

Facing the Future:

“Voices of Experience” Video Series
Helps Patients Find a Way Forward



Disclosures

“Voices of Experience” is a joint project of the Shirley Ryan AbilityLab and the Hill Foundation for Families Living with Disabilities.

It is partially funded by a grant from NIDILRR to the Midwest Regional Spinal Cord Injury Care System.



Learning Objectives

1. Discover techniques for using an easily accessible video and Internet resource with SCI patients
2. Discuss new ways to open conversations about emotionally-laden subjects with newly injured SCI patients
3. Analyze the value of virtual peer mentoring via filmed self-disclosures—why and how does it work?



Presenters

No financial interests to disclose.



Thea Flaum

President,
Hill Foundation



Allen Heinemann, PhD

Co-project director, Midwest Regional SCI Care System; Director, Center for Rehabilitation Outcomes Research, Shirley Ryan AbilityLab; Professor, Physical Medicine & Rehabilitation, Northwestern University; Licensed Clinical Psychologist, formerly provided direct services in SCI rehabilitation program



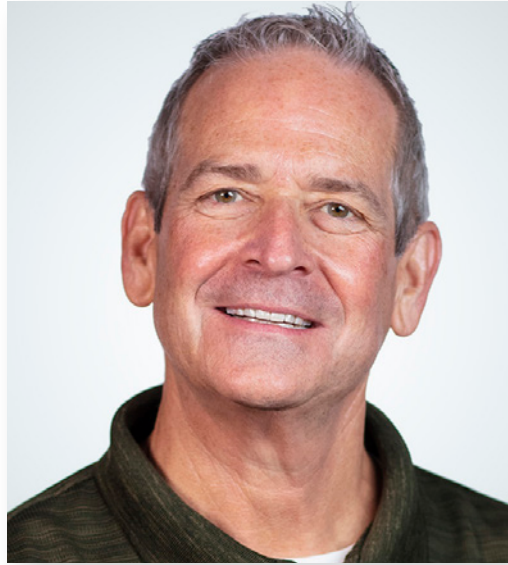
Stephanie Lollino

Vice President,
Hill Foundation

Panel



Jonathon Rose, PhD
Director,
SCI Outpatient Psychology
VA Palo Alto



Toby Huston, PhD
Director of Psychology
Craig Hospital

VOICES OF EXPERIENCE

Living with Spinal Cord Injury



New 10-Part Video Series

For SCI Model Systems In-Hospital TV Networks

For people with *new*
spinal cord injuries

Featuring people
who have been
*living with spinal
cord injuries for years*





**Nobody understands what you're going through
like someone who's already been there**

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



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





facingdisability.com

for families facing spinal cord injuries



YOU ARE NOT ALONE

Coping With 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

VOICES OF EXPERIENCE

Living with Spinal Cord Injury



Voices of Experience

10-part series

- What was your greatest fear at first?
- What was the hardest part of the first days in the hospital?
- What do you wish you had known at the beginning?
- How do you handle anger?
- How do you handle guilt?
- Men: What about sex and dating?
- Women: What about sex and dating?
- How do I deal with my friends?
- How do I deal with my family?
- Can I still participate in sports?

VOICES OF EXPERIENCE

Living with Spinal Cord Injury

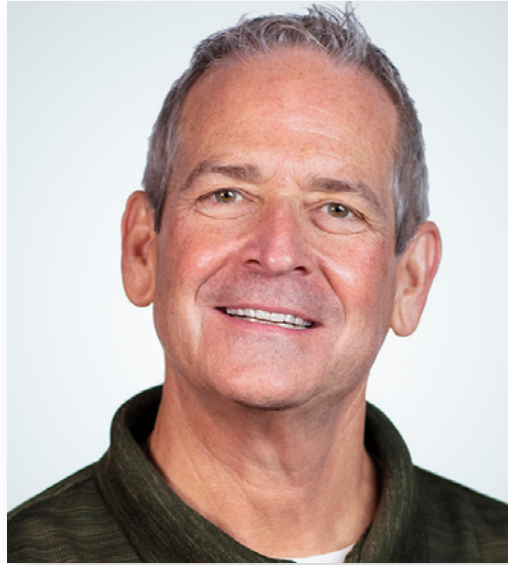
VIDEO 2: GREATEST FEAR



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Voices of Experience

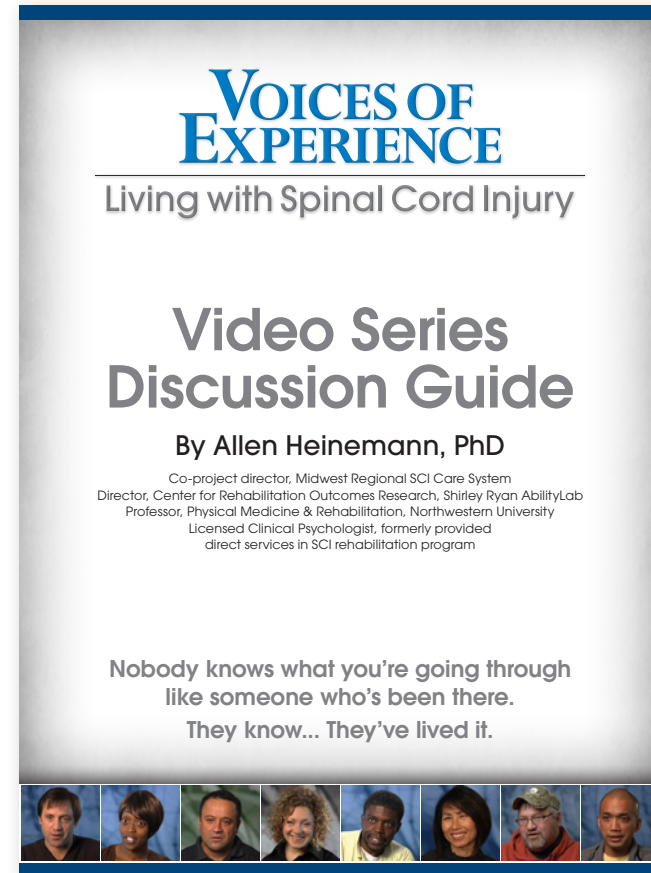
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Discussion Guide

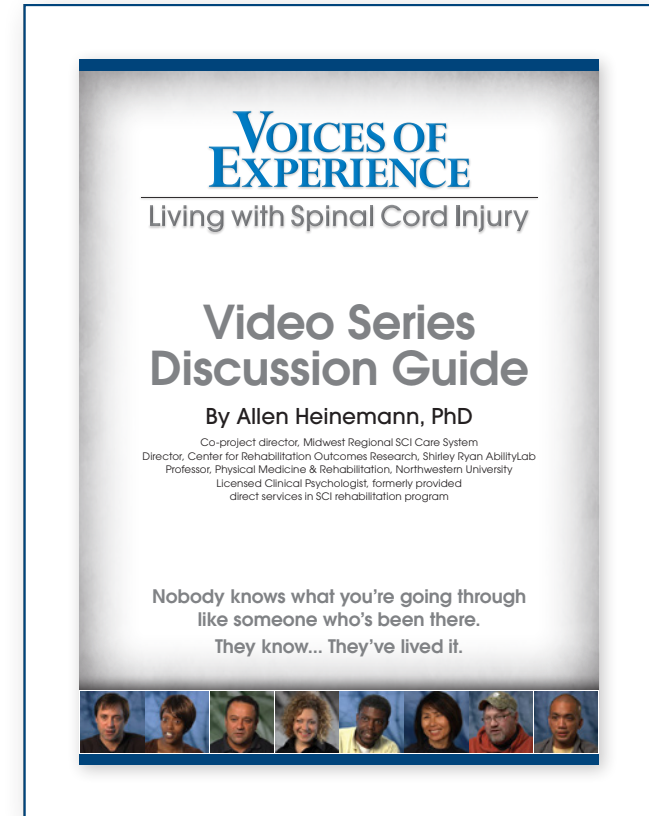
By Allen Heinemann, PhD

Shirley Ryan AbilityLab
Northwestern University



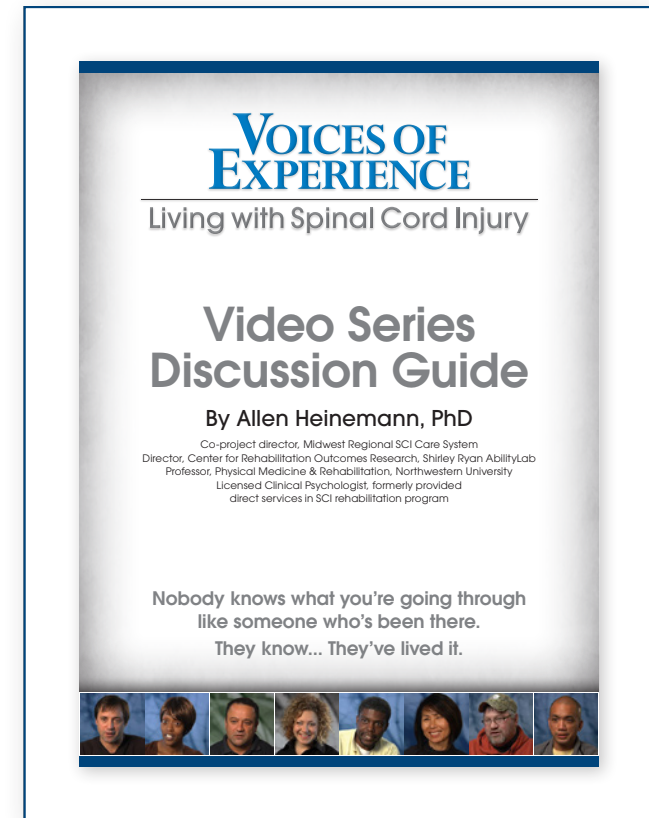
What are the Goals for “Voices of Experience”?

- Create an atmosphere that supports discussion of emotionally-laden topics
- Promote discussion of topics related to adjustment following SCI
- Encourage resumption of participation in valued activities



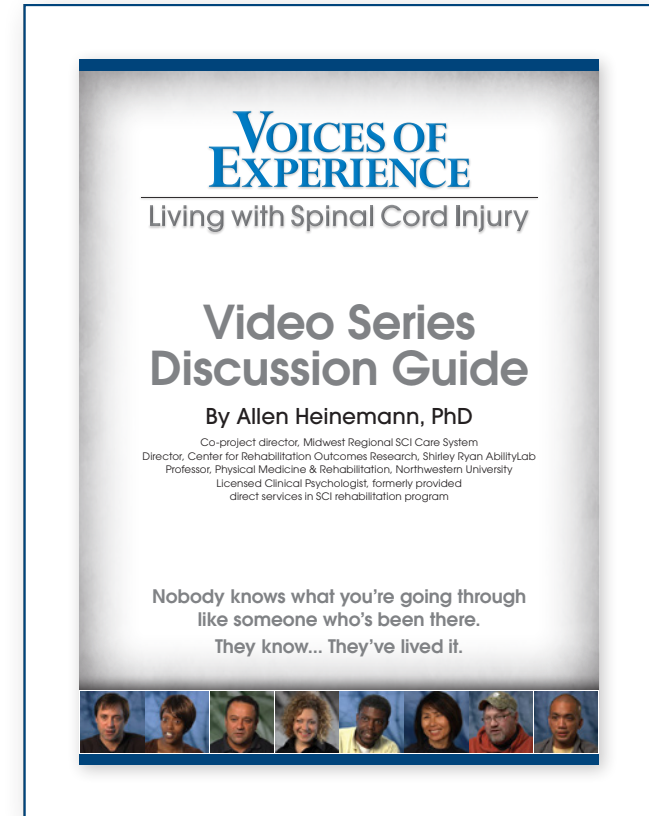
How can I use the Discussion Guide?

- During patient meetings with therapeutic recreation staff and during regularly scheduled patient education sessions
- Patients may view the videos via web streaming
- It may be helpful for psychology or patient-family support staff to determine when patients are ready to view the videos
- Staff members with mental health training who have established rapport with patients are in an ideal position to lead discussions of the video series



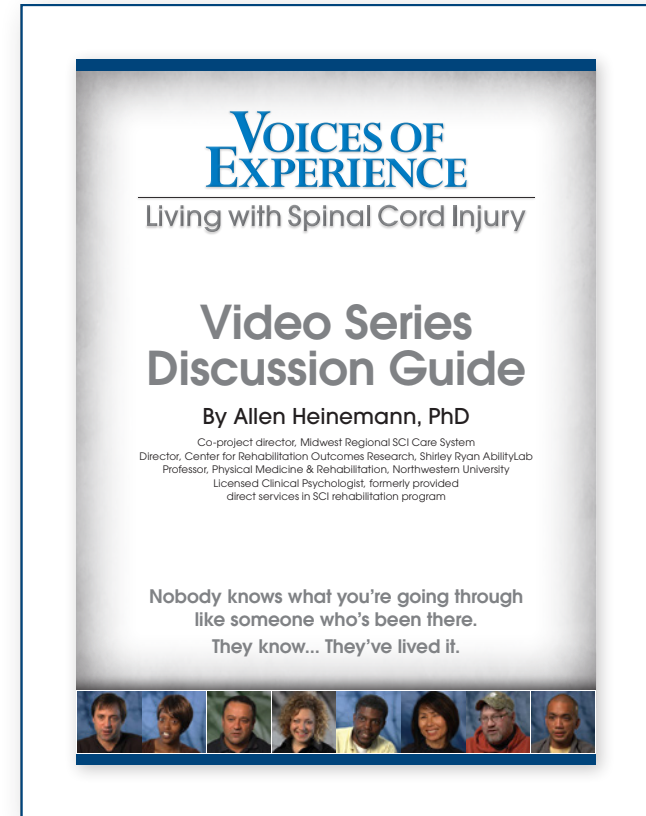
Sample Discussion Questions

- What is your reaction to this video?
- What was it like for you to watch that?
- What sort of thoughts or feelings did it bring up?
- What spoke to you in terms of your experience?
- Did one person's interview stand out for you?
- If yes, which one? Why?
- What topic or issue was most relevant to you? Why?
- Was there anything that surprised you?
- What questions do you have about the topics discussed?



After-Video Discussions

- Dealing with the medical, social, and vocational consequences of spinal cord injury can be challenging
- Grief and anger reactions are common
- Referral to mental health professionals is critical when reactions are extreme or prolonged



VOICES OF EXPERIENCE

Living with Spinal Cord Injury

Nobody knows what you're going through like someone who's been there. They know... They've lived it.



VOICES OF EXPERIENCE

Living with Spinal Cord Injury

To watch and download the 10-part series, go to:
facingdisability.com/voices-of-experience-videos



References

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