



# Learning to Live with Neuromuscular Disease

*A Message for Parents*

*At first we were devastated and felt quite helpless . . . Since then we've learned a great deal, most of it very hopeful. We've also found inner peace with the challenges facing us, and enjoy a full, rewarding family life. In time, you'll find that having a child with a disability isn't as isolating or frightening as you may fear . . . Most important, your love for your child will give you strength.*



This booklet is for parents who've recently learned their child has a progressive neuromuscular disease. Although medical interventions and technology have advanced dramatically over the years, and real hope exists for cures and treatments, neuromuscular disease still inflicts a heavy emotional load on parents and families, sometimes pulling them apart.

We hope that the strategies, advice and encouragement contained in this booklet will enable you to develop effective coping patterns that strengthen you and your family.

We're grateful to Sylvia E. McGriff for writing the original copy for this booklet in 1981, in such basic, practical terms that its message is timeless. McGriff, a licensed psychologist, holds a Ph.D. in clinical psychology.

We're also grateful to Scott Bennett for writing the foreword on page 3, and to MDA health care service coordinators and support group leaders. Finally we thank all the parents and children who have so generously shared their experiences and knowledge so that you'll know you're not alone.

**MDA**® Muscular  
Dystrophy  
Association  
Fighting Muscle Disease

*All of the artwork in this booklet is from the MDA Art Collection and was created by children with neuromuscular diseases.*

# It's All Where You Put Your Focus



*Scott R. Bennett*

When I was 18, I informed my doctor I'd be attending college in the fall. Later, he asked to speak to my parents privately. He told them that, because I have Duchenne

muscular dystrophy (DMD), they shouldn't expect me to survive to graduate.

Well, I finished college. I'm now in my 40s and working as a software engineer. Ironically, five years after making that statement, the doctor passed away.

Most predictions are based on statistical averages and not absolute certainties. In fact, the most accurate prediction that can be made is that you and your family should be prepared for anything.

Maintaining a positive attitude is certainly difficult, but just as certainly it will help your child do the same. I think the most important thing my parents did for me when I was growing up was to treat me the same as my nondisabled brother and sister, with the same expectations, while still helping me to deal with the physical limitations of my disability.

I hope you and your family will learn together how to live with and adapt to your child's neuromuscular disease, like making it part of a school project. You'll probably find that by working together, you're helping both your own and your child's emotional stability move further along. Yes, challenges lie ahead, but you'll also deal with those together, when the time comes.

When I was 15, my dad asked me if I was mad at God for giving me DMD, because he was. My response was that I wasn't angry at God or anyone else. Someone had to get this disability, so why not me?

My disease was due to a random genetic mutation and no one was to blame. I had to learn to adapt my life to my disability, I explained. I think that response made my father feel a lot better about my having DMD.

I've never felt that I was facing a fatal disease, but rather a disease that meant my life span would probably be shorter than average. I guess it's all in how you look at it. Rather than focusing on quantity — how many years of life — focus on quality — how much life in those years.

***Scott R. Bennett***  
***Software Systems Engineer***  
***Taunton, Mass.***

# Taking on the Challenge

The stress reaction is the body's response to a challenge. It's a state of heightened physical tension that prepares you to take action to deal with the challenge. A little stress is useful at times of threat. It can keep you alert and on your toes. But stress can get out of hand and become overwhelming, so that it prevents you from coping with the very threat that has produced it. Headaches, nausea, insomnia, muscle stiffness, accidents, and inability to work all can be signs of too much stress. Severe or prolonged stress can make you vulnerable to a number of serious illnesses. To safeguard yourself and your family in the days ahead, it's crucial for you to bring your stress down to a manageable level so that you have the energy to sustain the intimate, emotional relationships we all need.

When we believe we lack the resources to cope with a serious problem, intense anxiety results. People handle that anxiety in different ways. Many distort the situation to relieve their distress. Sometimes, for example, parents will not accept the diagnosis of progressive neuromuscular disease for weeks or even months. This flight from reality is one way people try to ward off painful feelings — by refusing to face the truth.

Others defend themselves with another kind of distortion — inappropriate anger. They may get angry with the physician who made the diagnosis or with the doctors who failed to make it earlier. Their anger may be directed at a world, at a universe, in which a disease like this can be visited on a child, or even at a Supreme Being who allows such a disease to occur.



*"Fishing" by  
Shawna Borman  
spinal muscular  
atrophy, type 2*

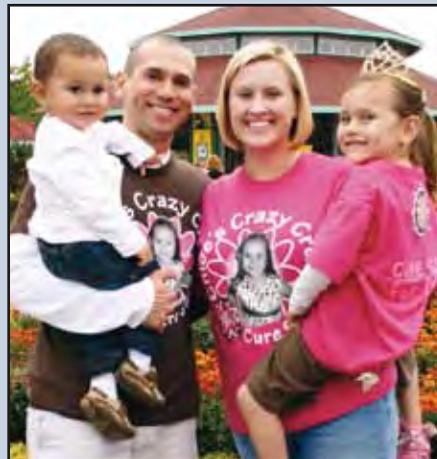
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Or they may become angry with themselves and/or their spouses for bringing a child with neuromuscular disease into the world. This response channels the force of their feelings away from the actual problem in order to cut off unbearable anxiety and fear.

You will have taken a giant step toward coping if you are able to realize in your innermost self that the stress you are experiencing can be managed ... that you have the capability to do it ... that there is a network of support available to help you do it. As a start, test yourself. Recall difficult times in your life when you have coped successfully, although it had often seemed you would not be able to. Make a list of friends, relatives, and other individuals you have been able to count on in past crises, and in this present one add the Muscular Dystrophy Association as a firm source of support.

Also, begin now — in your mind's eye — to create images of coping, visualizing how it would be to break through your feelings of despair. Your inner conviction about this will act as a self-fulfilling prophecy. You will cope if you believe you can.

*When we first learned our child's diagnosis, we naturally were very frightened and uncertain about the future. As time has unfolded, we've learned that we can do things we didn't think were possible — we can adapt to the uncertainty, control the fear, cope with changes as they occur and still have a "normal" happy family life.*



# Keeping Hope Alive

*by Albert Freedman*

I remember the simple congratulatory message I received from a friend a few days after Jack's birth. "You are now a family," she wrote, quite matter-of-factly.

Yes, indeed we were a family, and I'll always remember the hope baby Jack brought to our lives. I remember thinking about birthday parties, ballgames, bicycle rides, and perhaps a little brother or sister, or even two. For the first six months of Jack's life, I pictured myself coaching his Little League team and taking him to Phillies games. I pictured myself watching Jack perform in his elementary school play and play in the school jazz band just like Dad.

Those early days of parenthood were full of possibilities.

And then one day, the possibilities began to fall away. First, our pediatrician told us Jack wasn't developing normally. Then a pediatric neurologist expressed serious concern and told us to have further testing.

A few minutes after conducting an EMG test, the doctor told us Jack was likely affected by a neuromuscular disease called spinal muscular atrophy (SMA).

The doctor told us there was no treatment or cure for SMA. Jack would be severely physically disabled, and then he would die of

respiratory complications. Babies with his type of SMA were lucky to live to age 2, the doctor reported.

The doctor explained we would have an appointment with another specialist later in the day to hear more about SMA and how we would care for Jack for the next few months. He motioned to us to stay put with Jack in the examining room.

"Take all the time you need," the doctor said. Then he walked out and closed the door, leaving us with each other, our baby and our thoughts. But the doctor didn't leave us with any hope.

## Rebuilding hope

In a matter of minutes, Anne and I were thrust into a parenting world light-years from where we'd started.

Somehow many of us rediscover our sense of hope, a little at a time. And when we keep hope alive, we find ourselves feeling more positive and better prepared to care for our affected family members.

Today, I feel very fortunate to be Jack's father, despite the challenges my son faces. Slowly, as these years have passed, hope somehow has returned to my vocabulary and to my heart.

The words of others helped us reclaim and build our sense of hope one piece at a time. Through

organizations such as MDA, we contacted families with similar experiences who helped us feel we weren't alone. Jack's home care nurses, therapists and teachers all view him as a person worth getting to know, and they focus on what Jack can do.

Our MDA clinic became our primary resource for Jack's medical care. Even in the middle of the night during the scariest of medical crises, the professionals at the hospital somehow remain steadfast in their hopeful approach to caring for children. We continue to be lucky to have so many caring people in Jack's corner.

## Jack's hopes

It's easy to look at our son and see only his wheelchair. It's easy to listen to Jack and hear only his broken speech patterns and the words that can't be understood.

Entering Jack's bedroom, it's hard to miss the pulse oximeter, the feeding pump and the BiPAP breathing machine.

These are indeed things Jack needs, but these aren't the things Jack is focused on. These aren't the things Jack hopes for day-to-day.

Like any other 7-year-old, Jack hopes his friends will spend time with him. He hopes for birthday presents, family outings, holiday celebrations and success with his schoolwork. Jack hopes for new computer games. He hopes we'll take him places



*The Freedman Family*

with lots of space to zoom around in his power wheelchair. Jack hopes his little sister will be fair and take turns. He hopes to go swimming at the pool. And he hopes Dad will come home from work in time to give him a bath.

So it's Jack himself who now shows us the way, with his own sense of hope as our inspiration. Despite the many challenges he faces every day, Jack is a happy, motivated little boy who hopes for many of the same things other kids hope for. And seven years following his diagnosis, we're indeed grateful to have Jack sharing his hopes with us.

*Albert Freedman, Ph.D., is a child and family psychologist in private practice in West Chester, Pa.*

*Jack Freedman celebrated his 16th birthday in 2011.*

*Reprinted from Quest, February 2003, ©2003, Muscular Dystrophy Association Inc.*

# Facing Your Feelings

Your first task is learning to deal with your feelings in the most constructive way. The people who flee from their distress play a game of make-believe, pretending nothing has happened to disturb them seriously. But suppressed feelings have a way of backfiring, of taking control. Studies of people undergoing operations show, for example, that those who deny their fear do not recover as quickly as those who allow themselves to experience their underlying anxiety. Similarly, the more honestly you face the pain and shock of learning the diagnosis of your child's condition, the more quickly you will reduce your level of stress and gain a sense of competence.

Allowing yourself to get in touch with and experience your feelings does not put you at the mercy of uncontrolled emotions, but rather leads you to sources of strength. If you cannot acknowledge your feelings to yourself, you can't share them with those around you.

So denying your feelings has the hurtful consequence of cutting you off from the precious support that friends and loved ones can give you, support that is all-important in helping you to cope. The effect of denial is to build a wall between you and others — especially between you and your family, between you and the child you love. That child will experience you as



*"Friends" by  
Troy "T.C." Blackburn  
Duchenne muscular  
dystrophy*

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withdrawing and hostile, and will come to feel rejected and unlovable.

The energy generated by great stress can be used positively or negatively — the choice is yours. If the energy is used to deny reality or your feelings, it can't be used constructively. If the energy is channeled into prolonged anger and bitterness, it is no longer available for a positive response to your situation. Even more damaging, if it goes into attitudes of guilt and self-blame, it can undermine your self-esteem, your family and your marriage.

If you direct the tremendous force of this energy into coping creatively with your situation, however, it has the power to raise you and the members of your family to a new and more meaningful level of functioning, relating and living. Your attitude — the way you view your world — is what will determine the direction your life takes at this point. The well-known writer Richard Bach put it well: "What the caterpillar calls the end of the world, the Master calls the butterfly."

*It's very common for people to lose their sense of humor, or sometimes stop laughing altogether, when a child gets sick or becomes disabled. I strongly feel that is actually the time to keep laughing despite the fears and confusion which might be assailing us. We must develop and nurture a healthy sense of humor, look at the lighter and brighter side of things, and continue to laugh at life in the midst of our despair if we want to survive.*



# The Other Children in the Family

*by Christina Medvescek*

Siblings of children with neuromuscular diseases have a distinctive growing-up experience that shapes them in positive and, in some cases, negative ways.

It used to be thought that unaffected siblings would grow up “maladjusted” because of a lack of parental attention. But more recent studies have found that siblings’ adjustment level is generally good.

But the sibling experience isn’t easy, especially as children see their affected brother or sister decline physically. Sadness, resentment, jealousy, embarrassment, frustration, guilt and not a little fear — all are part of the story.

Siblings usually have the longest-lasting relationships in a family. It’s not uncommon for an adult sibling, having outlived the parents, to take on caregiving responsibilities for an affected brother or sister.

Families that foster a climate of security, belonging, love and caring — all the positives of a healthy family system — generally have children who cope well with the daily realities of neuromuscular disease, says Arden Peters, a psychologist who ran an MDA family support group in Wichita, Kan.

But a good family climate can’t guarantee that kids won’t struggle with their difficult

roles. Signs that sibs may be having trouble coping include: greater-than-normal bickering, anger, jealousy and complaining; acting out at school or home; sleep disturbances; clinging; and (ironically) overachieving and trying to be “perfect.”

How do you set a good family climate?

- **Be open and honest with kids about the disability.** “Parents should openly communicate about the disease process, treatment regime and especially their feelings,” says Laura Frobel, a social worker and MDA support group leader in Warwick, R.I.

When younger kids start asking questions about death, they’re ready to begin talking about it. If older children haven’t asked about death, maybe they’re worried they’ll cause something bad to happen by bringing it up.

“Children need to know that when parents cry about such things, it’s a sign of love and the children have done the right thing, not the wrong thing, in talking about it,” Peters says. “They need to know that mom and dad can handle tears and the child should never try to protect them.”

- **Listen.** Kids don’t always need you to fix things. A sympathetic ear and a hug can go a long way. Be strong enough to bear their “bad” feelings.

Says one mother, “After our son got his diagnosis, my oldest daughter asked if he would be in a wheelchair. She was concerned about him, and also about her being embarrassed. As much as I did not want to hear that, I had to let her express it.”

Counseling can be a valuable tool for some kids, but nontalkative kids may just need to know they can talk to you if they need to.

- **Treat them as individuals.** “Outside the home, children strive to be as much like others as possible. Inside the home, they want to stand out and feel special,” says Becky Speulda, social worker and MDA family support group leader in Portland, Ore.

Don’t lay on guilt by emphasizing how much luckier they are than their affected siblings. Find time to connect privately with each child. Give them private space. Take vacations that cater to their interests, not just built around hospital visits or physical limitations. Help them connect with a caring adult who is there just for them. Let overachievers know you love them for who they are, not what they do.

- **Don’t expect children to assume adult roles.** Caregiving is a character-building experience and many sibs say they’ve benefited from it. Too much caregiver responsibility robs siblings of their growing-up experiences, and can make them bossy and authoritarian.



How much is too much? The key is that the parents remain in charge, and that they ensure helper siblings get to be kids, too.

- **Remember they’re young.** Even though they understand intellectually that their siblings with disabilities need more attention, children don’t yet have good emotional control and often act immaturely. Be patient.

- **Plan for the future.** Even if you have few assets, it’s important to draw up a will, appoint guardians, outline your wishes for the affected sibling’s care, and establish a special needs trust, in case your affected child outlives you. Even a small inheritance can derail state and federal disability benefits, putting an additional burden on siblings. In addition, talk with older unaffected children about their possible status as carriers of a genetic neuromuscular disease.

*Excerpted from “The Other Children in the Family,” Quest, January-February 2004, © 2004, Muscular Dystrophy Association Inc.*

# The Importance of Reaching Out

You may have some work to do before you see your situation as a beginning rather than an end. Standing in the way of a positive attitude may be mistaken beliefs you hold, beliefs as to what your child's condition implies about you and your spouse. Your next task is to look squarely at these misconceptions and see them for what they are, for while the stress of coping with a child's neuromuscular disease can bring a husband and wife closer together, it also can drive them apart.

Parents often develop the superstitious conviction that their child's illness is a punishment for something they have done. You may not be aware of these thoughts and yet feel guilt-stricken for no logical reason. Your underlying thought may be, "What's wrong with me, with my spouse, or with both of us that we brought this disability upon our child?" Or, in another version, "Either I, my spouse or both of us are failures as parents because of our child's condition."

Ideas like these influence your feelings about your spouse and children and affect your behavior toward them. Although wholly without justification, such beliefs give rise to depression, guilt, and blame, the more so if your child's illness is an inherited condition.

If you are to maintain the caring relationship that is the foundation of your marriage, communication between you and your spouse must open up at this time. Allowing feelings of guilt and blame to cut off your support of each other can threaten your future together. You need to work through your feelings jointly if you can. By reaching out to each other, crying together, sharing your pain, you strengthen the bonds between the two of you and create for yourselves a safe and secure space in your relationship.



*"It's Wheely Art" by  
MDA summer  
campers*

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Husband and wife are likely to face separate emotional reactions to their child's illness. If the disease is transmitted through a defective gene carried by the mother, as it is in Duchenne muscular dystrophy, she may experience profound feelings of guilt. Although, clearly, a genetic disease is no one's "fault," she may blame herself and think that others are blaming her, and her feelings may drive a wedge between her family and herself. A father, especially if the child is a boy, may have a great difficulty accepting the fact that he has a son with a disability who will never be able to do some of the things fathers want their sons to be able to do.

Because men in our society are brought up to suppress their feelings, the father may find it very hard to cope with them now.

If you and your spouse need help in standing together at this time, it's important — both for the two of you and for your children — to turn to a physician, member of the clergy or other professional who can offer you guidance. Your efforts to understand and support each other in this initial period of stress will pay dividends later.

*At first, I was very negative, and my husband was very positive.*

*It tended to kind of drive us apart because he couldn't understand me, and I couldn't understand him.*

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*My wife and I had been unexpectedly launched into a world no parent could imagine. But it was clear we needed to reach out. This was too hard a situation to try to manage on our own.*



# When Family Doesn't Understand

When the chips are down, we expect our extended family (parents, adult siblings, aunts, uncles and cousins) to be there for us. Sometimes they are, but sometimes they aren't.

Where we hope to find support, instead we find empty phrases, or criticism, or denial, or worse, nothing at all. Instead of helping us cope, their responses make things harder. Comments and actions that would bounce off coming from a stranger cut to the heart because the source is a family member.

## What do they do?

The unhelpful ways extended families may respond to neuromuscular disease include:

- Denying, minimizing, avoiding
- Hurtful statements, criticisms and unhelpful advice
- Treating children unequally — catering to the affected child to the exclusion of unaffected siblings, or vice versa
- Cluelessness — not understanding the situation and not realizing the effects of what they say and do

## Why do they do it?

People may assume family members behave insensitively because they don't care, but that's rarely the case. Usually other factors are at play, including:

- **Family dynamics.** If you had communication difficulties or lack of family support before the diagnosis, you'll be facing the same thing after it. On the plus side, a family with strong relationships usually will come through in the end. Time, patience and education are the keys.

- **Grief** often underlies many seemingly heartless acts, especially by grandparents. They're going through a difficult process, too. They may be overwhelmed and not know what to do, so they don't do anything.

- **Personal discomfort.** Inappropriate or insensitive reactions often are an unconscious way of easing pain from strong emotions like grief and helplessness.

- **Guilt.** Neuromuscular diseases usually are genetic and relatives subconsciously may feel responsible. People sometimes deny the problem exists by saying, "No one else in our family has it, so why would you?"

- **Fear and uncertainty.** People often don't know how to react to disability or serious illness. They're afraid of the unknown, and disability scares them. Lack of education about the disease and the way it progresses also makes it difficult for relatives to respond appropriately.

- **Stereotypes and cultural assumptions.** Old-fashioned or culturally influenced attitudes toward disability die hard.

## What can you do?

Some tried-and-true solutions include:

- **Communicate.** Set clear boundaries, and say what you need and what you expect. Practice saying it in advance. "I need ..." "It would help me if you would ..." Focus on what you want and need, not on blame and accusations. You may need help from a counselor or neutral third party. Or it may be more comfortable to write a letter than to speak in person.

- **Educate.** Teach family members about the disease and how it manifests itself. Give family members books, MDA pamphlets and information obtained online (mda.org). Invite selected family members to come to an MDA clinic appointment.

Encourage loved ones to be upbeat and focus on the positive, and to treat your child as normally as possible. Educate family members about how to act around someone with a disability, by helping them get to know your child better.

- **Blow it off.** Don't waste precious emotional energy trying to straighten out every clueless relative. Practice what to say when hearing unwanted advice, criticism or insensitive comments: "Thank you for your concern"; "I'll keep that in mind"; "I appreciate that you care. We've decided that this is the best way to handle the situation."

Try to focus on the person's intention, rather than the words. If you have the energy to educate them, then go for it. But don't feel as if you have to fight every battle.

- **Accept and move on.** Your family may never become the support system you want, no matter what you do or say. Don't expect from somebody what they really can't give you. This attitude can be emotionally liberating. Above all, don't blame yourself for your family's lack of support.

- **Get counseling.** If you can't let go of your expectations no matter what you do, discuss your feelings with a counselor, in order to get help moving past a difficult situation.

- **Find other support.** For many people, their best support comes not from family but friends. Minimize contact with people who bring you down. Maximize time with those who respect and support you and your child. Support also can be found in church communities, local MDA support groups and online communities.

- **Focus on the positive.** Given time, many people adjust and their wonderfulness emerges. Accept that they'll offer what they can when they can and not before. In the meantime, focus on positive aspects of the relationship, while taking steps to insulate yourself from the negative.

*Adapted from "When Family Doesn't Understand," Quest, April 2002, © 2002, Muscular Dystrophy Association Inc.*

# Strength in Family Relations

Another mistaken belief common among parents of children with progressive neuromuscular disease is that everything else must take second place to the care of the child who is sick. A mother — especially if she still has feelings of guilt — may become totally absorbed in this child at the expense of her marital relationship and of the other children in the family. Inevitably her "self-sacrifice" leads to problems for all concerned, including the child with neuromuscular disease. The importance of maintaining a home life that meets the needs of all members of the family cannot be underscored too strongly.

In the family that furthers the best interests of each family member, husband and wife have a marital relationship that in some ways takes precedence over their role as parents. They safeguard their relationship by giving themselves time to be alone with each other — for companionship, a joint social life, the pursuit of mutual interests and intimate relations. The

children understand that there properly is a part of their parents' lives in which they do not participate.

A strong, sharing relationship between husband and wife is especially crucial in the family with a child who has a progressive neuromuscular disorder; it is the source of sustaining emotional support that acts as a powerful antidote to the stress each of them experience.

Grandparents and other members of your extended family may be able to give you and your spouse time to be together — or if you are a single parent, time to pursue your social life as a single person.

The brothers and sisters of the child with a neuromuscular disease must not be made to feel that their needs are disregarded. They should assist with the affected sibling but should not be deprived of outside activities. Your other children will probably have feelings of guilt



*"Free to Fly" by  
Julia Lee Sanders  
congenital muscular  
dystrophy*

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about being "normal" when their brother or sister is not, and you and your spouse will have to help them with these feelings. They will adapt well if no more emphasis is placed on the affected sibling's condition than is necessary. Brothers and sisters ought never to be pressured to take care of the social needs of the child with a neuromuscular condition, who should be encouraged to develop his or her own friendships.

Children in all families get into arguments; the fact is that they learn how to get along with other children by first working, playing, and fighting with brothers and sisters. Short of preventing injuries that could result from their children's squabbles, parents should let their offspring work things out by themselves. The hands-off approach is a matter of special urgency in your family. Children with neuromuscular diseases need practice in becoming emotionally self-reliant and independent, since they can't avoid dependence of a physical nature.

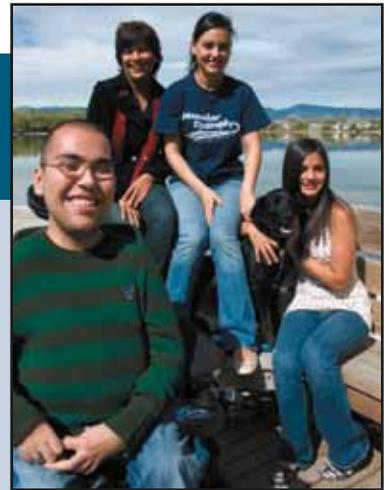
One more point about the "ideal" family — the family that is most stable, that protects its members, and that promotes their development. In such a family, the parents make the rules and set the consequences for breaking them. The parents also make the family's final decisions, although they may permit input into decision-making from the children. In the "ideal" family, children earn privileges by taking responsibility, but they are not thrust into adult roles prematurely.

*My advice to parents is, you aren't the only ones watching your child go through the effects of muscular dystrophy. Your other children are experiencing it, too, only they may not know how to handle what they're feeling. Watch them, pay attention to them, and look for any signs that they might need some help dealing with their emotions.*



# Going It Alone

## Advice from Single Parents



### Joy and hope

"I decided I'm just going to make his life as good as I can for as long as I can."

"I'm showing him that, hey, we're in a wheelchair but we can do things. Have van, will travel. We're still going to go places, do things. It's important that he realizes that."

"I don't feel that I'm burdened with it. He's a blessing."

"I've really learned to be patient. He brings a lot of joy to my life."

### Support system

"Share your fears and frustrations. You're so used to doing it on your own, you forget you can pick up the phone and ask somebody, 'Hey, I need somebody to come over today.'"

"My friends have pitched in wherever they can, whenever I need a break, or just little things they've done for me."

"Do not go into a shell. Get to know everybody at your kid's school. It's good to know that everybody's aware of your child."

"You may not have father and mother and siblings, but you build a family through MDA and through the people that get attached."

### Coping

"A lot of people ask me, how do you do it? I look up at the sky and say, I pray every day, just let me get through this day. There's no magic pill. I just get through the day."

"When you feel overwhelmed, 'Sit down and have a good old boo-hoo. Get it all out. Then pick yourself up and then you go again.'"

"I'm going to the gym to build myself up because it is getting harder now that he's grown, even just rolling him."

### The future

"I'm trying to save enough money to be able to hire help when the time does come that I need it, because I know I can't do it myself."

"You can pretty much take the effects of the disease in stride because the kids will."

"Don't deal with the future. Deal with now. Take it one day at a time. If you have to, take it an hour at a time."

*Adapted from "Going It Alone," Quest, October 2000, © 2000, Muscular Dystrophy Association Inc.*

# Teaching Independence

As children become adults, they naturally want independence from their parents. But this can be tricky when children have severe disabilities, because parents often remain their primary caregivers into adulthood.

Instead, a transition may be made to *interdependence*. This may include ongoing physical and financial support from parents, but with boundaries, responsibilities and, as one child development expert emphasizes, “no victims, no martyrs, everybody has a life.”

Experienced parent-caregivers offer these tips for teaching independence skills from an early age:

- **Envision a future for both your child and yourself.**

No one knows for certain what’s going to happen, so plan for the long run. Encourage children’s dreams and goals, and take time for your own. Caring for the caregiver is an essential piece of teaching independence skills.

- **Foster responsibility.**

Devise realistic chores; find age-appropriate ways to let them direct their health care; encourage participation in outside activities and volunteering.

- **Help children get used to receiving and directing care from others.**

Outside assistance enables more independence for everybody, even when children want help only from their parents. Part of adulthood is knowing how to get help and how to deal with poor service.

- **Don’t take over.**

Patience, patience, patience. Let children do what they’re able, even if it takes longer. As they age, ask questions but respect choices. Allow children to deal with the consequences of their mistakes. If they forget to charge their wheelchair batteries and get stuck at school, they’ll probably remember in the future.

- **Get assistive equipment.**

Technology is the ticket to independence. Research your options. Once you know what you want, there often are creative ways to finance it.

- **Push past the fear.**

Independence is scary for parents, but do it anyway. Says one parent-caregiver, “They say you should give your children roots and wings — in our case it’s roots and wheels.”

*Excerpted from “Parent-Caregiver Transition — Learning to Let Go,” Quest, November-December 2004, © 2004, Muscular Dystrophy Association Inc.*

# What Your Child Needs

When a child is seriously, chronically ill, the ideal family model is much more difficult to achieve, but doubly important to strive for. Your efforts to prolong your child's independence by forgoing your understandable impulse to overprotect — as well as by emphasizing self-help aids — will have many beneficial effects, not the least of which is to lessen the possibility of future emotional and learning problems. If your child is already doing chores, these responsibilities should continue. He or she should be disciplined as are other children in the family and also receive normal rewards for achievement.

Independence to a small child almost always means independence from parents. Beginning in the toddler years, children begin to give up their dependence on parents in favor of "grown-up" activities like buttoning their own clothes, tying their shoelaces and exploring the world by themselves. The child with muscular dystrophy or another progressive neuromuscular disease

has the same need to move away from parents but is, in fact, becoming more dependent on them physically.

Look for opportunities to support children in moving toward independence, despite their increasing need for physical help. Teach them how to take charge of their own care, how to be assertive yet respectful in getting their needs met, and how to work with helpers other than their parents. Encourage them to be active participants at doctor visits.

Although you may feel protective, look for chances for children to experience the normal give-and-take of social interactions with other kids. Don't be shy about hosting play dates at your house, where you can make any needed accommodations.

Actively seek out opportunities for children to experience feelings of competence and to express themselves through age-appropriate



*"Fishing Buddies" by  
Samuel Williams  
Charcot-Marie-Tooth  
disease*

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activities such as adapted sports, play groups, MDA summer camp, and creative activities like arts, crafts and music.

One way to support the deep-rooted need for self-reliance is to make sure children spend quality time with a supportive adult male role model — whether a father, uncle or family friend. When a child — any child — moves toward independence, male role models take on new significance in their lives.

Without diminishing the growing influence of women in positions of authority, children still have a need for males who demonstrate positive approaches to achievement, competition, aggression, autonomy and mastery. For children with neuromuscular diseases, these male figures are especially crucial, because often there aren't as many opportunities for them to explore these areas otherwise. Emotional problems in children with neuromuscular disease often are related to a lack of significant men in their lives and a lack of appropriate outlets for their normal urges of aggression and mastery.

Having outlets for feelings of aggressiveness in play and fantasy will benefit your child not only by providing scope for normal development but also by helping to maintain muscle strength and preventing a withdrawal into social and emotional isolation. Each parent has a part to play in striking the balance between protecting the child from failure in activities that are too demanding, on the one hand, and unnecessary dependency, on the other.

*I think the most important thing my parents did for me when I was growing up was to treat me the same as my nondisabled siblings, with the same expectations, while still helping me deal with my physical limitations.*



# Touch the Future — Become an MDA Advocate

Advocacy is a way for parents to set a powerful example for their children by showing them that their rights are important, and that individuals who speak up are capable of creating change.

MDA's Advocacy program provides a unified voice for the hundreds of thousands of Americans affected by neuromuscular diseases. MDA advocates make a difference to future generations by helping shape governmental decisions in such areas as public policy and research advancement, as well as raising public awareness of the concerns and priorities of our community.

MDA's Advocacy program provides practical ways for busy parents to become involved through its "Take 5!" initiative.

"Take 5!" means that becoming an active, effective participant in the democratic process can be as simple as taking just five minutes to contact elected officials in Congress about legislation affecting the MDA community. To start, go to MDA's Advocacy Web pages ([mda.org/advocacy](http://mda.org/advocacy)) to find specific information about relevant legislative issues, and detailed materials to help you easily advocate by letter, email or phone. By registering as an MDA advocate, you will receive email updates on policy and legislation that may impact your family.

Thanks to medical advances, many children with pediatric diseases now live well into adulthood. This "transition" from child to adult can raise new challenges for youth and families. MDA's transitional services program works to identify the needs of our young adult community, and then to identify the necessary supports and services needed to get past barriers.

Through its national advocacy program, MDA is working to support independent living, and encourage young people to pursue their hopes and dreams for the future. Learn more about transition services and resources through MDA's Transitions Resource Center, [mda.org/transitions](http://mda.org/transitions), or by contacting your local MDA office (800-572-1717).

Together, our voices are strong. Together, we are breaking barriers and building successful futures.



*"Untitled" by  
Stacey Wilson  
spinal muscular  
atrophy*

# Resources for Families

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## Muscular Dystrophy Association

MDA offers support groups, online communities and referrals to social workers and family counselors. Check with your local MDA office by calling (800) 572-1717 or visiting [mda.org](http://mda.org).

### MDA PUBLICATIONS

MDA publishes a variety of materials for individuals and families affected by neuromuscular diseases. Most publications are available free online or through your local MDA office.

**Quest** magazine is an excellent resource for information about parenting, education, activities and adaptive products. The magazine is mailed quarterly to all those registered with MDA and also is available online at [quest.mda.org](http://quest.mda.org). Search for stories by category or keyword, and browse back issues.

### Other MDA publications geared to the needs of children include:

#### ***A Teacher's Guide to Neuromuscular Disease*** (available in print and online)

Designed to be given to your child's teacher, this booklet explains the specific ways in which muscle disease can impact a student's performance and offers suggestions for accommodations. Available in English or Spanish.

#### ***Everybody's Different, Nobody's Perfect*** (available online)

This bilingual story for young children looks at all the ways in which children are unique, whether or not they have disabilities.

#### ***Hey! I'm Here Too!*** (available online)

This booklet for brothers and sisters of children with neuromuscular disease explains what's happening to their siblings and acknowledges their feelings. Available in English or Spanish.

#### ***Travis: I Got Lots of Neat Stuff*** (available online)

Written by the mother of a boy with muscular dystrophy, this bilingual picture book helps children realize that life can be fun even with muscle disease.

### MDA HOP-A-THON

Visit [mdahops.org](http://mdahops.org), or contact your local MDA office to find out more about this curriculum for young children, which is both a fundraising activity and a way to teach disability awareness.



**MDA**® Muscular Dystrophy Association  
Fighting Muscle Disease



*"Possibilities" by Mallory Parton  
limb-girdle muscular dystrophy*

MDA's website, [mda.org](http://mda.org), is constantly updated with the latest research news and information about the diseases in its program. Follow MDA on Facebook, Twitter and YouTube.