



CURE SMA

CARE SERIES BOOKLET

A SOURCE OF INFORMATION AND SUPPORT FOR INDIVIDUALS LIVING WITH SPINAL MUSCULAR ATROPHY AND THEIR FAMILIES.

CARING FOR YOUR EMOTIONAL AND MENTAL HEALTH



Make today a breakthrough.

UNDERSTANDING EMOTIONAL AND MENTAL HEALTH

Receiving a Life-Changing Medical Diagnosis

When someone receives a serious and life-altering medical diagnosis, there are bound to be a wide variety of emotions experienced—from shock and sadness to anger and frustration and every emotion in between. No single person’s experience is the same and there is no right or wrong way to feel or cope with the emotions you experience. What is important is that you face what you’re feeling and find the support you need to work through the emotions and care for your mental health, which is just as important as your physical health. Changes in care and symptoms will be ongoing and learning how to cope with the emotional side of managing a medical diagnosis like spinal muscular atrophy (SMA) is important. This booklet will outline mental and emotional health considerations for those with SMA or those who care about someone who has SMA, as well as strategies for support and coping.

What is Emotional Health vs. Mental Health?

People define these terms differently. In this booklet, we mean the following:

- Mental health refers to how we process information and experience that information. It is the result of our emotional, psychological, and social well-being. Some refer to it as “matters of the mind.”
- Emotional health is how we manage and express our emotions. In comparison to mental health, some may refer to it as “matters of the heart.”

The two are intertwined. Your mental health has an impact on your emotional well-being and vice versa. Lastly, our emotional and mental health can change day-to-day or hour-to-hour, depending on what we are experiencing.

Chronic Illness and Its Impact on Mental and Emotional Health

It is no secret that managing chronic illness can take a toll on one’s mental health, too. Constantly experiencing symptoms of a disease that does not go away can result in feeling angry, depressed, frustrated, and more. A primary cause of this is the obvious lack of control that a chronic health condition presents to those with it and to their families. So much is outside of one’s control when it comes to illness. It is not uncommon for individuals coping with chronic medical issues to also deal with anxiety and/or depression.

The good news is that both are treatable and manageable through seeking professional care and support from others. One way to help address these challenges is to seek out support groups, either online

or in-person. Others who are experiencing similar symptoms as you can provide support by listening, validating your experiences, and sharing strategies for coping. It can also be very helpful to meet with someone who is not part of your family and can provide you with an unbiased, objective perspective. A counselor (often referred to as a therapist) can also provide you with useful strategies and activities to employ when you are feeling overwhelmed at home or in the community. You may also be connected to a social worker, a psychologist, or psychiatrist. These are all different professions that can help support you.



ANTICIPATORY GRIEF

Some individuals, both those with SMA and those caring about someone with SMA, experience what is referred to as “anticipatory grief” after receiving the news of the SMA diagnosis. Anticipatory grief is when one grieves a loss that has not yet occurred but that they anticipate may come. This may be a loss of ability such as walking, independence like feeding oneself, or worry about early death.

While the term includes the word “grief,” the result of this experience is an increase in anxiety and/or depression. A common sign of anticipatory grief is experiencing emotions without understanding the origin of those feelings. For example, one may feel angry, afraid, or generally unsettled without being able to identify why they are feeling that way. Because these feelings cannot be attached to a specific event (since the possible event has not yet occurred), it can be difficult to understand where these feelings are coming from or how to cope with them.

Experiencing anxiety about the unknown of the future can feel very isolating. It is important to remember that you are not alone and there are other individuals that are in the same situation as you. Cure SMA is here to provide you with support and to connect you with others in the community with whom you can relate.

Anxiety & Sleep

Many times, anxious feelings will disrupt our ability to sleep. The resources below can help our bodies and minds calm enough to fall asleep.

- www.audible.com/ep/sleep
This free resource provides sleep meditations and stories, tailored primarily for adults.
- www.newhorizonholisticcentre.co.uk/
This offers meditation and sleep stories specifically for children. You can also access free meditations and sleep stories on New Horizon’s YouTube channel. Additionally, New Horizon has a meditation app available to download for free, though some content is only available with a \$3.99 monthly subscription.

If meditation apps don’t help and your sleep continues to be disrupted due to anxious thoughts, reach out to your primary care doctor for more help.



ANXIETY

Anxiety is a normal part of life. Everyone experiences varying levels of worry and often individuals can manage these feelings without too much difficulty. Sometimes, however, feelings of anxiety can become overwhelming and can interrupt your ability to function in your daily life.

Anxiety can manifest itself into a general anxiety or specific phobias that result in anxiety. It can affect both children and adults. If you notice that worry or panic is preventing or interfering with daily activities at home, work, or school, it is recommended to seek out help from a mental health professional.

Symptoms of anxiety include:

- Feeling nervous or tense.
- Feeling that something “bad” is to come or you are in danger.
- Physical symptoms, such as rapid heart rate, sweating, shallow or rapid breathing, feeling exhausted, or gastrointestinal problems.
- Trouble concentrating.
- Trouble falling asleep or staying asleep.
- Avoiding activities that have to do with your panic or worry (e.g., never leaving the house or avoiding social interaction due to a fear of things that could happen).

A counseling professional can help you identify triggers for what is causing your anxiety and develop ways to cope with these overwhelming feelings so you can manage the anxiety without it interrupting you and your family’s daily life.

Grounding: A Simple Exercise to Combat Anxiety

“Grounding” is a way to use your five senses to bring your focus back to the present when your thoughts are spiraling into an anxious space. It is a simple exercise you can do at any place or time to help decrease your level of anxiety.

Sit in a comfortable spot and close your eyes. Inhale deeply and slowly, holding your breath for three counts, and then slowly releasing your breath. Open your eyes and do the following:

- Name 5 things you can see.
- Name 4 things you can feel.
- Name 3 things you can hear.
- Name 2 things you can smell.
- Name 1 thing you can taste.

Finish with a deep, cleansing breath just as you started the exercise.



DEPRESSION

Depression can be a serious or mild condition that results in persistent feelings of sadness or lack of interest or joy in participating in daily life activities. Depression can affect anyone, so those directly or indirectly impacted by a neuromuscular disease, like SMA, may also develop symptoms. Thankfully, there are treatments for depression as well as ways to cope with and alleviate the symptoms.

Symptoms to watch for include:

- Consistently feeling sad or hopeless.
- Low energy level, poor sleep, or an increased desire to sleep.
- Physical symptoms, such as headache or gastrointestinal issues.
- Irritability and lack of patience.
- A lack of interest in activities previously enjoyed.
- A lack of motivation to care for one's self, such as caring for personal hygiene.
- A general disconnected feeling from those around you and a lack of interest in connecting.
- Inability to concentrate.
- Crying or mood dysregulation.
- Thoughts of suicide or harm to one's self.

It is important to remember that none of these symptoms, or even a cluster of these symptoms, necessarily indicate a diagnosis of depression. Many people experience these symptoms at one time or another. The key is to monitor for symptoms that are persistent, last over a prolonged period, and interrupt one's ability to function as they typically would at home, work, school, or in the community.

Although experiencing these symptoms can be isolating, you are not alone and there are treatment options. Professional counseling can help you develop strategies and interventions to cope with and alleviate feelings of depression. Medication may be able to support your treatment and can also be explored with a mental health professional.

Do not wait to ask for help, no matter what you are experiencing. If a symptom or experience is creating challenges for you or your family member, reach out sooner rather than later to be connected to help and support.

If you or your loved one are experiencing any ongoing symptoms of depression, especially suicidal thoughts or thoughts of self-harm, it is important to talk to a trusted medical provider as soon as possible. To gain immediate support, you may call the National Suicide Prevention Lifeline at 1-800-273-8255. This line is available 24 hours a day, 7 days a week, at no fee, for anyone experiencing suicidal thoughts or emotional distress.

DISORDERED EATING AND HEALTHY BODY IMAGE

There is little research done on the comorbidity of physical disabilities and disordered eating; however, we do know that some research suggests that individuals with a physical disability are at an increased risk for developing an eating disorder. There is much to learn surrounding these topics still but given society's general outlook on physical appearance and the emphasis to look a particular way and be "in shape," it should be no surprise that those with a physical disability may experience stress as a result.

Although some progress has been made towards inclusiveness, disabled bodies are still not often represented in media, perpetuating the notion that there is a "right" way to look, which is harmful. This is particularly important to keep in mind as children grow. There is much to learn regarding the etiology of disordered eating amongst those living with a physical disability but there are common sense ways to help you or your loved one develop a positive sense of self, positive body image, and confidence. For instance, help young children learn that each body is made to look differently and may work differently, depending on the person and that those differences are good and to be celebrated. Share children's books that celebrate differences, from body shapes to physical abilities. This helps to build self-confidence as they learn that all bodies are valued and important, not despite of but because they are so diverse.

For caregivers, it is helpful to avoid placing value or judgement on their loved one's physical appearance and weight. Individuals who need assistance being transferred or lifted can grow self-conscious and tired of hearing a parent or caregiver mention how much they weigh when they are being lifted. Repeatedly hearing this can result in a child or adult feeling they are a burden or they may become fixated on their weight. This can result in disordered thinking about eating which can lead to an individual limiting food and losing weight in an unhealthy manner.

If you notice a change in eating behaviors and have concerns about a loved one, share it with them directly and encourage them to seek help from their medical provider.

Words Matter: Teaching Self-Love

Here are some "dos" and "don'ts" to promote self-love and body-positive thoughts:

DO:

- Talk to a professional physical therapist about the best way to do lifts and transfers without injuring yourself and about accommodations or equipment that can be helpful in lifting, transferring, and picking items up.
- Consider a safe, reasonable exercise program to help you increase your lifting capabilities.
- For growing children, highlight the actions and positive activities that their body provides for them.
- Practice self-love for yourself and model self-love for others around you.

DON'T:

- Grunt or make noises when lifting. This can make someone self-conscious and even send a message of judgment of someone's weight even though unintentional.
- Say things like, "Oh, you are getting really heavy!" or some similar version of this kind of statement.
- Talk about how lifting or bending over to pick up items is becoming difficult for you in front of the person you care about.



SUBSTANCE MISUSE

Substance misuse is using alcohol or drugs in a way that has a negative impact on one's daily routines and responsibilities at work, school, home, or the community. Substance misuse can occur one time, occasionally, or consistently. Individuals who consistently misuse substances can be diagnosed with a substance use disorder.

General understanding of substance use disorders and addiction is changing, and it is understood now that substance use changes how our brains function. Therefore, it is understood as a medical brain disorder versus a moral failing or individual weakness. It is important to understand this so that if you or a loved one are struggling with substance use, there are not feelings of shame or guilt in seeking help. Just as you would seek medical care for a physical health symptom that is bothersome to you, you can seek care and treatment for substance use that you notice is growing out of you or your loved one's control.

Learning how to cope with the emotional side of SMA can be challenging. There are often fears associated with the unknown of how the disease will progress overtime and what kinds of challenges you or your loved one may face. If you notice yourself or someone else using alcohol or drugs to cope with stress, "take a break" from reality, or "let off steam" with increasing frequency, you should feel comfortable talking to a medical provider about your concerns. There are treatment options and support available to you and to your loved ones to ensure that you can feel more confident in managing any increased stress that you are experiencing.



HEALTHY STRATEGIES FOR COPING

Consistent physical health check-ups are a part of life that are generally expected and accepted. What is often not prioritized is caring for our emotional and mental health. For many of us, if we scheduled a “mental health check-in” annually, the same way we go about getting our blood pressure and cholesterol checked, we would be able to better manage the day-to-day stress we experience. Then, when we faced a life-changing diagnosis like SMA, we would have resources readily available to rely on. Now that you or your loved one has received an SMA diagnosis, feeling supported in caring for your emotional health is important.

Mental Health Counseling

Many people search for a professional counselor or psychologist to meet with regularly after receiving a life changing diagnosis like SMA. They may continue for months or years and often decrease the frequency of sessions as time goes on and are feeling better equipped to manage their mental health. Some individuals may combine counseling with some kind of medication prescribed by a psychiatrist or MD. Others may also rely on support from a social worker on their medical team. Therapeutic approaches and philosophies will vary amongst clinicians and many therapists will combine different approaches to meet the unique needs of an individual. If your schedule or responsibilities make it difficult for you to leave the home, you can also seek out support that can be done via video or telephone. The key is that you find a therapist you feel safe and comfortable speaking openly with.

You may need to “interview” or speak with multiple potential therapists before feeling comfortable starting therapy. It is okay if you meet with more than one therapist before you find the right one for you. Once you begin working with a therapist, it is also important to remember that feeling some emotional discomfort at times is to be expected. Sometimes we must challenge our incorrect or errored beliefs and thought processes in a way that can make us feel unsettled. However, you should not feel unsafe or dismissed by any mental health professional. And over time, the emotions you are working through should start to feel more manageable and your outlook on being able to care for your mental health should also improve.

Counseling – What to Keep in Mind!

Common Types of Therapy

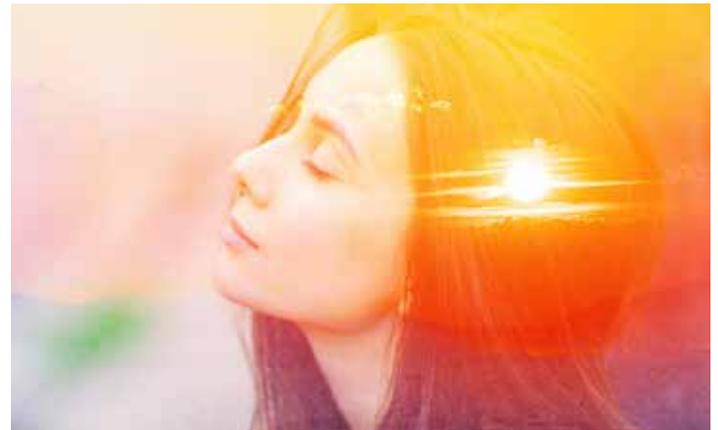
- Cognitive Behavioral Therapy (or CBT) – This focuses on inaccurate thoughts and perspectives that an individual has about themselves or the world around them. It explores how those thoughts affect their behavior, and a therapist can help you develop more positive thoughts and healthier actions, or behaviors.
- Interpersonal Therapy - This therapy focuses primarily on relationships and healthy ways to express emotions and relate to and interact with other people in your life. Licensed Family and Marriage Counselors - This therapy will focus on relational aspects of your experiences to help support you.

Helpful Tips for First Session

- Keep a journal of concerning symptoms, frequency, and any details that you feel might be helpful to discuss the experiences that often trigger stress or difficult symptoms.
- Prepare any questions or concerns that you would like to discuss at your first session.

Involving Other People in Your Therapy:

- Some therapists specialize in Marriage or Family Counseling. If you feel it would be helpful to include others in your counseling, keep this in mind when looking for a therapist to meet your needs.



Support Groups

Another source of support can be found through in-person and online support groups. These groups can be formal or informal, ongoing or short-term groups. As recommended for finding a counselor, it is best to try out multiple groups until you find the one or ones you feel comfortable sharing in. Being amongst others who have similar experiences can be profoundly healing when you are facing difficult times. If you are a part of a faith community, you may want to reach out to your spiritual advisor for guidance for potential support groups in your community that may be helpful.

Both online and in-person support groups can:

- Help to reduce feelings of isolation and loneliness.
- Give you a space to talk openly and honestly without being judged by others who do not understand your experience.
- Help you feel more in control by learning what to expect as others share their experiences.
- Help to reduce the feelings of anxiety or depression.

Practicing Mindfulness and Being Present

Much of the stress that exists after a diagnosis like SMA is caused by the unknown of what to expect in the future. One way to combat anxiety over the unknown is to practice mindfulness. Practicing mindfulness, or meditating, means to train your mind to return to the present any time it wanders to the future or the past. It is to focus on how you feel, see, and what you are experiencing in the moment. It does not mean that your thoughts will never wander to past regrets or to future worries but that when that happens, you calmly refocus your thoughts to the here and now.

Practicing mindfulness can help to reduce anxiety, sleep better, lower stress levels, and release distracting negative thoughts. Mindfulness is most beneficial when it is practiced regularly. If you are interested in learning more about the benefits of mindfulness, speak with a mental health professional in your area and check out available apps.

At Your Fingertips: Mindfulness Apps



- **The Mindfulness App** can suit both those new to meditation and those already familiar with the practice. This app is free for Android and iPhone devices, with additional content available for purchase.
- **Headspace** provides guided meditations for daytime use or for nighttime to help with falling asleep. This app is free for Android and iPhone devices, with additional content available for purchase.
- **Calm** includes calming exercises, breathing techniques, and a section devoted to children aged 3-17 years. It also includes nighttime meditations to help you relax into sleep. This app is free for Android and iPhone devices, with additional content available for purchase.

BUILDING RESILIENCY

Resiliency is one’s ability to adapt and “bounce back” from traumatic or life-altering challenges. According to the American Psychological Association, there are four primary elements that serve to increase one’s resiliency.

- **Building Connections:** Connecting with others and sharing your experiences will help you build relationships that can support you during challenging times, helping you to not feel alone.
- **Caring for Physical Wellness:** This means focusing on getting restful sleep when you can, exercising in a way that works for you, eating well, and staying hydrated. These simple activities can help to boost your mood and confidence to manage stressful times.
- **Healthy Thinking:** We have highlighted the importance of mindfulness and staying in the present with your thoughts. Practicing these strategies help you overcome challenges without becoming stranded in them, while staying realistic and focused on what we can control and have a meaningful impact in our lives.
- **Finding Meaning in Challenges:** It can be helpful to look for an opportunity for personal growth in difficult experiences. Finding a way to have purpose and have a direct, positive impact on the challenge you are facing can be a coping tool during challenges times.

A lot of information was just discussed in this booklet and much of it may be difficult to initially absorb, but one of the key takeaways we would like for you to always remember is that **you are not alone**. Cure SMA is here to help all individuals with SMA and their loved ones by providing unbiased resources and mental health support needed to build resiliency and feel empowered to overcome the challenges that SMA may bring. We are committed to providing opportunities in advocacy, fundraising, and engaging with the community. These opportunities can help individuals with SMA and their families find meaning in the challenges they face by supporting and having a positive impact on the community that they are now a part of.

You are now also a part of the SMA community, which is here to welcome you into a space where you can feel understood and connected to those around you. The SMA community is an incredibly caring and strong community that will help you and your family navigate life with SMA. It won’t be easy and you will have many challenging days, but if you prioritize your mental health and communicate openly and honestly, you can have many more good days than bad.

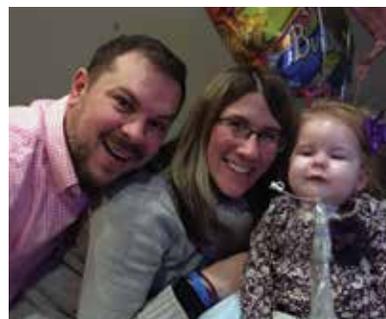


CURE SMA



Cure SMA is a non-profit organization and the largest worldwide network of families, clinicians, and research scientists working together to advance SMA research, support affected individuals/caregivers, and educate the public and professional communities about SMA.

Cure SMA is a resource for unbiased support. We are here to help all individuals living with SMA and their loved ones, and do not advocate any specific choices or decisions. Individuals and caregivers make different choices regarding what is best for their situation, consistent with their personal beliefs. Parents and other important family members should be able to discuss their feelings about these topics, and to ask questions of their SMA care team. Such decisions should not be made lightly, and all options should be considered and weighed carefully. All choices related to SMA are highly personal and should reflect personal values, as well as what is best for each individual and their caregivers.



Remember that your healthcare team and Cure SMA are here to support you. To continue learning, please see other available Care Series booklets:

- Breathing Basics
- Caring Choices
- Genetics of SMA
- Musculoskeletal System
- Nutrition Basics
- Understanding SMA



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Last updated December 2020