

# Understanding Spinal Cord Injury: A Free Resource to Enhance Training of Personal Care Assistants

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*Kessler Foundation*



# Background

# Many Thanks to Our Sponsors





# Collaborators



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Steering Committee



Production Team

# Course Context

- Personal care assistance is critical to health and quality of life for many people with SCI
- Most personal care assistants (PCAs) have little knowledge of SCI
- Wanted to create a course to:
  - Introduce PCAs to SCI in a “big picture” way
  - Lay a foundation for hands-on training



# Vision for the Course

## Want to:

- Give PCAs a better idea of what to expect when they walk in the door
- Help them ask good questions during hands-on training
- Improve understanding of WHY care tasks are needed
- Increase motivation
- Promote mutual respect

## Do NOT Want to:

- Reinvent the wheel
- Replace hands-on training
- Get too technical
- Get too specific

# Potential Users

- Home health care organizations
- People with SCI or family members
- Rehabilitation programs
- Individual PCAs seeking more knowledge



# Community Partner Collaboration



# Key Partners

- People with SCI
- Family Members of People with SCI
- Experienced Personal Care Assistants (PCAs)
- Home Health Care Agency Leaders
- Rehabilitation Professionals



# Partner Contributions

- Steering Committee
- Focus Groups/Interviews
- Workgroups
- Pilot-Testers



# Steering Committee

- Advised us on content of question guides
- Gave input on proposed content before pilot-testing
- Helped us decide what revisions to make
- Informed worksheets/guides/resource list
- Helping to share the course with the SCI community
- \$50/meeting was provided in appreciation of members' time



# Focus Groups and Interviews

- Goal was to understand the priorities and perspectives of key partners
- Conducted 10 interviews, 7 focus groups
- Identified emerging themes
- Proposed course module topics



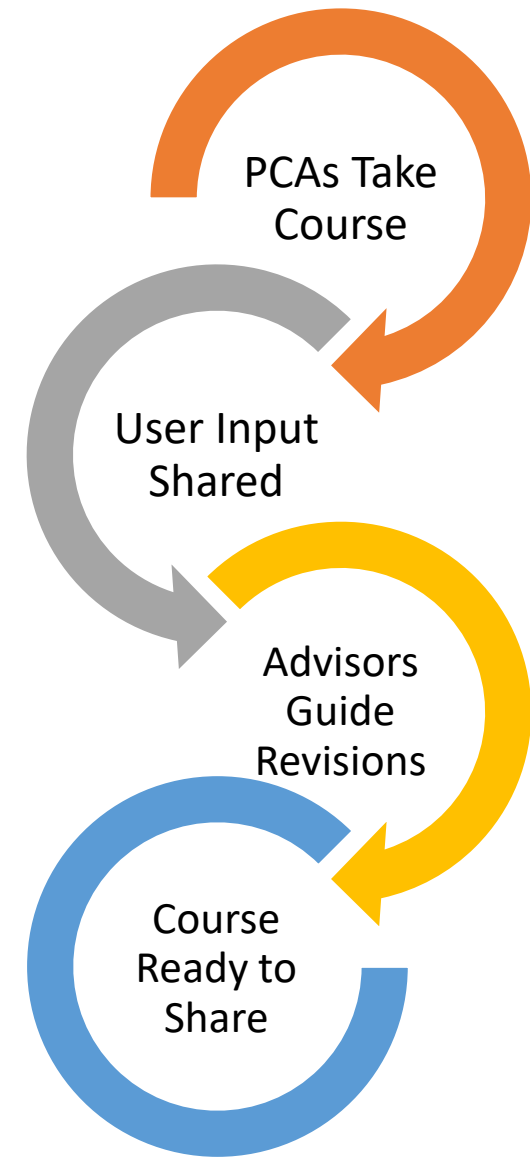
# Workgroups

- Provided guidance to help create specific content for course
- Each group focused on a major theme
  - Theme 1: What is SCI?
  - Theme 2: Secondary Complications
  - Theme 3: Misconceptions/Non-physical effects of SCI
- Composition
  - 3 groups of 3-4 members
  - 3 people with SCI, 3 PCAs, 2 clinician, 2 home health care agency leaders
- Met twice a month during content drafting/finalization



# Pilot-Testing

- Participants
  - 15 PCAs with little experience assisting clients with SCI
  - 5 PCAs with SCI experience who were not involved in the course production
- Input gathered through:
  - Questionnaires
  - Interviews (subset of testers)
- Steering Committee/Workgroups guide revisions



# Course Content Overview

# Course Modules

|   |   |
|---|---|
| 1 | You Make a Difference                         |
| 2 | What is Spinal Cord Injury?                   |
| 3 | Physical Functions Affected by SCI            |
| 4 | Personal and Social Challenges Created by SCI |
| 5 | Common Misunderstandings about SCI            |
| 6 | Complications of SCI                          |
| 7 | Applying What You've Learned                  |
| 8 | Special Topics                                |



# Course Modules

|   |   |
|---|---|
| 1 | You Make a Difference                         |
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| 6 | Complications of SCI                          |
| 7 | Applying What You've Learned                  |
| 8 | Special Topics                                |

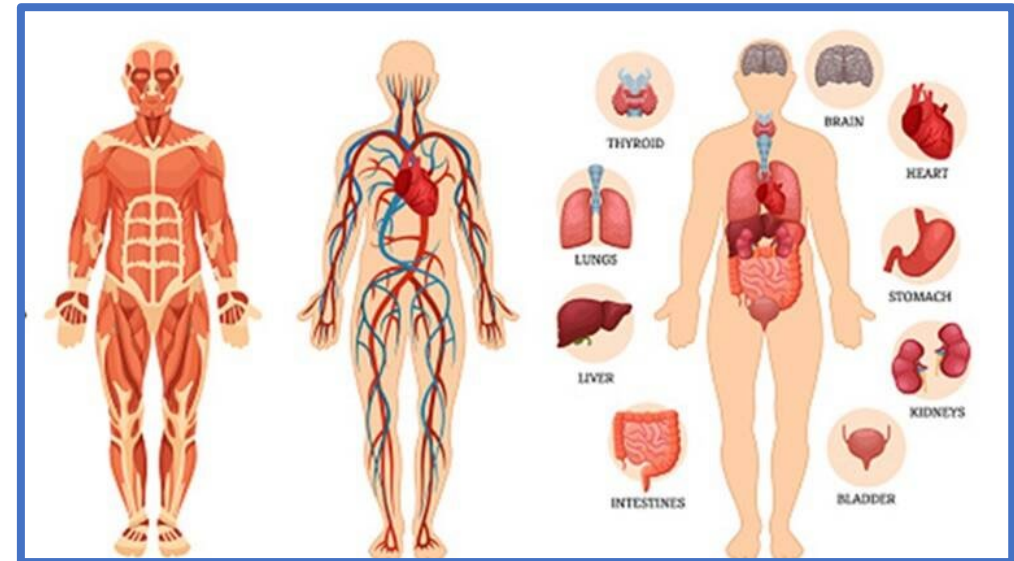
# Module 2: What is SCI?

- Definition of spinal cord and SCI
- Causes of SCI
- Characteristics of people with SCI
- Paraplegia vs. tetraplegia
- Level
- Completeness
- How everyone with SCI is different



# Module 3: Physical Functions Affected by SCI

- Movement
- Sensation
- Breathing
- Reflexes
- Temperature control
- Blood pressure control
- Bowel and bladder control



# Module 4: Personal and Social Challenges Created by SCI

- Loss of control
- Feelings of vulnerability
- Loss of privacy
- Sadness/lack of confidence
- Social isolation
- Financial stress



# Module 5:

## Common Misunderstandings about SCI

- Three major categories of “myths” addressed:
  - Physical effects
  - Thoughts and feelings
  - Preferences for help

# Module 5:

## Common Misunderstandings about SCI

| <b>Myth</b>                                      | <b>Fact</b>  |
|--|--|
| All people with spinal cord injury are the same. | No two people with spinal cord injury are the same, even if they have injuries in the same place in the spinal cord. |
| SCI affects both moving and thinking ability.    | People with SCI can think and make decisions just like you.  |

# Module 5:

## Common Misunderstandings about SCI

| <b>Myth</b>  | <b>Fact</b>  |
|--|--|
| If it looks like your client is “struggling” with a task, you should help. | There are many reasons why a person with a spinal cord injury may prefer not to have help in certain situations. |
| People with spinal cord injury who cannot walk must be unhappy.            | People with spinal cord injury are capable of living happy, fulfilling lives even if they cannot walk.           |

# Module 6: Complications of SCI

- Skin issues (pressure injuries, burns)
- Autonomic dysreflexia
- Low blood pressure
- Infections
- Pain
- Blood clots
- Problems with joints, muscles, or bones
- Mental health challenges





# Module 8: Special Topics

## Building Positive Working Relationships

- Establish expectations
- Define responsibilities
- Identify who is directing care
- Encourage a professional relationship
- Speak up
- Check in regularly
- Identify helpers

## Equipment

- Importance for function/safety
- Importance of maintenance
- Types and general function
- Who to ask for more information

## Tips for Safe Transfers

- Overview of techniques/range of help needed
- What to check before you move
- Mechanical lift overview
- Importance of assessing individual client needs/preferences
- Pause if needed

## Blood Pressure

- Autonomic dysreflexia (definition, signs responses)
- Hypotension (definitions, ways to prevent and manage)

# Supplemental Materials

- Discussion guide for conversation about needs and preferences
- List of web-based resources



# Course Platform

# Delivery Platform

- Subscription service
- Facilitates web-based course creation and sharing
- Enables access from any internet-connected device
- Platform for the Kessler Foundation Learning Center

THINKIFIC



# Course Structure and Elements

- Divided into chapters (modules)
- Lessons are nested within chapters
- Content types
  - Slides with images and voice over
  - Videos
  - Assessments (quizzes)



# Laptop/Desktop View

The screenshot displays a course interface for "Understanding Spinal Cord Injury: A Course for Personal Care Assistants". The main content area features a video player with the title "02: What is Spinal Cord Injury?". The video player includes a progress bar at 0:02 and standard playback controls. The sidebar on the left contains a navigation menu with the following items:

- Go to Dashboard
- Understanding Spinal Cord Injury: A Course for Personal Care Assistants
- Chapters
- Achievements & Progress (0 / 50)
- Search by lesson title
- Module 1: You Make A Difference
- Module 2: What is Spinal Cord Injury? (indicated as completed with a green circle)
- What is Spinal Cord Injury? (indicated as completed with a green circle)
  - VIDEO
- What does an assistant help you to do?
  - VIDEO
- Module 2: Show What You Know
  - QUIZ
- Module 3: Physical Functions Affected by Spinal Cord Injury
- Module 4: Personal and Social Challenges Created by SCI
- Module 5: Common Misunderstandings about SCI
- Module 6 (Part 1): Complications of SCI

# Laptop/Desktop View

The screenshot shows a course interface for "Understanding Spinal Cord Injury: A Course for Personal Care Assistants". The interface is divided into a left sidebar and a main content area. The sidebar contains a navigation bar with a "Go to Dashboard" link, the course title, a "Chapters" section with a book icon, and an "Achievements & Progress" section showing "0 / 50". Below this is a search bar labeled "Search by lesson title". The main content area displays a video player with the title "What is Spinal Cord Injury?". The video player has a progress bar at the bottom showing "0:02" and various control icons. Three red callout boxes with arrows point to specific elements: "Navigation Bar (also shows completion status)" points to the top of the sidebar; "Chapters (Modules)" points to the "Module 2: What is Spinal Cord Injury?" entry in the sidebar; and "Lessons" points to the "What is Spinal Cord Injury?" video entry in the sidebar.

Navigation Bar  
(also shows completion status)

Chapters  
(Modules)

Lessons

# Laptop/Desktop View

[Go to Dashboard](#)

## Understanding Spinal Cord Injury: A Course for Personal Care Assistants

Chapters

Achievements & Progress 0 / 50

Search by lesson title

- Module 1: You Make A Difference
- Module 2: What is Spinal Cord Injury? ○
  - What is Spinal Cord Injury? ○  
VIDEO
  - What does an assistant help you to do?  
VIDEO
  - Module 2: Show What You Know  
QUIZ
- Module 3: Physical Functions Affected by Spinal Cord Injury
- Module 4: Personal and Social Challenges Created by SCI
- Module 5: Common Misunderstandings about SCI
- Module 6 (Part 1): Complications of SCI

What is Spinal Cord Injury?

# Understanding Spinal Cord Injury:

## 02: What is Spinal Cord Injury?

0:02

CC

Audio Player

Captioning

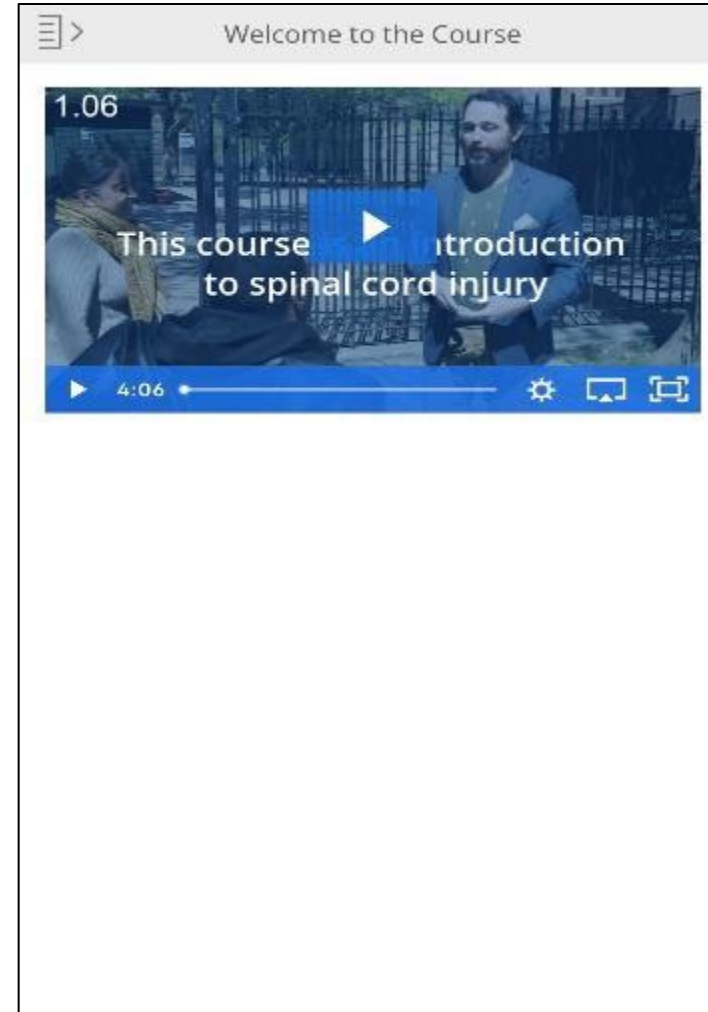
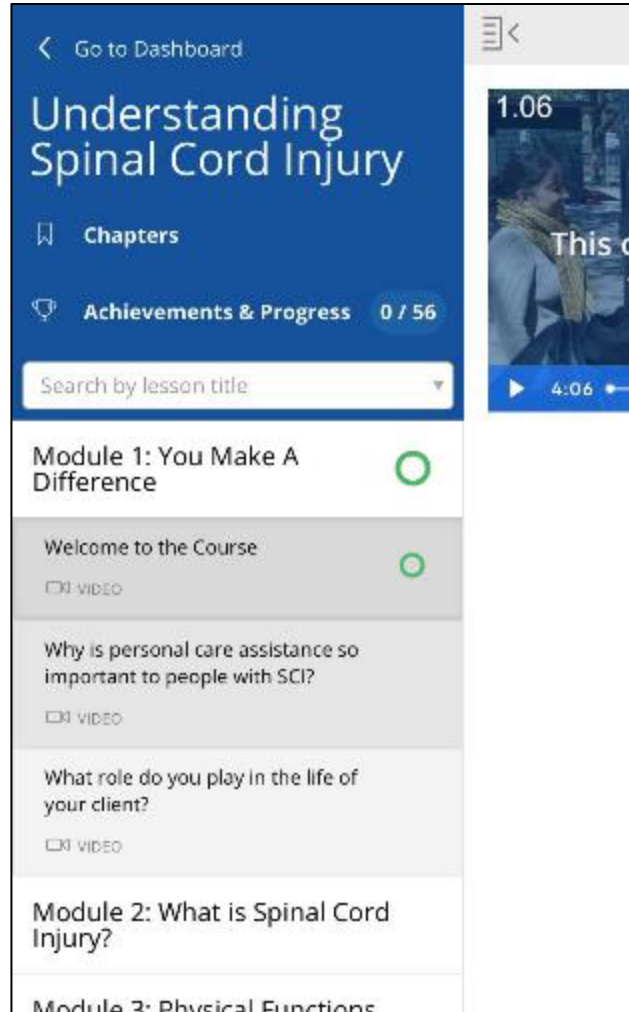
Content Window

Captioning

Audio Player

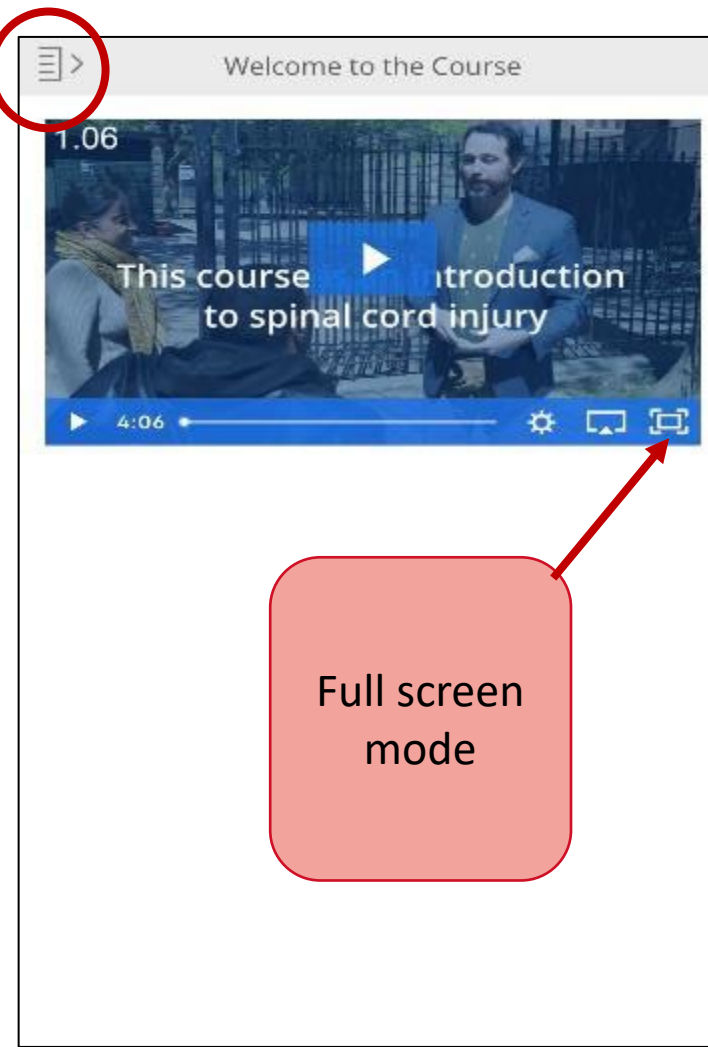
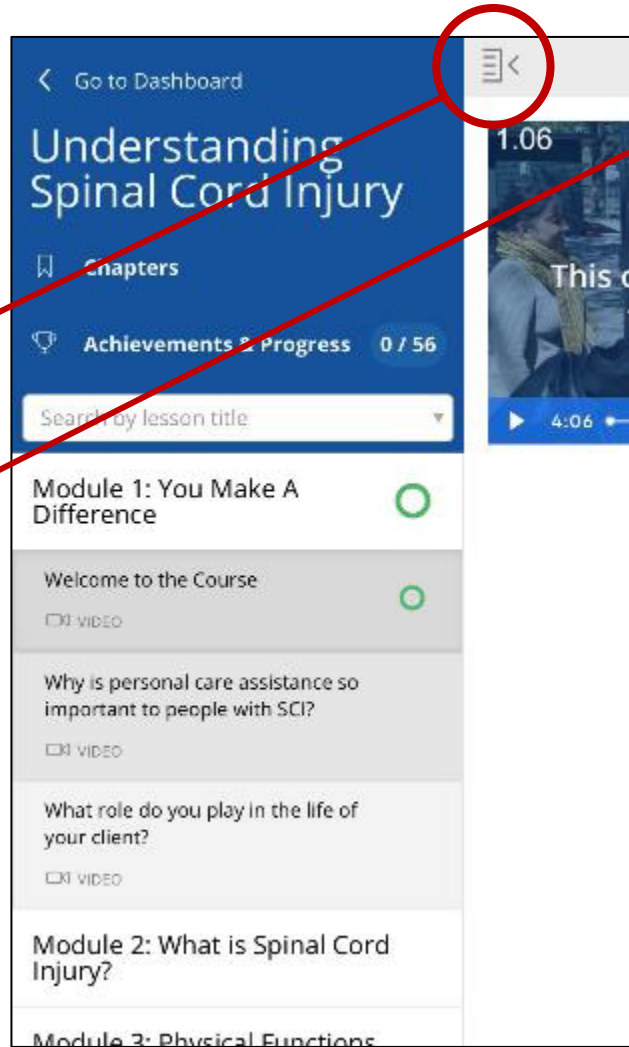


# Mobile Device View



# Mobile Device View

Users can view or hide the navigation bar to maximize use of screen space



Full screen mode

# Lesson Sample

Module 3: Physical Functions Affected by Spinal Cord Injury

Module 4: Personal and Social Challenges Created by SCI

Introduction

VIDEO

Loss of Control

VIDEO

Feelings of Vulnerability

VIDEO

Loss of Privacy

VIDEO

Sadness, Depression, and Lack of Confidence

VIDEO

Social Isolation

VIDEO

Financial Stress

VIDEO

Module 4: Show What You Know

QUIZ

Module 5: Common Misunderstandings about SCI

Module 6 (Part 1): Complications of SCI

Module 6 (Part 2): Complications of SCI

Module 7: Applying What You've Learned



Feelings of Vulnerability

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## Personal and Social Challenges: Feelings of Vulnerability

0:03



# To Access the Course



<https://bit.ly/understandingSCI>

# Dissemination (You can help!)

- SCI rehabilitation centers
- Independent living centers
- SCI organizations (United Spinal, PVA, Paralysis Resource Center)
- Home health care agencies
- Agency associations
- Accrediting bodies
- Other suggestions?
- **Contact [jzanca@kesslerfoundation.org](mailto:jzanca@kesslerfoundation.org) for media toolkit**



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# Questions?

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