

Accelerated Cure Project for MS

May 2019



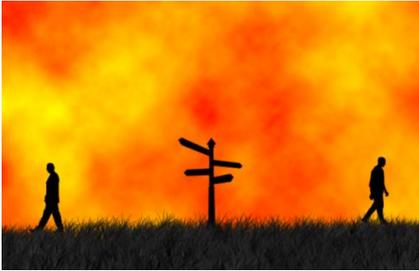
Friendships and MS – Standing the Test of Time

According to Proverbs 27:9, “A sweet friendship refreshes the soul.” Camaraderie can stave off loneliness and foster a sense of belonging and purpose in life. Having a companion can boost one’s spirits and ease stressful times, improve one’s self-confidence and sense of self-worth. Friends can help celebrate good times and offer support during bad times. A good rapport with another person can also improve one’s health and wellbeing. These relationships take on an entirely new dimension when it comes to MS. The disease can scare or push some people apart, or it can bring them closer. It can change the qualities individuals look for in relationships, and how they meet new people. Friendships are a vital and enriching part of life, but it’s not always easy to build or maintain them. Every situation, and friendship, is different. No matter what the circumstances, the effort is worthwhile.



Maintaining friendships can be difficult for anyone, but when a chronic illness like MS enters the picture, it can be especially challenging. No matter how close two people may be, some don’t know how to react, or what to say, when they learn the other has been diagnosed with MS. People living with the disease may find they are treated differently, friends may not joke around like they used to, or the news may cause some to be more distant. Individuals with MS may find conversations center around their health too frequently and they may have to work to ‘normalize’ interactions and relationships again. Once things settle down, this cycle of unhealthy interaction may repeat itself following a flare. Some friends handle the ups and downs of living with the disease better than others. It may be difficult for them to understand the changes that take place because of MS. While some are quite sudden and visible, others are more insidious and less obvious. The invisible symptoms, like fatigue or pain, are often the most difficult to understand. Fear can also undermine camaraderie. If two people are close, and one of them is diagnosed with a chronic disease like MS, the other may anticipate a loss and

withdraw because they are afraid. When a person is diagnosed with MS, their interests may also change. People living with the disease often have to adapt by changing their activities to better fit with their abilities. Individuals with MS may need to cancel plans for a variety of reasons. As a result, they may find they have less in common with their friends, who may end up calling less frequently over time.



Sometimes a friendship fades because it's easier for the person with MS. Adjusting to an MS diagnosis and the changes the disease brings often takes up a lot of bandwidth. It's easy to see how the effort to keep friendships going, or form new ones, would be too much, causing one to withdraw. Researchers in Norway conducted a [study](#) looking at the stigma that people with MS experience in social relationships. Results suggest that individuals living with the disease feel their physical performance and how they

present themselves (trying to make a good impression) is being judged in interpersonal interactions. Subjects reported being ignored or, the opposite, having people overemphasize MS during conversations. Even though the people they were interacting with were trying to be tactful, their actions were perceived as disapproving. Consequently, according to researchers, during interaction and in social relationships, people with MS experience a sense of "feeling more ill." In this world of electronic communication through social media, so much of what people are doing is broadcast for all to see. In some cases, it may be easier for individuals living with MS not to see these constant strings of interaction because they are struggling and miss that normalcy. People with MS may intentionally weed out friendships because their priorities shift. As a result of limited reserves, they may become more selective about what's of value in many aspects of their life, including friendships. In the end, there are a lot of reasons why friendships fail when one is living with a chronic illness like MS. Try not to dwell on this fact. The bottom line is having MS is a major life event and such events tend to shuffle relationships. The good news is MS also has the potential to bring people together. Many existing friendships get stronger. Friends often rally to a comrade's side after learning of their diagnosis, or to lend a helping hand when needed. Individuals with MS may find that people come into their life because of the disease, including old friends that have been out of touch for a while.



[Researchers](#) at Harvard conducted a study looking at the influence of a social network on the health and wellbeing of people with MS. The study results are based on observations of over 1,400 people with a first-degree family history of MS (having a parent, sibling or child with MS). Study participants were asked to complete an online questionnaire assessing social networks and current neurological disability. Investigators found the social network of

someone with MS can have an impact on their health. The habits of people surrounding a person with MS are very influential and can affect that individual's disability level. Data shows if friends exercise, take their medicine or keep doctor appointments, for example, these good habits positively influence the disability level of the individual with MS. Social networks with an unhealthy influence (smoking, sedentary lifestyle, not visiting doctors regularly or poor compliance with prescription medications) were strongly associated with disability. This is independent of age, race, and gender. These results shed new light on the well-known phrase "choose your friends wisely," as this practice may optimize function and wellbeing for those living with MS.

A number of strategies may help people with MS forge new friendships. One idea is to reach out to others living with the disease. These relationships are often an important part of an individual's support system. It may be easier to talk to someone walking in the same shoes about MS symptoms, and it may be easier for them to offer support in return. While social media can be tough on former friendships, it can also make new ones blossom. For individuals with limited energy, the Internet offers a wealth of social opportunities. An MS diagnosis may serve as the motivation for an individual to try doing something they've been considering for a long time, especially if it will help them associate with like-minded people. Pursuing a hobby or joining a club may help expand one's social circle. In all relationships, it's important to set healthy boundaries, for example, when activities feel overwhelming. This may be difficult at first, but saying "no" often gets easier with practice. Another universally helpful strategy in relationships is to identify and respect what's most important to the other person. Getting this information from the source (asking a friend directly) is the best way to know their feelings are being honored.

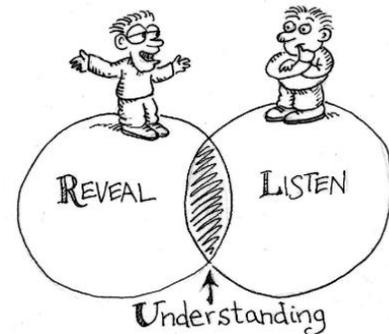
In many cases, educating friends about MS may help them better understand what a person living with the disease is experiencing. There are many ways to do this, including [printed](#) and [online/phone](#) resources. There are a few simple ways to give friends a glimpse of the inside story. One way to do this is to take them to a doctor's visit. This will allow them to hear directly about the challenges of the disease. This individual could also serve as an extra set of ears to reap the most benefit from the appointment. People with MS may also find it helpful to involve friends in their treatment plan. This may open their eyes to times their support may be needed. Attending an MS function together may also be an educational opportunity. Friends may better understand MS symptoms and the challenges they present if they hear a professional explain it or meet others living with MS. It's important to keep in mind some friends may not be ready to take a deeper dive into the experiences of living with the disease and may be afraid. Also, while educating some friends, people with MS may need to turn to others to comfort and guide them through fears of their own.



While the challenges MS imposes on an individual may cause them to distance themselves at times, rekindling friendships is certainly possible and often very meaningful. Reaching out to an estranged comrade may feel awkward. Every relationship is different, as is the most effective way people choose to communicate. As mentioned earlier, many people in today's society rely entirely on electronic methods of communication (email, texting and social media, to name a few). [Educators](#) at Des Moines University suggest that this boom in technology is preventing people from effectively "connecting" with one another. The age-old practice of sending a hand-written letter is a thoughtful way to tell a friend they are missed and may go a long way toward making them feel special. Electronic communication frequently lacks the sincerity of a good old-fashioned conversation. Picking up the phone and calling a friend may allow for a much more meaningful interaction. Dropping by and visiting a friend, or inviting them over, can also be powerful ways to begin the process of rebuilding a relationship.

On the flip side, there are a number of ways that friends can better support a comrade living with MS. As mentioned above, it's important for healthy friends to learn about MS in order to better understand what

someone living with the disease is going through. Try not to generalize in the process as there is no “normal” when it comes to MS. The disease affects each person differently, and how MS affects any one person can change over time or even fluctuate from day to day. It's important for healthy friends to meet those living with the disease where they are. Be sure to talk and ask questions to be better in touch with what a comrade with MS is experiencing. It's important to keep in mind that helping someone is not the same as valuing and respecting that person as a friend, so try not to let all interactions be about the disease and providing assistance. Listening without judgment or interruption is one of the most helpful things friends can do for each other, whether MS is involved or not. An MS diagnosis or a change in symptoms can alter the relationship between friends. It's important for both parties to be open to that change.



Having a chronic illness like MS requires one to learn to adapt, not just physically, but socially as well. Losing friends due to chronic illness is a sad, but common experience. It may feel like one more challenge that the disease presents. That may be true, but not every challenge is a bad thing in the end. Friends may be lost or gained, regardless of an MS diagnosis. It's important not to focus on the loss, rather try to focus on adapting and meeting new friends. Keep in mind friends are not all created equal and remember all friends do not have to meet all needs. Individuals with MS may find themselves relying on one friend that can help with some things and others for different needs. According to Betty White, “Friendship takes time and energy if it's going to work. You can luck into something great, but it doesn't last if you don't give it proper appreciation. Friendship can be so comfortable, but nurture it, don't take it for granted.” No matter what form of MS a person has, their degree of disability, whether they're newly diagnosed or have had the disease for a long time, support from others is key. It may take more effort, but it is worth the work to form and maintain friendships.

