



Academy of
Spinal Cord Injury
Professionals, Inc.

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Voices of Experience

SCI Video Series Features Real-Life Stories

Presenters

No financial interests to disclose.



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Voices of Experience

Living with Spinal Cord Injury

New Video Series

For SCI Model Systems In-Hospital Television Networks



Here's the Problem:

Communication with Patients and Families

All members of the rehabilitation team have a role

- Explaining injury and neurological condition
- Prognosis
- Expectations
- Teaching and Training



Here's the Problem:

What do Patients and Families Hear?

- Educational level
- Health literacy
- Prior experience with healthcare system
- Time since injury



Here's the Problem:

Delivering the Message

We have different communication styles

- Personality
- Experience
- One size does not fit all



Finding the Solution

Midwest Regional Spinal Cord Injury Care System

One of the 14 hospitals comprising the National SCI Model Systems

NSCIMS Goals:

- Demonstrate excellence in SCI rehabilitation
- Contribute to a national database documenting patient outcomes
- Conduct a site-specific project
- Collaborate in multi-site research modules
- Participate in knowledge translation activities



Finding the Solution

Motivation for This Project

- Psychosocial adaptation during inpatient rehabilitation can be challenging
- Physicians, nurses, psychologists, social workers, chaplains — all serve an important professional role in helping patients anticipate a life that's worth living



Finding the Solution

- We lack the authentic, first-person experience of living with disability
- Only patients and their families live this experience
- AbilityLab has a long-standing collaborative relationship with the Hill Foundation and FacingDisability, which produces excellent first-person video accounts of life after SCI



Finding the Solution

Project Goal

- Enhance the psychosocial adaptation of persons with new SCI and their families by producing a set of videos focused on common concerns

Project Aims

- Create an education resource for use during inpatient rehabilitation by patients and their families
- Provide a discussion guide for SCI rehabilitation clinicians
- Provide access via the in-house video networks used by SCIMS hospitals
- Share the video resource widely via YouTube



Finding the Solution

Project Methods

- Conduct focus groups with SCI clinicians to select subjects for videos
- Review FacingDisability's extensive video library
- Select patients with diverse backgrounds and injury experience
- Emphasize coping and resilience





Nobody knows what you're going through like someone who's been there



YOU ARE NOT ALONE
Coping With A Spinal Cord Injury

Explore over 2,000 videos from our
unique video library of family experiences



facingdisability.com

for families facing spinal cord injuries

VIDEO 1: INTRO

“What was your greatest fear at first?”

SPINAL CORD INJURY PERSONAL VIDEOS BY TOPIC

Search

TOPICS

Choose a topic to watch videos that answer real-life questions

- Life After Spinal Cord Injury
- First Days After Spinal Cord Injury
- Rehabilitation
- Going Home After Spinal Cord Injury
- Caregiving Issues
- Family Life and Friendships
- Adaptive Sports
- Social Life and Sex
- Marriage and Children
- Handling Anger, Guilt and Depression
- Education After Spinal Cord Injury
- Employment and Returning to Work
- Dealing with Financial Issues

What was your greatest fear at first?

What was your greatest fear at first?

ALICIA

Injured in 2002 at age 25, Paraplegic

What was your greatest fear at first?

AMANDA, spouse

Husband injured in 2016 at age 25, Quadriplegic

What was your greatest fear at first?

ANDRE

Injured in 2007 at age 22, Quadriplegic

What was your greatest fear at first?

ANGELA

Injured in 1996 at age 15, Quadriplegic

What was your greatest fear at first?

ANTONIO

Injured in 1996 at age 15, Quadriplegic

What was your greatest fear at first?

APRIL

Injured in 2014 at age 31, Quadriplegic

What was your greatest fear at first?

What was your greatest fear at first?

What was your greatest fear at first?



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VIDEO 2: GREATEST FEAR

“What was the hardest part of the first days in the hospital?”

SPINAL CORD INJURY PERSONAL VIDEOS BY TOPIC

TOPICS

Choose a topic to watch videos that answer real-life questions

- Life After Spinal Cord Injury
- First Days After Spinal Cord Injury
- Rehabilitation
- Going Home After Spinal Cord Injury
- Caregiving Issues
- Family Life and Friendships
- Adaptive Sports
- Social Life and Sex
- Marriage and Children
- Handling Anger, Guilt and Depression
- Education After Spinal Cord Injury
- Employment and Returning to Work
- Dealing with Financial Issues

What was the hardest part of the first days in the hospital?

What was the hardest part of the first days in the hospital?

ALICIA
Injured in 2002 at age 25, Paralysis

What was the hardest part of the first days in the hospital?

AMANDA, spouse
Husband injured in 2010 at age 25, Quadriplegia

What was the hardest part of the first days in the hospital?

ANGELA
Injured in 1996 at age 15, Quadriplegia

What was the hardest part of the first days in the hospital?

ANTONIO
Injured in 1998 at age 11, Quadriplegia

What was the hardest part of the first days in the hospital?

APRIL
Injured in 2014 at age 21, Quadriplegia

What was the hardest part of the first days in the hospital?

ARIC
Injured in 1983 at age 14, Paralysis

What was the hardest part of the first days in the hospital?

What was the hardest part of the first days in the hospital?

What was the hardest part of the first days in the hospital?



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VIDEO 3: HARDEST PART

Top Ten Topics

1. What was your greatest fear at first?
2. What was the hardest part of the first days in the hospital?
3. What do you wish you had known at the beginning?
4. Can I still have sex? (Men)
5. Can I still have sex? (Women)
6. Can I still have children ?
7. How do you handle anger?
8. How do you handle guilt?
9. Can I still participate in sports?
10. How do I deal with my friends and family?



Disclosures

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Accreditation Statement

This activity has been planned and implemented in accordance with the accreditation requirements and policies of the Accreditation Council for Continuing Medical Education (ACCME) through the joint provider-ship of the New Jersey Academy of Family Physicians, the Firm, and ASCIP. The New Jersey Academy of Family Physicians is accredited by the ACCME to provide continuing medical education for physicians.

The New Jersey Academy of Family Physicians designates this live activity for a maximum of 31 AMA PRA Category 1 Credit(s).™

Physicians should claim only the credit commensurate with the extent of their participation in the activity.



Learning Objectives

- Discover a new, easily accessible resource for hospitalized SCI patients
- Discuss the subjects of greatest concern to newly injured patients
- Analyze the value of personal experiences — do they lead the way?



Obtaining CME/CE Credit

Credit is only given to attendees who:

- Successfully complete the entire course/session
- Evaluate the course — by clicking on the link in an email sent to them
- After you have completed the evaluation, an email will automatically be generated to you with a link to print your certificate
- The evaluation system will close 30 days after the date of the conference



New Video Series

For SCI Model Systems In-Hospital Television Networks



For links to the videos:

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