

LIVING WITH PARALYSIS

Parenting with Paralysis



CHRISTOPHER & DANA
REEVE FOUNDATION

TODAY'S CARE. TOMORROW'S CURE.®

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This guide has been prepared based on scientific and professional literature. It is presented for the purpose of education and information; it should not be construed as medical diagnosis or treatment advice. Please consult a physician or appropriate healthcare provider for questions specific to your situation.

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CHRISTOPHER REEVE

Christopher Reeve was the father of three children when he sustained a spinal cord injury in 1995. The accident changed his life in countless ways. He could no longer walk or breathe on his own. He needed help eating, dressing and going to the bathroom.

But paralysis didn't prevent him from being a father: Christopher watched Will's baseball games from the edge of the field; he beamed from the audience as Matthew graduated from college; and he celebrated in the kitchen with Alexandra after she got her driver's license.

A wheelchair became part of Christopher's life, but didn't define who he was; his ability to love his children remained untouched.

There are more than 4 million parents with disabilities caring for children under the age of 18 in the United States. From the moment they're born, children upend the life of every family, creating a world that is unpredictable, stressful and joyful — sometimes all in the span of a few minutes. All parents, whether living with a disability or not, must adopt strategies and philosophies that work for their specific families, whether facing a toddler tantrum in a grocery store or building traditions around board games and backyard barbecues.

Disabilities change the shape of a life — but need not limit its potential. While living with paralysis will create different parenting challenges, resources and support are available to help map the journey.

Begin by believing that it can be done. Plan, strategize and get creative to find the adaptations that work for you. Accept that there will be challenges, but also great rewards. And don't forget to enjoy every minute — dirty diapers, bleary-eyed mornings and all; it will fly by.



WHAT TO EXPECT WHILE PREGNANT

Paralysis does not prevent a woman from becoming pregnant and having a baby. Morning sickness, headaches and swollen ankles are among the familiar and normal side effects of pregnancy that women with spinal cord injuries are as likely to experience as any woman.

But pregnancy will amplify secondary health conditions, including urinary tract infections, pressure wounds and spasticity. To mitigate risks, women living with paralysis who become pregnant should ensure the best possible care by finding doctors who are familiar with spinal cord injuries. The more knowledgeable the individuals overseeing the pregnancy are, the better served mother and baby will be.

There isn't one definitive guide to pregnancy. Every woman has a different experience, but all women living with paralysis should understand and anticipate potential complications stemming from existing health issues.

Begin by visiting a urologist before becoming pregnant to get a baseline checkup of the kidneys, bladder and ureters; this will help doctors monitor any changes that occur during pregnancy. Bladder management is critical to the overall health of people with spinal cord injuries. Pregnant women should be especially alert to urinary tract infections, as they can cause early labor.

Catheterization will be monitored during pregnancy. A growing baby bears down on the bladder, leaving less room for urine to gather. At some point during pregnancy, it will likely be necessary to use an indwelling catheter in order to continuously drain urine.

Seek out obstetric referrals from other parents with disabilities or from physiatrists, rehabilitative doctors who treat medical conditions related to the brain, bones, nerves and muscles, including those sustained through spinal cord injury. The American Academy of Physical Medicine and Rehabilitation provides a searchable database of practicing members throughout the country.

A high-risk obstetrician might be best equipped to manage comprehensive care for pregnant women with spinal cord injuries. Respiratory therapists, physical therapists and occupational therapists can help monitor and address additional changes to overall health caused by pregnancy. Be sure new doctors are aware of all underlying health



conditions and current medications; adjustments to prescriptions may be needed during pregnancy to ensure a healthy baby.

Women with spinal cord injuries at T6 or above are at increased risk of developing autonomic dysreflexia (AD) while pregnant. This potentially life-threatening condition, triggered when the body feels pain below the level of injury,

causes dangerously high blood pressure and its symptoms, including painful headaches and nausea, can be mistaken for normal side effects of pregnancy. It is critical that doctors understand how to detect and monitor these symptoms throughout pregnancy.

Pregnant women who are at risk of AD should consider carrying an AD wallet card containing baseline blood pressure, level of injury and emergency contacts. Copies are available online for download or call the Reeve Foundation's Paralysis Resource Center directly at 800-539-7309 to have one mailed to you.

Labor and Delivery

By the third trimester, doctors will likely be closely monitoring an expectant mother's breathing and circulation. The additional weight of a baby can slow blood flow; wearing compression stockings and elevating feet when possible is recommended.

Weight gain might make moving more difficult, but it is important for women living with paralysis to be conscious of regularly shifting body position; examine skin often in order to prevent pressure wounds,

especially if bed rest is prescribed. Additionally, some women with muscle atrophy will be at risk for pathologic fractures; transfers should be undertaken carefully at this stage.

Discuss and decide on a delivery plan with doctors as early as possible. Vaginal delivery is feasible for many women with spinal cord injuries. Plan to attend a birthing class. Visit the hospital and speak with staff ahead of time to make sure it is fully accessible and prepared for labor issues unique to patients with spinal cord injuries.

Women with paraplegia will be able to learn how to feel the uterus to monitor labor; others may need to use a contraction monitor at home. Women with limited uterine sensation should receive weekly cervical exams beginning at 28 weeks and should be admitted to the hospital once cervical dilation or effacement begins.

During labor, women should be repositioned every two hours to prevent pressure injuries. Blood pressure, heart rate and body temperature will need to be monitored, and doctors and hospital staff should be particularly alert for signs of autonomic dysreflexia (AD), even if it did not manifest earlier during pregnancy. Women with spinal cord injuries should be evaluated by an anesthesiologist prior to labor to plan for early and continuous epidural anesthesia in order to prevent the onset of AD.

BUSY DAYS: INFANTS, TODDLERS AND HAPPY CHAOS

Life with a baby is a learning curve for every new parent. Each day brings unexpected challenges, from frantically trying to soothe a colicky baby to cracking the code of complicated car seats. For parents living with a disability, there will also be a period of discovering what adaptations are necessary. There is no right or wrong way to approach parenting, no one set of rules that works for every family. Be patient; there will be bumps in the road. But remember, parenting with a disability is nothing new. Many people have done so before you — and many others are doing so at this very moment.

Build a Support System

Begin by building a network of support, both in and out of the home. Before the baby is born, stock shelves with parenting books that suit your style and supplement these with specific resources and advice for people living with paralysis.

SHERMAN GILLUMS, JR.

Sherman Gillums, Jr. is a father of six children and a Marine veteran who sustained a cervical spine injury during a vehicle rollover. He and his family enjoy cooking and playing games that cultivate teamwork. Sherman believes that building an expansive support system is key for parents with disabilities.

“There’s not a single problem you will face as a parent with a disability that someone else has not faced and already overcome. The question is ‘How will you deal with it, and what can you learn from others’? Look for the support and information you need to make informed decisions. Use the strongest muscle in your body — your tongue — to ask for help when you need it. That takes true strength when you live with a spinal cord injury.”

Seek out local baby playgroups, but also join online message boards used by parents with disabilities. The National Research Center for Parents with Disabilities at Brandeis University offers online resources including webinars, how-to videos and community blogs tackling topics ranging from adaptive technology to managing nighttime feedings.

The Reeve Foundation’s Paralysis Resource Center can match parents to peer mentors with similar disabilities or levels of injury. Emotional support is critical for all new parents. Meeting other parents with disabilities can help overcome doubts, boost confidence and serve as a real-time reminder of all that is possible.

Think Outside the Box

The early days of a baby’s life can feel like a never-ending loop of diapering, feeding, and sleeping. Parents with disabilities should consider what specific adaptations they need for this busy time. Solutions might come via message board tips from seasoned parents or simply by trying new strategies until something sticks; getting creative is key.

When it comes to sleeping arrangements, strategize with your spouse or partner to determine what setup best fits the family: Moses baskets and co-sleepers that attach to the bed will keep the baby close by and eliminate the need for nighttime transfers; bassinets on wheels or attached to portable play yards may be moved around the home; and traditional cribs can be shortened to a height that is accessible for wheelchair users.

Safely feeding a baby can be a challenge for parents with limited dexterity or arm mobility. Nursing mothers might enlist help from a family member to lift and position the baby or use products that offer additional support; sling shaped carriers specifically designed for nursing can hold the baby in place and free up a mother's hands, while specially designed nursing pillows lessen the strain on a mother's arms and upper body.

Baby bottles come in a wide variety of different shapes and sizes, a luxury of choice that can help parents with disabilities adapt. The same holds true for hundreds of other baby products available in an array of designs, from sleepers made with zippers rather than snaps to hands-free carriers that can rest a baby on the chest, back or hip.

The 21st century consumer has more choice than ever before for both traditional and adaptive products. AbleData, a searchable database developed by the National Institute on Disability, Independent Living, and Rehabilitation Research at the Administration for Community Living, provides information on assistive technology, resources and products ranging from recreational to housekeeping to therapeutic aids. Parents with disabilities can take advantage of the many options available on the market to find solutions that support their specific needs.



Sherman Gillums, Jr.

Conquering Logistical Challenges

Life is unpredictable. Anticipating everything that might go wrong isn't possible. Instead, parents with disabilities should focus on how to stack the deck to ensure that most things go right.

Mapping the layout of a baby's life is one thing a parent can entirely control. Forget where things are "supposed to go" and design a floor plan



Kieran O'Brien Kern

around what works best for your individual needs. For a parent with mobility issues, this might mean that rather than using one central changing table in the baby's room, changing stations would instead be positioned throughout the home. There's no reason that baskets or bags filled with diapers, a change of clothes and other essentials can't be placed in every room; one basket beside the bed, along with a bottle warmer or nursing sling, can help mothers more easily manage nighttime feedings.

As the baby becomes a toddler, parents might expand this strategy beyond diapering. Moving well-stocked baskets of toys and books from room to room or setting them up in triangular stations around a wheelchair can reduce a parent's need to constantly rush around the house and might keep a busy toddler in one place a little longer.

Adaptations to Fit Abilities

The reality for parents with disabilities is that certain tasks surrounding the baby's care will need to be tweaked. Remember, there is no one-size-fits all when it comes to parenting. Like learning to drive again after a spinal cord injury, the method may look different, but the end destination remains the same; it doesn't matter how you get there.

Some adaptations are likely already part of a parent's daily routine. A person with limited dexterity might use a piece of a pool noodle or rubber grips to open a jar of tomato sauce. If pouches and containers of baby food present a challenge, see if the same strategy works.

Grabbers used to access out-of-reach kitchen shelves can also be used to retrieve diapers, wipes and even toys that bounce under the dining room table. Other hacks — like dressing a toddler in overalls not only because they're cute, but because they also provide a readymade strap through which to scoop that child up — will reveal themselves through trial and error.

Car seats can be cumbersome depending on specific disabilities. Before purchasing, examine different options in stores to assess which buckling system works best for you. If accessing or lifting the seat itself is a concern, leave this task to a spouse or partner; if they can't go on an outing, ask a friend to meet you at the destination to help transfer the baby in and out of the car.

Limited mobility or sensory issues caused by a spinal cord injury can make safely bathing babies and toddlers difficult. Adaptations might include using a sink at wheelchair height and testing water temperature with a thermometer. If this isn't enough, make bath time an all-family activity so there are many helping hands.

Caring for babies and very young children can be overwhelming, no matter how creatively or ingeniously parents adapt to accommodate a disability. In those early years, remember that for every parent — living with paralysis or not — there is strength in numbers. Ask a spouse, partner, family member or friend for help if needed. A child can never be loved by too many people.

KIERAN O'BRIEN KERN

Kieran O'Brien Kern is a 43-year-old mother of two girls, ages 2 and 7. She has brown eyes, freckles and spastic quad cerebral palsy; her daughters are growing up motoring around on Ms. Kern's scooter, dubbed The Beast.

"One of the greatest things you'll find as a parent is that your kids will adapt to you. You don't have to be perfect. Do your best. Sit. Think. Strategize. Do. And, however you make things work, it will be normal to your kids. And your kids will love you no matter what."

LITTLE EXPLORERS: LIFE WITH PRESCHOOLERS

The day will arrive when parents find that their baby has disappeared — replaced by a child waking up to a wider world. By age three, children are beginning to develop a sense of independence; curious and busier than ever, they are eagerly expanding the boundaries of their universe.

Children whose parents have disabilities often become helpers at a younger age than those with able-bodied parents, learning to retrieve toys for younger siblings or choose their own clothes from a low dresser drawer.

Encouraging this kind of independence not only helps a parent work around physical challenges in the home but also aligns with what children naturally seek to do at this developmental stage. Establishing a daily to-do list of chores — like helping dress themselves, sweeping the kitchen with a toy broom and shelving their own books — can boost a child's confidence and foster that need for independence.

For the same reason, parents should take advantage of this stage to teach the importance of safety. As they begin to spend more time outside the home, all children, and especially those whose parents have mobility issues, need to understand why it is dangerous to run away from a parent.



Teach them to stay off the streets, watch out for traffic and ask for help retrieving stray balls, rather than chasing them into the roads themselves.

When the family is out of the home, whether in crowded shopping areas or parks, establish that running away from or out of reach of a parent with a disability is not an option. Frame it as a safety practice and a way to help by being a “big kid.” And until the lesson is learned, tie bells to their shoes so you can hear them jingling when you’re out and about.

Navigating an Expanding World

Families of preschoolers will likely find themselves adventuring more and more outside the home. Navigating new spaces will be necessary; a little research ahead of time can help parents with disabilities maneuver more easily.



Parks and playgrounds are a source of joy for many families and play a critical role in a child's physical development; those designed for children with disabilities will likely provide the access disabled parents also need. Some cities, such as New York, offer a searchable database specifying levels of

accessibility at each site. Another option is to simply call the Department of Parks and Recreation to see what's available. If accessible options are few and far between, become an advocate to create them — increasing inclusive spaces benefits the entire community.

Making friends is important for children this age, but not every friend's house will be accessible to parents with disabilities. Parents might suggest meeting at neutral venues, such as the local YMCA or library, along with offering to host regularly scheduled playdates or playgroups at their own home, ensuring inclusion for themselves and their children.

Building Family Life

Every family is different; some love to visit museums, others to camp beneath the stars. As your child's personality develops, begin to explore the activities and rituals that will create a foundation for family life. Work around disabilities — and don't rule anything out until you investigate what's possible.

There are many things a family can do together at home that support various levels of mobility and dexterity: young thespians might reenact their favorite fairytales, with parents filling in for dastardly villains; little chefs can watch cooking shows and recreate cupcake challenges in the kitchen;



budding scientists can experiment with baking soda volcanos and listen for birds through open windows; and kids who love competition can build a board game library for family tournaments.

Getting creative can help parents with disabilities be part of active play, too. Marathon Lego sessions can unfold on tabletops,

rather than the floor. Fishing trips can take place along an accessible pier. If a ball cannot be kicked, perhaps it can be rolled with help from a broom.

There is no disability that prevents parents from engaging with their children. No matter what adaptations are needed, being present is what matters most.

ELEMENTARY SCHOOL DAYS

The first day of kindergarten marks the start of what will be many school-centric years for children and families. Much of a child's life will now revolve around the learning and socializing happening in and out of the classroom.

Parents with disabilities should begin this stage by identifying any challenges surrounding school visits in order to avoid surprises. Both private and public schools are bound by the Americans with Disabilities Act; accessibility should not be an issue, but logistical problems can still occur. Before attending parent-teacher conferences or back to school evenings, speak with school officials to make sure there is space created among the desks to accommodate a wheelchair, or to doublecheck that elevators in multi-floor buildings are working and ready for use. Plan to arrive early whenever possible as accessible parking spaces will be limited.

Whether volunteering to serve as room parent or helping plan fundraisers, parents with disabilities can be as involved in classroom life as any

other parent. But, at times, extra planning and research may be needed. Though schools must remain accessible, field trips can pose a challenge. Parents who wish to chaperone these outings will need to make sure the destination is accessible by checking with teachers or on-site staff ahead of time. Brainstorm with school staff before concerts, plays and other all-school events to determine what seating options and entry and exit points will best serve your specific needs.

Muddy Fields and Penalty Shots: Getting to the Game

Exercise is vital for the physical and mental health of growing children. For many, participating in organized sports helps maintain fitness and develop confidence, problem-solving skills and grit.

But accessing children's sports is a recurring frustration for parents with disabilities. Indoor events like gymnastics and swim meets can pose logistical challenges for people with limited mobility. And while the wide-open fields of outdoor sports might seem like an easy alternative, looks can be deceiving: Field conditions can range from rough and rocky to muddy and uneven. While parking lots provide accessible spaces, parents frequently must trek across several fields to find their child's game.

Health issues also cause complications. Spending too much time in the sun is a risk for many people with paralysis. With less sensitive skin, sunburns can happen easily and unnoticed. Wheelchairs themselves can overheat and become hot to the touch.

Regulating body temperature in both hot and cold settings is another consideration for parents with high level spinal cord injuries whose bodies cannot signal the brain about changes in temperature. Too much time spent under sunny skies at soccer fields puts parents at risk of hyperthermia, while a cold hockey rink or ski race might cause hypothermia.

BERNADETTE MAURO

Bernadette Mauro is a quadriplegic mother of two grown sons who never knew her without a spinal cord injury. When her boys were young, she sought creative ways to adapt to the physical challenges she faced, found support through a tight-knit group of friends and chose to parent as if there were no obstacles.

"The best thing you can do for your child is give your heart, your brain and your emotions. Be present. Paralysis will not stop you from doing that."



Bill Cawley

lowest bleacher or use areas designated for wheelchairs to watch indoor events. For outdoor games, ask a team parent to meet you in the parking lot to navigate the journey across multiple fields or inquire about parking on the field itself. A SmartDrive power assist device, which helps move manual wheelchairs over grass and rough terrain, might be a worthwhile investment for parents with young athletes whose games dominate the family schedule.

Be mindful of personal health: Always pack lots of water to prevent dehydration, seek shady areas to watch games and consider setting up a canopy for longer tournaments.

BILL CAWLEY

Bill Cawley is the father of four kids ages 16, 15, 13 and 10. Paralyzed from the chest down before they were born, his wheelchair is a normal part of the family's life, not something that limits it. Bill's approach to parenting is simple: Be there.

"I have learned kids really don't care if you're building the sandcastle with them, what matters is that you're there talking to them about it. At the end of the day, they're going to know you were there. It doesn't matter if you dig the hole or throw the ball or put them on your shoulders. What matters is that you are there. That's what they remember."

There are no easy answers, but for parents wanting to cheer their children on, the simplest solution might be not to let perfect be the enemy of good.

Begin by asking for help with access. Call schools to determine what type of seating and space is available. If possible, sit on the

But sometimes adaptations are not enough. Do the best you can, whether it's helping to sell hotdogs at the concession stand or watching the game from a distance in an air-conditioned car. The reality is, it might not always be possible to be on the sidelines and that's ok; your child will know you're as close as you can be.

GROWING UP: LIFE WITH TWEENS AND TEENS

Guiding children through the topsy-turvy teenage years that begin in middle school is a challenge for every parent. With the onset of puberty, tweens and teens will juggle an array of physical, social and mental changes. These years can be especially emotional and unpredictable; short tempers, moodiness and one-word answers might become the temporary norm. While kids will naturally turn away from their parents at this stage, they also need that love and support more than ever.

Parents with disabilities will face the same challenges raising teenagers as any other parent, including one of the most vexing: Being ignored. But keeping the lines of communication open is critical even as kids disappear into their bedrooms.

For parents whose mobility issues prevent them from easily moving throughout the house, embracing assistive technology like smart speakers can help. Strategically placing these devices throughout the home creates an intercom system that makes it easier to access out-of-reach teens. And if kids prefer to talk via text, parents with dexterity issues can use voice activation to 'type' and even preload messages to their phones to more easily keep the conversations going.

Questions and Conversations

At some point, children who have only ever known their parent with the disability might wonder about it through a stranger's eyes.

For teenagers who are suddenly self-conscious about appearance and their social position in the world, the issue may come up indirectly. Be mindful of a teenager's desire — and perhaps reluctance — to ask questions.

At this age, a growing awareness of discrimination in the world might create a hard-to-define worry about their parent that a teen can't easily articulate. New friendships can also lead to new questions about families; not knowing how to explain the specific disabilities they've likely grown so used to over a lifetime might cause anxiety.



Offer to answer questions about your life and disability without judgement; this might help kids build the vocabulary they need to engage with friends or ease their own concerns. Never make them uncomfortable about asking; disabilities are normal and so is curiosity about others. Remember, children see their parents as an extension of themselves. If you are comfortable with your disability, they will be too.

Staying Connected

As tweens and teens expand their social circles, it's important for parents to stay in the loop. Offering the home as a place for hanging out allows parents with disabilities to get to know new friends without having to work around inaccessible spaces. This also creates more chances for parents and teens to be together.

A sense of lost time lingers over these years. Not only are kids growing up, they're away from home more and more, whether traveling with a sports team or working at an after-school job. The realities that accompany specific disabilities can exacerbate this feeling of loss for some parents. Middle and high school classes start early, and teens are often out the door long before parents living with paralysis have completed their own morning routines, including dressing, showering and bowel and bladder management.

Adapt by building in extra family time later in the day. If regular dinners together aren't possible, encourage everyone to gather instead around dessert. Teens will likely become more resistant to regular board games and movie nights but keep asking. Sometimes they might say yes.

Many schools require students to perform community service; if possible, find a volunteer opportunity you can do with your teenager. And don't

count out the car as a space to stay connected; parents chauffeuring teens from one activity to the next might be surprised at the quality of conversations that take place while on the road.

FROM GRADUATION TO GRANDKIDS

Life after high school is different for everyone. For some children, further study at college lies ahead, while others will seek opportunity by joining the military or getting a job. New adventures for graduates are on the horizon, but they will likely unfold away from the family's home.

Parents with disabilities should consider ahead of time what boundaries they will set in their relationships with their adult children. Some children might want to become more involved in their parent's physical care. This is a personal decision that will be different in every family, but clearly defined boundaries can help both parent and child avoid becoming overly reliant on one another. If help is welcomed, try to maintain a balance; it is important for adult children to create independent lives away from their parents.

Watching adult children become parents themselves will bring much joy to many families. Grandparents provide an extra layer of love for children and in some families, additional help for working parents. If you are able and willing to help with childcare, determine what activities you're comfortable supervising, whether ferrying kids to sports practice or volunteering in their school classroom.

ALAN BROWN

Alan Brown sustained a spinal cord injury that paralyzed him from the neck down before his two sons were born. Though he regained use of his arms, accepting that his limited mobility made certain things impossible helped Alan appreciate all the ways he could connect with his sons, from going fishing to cheering on the New York Rangers to playing backgammon together.

"Be realistic. A lot of things are feasible. Prepare yourself and have resources to back yourself up. And ask for help when you need it, so your partner has relief, too. That's where in-laws and parents and uncles and aunts and friends come into play. Have a crew you can depend on."

DONNA LOWICH

Donna Lowich sustained a spinal cord injury that paralyzed her from the shoulders down when her son Jeff was 4 years old. She worried about how her paralysis would affect him, but when she returned from the hospital, Jeff's resilience and pint-sized pep talks — “You can do it if you believe in yourself!” — helped her realize that life might be different, but she was no less a mother.

“If I could tell parents with new spinal cord injuries one thing, it would be that even though it feels scary, it's going to be ok: A disability doesn't change the relationship between a parent and child.”

Grandparents are a key part of many children's lives. And, just like parenting with a disability, adapting around a new family's needs will be necessary. But, by the time they are grandparents, those living with disabilities will have many tricks in their arsenal. Think back to the activities and hacks that worked with your own children, whether tossing pop flies from a wheelchair or deploying your best character voices while reading Cinderella. As always, what matters most in the end, is the love you share.

Parenting with Disabilities: It Can Be Done

Disabilities do not determine whether a person can be a parent. When Christopher Reeve taught his son Will to ride a bike, he was no longer able to do so himself; he couldn't run alongside the bike or hold the bike steady until it was time to let go.

But Christopher coached Will from his wheelchair. The method was different, the result the same: A boy learned to ride a bike and a father demonstrated his love.

If you wish to become a parent, know that it can be done. Create adaptations that fit your family. Find a supportive community. And be there — in whatever way you are able — for your children. It's simple. It's complicated. It's an adventure that is accessible to everyone.

Parental Rights: What to Know

People living with disabilities have achieved significant gains throughout the last half century. In that time, the Rehabilitation Act of 1973 (Rehab Act) and the Americans with Disabilities Act of 1990 (ADA) became cornerstones of a legal framework that not only prohibits discrimination in housing and employment practices, but also protects the civil rights of those living with disabilities.

However, despite the intent of these laws, parents with disabilities continue to face discrimination and bias from medical and government agencies; understanding your rights as a parent is critical.

Beginning with conception efforts, the rights of people with disabilities are protected. If you experience fertility issues while trying to become pregnant, you have the right to access invitro fertilization or other assistive reproductive technologies. Doctors providing these treatments must comply with the ADA and, if they receive federal funding, the Rehab Act.

Similarly, the ADA and Rehab Act apply to both public and private adoption agencies, specifically prohibiting discrimination against prospective adoptive parents living with disabilities.



Donna Lowich

If you become a parent, the Reeve Foundation's Parenting with a Disability: Know Your Rights Toolkit provides an overview of disability law and the safeguards that exist to protect your rights as a parent, including information on adoption, custody, visitation law,

family law and the child welfare system. Copies are available online or call the Reeve Foundation's Paralysis Resource Center directly at 800-539-7309 to have one mailed to you.

RESOURCES

If you are looking for more information on parenting with disabilities or have a specific question, Reeve Foundation Information Specialists are available Monday through Friday, toll-free at 800-539-7309 from 9 am to 5 pm EST.

The Reeve Foundation offers comprehensive resources and booklets on hundreds of topics related to living with paralysis, including:

Autonomic Dysreflexia

<https://www.christopherreeve.org/living-with-paralysis/health/secondary-conditions/autonomic-dysreflexia>

Peer & Family Support Program (PFSP)

<https://www.christopherreeve.org/get-support/get-a-peer-mentor/pfsp-overview>

You can ask the PFSP for a peer mentor who is a parent.

Parental Rights Booklet

https://s3.amazonaws.com/reeve-assets-production/Parenting-Booklet-Digital_Finalv2.pdf

Sexuality and Reproductive Health after Paralysis Booklet

<https://s3.amazonaws.com/reeve-assets-production/Sexual-Health-Booklet-4-19.pdf>

Below are some additional resources related to parenting with disabilities:

American Academy of Physical Medicine and Rehabilitation: Physiatrist Finder

<https://www.aapmr.org>

Physiatrists are doctors who specialize in physical medicine & rehabilitation.

Model Systems Knowledge Translation Center: Pregnancy and Women with Spinal Cord Injury Fact Sheet

<https://mskctc.org/sci/factsheets/Pregnancy>

National Research Center for Parents with Disabilities

<https://heller.brandeis.edu/parents-with-disabilities>

NSW State Spinal Cord Injury: Talking to Your Children about Spinal Cord Injury: A Practical Guide for Families

https://www.aci.health.nsw.gov.au/__data/assets/pdf_file/0008/194399/Talking_to_children_about_SCI_guide_for_families_A4_book_LR.pdf

Shepherd Center Video Series Featuring Women with Spinal Cord Injuries

<https://www.shepherd.org/more/resources-patients/women-sci-resource-videos>

Includes one video on Parenting and one video on Pregnancy, Labor and Delivery





We're here to help.

Learn more today!

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