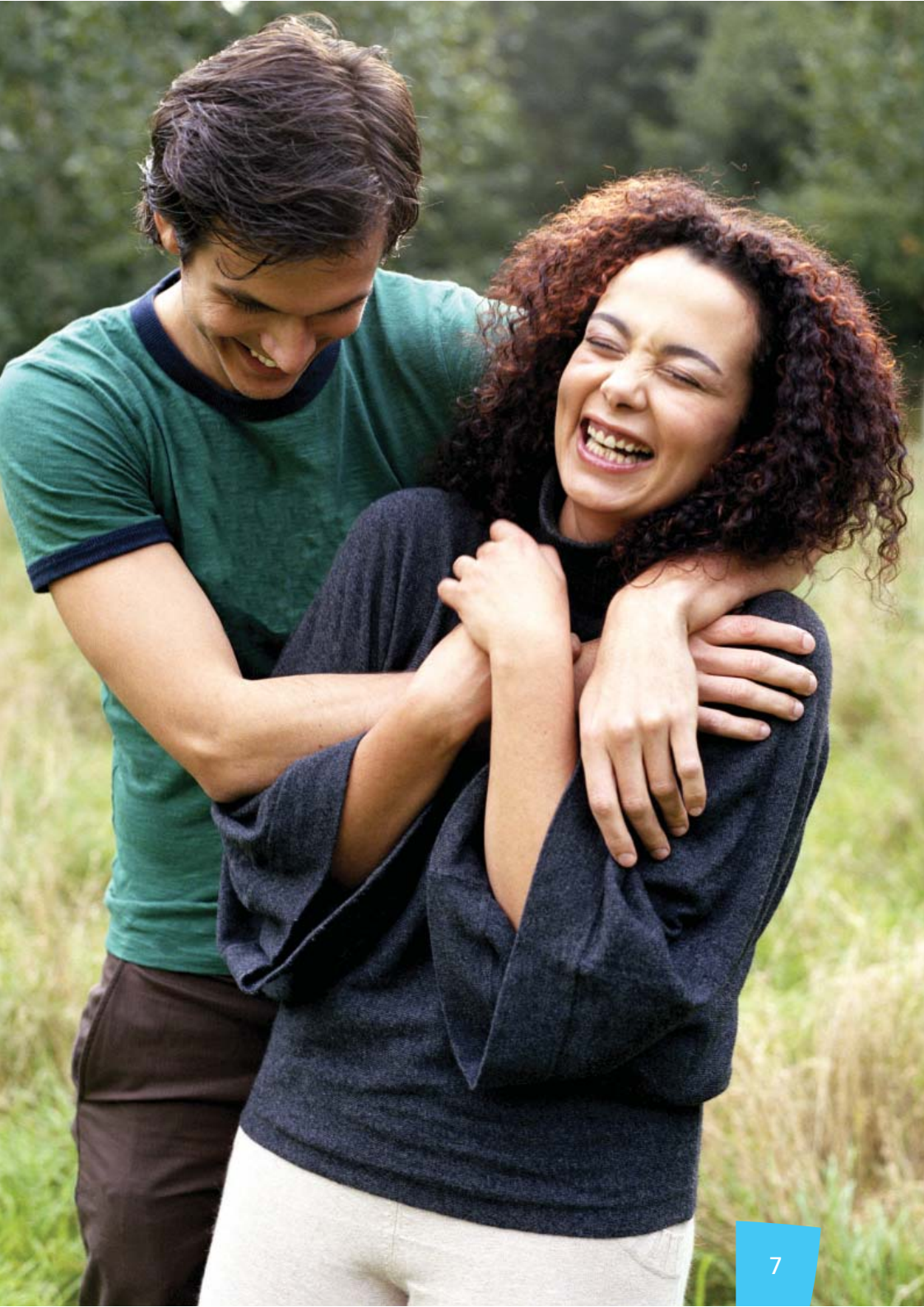
- **Talk with your partner:** Confiding in your partner deepens feelings of closeness and reduces anxiety. Have an honest conversation about the importance of intimacy in your life. While opening up a conversation about sex can be intimidating for some, it is the best way to ensure both partners' needs are met.
- **Talk with your doctor:** Communicate sexual symptoms to your doctor. Many symptoms can be managed with medication.

- **Talk with a relationship counselor:** If you need help talking about issues related to intimacy, consider seeing a relationship or marriage counselor. An expert can make sure feelings and concerns are addressed in a comfortable way. Ask your doctor for a referral to a relationship counselor near you. You also may be able to find a listing of local counselors online.
- **Examine other things that may be contributing to a lull in physical intimacy:** Most couples experience ups and downs when it comes to physical intimacy. While symptoms of MS can affect sexual response, lifestyle issues and other types of stress may also contribute to a dip in romance. A counselor or healthcare professional can help you determine what obstacles need to be addressed.

Communicating openly about her sexual symptoms with her doctor and her husband helped Maria Teresa of Spain feel less anxious about the changes she was experiencing.

“I asked my doctor whether a person’s sex life changes a bit with this condition since I am less responsive and not as keen as before. The doctor said that was normal. My husband has also read a lot of information about MS, and he understands what I am going through very well.”

- Maria Teresa, Spain



Facing Changes with Your Partner

The best way to minimize the effects of MS on your relationship is by talking openly with your partner about what you are experiencing.

- **Communicate what feels good.** When something feels good, tell your partner. Conversely, make sure to communicate when something is uncomfortable or doesn't give you pleasure. Through acknowledging how you feel, you both will be able to discover what is most enjoyable.
- **Try new things.** We often get comfortable in our routines. This can cause us to miss out on new things we might really enjoy. Share your fantasies and talk about things you would like to explore with each other. This can open the door for a new level of physical intimacy.
- **Expand your definition of the word "sex."** There are many ways to experience physical intimacy without intercourse. *"You'd be surprised how many things can create feelings of arousal or help build a sense of closeness. Try bathing together, giving your partner a massage and taking longer to kiss."*
- **Denise Knowles, relationship expert**

- **It's okay to not be in the mood.** Sometimes you may feel tired or preoccupied, and you might not feel like being sexual. This is perfectly acceptable. If you communicate how you feel, your partner will be less likely to take it personally.
- **Rediscover your own body.** After all, if you don't know what feels good to you, how will you be able to verbalize your needs and desires? It also is important to know what you are able to do for your partner.

"It's important to discuss any sensory changes you are experiencing with your partner. If you explain that your body is responding differently to certain types of touch or sensation, together you can explore new ways of being intimate that feel good to both of you. Not communicating openly about your experience can lead to hurt feelings and resentment. I've seen many people misinterpret changes in their partner's sexual response as a sign that they are no longer desired. They may even wonder if their partner is having an affair."

- Denise Knowles

Keeping the Romance Alive



- **Split the caregiving responsibility** with a relative or professional caregiver. This will give your partner the opportunity to regain the role of lover.
- **Make sure you both take personal time.** Taking time apart gives each person the opportunity to regenerate. When you have some space, you are able to bring new things to the relationship to help keep it fresh.
- **Don't forget to flirt.** *"When a relationship is new, we instinctually give our mate signals with our eyes or body language that let them know we desire them, but this often fades over time. Reviving those sexy glances or enticing gestures can build anticipation and rouse passion."* - **Denise Knowles**

Having Children



In each family, there are many factors involved in deciding when to have children. Becoming a parent is an enormous responsibility and represents a major life change for both you and your partner. Before rushing into it, find time for open discussions about your plans and expectations to make sure you are both on the same page when it comes to having kids. Possible questions to discuss are: How will taking time off from work impact your career? How will you split the responsibility of child care? Are you prepared financially?

When one parent has MS, it is important to discuss what extra support might be useful during this time. Remember, this should be an exciting and positive time for both of you. Talk to your partner about your fears and

concerns surrounding pregnancy or birth and MS. There may be simple ways to alleviate some of the stress. For example, making a list of people you can call for an extra hand around the house, such as family members or a professional caregiver. This can take pressure off both partners so they can enjoy the early days of parenthood. It can also be useful to talk with a relationship counselor to help you both express your feelings or concerns.

“Having children can be one of the most joyful and rewarding experiences of adult life. Before you start a family, there are some important things to discuss with your partner. Having children will change your relationship, impact your future and reconfigure your priorities in life. When one partner has MS, the other partner may have to take on a greater share of the responsibility as a parent. Open, honest discussions about each partner’s expectations is the best way to ensure you are both ready to take the leap.” - Denise Knowles

Discussing Children with Your Doctor

Having MS has not been shown to have a significant impact on fertility. Nor has it been associated with an increased progression of the disease. In fact, the symptoms of MS often subside during a pregnancy. However, each woman should consult with her doctor to learn more about options and personal health risks before becoming pregnant.

Genetic Risks and MS

The causes of MS are still unclear. While scientists have shown that certain genes may be linked to MS, many other factors are also thought to contribute.

It has been shown that the chances of passing MS onto your children is actually very low – only **2 to 3 percent** for a firstdegree relative.

Starting a New Relationship

If you are thinking about dating, then you will want to consider when and how you will tell the other person about your MS. While it may not be necessary to disclose your condition in the earliest stages of dating, it is important to be prepared to talk about your MS when the time is right. Remember, all relationships should be built on trust and honesty.

Gauge the timing for your conversation wisely. Discussing MS on the first date may be premature; the first few dates are an opportunity to see if you like the other person and whether you enjoy spending time together. However, waiting until you are both deeply invested in the relationship can make it more difficult for you to bring up the topic, or harder for the other person to hear.

When preparing to have the conversation, it can be helpful to consider how you would like to receive the information if you were in their shoes. Ask yourself:

- At what point would I feel it is important to have this information?
- How much information would I want to have?
- What kinds of questions would I ask?
- How would I like brought up?
- Where would I want the conversation to take place?

It can also be helpful to bring them some literature on MS, or direct them to an online resource to learn more about MS, and to dispel any myths or misconceptions they may have.

*“Most of all, remember that you are not defined by your MS. When a person truly loves you, they will see beyond any condition you may have to the wonderful person you are.” - **Denise Knowles***

*“I wasn’t in a relationship when I was first diagnosed with MS, and I worried my sickness might scare people off. When I met Paul through mutual friends, we both knew we already each had an illness – he has a neuromuscular disorder called myasthenia gravis. It’s been six years now since we’ve been together. He gives me support and motivates me to take risks and explore new things. He even helps me inject my medication where it’s hard to reach.”
- **Monique, The Netherlands***

The Importance of Managing Symptoms

While couples living with MS have different health and emotional challenges in their relationships, there are things they can do to minimize the effects.

Early treatment can delay the onset of the sexual symptoms of MS and help preserve your romantic relationship with your partner.



Contributors



Denise Knowles is a certified relationship counselor, psychosexual therapist and media specialist. She has more than 16 years of experience helping couples and families deal with different life issues, including the challenges associated with the diagnosis of a chronic illness like MS.

Resources

- www.ms-gateway.ie

All the people with MS mentioned in the “Mastering MS” brochures have been diagnosed with multiple sclerosis (MS), and are currently receiving treatment for their disease.

The testimonials represent each person’s own experience, both with the disease and any treatment history. Statements regarding MS treatment represent the individual’s own experience and perspective. Not all people receiving treatment will have the same results.

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