A Spinal Cord Injury Affects The Entire Family

Facing Disability.com: The Changing Face of Spinal Cord Injury Education and Support

Faculty

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for families facing spinal cord injuries



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Sara J. Klaas, MSW, C-ASWCM

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Today's Learning Objectives

 Discuss the importance of education and peer support for those affected by SCI

 Describe a new intervention that may assist in achieving the goal of delivering excellence through state-of-the-art healthcare via support and education online

 Offer an important resource for people with SCI, their family, friends, and healthcare providers on the rehab team



Background...

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

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

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

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!!



What Those with SCI Tell Us...

- Develop a support network
- Keep up to date... get on every mailing list you can
- Talk, talk... with each other

 Use technology to keep you connected – social networking, emails, care pages, etc.



Facing Disability.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





- 11 hospital days
- 36 rehab days



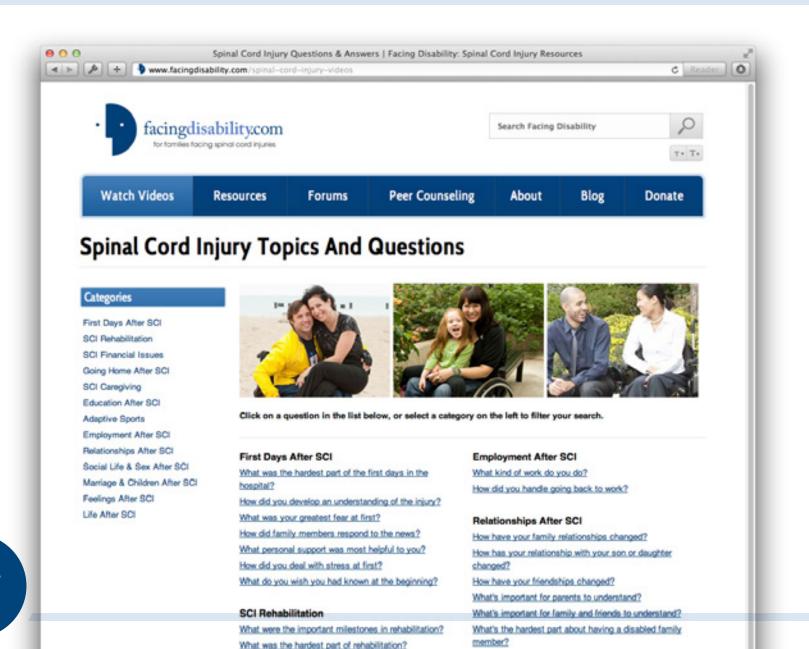
Now what???

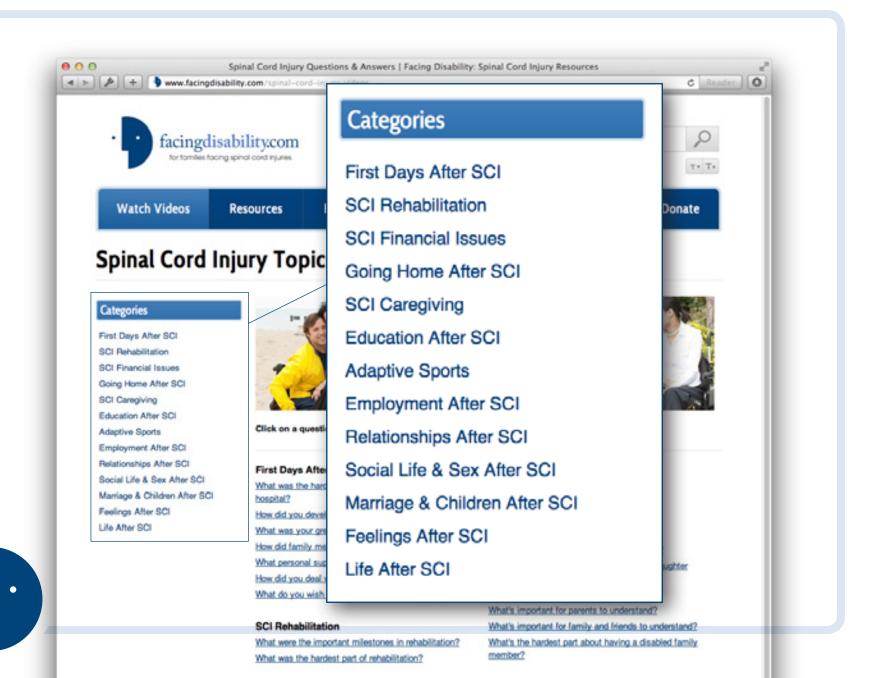




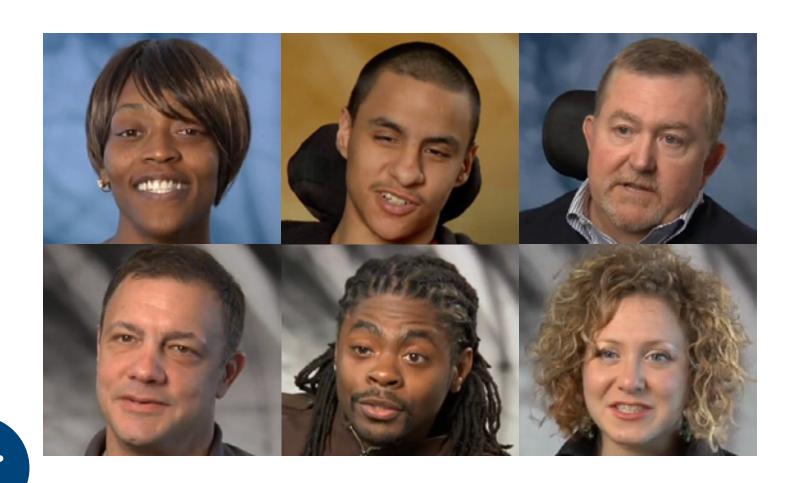
Collecting Life Experiences In Coping With SCI







Close-Ups are Powerful



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 ChicagoShriners Childrens

Hospital - Chicago

 Schwab Rehabilitation Hospital - Chicago

 Magee Rehabilitation Hospital - Philadelphia

 Marianjoy Rehabilitation Hospital - Chicago



Keep It Short

The internet is an impatient medium

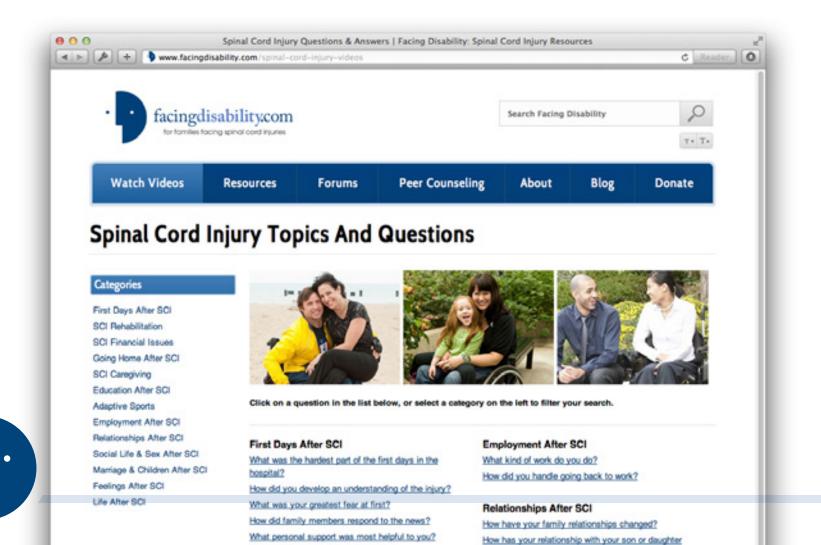
1350 videos today...

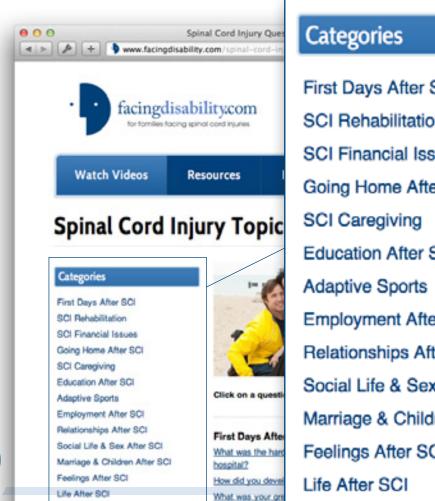
90 percent of them are

LESS THAN ONE MINUTE LONG









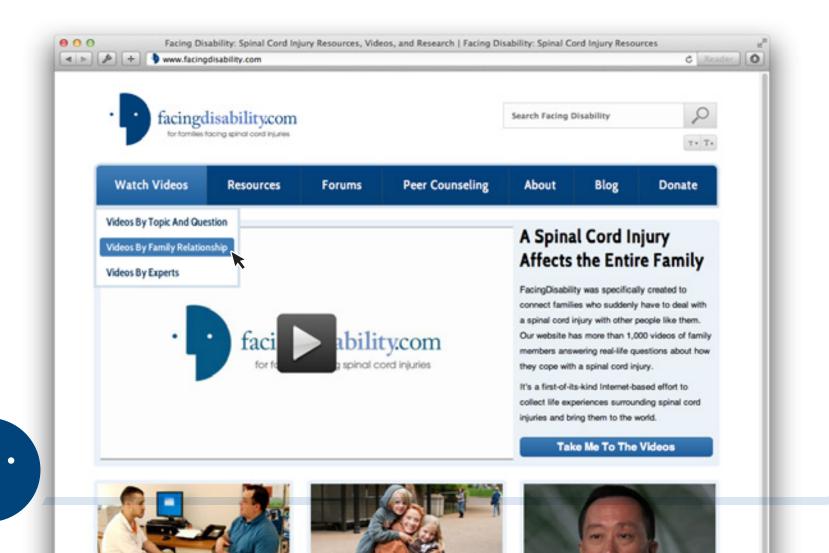
What personal support was most helpful to you?

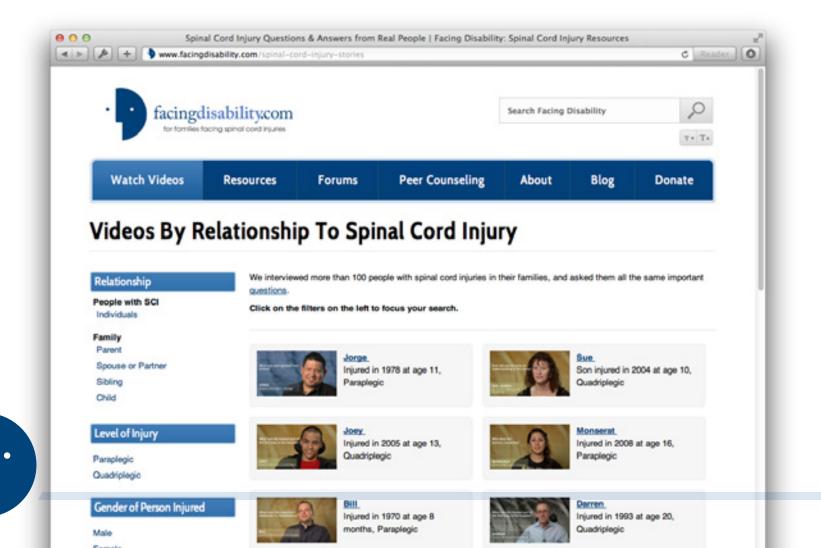
First Days After SCI SCI Rehabilitation SCI Financial Issues Going Home After SCI Education After SCI Employment After SCI Relationships After SCI Social Life & Sex After SCI Marriage & Children After SCI Feelings After SCI

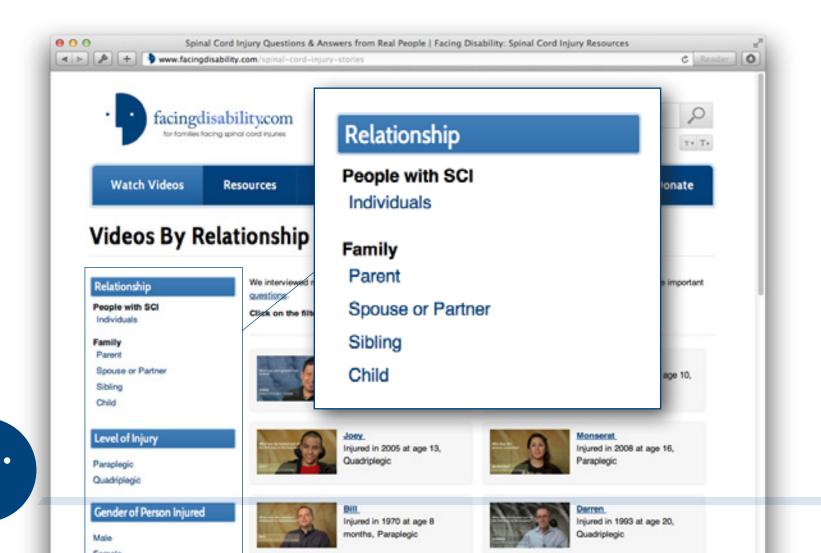
How has your relationship with your son or daughter

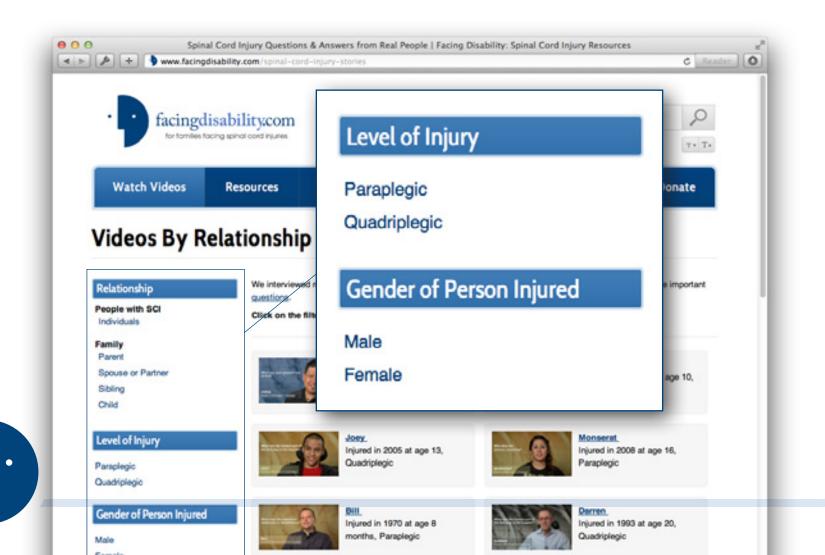


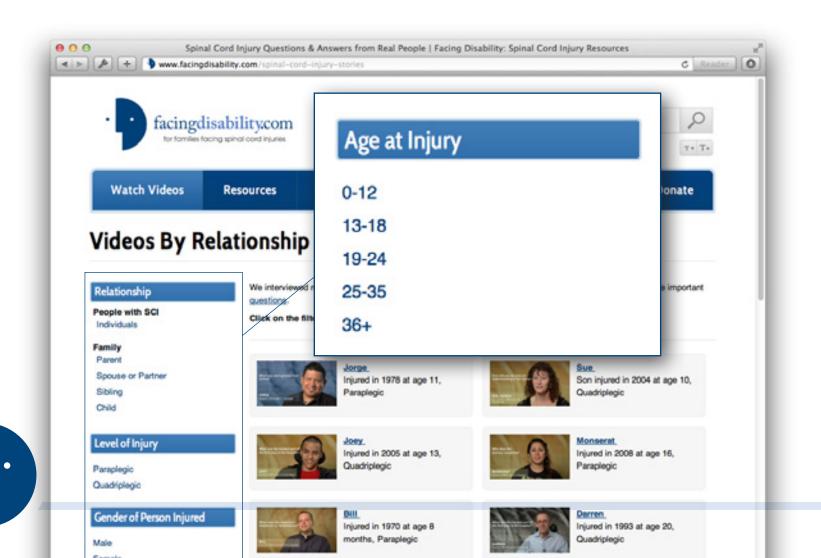






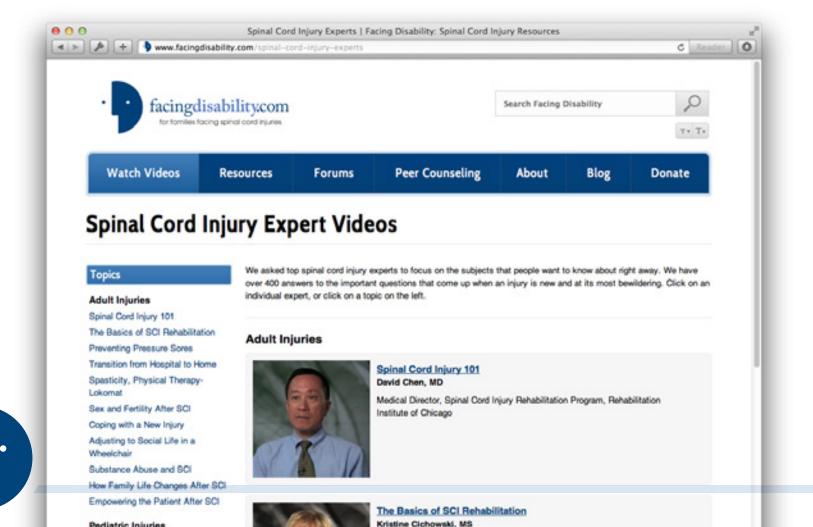








Pediatric Injuries





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

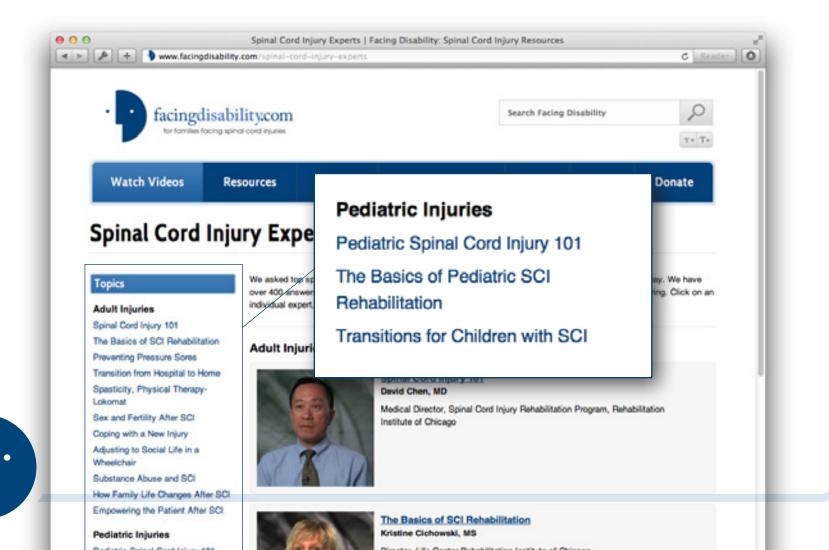
Adjusting to Social Life in a

Substance Abuse and SCI

How Family Life Changes After SCI

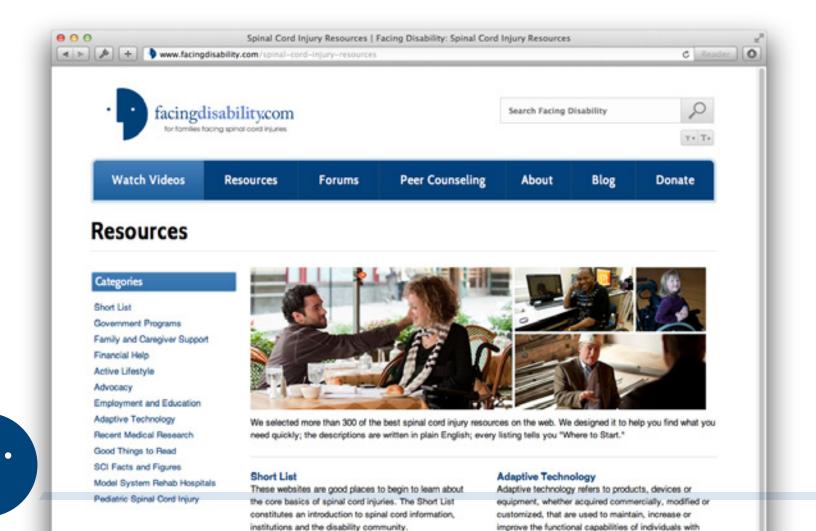
Empowering the Patient After SCI





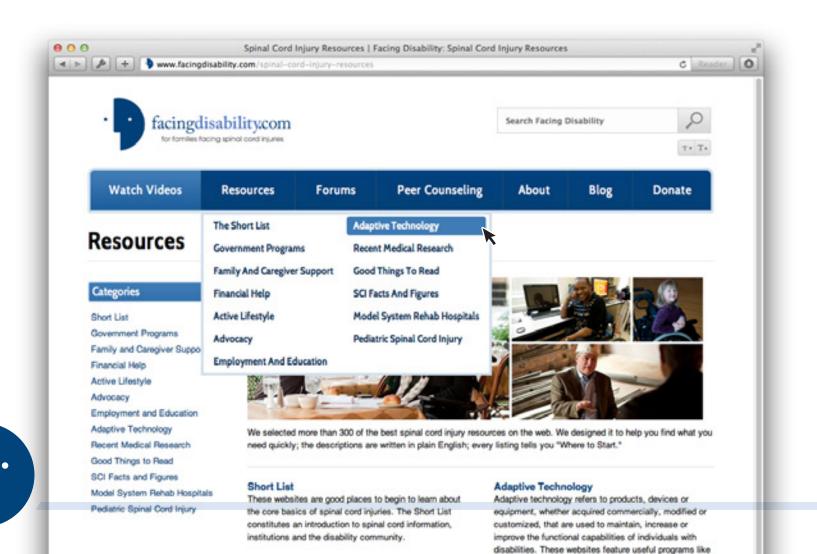


How to Find Resources

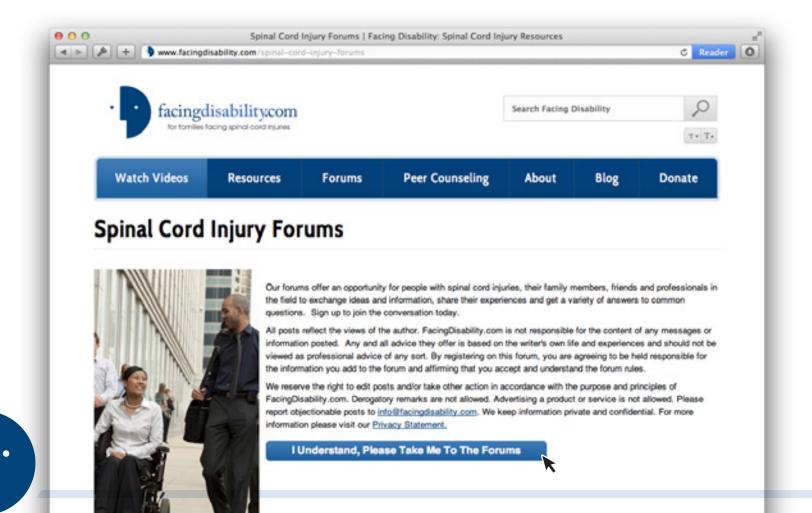


disabilities. These websites feature useful programs like

How to Find Resources



Forums



Peer Counseling



Home

Google Analytics (12-month statistics)

1,200 unique visitors per week

60,000 per year

250,000 page views



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%

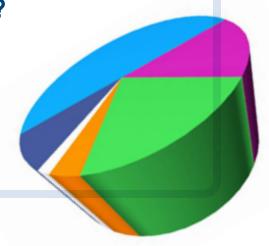
35-50: 30%

25-34: 22%

How easy was it to navigate our website?

Extremely Easy: 26%

Very Easy: 46%



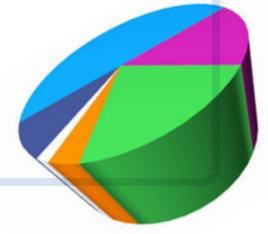
Online Survey (123 Responses)

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



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



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%



What's Next?

A new mobile app that will enable users to make their own videos and send them to us



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for families facing spinal cord injuries

