

# VOICES OF EXPERIENCE

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## Living with Spinal Cord Injury

To watch and download the 10-part series:  
[FacingDisability.com/voices-of-experience-videos](http://FacingDisability.com/voices-of-experience-videos)

## Video Series Discussion Guide

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



## Who?

This guide is for organizations implementing the **Voices of Experience** video series as part of their rehabilitation services for adults with spinal cord injuries. Discussion leaders typically will be nursing or allied healthcare staff members with responsibilities for patient education. Videos may augment ongoing patient- education programming and support discussion of issues among viewers.

## Why?

All members of the rehabilitation team have a role in patient education regarding SCI and neurological consequences, prognosis, expectations, and patients' futures. Motivation for this video series reflects a shared concern regarding patients' psychosocial adaptation during inpatient rehabilitation. Physicians, nurses, allied health therapists, psychologists, social workers, and chaplains all serve an important professional role in helping patients anticipate a life that is worth living. We need the authentic, first-person experiences of living with disability to provide patient-centered care. Only patients and their families live this experience. The Shirley Ryan AbilityLab has a long-standing collaborative relationship with the Hill Foundation and FacingDisability.com, which produces excellent first-person video accounts of life after SCI.

Thus, the goal of this video series is to enhance the psychosocial adaptation of persons with new SCI and members of their families by producing a series of videos focused on common concerns. The aims are to (1) Create an educational resource for use during inpatient rehabilitation by patients and their families, (2) Provide a discussion guide for SCI rehabilitation clinicians, (3) Provide access via the in-house video networks used by SCIMS hospitals, and (4) Share the video resource widely via the Internet.

Project staff conducted focus groups with SCI clinicians to select subjects for videos. They reviewed FacingDisability's extensive video library and selected patients with diverse backgrounds and injury experiences that emphasize coping and resilience.

We designed the **Voices of Experience** video series to support discussion about challenging topics that allow improved health, function, and quality of life after SCI.

## When?

The **Voices of Experience** video series is for use during inpatient rehabilitation. The videos may also be useful during outpatient rehabilitation and by community organizations that promote independent living.

## What are the Goals?

**Voices of Experience's** goals are to:

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

## How?

The video series can be used during patient meetings with therapeutic recreation staff and during regularly scheduled patient education sessions; patients may also 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.

## General Discussion Questions

The following general questions encourage discussion by **Voices of Experience** viewers. Discussion leaders can select the questions that are most appropriate given viewers' reactions. You can use participant feedback to gauge how deeply to delve into specific topics.

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

## Discussion Questions for Each Video

- 1. What was your greatest fear at first?**
  - a. What was your greatest fear right after your injury?
  - b. How did your fears change over time?
  - c. What allowed your fears to diminish?
  - d. Who helped you deal with your fears?
  - e. If not a person, what helped you deal with or manage your fears?
  - f. What fears do you have now?
  - g. What can you do to resolve them?
- 2. What was the hardest part of the first days in the hospital?**
  - a. What was the hardest part for you early in your hospitalization?
  - b. How did this issue resolve?
  - c. What person – or thing – was helpful in dealing with this issue?
- 3. What do you wish you had known at the beginning?**
  - a. What do you wish you had known at the beginning?
  - b. What questions do you now have about your future?
  - c. Who do you think will be helpful in getting answers to these questions?
- 4. How do you handle anger?**
  - a. Has anger been a concern for you? How so?
  - b. What triggers your angry responses?
  - c. What do you want to say or do when you are feeling angry?
  - d. What strategies have you found to be useful in managing anger?
- 5. How do you handle guilt?**
  - a. Has feeling guilty been a concern for you? How so?
  - b. What triggers guilty feelings in you?
  - c. What do you want to say when you feel guilty?
  - d. What strategies have you found to be useful in managing guilt?

**6. What about sex and dating? (Men)**

- a. In what ways is sex or intimacy important to you?
- b. What concerns do you have after watching this video?
- c. Can you see yourself reflected in any of the men who spoke? Which one(s)? Why?
- d. Would you like to talk with someone about this topic?

**7. What about sex and dating? (Women)**

- a. In what ways is sex or intimacy important to you?
- b. What concerns do you have after watching this video?
- c. Can you see yourself reflected in any of the women who spoke? Which one(s)? Why?
- d. Would you like to talk with someone about this topic?

**8. How do I deal with my friends?**

- a. What reactions do you have after watching this video?
- b. In what ways can friends demonstrate support?
- c. What do your friends do that you find unhelpful?
- d. How have you dealt with their actions?
- e. What would you like to tell your friends about relating to you as a person with a disability?

**9. How do I deal with my family?**

- a. What reactions do you have after watching this video?
- b. In what ways can family members demonstrate support?
- c. What does your family do that you find unhelpful?
- d. How have you dealt with their actions?
- e. What would you like to tell your family about relating to you as a person with a disability?

**10. Can I still participate in sports?**

- a. What reactions do you have after watching this video?
- b. What kinds of sports do you enjoy?
- c. What barriers do you perceive to getting involved with sports again?
- d. How have your sports interests changed over time?
- e. What kinds of sports activities do you want to pursue?

## **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.

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