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breakthrough.



**LIVING UNLIMITED WITH SMA:**

A BOOKLET FOR NEWLY DIAGNOSED PARENTS

If you are holding this booklet, it likely means that you are new to the spinal muscular atrophy (SMA) community, in which case, Cure SMA and I would like to extend our warmest welcome to you. We know that entering the SMA world can be an overwhelming experience, to say the very least.

While I have worn many hats in the SMA community, my very first was as an SMA Mom. In 2013, both of my children were diagnosed within 6 months of one another. There were so many things about our lives that seemed up in the air during that year and, to be honest, still do at times. One thing I quickly learned is that my experience in the mental health field was going to be very beneficial as we walked this new path, and I wanted to offer whatever support I could to others as well.

So often, when faced with a diagnosis like SMA, we are quickly connected with a team of medical providers to develop a plan to care for all our children's physical health needs and treatment. What is often missing, however, is prioritizing access to resources that support the mental and emotional health of the whole family. Perhaps the most important thing to remember as you navigate the impact SMA has on your family and your life is to give yourself grace. There are no easy answers, no easy decisions, but showing each other kindness and grace can provide a solid foundation for whatever challenges you and your family face.

One place to find support is amongst the stories of others who have walked—and are walking—the path you are now on. 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 to strengthen your family and live without limits.

Very Best,

*Danyelle Sun*

Dany Sun  
SMA Mom  
Social Work Manager, 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 an SMA diagnosis, in general. 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.



# WELCOME TO HOLLAND

By Emily Perl Kingsley

I am often asked to describe the experience of raising a child with a disability-to try to help people who have not shared that unique experience to understand it, to imagine how it would feel. It's like this...

When you're going to have a baby, it's like planning a fabulous vacation trip-to Italy. You buy a bunch of guidebooks and make your wonderful plans. The Coliseum. The Michelangelo David. The gondolas in Venice. You may learn some handy phrases in Italian. It's all very exciting.

After months of eager anticipation, the day finally arrives. You pack your bags and off you go. Several hours later, the plane lands. The flight attendant comes in and says, "Welcome to Holland."

"Holland?!?" you say. "What do you mean Holland? I signed up for Italy! I'm supposed to be in Italy. All my life I've dreamed of going to Italy."

But there's been a change in the flight plan. They've landed in Holland and there you must stay.

The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine, and disease. It's just a different place.

So you must go out and buy new guidebooks. And you must learn a whole new language. And you will meet a whole new group of people you would never have met.

It's just a different place. It's slower paced than Italy, less flashy than Italy. But after you've been there for a while and you catch your breath, you look around...and you begin to notice that Holland has windmills...and Holland has tulips. Holland even has Rembrandts.

But everyone you know is busy coming and going from Italy...and they're all bragging about what a wonderful time they had there. And for the rest of your life you will say, "Yes, that's where I was supposed to go. That's what I had planned."

And the pain of that will never, ever, ever, ever go away... because the loss of that dream is a very very significant loss.

But...if you spend your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things...about Holland.

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# DIAGNOSIS AND MOVING FORWARD WITH HOPE

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The time around diagnosis can be some of the most overwhelming times you've ever experienced as a parent. It's understandable why that may be. Many parents feel a sense of loss and grief during this time. The future that you imagined for your child may look different to you now, or perhaps you're unsure of what to envision at all. Grieving the loss of what you once thought was to be is okay.

Parents may also experience feelings of guilt, isolation, worry, fear, and more. There is no "right" or "wrong" way to feel and what is most important is to identify what you're feeling, acknowledge it, and explore healthy strategies for coping with the feelings. Listed below are some strategies you can explore to help you cope with stressors that arise.

- 1. Connect with other parents who have experienced similar diagnoses.** Sometimes these connections can be found in online support groups, but also by searching for parenting groups or organizations in your area that support parents of children with disabilities. Cure SMA can help to connect you to families who have had similar experiences with SMA as you, both virtually and in-person. We host local events, like our Summits of Strength, and the yearly Annual SMA Conference, which offers networking opportunities for everyone in the family.
- 2. Consider connecting with a therapist.** Some people avoid seeking out professional therapeutic support because they feel they will be viewed as unable to handle the stressors of life. The truth is, seeking out support means you are caring for yourself and caring better for those around you. A therapist can listen to your experiences and help you develop coping skills, self-care routines you can stick to, communication skills during stressful times, and advocacy skills. It is helpful to simply get your thoughts out of your head and share them with someone else who is neutral and non-judgmental.
- 3. Try taking up journaling.** There's something helpful about a "brain dump" when you're feeling overwhelmed. Whether this is a quick journal entry to get all your thoughts out or drawing the emotions you're feeling, it can help. Putting your thoughts on paper can allow you to clear your mind and make sense of what you are feeling.
- 4. Care for your physical health.** Drink plenty of water, get sleep when you can, and stay active—even if it's just getting outside with your family. Don't underestimate the natural mood boost that getting some fresh air can be for you. Just as every person with SMA is different, each parent's journey is also different. As such, while the self-care that benefits each parent will vary, we can all agree that caring for physical health is an important part of emotional well-being.
- 5. Make a schedule of appointments and organize important information in one place.** Cure SMA's Medical Binder and/or the Cure SMA App can be helpful in this way. Many families like to utilize a "command center" of sorts at their home. This is one area of the home (e.g., a cork board or wet erase board) that includes a calendar, daily routines, medication schedules, and other important information. It can be especially helpful if more than one person is caring for your child so that everyone can be on the same page with their care.

Seeking out support is important right now as you make sense of your feelings surrounding an SMA diagnosis.

Please feel free to reach out to Cure SMA  
at [familysupport@curesma.org](mailto:familysupport@curesma.org) for additional support.

# THE IMPORTANCE OF SELF-CARE

Many parents feel as though they need to “do it all” for their children, and parents of a child with SMA are no exception. As a result, often the first thing to get cut out from their busy schedules when they become overwhelmed is caring for themselves. When we talk about self-care we aren’t talking about massages, bubble baths, sweet treats, and movie marathons (although those things can all help us relax!). The self-care discussed here refers to what parents can do to help maintain a sense of peace, acceptance, and contentedness in their lives. No one feels like this all the time but there are things that can be done to help you feel positive more often.

**If you’re feeling overwhelmed with life’s responsibilities and your schedule, it’s okay to take steps to eliminate some of this stress.**

SMA will bring new routines and expectations into your and your loved one’s life. Your schedule may fill with appointments for therapy, doctor’s visits, treatment, special education meetings, and so on. You may feel frustrated or overwhelmed to learn that you don’t have the time or energy to participate in activities you used to, such as volunteering, spending time with friends, or even working. You may need to say “no” to activities you previously participated in, and that is okay.

You may need to decline an invitation to a birthday party due to the risk of exposure to an illness, and that is okay. These don’t have to be permanent changes and as you become more comfortable with the challenges SMA can bring, you will feel more equipped to handle whatever comes your way.

**You may need to ask for help from others sometimes.** Many parents are used to running their home and managing their children’s schedules without help but that may change. If you can, utilize grocery delivery or ask a friend or family member to do a grocery run or another simple errand for you occasionally. Even taking one task off your plate can do wonders for your state of mind and well-being. This also gives you a chance to see that you can ask for help and allows for others in your life to be able to provide you with support.

**Establish boundaries with those around you and ask for the things you and your family need without feeling shame, guilt, or fear.** The tips above fall under the umbrella of learning how to advocate for your needs and those of your loved ones. When individuals learn to do this in a healthy way, they are no longer tied to activities or commitments that are contributing negatively to their mental health. For example, helping your child advocate for a specific protocol when receiving treatment may not be easy. You may not be received well by the provider or you may feel like a burden asking the provider to adjust their protocol. However, learning to respectfully speak about your child’s needs is the only way to find solutions that work for you and your family. This can ease stress and help everyone feel calmer. Advocating for your needs and those of your child is not always easy, but it is an important tool in caring for your mental well-being.

## SELF-CARE CHECKLIST



**Rest**



**Ask for Help**



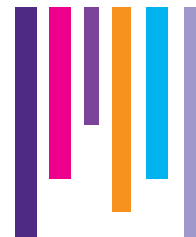
**Self Advocate**



**Eat Well**



**Be Present**





# Overcoming Challenges

By Amy Medina

As a parent of three children with SMA, I have known my fair share of challenges and heartache. The words “spinal muscular atrophy” first entered our life on August 10, 2011, when our first son, Mateo, was exactly one month old. My husband and I left that doctor’s office with no hope and a death sentence for our first child.

At the time, there were no approved treatments for SMA. Luckily, August is SMA Awareness Month and I came across a post about SMA on Facebook. This post would eventually connect us to a knowledgeable care team near us. As we anxiously waited for Mateo’s first appointment, I was filled with a mix of emotions—happiness, anger, sadness, and denial. We left that appointment with all the equipment we would need to manage Mateo’s SMA.

In the months that followed, Mateo would have surgery to have a g-tube and tracheostomy placed. Still, we had too many 911 calls and hospitalizations, and each would trigger me back to the words we heard upon Mateo’s diagnosis: “He won’t live to see his 2nd birthday.” We learned to grieve but we also learned to move on and live. We were determined to show Mateo the world and live in the moment. Mateo began school at 3 years old and completed second grade this year, where he thrives in the school setting with all his peers.

We slowly learned how to travel with all the equipment and not let SMA keep us from experiencing things. Mateo has been to 32 states and has been able to experience Times Square, Niagara Falls, Disney World, Las Vegas, Mount Rushmore, and many more tourist attractions.

Once we became comfortable with SMA, and all the challenges this disease can bring, we decided it was time to expand our family. We knew the odds of another SMA diagnosis and hoped for the best. After weeks of waiting on my amniocentesis results, we learned our second baby would also have SMA. As much as I felt I was prepared for this news, I was not. I cried and grieved just as I did with Mateo.

**There will be days you feel knocked down and defeated, but if you never give up, you will be picked back up and be able to enjoy the ride.**

There had been advancements in the SMA world since having Mateo 4.5 years prior and we were able to enroll Javier in a clinical trial where he received his first treatment at 12 days old! Instead of living in fear of how SMA will impact Javier, we learned to live every day with hope and celebration.

Javier would eventually roll off the bed and get close to putting his finger in an electrical socket, but this was because I was not prepared for needing to babyproof the house. But even those scary moments turned into moments of celebrating! Javier was doing things he would never have been able to do because of the treatment he was receiving. As the months and years continued, we have been able to celebrate more milestones such as crawling, walking, eating by mouth, and talking non-stop.

Two years after Javier was born, we once again rolled the SMA dice and were blessed with our only girl, Amelia, who also has SMA. The third diagnosis did not get any easier and I grieved, was angry, and asked “why?” but I did not allow myself to stay in that dark spot long and focused on all the good SMA has brought to our lives.

By 2018, there were more developments in clinical trials, and we were blessed to be able to enroll Amelia into a different trial where she received treatment at 11 days old. Amelia is now 2 years old and I often forget she has SMA. She is hitting all her milestones without any type of medical intervention. She has helped pave the way for the new world of SMA.

I have faced many challenges over the past 9 years due to SMA, but one thing is for sure: it has not taken away my ability to love and enjoy life with my family. We don’t let SMA stop us. To do this, I must make sure I take care of myself. I have been seeing a therapist since Mateo’s diagnosis, which is my safe place to release my emotions and fears while also celebrating the good in my life. SMA life goes in waves. There will be days you feel knocked down and defeated, but if you never give up, you will be picked back up and be able to enjoy the ride.



**I have faced many challenges over the past 9 years due to SMA, but one thing is for sure: it has not taken away my ability to love and enjoy life with my family. We don’t let SMA stop us.**

# SUPPORTING YOUR CHILD WITH SMA

It can be difficult to know the best way to support and help your child work through an SMA diagnosis and the challenges it may bring to their lives. Understandably, some parents worry about “saying the wrong thing” to their child when explaining what an SMA diagnosis may mean for them. The most important thing to remember is to be honest when discussing topics related to SMA while also keeping explanations at their age level and understanding. Children are perceptive and know when something is going on, even if they don’t ask questions directly, so it can be helpful to think ahead on ways you may support your child.

## Below are some strategies that may help.

1. Allow children to express frustration, doubt, anger, sadness—whatever emotions they have—and validate those feelings.
2. Provide books to help talk about differences and what makes us all unique. There are many options that encourage celebrating diversity, overcoming challenges, and that allow children an opportunity to ask questions. These books can also spur meaningful discussion on this topic. If you would like a curated list of diverse children’s books compiled by Cure SMA, please reach out to [familysupport@curesma.org](mailto:familysupport@curesma.org) and we will be happy to provide that to you.
3. Give your child examples of adults or teens with a disability. Consider helping your child connect with teens or adults with SMA who you know well and trust.
4. Let your child see you advocate for them and include them in the process. Ask for their insight or to ask questions they may have, as they are able, during school meetings or medical appointments. This helps them to build confidence in stating their needs with those around them.



When you talk honestly to your child about their disability, you model for them how to talk to others about it, too. You are also teaching them that their disability is nothing to hide or be embarrassed of. It is a part of who they are and should be celebrated and appreciated.





Consistent conversations over time about the beauty of everyone's uniqueness, strengths, challenges, and successes will help your child build confidence in themselves and establish healthy coping skills they can use during stressful times. Some days will be better than others but continuously going back to these values will help to make those days more manageable.

## WAYS TO HELP YOUR CHILD LEARN TO COPE

- Journal or work on another form of art
- Practice gratitude (e.g., writing down 5 things you're thankful for each day)
- Spend time with good friends
- Find a hobby or develop a skill that your child enjoys and can practice
- Talk to a friend who understands (e.g., someone living with SMA)
- Attend a Cure SMA event in your area or the Annual SMA Conference
- Spend time outside and explore nature
- Listen to music or have a dance party to lift their spirits
- Seek out a professional counselor for your child to work through social and emotional challenges they face as they get older. Finding a counselor trained in art or play therapy can be very effective with children.



# The 9 Highs, Lows, and In-betweens of Having SMA

By Angela Wrigglesworth, Adult with SMA

I find myself being drawn to articles in the news with eye-catching lists that describe such things as “What to Binge Watch This Weekend” or “The 32 Things You Can’t Live Without.” So, allow me to simplify my 42-year life in this listicle.

**1. SMA is a natural magnet for kind people.**

I am starting the list off with a positive, but it’s completely true. My entire life, I’ve been surrounded by family, friends, and quite often complete strangers who offer to help me in difficult situations. This is not an anomaly. Families in the SMA community will echo this sentiment.

**2. Having a spinal fusion at the age of eight was hard.**

The year was 1986 and I had to stay in a children’s ward with seven other kids. My parents could not stay in the hospital with me and I was there for a month. I grew up quickly. It was, however, a life-saving procedure and the very best decision that my parents ever made for my body. These sorts of choices are real and their gravity is powerful, but I have lived a healthier existence because of this choice.

**3. Physical therapy is essential, but tenacious me convinced my parents otherwise.**

I would have made a great politician in elementary school, because despite my mom and dad’s concerted efforts, I managed to weasel my way out of therapy. I made them believe that physical therapy was torture. I blocked out whispers from my future self, encouraging me to stick with it, to protect my bones and muscles from deterioration. Coulda-Woulda-Shoulda. I don’t regret much but skipping out on therapy was a huge mistake.

**4. Going to camp every summer was like Christmas and Disney and the best birthday party ever, all combined into one annual week of bliss.**

The happiest times in my childhood were spent in a bug-ridden, make-shift accessible camp in the middle of Nowhere, Texas three hours away from my family. It was the greatest. I got to ride horses and swim and make crafts that I think my mom still has somewhere at the top of her closet. More importantly, my future was foreshadowed. I learned to ask for help, to make my needs known, and to see examples of success in the campers that were older than me.

**5. I should've focused more on my grades in college.**

Isn't this sort of everyone's story though? My grades were last on my list. Luckily, people with SMA are statistically smarter than the able-bodied population and I ended up having a decent GPA. Instead of diligently showing up for class though, I was busy experiencing my social life to the fullest at Texas A&M University. I was on my own and on my way to adult independence.

**6. I cried every single day the first six weeks of my teaching career.**

UGLY cry. There I sat at my desk bawling my eyes out with papers piled up above my head—student work waiting to be stapled on the wall and endless copies needing to be made. I was failing at my job. Not because I wasn't a good teacher, but because I could not complete the physical tasks. I can barely move my arms and don't even think of asking me to open a marker cap. I went to my principal to ask for help (using those lessons I learned at camp in #4 above!) and thank goodness she recognized my value. My school district(s) have paid for me to have an assistant in the classroom for the last twenty years. I've been "Teacher of the Year" three times, so I'd like to think I'm worth it.

**7. Receiving treatment is saving my life.**

My parents were waiting for me in the recovery room as the nurse wheeled the stretcher in and said, "He got it!" The nurse was referring to my doctor and that he had found the microscopic hole in my spine to inject the medicine. The three of us wept in relief that the procedure worked, in grief for the friends who did not live to see a treatment, and in celebration of the longer future I can look forward to.

**8. They don't let you cut in line at the Eiffel Tower just because you have a wheelchair.**

... but you're treated like royalty in London. Cutting in line is a legit perk, both domestically and internationally. And whereas traveling is certainly not easy in a motorized wheelchair, I travel anyways. I've been to countless cities in our great country and the number of stamps on my passport grows each year. I know the world is bigger than SMA, as is my desire to see it.

**9. My husband and I don't take SMA too seriously.**

He comes up with new acronyms for SMA like, "Skinny Margarita Addict" or "Somebody Move-My Arm." He's sincerely the funniest person alive and I love that he finds humor in my condition because I do, too. We don't focus on my disease and we certainly don't talk about it on a regular basis. We discuss typical couple things, like what will we have for dinner or what we will do this weekend. The normalcy of our conversations sums up my life with SMA and this entire list: having SMA certainly has highs, lows, and in between, but so does living a "normal" life without it.



# SHARING AN SMA DIAGNOSIS WITH OTHERS

Receiving an SMA diagnosis can be overwhelming for you and your family, let alone figuring out how to share the news with extended family and close friends. It can be emotionally draining to keep your family and close friends updated on what is happening in your life. It is a decision to be made by families on when to share, how much to share, and with whom to share such life-changing information. Many have shared that, upon diagnosis, it was helpful to find a way to help other important people in their lives understand what SMA is and how it may impact their lives moving forward.

**If this is the place you find yourself in, here are some ideas to consider from other SMA families as you seek to share information with your close friends and family:**

- Write a letter to email or send copies by “snail mail.” In the letter, share basic information about SMA and link to the Cure SMA website to help others learn and understand the impact it may have on your family’s life and on others in the SMA community.
- Create a social media page or account to share the diagnosis. This can also be a space where you can continually share updates on treatment, therapy, fundraising, awareness, etc., if you so choose. A helpful part of having an ongoing platform like this is the ability to provide ongoing updates about what is happening in your family’s life, as well as within the SMA community to a wide audience all at once.
- Create a Caring Bridge if you’re looking to share updates on an ongoing basis but prefer not to use a social media platform. This is a non-profit website that allows individuals to share information and updates related to a medical diagnosis. The pages are not public so only those you invite will be able to access and respond to the information you share.

## FOOD FOR THOUGHT

As you consider the above ideas, especially regarding social media sharing, it is helpful to remember that photos and information shared can be seen and shared by anyone. If your child is old enough, consider talking with them about what they feel comfortable being put on the internet. If they are not quite old enough to give permission on what they want shared, consider how they may feel about it as they grow up and understand their SMA better. If these are concerns you or your child have, you could keep the information shared about your child’s health general and focus on sharing updates regarding happenings in SMA research, treatment, or upcoming events to keep family updated. Another fun idea is to include your child in sharing updates if they are interested. This way they can choose which photos or information is shared and practice an important skill—deciding when and how they share their diagnosis and life experiences with others.



# TEACHING INDEPENDENCE

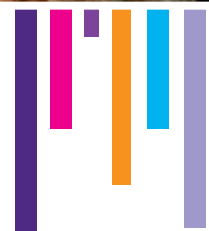
While parents love to cuddle and care for their children as babies and toddlers, watching them grow into their own person, spreading their wings, and gaining independence is something parents also love to see. While your child may face challenges to independence at times, with some creativity and flexibility, you can support them by fostering independence as they grow. It's important to remember that children with disabilities are children first. As such, they should be treated like any other child as much as possible. Below are some strategies to consider implementing to grow your child's independence.

**As your child grows, encourage them to try things on their own before intervening to help.** As a parent, we are often quick to help. You may be surprised to learn what skills your child has when given the chance to test them out. Likewise, children may be used to asking for help, but when encouraged to “try first” they may be surprised and then encouraged by what they can do on their own. Trying helps them learn just how much help they need, if any.

**The best way to teach anyone independence is to teach them how to advocate for themselves.** It's true that children are always watching those around them for how to act and react in life. Because of this, parents are provided with endless opportunities to show children how to be advocates for themselves. Even if a person is unable to complete a particular physical task, they can speak to someone else about what exactly they need to accomplish this goal. Encourage your child to ask questions at medical appointments, school meetings, and to speak up when they have concerns. If you know they have worries, but perhaps lack the ability or willingness to say them, ask permission to share these concerns with others who should hear it so that your child can hear the words you are using and the tone in which you say them. Modeling this will help them to learn how to advocate for themselves.

**Arrange for your child to work with caregivers other than yourself before they are adults.** This is a common topic of discussion for parents of children with SMA. It could mean having a responsible, older teenager in your neighborhood or a trusted family friend come once a week to provide an extra hand while you stay home and get other tasks done. This provides an opportunity for your child to practice communicating their needs. Parents often accurately predict their child's needs before they even express them. If children are not provided opportunities to practice working with caregivers other than parents, they may struggle with this change when they are older and need to depend on other people to provide them with assistance. Attending day camp or overnight camp, when they are ready, is another great opportunity to help encourage independence in your child as they grow up.

When considering any of these ideas, remember that you know your child best. Try strategies you think may work for you, get creative with other ways to encourage independence, and remember that not every strategy will work for everyone and that is okay. The most important thing to remember is that teaching independence is important. Rest assured that you'll find the best way to do that within your family.



# SUPPORTING SIBLINGS

Siblings are special and the relationship between someone with SMA and their siblings is no exception. When a family receives an SMA diagnosis, everyone in the family will experience the diagnosis in different ways, both in ways that will challenge them and help them grow.

The sibling journey is not easy. Providing each of your children with unconditional love, practicing kindness, fostering a sense of belonging within the family, and offering all children a sense of security can help children cope better and create a safe home environment for all. With all that said, no matter how great a home life they have, at different points in their life unaffected siblings will face difficulties because of a sibling's SMA diagnosis. Below are some of the emotions unaffected siblings may experience and things to look out for to help prevent more serious challenges.

- Some siblings feel guilt at times for being able to do things that their sibling is physically unable to do or that they do not have to face other challenges their siblings do.
- Some siblings strive for perfection because they see the extra care and time that their parents spend with their sibling with SMA. They worry about bringing further stress to their parents and thus strive to be as “perfect” as possible.
- It is expected that siblings will feel frustration, at times, due to the additional time and attention that their sibling with SMA may receive from their parents. This can also lead to feelings of isolation or loneliness at times, depending on the needs of their sibling.

Despite the difficult emotions that siblings may experience, there are also many positives that help shape them into caring individuals. Personality traits like independence, sensitivity, and empathy are common traits amongst siblings. They grow up learning the strengths in differences and the value of creativity and flexibility. They see the world differently than those around them and, as a result, can also be excellent advocates for their siblings, themselves, and others.



Below are some easy strategies and tips to help everyone in your family feel valued and supported.

1. **Be open and listen to their perspectives and feelings.** Resist the temptation to solve their problems immediately. Problem solving can happen together if your child needs help in this way, but simply listening and hearing their frustrations or concerns is the first step in providing support.
2. **Try to regularly set aside one-on-one time to spend with your children without SMA.** This could be a walk or even just dedicated time before bed each night to read together or talk about the day. One routine that can be fun and help to connect is to discuss your “peak and pit” of the day each evening. Before bedtime, take some quiet time together to each share the best part and the worst part of the day. It’s a great way to spend one-on-one time together and connect amid busy schedules.
3. **Include siblings in decision-making, along with your child with SMA.** Decisions that affect the entire family can be made by you or you and your partner with input from each of your children. Teaching them to take some ownership and practice self-advocacy within family discussions is a useful tool for them as they grow and ensures they feel heard.
4. **Limit expectations on helping their sibling with SMA, especially at a young age.** When too many expectations are put onto children at a young age, it can take away from their childhood experience or give them too much control over their sibling with SMA. Both of which can put a strain on the sibling relationship. Helping with caregiving can certainly build character and many siblings benefit from it, but it is important for parents to make sure unaffected siblings get to be kids, too.

## WHEN TO SEEK MORE SUPPORT FOR YOUR CHILD

- Concerning changes in behavior across various areas of life – school, home, work, or in the community
- Constantly expressing feelings of hopelessness
- Excessive worry about the future
- Withdrawing from activities previously enjoyed with friends or family
- Significant changes in sleep or eating patterns
- Any self-harm behavior or expressed thoughts of suicide

If you observe these behavioral changes, reach out to a mental health counselor or your child’s primary care provider for guidance on the next steps to take to support your child.



# HELPING EXTENDED FAMILY UNDERSTAND WHAT SMA MEANS

Receiving an SMA diagnosis is difficult on the entire family. While your immediate family is most directly impacted, extended family may also be affected as well. As the parent receiving this diagnosis, you might expect extended family to be supportive and while that is true for some families, it is not always the case for others. Sometimes you may find extended family members that do not understand some of the changes you have had to make in your life or your child's life due to SMA. This can be difficult since we expect family to give us the support we need during a challenging time. Common ways extended family respond that are hurtful may include:



- Minimizing or denying the seriousness of the effects of SMA
- Questioning decisions you make regarding your child's treatment and care
- Giving unhelpful or unsolicited advice
- Showing favoritism amongst siblings, such as giving more attention to your child with SMA or doing the opposite, and only interacting with your child(ren) without SMA
- Not supporting or dismissing safety protocols you may follow for your child, such as missing a family gathering or holiday to avoid exposure to illness



If this arises, there are helpful reminders to keep in mind. First, although family members may not respond the way you hope, it is unlikely that it is due to them not caring. It is possible that they are also having a difficult time accepting the diagnosis—grieving or feeling guilty/bad for what you are experiencing with this diagnosis. They may not know the best way to respond and support you. As such, consider assuming the best in family members who change their behavior or attitude towards you or your child right after diagnosis before assuming they are purposefully trying to be hurtful.

Oftentimes, these conflicts can be worked out with a little grace for one another, honesty, and allowing everyone to be vulnerable and share their feelings. It is important to communicate openly and to set clear boundaries with them and explain what you and your family need to feel supported. You can also provide information and education to help your extended family members understand your family's experience. This may help if your family member does not understand SMA or if they are afraid of what SMA may mean for your child's life. Perhaps it would be helpful for that family member to connect with someone in the community who is in the same role as them (i.e., connecting your parent to another grandparent of a child with SMA, etc.).

If you have taken the time to try to educate and talk to family members, but they are still unwilling to change their unsupportive behavior, it is okay to accept that your family may not provide the support system you need and to move on. In doing so, it is important to remember that it is not your fault for your family's lack of support, so do not blame yourself. Blaming yourself will lead you to wasting valuable emotional energy that can be spent better elsewhere. You may find that you need to seek the support you need from other family, friends, or a counselor. At the end of the day, you should feel at peace with the decisions that you and your family make, regardless of what others may think of them.



## POSITIVE RELATIONSHIPS WITH PARTNERS

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Some couples find themselves growing closer during times of unexpected change, like an SMA diagnosis. They learn to lean on each other and communicate better. Other couples find themselves growing apart and not agreeing. Regardless of where you find yourself, continuing to be open and honest about your feelings and allowing your partner to do the same is helpful in working through obstacles in a way that is healthy for you both.

All couples experience conflict, but SMA can bring another layer of stress due to a variety of factors. For example, the financial costs connected to treatment and physical, occupational, or speech therapy can result in couples feeling pressured to manage the increased financial burdens. Additionally, some children with SMA need more physical assistance with day-to-day needs. It can be a challenge to ensure that each parent feels supported by the other when it comes to providing care for their child, and making sure there is a clear understanding of who is providing the care throughout the day and night. Making decisions together about treatment and care is crucial. Giving your partner an opportunity to share their perspective and priorities regarding these decisions will help everyone feel valued and heard. Difficult decisions cannot be avoided, but the way in which those decisions are made can result in either growing closer together or creating unnecessary conflict.

There are strategies to help couples work through challenging times. One option is to seek out support from a counselor who can sit with you and your partner and help work through challenges you are facing. Some people worry about meeting with a professional mental health provider, such as a therapist, because they are unsure of what the experience will be like or what others will think of this decision. As with stress in any area of your life, it is important to remember that caring for your mental health is important and should be treated the same as caring for your physical health. Just like it is necessary to meet with a medical doctor regularly to keep your body healthy, regular check-ins with a mental health professional can help you stay emotionally healthy. Having a neutral person help sort through the myriad of emotions that you and your partner may be experiencing can help to simplify the process and focus the discussion on tangible strategies.

Another strategy that can help is to set aside time to spend together. The length of time spent together is not important. What is important is the consistency and quality of time spent together. Setting aside a little bit of time at the end of each day or scheduling a weekly date time (and sticking to it) is vital in staying connected. In the busyness of life and the whirlwind of day-to-day activities, it is easy to become disconnected from your partner. Focusing on one another, even for a just short period of time each day, helps to repair the division that can inadvertently happen while you are busy caring for your children. And given how chaotic schedules can be at times, it can be tricky to find the time. You may need to ask for help to make it happen or get creative, but it will be worth it when you can feel more connected to one another.

Lastly, and most importantly, each parent processes a diagnosis like SMA differently. There's no right way to do so. Some people need time and space to process new experiences, while others like to talk it out. As a result, one of you may be inclined to reach out to other parents online or in support groups to share experiences and the other may be more withdrawn and need to work through their feelings on their own. All of this is typical and to be expected. Feelings of guilt or blame are also common due to the inherited nature of SMA. It can be difficult to admit these feelings but providing space for you and your partner to be vulnerable with one another, sharing in the pain and difficult parts of SMA, can serve to strengthen your relationship and your ability to work through challenging times together.

# POSITIVE RELATIONSHIPS WITH FRIENDS



Many parents experience changes in their friendships in the years after receiving an SMA diagnosis. You may find that suddenly your schedule becomes busier than it has been, filled with appointments for specialists, treatments, and therapy. When you are trying to adjust to what life looks like with SMA in it, it's normal to spend more time focusing on your family and yourself. Some friends will understand this, and others may not and feel like you're suddenly distant.

If you find that some of your friendships are changing, give grace to your friends and require it from them, too. Be honest and open. Accept that your existing friends may not understand what you are experiencing but it is also okay for you to expect them to understand that your lack of time and energy is not a reflection of your feelings towards them. You are simply trying to adjust to a significant life change. Friends who give one another grace and assume the best in one another can create friendships that last. Above all, it is important to remember that, it is completely normal for friendships to change over time and a significant life event such as an SMA diagnosis can certainly be cause for relationships to change.

For example, you may find yourself growing apart from friends that you used to be close to. After experiencing an SMA diagnosis, your priorities may be shifting, and some friends may not be able to understand why. Be open to that potential change and cultivate the friendships that matter most to you. Many people have shared that they learned which friendships in their lives were the strongest after an SMA diagnosis because those were the friends that stuck with them through the hard times, lending a non-judgmental ear to listen or a shoulder to cry on. Just like we learn and grow through difficult times, so do our relationships. You will likely find that some of your friendships deepen and become stronger as you rely on your friends for more support.



It is likely that you will meet and become close with other parents within the SMA community as you hear of similar experiences and begin to feel a sense of belonging with others who have children with SMA. There is no quicker way to build a friendship than to hear another parent describe an experience just like you have been having and being able to reach out to them and say, "That's how I feel, too! I thought I was the only one!" Indeed, you are never alone once you and your family join the SMA community. We are a community that is large, diverse, and welcoming with many ways to connect. Cure SMA hosts in-person events throughout the year—including local one-day symposiums and an annual national conference—that allow you and your family to connect with others. There are also many online support resources that you can seek out. It can be quite useful to be able to browse posts and read comments to gain the perspectives of others and their helpful ideas. This can guide you in finding other families whose experiences are like yours. It is powerful being able to connect with another parent who has been where you are now.

**Reach out to Cure SMA at any time if you need help connecting to a family with similar experiences as your family. It's our goal to help connect you to whatever support you need.**

# SINGLE PARENTING

Parenting is a challenge at times, without adding any unexpected twists like an SMA diagnosis. And if you are a single parent, upon diagnosis, there may be moments when you wonder how you are going to handle added appointments, at-home therapies, and learn how to support your child's use of new equipment on your own. Remember that you are not alone. There are many single parents who have walked this path and are here to support you. Please do not hesitate to reach out to us at Cure SMA to get connected.

Below are more helpful topics to consider as you move forward. Each family situation is unique, so not everything here will apply to you. We do hope you will find some of the topics below to be helpful as you move forward.

- 1. Connect with others who are single or co-parenting.** Online or in-person support groups in your local area can help you find others with similar experiences, worries, and hopes who you can bond with and who can support you.
- 2. Create a consistent routine or daily schedule.** If you are recently separated from your partner, consistency can help your child(ren) feel more stable. Consider working with your co-parent partner to keep a similar schedule while your child is at their home.
- 3. Remember to ask for help from others when you need it.** Parenting on your own can often leave little time for you to care for yourself or have downtime. Even having a trusted friend or family member come to spend time with your child while you take some time to read a book or watch a movie at home can help to refuel your energy. Practical help like asking a friend to drop off a meal, pick up groceries, or help with laundry is okay to ask for, too. Your loved ones want to help but may not know what would be most helpful. It's okay to ask them for the specific help you need.
- 4. Seek out counseling to help you and your child talk about and cope with any stress that is arising.** Separation and divorce can be difficult for everyone in the family, whether it has recently occurred or not. A non-biased person to listen and provide strategies for coping can make all the difference in maintaining relationships and everyone's well-being.
- 5. Insist on clear communication.** Share a family calendar with your co-parent partner to keep appointments and schedules organized. Consider setting up a group chat or email thread for therapists or school staff to be able to communicate easily and directly with both parents quickly. Keeping everyone on the same page as much as possible can help to prevent conflict and help everyone feel included in decision making.
- 6. Identify community resources and programs that can help offset the cost of equipment, monthly bills, or medical insurance.** You may find your financial situation changing after a divorce or separation. Community resources like those noted above exist to help people who are in need. You won't always need to utilize the support, but it can be invaluable in helping to decrease stress around finances until you find yourself in a more stable situation.



Remember to trust in your strengths and in the strengths of your parenting partner. Talk about your goals together and ways to achieve those goals. Focus on the positives and what you can control and accept help from others when you need it. Soon enough, you'll find a new routine that works for all.

# PREPARING FOR SCHOOL DAYS

Although your child may be a few years from attending school, it's possible you may already be wondering what changes SMA could bring to what you envision school to be like for your child. The most important thing to keep in mind is that no matter what accommodations need to be put in place, children with SMA can and do have exciting, fun, successful experiences at school with their teachers and peers. As with many things related to SMA, there will be some pre-planning needed, but your child can have the same experiences at school as all their peers. Cure SMA has many school related resources available to you when the

time comes so please reach out to [familysupport@curesma.org](mailto:familysupport@curesma.org) to learn more. The article here shares one parent's perspective on how they worked together with their child's school to result in a wonderful experience for their son, who lives with SMA.



## Making It Work

*Kimberly Cook*

I must smile to myself sometimes when I think of some of the crazy things, we have done to meet the needs of our son, Spencer. My favorite has always been the emergency plan we developed when he was in second grade, which involved several dollies, lots of bungee cords, and all staff on board. Because Spencer was not always in his wheelchair during class—he often wore leg braces for standing at his desk—my biggest concern was getting him out of the school building if something went wrong. There was no way to get those braces off and Spencer into his chair quickly enough. But he was small: we figured out that with a dedicated person responsible for his transport, we could strap Spencer to a dolly and ensure he was always the first person out of the building during a drill. So, we put a dolly in every classroom, and I got my peace of mind. (Was this the safest option, in hindsight? Maybe not. But at age 33, Spencer still remembers those drills fondly!)

Whether planning for an emergency or for an average school day, I often had to think outside the box—not only as Spencer's parent, but as an educator, too. I befriended many teachers to broaden access to programs, curriculum,

environment, and social activities so children with unique needs, including my own son, would be faced with opportunities, not barriers.

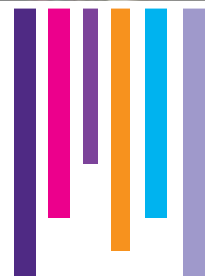
Physical education was often a tough one as far as access and participation, but it wasn't always an insurmountable challenge. Spencer was a star hockey goalie: his power chair perfectly prevented the puck from getting through to the net and he was usually chosen first for a team. When it came to other activities, like the class play, we made sure the whole show was inclusive. When Spencer played Rafiki in his school's production of "The Lion King," he held a stuffed lion in the middle of the gym while his peers circle him, acting in different animal roles. Each student wore a mask rather than a full costume, eliminating the need to "dress" Spencer's wheelchair. Instead of sitting on the floor to face the stage, the audience sat in the bleachers to watch the show with no obvious accommodations and Spencer seamlessly included—a beautiful thing to watch on its own.

What I've learned from our experiences with Spencer is that the easiest solution is often the best solution—less expense, less trouble, less time. A red tipped dowel stick was a great replacement for raising a hand in class. The hook we attached to the side of Spencer's wheelchair always held his service dog's leash securely. And the chest strap cut from an old wetsuit held up well enough to get him to his summer job. His power chair and a few simple accommodations continue to ensure Spencer's participation in his community. And in case of emergency, we do still have a plan in place. It's just as inventive as the original—even though Spencer has graduated from the dolly. That's why there's always a wheelbarrow in the yard and a designated friend to get him to safety if need be.

# TRAVELING WITH SMA

This topic may not be at the forefront of your mind right now, if your child was recently diagnosed at a young age and you are new to the SMA world but we felt it was important to mention for future reference. Traveling when children are young may not require many adaptations or special pre-planning, but you may find as your child grows, that planning becomes more involved if your child travels with a wheelchair or other medical equipment. The good news is that if that time comes, the SMA community has a wealth of knowledge to share with you to help your family plan wonderful vacations!

Although travel can sometimes be a challenging endeavor for individuals with a disability, the benefits of having new experiences, in new places, and meeting new people often far outweigh the challenges. You do not have to rule out seeing all the sites you have dreamed of because you are unsure of how you will make it work now. You will learn that necessity truly is the mother of invention and that you and your family can still make wonderful memories traveling the world, if that is important to you. Many individuals opt to “hit the road” in search of travel adventures so as not to have to deal with complications that can arise while flying with medical equipment. Cure SMA has travel related resources available to you when the time comes so please reach out to [familysupport@curesma.org](mailto:familysupport@curesma.org) to learn more. No matter what your travel goals are, a little extra planning, patience, and flexibility can result in memorable trips and experiences.



# CONCLUSION

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Throughout the booklet, we highlighted several resources to further support you and your family. If you'd like more information on these resources, please reach out to [familysupport@curesma.org](mailto:familysupport@curesma.org).

We hope that this booklet has helped you feel supported and know that you are not alone. While your life may not look or feel quite the same after you learn of your child's SMA diagnosis, those who have walked this path before you are always here to encourage you, give you hope, and invite you and your family to leave your own unique, positive impact on the SMA community. Years from now, as the poem below suggests, we hope you have found that life has been more wonderful than you could have ever imagined when you first heard the words "spinal muscular atrophy."



# WELCOME TO HOLLAND *(Part 2)*

By Anonymous

I have been in Holland for over a decade now. It has become home. I have had time to catch my breath, to settle and adjust, and to accept something different than I'd planned.

I reflect on those years of past when I had first landed in Holland. I remember clearly my shock, my fear, my anger—the pain and uncertainty. In those first few years, I tried to get back to Italy as planned, but Holland was where I was to stay.

Today, I can say how far I have come on this unexpected journey. I have learned so much more. But this too has been a journey of time. I worked hard. I bought new guidebooks. I learned a new language and I slowly found my way around this new land.

I have met others whose plans had changed like mine, and who could share my experience. We supported one another and some have become very special friends. Some of these fellow travelers had been in Holland longer than I and were seasoned guides, assisting me along the way. Many have encouraged me. Many have taught me to open my eyes to the wonder and gifts to behold in this new land. I have discovered a community of caring. Holland wasn't so bad.

I think that Holland is used to wayward travelers like me and grew to become a land of hospitality, reaching out to welcome, to assist, and to support newcomers like me in this new land. Over the years, I've wondered what life would have been like if I'd landed in Italy as planned. Would life have been easier? Would it have been as rewarding? Would I have learned some of the important lessons I hold today?

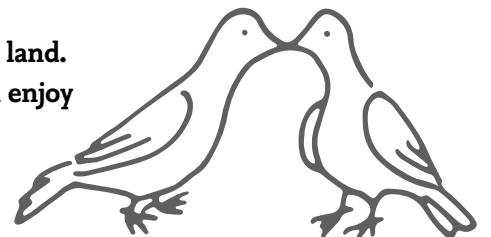
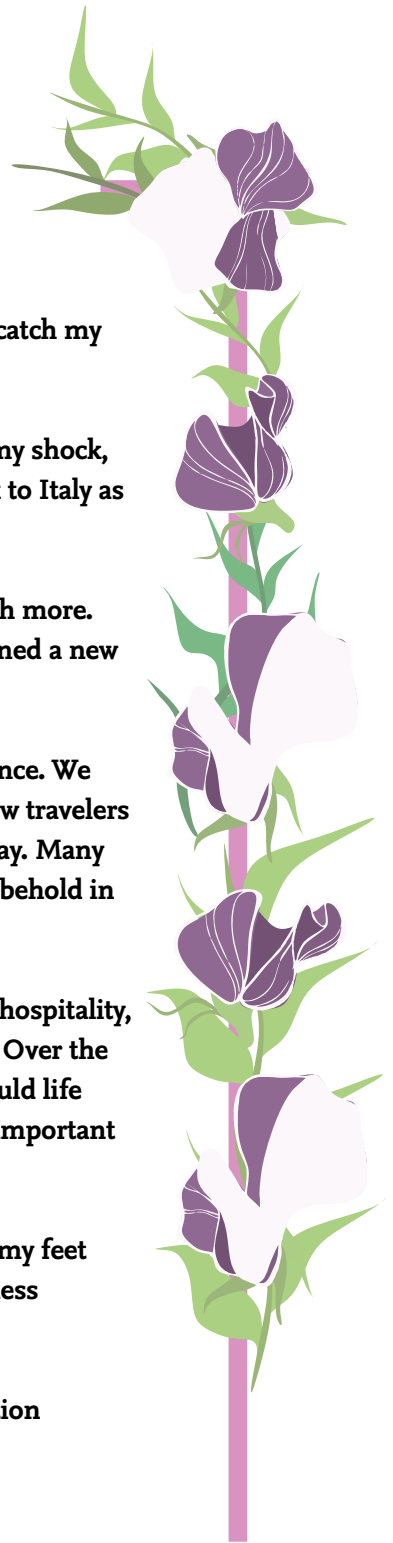
Sure, this journey has been more challenging and at times I would (and still do) stomp my feet and cry out in frustration and protest. And, yes, Holland is slower paced than Italy and less flashy than Italy but this, too, has been an unexpected gift.

I have learned to slow down in ways, too, and look closer at things, with a new appreciation for the remarkable beauty of Holland with its' tulips, windmills, and Rembrandts.

I have come to love Holland and call it Home.

I have become a world traveler and discovered that it doesn't matter where you land. What's more important is what you make of your journey and how you see and enjoy the very special, the very lovely, things that Holland, or any land, has to offer.

Yes, over a decade ago I landed in a place I hadn't planned.  
Yet I am thankful, for this destination has been richer than I could have imagined!





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*Last updated June 2021*