According to Francis Ray, “Relationships are a never-ending work in progress.” When a chronic disease, like MS, is added to the mix, the work becomes more challenging. MS is a disease that brings with it times of crisis. Relationships can either be strained, strengthened, or both, depending on the individual case of MS, the nature of the relationship, and the personalities of those involved. A parent with MS must tend to their own needs (which may, at times, be more pressing), in addition to those of their family. The physical, cognitive and emotional challenges the disease often poses can make many aspects of raising children more difficult. While MS may make parenting harder, it doesn’t make it impossible. Our first article sheds light on parenting with MS, including some possible solutions to challenges that may arise.

Intimacy and sexuality are important components of a healthy and contented life. While MS may affect these important feelings, they do not have to disappear from the lives of couples when one or both partners have the disease. Whether one is newly diagnosed, physically disabled, young, mature, single or in a long-term relationship, partners can find satisfying ways to overcome any barriers to intimacy they may encounter and possibly find a closeness that is stronger than any they shared before. Learn more about overcoming the challenges MS may pose in romantic relationships.

Friendships are an important and enriching part of life, however it’s not always easy to build or maintain them. 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. Every situation, and friendship, is different. No matter what the circumstances, support from others is key when living with MS. Read more about friendships and MS, along with some ideas on how to form and cultivate them.

There is evidence that there is genetic risk for MS that may be inherited, and that many genes contribute to MS susceptibility. In addition, researchers believe one or more factors in the environment trigger those genetically at risk to develop MS. Our Repository Spotlight focuses on the heritable aspect of MS.
iConquerMS empowers everyone living with MS to participate in research. Our iConquerMS Spotlight welcomes family members and caregivers to participate in iConquerMS along with their loved one or care partner with MS. Whether you have MS or not, every piece of data is important and expands the pool of information that investigators can draw from. Coming soon is an exciting research opportunity that all can participate in!

We hope you enjoy this newsletter and encourage you to share it with anyone you think may be interested in learning more about MS.

Jan and Lindsey, on behalf of the Accelerated Cure Project Team

Parenting with MS – Should we tell the kids?

Being a parent is a challenging task. When MS enters the picture, this task can be even more difficult. A parent with MS must tend to their own needs (which may, at times, be more pressing), in addition to those of their family. The physical disability often caused by the disease may pose problems in many aspects of raising children. Parents with MS may find themselves too fatigued to take part in their son or daughter’s extracurricular activities. Cognitive difficulties can result in slower thinking, memory loss and difficulty multitasking (an essential skill for most parents). This can make it hard to plan meals or help with homework, among other things. Emotional difficulties may also be challenging for parents with MS. As we mentioned last month, depression is common in people living with the disease, which can make childrearing feel overwhelming. For some, the fear that children will develop MS adds to these unnerving feelings. While MS may make parenting harder, it doesn’t make it impossible. With teamwork and creativity, it’s possible to find solutions to challenges that may arise.

One of the most perplexing decisions mothers or fathers with MS must face is telling their children about their disease, if at all. One difficult aspect of this decision is determining how much information to give them. Some parents talk to their children on a “need-to-know” basis, telling them only about things they can see, such as going to the hospital for treatment, or using a new mobility aid. However, children are smart and perceptive, and can often sense problems, and react to them, before they can be seen. Their imagination may conjure up a reason for why their parent doesn’t feel well, which may be far worse than the truth. There is also a possibility if they are not told, they may find out some other way. Either scenario may cause undue stress for all concerned. Research suggests children have more difficulty adjusting when their knowledge and understanding of MS is limited, particularly young children. According to investigators, those that are unaware of their parent’s MS may experience high levels of anxiety and distress due to witnessing family tension without being aware of its source. Other studies confirm children with limited knowledge of their mother or father’s disease tend to experience more difficulties. These results illustrate the importance of open and honest communication with children about MS and its symptoms. Beginning this dialogue early on allows a child’s understanding of it to grow and develop over time. That being said, every family is unique and each person's experience of MS is
different. Individuals generally know their own circumstances and children best, and therefore are the best judges of how to proceed in this regard.

Conversations about MS may vary depending on the age of the child. Discussions with younger children may be much simpler and shorter as the big picture may be too much for them to understand all at once. The National MS Society (the Society) offers a *Keep S’myelin Activity Book* for children ages 5–12 that may be a helpful resource for this age group. Older children may need to know more about MS and its treatments so they have a better understanding of any symptoms their parents may be struggling with, or to avoid any misunderstanding from a conversation they may inadvertently overhear. The Society’s brochure entitled “*When a Parent Has MS: A Teenager’s Guide*” is intended to provide useful information and insight to teenagers or young adults. It’s important to note that each child may have a unique learning style. Some may find written materials helpful, while others may respond better to talking. Some children may feel more comfortable sharing with the parent who isn’t diagnosed with MS, or if they don’t want to speak with a parent, they may prefer sharing with a grandparent, sibling or close friend. For those who benefit most from videos, the Society’s YouTube Channel offers a number of educational movies for parents and children living with MS. Some kids benefit from accompanying their parent to a doctor’s appointment, while others find this too upsetting. No matter what their age and stage, it’s important to validate a child’s feelings, let them know they can ask questions, and allow them to talk about MS as much or as little as they need to. Youth may ask many interesting and challenging questions. The best strategy is to answer any questions they have as simply and honestly as possible. As children grow up their understanding of MS will change and they may want more detail. It’s essential to keep talking in order to provide this important information. This open communication not only reassures children that it’s okay to talk about MS, but also helps set the stage for effective communication about other important topics that may arise.

*Studies* show when families begin talking about MS (and no longer keep it a “secret”), understanding between parent and child improves and the pressure parents may feel trying not to let MS “show” is alleviated. Broaching the subject of MS for the first time with children may be daunting and finding the right moment a challenge. Many factors may affect the timing of this first conversation, such as the number of children involved, their ages and personalities, as well as the parent’s relationship to them. The nature of a parent’s MS, the timing of their diagnosis, as well as how they personally feel about the disease may also be influencing factors. In any case, the initial conversation is important as it opens up the topic for discussion and sets the tone for future conversations about MS. In cases where individuals with MS have more than one child, some feel it’s best to begin by telling them all together so they start with the same information, at the same time (and talk them individually at a later date, as needed). Others prefer not to start with a family meeting. In either case, the first conversation can be simple (it doesn’t need to cover everything about MS). The most important message is to reassure children that, while things may change, they are loved and cared for.
Children may react to the news in a variety of ways, both positive and negative. How they respond often depends on the child’s age and stage of development. It’s also important to note that children may change their reactions as they reach different stages of life. A younger child may relate everything to him or herself and worry that they might have caused their parent’s MS. Some may revert to behavior that is more appropriate for a younger child. Others may express their negative feelings by behaving badly. Older children may withdraw or become consistently angry. In extreme cases, children may display signs of mental health problems like obsessional behaviors, severe anxiety, eating disorders or substance misuse. If negative reactions occur, it’s important to remember the upheaval children feel may not be entirely due to MS, particularly during the teenage years. There are many other obstacles youth may encounter at this time in their life that can cause emotional difficulties. Parents should not automatically assume a change in their behavior or mood is the result of MS. The National MS Society’s counseling services and support groups are among the many resources available to help parents tease out the source of their child’s difficulties and help with any problems that may be beyond what can be managed at home.

A recent review of 70 studies showed children who have a parent with a chronic illness like MS struggle more with their body image, tend to display somatization (turning a mental state, like anxiety or depression, into physical symptoms), and have more difficulty relating to others (tend to withdraw more) than children with healthy parents. This research summary suggests children living with parental MS also experience significantly more emotional problems (such as anxiety, fear, and depression) and behavioral problems (for example, aggression and delinquent behavior). Investigators concluded caregiving duties and the stigma attached to a parent’s MS were sources of stress for children, especially for adolescents. This age group was stressed by these added responsibilities and had fewer social relationships. Researchers in the United Kingdom have confirmed this negative social impact on teenagers. Other investigators suggest that children of parents with MS feel a greater sense of burden and obligation than children of healthy parents, and also a greater degree of anger. A 2015 study explored the negative impact of parental MS further and concluded the emotions and distress expressed by the parent impacts adolescents’ psychological difficulties more than the severity and type of their MS.

There is also evidence that children adapt very well when they learn their mother or father has MS, and an open communication about living with the disease has a number of benefits. This can provide children a living example of how to effectively manage challenging situations in life. Researchers at Penn State University found adolescent children of parents with acquired physical disabilities like those that may occur in MS report spending more enjoyable free time with their parent. Results showed family members tend to joke with each other more, which improves relationships between all concerned. The research team also found the vast majority of adolescents didn’t mind or even enjoyed the household tasks they frequently helped their parents with. Another study suggests having a parent with MS leads to children feeling more grown up, empathetic and sensitive to the needs of others. Interestingly,
investigators in Denmark found children of MS parents receive higher grades in school and often choose a health-related education in college.

Ora Grodsky, owner of Just Works Consulting, has facilitated ACP’s Leadership Summit for the past two years. Ora’s mother was diagnosed with relapsing remitting MS in 1985, when Ora was 24 years old. Today, Ora’s mother is significantly disabled. In Ora’s words, “I don’t know that I’d heard of MS before my mother was diagnosed and I didn’t know much about it… My mother having MS has certainly made me more aware of issues of disability. It’s made me a more empathetic person because my expectations of her have to be realistic.” As mentioned in our July 2018 newsletter, Richard Cohen is a well-known journalist, television producer and bestselling author. Richard was diagnosed with MS when he was 25 years old. Richard and his wife, Meredith Vieira, openly talked about MS with their three children as they were growing up. In his words, “We were very understated, as reassuring as we could be without being dishonest. Once you create a culture of openness in the house, they’re not afraid to ask questions … it all becomes very casual and second nature.” Now that his children are grown, Richard shares that his children watch over him. “They’re just very tuned in to it … on the one hand you don’t wish it on your children, and on the other hand I really do believe that kids become better persons for growing up in a family with illness. They learn very early that life is not fair. They understand, on a very basic level, that it can be painful. They’re fully aware that they are in a position to help and I think it just becomes second nature to them… So, it’s not entirely just the ‘down’ side you’ve got to deal with. I think there’s an ‘up’ side, too.”

Parenting with MS requires a good game plan. First and foremost, it’s important for parents living with the disease to take care of themselves. It’s important to try to eat and sleep well, exercise, and adhere to their MS treatment plan to keep their disease under the best control possible. Individuals should strive to plan, pace and prioritize activities to conserve energy and avoid situations that will be over taxing. This will also serve to keep stress and anxiety to a minimum. It may be helpful to encourage family members to pitch in around the house and do age-appropriate chores. Teach kids as many household tasks and skills as possible, starting at an early age, and encourage them to be independent. Not only parents benefit from the assistance, many children enjoy helping and doing so may boost their self-esteem. It’s important for parents to be open and honest with their children about their MS and any symptoms they may be experiencing. These difficult times may serve as “teachable” moments for children to help them learn kindness and compassion for others. If mom or dad isn’t feeling well, distraction may come in handy. Pulling out a toy or game to play together may help the whole family feel better by focusing on something else. Above all else, try to maintain a sense of humor. Being a positive role model by embracing difficulties with a laugh or smile will not only help ease them, but sends a positive, powerful message to young members of the family.
In general, children have a much more difficult time understanding and coping with the less visible symptoms of MS such as fatigue, visual difficulties or sensory changes. They may misinterpret these problems (for example, mistaking a parent’s fatigue for disinterest). There are a number of creative ways to teach kids about these “hidden” symptoms. For instance, to show them how fatigue feels, ask them to walk for a few minutes with weights on both feet. To demonstrate visual distortion, have them look through a pair of eyeglasses with a smear of petroleum jelly. To give them a sense of the awkwardness that can come with sensory changes or weakness in the hands, let them try to unwrap a candy or button a shirt while wearing a pair of rubber kitchen gloves. Whether a parent has MS or not, it’s essential for them to show interest and participate in their child’s activities to the best of their ability. If disability poses a problem, take full advantage of mobility devices to stay involved (even if these aids are not needed at home). Experts suggest that children want their parent to attend their school or sport function, even if they are in a wheelchair or have a cane, as opposed to not attending at all. Research shows having a social network makes it easier for a child to cope with having a sick parent. It may be helpful to encourage children to make friends and spend time with other people so that they feel they have someone else to talk to. There is evidence that support from the healthy parent is of vital importance in this regard, as well. Once MS is a topic that is openly discussed in a household, some may find it helpful to offer their child the opportunity to talk with other children who have a parent with MS. The National MS Society offers family programs where children can connect with their peers and learn more about MS.

According to George Bernard Shaw, “The single biggest problem in communication is the illusion that it has taken place.” Open and honest dialogue about MS between parents and children is very important. Accurate information about the disease can be very reassuring to children and help them feel more secure. It can create a boundary around their fears so that overactive imaginations don’t make things more frightening than they need to be. It can provide children with a vocabulary for asking questions and help prevent children from blaming themselves unnecessarily for hardship or changes in the household. Information can reduce the need for secrecy and thereby promote an atmosphere of openness and trust within the family. Communicating openly about the challenges that MS brings to your life, and the coping strategies you are using to meet those challenges, gives children the important message that family members can work together to meet life’s challenges, whatever they may turn out to be.
**Live, Laugh and Love with MS**

Intimacy is defined as “a close, familiar, and usually affectionate or loving personal relationship with another person.” It refers to all of the ways, both emotional and physical, in which partners connect and feel close to one another. The emotional aspect of intimacy involves trust, open and honest communication, shared goals and expectations, as well as mutual respect and concern. Physical intimacy is an act of sensual contact (touching) between people, such as hugging, kissing, or having a sexual relationship. Intimacy and sexuality are important components of a healthy and contented life. While MS may affect these important feelings, they do not have to disappear from the lives of couples when one or both partners have the disease. Whether one is newly diagnosed, physically disabled, young, mature, single or in a long-term relationship, partners can find satisfying ways to overcome any barriers to intimacy they may encounter.

Generally speaking, sexual function typically changes throughout an individual’s lifespan, however MS can have a compounding negative effect. Studies show sexual dysfunction (SD) is common in people living with the disease, affecting 40-80 percent of women and 50-90 percent of men. The ways that MS can affect intimacy and sexuality can be divided into three categories: primary, secondary and tertiary SD. Sexual response and intimate feelings are mediated by the central nervous system (the brain and spinal cord). Sexual messages are communicated via nerve pathways between various sections of the brain, spinal cord and genitals throughout the response. Primary SD is caused by demyelination of these pathways. Since MS lesions may randomly occur along many of these nerves, it is not surprising that changes in sexual function are common. Women may struggle with decreased vaginal lubrication, and men may have erectile dysfunction. Examples of primary SD found in both genders may include loss of libido, changes in sensation, or difficulty achieving orgasm.

Secondary SD is caused by MS symptoms that do not directly involve nerve pathways to the reproductive system, but still have a negative impact on the sexual response. As discussed in our [March 2019 newsletter](#), fatigue is perhaps the most common symptom reported by people with MS, and it can be the most disabling. Regardless of the type or cause of fatigue, it can have a negative affect on interest in sex and lead to a reluctance to initiate lovemaking, or even an avoidance of intimacy. Muscle weakness may necessitate alterations in sexual practices. Lack of coordination may make sex and sexual expression feel clumsy, as can tremor. Another possible source of anxiety and distress is bowel and bladder dysfunction. Incontinence, or even fear of having an accident, can cause a person to avoid sex entirely. Urinary tract infections are common in MS and are sometimes aggravated by sexual activity. Pain may significantly impact sex as well as performance ability. Medications used to relieve pain may add to sleepiness or fatigue. Changes in sensation can also interfere with sexual pleasure. Spontaneity may be a problem if mobility is an issue and asking for help is often difficult. Cognitive changes can also cause a problem in this regard. Changes in mood, memory loss and depression can be frightening, frustrating and sometimes aggravating. All interfere with intimacy.
Tertiary SD results from the emotional factors related to living with MS. The disease can alter a person's perception of him or herself as an individual and have a resulting negative impact on sexual and intimate functioning. In many ways, these feelings raise the most difficult barriers to intimacy, as they can affect both the person with MS and his or her partner. Cognitive issues have the potential to undermine a person's self-esteem. Altered attention and concentration may be perceived as lack of interest or love, and may strain a couple’s relationship. Mobility devices, such as canes, wheelchairs, braces or walkers, can damage confidence and self-image. Tertiary SD may also stem from many other things, including depression, performance anxiety, or changes in family roles.

Although SD in people with MS often has a neurological cause, its evaluation is not always included in routine clinical practice. As a result, health professionals often miss important information and problems experienced by the individual with MS are left unaddressed. More often than not, the person with MS needs to bring up the subject, as most physicians don’t routinely ask about it. Assessment and treatment of these problems is complicated, as there are many factors involved. An evaluation should include a full medical history, physical examination (including a pelvic exam for women) and laboratory testing to exclude contributing conditions, such as diabetes, high cholesterol and testosterone deficiency in men. Careful assessment of the impact of medications and substance use is also important. Because SD is multifactorial, it’s important to work with one’s healthcare team to manage other MS symptoms (physical, cognitive or emotional) that may be an underlying cause. Once these factors have been addressed, individuals can work with their healthcare team to identify the most effective treatment strategy for any primary SD that may exist. There are many therapies that can help once the subject has been raised, including medications, devices and other alternatives. Not all treatments are successful for everyone, and individuals may need to work with their physician to find the right one.

As mentioned above, the majority of women with MS suffer from SD at some stage of the disease. The most commonly reported sexual problems in women are low desire, vaginal dryness, lack of sensation, difficulty with arousal, trouble reaching orgasm, and pain. Estrogen creams or suppositories may be useful for women experiencing vaginal dryness, pain or burning. Water-soluble lubricants, such as K-Y Liquid and Astroglide may also help with lubrication, as can coconut oil. Medications such as phenytoin and carbamazepine may reduce discomfort or pain. Sensory changes like numbness, which sometimes occur in the vaginal area, can make intercourse uncomfortable or interfere with orgasm. Gently rubbing the genital area with a cold pack may reduce discomfort. Increasing stimulation to the genital area with oral or manual stimulation can help overcome numbness. Kegel exercises can help with muscle weakness in the vaginal area, and also enhance vaginal lubrication, arousal and satisfaction.

As discussed in our June 2018 newsletter, SD is an issue that most men struggle with at some point in their lives, whether they have MS or not. As mentioned earlier, it is common in men with MS and may occur at any stage of the disease, even without
Erectile dysfunction (ED) is one of the most common symptoms of MS in men, affecting up to 91 percent. ED can be treated with oral medications, such as Viagra, Levitra, or Cialis. As an alternative to oral ED drugs, injectable medications such as alprostadil, papaverine, and phentolamine can often enhance erection by increasing blood flow in the penis. In cases of severe ED in which other options have failed, penile implants can help. Between 35 and 50 percent of men with MS experience problems with ejaculation. These problems may include premature, delayed or retrograde ejaculation, or not being able to ejaculate at all. Although the treatments described above can help with ED, there are no medications that help with ejaculatory dysfunction. While a man’s sexual performance may be improved by being able to maintain an erection for longer, ejaculation may remain a problem.

There are a number of strategies to help individuals struggling with secondary SD. In cases where fatigue is a problem, energy conservation is generally helpful throughout the day. These techniques can be applied to sexual issues as well. For example, time for intimacy can be prioritized for a time of day when the person with MS has the most energy. If medication side effects are suspected to be worsening fatigue, a schedule adjustment could provide relief. Dosing can be timed to allow for more energy when intimacy is planned. If weakness is a problem, fitness programs modified to work with a person’s physical limitations may be helpful. Comfort measures, such as properly placed pillows, or different positions can also be used. For bowel and bladder dysfunction, limiting fluid intake for a few hours before sexual activity, or simply padding the bed can be effective. For men, leakage of small amounts of urine can be managed by wearing a condom. Another strategy is performing intermittent self-catheterization to empty the bladder completely prior to intimacy. If pain is an issue, an extra or well-timed dose of pain medication before intimacy may provide relief and reassure one’s partner that he/she is not adding to any discomfort. As mentioned earlier, lubricants can make intercourse more comfortable. A number of sexual aids can also be used to help with sensory issues, or simply to enhance intimacy in a relationship.

Open communication is key to resolving any problems with sexuality. In many cases, the biggest problem is the inability to discuss sex and intimacy with one’s partner. Avoiding the subject can easily result in misunderstandings, resentment, or stopping sex and other intimate contact. When changes to intimacy and sexual function occur, a reciprocal communication between partners about what feels good and what doesn’t becomes crucial, particularly if intimate activities previously enjoyed together are no longer possible. Individuals who experience these problems need to allow themselves time to assess their overall situation and feel confident about communicating their difficulties to their partner. Deciding on a time and a peaceful setting to talk helps to create an atmosphere of mutual commitment. It is important to be gentle and express feelings without blame or accusation. Couples should explore this sensitive subject slowly, listen to each other carefully, and respect each other’s opinions. Writing down thoughts may help put the problems into language and start the difficult process of communicating. Couples may find confiding in each other actually deepens intimacy and may go a long way toward resolving fears.
It may also help to seek the advice of a health professional. Counseling can help individuals to explore their feelings and facilitate discussion in a respectful and professional way. Strategies for improving the situation, or adopting new ways of considering and developing sexuality, can be introduced. It is important to find an MS healthcare provider with whom one feels comfortable, preferably someone specializing in this area. Couples may find going together to be helpful, and pre-written questions may provide focus for the initial consultation. The National MS Society’s MS Navigators program provides people affected by MS with the information, resources and support they need to address challenges like SD. The Society can also refer individuals to community-based counseling services in their area.

Sexuality is an important aspect of intimacy for most couples. When MS enters the picture, the best way to hold on to feelings of intimacy is for partners to function as a team, working together to adjust and adapt while making sure that any feelings of frustration are directed at the MS rather than each other. When shared expectations and dreams are threatened, partners can team up to identify “work-arounds” that allow them to pursue their shared goals and avoid blame and guilt. When living with MS, creativity, flexibility, and a good sense of humor are the key ingredients for making many things work, including problems with intimacy. Many couples living with the disease report that facing such challenges in this way has allowed them to connect with one another in new and powerful ways, finding an intimacy that was stronger than any they shared before.

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 well-being 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 well-being 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.
Repository Spotlight – Genetic Relationships in MS

There is evidence that there is genetic risk for MS that may be inherited, and that many genes contribute to MS susceptibility. In addition, researchers believe one or more factors in the environment trigger those genetically at risk to develop MS. Identifying and understanding the genetic and environmental factors in MS may provide key information regarding the cause of the disease and ways to prevent it. Specific genes may also represent new therapeutic targets for the development of more effective MS treatments.

Researchers from 15 countries are working together to shed light on the genetics of MS, as part of the International MS Genetics Consortium (IMSGC). ACP Repository samples from subjects with MS have been made available to investigators in the IMSGC as part of this effort. While the genetic factors in MS are not as clear as they are in other diseases, significant progress has been made in identifying them. In 2007, researchers with the IMSGC discovered two genes that predispose people to developing MS. In 2016, a genome-wide analysis of over 110,000 people revealed 200 genetic variations related to MS. Work is underway to interpret these genetic variations, as well as identify the specific immune cells and proteins that may be involved. This information may lead to the development of tools to predict an individual’s risk for developing MS, as well as better diagnostic tools (for example, a blood test that would use genetic information to diagnose MS early in the disease course). Studies are also underway to better understand the interaction of genes with lifestyle and environmental factors (such as smoking or lack of sun exposure) and how this interplay affects MS risk. This knowledge may enable those with MS-affected relatives to take preventive measures against developing the disease. In addition, investigators focusing on ethnic groups with varying levels of susceptibility to MS may help to understand the clinical differences between ethnic groups, and help pinpoint genes that may be specific to a given population. The powerful collaborative effort within the IMSGC is just one of the many ways ACP Repository samples have been used to advance and accelerate research into MS.
iConquerMS™ Spotlight – A Network That Includes Everyone Living with MS

iConquerMS empowers everyone affected by MS to participate in research. Network members are invited to contribute health information, participate in clinical studies, as well as suggest topics for research in the future. This valuable input will bring researchers closer to better diagnoses, improved treatments, and one day, a cure for MS. Data from caregivers and family members are also essential to the initiative’s mission as they help investigators better understand the impact of MS on those who live as care or support partners to someone living with the disease. We will soon be inviting iConquerMS members to join a mindfulness study that hopes to recruit more than 2,000 adult subjects nationwide, including people with MS, their caregivers and family members. The knowledge gained will help those living with MS and their clinicians better understand the best dose of mindfulness to manage stress and increase wellness, with a substantial impact on care. Are you an iConquerMS member and are you interested in learning more? Email us! Do you have a spouse, parent or care partner that might be interested in participating? Encourage them to join the network and start contributing their data today! If you haven’t already done so, please consider enrolling in iConquerMS. Whether you have MS or not, every piece of data expands the pool of information that investigators can draw from.

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