

KNOW YOUR RIGHTS

A Legal Guide for People Living with Multiple Sclerosis

Carole, diagnosed in 2005



**National
Multiple Sclerosis
Society**



Center for Law in the Public Interest

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A Legal Guide for People Living with Multiple Sclerosis

Washington Appleseed
Center for Law in the Public Interest

National Multiple Sclerosis Society,
Greater Northwest Chapter

Project Team Partners:

Jim Copacino
Betti Fujikado
Todd Hofmeister
Copacino+Fujikado LLC

Patricia E. Kahn,
Attorney

Miller Nash LLP

Elizabeth Pelley
First Choice Health



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Beverly, diagnosed in 2001

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Acknowledgments, Team Members, and Partners

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Project Team & Partner Organizations

Danielle Cross,

Seattle University School of Law, Class of 2009, Summer Clerk, Miller Nash LLP

Sue Donaldson,

Executive Director, Washington Appleseed

Todd Hofmeister,

Copacino+Fujikado LLC

Patricia E. Kahn,

Attorney

Legal Assistance Task Force,

National Multiple Sclerosis Society, Greater Washington Chapter

R. Thomas Olson,

Partner, Miller Nash LLP

Elizabeth Pelley,

Vice President, Operations, First Choice Health

Nancy Pritchard,

Volunteer, National MS Society, Greater Washington Chapter

Tyler Rogers,

Seattle University School of Law, Class of 2009, Summer Clerk, Miller Nash LLP

Robert Zech,

Partner, Miller Nash LLP

Partner Organizations

Washington Appleseed is a nonpartisan, nonprofit advocacy organization dedicated to making the state of Washington a better place for its underrepresented and underserved populations. Appleseed works on issues from education and juvenile justice reform to job benefits and affordable housing. Working with volunteer attorneys, business leaders, and community experts, Appleseed identifies issues, conducts research and analysis, makes specific recommendations for reform, and advocates effective solutions. Appleseed's experienced staff organizes project teams and leverages thousands of hours of pro bono time to meet the team's objectives.

The National Multiple Sclerosis Society, Greater Northwest Chapter, serves 8,500 people with MS and more than 40,000 others affected by the disease, including families, friends, caregivers, and employers, in twenty-three counties throughout western and central Washington. The National MS Society addresses the challenges of each person affected by MS by funding cutting-edge research, driving change through advocacy, facilitating professional education, collaborating with MS organizations around the world, and providing programs and services designed to help people with MS and their families move their lives forward. For more information, please visit: www.nationalmssociety.org/Chapters/WAS.

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The information provided by the National MS Society is based on professional advice, published experience, and expert opinion. Information provided in response to questions does not constitute legal advice. The Society recommends that all readers seek their own personal legal counsel; as this is only an educational resource.



Judy, diagnosed in 1982

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Chapter 1: Employment Q & A

Am I obligated to tell my employer about my MS diagnosis?

It depends. First, under the American's with Disabilities Act (ADA) employers have different rules about asking individuals for medical information depending on the stage of employment. At the application stage, employers are prohibited from making medical inquiries or requiring medical exams. At the application stage, you are not required to tell a prospective employer about your MS unless you need an accommodation for the application process.

However, once an individual is offered a job, but before the individual starts working, employers are free to ask any medical questions they want or require any medical exams they choose as long as all new hires in the same job category are asked to do the same. This stage is called the “post offer” stage. If an employer asks you about your medical condition at this stage then you must tell the employer that you have MS.

The next stage is the employment stage. At this stage, disability-related inquiries and examinations of employees must be “job-related and consistent with business necessity.” According to the Equal Employment Opportunity Commission (EEOC), the federal agency charged with enforcing the ADA, a medical inquiry or examination is job-related and consistent with business necessity when:

- an employer has a reasonable belief, based on objective evidence, that an employee's ability to perform essential job functions will be impaired by a medical condition;
- an employer has a reasonable belief, based on objective evidence, that an employee will pose a direct threat due to a medical condition;

- an employee asks for a reasonable accommodation and the employee's disability or need for accommodation is not known or obvious;
- required in positions that affect public safety, such as police and fire fighters.

According to the EEOC, if you request an accommodation and your employer asks for your diagnosis in order to determine whether you have a disability under the ADA, you must disclose that you have MS.

What obligations does my employer have in keeping my diagnosis confidential among my co-workers?

If you choose to reveal your diagnosis to your employer for the purpose of requesting an accommodation, your employer is required under federal law to keep that information confidential. Additionally, your employer is required to keep any information obtained regarding your medical condition in a separate medical file. Employers can speak only with supervisors and managers about your work restrictions and necessary accommodations. First-aid and safety personnel may also be informed if your disability may require emergency treatment. Additionally, government officials investigating compliance with federal law may be provided with relevant information regarding your diagnosis.

What considerations should I keep in mind when I am deciding where to work?

Considerations will vary with each individual and plan of employment. Because symptoms related to MS can be unpredictable, some individuals seek out jobs that provide a certain level of flexibility and support. *Career Crossroads: Employment and MS* is a program designed by employment and MS experts to help individuals living with MS remain in the workforce. Access the six part video series and the self-study workbook at www.nationalMSSociety.org/Resources-Support/Employment

What if my symptoms affect my ability to do my job?

Employers are not permitted to consider your diagnosis when making decisions regarding your advancement or termination. Employers are, however, permitted to consider your current ability. The ADA provides that employers are not liable for employment discrimination when denial of a job to an individual with a disability is consistent with business necessity and the job in question cannot be accomplished with reasonable accommodations. The ADA does offer some solutions to barriers that may arise on the job: restructuring of the job, modification of work schedules, modification, installation of equipment or reassignment to another position.

Can I be let go from my job because of my MS?

Possibly. If you are not able to perform the essential functions of your job even with reasonable accommodations, your employer is not required to continue your employment. Additionally, your employer is not required to make accommodations for you that would pose an undue hardship for the employer. But your employer must consider all reasonable accommodations that may help you continue your employment. You cannot be terminated until all possibilities have been exhausted.

What leave of absence laws exist to protect me?

There are applicable leave of absence provisions in the ADA and in the Family and Medical Leave Act (FMLA). Under the ADA, disability leave is one of the reasonable accommodations that an employer with fifteen or more employees is required to make for its employees who have a disability. So long as your requests for leave are not unreasonable, they are likely protected under the ADA. The FMLA offers similar reasonable accommodations by allowing employees of public agencies, schools, and companies with fifty or more employees to take intermittent leave for periodic treatments or to negotiate reduced work hours.

What is the ADA?

The ADA is the “Americans with Disabilities Act,” which became a law in 1990 and was amended in 2008. The ADA is designed to ensure that people with disabilities are able to fully participate in society and be free from discrimination.

How do I know whether I qualify under the ADA?

Technically, the ADA requires that you have a physical or mental impairment that substantially limits a major life activity, such as hearing, seeing, speaking, thinking, walking, breathing, or performing manual tasks. The ADA is often interpreted broadly, however, and most people with MS qualify under the ADA.

With regard to discrimination in the workplace, the ADA applies to non-Federal employers that have fifteen or more employees. If your employer has fifteen or more employees, the protections of the ADA extend to applicants, recent hires, and employees who are impaired when they begin working or become impaired at any time during the course of their employment.

What are my rights under the ADA?

Generally, the ADA gives you the right to be free from discrimination in the workplace. That means that your employer cannot discriminate against you for having MS when making employment-related decisions, including hiring, firing, promotions, training, leave, and benefits.

For example, the ADA prohibits an employer from refusing to hire or promote an individual because he or she has been diagnosed with MS. The ADA also prohibits an employer from using screening criteria that effectively discriminate against people with disabilities and requires that any tests or screening procedures be directly related to the job duties. The ADA also gives you the right to reasonable accommodations throughout the hiring process and while performing your job.

What obligations does my employer have to accommodate me?

If you qualify under the ADA, your employer must provide you with the reasonable accommodations you request or an effective alternative, making it possible for you to perform your job. If your employer refuses to make such accommodations, your rights under the ADA may have been violated. There are limits, however, to the extent to which an employer must accommodate a person with a disability. The employer is not required to make accommodations that would impose an undue hardship on the employer or accommodations that would create a direct threat to health or safety in the workplace.

What qualifies as an undue hardship under the ADA?

The employer decides what qualifies as an undue hardship on a case-by-case basis. Employers are not required to make accommodations that are impractical, would cause unreasonable problems, or would be cost-prohibitive. If your employer has decided that a particular accommodation would create an undue hardship and you disagree, you may request that the EEOC review the decision.

What rights do I have if my place of employment has fewer than fifteen employees?

The ADA applies only to employers with fifteen or more employees. But the law in your state might offer broader protection. You may contact the state agency that oversees discrimination complaints for more information about specific state laws.

Would my employer's obligation to me vary based on the nature of my job?

Yes. Your employer is required to make reasonable accommodations so that you may perform your "essential job functions," which are typically defined

by your employer. The particular symptom you are dealing with will also affect the reasonable accommodations that your employer is obligated to offer. For instance, an employee who is responsible for reviewing files, but is experiencing vision impairment, may be provided with magnifiers or larger-print material.

What reasonable accommodations may I ask for?

Reasonable accommodations ensure that you are able to perform your job. They include but are not limited to modified working hours, changing the location where the work is performed, providing reserved parking, allowing employees to use earned or unpaid leave for treatment, and providing you with modified equipment and wheelchair accessibility. The ADA requires that you and your employer discuss and plan necessary accommodations. Several organizations can help you research reasonable accommodations, including, but not limited to the following:

- The ADA: www.ada.gov, or 1-800-514-0301, or TTY 1-800-514-0383.
- The Equal Employment Opportunity Commission: www.eeoc.gov, or 1 800 669-4000, or TTY 1-800-669-6820.
- The Job Accommodation Network: <http://askjan.org>, or 1-800-526-7234, or TTY 1-877-781-9403.

What should I do if I think my rights are being violated?

You should contact the EEOC, which is tasked with investigating discrimination under the ADA. When you contact the EEOC, you should say that you think your rights have been violated and that you would like to file a charge against your employer. You have from 180 to 300 days (depending on your state) to file a charge under the ADA, so it is important that you do not wait too long to contact the EEOC if you think your rights have been violated.

The EEOC can be contacted at 1-800-669-4000 or www.eeoc.gov.

How do I pursue a discrimination claim?

After you contact the EEOC, the EEOC will inform your employer that a charge has been filed. At that point, the claim will proceed in one of several different ways. First, the EEOC might suggest mediation, in which an impartial party will work with you and your employer to resolve your dispute. Mediations through the EEOC are free, confidential, and voluntary.

If mediation is not pursued or is not successful, the EEOC will investigate your claim to determine whether it has merit. If the EEOC finds evidence of discrimination, it will generally attempt to settle the claim. If settlement is not successful, the EEOC will either bring a lawsuit on your behalf or inform you that you can file your own lawsuit.

If the EEOC does not find evidence of discrimination, you may still file your own lawsuit by hiring a lawyer and pursuing your claim without the EEOC's help.

Resources:

ADA & People with MS, Employment Issues,
National MS Society, available at <http://www.nationalMSSociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-ADA-and-People-with-MS.pdf>

A Guide to Disability Rights, Department of Justice, available at
<http://www.ada.gov/cguide.htm>.

Americans with Disabilities Act of 1990, as amended, available at
<http://www.ada.gov/pubs/ada.htm>.

Americans with Disabilities Act:
A Guide for People with Disabilities Seeking Employment, available at
<http://www.ada.gov/workta.htm>.

The Job Accommodation Network
Employees with Multiple Sclerosis, available at
<http://askjan.org/media>

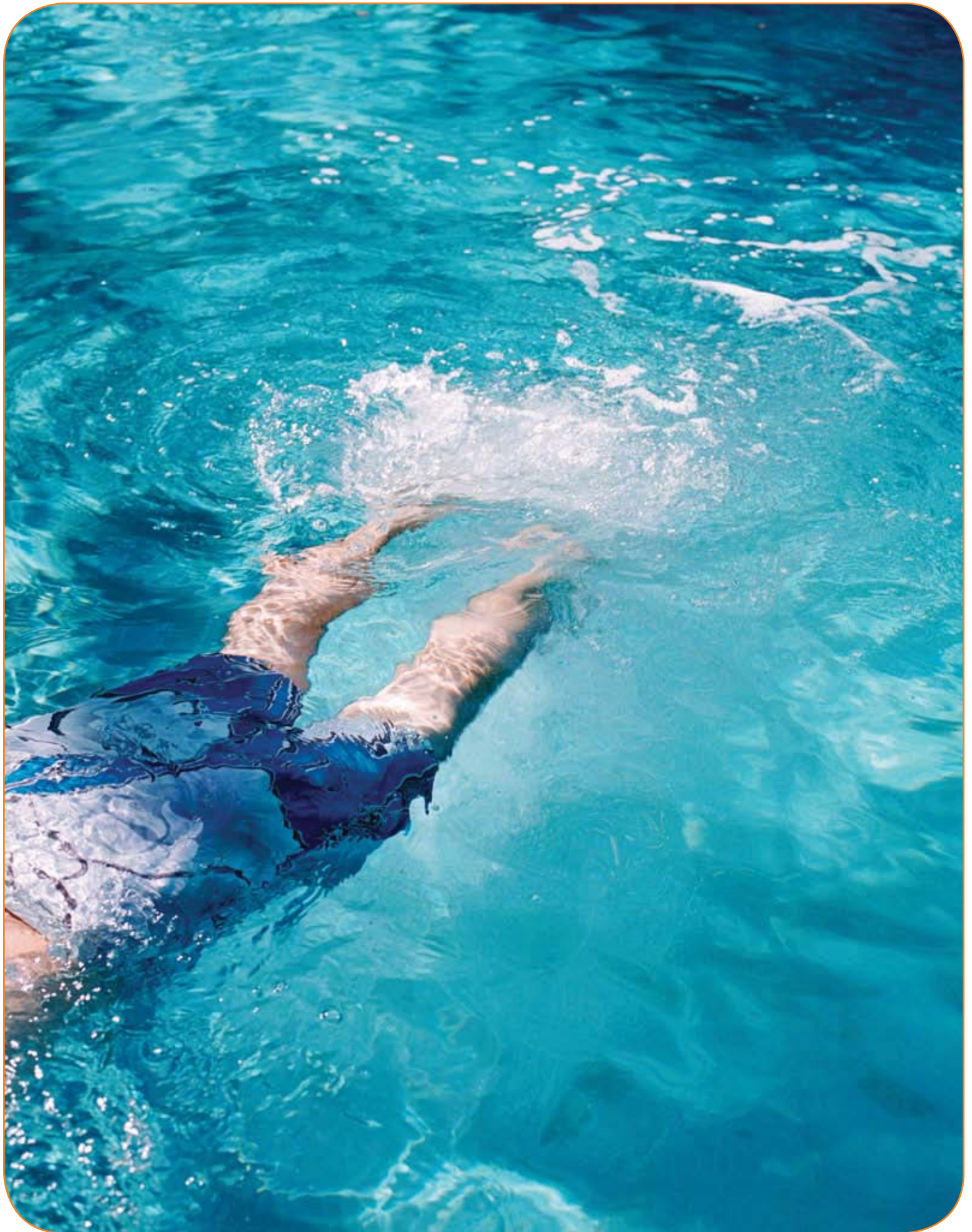
Rosalind C. Kalb, Multiple Sclerosis:
The Questions You Have, the Answers You Need, 3rd ed.

A Win-Win Approach to Reasonable Accommodations,
National MS Society, available at
<http://www.nationalMSSociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Brochure-Win-Win-Approach-to-Reasonable-Accommodations-Enhancing-Productivity-on-Your-Job.pdf>

Career Crossroads: Employment and MS (DVD),
available by order from National MS Society Chapters: 1-800-344-4867 or at
<http://www.nationalMSSociety.org/Resources-Support/Employment>

Resources: (CONTINUED)

Disclosure Decisions,
National Multiple Sclerosis Society, available at
[http://www.nationalMSSociety.org/Resources-Support/Employment/
Disclosure-Decisions](http://www.nationalMSSociety.org/Resources-Support/Employment/Disclosure-Decisions)



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Chapter 2: Insurance Q & A

What medical insurance coverage is recommended for someone who has MS?

In the past, it has been difficult for some people with MS to get individual insurance coverage. Starting January 1, 2014, the new Affordable Care Act (ACA) will allow individuals with a pre-existing condition such as MS apply for coverage through the new Health Insurance Marketplace.

Historically, federal law has prohibited the denial of pre-existing conditions for group health insurance through your employer, as long as you do not have a break of more than 63 days between policies and have at least 18 months of coverage with your prior insurer. Under the ACA, private insurance providers will also now be prohibited from denying coverage for a pre-existing condition, making it much easier for people with MS to get health insurance. It is now mandatory that all Americans, including people with MS and other disabilities, have health coverage and those without may be obligated to pay a fine.

You may already have insurance with a private insurer or a group health plan through your employer. In either case, it will be important to review your health benefits as some of the benefits offered under the new ACA rules may not apply to your existing plan. This could be the case if your plan is "grandfathered", meaning plans that were in existence on March 23, 2010 and haven't been changed in ways that substantially cut benefits or increase costs. Plans which are grandfathered by a job-based employer versus those by individual insurance providers have different restrictions. Check with your member services representative to find out more if this situation applies to you.

If you do not currently have insurance, start by reviewing your options on the Health Insurance Marketplace at www.healthcare.gov or your State's corresponding health exchange. You may qualify for lower premiums or cost-sharing reductions based on your income. In addition, you may be able to qualify for government-sponsored programs such as Medicare. Medicare is a public health insurance program for senior citizens and individuals with disabilities.

In order for a disabled individual under sixty-five to qualify for Medicare, the Social Security Administration (SSA) must have already determined that the individual was permanently disabled and the person must wait twenty-four months from the date of disability provided by the SSA. Also, individuals with MS will qualify for Medicare once they reach the age of sixty-five if they receive Social Security benefits.

Medicaid may also be an option. To qualify, you must meet certain income and asset requirements and fall under specific categories set by the federal and state governments. Medicaid is specifically designed to assist income-qualifying individuals in paying for medical care. For more information about the program or to apply for assistance, you can contact your local Medicaid office or state Department of Human Services.

For more information on Medicare and to find out whether you are eligible, you can contact the National MS Society at 1-800-344-4867 or the Center for Medicare Advocacy at <http://www.medicareadvocacy.org>. Medicare questions can be answered by lawyers who specialize in elder law and disability matters. Additionally, the National Academy of Elder Law Attorneys offers helpful information regarding Medicare: <http://www.naela.com/>.

How do I find an MS care provider?

Speak with your primary-care physicians, who should be able to refer you to an MS care provider or partner in MS care near you. In addition, the National MS Society has compiled a database of these partners throughout the United States. The database is organized by state and can be accessed at <http://www.nationalMSSociety.org/Treating-MS/Find-an-MS-Care-Provider>, or call 1-800-344-4867.

Call your member services representative or check your health plan's provider directory to ensure that the MS care provider is participating in your provider network.

individuals living with MS who may have recommendations. Your area's Society chapter can also provide you with information about treatment centers and physicians near you. Call your member services department or check your health plan's provider directory to ensure that the specialist is participating in your provider network.

Can I see an alternative-medicine provider, such as a naturopath or acupuncturist?

It depends. Increasingly, insurance providers are covering treatments from alternative-medicine providers. Because all plans and policies are different, you will need to review your individual policy to determine the scope of your coverage.

What is a preexisting condition?

A preexisting condition is a condition that was present before an individual's enrollment in a coverage plan. Under federal law, a preexisting condition is a physical or mental condition, regardless of cause, for which medical advice, diagnosis, care, or treatment was recommended or received within the six-month period ending on the enrollment date.

The ACA prohibits health insurance companies from denying coverage or charging you more because you have a pre-existing condition. The exception to this pre-existing coverage rule is for grandfathered individual health insurance plans, which are individual policies that were purchased on or before March 23, 2010. These are policies that you buy yourself, not through an employer. Grandfathered individual health insurance plans do not have to cover pre-existing conditions. More information available at: <https://www.healthcare.gov/how-does-the-health-care-law-protect-me/pre-existing-conditions/>

What is the appeals process if my insurer will not authorize recommendations made by my physician?

Some insurance companies require an authorization for services before treatment or the filling of a prescription. There are several reasons why that authorization may be denied. You should receive a written explanation as to why the treatment, prescription, or equipment was not approved. You will want to review the denial explanation or contact your insurer for an explanation. After you understand why the authorization was denied, discuss next steps with your doctor.

First, make sure that there are no errors in the authorization request. Also, make sure that your insurer had all the necessary documents available to make an informed decision. You and your doctor may also want to consider sending additional documentation to your insurer showing why the prescribed treatment, drug, or medical equipment is necessary. The National MS Society has compiled expert opinion papers and other reports describing the need for and benefit of certain therapies in the treatment of MS. You may want to consider sending those documents to your insurance company as well.

This appeals process may be effective because insurance companies will occasionally consent to authorizing medical treatment because of compelling information provided during this appeals process. Here is some general information about appeals along with appeals toolkit at the bottom of the page: <http://www.nationalMSSociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance/Appeals>

What recourse do I have if my insurance company refuses to pay for a medical procedure or a prescription?

Generally, there are two steps to the appeals process: internal appeals, whereby a patient appeals directly to his or her insurance company; and external appeals, whereby the patient appeals to an outside appeals board.

The internal appeals process is your first step. Individuals do not have access to any external appeals process until they have exhausted their internal appeals. First, review the denial, which should be documented in an

Explanation of Benefits (EOB), explaining why the procedure or prescription was denied. It is important to take action immediately and read your policy to understand what is covered. It also helps to review your plan's deductibles, co-payments, and maximums. If your insurance is through your employer, the plan administrator can be a valuable resource.

Once you are familiar with your plan and have reviewed the EOB, call the insurance company directly and speak to a representative. Explain why you think you should be covered, referring to specific provisions of the plan, if possible.

If this route is not successful, ask to speak with a supervisor. Do not be afraid to work your way up through the chain of supervisors if the individual you are speaking with is unable to help. It is extremely important to take notes during every conversation so that you can refer back to specific individuals or comments that were made in previous discussions.

If phone calls do not work, you can file a written appeal with the insurance company. Each insurance company has its own requirements for what should be included in such an appeal, but be sure to include your name and address, the name and address of your doctor, and a detailed explanation of what was denied and why you believe that denial was wrongful. In addition, you may contact your chapter of the National MS Society, which has access to expert opinion papers and other reports describing the need for and benefit of certain therapies in the treatment of MS. You may want to consider sending those resources to your insurance company as well. It is important to actively engage your doctor in the appeals process. Include any letters of support in your written complaint. Save copies of any communications you send, and call to follow up if you do not receive a response within a reasonable time.

In addition, the federal healthcare reform law assures the same level of appeal rights to everyone with private health insurance, if they buy their own policy or get coverage through a group plan provided from their job. For new health plans that you or your employer purchase after March 23, 2010, if you disagree with your plan's refusal to pay for care, the plan will have to review its decision.

If you have exhausted your internal appeal options, and are still not satisfied, you will have the right to appeal that decision to an independent reviewer who is outside of the health plan. (If you are in a health plan that you or your employer purchased before March 23, 2010, check with your state insurance department, your employer, your health plan to find out whether you have similar appeal rights.

Other Insurance Policies

Can I get long-term care insurance if I have MS?

Possibly. Many insurance companies do not offer long term-care insurance to individuals with neurological conditions such as MS. But the National MS Society has compiled a list of companies that do and do not offer long-term care insurance to individuals with MS. You can contact the National MS Society for further information: 1-800-344-4867, and press 1.

Can I get life insurance if I have MS?

Possibly. Your MS diagnosis should not automatically disqualify you from obtaining life insurance, but it might make it more difficult. You may be charged a higher premium, and may not be eligible for certain packages.

Generally speaking, there are two ways of obtaining life insurance: 1) group coverage or 2) an individual plan. Group coverage is typically provided by your employer and issued without a medical examination. Members of your family may also be eligible for group coverage through their employers that will extend to all members of your family. For more information regarding group coverage, contact the human resources department at your workplace or the individual responsible for employee insurance policies.

If group coverage is not an option, you will want to consider obtaining an individual policy. It can be helpful to contact a licensed insurance broker to help you find a policy that is right for you. You should inform the insurance broker that you have MS and make sure that the broker is willing to work on your behalf to find the best policy possible. You can contact your chapter of the National MS Society for referral information.

Can I get disability insurance if I have MS?

Unfortunately, if you are trying to obtain private commercial disability insurance after being diagnosed with MS, you will probably be turned down. But you are not completely out of luck. The Social Security Administration provides disability insurance to all eligible individuals, called SSDI. You can review the SSDI portion of this pamphlet for more information on SSDI.

If I already have disability insurance, can I qualify for benefits under my policy because of my MS?

Possibly. You will want to review your policy carefully and thoroughly so that you know exactly what you will need to show in order to qualify for benefits. For example, how does your insurer define “disability”? Does your insurer require that you stop working before you apply for benefits? Because policies vary, it is hard to know exactly what you will need to prove or show in order to qualify, but there are some things that everyone can do to make the process easier.

For example, track your symptoms. It may be helpful to keep a journal chronicling your symptoms and how your MS is affecting your ability to work. It also helps to be specific. You will be required to show that you are entitled to the benefits under your policy. Your doctor will be a big part of this process. You and your doctor will want to decide how you will demonstrate that your MS renders you unable to perform your required job duties.

In addition, the National MS Society has a significant number of resources to help individuals with MS navigate through the disability insurance process. You can contact your local chapter for support or visit the following site for more information:

<http://www.nationalMSSociety.org/Resources-Support/Insurance-and-Financial-Information/Social-Security-Disability>

What if my disability insurance provider denies my claim?

The National MS Society suggests that you contact a lawyer if your initial claim is denied. Be aware that your insurance provider may have a deadline for you to file an appeal.

What is the difference between short and long-term disability insurance?

Short-term disability insurance is a benefit that provides partial income replacement while a policyholder is unable to work due to a disabling condition for a period of time (typically a few weeks to several months). Short-term disability insurance can also be used for those individuals waiting to go on long-term disability insurance.

Long-term disability insurance covers individuals who have been disabled for six months or more and are not expected to return to work. This type of insurance provides partial income replacement to offset the income that an individual can no longer earn.

It is important that you review your disability insurance coverage and understand which of the two types of coverage you have. This is important because the short and long-term disability insurance will differ in terms of how long the benefits will last.

If I am offered the opportunity to purchase supplemental insurance, should I?

That depends. There are several different types of supplemental insurance, and depending on which type you are being offered, there are different considerations to take into account.

The three basic types of supplemental insurance are disease-specific insurance, accident or dismemberment insurance, and hospital indemnity insurance. Consider how likely it is that you would use the insurance benefits. Also determine whether, without the supplemental insurance coverage, you would have adequate funds to cover the expenses that your

health insurance would not otherwise cover. Additionally, consider whether you can afford the supplemental insurance. Finally, speak with a lawyer to make an informed decision about whether supplemental insurance is necessary.

Resources:

Center for Medicare Advocacy Inc available at
<http://www.medicareadvocacy.org>.

Disability Insurance, National MS Society, available at
<http://www.nationalMSSociety.org/Resources-Support/Insurance-and-Financial-Information/Social-Security-Disability>

Health Insurance Marketplace, available at
<https://www.healthcare.gov>

Health Insurance, National MS Society, available at
<http://www.nationalMSSociety.org/Resources-Support/Insurance-and-Financial-Information/Health-Insurance>

Life and Long Term Care Insurance, National MS Society, available at
<http://www.nationalMSSociety.org/Resources-Support/Insurance-and-Financial-Information/Life-and-Long-Term-Care-Insurance>



Kim, diagnosed in 2000

National MS Society & Washington Appleseed

Chapter 3: Family Law Q&A

What issues fall under family law?

Family law encompasses family related issues and domestic relations, including marriage, divorce, child custody, child support, and adoption. In addition, family law can also include end-of-life care and trust and estate planning.

What resources are available to help with family-law issues?

Laws regarding family law are state-specific. Therefore, you will need to find a resource that discusses the state laws where you reside. Some websites offer a great starting point for research and can also direct you to more specific information regarding state law. For example, <http://family.findlaw.com> offers basic information regarding family law issues and also provides some information about state specific laws.

MS & Divorce

Will my MS diagnosis affect child custody?

Unless certain limiting factors are present, most states do not award custody to a single parent. Rather, both parents share the responsibility of parenting and share parenting time. The best interest of the child is the primary factor in determining the allocation of parental responsibilities and a time-sharing schedule regardless of whether a state awards custody to a single parent or to both parents.

Determination of the best interests of the child, evaluates all the factors affecting the welfare and interests of the child. The hierarchy of factors considered may vary by state, but most states do consider the physical and

mental health of the parents before determining custody. Furthermore, the Americans with Disabilities (ADA), which forbids discrimination against people with disabilities, does not apply to child-custody determinations. However, a diagnosis of MS does not, in itself, mean a parent cannot retain custody.

Your MS diagnosis is likely to become an issue if your symptoms adversely affect a child's or children's interest and welfare. That determination is made on a case-by-case basis after considering the specific facts presented. If your symptoms do not affect your ability to perform the parental functions necessary for the care and growth of your child or children, your diagnosis will probably not be detrimental to obtaining parenting rights.

Will my MS diagnosis affect my visitation rights?

As with custody, a court may consider your physical health when determining or modifying visitation or time-sharing schedules. Generally, your parenting time will be affected only if your symptoms are such that you are unable to care for your child or children.

Will my MS diagnosis affect child support?

A diagnosis of MS does not annul one's responsibility to pay child support. The amount of child support you will be required to pay depends on your income. If your state considers your disability benefits as income, and you are receiving disability benefits, then those benefits will become part of the equation when the court determines your child support contribution.

Will my MS diagnosis affect alimony or maintenance?

If you are receiving disability benefits because of your MS, those benefits may affect alimony or maintenance. Some states will take into account any disability benefits you are receiving when determining your ability to pay alimony or maintenance. Some states also consider the physical condition of the spouse seeking alimony or maintenance. Because the award of alimony or maintenance is typically within the discretion of the court, and many

factors are considered, it is hard to know how and to what extent your MS diagnosis will factor into the ultimate decision.

Estate & Healthcare Planning

What is a power of attorney? Do I need one?

A power of attorney is an authorization for another person or institution to act on your behalf. Powers of attorney can be very useful tools for people with MS because they empower a trusted family member, friend, or institution to make important legal and medical decisions on your behalf if you become incapacitated. There are a few different ways to distinguish powers of attorney. One has to do with when they are effective, when they come into force, and when they end. Another has to do with what tasks the agent can do for you under the power of attorney.

A “nondurable” power of attorney is one that expires when the person who grants it becomes incapacitated. For that reason, nondurable powers of attorney are not recommended for people who have potentially incapacitating medical conditions, since they will become ineffective when they are needed most.

A “durable” power of attorney is probably the most important power of attorney for individuals with MS. A durable power of attorney empowers someone else to act on your behalf at any point until it is revoked or no longer needed. This can be extremely important if you become mentally or physically incapacitated and need a trusted friend or family member to manage your healthcare and financial affairs. Durable powers of attorney are often made effective immediately, so the individual you designate as the decision-maker is empowered to act without having to prove that you are incapacitated.

Finally, a “springing” power of attorney is one that becomes effective upon the happening of some future event. Springing powers of attorney

are generally not adequate for healthcare decisions, however, because of restrictions placed on them by the Health Insurance Portability and Accountability Act, or HIPAA, which was enacted in 1996. For that reason, an immediately effective durable power of attorney may be a better choice for many people with MS.

As to what agents can do, there are in general two kinds of powers of attorney: one for financial and personal business and one for healthcare and medical decision-making.

The general financial power of attorney authorizes an agent to handle your assets: collect your income, use your money and income to pay your bills, invest and reinvest your funds, make insurance claims, file tax returns and collect tax refunds, collect money from others, and do all the other things required for your care in modern society. Although relatively simple as legal documents go, powers of attorney must be drafted with care because what is or is not included can be quite significant. If a problem is discovered after you are incapacitated, the cost of correcting the problem can be high.

You can also have a durable power of attorney for healthcare. That document would function as a durable power of attorney but would be limited to healthcare decisions. For example, your trusted friend or family member would be able to make decisions related to your healthcare once you are no longer able make those decisions yourself, but he or she could not make other legal decisions on your behalf.

With any power of attorney, it is extremely important that you discuss your wishes with a trusted friend or family member early, should you later become incapacitated. This should be a collaborative process. It can be difficult to discuss such sensitive issues, but it is crucial that you plan early and are willing to communicate because it can save valuable time, energy, and money in the future.

What is a do-not-resuscitate order (DNR)? Do I need one?

A DNR is a type of advance healthcare directive, which means that it indicates what you want to have done in certain medical emergencies. Specifically, a DNR states that you would not like to have CPR performed on you if your heart stops or if you stop breathing. The procedure for drafting and enforcing a DNR varies slightly from state to state, but your physician or lawyer should be able to discuss the process with you. Whether to have a DNR is a personal choice and one that you should discuss with your physician and your loved ones.

What is a will? Do I need one?

A will is a legal document that describes what will be done with your personal assets when you pass away. Wills can be very important documents because they allow an individual to control what happens to his or her assets after death. But a will does not control most jointly owned property if the other owner survives, and it does not usually control life insurance, annuities, retirement, survivor and dependent benefits, or IRAs. Wills do provide structure for the deceased's friends and relatives and can ease the often emotionally and financially difficult task of dividing assets after the death of a loved one. A will, unlike a trust, must go through the court system after an individual's death. That process is called "probate." Depending on the state you live in, there may be fees and taxes associated with the probate process that can reduce the assets in an individual's estate.

What is a trust? Do I need one?

Like a will, a trust is a way to control the transfer of assets in an individual's estate. Trusts can also be useful tools to manage your assets while you are still living. Unlike a will, a trust establishes a separate entity to which assets can be transferred either before or after an individual passes away. A trust set up by a living individual is called a "living trust," while a trust that comes into being as the result of a provision in a will is called a "testamentary trust."

Either kind of trust may be managed by a person of your choosing (often a close, trusted, family member or friend) who distributes the assets according to a set of directions that you create when the trust is established. This person is known as the “trustee.” If you establish a living trust, you may also choose to become the trustee and manage the trust yourself. If you choose to manage your own living trust, it is important to have a backup trustee in case you become incapacitated. Because of the unpredictable nature of MS, you should include a mechanism to automatically empower the backup trustee if you become incapacitated.

In addition to avoiding the probate process, trusts can be particularly useful when transferring money to minors because you can direct that the money be managed by a trusted adult, when the child may not have the sophistication and experience to handle a significant amount of wealth.

If you are considering a will or a trust, it is strongly recommended that you consult a lawyer to discuss your options.

What is a special needs trust?

A special needs trust is a trust established for a person with a disability who is or may be reliant on government benefits. The trust allows the individual to have assets and still maintain eligibility for government benefits such as Medicaid, SSI and housing assistance.

There are two types of special needs trusts. A self-settled trust is available to persons under 65 with a disability and allows them to transfer assets to a trust without incurring a period of ineligibility for benefits. This is often used for someone who has received an inheritance or a personal injury/medical malpractice settlement. The second type of special needs trust is a third party trust, which is usually established by parents for a child with a disability, allowing the child to inherit but still receive all government benefits to which the child is entitled. Both types of trusts can be very useful in a number of situations.

What is an advance healthcare directive? Do I need one?

An advance healthcare directive is a document that informs your doctor and your family of the medical treatment you would like to receive if you become unable to make decisions about your healthcare. Advance healthcare directives can be crucial documents for individuals with MS because they allow you to make important decisions that will protect your wishes once you are no longer able to direct your own care.

How do adult protective services work?

Adult protective services are programs designed to protect elderly or adults with disabilities from abuse or neglect. Adult protective services are typically administered by a state agency, and the programs vary from state to state. Your lawyer or your National MS Society chapter can help you learn about the program in your state and help you determine if it meets your needs.

How do I go about getting the documents and services described above?

A good family law lawyer is an excellent resource. A lawyer can help you understand which documents are the most important for you, help you organize your assets, draft the necessary documents, and make certain that those documents meet the requirements of your state to be deemed legally binding and effective. A lawyer can also give you important legal advice regarding your rights and options under the law.

Checklist of documents to have in order before meeting with a lawyer:

Many estate planners and elder and disability planners will provide you with a checklist of documents to bring to your first meeting.

At a minimum, you should try to bring:

- A general listing of your assets;
- A list of any individuals whom you are supporting financially;
- A list of immediate family members;
- Copies of any existing documents that you have (will, trusts, advance directives, powers of attorney, DNRs, etc.);
- Information about your sources of income, including disability, retirement and survivor benefits;
- Information about each insurance policy you have (life, health, long-term care, disability);
- A list of family members and others who are involved in your care or estate plan; and
- Any other documents you deem helpful to give your lawyer

Resources:

FindLaw,
<http://family.findlaw.com>.



Tahirah, diagnosed in 2003



Beverly, diagnosed in 2001

National MS Society & Washington Appleseed

Chapter 4: Social Security Disability Insurance Q&A

What is SSDI?

“SSDI” stands for “Social Security Disability Insurance.” SSDI is an income-support program that provides income to qualifying individuals with disabilities. Additionally, an individual is eligible for Medicare 24 months after receiving their first SSDI monthly benefit. SSDI is funded through Social Security taxes. Certain family members of a disabled worker may also qualify to receive payments through SSDI.

Who qualifies for SSDI?

To qualify for SSDI, you must have worked in a job or jobs covered by Social Security, and you must have a medical condition that meets the definition of “disability” of the Social Security Administration (SSA). If you do not qualify for SSDI, it is possible that you would qualify for Supplemental Security Income (SSI). More information on SSI is available at the end of this section.

To determine whether your employer is covered by Social Security, look at your pay stub to see whether there is a Social Security withholding or ask your HR manager. Most private employers are covered by Social Security, but many county or state employers are not. To qualify for SSDI, adults normally must have worked in covered employment five out of the last ten years before the onset of disability and a total of ten years in their lifetime. This requirement is scaled back for younger workers.

To determine whether your condition meets the definition of “disability,” the SSA will use a five-step evaluation process that considers your current work activity, if any, along with your medical condition and how it affects your ability to work. More information about the determination process can be found at <http://www.ssa.gov/pubs/EN-05-10029.pdf>. No disability is covered unless it has lasted or is expected to last at least twelve consecutive months,

or is expected to result in death. Your physician must provide evidence of the diagnosis, test results and examination. However, the presence of a disability is determined by Social Security and may require evaluation by physicians hired by Social Security.

Benefits usually continue until you are able to work again on a regular basis. If you are not able to return to work the disability benefits will run until retirement age and then roll over into Social Security retirement benefits.

At such time as you may be able to try working, a number of special rules, called “work incentives,” provide continued benefits and healthcare coverage to help you make the transition back to work.

Certain family members may also qualify for benefits under your SSDI. They include:

- A spouse who is sixty-two years old or older;
- A spouse who is caring for a child if the child is disabled or sixteen years old or younger;
- An unmarried child who is under eighteen years old. If the child is in elementary or secondary education full-time, a child qualifies so long as he or she is under nineteen years old;
- An unmarried disabled child who is eighteen years old or older. The disability must have started before the age of twenty-two, and the disability must meet the SSA’s definition of “disability” for adults. Such a child can also receive benefits if one of his or her parents is retired, on Social Security, or deceased.

How much income can I earn and still receive SSDI?

If you are still working but not earning very much money, you might still qualify for disability benefits. In 2013, the maximum amount an employee can earn and still qualify for SSDI is \$1040 per month (this amount is \$1,740 for someone who is legally blind).

SSA uses this maximum income cap, called “substantial gainful activity” (SGA), to assess the impact of your MS symptoms on your ability to work. If you earn more than this amount, SSA will normally assume you are able to work and deny your application. SSA increases the SGA income cap annually. SGA applies only to income from work. For SSDI purposes, SSA does not count income you get from other sources, such as interest or investments. There is no limit on the assets you can own.

SSA has established a variety of “work incentive” programs that can help you keep your cash benefits and Medicare while you test your ability to work. Based on your participation in these programs, you can earn additional income and temporarily continue to receive SSDI benefits. For information, visit: www.socialsecurity.gov/pubs/10095.html.

What amount of money would I receive monthly under SSDI?

The amount of your monthly SSDI payment is based on your average lifetime earnings, which means that it will be a different amount for different people. You can set up an account at <http://www.ssa.gov/myaccount/> to check your estimated benefit amount and have access to other pertinent information. Alternatively, call the SSA toll-free at 1-800-772-1213, or TTY at 1-800-325-0778 to request a statement.

How do I file for SSDI?

There are a number of ways you can file for SSDI. You can file online, by telephone, or in person. To access the application over the Internet, visit www.socialsecurity.gov. To apply via telephone or in person, you will need to call the Social Security office to schedule an appointment (1 800 772 1213, or TTY at 1 800 325 0778). The interview lasts about one hour.

How do I proceed through the SSDI process?

You should begin the SSDI process as soon as possible after becoming disabled. It will take some time for you and your doctor to gather the information for your application, and the SSA typically takes three to five months to review an application once it is submitted. The following information will help you understand the process and what you need to be doing as you apply for SSDI benefits. If you choose to apply for SSDI over the Internet, the starter kit can be downloaded for free at http://www.socialsecurity.gov/disability/disability_starter_kits.htm.

1. Familiarize yourself with the process and determine whether you would like to hire a lawyer.

Download the SSA Starter Kit at http://www.socialsecurity.gov/disability/disability_starter_kits_adult_eng.htm to help you understand what to expect. The full pdf is available at the bottom of the page.

Once you have reviewed those documents, you will need to determine whether you would like to hire a lawyer or other representative to assist you throughout the process. A lawyer is not required, but many people find that it is helpful to have an experienced advocate as they move through the application or appeals process.

2. Gather the necessary information and submit your application.

There are three ways to apply for disability benefits:

- through the SSA website;
- through a phone interview with an SSA official; or
- by visiting your local Social Security office.

No matter which application method you choose, be prepared to include detailed information about your work history and the nature of your disability. Spend some time gathering documents and information before you apply. You can find a checklist of necessary documents in the Starter Kit on the SSA website. Gathering the necessary information can be very time-consuming, but very important and helpful to your cause.

People with MS will benefit from having an MS neurologist involved in the submission of materials to the SSA. The doctor will be able to verify your condition and produce the detailed medical records that will be required with your application.

If you choose to apply through the SSA website, you will need to complete an application for Social Security benefits and an adult disability report. Both forms can be found at www.ssa.gov/applyfordisability. If you do not have Internet access or prefer assistance from the SSA while completing the application, you can call or visit your local Social Security office. You can find your local office with the office locator tool at <http://secure.ssa.gov/ICON/main.jsp>

Finally, you should keep records of your condition and your dealings with the SSA throughout the application and appeals process. Some applicants will be asked for additional information after the process has begun, and it is very helpful to have a record of any appointments or health episodes that have occurred during the SSDI process.

3. Wait to hear whether your application has been approved.

The SSA will review your application using a five-step evaluation process to decide whether you are eligible for benefits. The process considers your current work activity, if any, along with your medical condition and how it affects your ability to work. Because the process requires extensive review of your medical and employment history, it typically takes the SSA from three to five months to approve or reject your application.

If your application is approved, you will begin receiving benefits immediately, so long as at least five full months have passed since your disability began. Benefits are not available during the first five months after a disability begins to ensure that benefits are distributed only to those with long-term disabilities.

4. If your application is rejected, decide whether to appeal.

Ideally, your application will be approved and an appeal will not be necessary. If your application is denied, however, you are allowed to appeal the decision. If you choose to appeal, you must notify the SSA within 60 days of receiving the letter denying benefits.

The appeals process can be lengthy, and you should consider whether you would benefit from the assistance of a lawyer before you begin. If you choose to appeal and do not wish to hire a lawyer, you should ask for assistance from your local Social Security office and National MS Society chapter. Once you file an appeal, there are five levels of possible appeals. Your application could be approved or rejected at any of the five levels. You should be aware, however, that you will not receive any SSDI benefits during the appeals process if you were not initially approved.

Is it common for SSDI to be denied?

Statistically speaking, you are more likely than not to be denied SSDI the first time you apply. SSA statistics detailing denial rates in 2012 indicated that 67% of all first-time applicants were denied. The statistics also showed, however, that 49% of all SSDI applications were ultimately approved.

What is the appeals process?

The appeals process can be lengthy and you should consider whether you would benefit from the assistance of a lawyer before you begin. It is recommended that you obtain an experienced Social Security lawyer. Please

be aware that the SSA must approve all lawyer fees and that the standard fee agreement that the SSA approves is a contingency fee agreement in which the lawyer does not get paid unless you are awarded benefits. The fee that the SSA normally approves is only paid from past-due benefits that you may be awarded. SSA normally approves a fee of 25% of the past-due benefits you may be awarded, with a cap on fees of \$6,000.00 through the Administrative Law Judge (ALJ) hearing. Furthermore, it is standard practice for lawyers to provide free consultations on these claims. Therefore, virtually anyone can afford a lawyer. If you choose to appeal and do not wish to hire a lawyer, you should ask for assistance from your local Social Security office. Once you file an appeal, there are five levels of possible appeals (in most states). Your application could be approved or rejected at any of the five levels. You should be aware, however, that you will not receive any SSDI benefits during the appeals process if you were not initially approved.

	Appeals Process	Next Step
1	Application	If your application is denied, you may request a reconsideration within sixty days.
2	Reconsideration (not in all states)	If denied, you may request a hearing before an administrative law judge.
3	Hearing	If denied, you may appeal the decision to the Social Security Appeals Council.
4	Social Security Appeals Council	If you are denied a hearing or if your application is denied following a hearing, you may file suit in federal district court.
5	Federal District Court	The federal district court is your final level of appeal.

Appeals Process Step 1:

What happens if my application for SSDI is denied?

If you get a letter indicating that you did not qualify for SSDI, you have the right to appeal the decision. You will have sixty days from the day you received the letter to request, in writing, a reconsideration. A reconsideration is a complete review of your application by an individual who did not take part in the initial review process. All evidence presented when you first applied for SSDI will be considered, along with any new evidence.

Visit this site to request reconsideration:

<https://secure.ssa.gov/apps6z/iAppeals/ap001.jsp>

Appeals Process Step 2:

What if my reconsideration is denied?

As noted above, this step is not available in all states. If you are again denied SSDI after the reconsideration process, you may appeal that decision and ask for a hearing before an administrative law judge (ALJ).

Visit the same site as above to request a hearing:

<https://secure.ssa.gov/apps6z/iAppeals/ap001.jsp>

Appeals Process Step 3:

What will happen at the hearing?

You may be asked for more information regarding your case, and you are also permitted to present new evidence. New evidence includes any relevant changes or developments in your condition that the ALJ should be aware of. If there have been no changes or developments in your condition, you need not present anything new. At the hearing, the judge will place you and any witnesses under oath and ask you questions regarding your disability. This will usually include questions about your age, education and work history, as well as your medical conditions, limitations on activities and how you spend a typical day. Most hearings also include a vocational expert called by the ALJ and may also include a medical expert called by the ALJ. You should consider obtaining statements from family, friends or coworkers

and bringing one of them as a witness with personal knowledge of your condition. The judge is unlikely to make a decision immediately; instead, the decision will be sent to you along with a letter.

If you are denied after the hearing, you may appeal that decision to the Social Security Appeals Council. The Appeals Council is not required to take your case, and may deny it if the Council thinks the ALJ decided your case correctly. If the Appeals Council accepts your case, it will review your case and make a new determination regarding your eligibility. You will be notified by mail of any decisions.

Appeals Process Step 4:

What if the Appeals Council denies my claim or refuses to hear my case?

Another avenue to pursue if the Social Security Appeals Council also denies your claim is to review your case. You can appeal an Appeals Council decision by filing a lawsuit in federal district court. Any correspondence you receive from the Appeals Council regarding a denial of your claim will include information about this process. But you may want to consider filing a new claim with the SSA if you are experiencing new symptoms or have new evidence.

Appeals Process Step 5:

What if the federal district court denies my claim?

If a claimant files at the federal district court and loses, an appeal can be made to the U.S. Court of Appeals, and may even be able to be taken to the U.S. Supreme Court. In this case, it is important that the claimant consult with a lawyer who is experienced in representing people in federal court. While you are waiting for the appeals process, it is possible, and in some cases even advisable, to file another application for SSDI.

What can a lawyer help me with when I am applying for an SSDI claim?

If you choose to hire a lawyer, he or she can help you understand your rights and assist you through the application process. Specifically, your lawyer can help you by preparing documents, getting information from your Social Security file, helping you get medical records or information to support your claim, helping you prepare for a hearing, and requesting a reconsideration or appeal if your claim is denied.

If you choose to hire a lawyer, you are required to inform the Social Security office in writing as soon as possible. Your lawyer will be able to assist you in this process.

What is the national payment standard for SSDI lawyers?

Lawyers are prohibited from charging their clients fees for work before SSA without first getting written approval from the SSA. The SSA must review and approve the fee agreement between you and your lawyer. The only fee agreement that will be approved is a contingency fee agreement that provides for a fee of 25% of past-due benefits, with a cap of \$6,000.00 through an ALJ hearing. A lawyer may have a fee agreement that provides for an hourly fee or larger fee than described above. That fee agreement will not be approved for automatic payment and the lawyer will be required to file a fee petition seeking approval of that fee. A lawyer may charge you for out-of-pocket expenses, such as the cost of obtaining medical reports, without approval from the SSA.

Your community might also have an organization that provides free or reduced-rate legal services to people who qualify, so be sure to consider this option if you are concerned about your financial ability to pursue your claim. Your local bar association may also be able to help you find a lawyer who fits your budget.

What is Supplemental Security Income (SSI)?

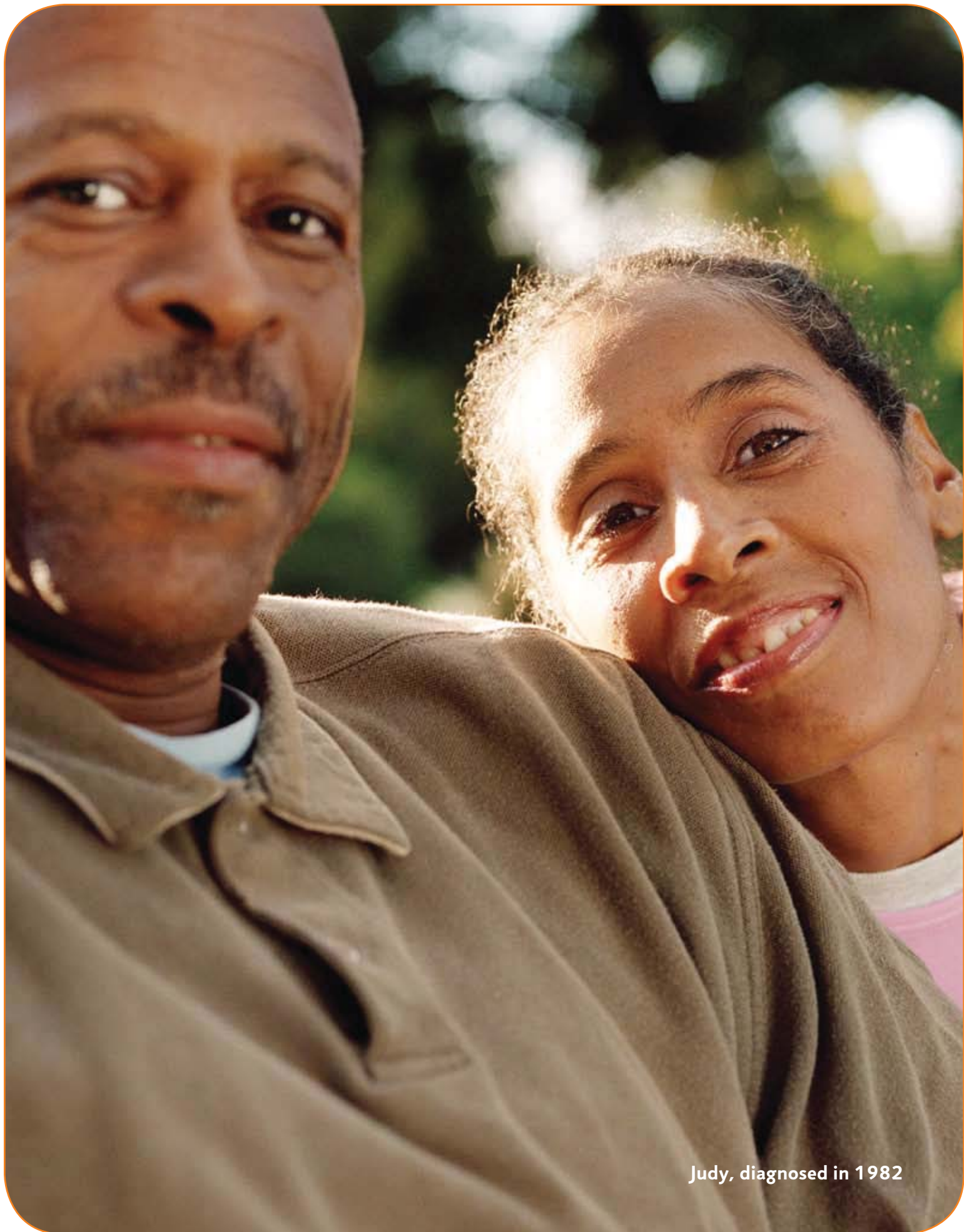
SSI is also managed by the SSA and provides benefits for people who have very limited income, are elderly, blind or disabled. Unlike SSDI, SSI is available for those that have not had a previous work history. The SSI program uses the same definition of disability as the SSDI program. One must have a limited income and assets low enough to meet certain thresholds. Both SSDI and SSI use the same disability determinations, and it is possible to qualify for both at the same time.

Resources:

Social Security Administration Web site:
<http://www.socialsecurity.gov>.

Social Security Disability Benefits, A Guide for People Living With Multiple Sclerosis, National MS Society, available at:

<http://www.nationalMSSociety.org/NationalMSSociety/media/MSNationalFiles/Brochures/Guidebook-Social-Security-Disability-for-People-with-MS.pdf>



Judy, diagnosed in 1982

National MS Society & Washington Appleseed

Chapter 5: Finding Legal Resources Q&A

How do I find a lawyer, and how do I know whether he or she is qualified to help me?

Most lawyers build their practice from referrals, so find out whether your friends or family members have worked with a lawyer that they liked. The local bar association is also a good resource that can help you find a qualified lawyer in a particular practice area.

Once you have found a lawyer, ask the lawyer whether he or she has pursued similar claims in the past. If not, most lawyers will be happy to refer you to another lawyer who will be well suited to handle your case.

What information does my lawyer need to know about MS?

Your lawyer does not need to have specialized knowledge regarding MS in order to effectively represent you. It will be your lawyer's job to learn about your condition and ask you questions about your symptoms. It will be important to let your lawyer know that MS can be debilitating, progressive and unpredictable. Be ready to provide your lawyer with detailed information about your symptoms and limitations on activities as well as your education, work history and medical treatment.

What will happen during my visit with a lawyer?

Most likely, the lawyer will ask you a lot of questions and try to gather information from you. He or she will probably also discuss the standard fee arrangements with you during your first visit to make sure that you are comfortable moving forward.

After the lawyer understands your situation, he or she is likely to discuss your options with you and recommend a strategy. This might not happen

in the first meeting, however, so do not be surprised if the lawyer tells you that he or she will have to think over your situation before providing a firm answer. Lawyers often have to research issues that are unique to your situation before they can recommend what is right for you.

What should I expect my lawyer to do/not to do?

You should expect your lawyer to explain and discuss your options with you. You should not be surprised, however, if your lawyer does not answer all your questions right away. Your lawyer might need to spend some time researching your particular issues before he or she is able to fully explain your options.

Once he or she has done the due diligence, your lawyer will provide counsel and recommend the documents or services that are right for you. Your lawyer should not force you to pursue a particular strategy, however, and you should expect the process to be collaborative.

What fees do lawyers charge?

The fees that lawyers charge vary. Generally, lawyers charge an hourly rate and bill you monthly for their services. These rates are occasionally negotiable depending on the complexity of your issues.

Your community might also have an organization that provides free or reduced-rate legal services to people who qualify, so be sure to consider this option if you are concerned about your financial ability to pursue your claim. Your local bar association should be able to help you find a lawyer who fits your budget.

Resources:

Your state and/or local bar association

Lawyer Locator through Martindale/Hubbell, available at
<http://www.martindale.com>.

Lawyer Locator through FindLaw, available at
<http://www.lawyers.findlaw.com>.



Eric, diagnosed in 1951

National MS Society & Washington Appleseed

GLOSSARY

Acupuncture – involves the insertion of thin metallic needles into specific points on the body. It is believed that this can improve the flow of energy in the body and thus treat a disease or relieve pain.

ADA is the “Americans with Disabilities Act,” which became a law in 1990. The ADA is designed to ensure that people with disabilities are able to participate fully in society and be free from discrimination.

Advance healthcare directive – a document that informs your doctor and your family of the medical treatment you would like to receive if you become unable to make decisions about your healthcare.

Administrative Law Judge (ALJ) – judge who presides over a Social Security Administration appeal, hearing claims that were denied by a state disability determination services office.

Affirmative duty – requires an employer to provide reasonable accommodations to a disabled employee; requires the employer to help you identify and apply for available jobs within the employer’s business for which you are qualified.

Alternative medicine – describes MS treatments that are used instead of conventional medicine; often associated with complementary medicine, which refers to therapies that are used in addition to conventional medicine

Bar association – the professional organization for lawyers.

Claimant – the individual claiming benefits under a Social Security Program, or appealing the decision of an insurance company, an appeals council or a federal court.

Complementary medicine – with alternative medicine, refers to unconventional medical practices that are not part of mainstream medicine.

CPR – Cardiopulmonary resuscitation – medical procedures used to attempt to revive a person when his or her heart has stopped or the person has stopped breathing.

Disability Starter Kit – includes a fact sheet with frequently asked questions, a checklist of documents and information that will be requested by the Social Security office where you have applied, and a worksheet to help you gather and organize all the information.

Do-not-resuscitate order (DNR) – an advance healthcare directive that indicates what you want to have done in certain medical emergencies; specifically, that you do not want CPR performed if you stop breathing or your heart stops.

Due diligence – the proper degree of care or attention expected of a person in a given situation.

Durable power of attorney – a formal legal document that designates a friend, family member, or other person as your agent to take action on your behalf, such as signing documents, buying and selling property, authorizing medical treatments.

EOB – an Explanation of Benefits usually accompanies documents that explain why coverage of a medical procedure or prescription was denied.

Equal Employment Opportunity Commission (EEOC) – the enforcement arm of the ADA, Title I, that investigates charges of discrimination in the workplace and tries to resolve them without a costly lawsuit.

Family and Medical Leave Act (FMLA) of 1993 – protects an employee's rights to take unpaid leave of absence in order to attend to important family health concerns or to negotiate reduced work hours. Gives the worker some assurance that in the event of a health care emergency, workers would not have to choose between his or her job and personal or family obligations.

Healthcare directive – a directive that allows a person to name a personal representative or agent who will make medical decisions on your behalf, should personal decision making become impaired. Sometimes called a health care proxy or medical power of attorney.

HIPAA – Health Insurance Portability and Accountability Act of 1996 - also known as the Kassebaum-Kennedy Bill, mandates various requirements for “group health plans” and is intended to reduce barriers by guaranteeing that most workers who change or lose jobs will have access to health insurance coverage.

Law Against Discrimination – The Washington state law corresponding to but slightly different from the federal Americans with Disabilities Act (ADA). See ADA, on page 49.

Living trust – establishes a separate entity set up while you are living to which assets can be transferred either before or after you die.

Long-term care insurance – covers the extended cost of health support services to persons in need of them for a prolonged period of time. Care is usually provided in a nursing home or in the house of the person requiring the care.

Long-term disability – a disability in which the individual is not expected to return to work after an injury or illness.

Medicaid – a federal/state program that finances health and long-term care services for low-income individuals with disabilities, ranging from health services to personal attendant care to prescription drugs to long term care; generally provides coverage for individuals who have high levels of need and low income and assets.

Medicare – is a public health program of health and hospital insurance for senior citizens and individuals with disabilities. It is funded jointly by the federal government and individual states.

Naturopath – a person who practices a system of treating diseases through natural agencies such as air, sunshine, water, and diet and rejects the use of drugs and medicines.

Necessary documents – forms and/or letters requested by your insurance company to accompany an application for services, such as information about medications you take, letters from physicians who have treated you, contact numbers for former employers.

Nondurable power of attorney – a power of attorney that expires after a certain period of time, is revocable during its existence, and will automatically expire when the person who grants it becomes incapacitated.

Permanently disabled – condition of an individual's being unable to engage in any substantial gainful activity by reason of one or more medically determinable physical or mental impairments which can be expected to result in death, or have lasted or can be expected to last for a continuous period of not less than twelve months.

Preexisting condition – a condition that was present before an individual's enrollment in a health care insurance plan.

Probate – the process of proving, usually before a judge, that a document submitted for official certification and registration, especially a will, is genuine.

Reasonable accommodation – a modification or adjustment to a job or worksite that will allow a qualified applicant or employees with a disability to have privileges equal to those of nondisabled employees.

Revocable – capable of being repealed, canceled or annulled.

Short-term disability – a disability in which the individual is expected to return to work after a temporary injury or illness.

Social Security Administration (SSA) – administers an insurance program funded through payroll withholding and employer contributions that covers most American workers.

Social Security Appeals Council – The third step in the appeals process if SSA turns down your request for SSDI.

Social Security Disability Insurance (SSDI) – The federal disability insurance program for workers unable to work due to long-term disability, and the chief source of coverage for the elderly and certain people with disabilities. See Medicare, on page 51.

Springing power of attorney – a power of attorney that becomes effective upon the happening of some future event; subject to some restrictions by the Health Insurance Portability and Accountability Act (HIPAA). For that reason a durable power of attorney (see above) may be a better choice.

Statutorily blind – legally blind; having a visual acuity of 20/200 or worse.

Substantial Gainful Activity (SGA) – the figure that the Social Security Administration considers to represent competitive employment. To be eligible for disability benefits, you must demonstrate an inability to work, i.e., you are not working above the SGA level, which is adjusted each January 1.

Supplemental Security Income (SSI) – a program intended to help aged, blind, and disabled people who are unable to work and who have limited income.

Testamentary trust – trust that comes into being as a result of a provision in a will. See Living Trust, on page 51.

Trustee – a person to whom another's property or the management of another's property is entrusted.

Undue hardship – the situation for an employer in which an accommodation would be unduly costly, extensive, disruptive, or would affect other employees or customers in a negative way.

Will – a legal document that describes what will be done with your assets and possessions when you die. Important because it allows you to have control over your assets and provides information for your friends and relatives to ease the task of dividing assets.

Work incentives – provisions for continued benefits and healthcare under Social Security Disability Insurance coverage, to help you make the transition back to work; tax provisions through credits, deductions, favorable tax treatment for a variety of costs incurred as the result of working, obtaining technology and training, etc.

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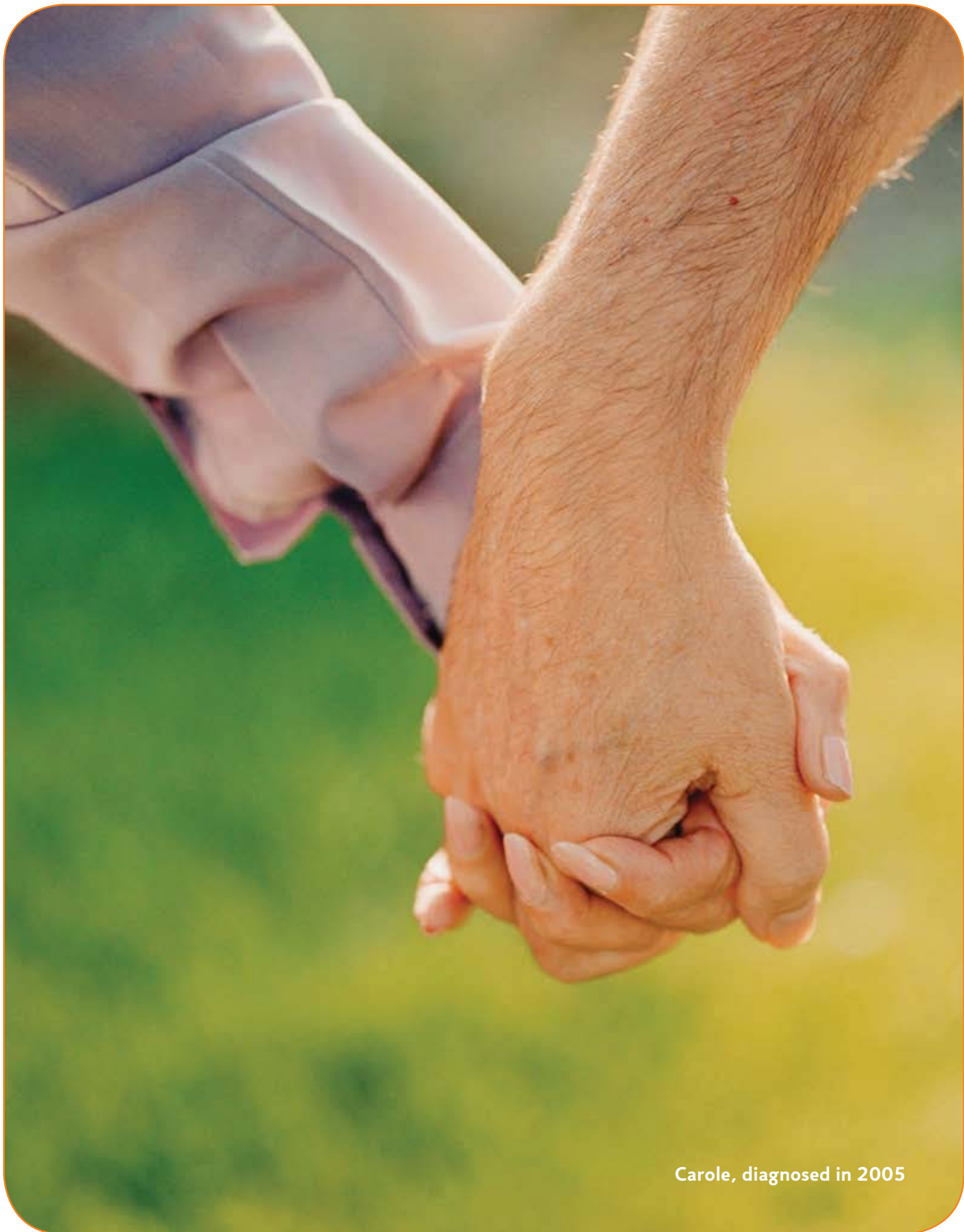
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Carole, diagnosed in 2005



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