

# A Spinal Cord Injury Affects The Entire Family

## **FacingDisability.com:**

State-of-the-Art Rehabilitation Information  
and Support in an Online World

### **Faculty**

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Shriners Hospital for  
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Shriners Hospitals for Children®  
Chicago  
Love to the rescue.®

**Thea Flaum,** Founder and President,  
Hill Foundation for Families Living  
With Disabilities – Chicago

**facingdisability.com**

for families facing spinal cord injuries



# Disclosures

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Presenters have no financial interest to disclose.

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PESG and ACRM staff have no financial interest to disclose.



# Today's Learning Objectives

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At the conclusion, the participant will be able to:

1. Discuss the importance of education and peer support for those affected by spinal cord injury and other life-changing diseases.
2. Describe a new intervention that may assist in achieving the goal of delivering excellence in state-of-the-art healthcare via support and education online.
3. Offer an important resource for people with SCI, their families, friends and rehab healthcare providers.
4. Provide a road map which outlines the process for creating a similar website for other diseases.



# Background...

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## **Spinal cord injury is sudden and life changing**

Life is turned upside down

- Entire Family
- Friends
- Community

Coping with the injury

- Physical
- Psychological
- Social
- Financial



# Trauma, Hospitalization, & Rehab

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## Balancing Physical and Psychological Needs

- Level of injury
- Immediate medical concerns
- Treatment, meds, rehab
- Complications – pain, spasticity, UTI's, blood clots, pressure ulcers, autonomic dysreflexia

## Emotional Shock

- This can't be happening to me

## Denial vs. Hope

- This is only temporary



# Trauma, Hospitalization, & Rehab

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## Initial Goals

- Impart knowledge of new injury
- Enhance level of independence
- Prepare for rejoining pre-injury activities including work or education
- Return to the community as soon as possible

Focus is, primarily, on the injured individual

- Shorter lengths of stay



# Disability: A Family Affair

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Disability is truly a family affair as it changes the balance in the family system

All family members are impacted in unique and diverse ways

The initial post-disability period is often a time of crisis but also represents a time of opportunity



# The Goal of Rehabilitation

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It's all about community: re-integrating back into the community and returning to family and friends!!



# Treatment & Interventions

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## **Psychosocial education**

- Acquire needed knowledge both psychosocial and physical
- Understand the concepts of grief and loss

## **Affect expression**

- Recognize and identify feelings
- Mourn the loss

## **Cognitive affect regulation & processing**

- Understand the relationship between thoughts, feelings, and behavior
- Recognize and correct inaccurate thoughts and beliefs



# Treatment & Interventions

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## **Stress management skills**

- Relaxation techniques
- Positive self-talk

## **Trauma narrative**

- Tell your story
- Find meaning, help others
- Peer mentor



# Challenges

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## **For in individual who is injured**

- Loss of control
- Sense of identity
- Body image
- Peer relationships
- Return to work/school/community role
- Dating and sexuality

## **For the family, friends, and caregivers**

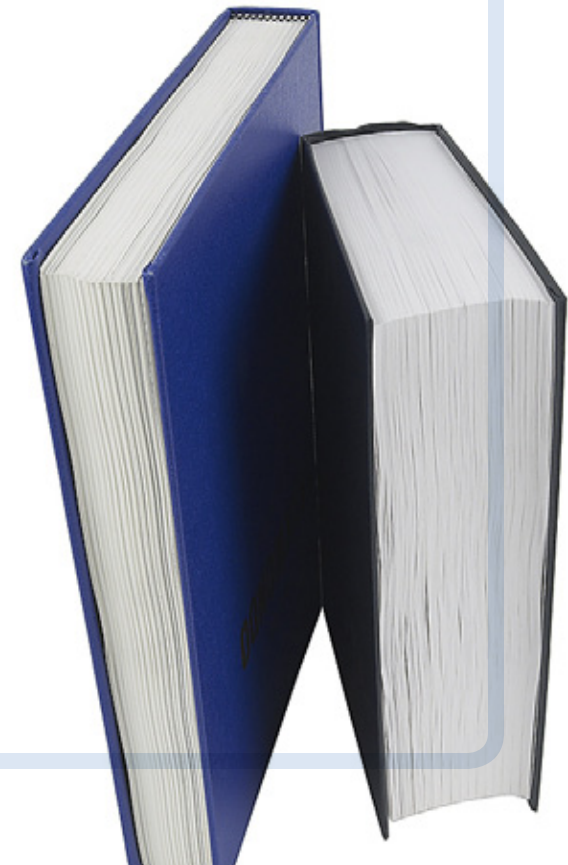
- Learning medical care and terminology
- Becoming a caregiver
- Feelings of overprotectiveness, fear, anxiety, depression, guilt
- Learning to balance hope with present day
- Finding others who understand



# What We Know...

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- Relationships, belonging, and support are essential to quality of life
- Make connections
- Enhance your disability knowledge
- Focus on the entire family
- Reach out to your community
- Seek role models within the disability community
- Find an expert



# What Those with SCI Tell Us...

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- Develop a support network
- Keep up to date... get on every mailing list you can
- Talk, talk, talk... with each other
- Use technology to keep you connected – social networking, emails, care pages, etc.



# FacingDisability.com

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- Cutting edge, internet-based project
- Decreased isolation, educate, & support
- Connect with experts, peers & family members
- Instantly available



# After an SCI, the Family Often Has a Sense of Isolation

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- 10,000-12,000 U.S. spinal cord injuries per year
- Half aged 16-30 at time of injury
- 80 percent male
- Half result in quadriplegia/tetraplegia
- 270,000 people now living with SCI



# After only...

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- 12 hospital days
- 37 rehab days

9 out of 10 people  
with SCI return home



# Now what???





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for families facing spinal cord injuries

VIDEO 1: INTRO

# Collecting Life Experiences In Coping With SCI

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- What do family members need to know right away?
- What are the most important questions?





Search Facing Disability



T T+

Watch Videos

Resources

Forums

Peer Counseling

About

Blog

Donate

## Spinal Cord Injury Topics And Questions

### Categories

First Days After SCI  
SCI Rehabilitation  
SCI Financial Issues  
Going Home After SCI  
SCI Caregiving  
Education After SCI  
Adaptive Sports  
Employment After SCI  
Relationships After SCI  
Social Life & Sex After SCI  
Marriage & Children After SCI  
Feelings After SCI  
Life After SCI



Click on a question in the list below, or select a category on the left to filter your search.

### First Days After SCI

[What was the hardest part of the first days in the hospital?](#)  
[How did you develop an understanding of the injury?](#)  
[What was your greatest fear at first?](#)  
[How did family members respond to the news?](#)  
[What personal support was most helpful to you?](#)  
[How did you deal with stress at first?](#)  
[What do you wish you had known at the beginning?](#)

### SCI Rehabilitation

[What were the important milestones in rehabilitation?](#)  
[What was the hardest part of rehabilitation?](#)

### Employment After SCI

[What kind of work do you do?](#)  
[How did you handle going back to work?](#)

### Relationships After SCI

[How have your family relationships changed?](#)  
[How has your relationship with your son or daughter changed?](#)  
[How have your friendships changed?](#)  
[What's important for parents to understand?](#)  
[What's important for family and friends to understand?](#)  
[What's the hardest part about having a disabled family member?](#)

Spinal Cord Injury Questions & Answers | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-questions-answers

facingdisability.com  
for families facing spinal cord injuries

Watch Videos Resources

## Spinal Cord Injury Topics

### Categories

- First Days After SCI
- SCI Rehabilitation
- SCI Financial Issues
- Going Home After SCI
- SCI Caregiving
- Education After SCI
- Adaptive Sports
- Employment After SCI
- Relationships After SCI
- Social Life & Sex After SCI
- Marriage & Children After SCI
- Feelings After SCI
- Life After SCI

Click on a question to read the answer

**First Days After SCI**

What was the hardest part about being in the hospital?

How did you develop coping strategies?

What was your greatest fear?

How did family members cope?

What personal support did you need?

How did you deal with the physical changes?

What do you wish you had known?

**SCI Rehabilitation**

What were the important milestones in rehabilitation?



What was the hardest part of rehabilitation?

What's important for parents to understand?

What's important for family and friends to understand?

What's the hardest part about having a disabled family member?

Donate



# Close-Ups are Powerful

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# Interview Set-Up



# Look Who's Talking

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More than 100 people: mothers, fathers, siblings, spouses, children and people with SCI themselves

Recommendations from SCI professionals

- Rehabilitation Institute of Chicago
- Shriners Childrens Hospital – Chicago
- Schwab Rehabilitation Hospital – Chicago
- Magee Rehabilitation Hospital – Philadelphia
- Marianjoy Rehabilitation Hospital – Chicago



# Keep It Short

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The internet is an impatient medium

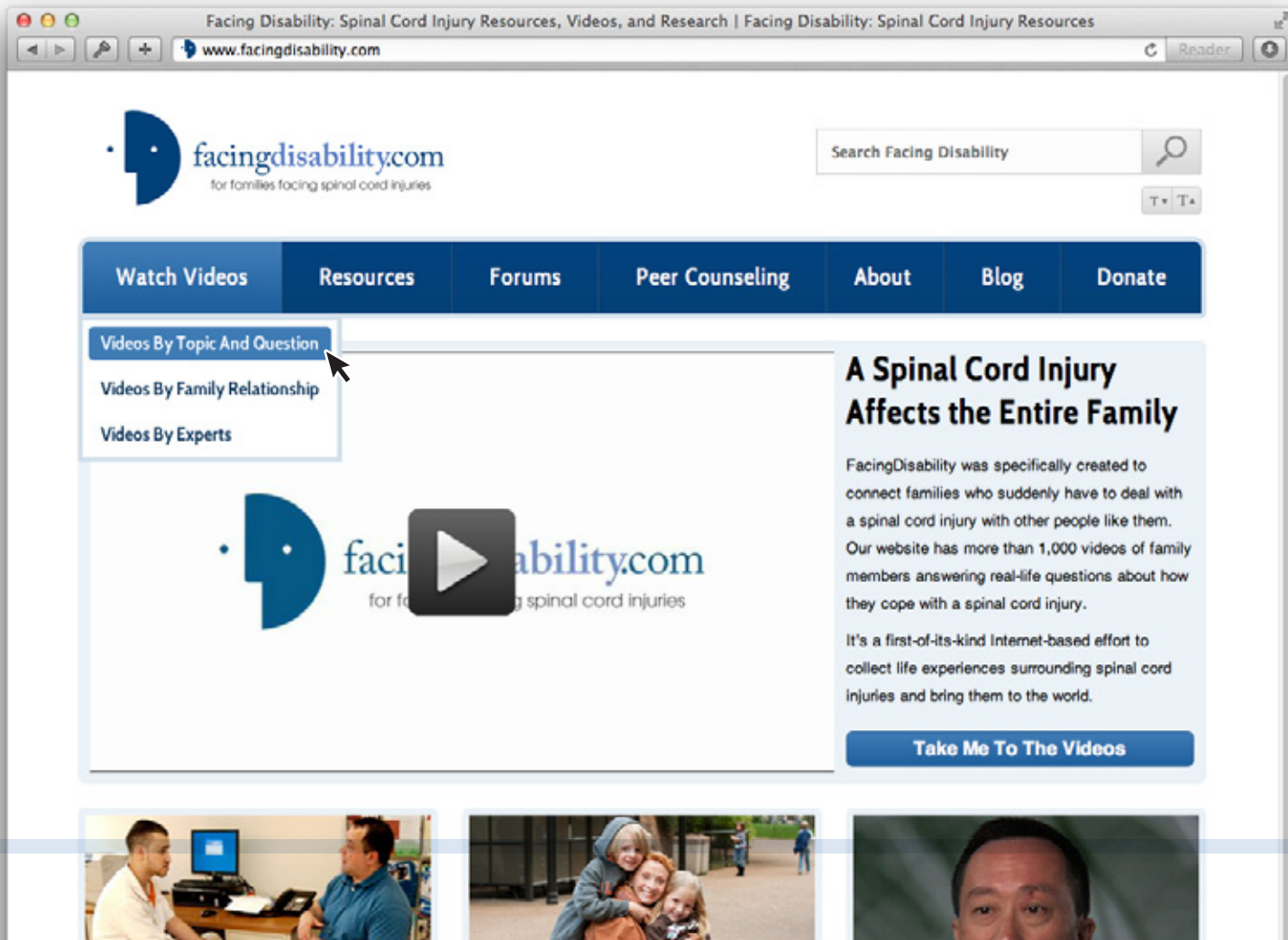
1350 videos today...

90 percent of them are

LESS THAN ONE MINUTE LONG



# How to Find What You're Looking For



# How to Find What You're Looking For

Spinal Cord Injury Questions & Answers | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-videos

facingdisability.com  
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

## Spinal Cord Injury Topics And Questions

**Categories**

- First Days After SCI
- SCI Rehabilitation
- SCI Financial Issues
- Going Home After SCI
- SCI Caregiving
- Education After SCI
- Adaptive Sports
- Employment After SCI
- Relationships After SCI
- Social Life & Sex After SCI
- Marriage & Children After SCI
- Feelings After SCI
- Life After SCI



Click on a question in the list below, or select a category on the left to filter your search.

**First Days After SCI**

- [What was the hardest part of the first days in the hospital?](#)
- [How did you develop an understanding of the injury?](#)
- [What was your greatest fear at first?](#)
- [How did family members respond to the news?](#)
- [What personal support was most helpful to you?](#)
- [How did you deal with stress at first?](#)

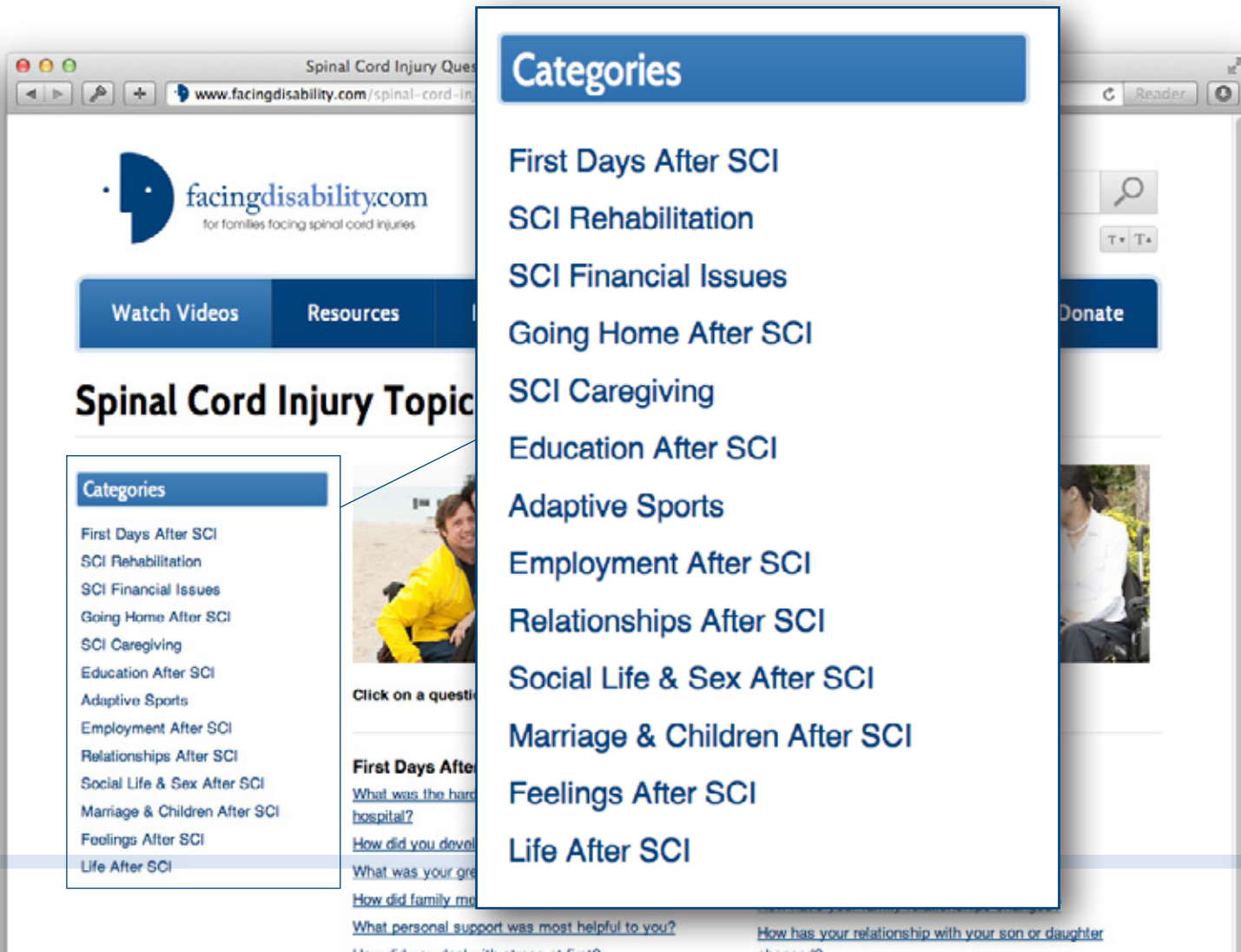
**Employment After SCI**

- [What kind of work do you do?](#)
- [How did you handle going back to work?](#)

**Relationships After SCI**

- [How have your family relationships changed?](#)
- [How has your relationship with your son or daughter changed?](#)

# How to Find What You're Looking For



The image shows a screenshot of the facingdisability.com website. The browser address bar displays "www.facingdisability.com/spinal-cord-injury". The website header includes the logo "facingdisability.com for families facing spinal cord injuries" and navigation buttons for "Watch Videos" and "Resources". The main heading is "Spinal Cord Injury Topics". A "Categories" dropdown menu is open, listing various topics. The background of the website shows a person in a yellow jacket and a "Donate" button.

**Categories**

- First Days After SCI
- SCI Rehabilitation
- SCI Financial Issues
- Going Home After SCI
- SCI Caregiving
- Education After SCI
- Adaptive Sports
- Employment After SCI
- Relationships After SCI
- Social Life & Sex After SCI
- Marriage & Children After SCI
- Feelings After SCI
- Life After SCI

Click on a question

**First Days After SCI**  
[What was the hardest part of the hospital?](#)  
[How did you develop your independence?](#)  
[What was your greatest challenge?](#)  
[How did family members cope?](#)  
[What personal support was most helpful to you?](#)  
[How did you deal with stress at first?](#)

**Relationships After SCI**  
[How has your relationship with your son or daughter changed?](#)

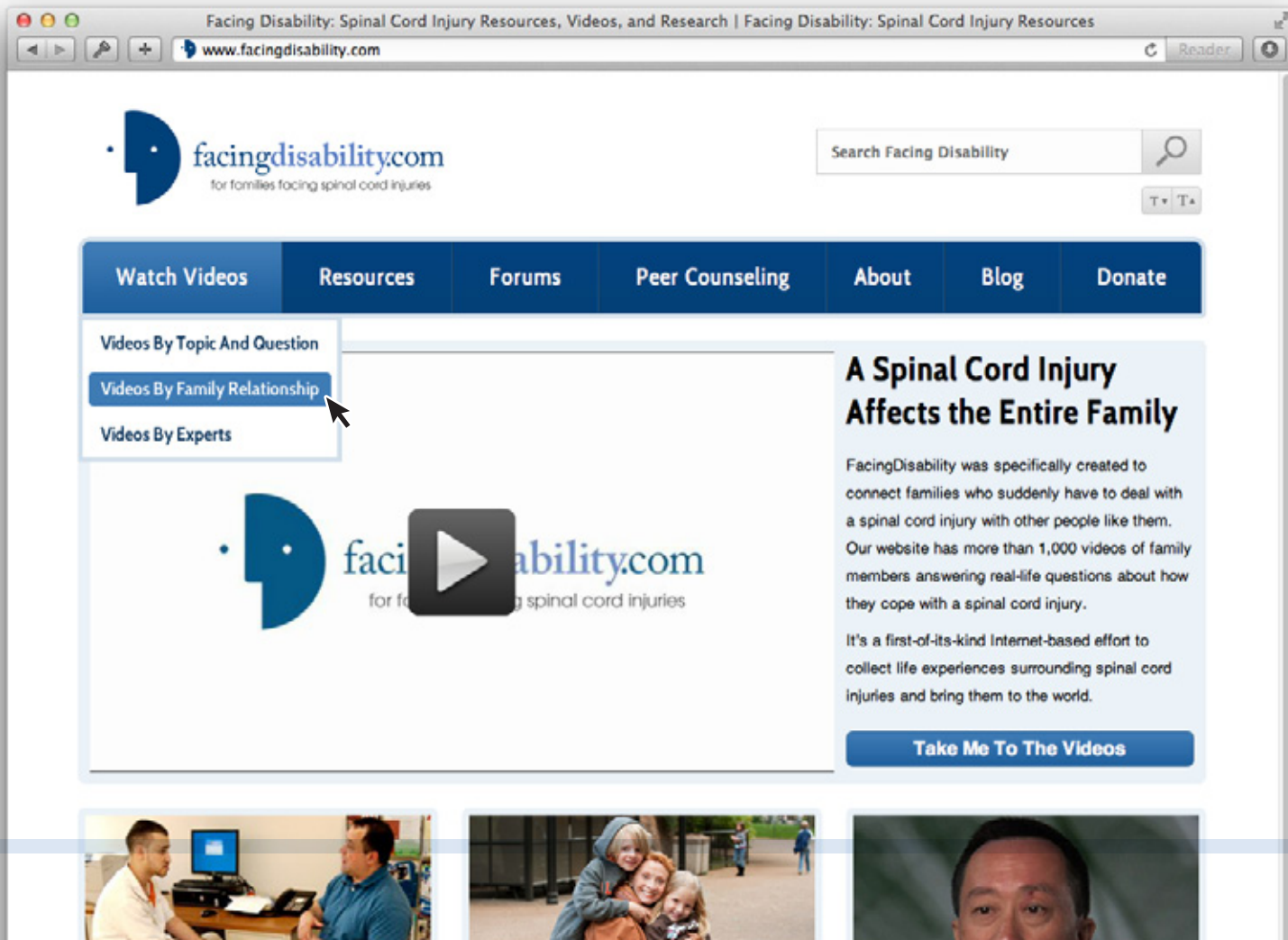


facingdisability.com

for families facing spinal cord injuries

VIDEO 2: TOPICS & QUESTIONS

# How to Find Who You're Looking For



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Facing Disability: Spinal Cord Injury Resources, Videos, and Research | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Videos By Topic And Question

Videos By Family Relationship

Videos By Experts

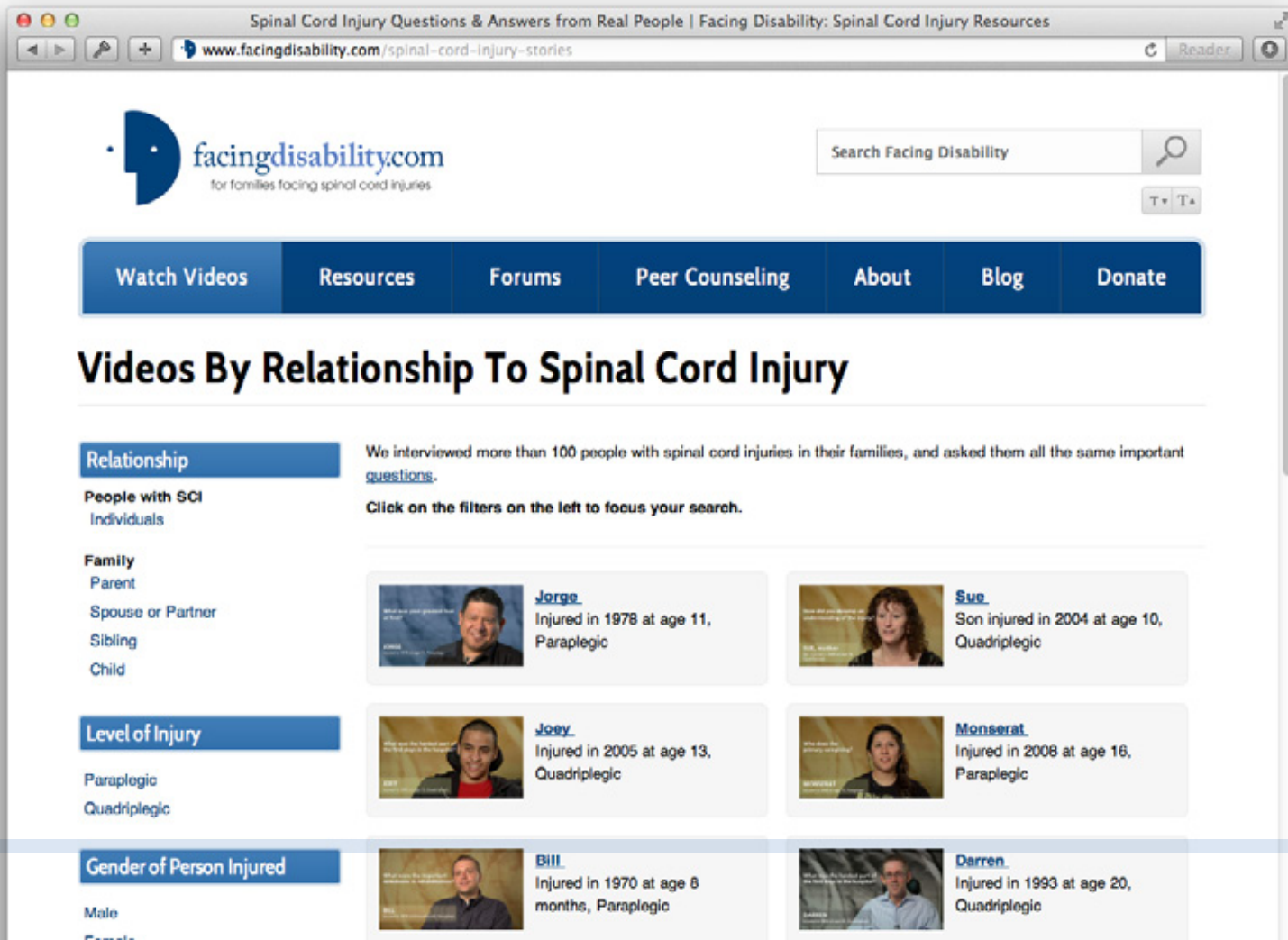
**A Spinal Cord Injury Affects the Entire Family**

FacingDisability was specifically created to connect families who suddenly have to deal with a spinal cord injury with other people like them. Our website has more than 1,000 videos of family members answering real-life questions about how they cope with a spinal cord injury.

It's a first-of-its-kind Internet-based effort to collect life experiences surrounding spinal cord injuries and bring them to the world.

**Take Me To The Videos**

# How to Find Who You're Looking For



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-stories". The page title is "Spinal Cord Injury Questions & Answers from Real People | Facing Disability: Spinal Cord Injury Resources". The website logo is "facingdisability.com for families facing spinal cord injuries". A search bar is labeled "Search Facing Disability". A navigation menu includes "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The main heading is "Videos By Relationship To Spinal Cord Injury".

**Relationship**

**People with SCI**  
Individuals

**Family**  
Parent  
Spouse or Partner  
Sibling  
Child

**Level of Injury**  
Paraplegic  
Quadriplegic

**Gender of Person Injured**  
Male  
Female

We interviewed more than 100 people with spinal cord injuries in their families, and asked them all the same important [questions](#).  
Click on the filters on the left to focus your search.

Relationship	Level of Injury	Gender	Name	Age at Injury	Condition
Parent	Paraplegic	Male	Jorge	11	Paraplegic
Parent	Quadriplegic	Female	Sue	10	Quadriplegic
Spouse or Partner	Paraplegic	Male	Joey	13	Quadriplegic
Spouse or Partner	Paraplegic	Female	Monserat	16	Paraplegic
Sibling	Paraplegic	Male	Bill	8 months	Paraplegic
Sibling	Quadriplegic	Male	Darren	20	Quadriplegic

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Spinal Cord Injury Questions & Answers from Real People | Facing Disability: Spinal Cord Injury Resources

[www.facingdisability.com/spinal-cord-injury-stories](http://www.facingdisability.com/spinal-cord-injury-stories)

facingdisability.com  
for families facing spinal cord injuries

Watch Videos Resources

Donate

Videos By Relationship

**Relationship**

- People with SCI
- Individuals
- Family
- Parent
- Spouse or Partner
- Sibling
- Child

**Level of Injury**

- Paraplegic
- Quadriplegic

**Gender of Person Injured**

- Male
- Female

We interviewed [questions](#).  
Click on the filter

**Joey**  
Injured in 2005 at age 13,  
Quadriplegic

**Monserat**  
Injured in 2008 at age 16,  
Paraplegic

**Bill**  
Injured in 1970 at age 8  
months, Paraplegic

**Darren**  
Injured in 1993 at age 20,  
Quadriplegic

page 10,

# How to Find Who You're Looking For

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Navigation buttons include "Watch Videos" and "Resources". A "Donate" button is visible on the right. A search icon and text size controls (T, T+) are also present.

The main heading is "Videos By Relationship". Below it, there are three filter sections:

- Relationship**
  - People with SCI
  - Individuals
  - Family
    - Parent
    - Spouse or Partner
    - Sibling
    - Child
- Level of Injury**
  - Paraplegic
  - Quadriplegic
- Gender of Person Injured**
  - Male
  - Female

Below the filters, there is a section titled "We interviewed real people with questions. Click on the filters to narrow down the results." This section displays a grid of video thumbnails with names and descriptions:

- Joey**: Injured in 2005 at age 13, Quadriplegic
- Monserat**: Injured in 2008 at age 16, Paraplegic
- Bill**: Injured in 1970 at age 8 months, Paraplegic
- Darren**: Injured in 1993 at age 20, Quadriplegic

# How to Find Who You're Looking For

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**Relationship**

- People with SCI
- Individuals
- Family
  - Parent
  - Spouse or Partner
  - Sibling
  - Child

**Level of Injury**

- Paraplegic
- Quadriplegic

**Gender of Person Injured**

- Male
- Female

**Age at Injury**

- 0-12
- 13-18
- 19-24
- 25-35
- 36+

**Videos By Relationship**

We interviewed [questions](#).  
Click on the filter to refine your search.

Name	Age at Injury	Level of Injury
<a href="#">Jorge</a>	Injured in 1978 at age 11,	Paraplegic
<a href="#">Sue</a>	Son injured in 2004 at age 10,	Quadriplegic
<a href="#">Joey</a>	Injured in 2005 at age 13,	Quadriplegic
<a href="#">Monserat</a>	Injured in 2008 at age 16,	Paraplegic
<a href="#">Bill</a>	Injured in 1970 at age 8 months,	Paraplegic
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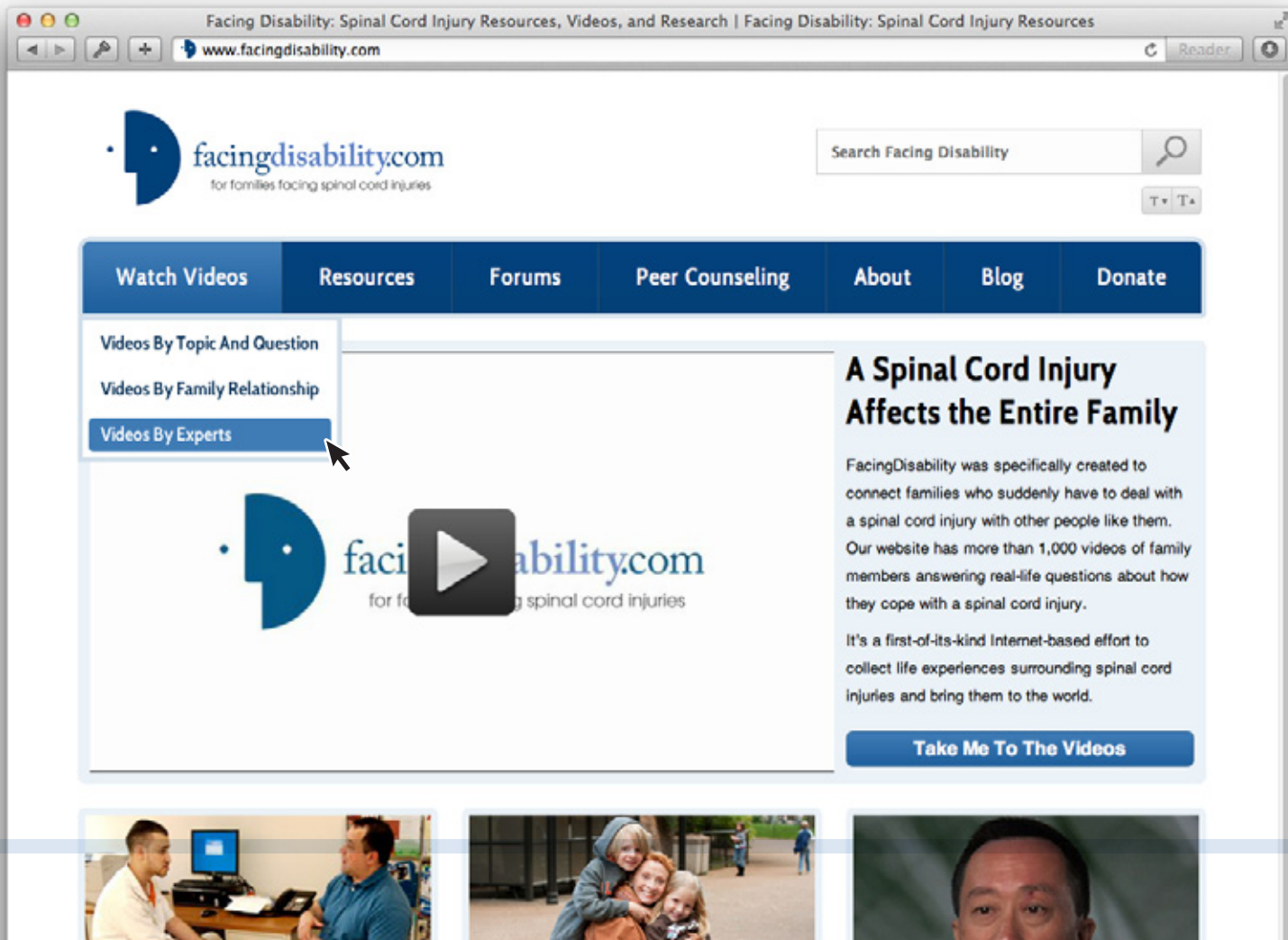


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for families facing spinal cord injuries

## VIDEO 3: RELATIONSHIPS

# How to Find an Expert



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[www.facingdisability.com](http://www.facingdisability.com)

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

Videos By Topic And Question

Videos By Family Relationship

Videos By Experts

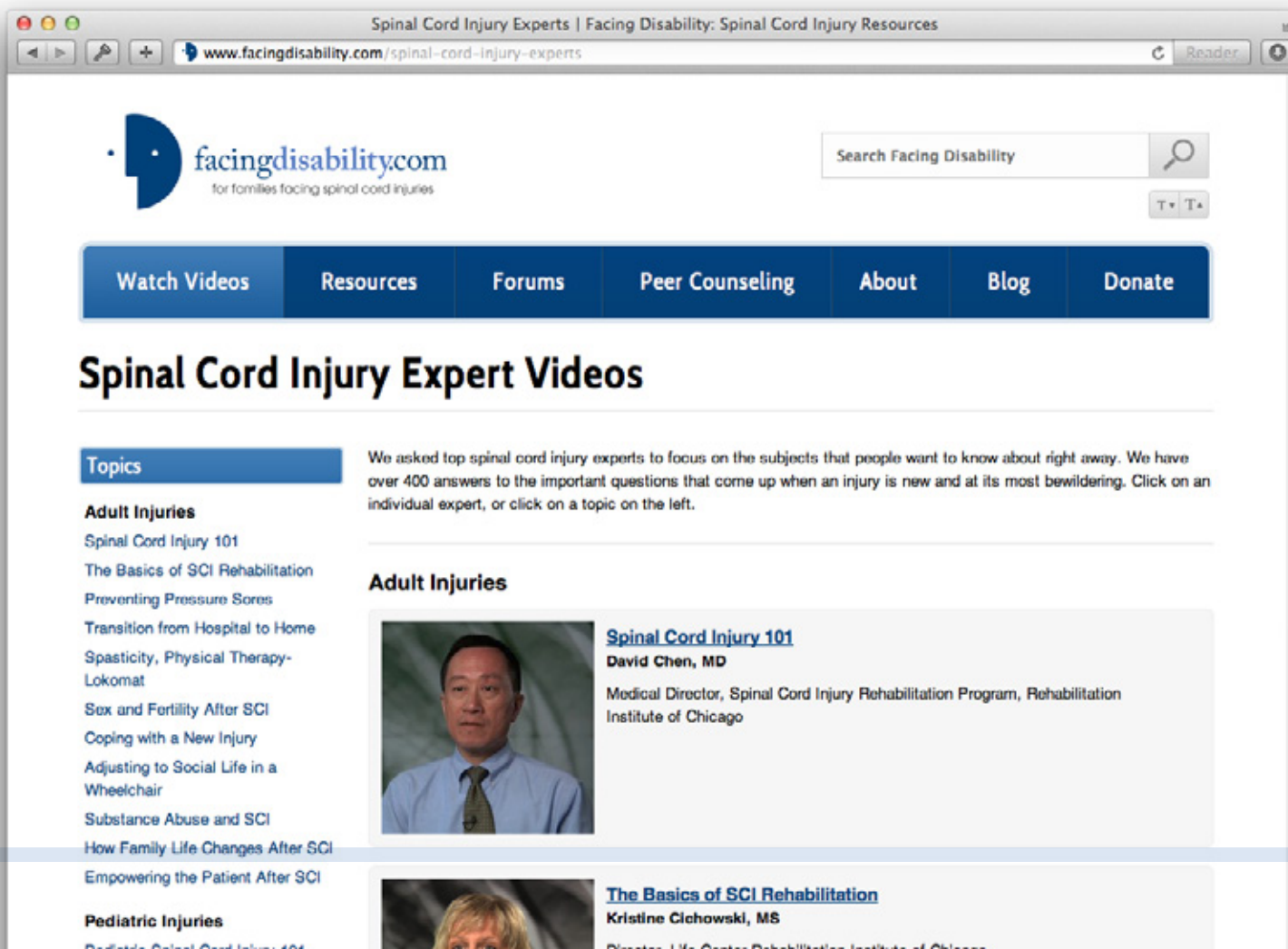
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[Take Me To The Videos](#)

# How to Find an Expert



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-experts". The page features the Facing Disability logo, a search bar, and a navigation menu with links to Watch Videos, Resources, Forums, Peer Counseling, About, Blog, and Donate. The main heading is "Spinal Cord Injury Expert Videos". Below this, there is a "Topics" section with a list of links for Adult Injuries and Pediatric Injuries. The "Adult Injuries" section is expanded, showing a list of topics and a video player for "Spinal Cord Injury 101" by David Chen, MD. The video player shows a portrait of David Chen, MD, and the text "Spinal Cord Injury 101" and "David Chen, MD". Below the video player, there is a section for "The Basics of SCI Rehabilitation" by Kristine Cichowski, MS.

Spinal Cord Injury Experts | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-experts

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for families facing spinal cord injuries

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## Spinal Cord Injury Expert Videos

**Topics**

**Adult Injuries**

- Spinal Cord Injury 101
- The Basics of SCI Rehabilitation
- Preventing Pressure Sores
- Transition from Hospital to Home
- Spasticity, Physical Therapy-Lokomat
- Sex and Fertility After SCI
- Coping with a New Injury
- Adjusting to Social Life in a Wheelchair
- Substance Abuse and SCI
- How Family Life Changes After SCI
- Empowering the Patient After SCI

**Pediatric Injuries**

We asked top spinal cord injury experts to focus on the subjects that people want to know about right away. We have over 400 answers to the important questions that come up when an injury is new and at its most bewildering. Click on an individual expert, or click on a topic on the left.

### Adult Injuries

**Spinal Cord Injury 101**  
**David Chen, MD**  
Medical Director, Spinal Cord Injury Rehabilitation Program, Rehabilitation Institute of Chicago

**The Basics of SCI Rehabilitation**  
**Kristine Cichowski, MS**  
Director, Life Center Rehabilitation Institute of Chicago

# How to Find an Expert

Spinal Cord Injury  
www.facingdisability.com/spinal-cord-injury



Watch Videos

Resources

## Spinal Cord Injury Experts

### Topics

#### Adult Injuries

Spinal Cord Injury 101  
The Basics of SCI Rehabilitation  
Preventing Pressure Sores  
Transition from Hospital to Home  
Spasticity, Physical Therapy-Lokomat  
Sex and Fertility After SCI  
Coping with a New Injury  
Adjusting to Social Life in a Wheelchair  
Substance Abuse and SCI  
How Family Life Changes After SCI  
Empowering the Patient After SCI

#### Pediatric Injuries

Pediatric Spinal Cord Injury 101

We asked top experts  
over 400 answers  
individual experts

#### Adult Injuries



### Topics

#### Adult Injuries

Spinal Cord Injury 101  
The Basics of SCI Rehabilitation  
Preventing Pressure Sores  
Transition from Hospital to Home  
Spasticity, Physical Therapy-Lokomat  
Sex and Fertility After SCI  
Coping with a New Injury  
Adjusting to Social Life in a Wheelchair  
Substance Abuse and SCI  
How Family Life Changes After SCI  
Empowering the Patient After SCI

Kristine Cichowski, MS

Director, Life Center Rehabilitation Institute of Chicago

Reader




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Donate

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# How to Find an Expert



The screenshot shows a web browser window with the URL [www.facingdisability.com/spinal-cord-injury-experts](http://www.facingdisability.com/spinal-cord-injury-experts). The page features the Facing Disability logo, a search bar, and navigation links for "Watch Videos", "Resources", and "Donate". A sidebar on the left lists "Topics" under "Adult Injuries" and "Pediatric Injuries". The main content area displays a list of pediatric injury topics, with a white box highlighting the "Pediatric Injuries" section. Below this, a list of experts is shown, including David Chen, MD, and Kristine Cichowski, MS.

Spinal Cord Injury Experts | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-experts

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Search Facing Disability

Watch Videos Resources Donate

Spinal Cord Injury Experts

**Pediatric Injuries**

- [Pediatric Spinal Cord Injury 101](#)
- [The Basics of Pediatric SCI Rehabilitation](#)
- [Transitions for Children with SCI](#)

**Adult Injuries**

- [Spinal Cord Injury 101](#)
- [The Basics of SCI Rehabilitation](#)
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**Pediatric Injuries**

- [Pediatric Spinal Cord Injury 101](#)

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**David Chen, MD**  
Medical Director, Spinal Cord Injury Rehabilitation Program, Rehabilitation Institute of Chicago

**The Basics of SCI Rehabilitation**  
**Kristine Cichowski, MS**  
Director, Life Center Rehabilitation Institute of Chicago



facingdisability.com

for families facing spinal cord injuries

VIDEO 4: EXPERTS

# How to Find Resources



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-resources". The page title is "Spinal Cord Injury Resources | Facing Disability: Spinal Cord Injury Resources". The website logo for "facingdisability.com" is visible, with the tagline "for families facing spinal cord injuries". A search bar labeled "Search Facing Disability" is present. A navigation menu includes links for "Watch Videos", "Resources", "Forums", "Peer Counseling", "About", "Blog", and "Donate". The "Resources" section is active, displaying a list of categories on the left and a grid of resource images on the right. The categories listed are: Short List, Government Programs, Family and Caregiver Support, Financial Help, Active Lifestyle, Advocacy, Employment and Education, Adaptive Technology, Recent Medical Research, Good Things to Read, SCI Facts and Figures, Model System Rehab Hospitals, and Pediatric Spinal Cord Injury. The "Short List" category is highlighted. Below the categories, a paragraph states: "We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you 'Where to Start.'" The "Short List" section begins with the text: "These websites are good places to begin to learn about the core basics of spinal cord injuries. The Short List constitutes an introduction to spinal cord information, institutions and the disability community." The "Adaptive Technology" section begins with the text: "Adaptive technology refers to products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities. These websites feature useful programs like".

Spinal Cord Injury Resources | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-resources

facingdisability.com  
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

## Resources

### Categories

- Short List
- Government Programs
- Family and Caregiver Support
- Financial Help
- Active Lifestyle
- Advocacy
- Employment and Education
- Adaptive Technology
- Recent Medical Research
- Good Things to Read
- SCI Facts and Figures
- Model System Rehab Hospitals
- Pediatric Spinal Cord Injury

We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you "Where to Start."

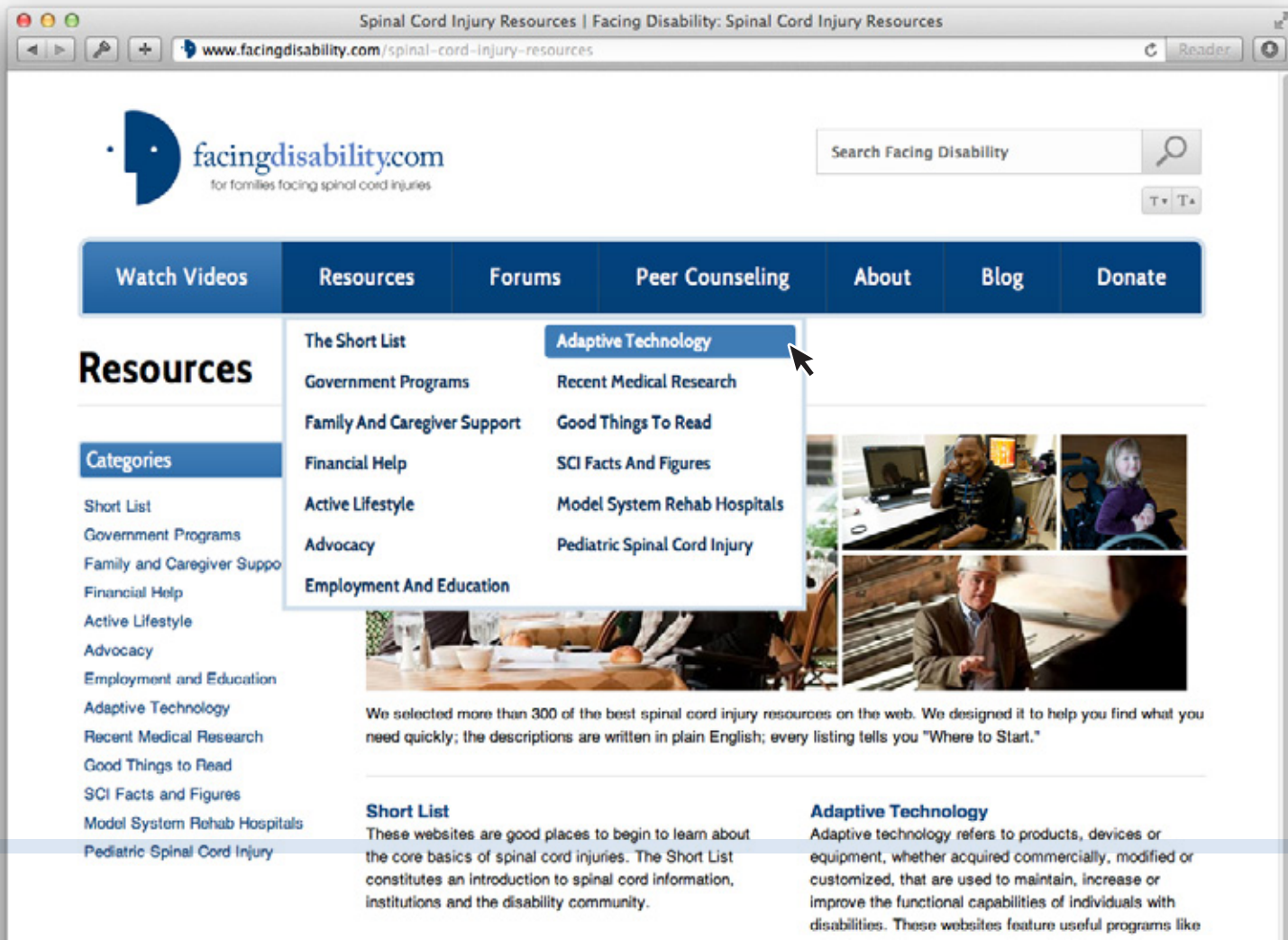
### Short List

These websites are good places to begin to learn about the core basics of spinal cord injuries. The Short List constitutes an introduction to spinal cord information, institutions and the disability community.

### Adaptive Technology

Adaptive technology refers to products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities. These websites feature useful programs like

# How to Find Resources



The screenshot shows a web browser window with the URL [www.facingdisability.com/spinal-cord-injury-resources](http://www.facingdisability.com/spinal-cord-injury-resources). The page features a navigation bar with links: Watch Videos, Resources, Forums, Peer Counseling, About, Blog, and Donate. The 'Resources' link is highlighted, and a dropdown menu is open, showing a list of categories: The Short List, Government Programs, Family And Caregiver Support, Financial Help, Active Lifestyle, Advocacy, Employment And Education, Adaptive Technology (highlighted with a mouse cursor), Recent Medical Research, Good Things To Read, SCI Facts And Figures, Model System Rehab Hospitals, and Pediatric Spinal Cord Injury. On the left, there is a 'Categories' section with a list of links: Short List, Government Programs, Family and Caregiver Support, Financial Help, Active Lifestyle, Advocacy, Employment and Education, Adaptive Technology, Recent Medical Research, Good Things to Read, SCI Facts and Figures, Model System Rehab Hospitals, and Pediatric Spinal Cord Injury. The main content area has a heading 'Resources' and a paragraph: 'We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you "Where to Start."' Below this, there are two columns of content. The left column is titled 'Short List' and describes the purpose of the Short List. The right column is titled 'Adaptive Technology' and explains what adaptive technology refers to.

Spinal Cord Injury Resources | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/spinal-cord-injury-resources

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

**Resources**

**Categories**

- Short List
- Government Programs
- Family and Caregiver Support
- Financial Help
- Active Lifestyle
- Advocacy
- Employment and Education
- Adaptive Technology
- Recent Medical Research
- Good Things to Read
- SCI Facts and Figures
- Model System Rehab Hospitals
- Pediatric Spinal Cord Injury

The Short List

Government Programs

Family And Caregiver Support

Financial Help

Active Lifestyle

Advocacy

Employment And Education

Adaptive Technology

Recent Medical Research

Good Things To Read

SCI Facts And Figures

Model System Rehab Hospitals

Pediatric Spinal Cord Injury

We selected more than 300 of the best spinal cord injury resources on the web. We designed it to help you find what you need quickly; the descriptions are written in plain English; every listing tells you "Where to Start."

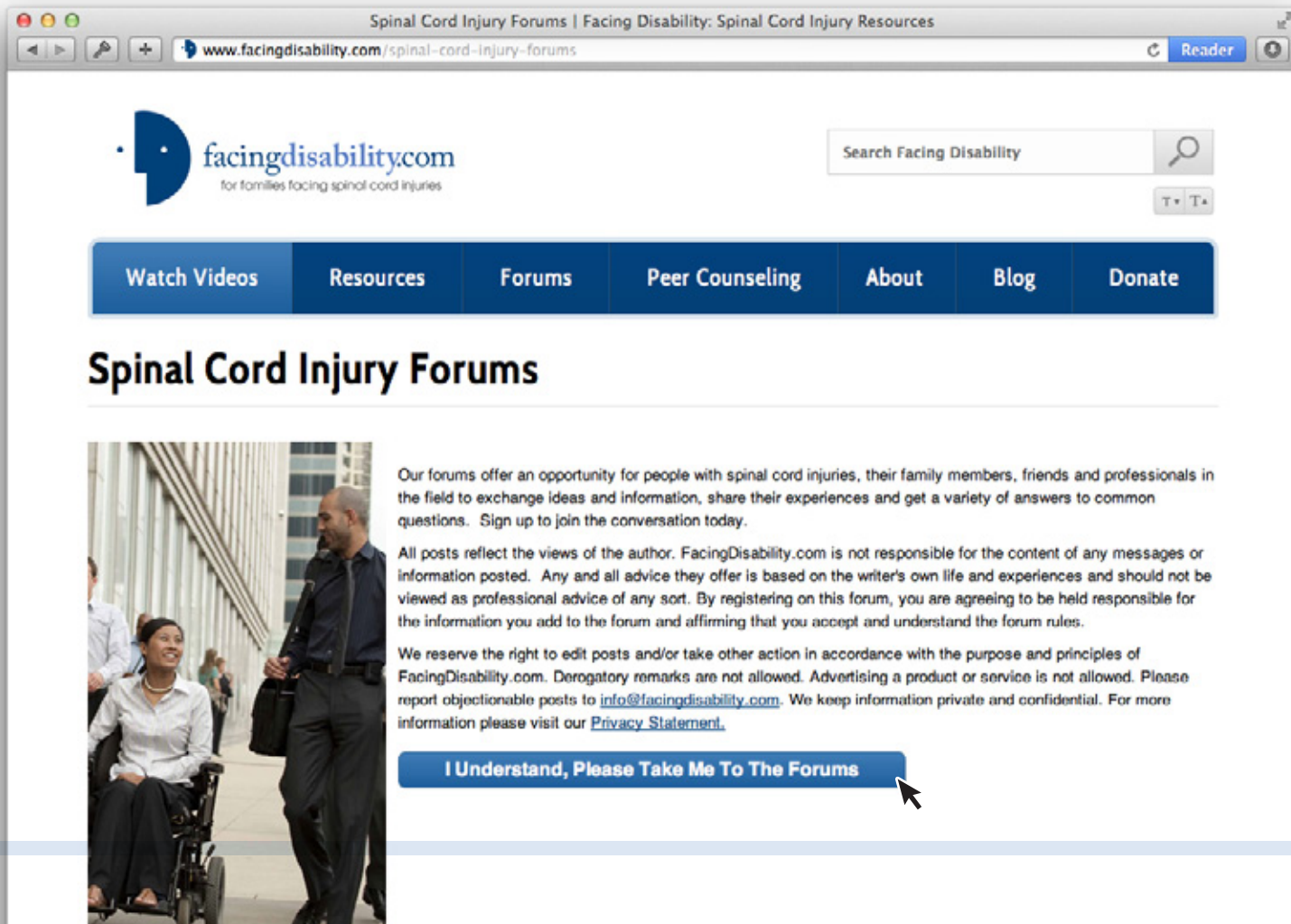
**Short List**

These websites are good places to begin to learn about the core basics of spinal cord injuries. The Short List constitutes an introduction to spinal cord information, institutions and the disability community.

**Adaptive Technology**

Adaptive technology refers to products, devices or equipment, whether acquired commercially, modified or customized, that are used to maintain, increase or improve the functional capabilities of individuals with disabilities. These websites feature useful programs like

# Forums



The screenshot shows a web browser window with the address bar displaying "www.facingdisability.com/spinal-cord-injury-forums". The page features the Facing Disability logo, a search bar, and a navigation menu with links to Watch Videos, Resources, Forums, Peer Counseling, About, Blog, and Donate. The main heading is "Spinal Cord Injury Forums". Below this is a photograph of a man in a suit and a woman in a wheelchair walking outdoors. To the right of the photo is a text block explaining the forum's purpose and rules, followed by a blue button labeled "I Understand, Please Take Me To The Forums" which is being clicked by a mouse cursor.

Spinal Cord Injury Forums | Facing Disability: Spinal Cord Injury Resources


www.facingdisability.com/spinal-cord-injury-forums

facingdisability.com  
for families facing spinal cord injuries

Search Facing Disability

Watch Videos Resources Forums Peer Counseling About Blog Donate

## Spinal Cord Injury Forums



Our forums offer an opportunity for people with spinal cord injuries, their family members, friends and professionals in the field to exchange ideas and information, share their experiences and get a variety of answers to common questions. Sign up to join the conversation today.

All posts reflect the views of the author. FacingDisability.com is not responsible for the content of any messages or information posted. Any and all advice they offer is based on the writer's own life and experiences and should not be viewed as professional advice of any sort. By registering on this forum, you are agreeing to be held responsible for the information you add to the forum and affirming that you accept and understand the forum rules.

We reserve the right to edit posts and/or take other action in accordance with the purpose and principles of FacingDisability.com. Derogatory remarks are not allowed. Advertising a product or service is not allowed. Please report objectionable posts to [info@facingdisability.com](mailto:info@facingdisability.com). We keep information private and confidential. For more information please visit our [Privacy Statement](#).

**I Understand, Please Take Me To The Forums**

# Forums

The screenshot shows a web browser window with the address bar displaying "forum.facingdisability.com". The page title is "Recent Discussions - facingdisability". The main navigation bar includes links for "Watch Videos", "Resources", "Forums", "Peer Counseling", "About Us", "Blog", and "Donate". Below this is a secondary navigation bar with "Navigation: Discussions Activity Sign In". The "Forums" section is active, displaying a list of recent discussions. The discussions listed are:

- thanuja**: 1 view, 0 comments, Started by **thanuja**, April 11, General
- The Day My Life Changed**: 2 views, 3 comments, Most recent by **MsMarie**, March 26, General
- splints**: 1 view, 0 comments, Started by **stieber**, January 24, General
- Nerve block**: 1 view, 0 comments, Started by **Gentrie**, December 2012, General
- Caregiver scholarship-how cool!**: 1 view, 0 comments, Started by **Gentrie**, December 2012, General
- Successful fertility in c5/c6 male?**

On the right side of the page, there is a search bar and a message: "It looks like you're new here. If you want to get involved, click one of these buttons!" with links for "Sign In" and "Register". Below this is a "Categories" section with a list of categories and their respective post counts:

Categories	Count
All Categories	38
General	30

# Peer Counseling

Peer Counseling for People With Spinal Cord Injuries | Facing Disability: Spinal Cord Injury Resources

www.facingdisability.com/peer\_counseling/info/overview

Reader



facingdisability.com  
for families facing spinal cord injuries

Search Facing Disability

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Watch VideosResourcesForumsPeer CounselingAboutBlogDonate

## Peer Counseling Overview

Peer Counseling

Overview  
Sign up  
How the Match-Ups Work  
Starting the Conversation  
Tips for Success  
Volunteer to be a Peer Counselor

Sign In



A "peer counselor" is someone who has "been there, done that" and who has had several years of real-life experience in dealing with a spinal cord injury similar to yours.

The communication between you is through written messages in a private conversation on the FacingDisability website. The people on both sides are anonymous. The service is free.

Our peer counselors are not trained professionals. They are people like you who have encountered the same issues and problems that you are now facing. They are unpaid volunteers who have agreed to use their knowledge and experience to offer emotional support and practical help.

We want to connect you with someone who is as much like you as possible. Another mother, father, wife, husband, sister, brother, or person with a spinal cord injury whose profile is similar to yours. Nobody understands what you're going through the way someone who has actually been there.

Click Here To Sign Up Or Call 312-284-2525

A spinal cord injury affects the entire family

Home  
Videos by Topic and Question  
Blog  
About Us

# Is It Working?

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## Google Analytics (12-month statistics)

2,500 unique visitors per week

130,000 per year

412,000 page views



# What Videos are They Watching?

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## Ooyala Content Analysis (June 1, 2013 – May 31, 2014)

45,000 video plays

700 hours

55-seconds = average video play

17% = Sex, Fertility,  
Social Life, Relationships



# Is It Working?

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## Online Survey (123 Responses)

### What sentence describes you best?

I am a person with SCI: 48%

I am a family member of a person with SCI: 19%

I am a healthcare professional: 16%

### How old are you?

51 and up: 36%

35-50: 30%

25-34: 22%

### How easy was it to navigate our website?

Extremely Easy: 26%

Very Easy: 46%



# Is It Working?

---

## Online Survey (123 Responses)

**How helpful were videos by spinal cord injury experts?**

Extremely Helpful or Very Helpful: 71%

**Most helpful expert topics:**

Spinal Cord Injury 101

Sex and Fertility

Adjusting to Social Life in a Wheelchair

Basics of SCI Rehabilitation



# Is It Working?

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## Online Survey (123 Responses)

### How helpful were personal experience videos?

Extremely Helpful or Very Helpful: 70%

### Most helpful personal experience topics:

Life After SCI

Relationships After SCI

Feelings After SCI

SCI Rehabilitation



# Is It Working?

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## Online Survey (123 Responses)

**How would you rate the overall effectiveness of the website?**

Extremely Effective: 28%

Very Effective: 36%

Moderately Effective: 27%

**How likely are you to recommend our website to a friend or co-worker?**

Extremely Likely: 40%

Very Likely: 31%

Moderately Likely: 15%



# The Road Map

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## How to Use FacingDisability.com as a Model:

- Collect Personal Experiences—find the right people to interview who have “been there and done that”
- Develop interview questions that focus on personal coping experiences—what have you learned and what do you know that will be helpful to others?
- Keep answers short—it’s okay to stop & start during interviews
- Edit to keep the best and discard the rest
- Use the highest-quality technical equipment you can afford for the interviews: camera, audio, lights, editing system



# The Road Map

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## How to Use FacingDisability.com as a Model:

- Find a competent, cooperative web developer to design your site
- Develop a critical mass of videos (at least 500) before going live
- Develop a selected list of the most helpful resources—the list should be a good place to start looking for information, not the last word
- Conduct question-and-answer interviews with important medical experts on topics people need to know about right away
- We are only a phone call or an email away



# Is It Working?

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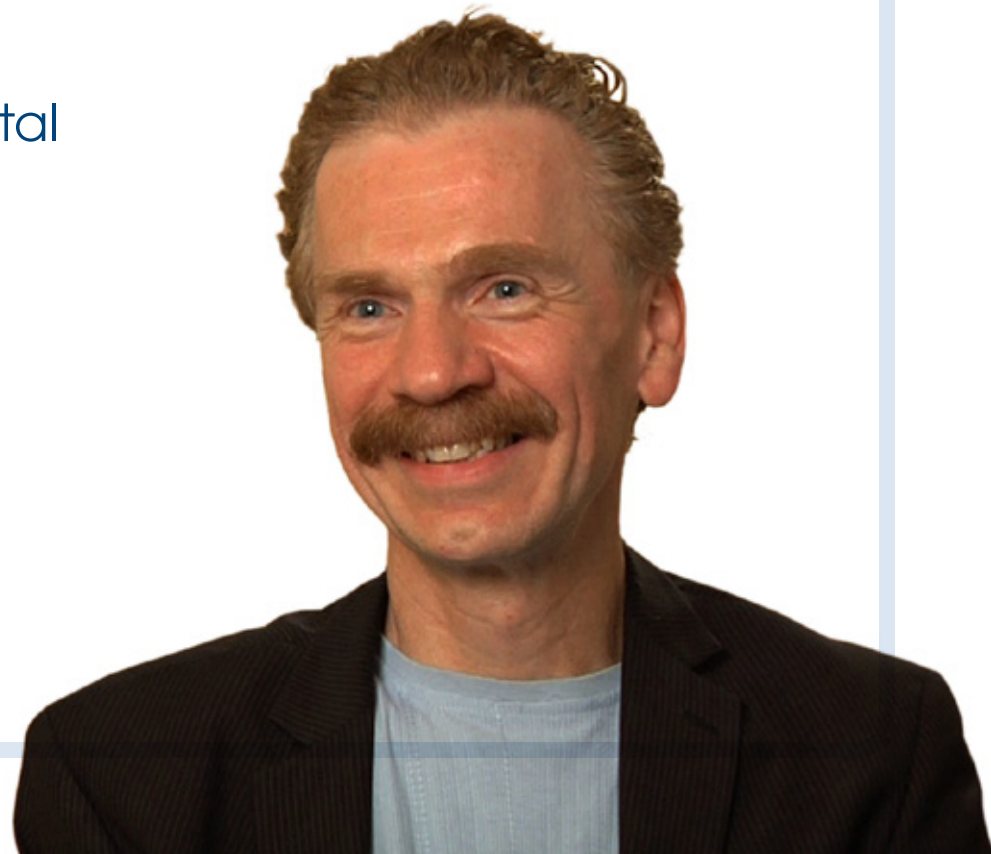
## Dr. Fried gets the last word

**Guy W. Fried, MD**

Chief Medical Officer

Magee Rehabilitation Hospital

Philadelphia





facingdisability.com

for families facing spinal cord injuries

VIDEO 5: DR. FRIED

# A Spinal Cord Injury Affects The Entire Family

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## Claiming CE Credit

If you would like to receive continuing education credit for this activity, please visit:

<http://acrm.cds.pesgce.com>



**Shriners Hospitals**  
for Children™

**facingdisability.com**

for families facing spinal cord injuries

