A Spinal Cord Injury Affects The Entire Family

FacingDisability.com: State-of-the-Art Rehabilitation Information and Support in an Online World

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for families facing spinal cord injuries
Disclosures

Presenters have no financial interest to disclose.

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Today’s Learning Objectives

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.
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
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
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 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

It’s all about community: re-integrating back into the community and returning to family and friends!!
Treatment & Interventions

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

**Stress management skills**
- Relaxation techniques
- Positive self-talk

**Trauma narrative**
- Tell your story
- Find meaning, help others
- Peer mentor
Challenges

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…

• 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...

• 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

• 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

- 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...

- 12 hospital days
- 37 rehab days

9 out of 10 people with SCI return home
Now what???

1,500 videos of the best answers to the most important questions
Collecting Life Experiences in Coping With SCI

• What do family members need to know right away?

• What are the most important questions?
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?
Close-Ups are Powerful
Interview Set-Up
Look Who’s Talking

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

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 Topics And Questions

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?

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

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 more...

What was the hardest thing about hospital?
How did you develop this passion?
What was your greatest challenge?
How did family and friends help you?
What personal support was most helpful to you?
facingdisability.com
for families facing spinal cord injuries
How to Find Who You’re Looking For
How to Find Who You’re Looking For

Videos By Relationship To Spinal Cord Injury

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
People with SCI
Individuals

Family
Parent
Spouse or Partner
Sibling
Child

Level of Injury
Paraplegic
Quadruplegic

Gender of Person Injured
Male
Female
How to Find Who You’re Looking For
How to Find Who You’re Looking For

Videos By Relationship

Level of Injury
- Paraplegic
- Quadriplegic

Gender of Person Injured
- Male
- Female
How to Find Who You’re Looking For

Videos By Relationship

Age at Injury

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

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

Level of Injury
- Paraplegic
- Quadriplegic

Gender of Person Injured
- Male
- Female

Jorge
Injured in 1978 at age 11, Paraplegic

Sue
Son injured in 2004 at age 10, Quadruple

Joey
Injured in 2005 at age 13, Quadruple

Moneret
Injured in 2008 at age 16, Paraplegic

Bill
Injured in 1970 at age 8 months, Paraplegic

Darren
Injured in 1993 at age 20, Quadruple
How to Find an Expert


How to Find an Expert

Watch Videos
- Videos By Topic And Question
- Videos By Family Relationship
- Videos By Experts

Resources

Forums

Peer Counseling

About

Blog

Donate

Facing Disability 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 an Expert

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
Pediatric Spinal Cord Injury 101

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 Expert

Adult Injuries
- Spinal Cord Injury 101
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Watch Videos
Resources
Donate

www.facingdisability.com/spinal-cord-injury-expert
How to Find an Expert

Pediatric Injuries
Pediatric Spinal Cord Injury 101
The Basics of Pediatric SCI
Rehabilitation
Transitions for Children with SCI
How to Find Resources

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

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

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."
How to Find Resources
Forums

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. We keep information private and confidential. For more information please visit our Privacy Statement.

I Understand, Please Take Me To The Forums
Forums
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. It changes lives. It changes the way people live their lives. There is a lot of help available. You just have to know where to find it. And that’s where we come in. We help you find the resources you need to understand your situation and to move forward with confidence.
Is It Working?

Google Analytics
(12-month statistics)

2,500 unique visitors per week

130,000 per year

412,000 page views
What Videos are They Watching?

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?

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?

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?

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

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

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?

Dr. Fried gets the last word

Guy W. Fried, MD
Chief Medical Officer
Magee Rehabilitation Hospital
Philadelphia
A Spinal Cord Injury Affects The Entire Family

Claiming CE Credit
If you would like to receive continuing education credit for this activity, please visit: http://acrm.cds.pesgce.com