



*Joni Eareckson Tada* has lived in a wheelchair as a quadriplegic since 1967. Her experiences enable her to share a biblical view on suffering which is authoritative, yet personal. Joni has received honorary degrees from Gordon-Conwell and Westminster Theological Seminaries, and numerous awards from publishers, Bible colleges, and disability advocacy organizations.

Joni and Friends proclaims the Gospel through its various programs of evangelism, discipleship, and church training in disability ministry. The ministry works through U.S. Field Offices, as well as International Affiliates around the world. Joni and her husband Ken reside in Southern California. For more information on Joni and the work of her team, please contact:

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# *Disability:* When it First Touches Your Family

*Joni Eareckson Tada*

# Disability: When it First Touches Your Family



By  
Joni Eareckson Tada

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Scripture quotations, unless otherwise indicated, are taken  
from the *Holy Bible: New International Version*®.



*I*t takes time for your doctor's words to settle into your mind. But when they do, it hurts. Or for many, it's a feeling of numb disbelief. Disabilities happen to *other* people, to *other* families. Not yours. This time, however, disability has touched *your* family. And it's hard.

Slowly the initial impact gives way to the harsh reality and hard questions: "Will my son ever walk again?" "Will my wife regain her sight?" "Will my husband fully recover from his stroke?" "How will we cope?" "Who will pay for the bills?" and finally, "Where do I go for answers?"

That's why we at Joni and Friends International Disability Center have written this booklet. As a concerned family member, you may even feel overwhelmed by all the questions. Everyone pretty much charts his own path through the maze of appointments with specialists, second opinions, calls into your insurance company, and trips to rehab, but when it comes to answers to



other, more personal, questions, this booklet will guide your search.

The world of disability can be baffling, but we've included some appropriate "take-off" points as you begin your journey. Although every family's needs are different, this booklet will help you address the issues unique to your situation...from the first moment.

## Who Can Help?

When facing a disability – whether stroke, spinal cord injury, or MS – you'll discover your support system will be an unusual mix of medical resources, government agencies, family, friends, and your church. In fact, your church should be your first resource! If your congregation has a prayer circle, provide the prayers with specific requests – keep the prayer circle updated on the progress of your loved one who has suffered the injury or illness.

At different stages in this journey, you will be



involved with different support providers. In the acute stage — at the onset of disability — you will find yourself waiting at a hospital bedside where you'll become all too familiar with the names of nurses, aides, as well as hospital routines. As improvement and stability come, your family member will progress to the rehabilitation setting.

As a family member, much of the primary responsibility of tracking down resources and assistance for your loved one may fall on your shoulders. It may take some persistence, but you can be the catalyst to providing the best care possible for your loved one. The next few pages will help you do that.

## Acute Help – Who Will Help?

### *Medical Support...*

In the acute phase of a disabling illness or injury, you'll meet specialized professionals who, together, are on the scene to address the fragile



condition of your family member – you’ll meet an interesting mix of medical support staff throughout both the acute and rehabilitation phases.

You’ll also find yourself grappling with new medical words and technical jargon. Always ask for clarification from physicians when information seems confusing or your questions are unsettled. Please don’t be timid. You need to grasp what is happening from the very beginning, and the doctors have the best information available regarding a condition and prognosis. But realize they may not have all the answers. With a disability, some answers only come over time.

Other healthcare professionals you will meet throughout hospitalization and rehab will include the following:

- Nurses are skilled staff who work alongside physicians to provide care. A major goal of their care is to keep their patients healthy and free of complica-



tions. Nurses can teach you many things. Watch what they do and how they do it. Ask questions about their procedures, everything from bandaging to lifting and moving the patient, and more. Nurses know why certain techniques and methods are important. Observing and learning these procedures in the hospital will improve the care you can give your family member at home.

- Physical therapists (better known as PTs) instruct patients on exercise routines which can strengthen weak muscles and re-train nerve patterns. PTs encourage a patient to be as independent as possible. This includes not only helping a disabled child or adult to learn to sit up, or roll over in bed, or transfer from a bed to a chair; it also includes teaching exercises which are necessary to keep the body flexible.



- Occupational therapists (OTs) help patients learn to do everyday activities such as dressing, bathing, eating, typing, driving a car, or other routines. These routines are called “activities of daily living” or ADL skills. The OT is also instrumental in training people to adapt to a new barrier-free living environment at home. Many times, OTs will work closely with vocational rehab counselors to improve the work skills of a person who is newly disabled.
- Vocational counselors help patients set goals pertaining to employment and education, as well as play an important role in helping the patient find direction for his or her future.
- Social workers are assigned to a patient who requires long-term care and help a family through the transition of easing back into the community. Social workers



- not only assist in planning a rehabilitation program for the patient, but will give advice on career choices (a person struggling to deal with a new disability may have to consider learning different job skills). Social workers assist with job skills training and directing the person to accessible college campuses. In addition, social workers have information regarding Social Security benefits and services, or community agencies and resources which offer assistance to persons with disabilities, especially assisted-living resources.
- Psychologists are often assigned to a person who is recovering from brain trauma or post-traumatic stress syndrome (such as a serviceman wounded from war). Dealing with a new disability can be traumatic and a psychologist will assist the patient and his family in working through tumultuous emotions,



enabling them to overcome hurdles that may hinder successful rehabilitation.

- Recreational therapy helps people with new injuries or illnesses to learn new skills and adapt old ones in order to fill their leisure time in meaningful ways.
- Financial service workers are on staff in many hospitals and rehabilitation centers to assist in determining financial obligations and how to meet them.

### ***Financial Assistance...***

The financial fallout from disability may seem overwhelming, but your hospital's Social Services department or financial service worker can direct you to available support, including the following:

- Social Security – a source of information on Social Security Disability Insurance (SSDI) and Supplemental Security Income (SSI), as well as eligibility



requirements. The SSA includes a program for financial assistance for adult children who are injured before the age of 22. For more information, visit [www.ssa.gov/d&s1.htm](http://www.ssa.gov/d&s1.htm).

- SSDI – a basic living grant for those who have worked before becoming disabled.
- SSI – a basic living grant for disabled, blind or elderly persons.
- Medicaid – a source of assistance available through your state's Department of Health and Welfare (title may vary from state to state), functions to pay medical bills for those with financial need.
- Medicare – an available resource to those who have received SSDI for two years or those who require kidney dialysis.
- Aid to Families with Dependent Children (AFDC) – based on family income, it can subsidize general living costs. Contact



AFDC through the Department of Public Social Services (the name of this service varies from state to state). This department has information on AFDC, as well as other resources that can provide assistance with living costs, food purchases, and other needs.

- Workers' Compensation – a program which covers the major needs that arise as the result of a work-related accident or illness. Information is available through your employer and your state's Department of Labor.

Many factors are used in determining the benefits a person may receive, including:

- the patient's age
- work history
- family situation



### ***Spiritual Help...***

You and your family are not wrestling against mechanistic HMOs, PPOs, private insurance companies, or medical collection agencies; you are wrestling against “powers and principalities,” as the Bible calls the Adversary. Dark forces would love nothing more than to overwhelm you with depressing feelings and doubts about God and His goodness. Learn to see your Christian friends as the Body of Christ which will surround you with compassion, wisdom, and guidance. Seek their help often – and always remember to express your heartfelt gratitude for their assistance. No one should suffer alone – it's why God created spiritual community.

### **Rehabilitation – Preparing to Come Home**

Once the person's medical condition has stabilized, he will require rehabilitation, a crucial phase of recovery.





### ***Rehabilitation Centers...***

Rehab centers play a vital function in getting a person ready to come home. This is when you and your family will address issues such as personal care assistance, home and community accessibility, transportation, and vocational planning. Some rehab centers specialize in spinal cord injury rehab, such as Shepherd Center in Atlanta, Georgia or Craig Hospital in Denver, Colorado. Other rehab centers specialize in helping stroke survivors or individuals who have suffered brain injury, such as Casa Colinas Hospital in California.

### ***Centers for Independent Living...***

A local Independent Living Center (ILC) will serve as an excellent source of information – these are not residential facilities, but information centers which provide an array of services and information relating to transportation, hiring personal care attendants to help with home care,



job skills training and much more. These centers even provide instruction on how to hire and fire a personal care attendant (PCA). Your social worker or occupational therapist will have information regarding the location of an ILC in your area. For a complete national listing of Centers for Independent Living, go to [www.ilru.org/html/publications/directory/index.html](http://www.ilru.org/html/publications/directory/index.html).

### ***Finances...***

Your social worker will provide suggestions for meeting your family's needs during the transition to rehab and then home. Remember that your church can also provide financial assistance to cover home adaptations – whether a ramp to the front door for a wheelchair user, or a few widened doorways. Contact your elders for information about your church's "deacon's fund."

### ***Personal Care Assistance...***

Many states provide financial assistance for attendant care, that is, hiring someone to assist



a disabled person with personal care and household chores. These programs vary by region with regard to the amount of funds granted to cover the cost of personal care and housekeeping needs. Contact your social worker or ILC for detailed information. Your state's Department of Public Social Services may also have information available on attendant care funding. A good resource for those requiring attendant care is the book *Busting Loose to Independence*. This book is offered by Baylor College of Medicine, One Baylor Plaza, Houston, TX 77030; Phone: 713-798-4951; Website: [www.bcm.edu](http://www.bcm.edu)

### ***Accessibility...***

In order for a person with a disability to return home, modifications in the living environment must be made to ensure the home is accessible. Some modifications may be as simple as placing telephone books under a dining room table to accommodate the height of a person in a wheelchair; others may require a construction project.



Specific standards have been set for constructing ramps and making homes accessible. This information is included in a free publication:

### **Uniform Federal Accessibility Standards**

U.S. Architectural & Transportation

Barriers Compliance Board

1331 F ST., N.W., Suite 1000

Washington, DC 20004

Phone: 800-872-2253

TTY: 800-993-2822 • Fax: 202-272-0081

E-mail: [ta@access-board.gov](mailto:ta@access-board.gov)

Website: [www.access-board.gov/ufas](http://www.access-board.gov/ufas)

Contact your church for suggestions on carpenters, concrete workers, and others who could volunteer (or work for costs only) to make the necessary renovations to your home.

### ***Transportation...***

There are a variety of sources for transportation. Many cities now have public trans-



portation for persons with disabilities. Your local public transportation office can give you details regarding the availability of these services in your community.

Vehicles can be adapted to accommodate either disabled drivers or passengers. And rehab facilities have information on driver education for the driver who has a disability.

National Mobility Equipment Dealers Association (NMEDA) is an organization composed of independent dealers of adaptive equipment and vehicle modifications for accessibility.

#### **NMEDA**

3327 W. Bearss Ave.

Tampa, FL 33618

Phone: 813-962-8970

Fax: 813-931-4683

E-mail: [nmeda@aol.com](mailto:nmeda@aol.com)

Website: [www.nmeda.org](http://www.nmeda.org)



Accessible Vans of America (AVA) rents and sells both full-size and lowered floor minivans, through a national owner-operated dealer network.

#### **Accessible Vans of America**

Phone: 800-AVA-VANS

Website: [www.accessiblevans.com](http://www.accessiblevans.com)

#### ***Vocational Rehabilitation...***

Each state has an agency to help prepare individuals with disabilities for employment. These agencies have funds available to pay for education, job site modification, and other needs to help a person return to the work force. Check your telephone book under “Government Offices” for your local office of vocational rehabilitation.

You may also find valuable assistance with the “Higher Education and Training for People with Disabilities” organization.



### **HEATH Resource Center**

George Washington University

2134 G St. NW

Washington, DC 20052

Website: <http://gwired.gwu.edu/dss/faculty/resources/>

The book *Financial Aid for the Disabled and Their Families* by Gail Ann Schlachter and R. David Weber gives information on funding and loans available to help disabled persons further their education. This book is published by:

#### **Reference Service Press**

5000 Windplay Drive, Suite 4

El Dorado Hills, CA 95762

Phone: 916-939-9620

E-mail: [info@rspfunding.com](mailto:info@rspfunding.com)

Website: [www.rspfunding.com](http://www.rspfunding.com)

#### ***Disability Information...***

One of the best resources for information available to persons with disabilities and their



families is the magazine *SpecialLiving*. This publication includes articles on the latest in adaptive equipment, legislation affecting people affected by disability and events of interest. Inspiring stories of people who are managing their disabilities are published and books relating to disability are reviewed. The magazine publisher also operates a computerized retrieval service which can provide information on practically everything to do with disability needs, products and services.

#### **SpecialLiving**

P. O. Box 1000

Bloomington, IL 61702-1000

Phone: 309-661-9277

E-mail: [gareeb@aol.com](mailto:gareeb@aol.com)

Website: [www.specialiving.com](http://www.specialiving.com)

#### ***With Parents in Mind...***

Parents of children with disabilities may experience unique challenges in caring for their children. What to do about sibling rivalry now



that one child has a disability? What about disciplining a child with a disability? What vacation options exist for families affected by disability? There are materials designed specifically for parents. Three publications of interest are:

*Extraordinary Kids*

Cheri Fuller, Louise Tucker Jones

Publisher: Focus on the Family

*Nobody's Perfect: Living and Growing with Children Who Have Special Needs*

Nancy B. Miller

Publisher: P H Brooke

*Exceptional Parent Magazine*

Phone: 800-372-7368

Website: [www.eparent.com](http://www.eparent.com)

“Raising up God’s Special Kids” is a booklet of encouragement and practical help by Joni Eareckson Tada. It offers information on resources regarding education, rehabilitative services, advocacy and federal agencies relating



to children with disabilities. The booklet is available from Joni and Friends International Disability Center.

## **Keeping the Home Fires Burning**

In the midst of all that is happening at the hospital or rehab center, you probably still have family members at home who need your attention. How can one individual keep up with everything? May we suggest that you *ask for help!* A few friends and neighbors can lighten the load by lending a hand in simple ways. Siblings at home may need transportation to school or day care. There may be shopping or cleaning chores that could be accomplished by a neighbor, or even a group of friends on a rotating basis. Could someone return phone calls to concerned friends, or answer mail and get well cards? Friends could help gather materials for you, such as writing for the information we’ve mentioned in this booklet.



Maybe you would like to recruit an “organizer” to help you keep track of things you must do personally, like getting some rest – a close friend who would take on this task would be a great encouragement to you. Think of someone you can ask for help, then ask.

A meaningful task that a close friend or church member could organize is a prayer chain. This will keep people informed of the current needs within your family for which they can intercede. And what an encouragement to you – to know that others are praying for you daily!

## General Information

The agencies listed below are available to help you find more specific information than can be provided in this brief publication.

**National Organization on Disability (N.O.D)**  
910 Sixteenth Street, N.W. Suite 600  
Washington, D.C. 20006



Phone: (202) 293-5960  
FAX: (202) 293-7999 • TDD: (202) 293-5968  
E-mail: [ability@nod.org](mailto:ability@nod.org)  
Website: [www.nod.org](http://www.nod.org)

### **National Rehabilitation Association**

633 S. Washington Street  
Alexandria, VA 22314  
Phone: 703/836-0850  
Fax: 703/836-0848 • TDD: 703/836-0849  
E-mail: [info@nationalrehab.org](mailto:info@nationalrehab.org)  
Website: [www.nationalrehab.org](http://www.nationalrehab.org)

Another important resource is Protection and Advocacy Incorporated, a federally mandated program which advises disabled persons on legal and financial rights. Check your local telephone book for the office in your state.

The Christian Legal Society may be able to provide you with good legal advice or refer you to a Christian attorney in your area.



## Christian Legal Society

8001 Braddock Rd.

Suite 300

Springfield, VA 22151

Phone: 703-642-1070

E-mail: [clshq@clsnet.org](mailto:clshq@clsnet.org)

Website: [www.clsnet.org](http://www.clsnet.org)

## There is Hope

Facing a disability is never easy. It seems that every answer raises another question, but with diligence and perseverance, you can find the solutions for you and your family. And remember: What used to be “normal” is no longer – but take heart; you and your family will discover a new “normal” as you learn to embrace the world of disability for your loved one.

And remember this – God’s care is available to you, as you spend uneasy moments at a hospital bedside, or hours researching the needs of your loved one, or as you rush through your



day, meeting all the demands. God knows about every concern you have right this minute. You can “cast all your anxiety upon Him...” (1 Peter 5:7).

At the Joni and Friends International Disability Center, our prayer is that you will sense the Lord’s guidance and direction, helping you every step of the way through this new maze of disability concerns. And we are here to pray for you. Just contact [corresp@joniandfriends.org](mailto:corresp@joniandfriends.org) and share your detailed requests with our helpful and caring staff. And remember, Joni and Friends has a rich array of resources and programs, especially our Family Retreats which we run every spring and summer. Just go to [www.joniandfriends.org](http://www.joniandfriends.org) and find all the information you need. And if we didn’t answer your questions in this booklet, just let us know – we stand ready to help and support you through this difficult time. ■



*From all of us at Joni and Friends, we thank you for considering us as part of your circle of friends providing support through this challenging time. And remember, the Lord Jesus will be your guide, your constant Help through the days and weeks to come!*

**Joni and Friends International  
Disability Center**

P.O. Box 3333

Agoura Hills, CA 91376

818/707-5664; fax 818/707-2391

[www.joniandfriends.org](http://www.joniandfriends.org)

[corresp@joniandfriends.org](mailto:corresp@joniandfriends.org)