



Make today a breakthrough.



LIVING UNLIMITED WITH SMA:

A BOOKLET FOR ADULTS WITH SMA

If you are holding this booklet, it likely means you are part of Cure SMA—a network of individuals with SMA, families, researchers, clinicians, and other health professionals who are determined to make a difference in the SMA community.

Many of you will already know the ins and outs of SMA as you have been living with it since childhood. Others may have been recently diagnosed, in which case, Cure SMA and I would like to extend our warmest welcome to you. Regardless of when you were diagnosed, Cure SMA is here for you.

While I have been employed at Cure SMA over the past 12 years, I originally joined the SMA community when I was diagnosed with SMA at the age of two. So much has evolved over the last 30+ years but providing support to the entire community remains a top priority at Cure SMA.

So often, when faced with a diagnosis like SMA, you are introduced to a team of medical providers that focus on care itself, but what is often missing is prioritizing access to support resources and to others living with SMA. As I have learned over the years, one of the best places for support as well as tips and tricks at navigating daily life is by connecting directly with others living with SMA who are going through similar experiences and therefore can relate.

Thanks to contributions and feedback from other adults with SMA, we have collectively pulled together this booklet on topics that are important to the adult community specifically. It is the hope of all of us at Cure SMA that this booklet will provide you with strategies, advice, and encouragement from others to help you navigate and live unlimited!

All my best,

Shannon O'Brien
Adult with SMA
Vice President, Community Support
Cure SMA



DISCLAIMER: *The information and advice in this booklet is not intended to replace the advice of your medical provider(s). Information shared here is meant to provide direction and helpful guidance in navigating living with SMA. Specific questions regarding physical or mental health symptoms should be directed to a medical provider for consultation and direction. Great care has been taken to ensure useful information within this booklet, but any specific concerns should be directed and discussed with a medical provider individually.*

A NOTE FROM CURE SMA:

Hello there! We are so happy to be connecting with you through this book. At Cure SMA, it is our goal that everyone with SMA is empowered to lead independent, successful, and fulfilling lives. We hope the articles and information we've provided will help you do just that. If you have any questions or find you need additional support, please reach out to us at communitysupport@curesma.org.



TABLE OF CONTENTS:

Planning for Your Future & Financial Security	4 – 7
Career Planning and Accommodations	8 – 9
Advocacy	10 – 11
Caregivers & Personal Care Attendants (PCA)	12 – 14
Relationships	15 – 17
Mental Health	18
Primary Care & Preventative Health	19– 20
Accessing Care & Treatment	21 – 22
Family Planning	23
Creative Solutions- Paths to Independence	24 – 25
Becoming a Driver	26
Travel	27
Conclusion	28

PLANNING FOR THE FUTURE

Planning for your own future can be intimidating. Preparing to provide for the future financial care of yourself as an individual with SMA can bring on additional anxieties and concerns including the high cost of care today and in the future, as well as the cost of personal care assistants. Having a financial plan is an essential part of providing for your future care needs.

One primary resource for funding are government assistance programs. These programs can be confusing, but the benefits provided are a lifeline for personal attendant care, medical services, equipment needs and more, so it is important to fully understand these programs. A key part of financial planning is making sure you protect your eligibility for government benefits because you may unintentionally disqualify yourself if you don't plan.

How do you begin? Below is a breakdown of types of assistance, as well as a summary of specific programs you may be eligible for.



Needs-Based

Programs that are available regardless of whether you have paid into the system. Because these benefits are not purchased, the eligibility requirements are based on your income level and personal assets. Examples include SSI and Medicaid.

Entitlements

Programs that a person is entitled to because they bought these benefits by having money deducted from their paychecks throughout their working years. Examples include SSDI, SSA and Medicare.

Cash

Programs that provide cash payments to meet daily living expenses and supplement other benefits. Each program has distinct eligibility requirements. Programs include SSDI, SSI and SSA.

Goods and Services

Programs that cover residential and medical assistance and include Medicare and Medicaid.

Government Programs Breakdown

Supplemental Security Income (SSI) is a federal income supplement program. It's meant for people who aren't entitled to the benefit but need it, and it is subject to both the income rule and the asset rule. The program currently provides a maximum of \$794* per month to be used for basic needs such as food, clothing, and shelter. Recipients do not all receive the same amount per month, and the assets an individual can own are limited to qualify for this benefit. The allowable assets for a person receiving benefits are a home, one car, a pre-paid funeral, and \$2,000. If the person receiving benefits exceeds this by any amount, they are disqualified from receiving benefits. It is important to understand what an asset is to ensure that you are eligible and remain eligible.

**This figure can change over time. Check with your state programs to confirm the maximum monthly payment.*

Government Programs Breakdown Continued

Social Security Disability Insurance (SSDI) is a federal cash benefit that supports individuals who are disabled and have a qualifying work history, either through their own employment or a family member (spouse/parent). It pays benefits to the individual and certain members of the individual's family if you are "insured," meaning that you have enough work credits (based on years of work) and paid Social Security taxes. When a working person becomes disabled, they will receive disability based on how much they have paid into the system and if they are substantially and gainfully employed. This is called the "income rule."

Medicare is a federal health insurance program which begins two years after Social Security recognizes your disability. Medicare does not pay for prescriptions unless you have Medicare Part D. This benefit also follows the income rule when determining eligibility. Medicare is for people 65 years of age or older, certain younger people with disabilities, and people with End-Stage Renal Disease (permanent kidney failure with dialysis or a transplant). Medicare does not cover everything, and it does not pay the total cost for most services or supplies that are covered.

Medicaid is a program that is administered by states according to federal requirements. It provides medical assistance for certain individuals with disabilities who have low incomes and resources. Medicaid eligibility is limited to individuals who fall into specific categories and is subject to the income and asset rules. You can have both health insurance and Medicaid. Medicaid pays for deductibles and co-pays that your health insurance does not cover. Although the Federal government establishes general guidelines for the program, the Medicaid program requirements are established by each state. In addition to paying for some medical services and prescriptions, Medicaid may also pay for residential facilities, workshops, and other programs. Medicaid is funded jointly by states and the federal government.

Government programs provide important assistance in many ways, however individuals who work and receive government assistance may find it difficult to save money while maintaining their government benefits. This is especially important for Needs-Based benefits in which income and countable assets of more than \$2,000 are considered when determining eligibility. Protected savings accounts make it possible for individuals to have savings and financial resource limits greater than \$2,000 while still maintaining eligibility for benefits.

Looking for resources closer to home? Cure SMA has state resource guides available to you. These guides include resources that are specific to the state you live in and can help to direct you to organizations to apply for some of the programs outlined here. Email communitysupport@curesma.org to request a guide for your state organizations to apply for some of the programs outlined here.

PLANNING FOR THE FUTURE

This is just a general overview of assistance programs you may be eligible for. It's important to note that each state has specific options and rules about how much an individual can earn or save while receiving these benefits, so it is valuable to look at your state's specific rules. It can also be helpful to collaborate with a financial advisor who specializes in disability benefits and can advise on programs and laws relevant to your situation. As you plan for your future, remember to remain flexible with your financial plan to account for potential financial and health changes in your future.

In addition to government benefits, understanding the distinct types of trusts or accounts that may work best for you is important. Check out this chart for a detailed comparison of some of the most common options.



Protected Savings Option Comparison Chart

Comparison Criteria	ABLE Account (Investment and Savings Account)	1st Party Special Needs Trust (Legal Document)	3rd Party Special Needs Trust (Legal Document)
Eligibility	A person with a disability with an onset of the disability before age 26	Disabled beneficiary where trust needs to be established before age 65	Disabled beneficiary with no age limit
Created By	Anyone including the person with the disability	Trust established by parent, grandparent, legal guardian, court, or beneficiary (if competent)	Trust established by anyone other than beneficiary
Set Up	Done online through website portal	Attorney recommended as it is a legal document	Attorney recommended as it is a legal document
Startup Cost and Management Fees	\$0 to establish but may be a minimum deposit. Ongoing fees vary by state (average \$0-\$50)	Attorney fees vary and may include court costs so costs and fees can be significant	Attorney fees vary and may include court costs so costs and fees can be significant
Contribution Limit	\$17,000 total annual limit (2023) from all sources. Additional contribution allowed from beneficiary's work earnings up to poverty amount. \$100,000 total limit for SSI recipients	No limit	No limit
Who can contribute?	Anyone can, including the person with the disability	Only the person with the disability can contribute	Anyone except the person with the disability
Allowable Use	Qualified disability expenses (QDE's) which includes housing	Anything for the sole enjoyment and best interest of the person with the disability determined by the trustee, excluding food and housing. Distributions for food and shelter may reduce SSI.	Anything for the enjoyment and best interest of the person with the disability determined by the trustee, excluding basic support such as food and housing. Distributions for food and shelter may reduce SSI.
What happens to funds at death of beneficiary?	ABLE account funds will first be directed back to the state for reimbursement of Medicaid payments (claw back) from the date the ABLE account was opened and if funds are leftover, they will then be distributed to the accounts named beneficiaries	Trust funds will first be directed back to the state for reimbursement of Medicaid payments (claw back) made throughout the person's lifetime and if funds are leftover, they will then be distributed to the trusts named beneficiaries	The trust's terms will control distributions to the trusts named beneficiaries

Creating Financial Security

Sandy Spoonemore



Being a small business owner has given me a huge amount of freedom in my life as well as allowing me to have a better quality of life. Before having my own business, I worked in Corporate America for Fortune 500 companies. There was always an issue with bathroom needs, eating needs, and liabilities within the company for people that were my coworkers and friends assisting me in tasks I needed. For example, one of my supervisors when I was working in IT as a computer programmer, called me into her office and told me they were aware that my friend, whom I worked with from church, was assisting me in the bathroom. I was told that it had to stop immediately and if they found either of us doing it again, we would be fired. So, I was to work full-time every day and not use the bathroom because of potential liability issues.

I now am self-employed and own a consumable products business where I carry inventory and serve others through the products I offer. Owning my own business allows me to have whatever assistance I need to complete my day personally and business-wise. Due to the tax benefits of owning your own business, it allows me to meet the requirements of Medicare and my state-funded Medicaid program while working

and making a successful living. Many aspects of running my business are a tax deduction which allows me to meet the requirements of Medicare and Medicaid, so I can work and have health insurance in a career that I enjoy and am passionate about. It is important to understand the rules of your Medicare and Medicaid programs along with other financial programs allowing you to earn a living, take care of your needs, and enjoy your life. Make sure that you keep great records, employ experts such as CPAs to help you with taxes, and most of all, live a great life! Don't allow your disability to keep you from reaching your dreams.

Helpful Tools for Financial Planning

ABLE Accounts: <https://www.ablenow.com/>
“The federal Achieving a Better Life Experience (ABLE) Act authorized states to establish tax-advantaged savings programs so individuals with disabilities can save and invest money without jeopardizing eligibility for public benefits.”

You can also find useful information about ABLE Accounts on the Cure SMA YouTube channel from the 2021 Virtual SMA Conference and the 2020 Summit of Strength Webinar Series.

The ARC free financial planning resources – complete this form to receive free resources on the various protected accounts you can access and other financial considerations to take when planning: <https://thearc.org/financial-planning-resources/>

CAREER PLANNING & ACCOMMODATIONS

5 Tips from Working Adults with SMA

Career planning, interviewing, and maintaining a job one enjoys is a popular discussion topic and one that is quite important, especially for young adults starting their careers. It can be confusing to know when or if to disclose a disability, how to prepare for an interview, and how to request accommodations. We hope the information below helps as you make these decisions.

Because you are protected by federal law from having to disclose your disability to any potential employer unless it impacts your ability to complete the tasks of the position, it is up to you whether you volunteer this information. How you disclose it can send a message to your prospective employer regarding your level of confidence in your ability to complete the tasks of the position. When you disclose is also up to you, and there is no right or wrong way of doing so. Some people may reference it in a cover letter or résumé to highlight how they have overcome challenges. Others may decide to share details about their disability during the interview process and still others may not disclose it until they've been offered a position.

While it is up to you when and what to disclose about your disability, most people agree that it is best to directly address any potential concerns that an employer may have. We know that some people have prejudices about workers with disabilities and even though these are unfounded concerns, it is up to you to educate a potential employer on how you will accomplish the job tasks, what accommodations are helpful, how you'll communicate clearly with your colleagues, and how you'll utilize skills you've gained because of your disability. For example, having

1. Share about your disability however you are comfortable. Whatever route is most empowering to you—disclosing or not disclosing before your interview—is what's most important.

2. Managing fatigue—be up front about when you may need to take breaks and when and how you will make up the time. Being realistic about the rest you need will help you maintain high performance. You don't want to overdo it!

3. If you don't get a good impression from a prospective employer at the beginning of the interview process, you can move on to another opportunity. You're interviewing the prospective employer just as much as they are interviewing you.

4. You often set the tone for how your disability is viewed. If you talk about it matter-of-factly and in a way that shows it is not a big deal, others will come to view it that way, too.

5. Follow your passions to find a job that you will love. At the same time, be realistic about what work will be best suited for you. If you can't physically do something you're passionate about, get creative about another role you can take on that would still support that passion and allow you to be successful.

If you feel you've been discriminated against in the workplace, you can file a complaint with the U.S. Equal Employment Opportunity Commission. You can file online, in-person, over the phone, by mail, or a state or local fair employment practice agency.

For more information, visit <https://www.eeoc.gov/>.

CAREER PLANNING & ACCOMMODATIONS



and managing your own caregivers has allowed you to learn excellent organization and time management skills. These kinds of examples are valuable for potential employers to hear about. Also, the Covid-19 pandemic has helped employers understand more clearly how well virtual workplace arrangements can be managed, which provides employees with disabilities with precedent for being able to request alternate work arrangements.

If while you're interviewing for a position that you are qualified for you receive an inappropriate question about your personal life or medical history from a potential employer, you are entirely validated in responding clearly and firmly that you are qualified for the job described in the posting and that nothing in your personal or medical history would keep you from doing the job at hand. One way to feel more prepared for an interview is to practice interview questions with a family member or friend. Practice interviews are an excellent way to feel more comfortable with a variety of questions that may come your way.

Department of Vocational Rehabilitation – Support for Your Career Goals!

When it comes to planning for and reaching your employment goals, a resource to consider is your local Department of Vocational Rehabilitation (DVR) Services. DVR programs can assist with a variety of supports, including:

- Financial support for postsecondary school
- Transportation needs to and from postsecondary classes and work, including vehicle modifications in some cases
- Employment supports such as career guidance and counseling, job searching and placement, and more
- Case managers to assist you in applying for state waiver services and other services you may qualify for

You can and should apply for DVR services as soon as you are able. Students as young as 14 can apply. The earlier you get connected, the more support you can receive as you plan for your career after high school.

Resources for Professionals with Disabilities

Establishing yourself as a voice of authority when you have a physical disability can bring challenges. One way to address these concerns is to seek out organizations that work to ensure all people with disabilities are supported in reaching their professional goals. Below are examples of such organizations. You may consider seeking additional resources in your specific line of work.

- American Association of People with Disabilities
- Physicians with Disabilities Society
- Nurses with Disabilities
- American Bar Association
- Commission on Disability Rights

Want to hear career perspectives from other professionals with SMA?
Check out the Career Panel Webinar Series on Cure SMA's YouTube channel.

ADVOCACY

State and federal policies impact nearly all aspects of life for individuals with SMA. Advocacy is critical in advancing policies and helping lawmakers understand your experiences and unique perspective.

Cure SMA's Advocacy Team collaborates with our SMA community to develop and advance our public policy agenda which includes ensuring adults with SMA have the support services they need. Advocacy toolkits are available on our website and key priorities that have been identified include:

- Make Air Travel More Accessible
- Promote Employment Opportunities
- Promote Independent Living, Employment, & Economic Self-Sufficiency
- Promote Access To, and Coverage of, Assistive Technology
- Ensure Emergency Disaster Response Meets Needs of People with SMA
- Eliminate Marriage Penalty
- Promote Representation of People with Rare Diseases
- Ensure Full and Timely Access to Lifesaving Treatments
- Support Family Caregivers

Your voice is incredibly important, so check out our advocacy page at www.curesma.org/advocacy for simple ways to connect with your legislators and make your voice heard on topics that matter to you!

5 TIPS FOR ADVOCATING FOR YOURSELF

1. You are the best person to describe your experiences. Sharing your story fosters understanding and leaves a lasting impression.
2. Keep your message clear and concise. Bring notes to remember what you want to say and to stay on topic.
3. Share what you know. Don't worry about not having all the answers or being an expert. You can always gather more information and offer to follow up.
4. Have a specific ask. Be clear what you'd like the outcome of the meeting to be and what action you'd like to see taken.
5. Follow up after the meeting, thank everyone for their time, and ask for updates on any requests you made during the meeting. Continue to touch base with legislative offices to continue building your relationship



IMPORTANT LAWS TO KNOW

Law	Description
Americans with Disabilities Act (ADA)	Prohibits discrimination based on disability in employment, state and local government, public accommodations, commercial facilities, transportation, and telecommunications.
Olmstead Decision Supreme Court's decision in Olmstead v. L.C	Requires states to eliminate unnecessary segregation of persons with disabilities and to ensure that persons with disabilities receive services in the most integrated setting appropriate to their needs. ADA title II regulations require public entities to "administer services, programs, and activities in the most integrated setting appropriate to the needs of qualified individuals with disabilities."
Workforce Innovation and Opportunity Act	State vocational rehabilitation agencies must provide, or arrange for the provision of, pre-employment transition services for all eligible students with disabilities. Pre-employment transition services include job exploration counseling; work-based learning experiences; counseling on opportunities for enrollment in comprehensive transition or postsecondary educational programs at IHEs; workplace readiness training to develop social skills and independent living; and instruction in self-advocacy, including peer mentoring.
Individuals with Disabilities Education Act	Ensures that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for employment and independent living. IDEA ensures that the rights of children with disabilities and parents of such children are protected.
Section 504 of the Rehabilitation Act of 1973	As amended (29 USC § 794), prohibits discrimination against otherwise qualified individuals based on disability in programs and activities conducted by or receiving financial assistance from the U.S. Department of Health and Human Services.
Affordable Care Act	Prevents insurance companies from refusing coverage or charging more for individuals with a health problem you had before the date that new health coverage starts (AKA requires covering a "pre-existing condition")
Title II of the ADA	Title II of the ADA prohibits discrimination of a person with a disability based on disability and ensures equal opportunity and access for persons with disabilities in public transportation.
The Air Carrier Access Act (ACAA)	Prohibits discrimination based on disability in air travel.
Section 508 of the Rehabilitation Act of 1973	As amended, (29 USC § 794(d)), prohibits discrimination based on disability in electronic and information technology procured by the federal government, including computer hardware and software, websites, multimedia such as video, phone systems, and copiers.
Section 255 of the Telecommunications Act of 1996	Requires telecommunications products and services to be accessible to people with disabilities. Covered products include telephones, cell phones, routers, set-top boxes, and computers with modems, interconnected Voice over Internet Protocol products, and software integral to the operation of telecommunications function of such equipment.

CAREGIVERS & PERSONAL CARE ATTENDANTS (PCA)

Finding, hiring, and maintaining Personal Care Attendants (PCA) can be a daunting task but being prepared and having a game plan in advance can help alleviate some of the stress throughout the process so below are some helpful tips provided by other adults with SMA to get you started. PCAs can help with a variety of tasks from activities of daily living such as transferring, toileting and bathing, day-to-day tasks, and care at home to supporting you while you travel and are engaged in recreational or leisure activities. What assistance you require will be unique to your specific needs and lifestyle and should be catered as such. Below is an overview of topics to consider and research as you move through the process of hiring and maintaining your caregiver needs.

Know Your State Programs

Many individuals qualify for PCA services through a state-funded program. To take full advantage of these programs, you'll want to ensure that you qualify and understand the details of what the program covers. A simple internet search for "How to qualify for PCA services" in your state will provide you with a link to the program(s) for which you can apply. As you move through the process of obtaining authorized PCA hours, below are some questions you may want to ask and consider.

- What services are covered, specifically?
- What is the pay for PCAs?
- How many hours are covered per week or month?
- Is overtime available to your PCA(s)?
- Can you hire family members or friends?
- Do you need to use the hours you were given each month or will hours be cut if they are not consistently used?
- What, if any, are the training or licensing requirements by the program/your state such as CPR, First Aid, or other certifications?
- Gather enrollment forms and paperwork so you're familiar with the process before recruiting or interviewing.



Please reach out to Cure SMA's Community Support team at CommunitySupport@curesma.org if you'd like additional resources on hiring caregivers such as sample job listings or sample interview questions.

CAREGIVERS & PERSONAL CARE ATTENDANTS (PCA)

Job Posting Specifics

Once you're ready to put together a job listing, you'll want to include the "5 W's" of the job – who, what, where, why, and when. To start, share a little about yourself - your interests, what you do for work or for fun – anything that will help them get an understanding of the kind of person that they will be spending a lot of time with. You'll also want to share why you're looking for a caregiver. Once you've shared a little about yourself, you can get down to the details of the job description. Many people have the listing set up in a Google Form or Survey Monkey to make it easy for you to review applicants and easily weed out those that won't be a good fit prior to even having to speak to an applicant. This also allows you to not have to share your personal contact information in your job posting until you reach out to the applicants that are a good fit for a phone interview.



The job posting can include:

- The location of job and its proximity to landmarks, public transit, etc.
- The pay and expected schedule/hours
- Any lifting or physical ability requirements
- A general list of duties and with what you need assistance
- A clear understanding that reliability is of utmost importance and that the applicant should be timely
- Any medical equipment that they will need to be trained on or familiar with

Recruiting

Once you're ready to begin recruiting for a PCA, make sure that you are familiar with the paperwork that the potential PCA will need to complete so that once you've found a qualified candidate, you will be ready to move forward quickly. Here are some suggestions for where to post your job listing:

- Check how to advertise to local colleges and universities that have nursing, physical or occupational therapy programs, etc.
- Post to Craigslist, Facebook, or any other online networks you're a part of
- Each state has Independent Living Centers. You can reach out to them and ask about sharing your listing. You can use this directory to find a Center for Independent Living nearest you:
<http://www.ilru.org/projects/cil-net/cil-center-and-association-directory>
- Don't forget about good old-fashioned word-of-mouth. Email your listing to family, friends, colleagues, or anyone who you trust to share it with others who they deem to be reliable and trustworthy

CAREGIVERS & PERSONAL CARE ATTENDANTS (PCA)

Interview Process

You'll likely want to complete phone interviews with the applicants who seem the most promising. Then you can move on to in-person interviews with those who pass your expectations in the phone interview. During the interview, you can go over the job listing in detail, sharing any information that you feel the applicant should know about the job so that you can both feel the position is a good fit. It can be helpful to run through a typical day for you and highlight what tasks you need assistance with. In addition to reviewing and discussing the job listing, below are some additional questions you may want to consider asking.



- Why are you interested in this job?
- When can you start?
- Is your availability flexible or set?
- Are you comfortable with helping care for hygiene needs, toileting, bathing, dressing, etc.?
- Are there any parts of the job description you are uncomfortable with or need clarification on?
- Can you complete the tasks required for the job?
- What questions do you have for me?

Once you've had a successful interview and are ready to move forward, it's important to get good references on the applicant. Focus on two to three references that are not from family members. The references should be from work or volunteer positions and should give you a clear idea of the applicant's level of reliability and trustworthiness. You'll also want to confirm their dates of employment, responsibilities, and if they are re-hirable with the company. Additionally, because trustworthiness is of utmost importance, you may want to ask if the previous employer would trust the applicant to care for children, pets, someone's home or valuable assets. These give you an idea of how trustworthy they are. It is important to note that some companies will only provide confirmation of position and dates of employment. That's okay, but it is especially important to get an idea of someone's reliability and skill, as it will relate to the caregiving position. For this reason, you may need to ask if the applicant has a past manager or longtime colleague that you could gather a reference from.



Maintaining the PCA Professional Relationship

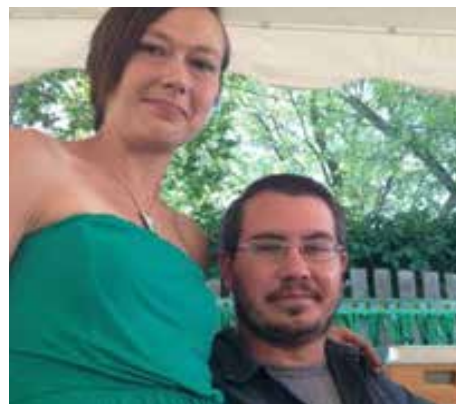
Congratulations! You've found a PCA that meets all your needs and is a good fit. It's a lot of work recruiting and hiring a caregiver so you want to do what you can to ensure the success of the working relationship. This is best done by outlining the expectations for both of you at the start of the relationship and then having open, honest communication when mistakes are made, or miscommunication happens—because it will. Be prepared by setting those expectations up front so that when issues or misunderstandings arise, you can easily address them and take the appropriate steps.

RELATIONSHIPS

Everyone in this world wants to feel a sense of belonging. They want to know that they can show up, exactly as they are, and be loved and valued. For those with a disability, who live in a world that is often not physically accessible and is permeated with ableist viewpoints, it can be challenging at times to feel a sense of belonging. Research shows that a positive sense of one's identity is impacted by perceived level of social support and contributes to an individual's sense of belonging. The more social support you have, the more likely it is you will have a positive sense of identity and belonging; therefore, it is important to surround yourself with people who support you and view you as an equal.

Romantic Relationships

Many people with SMA are in relationships, get married, and have children. Despite the many successful relationships and families built by other adults with SMA, there are some members of society who still have preconceived notions and stereotypes about disabilities resulting in ableist views therefore you may unfortunately be the recipient of unwanted comments, opinions, and advice. It is not uncommon for inter-abled couples to be mistaken as siblings or a nurse/patient relationship simply because there are stereotypes that people hold towards those with disabilities. Repeatedly experiencing these ableist remarks and prejudices can be exhausting. However, do not let that discourage you from getting out there and having the relationships and family that you want to! The possibilities for having and growing a family are up to you. It is never your job to take on the emotions or feedback from others. What matters is that you're happy in the relationship you are in and that you know your worth and value, as well as your partner's.



Help for Those in an Unsafe Relationship

If you find yourself in an emotionally or physically abusive relationship, please reach out for help. You can contact the [National Domestic Violence Hotline](https://www.thehotline.org/) at <https://www.thehotline.org/>. You can talk to someone via chat or phone and find local resources at this link. You can also search online for your local [Adult Protective Services Department](#). These offices exist to serve both older adults, as well as those who are disabled, and therefore face additional challenges when trying to get out of an abusive relationship.

RELATIONSHIPS

Parental Relationships

We all know that relationships between parents and children can be complicated. Add in something like SMA that can result in children needing additional physical assistance, and this dynamic can become even more complicated. A certain degree of dependency is expected for children but as someone with SMA grows up, the typical transition to becoming more independent and autonomous can be challenging. Despite the difficult discussions this may require, adults with SMA should absolutely be provided with the highest level of independence and autonomy possible. Now, as an adult with SMA reading this, you are likely thinking “Obviously. This is an easy decision.” But some young adults and even some older adults find themselves in a tense relationship with their parents because of their parent continuing to be their primary caregiver and not quite knowing how to let go and let independence grow. If this is you and you’re struggling with how to address this, consider some of the following ideas to start a conversation with your parent.



1. Honesty is the best policy.

The truth may sting a bit, especially if you’re telling your parent (or any caregiver for that matter) that you need some breathing room and space to grow.

2. You deserve dignity and independence.

No matter what physical assistance you need in life, you deserve to have control over when and who provides you with this assistance and in what way.

3. Healthy boundaries are important.

Although the conversations may be difficult, your relationship with your parent(s) can improve and your mental health will certainly be better when healthy boundaries are set. Remember this as you prepare to work through these conversations and advocate for your independence. Check out the chart on the next page when you’re thinking through what healthy vs unhealthy boundaries are.



RELATIONSHIPS

If you're feeling frustrated or "stuck" in your relationships with others in your life, the issue might be unhealthy boundaries causing tension. However, remember that healthy boundaries can also cause tension, that is good. When you hold to your boundaries, those violating those boundaries may push back. But that response doesn't mean that you've taken the wrong step. On the contrary, it often means that you are doing the right thing, and it's not your job to manage other's emotions. Establishing healthy boundaries can be a challenge. You may want to consider working with a therapist for support as you make these changes.

Want healthy relationships?

You need healthy boundaries.

Healthy Boundaries	Unhealthy Boundaries
Respecting your privacy	Overbearing or controlling
Listening to your ideas	Talking over you or for you
Respecting your beliefs	Belittling your ideas or thinking they know what's best for you
Trusting your intuition	Avoiding saying or doing something for fear of judgement

If you are feeling uncomfortable or unsafe in an unhealthy relationship, here are some steps you can take and resources to support you:

- Find a skilled therapist to help you develop healthy coping skills
- Seek out peer support from an online or in-person support group. Connecting with others with disabilities who have gone through what you're experiencing can be life changing and at the very least, help you to feel less alone
- Get "The Set Boundaries Workbook: Practical Exercises for Understanding Your Needs and Setting Healthy Limits" by Nedra Glover Tawwab, MSW, LCSW for a hands-on, step-by-step guide to establishing healthy boundaries and getting out of unhealthy relationships



MENTAL HEALTH

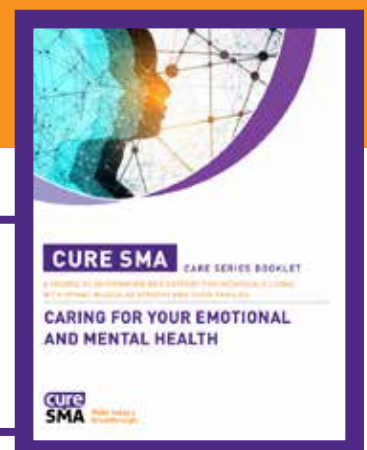
You likely know the challenges that can arise from having a physical disability – buildings and spaces that are not accessible, being unable to travel without the fear of mobility aids being broken and rendered useless, and so on. Having to constantly manage and process challenges such as these can lead to feelings of frustration, anger, anxiety, or isolation. You're not alone and there is support available to you.

When you live with a chronic disease like SMA, it is to be expected that you will feel overwhelmed at times, and you may experience a change in your mood or ability to cope with stress. This is your body's way of telling you that it's done all it can to deal with the stress and now it would be helpful to reach out for help. You can start by talking with your medical care team or your primary care provider. They can refer you to a mental health professional like a counselor or psychologist. These professionals can help you identify the stressors in your life and strategies for coping such as meditation, mindfulness, and other therapeutic approaches, including medications. It's especially important to know that seeking help is not anything to be ashamed of or a sign of weakness. Finding mental health professionals that you can trust to provide you with resources and strategies can make all the differences in getting through challenging times without unnecessary stress. There will always be external factors that can't be controlled, such as the attitudes and behaviors of others around you. This fact is more reason to seek professional mental health support. In addition, connecting with others living with a disability like SMA who you can vent to, ask advice of, and make friendships can be just as important. They may be able to relate to what you are experiencing as they may have gone through something similar. The key to authentic living is acknowledging and accepting what we can and cannot control and practicing being present in each day and what it brings. Formal (mental health professional) and informal (family and friends) support are both necessary for you to reach and maintain good mental health.

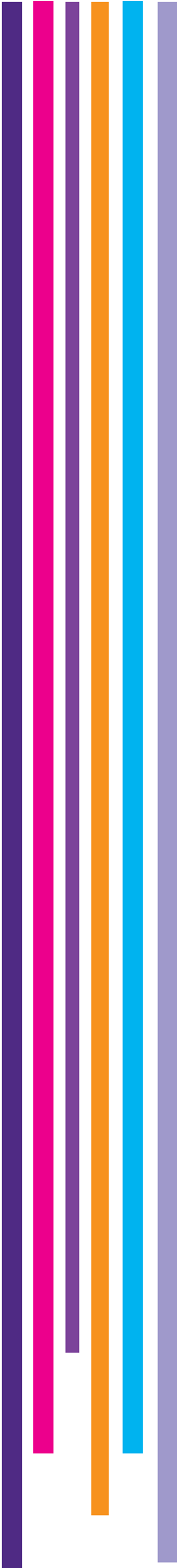
Check out these books for encouragement and empowerment:

- **Disability Visibility**, edited by Alice Wong
- **Sitting Pretty**, by Rebekah Taussig
- **The Pretty One**, by Keah Brown
- **Haben**, by Haben Girma
- **Care Work: Dreaming Disability Justice**, by Leah Lakshmi Piepzna-Samarashinha
- **Being Heumann: An Unrepentant Memoir of a Disability Rights Activist**, by Judith Heumann & Kristen Joiner

For a more in depth look at mental health support for those with SMA, check out our “Caring for Your Emotional and Mental Health” booklet. You can find it, along with all the other care series booklets, at <https://www.curesma.org/care-series-booklets/>



PRIMARY CARE AND PREVENTATIVE HEALTH



Individuals with SMA are often not strangers to medical settings and collaborating with doctors when it comes to care related to SMA-specific needs. However, when it comes to receiving regular health check-ups and preventative screening, disabled individuals can encounter obstacles to accessing high quality care. It's important to find a primary care provider who adjusts their care and treatment to you, listens to your concerns and specific physical needs, and with whom you feel all your preventative care is being addressed. If your needs are not being met and you find yourself feeling frustrated with the availability of providers to adjust their care to your specific physical needs, check out the information below for the importance of primary care and tips to accessing all the treatment you need.

Routine health screenings are important for everyone and, whether living with a disability or not, many of us are not up to date with our primary care screenings. You may find additional obstacles when seeking care, including:

- Lack of patient-centered care by providers who respect the patient's needs, values, and their experiences
- Lack of wheelchair accessible facilities and equipment, including weight scales that allow wheelchairs to roll on to them, height adjustable tables, accessible exam rooms, and more
- Lack of experienced healthcare providers, especially if living in a rural area
- Communication breakdown between healthcare providers

Some ways to overcome these challenges include:

- Bring a friend, family member, or another trusted individual to be a supportive advocate for you during your appointment. It can be so helpful to have "someone in your corner." Just make sure that your provider is speaking to you during the appointment and not bypassing you to speak to the person with you. Providers should be addressing you and your concerns, while supporting you in making medical decisions about your care. If you feel they are dismissing your ideas and questions, we suggest finding a new provider that is a better fit
- Ask for recommendations for providers from other disabled individuals who live in your area. Firsthand experience from others on what offices are most accessible and have the most empathetic providers who listen and will tailor care to your specific needs can lead you to a great provider.
- Ask to tour and interview a prospective primary care provider so you can see ahead of time what the office setup is, as well as whether you feel the provider is adequately prepared to meet your physical and emotional needs.
- Knowledge is power! Educate yourself on the preventative screenings that are recommended for you based on your age and family history. Bring any questions and concerns you have to your annual check-up with your primary care provider.

PRIMARY CARE AND PREVENTATIVE HEALTH

Breast Cancer Screening

It's been found that breast cancer screening for disabled women occurs significantly less than for non-disabled women due to the inaccessibility of medical care for those with disabilities. Regular screening is important to catch a diagnosis early. The CDC has gathered awareness materials specifically for disabled women. Those resources can be found at: <https://www.cdc.gov/ncbddd/disabilityandhealth/righttoknow/>

CROWD (provided by the Center for Research on Women with Disabilities) provides information on a variety of topics of importance to disabled women including sexuality, reproductive health, self-esteem, stress management, and more.

**The website can be accessed here:
<https://www.bcm.edu/research/research-centers/center-for-research-on-women-with-disabilities>**

Reproductive Health

There can be a lack of knowledge on the reproductive options for birthing people amongst primary care providers, however, if you seek out experiences from others and from neurological specialists, you will find that there are options for pregnancy, birth control, postpartum care, and sexual health. Due to stereotypes regarding disabled individuals, some providers will inaccurately assume that people with disabilities cannot have sex or become pregnant. We know this isn't true and it's important that you find a provider that supports you embracing the full range of life experiences you would like to have, no matter how your disability affects you.



A great resource for you to explore and to start this conversation is Cure SMA's webinar on Reproductive Health from our 2020 Virtual SMA Conference. Check it out on our YouTube channel!

ACCESSING CARE AND TREATMENT

It can be challenging for adults with SMA to find qualified providers who are knowledgeable in SMA care and treatment options. When you combine this with balancing work and other responsibilities plus the time it takes to make and attend treatment or therapy appointments, it is understandable why so many adults have difficulty accessing the treatment they want.

Therapeutic Interventions

One way to make physical therapy accessible to everyone is to provide activities that anyone can do at home. Some therapists do in-home visits and virtual physical therapy online may be an option you can explore with a physical therapist if you have the support to do so from home. Additionally, there are ways to make physical therapy more accessible and comfortable for you. Consider the ideas below as you research physical therapy options that may be right for you.



- **Adaptive bikes** – Some people have found adaptive bikes, like adult tricycles, are a fantastic way to exercise and stay active, while working on core strength and stability. Companies such as Liberty Trike make tricycles that may work for those with enough core strength, and you can also search for adaptive bicycle businesses in your area to find bicycles that may work for you. If riding a bike is beyond your physical abilities, check out “portable exercise bike pedals” which allow a person to pedal while sitting. It can even be used with your hands, while propped up on a table to help with range of motion.
- **Medicine or “peanut” ball** – These balls are excellent for helping people focus on their core muscles and practice balancing, using all the muscles that are required for that. Additionally, medicine balls can be used for stretching in ways you may not be able to do otherwise.
- **Equine (horse) therapy** – People with a variety of disabilities have benefited from equine therapy. Specifically for people with physical disabilities, horseback riding can help to improve core strength and balance. A horse’s gait creates similar neural pathways in the brain as when a human is walking and can help strengthen and support muscles that are otherwise not used.
- **Adaptive Sports and Recreation** – There are many options for adaptive sports and recreation, and these can be a wonderful way to enjoy staying active. Some common options are power soccer, floor hockey, basketball, baseball, and adaptive snow and water skiing. You can also research local art or craft studios. What will work for you will depend on how SMA affects you. You may need to get creative, talk to the owners or those in charge of the activities, and ask for help from others, but this can be a terrific way to stay active and enjoy a new hobby.
- **Aqua therapy** – Countless individuals have found physical therapy in the water to be incredibly beneficial and fun! Being in the water removes gravity and allows individuals who are otherwise unable to move freely and without restraints. You can connect with physical therapists in your area who have access to a pool for this kind of therapy. It can be a challenge to find a therapist who is trained in aqua therapy, but it is worth researching. If you can’t find a PT who can collaborate with you in the pool, there are a lot of activities that you can do on your own or with a friend’s help that are still beneficial.

ACCESSING CARE AND TREATMENT

SMA Standard of Care and Treatment

As you consider the variety of treatment, therapies, and other care that may benefit you, you can find printable or downloadable resources on the Cure SMA website. To view our care series booklet, visit <https://www.curesma.org/care-series-booklets/>. These booklets are available in several languages and are available to guide you and your care team as you make decisions on treatment and care.

Additionally, if you are interested in pursuing one of the FDA-approved treatments, the Cure SMA website has a treatment locator map for your convenience. You can find this resource at <https://www.curesma.org/find-a-location/>

Aqua-therapy DIY!

Created in collaboration with Jennifer Martyn, PT

Can't find a qualified PT in your area to lead you in aqua therapy? With a few simple tools, you can take to the pool and learn the benefits of this unique therapy on your own!

Equipment Ideas:

1. Head float – find one that is comfortable and works for you!
2. Waist float – to keep you upright in the water, if needed.
3. Ankle weighted wraps – to help keep you more stable and anchored to the pool floor.
4. Inflatable balls – a variety of sizes can be used to build respiratory strength as you “blow” them across the pool or push them under water, working against the resistance naturally provided.

As you think of ways you can use these tools to practice floating, stretching, and workout your respiratory muscles, make sure to attend the Annual SMA Conference to participate in a hands-on aqua-therapy session with a skilled physical therapist. This is also often a topic presented at our local Summit of Strength one-day events. These opportunities allow for you to try a variety of different kinds of equipment and receive professional feedback and support. If you can't make it to an in-person event, you can also search for the various aqua-therapy webinars on our YouTube channel.





Family Planning

Jaclyn Greenwood

Do you have SMA and are considering pregnancy? Many people with SMA have successfully given birth to a baby, but it is important to speak with your doctor to discuss potential challenges and to develop a care plan. Genetic counseling and genetic testing can also be important resources (before and during pregnancy) in assessing the chances of having a baby with an inherited genetic condition. Below is some information to consider as you make plans to have children.

What causes SMA?

SMA is a recessive genetic disease. We inherit two copies of every gene, one from each biological parent. SMA is caused when there is a mutation in both copies of the SMN1 genes we inherit, one from each parent. A person is a carrier of SMA when they have one functional SMN1 gene and one mutated SMN1 gene. A carrier does not have symptoms of SMA but does have the chance of having a child with SMA.

If I or my partner have SMA and have a child, will the child also have SMA?

If a person with SMA has a child, whether their child will also have SMA depends on the carrier status of their partner. If their partner is not a carrier, none of your children will have SMA, but 100% of your children will be carriers (Fig. 1). If their partner is a carrier, there will be a 50% chance their child will have SMA and a

50% chance their child will be an unaffected carrier (Fig. 2).

What genetic testing options are available?

SMA carrier screening is available through a blood test. While SMA carrier testing can identify most carriers, approximately 4% of SMA carriers are “silent carriers”. Silent carriers have an SMN1 mutation that traditional carrier screening cannot pick up.

There are two diagnostic testing options available during pregnancy to evaluate the developing baby. A chorionic villus sampling (CVS) is a placental biopsy that can be performed between 11 and 14 weeks of pregnancy. An amniocentesis uses a sample of amnio fluid and is usually performed between 15 and 20 weeks of pregnancy. These diagnostic tests can diagnose SMA in the baby. If you are considering testing during pregnancy, it is important to discuss the benefits, limitations, and potential risks of these tests with a genetic counselor and your doctor.

Additionally, once a child is born, they can receive an SMA genetic blood test. SMA testing is a part of many states’ newborn screening programs. Check your state to see if SMA is included in their newborn screening.

How can I find a genetic counselor near me?

Genetic counseling services are available in person and via telehealth. You can ask your doctor for a genetic counseling referral. You can also find a genetic counselor through the National Society of Genetic Counselors. “Find a Genetic Counselor” tool on their website (findageneticcounselor.nsgc.org).

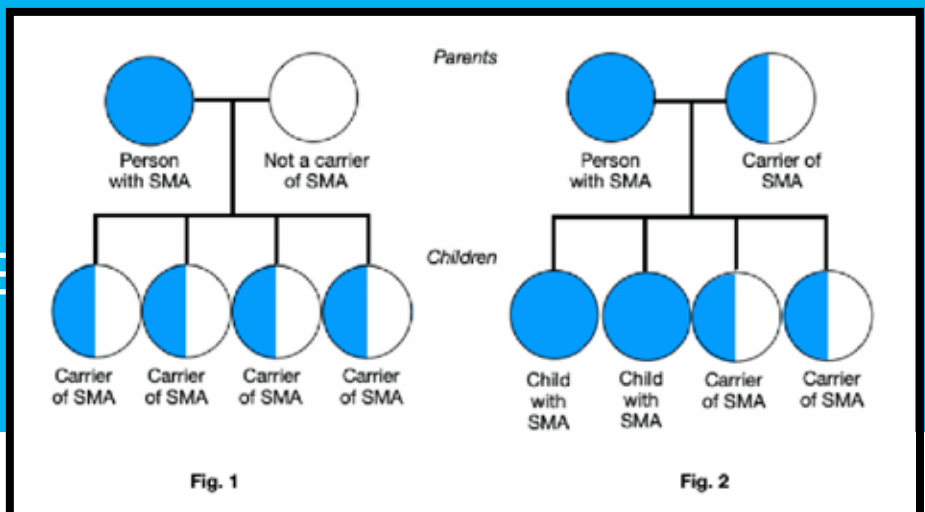


Fig. 1

Fig. 2

CREATIVE SOLUTIONS TO ACCESSIBILITY

▶ PATHS TO INDEPENDENCE!

Living with SMA can create difficulty with independence based on your physical strength and abilities, however there are many helpful items out there that can help you gain independence with things you might not be able to do. Below are different creative solutions to gaining independence that have been recommended by other adults with SMA!

Living a life as independently as possible means many different things – from finding a home that works for your needs, to getting ready for each day, to connecting with friends, family, and coworkers, to navigating your local community or the world while on vacation. Check out the tips below on accessing independence for yourself.

Adaptive Clothing Brands – Getting Ready for Your Day!

- Adaptive Clothing Showroom
- Alter UR Ego
- ANKHGEAR
- Billy Footwear (shoes)
- Friendly Shoes (shoes)
- June Adaptive
- MagnaReady
- Nike FlyEase
- Tommy Hilfiger
- Slick Chicks (women's undergarments)
- Smart Adaptive Clothing

Tip! Arrange your clothes at home in columns or sections that allow for you to clearly and easily direct caregivers to get the items you want.

Helpful Tools for Independence and Comfort

- Amazon Echo Plus
- Etekcity Remote Control Outlet Switch Kit
- EZ-Shampoo Hair Washing Basin
- Gooseneck Phone or Tablet Mount
- Jar Opener with Base Pad
- Long Grabber Reacher Tool
- Medical Fleece Ease Sheepskin
- Multi Kitchen Tools Set
- Neck & Shoulder Heating Pad
- Spry Positioner Pillow
- Telescopic Back Scratcher
- Telescopic Metal Straws
- Travel UV Sanitizing Wand
- Universal Cup Holder
- Wi-Fi Smart Plugs

*These items are available in our Teen & Adult packages – please email communitysupport@curesma.org for more information!



CREATIVE SOLUTIONS TO ACCESSIBILITY



PATHS TO INDEPENDENCE!

Medical Procedures for More Independence

A suprapubic catheter (SPC) is a semi-permanent catheter that is inserted through the abdomen and into the bladder. This allows for the user to independently empty their bladder through the tube into the toilet without moving from their wheelchair. Another procedure that can allow for more independent bathrooming is the Mitrofanoff procedure. For more information, reach out to your care team and a skilled urologist.

A g-tube is a tube that is inserted directly into your stomach through your abdomen. It allows you to feed, hydrate, and medicate yourself independently, or with help from a caregiver, as needed.

Making a House a Home

If you're looking to modify your home or apartment to make it work better for you, you may want to check out one of our home modification resource guides. These guides provide lists of equipment and simple home modifications that you want to consider when making your home more accessible.

Email communitysupport@curesma.org to request a copy of the home modification guide be sent to you.

Staying Connected – Tech That Supports You!

- AccessNow
- AssistiveTouch (Android and iOS)
- Dragon NaturallySpeaking
- Google Assistant (on Android and iOS)
- Google Voice Access (Android)
- Speak For Yourself
- Wheelmate

BECOMING A DRIVER



Although having SMA can limit your strength and abilities, there are different adaptations that can be made and some advanced technologies that are available that allow many adults with SMA to be able to drive independently. Going through the process to become a licensed driver can feel overwhelming when you begin looking into it, so we've put together some valuable information to help you along the way. This information should serve as a starting point, but you should make sure to verify the process in your local area to ensure that you follow any specific steps required to receive funding for an adaptive vehicle if that's something you need.

The first and most important thing to do is to meet with a Driver Rehabilitation Specialist (DRS) who can do an evaluation to make sure you are eligible to become a licensed driver. A Driver Rehabilitation Specialist (or a Certified Driver Rehabilitation Specialist, which is a credential offered to a DRS) is a professional that assesses a person's ability to drive a vehicle. This person is trained to recognize what support and adaptations are needed. They will conduct a clinical and behind-the-wheel assessment to assess what vehicle adaptations and supports you will need and to make sure you are capable. Once it is determined that you are a suitable candidate and what modifications are needed, the CDRS will then be able to provide training which allows you to practice behind the wheel driving to prepare you for the required DMV exam. Upon completion of your driving lessons, they can also take you to the DMV to take your driving exam allowing you to use their adapted vehicle. To find a CDRS in your local area, check out the Association for Driver Rehabilitation Specialist's database here:

<https://www.aded.net/search/custom.asp?id=1984>

Once your evaluation is complete, your CDRS will work with you to provide a prescription specifying all the modifications required for you to drive independently. We recommend you meet with a mobility dealership salesperson that is a part of the National Mobility Equipment Dealership Association (NMEDA) to ensure they are knowledgeable on matters about adaptive driving and vehicle modifications. For safety purposes, your mobility dealership salesperson should work closely with your CDRS to custom fit your vehicle with the best equipment available to meet your individual requirements. In most cases, a series of evaluations and custom fittings will need to be performed.

Abbreviations To Know:

DRS (Driver Rehabilitation Specialist)
CDRS (Certified Driver Rehabilitation Specialist)
DMV (Department of Motor Vehicle)
NMEDA (National Mobility Equipment Dealership Association)

For more information on becoming a licensed driver and/or adapting a vehicle to meet your needs, email communitysupport@curesma.org. We would be happy to send you literature on both topics to help you navigate the process.

A Checklist to Keep You Organized:

- ✓ Connect with a CDRS.
- ✓ Complete driving lessons and get licensed prior to modifying your vehicle or purchasing a new one.
- ✓ Look for a salesperson who is a part of the National Mobility Equipment Dealership Association (NMEDA) to ensure they are knowledgeable.
- ✓ Purchase a new vehicle so that you can get the most out of the modifications being made, especially if they are high tech modifications since the cost of installing these modifications is expensive.
- ✓ Be sure to check with the Department of Motor Vehicles in your state to find out how to register your car, obtain your license, and take care of any other specific requirements.

TRAVEL

When it comes to traveling within the U.S. or internationally, the key is research and planning. There are endless destinations to explore and enjoy with just a little time and planning. Below are some tips to help you get started.

- Start with a quick internet search for accessible travel blogs. There are many disabled travelers who have traveled the world and documented it online for all to see and learn from.
- Once you have an idea of where you'd like to travel, you can contact local tourism and transit providers. Some may include information on their websites about accessibility for people with disabilities.
- Consider asking for insight from online travel or Facebook groups. That firsthand experience is almost always the most helpful. You can get tips on what hotels are wheelchair accessible, the most accessible (and delicious!) restaurants nearby, and tourist activities that work best for wheelchair users or other mobility accommodations.



In Case of Emergency

- Consider travel insurance to cover the cost of any expensive trips in case you need to cancel due to a medical emergency.
- Contact your insurance provider, especially if you will be traveling outside of the country, to ensure that you're covered in the event of a medical emergency while on your trip. If there will be gaps in your coverage, consider looking into travel medical insurance.



Air Travel

Traveling by plane when you use a wheelchair can be stressful, to say the very least. There are some ways to prepare for your trip to make air travel less stressful.

- Check out the Transportation Security Administration (TSA) website for procedures and guidelines for those traveling with wheelchairs
- Contact the airline ahead of time and at least 48 hours before you travel to let them know you will be traveling with a wheelchair and get any questions you have answered
- Contact TSA Cares Program at 855-787-2227 or by email at TSA-ContactCenter@tsa.dhs.gov. TSA Cares helps travelers with disabilities plan for their trip and can provide support and guidance at the airport and through security.
- Once you arrive at your gate, check in with the gate agent to ensure that they have documented that you will need assistance with checking your wheelchair and transferring to your seat. Additionally, you can ask to meet with those who will be handling your chair so that you can provide specific instructions on how to move it and avoid damage.

Preparing to fly? Here are some tips to follow:

- Take direct flights whenever possible
- If no direct flights are available, allow at least three hours for layovers
- Ask how tall the baggage door is on the airplane. This way, you'll know if your chair can fit into baggage area without it being turned on its side
- Provide the flight crew with a simple letter that explains how to move your chair safely. If you need help writing a letter, reach out to us at communitysupport@curesma.org for a template

If you want more complete information on tips for traveling, please email communitysupport@curesma.org and request a copy of our Accessible Travel Guide.

CURE SMA IS HERE FOR YOU

We hope that this booklet has been helpful to you and that you've found the information to be useful. From opportunities to socialize with other adults with SMA to in-person and online events to keep you connected, Cure SMA exists to be a resource for you, no matter how SMA affects you or what you're going through now, or at any point in the future. We are grateful for the diversity, leadership, and experience you bring to the SMA community. Throughout the booklet, we highlighted many topics and mentioned several resources to further support you and your family. If you'd like more information on these resources or if there is anything we can do to support you, please reach out to communitysupport@curesma.org.

How can you get involved and connected to others in the SMA community?

- Visit our Annual SMA Conference page - <https://www.curesma.org/annual-sma-conference/>
 - Attend a half-day Summit of Strength in a city near you - <https://summit-curesma.donordrive.com/>
- Reach out to the Community Support team at communitysupport@curesma.org to request a list of suggested SMA Facebook groups. From treatment-specific support groups to groups just for adults with SMA, you can find others who have had similar experiences as you to give and get support!



Cure SMA offers resource guides to support those with SMA and their communities. These resources cover a range of topics to enrich daily living at home and in the community. Below are some sample topics currently available, but topics covered in these guides continue to grow so stay tuned for more to come!

- Advertising and Interviewing PCAs
- Hiring and Maintaining PCAs
- Driving- Becoming Licensed
- Accessible Vehicle Options and Considerations
- Protected Savings Options Comparison Chart
- Home Modifications Guide
- Bathroom Accommodations Guide
- Bathroom Equipment List
- Adaptive Equipment List
- Travel Guide
- Surgery Hospital Stay & Recovery Guide



To request a copy of any of these resources, please email communitysupport@curesma.org.

It is a priority at Cure SMA to support the adult community therefore we have created a variety of support programs. Below is information on those programs with links to apply.

SUPPORT PACKAGES AND PROGRAMS



Teen & Adult Support Package

The original package for teens and adults that is filled with helpful items that allow for increased independence and that have been recommended by other adults with SMA. Items include medical fleece ease sheepskin, Amazon Echo, telescopic back scratcher, long reacher grabber tool, gooseneck phone or tablet mount, remote control outlet switch kit, EZ-shampoo hair washing basin, neck and shoulder heating pad, and a fluidized positioner pillow.

www.curesma.org/SupportPackage



Teen & Adult Independence Assistance Package

A supplemental package for teens and adults with SMA that is filled with a new set of helpful items to help gain further independence with activities of daily living. Items include Logitech Blue Snowball Microphone, WiFi smart plugs, travel UV sanitizing wand, universal cup holder, telescopic metal straws, jar opener with base pad, and a multi kitchen tools set.

www.curesma.org/IndependencePackage



LifeVac Support Program

Through this program, a LifeVac Home Kit is provided to any individual with SMA who requests one, at no cost to this person. This is a non-powered, non-invasive, single-use only airway clearance device developed for resuscitating a victim with an airway obstruction. It is easy to use in an obstructed airway emergency and is beneficial for those who the Heimlich maneuver is not possible.

www.curesma.org/LifeVac



Medical Alert Bracelet

The Responder PHR with Medical Alert Bracelet and Keychain is offered to help identify medical needs in case of a medical emergency. Through this program, a Responder PHR (Personal Health Record) package is provided so medical personnel will have immediate access to the patient's medical records stored online, whether the patient is able to communicate for themselves or not.

www.curesma.org/ResponderPHR

SUPPORT PACKAGES AND PROGRAMS



Annual SMA Conference Sponsorship

The Adults with SMA Sponsorship offers adults with SMA ages 18 and older, as well as one caregiver, waived registration fees, a stipend for travel, and one hotel room for 3 nights for the Annual SMA Conference.

Email conference@curesma.org for sponsorship application!



Annual SMA Conference Events

Cure SMA holds workshops specifically geared toward adults with SMA, along with exclusive lounges and receptions throughout the 4-day conference.

www.annualsmaconference.com/agenda.html



Adults with SMA In-Person Socials

This program, which includes refreshments, snacks, and free parking for attendees, provides a space for adults with SMA to gather and socialize in person.

Email communitysupport@curesma.org for more details!



Adults with SMA Virtual Socials

Virtual socials offer an opportunity for adults with SMA to gather online in a friendly Zoom setting to catch up with friends and network.

Email communitysupport@curesma.org for more details!



Educational Webinars and Panels

Find informational webinars, including panels about going to college and pursuing a career, on Cure SMA's YouTube Channel.

www.youtube.com/c/CureSMA/playlists



twitter.com/cureSMA



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[youtube.com/user/FamiliesofSMA1](https://www.youtube.com/user/FamiliesofSMA1)



www.linkedin.com/company/families-of-sma

