

Social Isolation and Spinal Cord Injury

What do we know? What can we do?

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Overview



- What is Social Isolation?
- Why do we care?
- What do we know about Social Isolation and spinal cord injury (SCI)?
- What does the **SCI Longitudinal Aging Study** add to what we know about Social Isolation after SCI?
- How can this knowledge help to improve the lives of people with SCI?
- What can we do to prevent social isolation?
- Q & A



What is Social Isolation?

- **Social determinants of health** encompass the economic and social conditions that influence the health of people and communities.^[1]
- **Social support & social relationships** are important contributors to health.
 - › Family, friends, and strong supportive networks provide emotional and practical resources needed for good health.
- **Social isolation** is a lack of social connections and support.



What is Social Isolation?

- Social Isolation (SI) is complex.
 - › There are many ways people may experience SI.
 - › There are many factors that affect experiences of SI.
- There is no one definition of “Social isolation”.
 - › Often used interchangeably with “loneliness”.
- Research on SI requires a common language and clear definitions.
 - › How do we measure SI?
 - › How does information compare across studies and populations?



What is Social Isolation?

Two dimensions of SI are typically identified in the research literature.

1. **Objective:** a **measure** of social network size and the number and frequency of social contacts
2. **Subjective:** often described as **feelings** “loneliness” or an emotional state related to a perceived sense of unfulfilled social needs



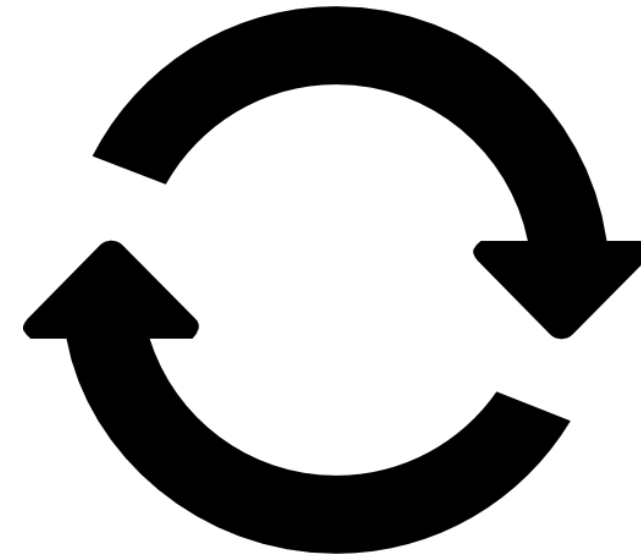
Cornwell & Waite (2009) defined these dimensions of SI as:

1. **Social Disconnectedness:** small social network, lack of contact with others, infrequent interactions, lack of social participation
2. **Perceived Isolation:** feelings of loneliness and a perceived lack of social support^[2]



What is Social Isolation?

- Studies on the relationship between Social Disconnectedness (SD) & Perceived Isolation have shown:
 - › Social disconnectedness is an initial state that can precede loneliness, low perceived social support, and depression onset.
 - › Perceived isolation predisposes to avoidance of others, social disconnectedness and subsequent depression.
- Personality traits may affect the relationship:
 - › People with few social connections may not feel lonely or isolated.
 - › People with many social connections may still perceive isolation.
- The combined and interactive effects of Social Disconnectedness & Perceived Isolation on health outcomes are not well studied.^[3]



Who is at risk for Social Isolation?

- The effects of SI were initially studied in older adults.^[3,4,5]
- Risk for SI is associated with consequences of aging.
- 40% of adults with a debilitating disability or chronic condition reported feeling lonely or socially isolated.
- More recent studies include younger people^[6,7] COVID-19 ^[8,9] and a few studies of people with disabilities.^[10]
 - › COVID-19 associated social distancing created potential for increased social isolation.

Significant **risk factors** for social isolation and loneliness include:



Living alone



Mobility disabilities



Major life transitions



Emerging health problems





“For most Americans with disabilities, this ‘new normal’ is not so new. Even though the ADA was signed 30 years ago, people with physical disabilities are still frequently stuck at home...”

Covid-19 Brings an Overdue Understanding of the Social Isolation Experienced by Many Americans with Disabilities

Share Article



Adhering to social distancing and quarantine bubbles means the number of people we see in person has dramatically diminished: suddenly, everyone's world is a much smaller place.

For most Americans with disabilities, this “new normal” is not so new. Even though the Americans with Disabilities Act was signed 30 years ago, people with physical disabilities are still frequently stuck at home, as communities lack accessible transportation for disabled individuals and workplaces are often unwilling to make



Why do we care about Social Isolation?

- In studies of older adults, SI was identified as a significant risk factor for poor health outcomes, comparable to smoking and obesity. [3]

Specific **health risks** associated with social isolation and loneliness include:



Increased mortality



Increased blood pressure and progression of Alzheimer's Disease



Depression, pain, and fatigue



Failing immune system, decreased restorative sleep

The health risks of prolonged loneliness are equivalent to smoking **15 cigarettes a day**

Seniors who report feeling lonely or socially isolated have a **45 percent greater risk of mortality**



What do we know about Social Isolation and SCI?

- SCI creates risk for Social Isolation due to:
 - › Mobility and functional limitations due to paralysis,
 - › Loss of independence,
 - › Adjustment and adaptation to new disability,
 - › Bladder and bowel dysfunction and management routines,
 - › Secondary conditions e.g., pressure injuries and urinary tract infections,
 - › Inaccessible environments.



What do we know about Social Isolation and SCI?



“These aren’t just any steps... These steps lead the way to social interactions between my friends from work, insights into private jokes, and the company of people I really enjoy... There is no ramp. These steps are my enemy”.

- Doug (T4-5 level of Injury)



SCI Longitudinal Aging Study

PI: Dr. Jim Krause PhD



Background and history

- The **SCI Longitudinal Aging Study** was initiated in 1973 by Dr. Nancy Crewe at University of Minnesota hospital. (Dr. Krause began his involvement in 1984)
- The goal was to better understand the life situation of people with SCI who were living in the community – very little was known at the time.
- The year coincided with the passage of the Americans with Disability Act.
- The study started as part of the SCI Model Systems (SCIMS) grant at the University of Minnesota, the study is not related to the SCIMS database, which is housed at the National Statistical Center at UAB.



Dr. Nancy Crewe



Dr. Jim Krause



Thank you, participants and team



Overview of participant recruitment

The inclusion criteria at enrollment were:

- Traumatic SCI
- Minimum of 2 years since SCI onset
- Adult (18 years+)

Five cohorts recruited from:

- The University of Minnesota hospital in Minneapolis MN.
- The Sister Kenny Institute, a former rehabilitation hospital in Minneapolis, MN.
- Shepherd Center in Atlanta, GA, specialty hospital and regional SCIMS.
- New cohorts were added on three occasions, coinciding with 10 year intervals, through 2003.



Participants

Table 1. Midwestern (S1, S2, S3) and Southeastern samples (S4, S5), and projected response.

Follow-up	Year	S1	S2	S3	S4	S5	New	Total Assessments
Baseline	1973	256	---	---	---	---	256	256
TOTAL							256	256

Note: Responses are projected based on previous follow-up.



Participants

Table 1. Midwestern (S1, S2, S3) and Southeastern samples (S4, S5), and projected response.

Follow-up	Year	S1	S2	S3	S4	S5	New	Total Assessments
	1973	256	---	---	---	---	256	256
11	1984	154	193	---	---	---	193	347
TOTAL							449	603

Note: Responses are projected based on previous follow-up.



Participants

Table 1. Midwestern (S1, S2, S3) and Southeastern samples (S4, S5), and projected response.

Follow-up	Year	S1	S2	S3	S4	S5	New	Total Assessments
	1973	256	---	---	---	---	256	256
11	1984	154	193	---	---	---	193	347
15	1988	135	151	---	---	---	0	286
20	1993	114	122	199	597	---	796	1,032
TOTAL							1,245	1,921

Note: Responses are projected based on previous follow-up.



Participants

Table 1. Midwestern (S1, S2, S3) and Southeastern samples (S4, S5), and projected response.

Follow-up	Year	S1	S2	S3	S4	S5	New	Total Assessments
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15	1988	135	151	---	---	---	0	286
20	1993	114	122	199	597	---	796	1,032
25	1998	95	104	163	398	---	0	760
30	2003	78	91	136	300	965	965	1,570
TOTAL							2,210	4,251

Note: Responses are projected based on previous follow-up.



Participants

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20	1993	114	122	199	597	---	796	1,032
25	1998	95	104	163	398	---	0	760
30	2003	78	91	136	300	965	965	1,570
35	2008	63	71	103	219	537	0	993
40	2013	50	56	91	182	389	0	768
45	2018	30	38	68	123	298	0	557
TOTAL							2,210	6,569

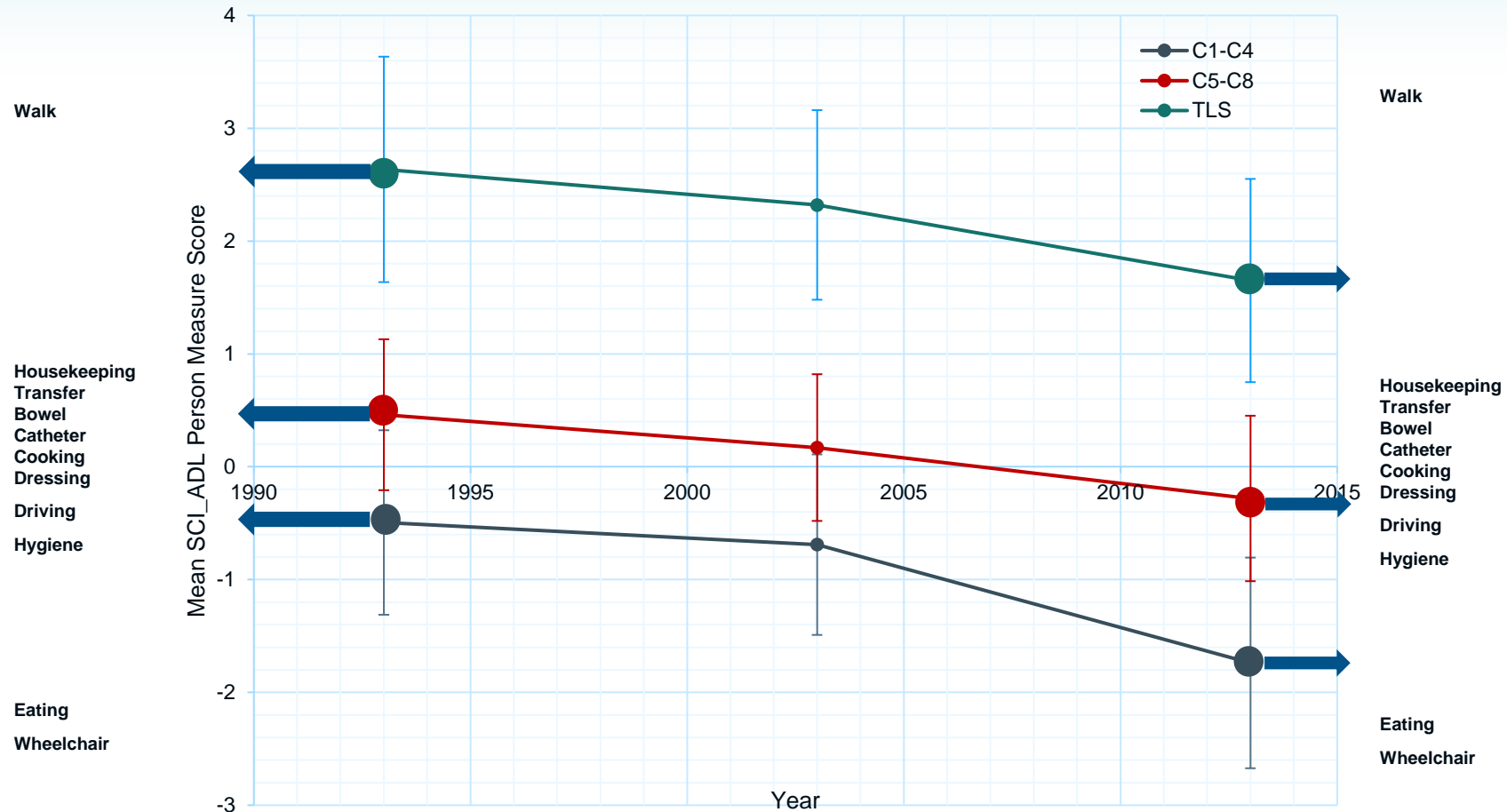
Note: Responses are projected based on previous follow-up.



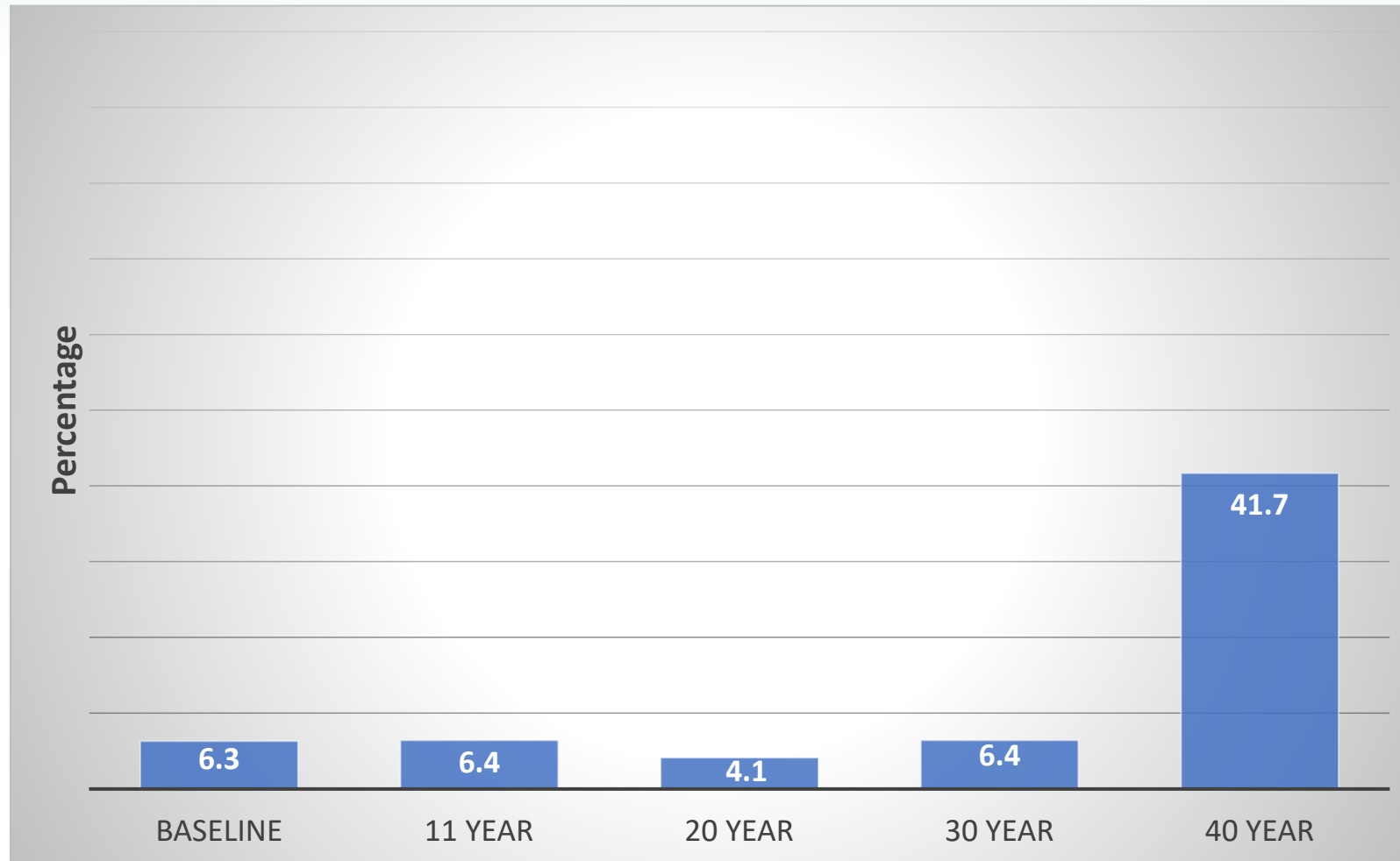
Challenges for people aging with SCI



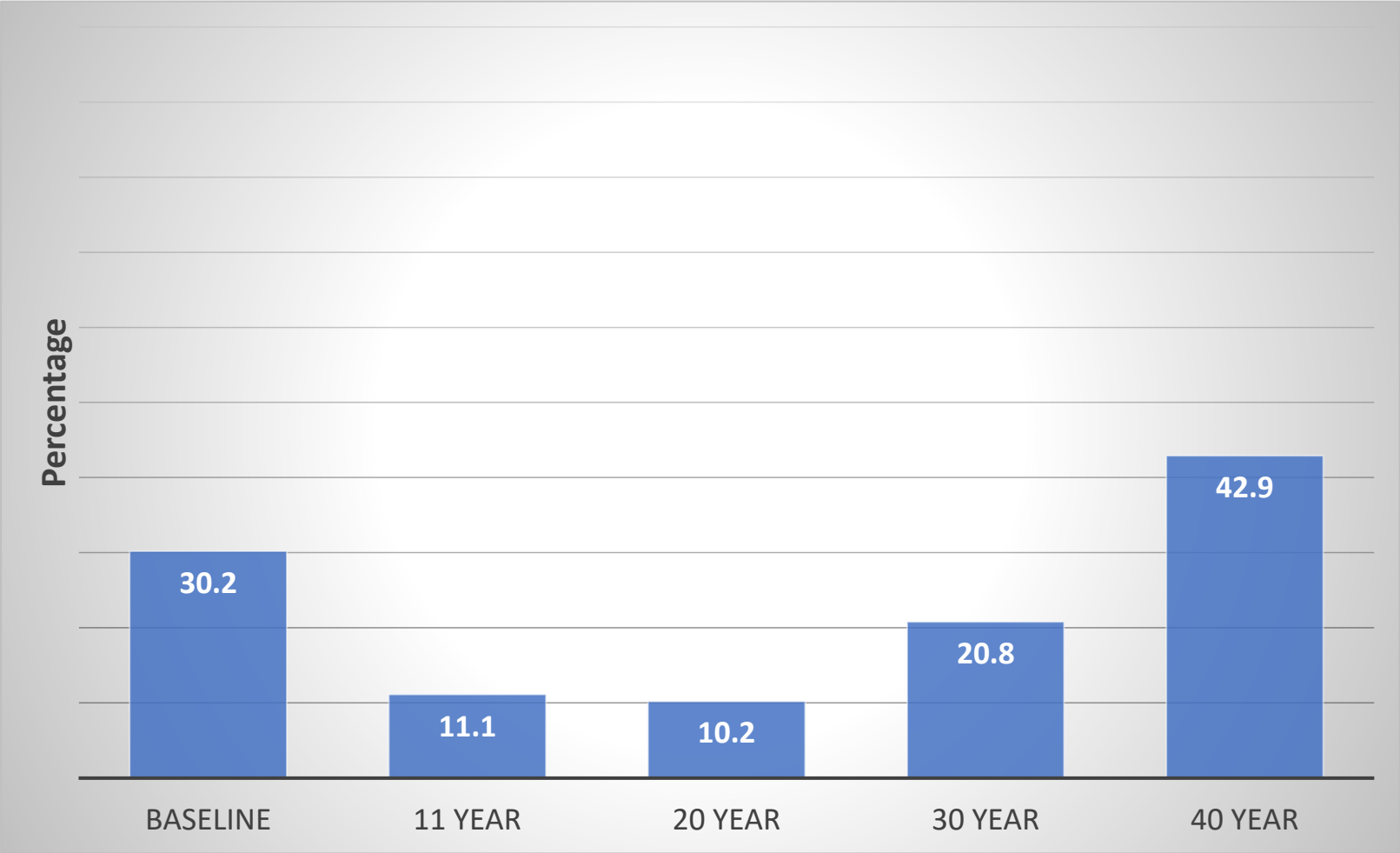
Twenty-year changes in function [19]



10 or more times of non-routine physician visits^[20]



Days with 1 or more weeks in the hospital^[20]



Social Disconnectedness and Perceived Isolation in the Longitudinal Aging Study



Measurement of Social Disconnectedness

- Survey questions that allowed us to measure and count social contacts and participation in social activities
 - Marital status
 - Number of individuals in the household
 - Frequency of people “coming to see you”
- Items of the Craig Handicap Assessment and Reporting Technique (CHART)
 - Days out of the house
 - Nights away from home
 - Leaving home specifically for social or entertainment purposes, and participation in volunteer activities



Measurement of Perceived Isolation

- Survey questions that addressed:
 - Feelings of being avoided, excluded, detached, disconnected from, or unknown by others)
 - Perceived availability of someone with whom to share enjoyable activities.
 - Feelings of being cared for and valued as a person; having a trusted friend
 - Perceived availability of assistance with tasks
 - Feelings of overall well-being
 - Perceptions of lack of control in life, difficulty making friends, boredom, and dependence



Analysis of SD and PI after SCI

- Goal: To study the relationships between social disconnectedness and perceived isolation within an aging sample of participants with SCI (N=768).
- We hypothesized that social disconnectedness and perceived isolation were distinct but related concepts within our sample.
- We investigated the relationships of personal characteristics, such as gender, age, race, severity of injury, and time since injury with social disconnectedness and perceived isolation.



Analysis of SD and PI after SCI

- What we found...
 - Perceived isolation was significantly related with social disconnectedness
 - Higher level and severity of injury (↑ disability) was associated with higher levels of social disconnectedness.
 - Participants with higher education were less likely to report SI.
 - Older participants were more likely to report higher levels of social disconnectedness and less perceived isolation.
 - Time since injury demonstrated an inverse relationship with both social disconnectedness and perceived isolation.





Individuals with higher levels and severity of injuries reported more social disconnectedness.

↑ years post injury →
↓ social disconnectedness
and ↓ perceived isolation

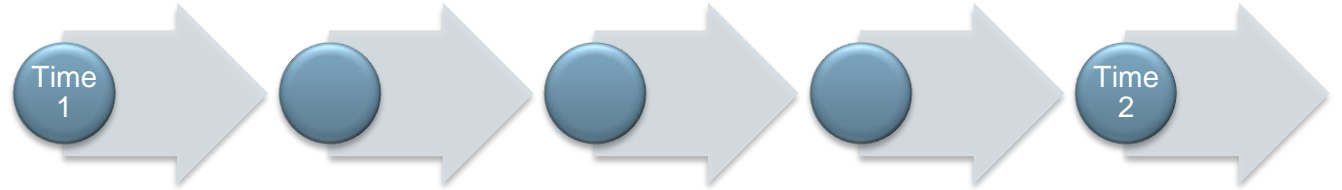
- Consistent with the findings of other researchers that more severe injuries have the most challenges in terms of social and community participation for a variety of reasons.

- This suggests that people adapt to the consequences of their injury over time and adjust their social activities and expectations.



Five-year analysis of SD and PI

- Goal: To study the relationship of social isolation and probable major depression (PMD) over a five-year interval among participants with SCI (n=557).



- What we found...
 - Both SD and PI, measured at Time 1, were significantly related with PMD, measured at Time 1 and Time 2.
 - This suggests participants with greater PI and SD were more likely to have greater likelihood of PMD, at one time point and over time.
 - PI was more strongly related to PMD compared with SD.
 - Years post SCI was negatively related to PMD.
 - \uparrow years post injury \rightarrow \downarrow depression





Social isolation was associated with both current and future depression symptoms.

People with more years post SCI were less likely to have PMD.



What does the Longitudinal Aging Study add to what we know about Social Isolation after SCI?

- Higher level and severity of injury was associated with higher levels of social disconnectedness.
- Time since injury demonstrated an inverse relationship with both social disconnectedness and perceived isolation, suggesting that long-term survivors of SCI indeed adapt to their circumstances.
- Those who survive more than 40 years with SCI appear to be highly resilient, so some of the decreases may reflect a survivor effect.
- It is important to conduct longitudinal examinations to truly understand the trajectory of perceived isolation and social disconnectedness, so that we can better understand how those areas change with aging.



How can this knowledge help to improve the lives of people with SCI?

Findings from the SCI Longitudinal Aging Study can inform:

- The development of predictive models for social isolation after SCI,
 - Understanding of the relationship between the objective and subjective dimensions of social isolation in the context of SCI,
 - Recognition of the reciprocal relationship of social isolation and post-injury physical and mental health,
 - Identification of factors that mediate the presence or effects of social isolation.
- › To inform intervention development



How can this knowledge help to improve the lives of people with SCI?



Interventions targeting social isolation after SCI may include strategies to:

- › Screen for social isolation risk during acute recovery and rehabilitation to inform discharge planning,
- › Expedite coping strategies, adjustment, and adaptation of social goals and expectations after injury,
- › Minimize disruption of the structure and composition of social networks,
- › Provide community-based social supports, such as peer support or mentoring,
- › Optimize the use of technology to facilitate social connections.



Research to alleviate Social Isolation after SCI

- **Caring Connections** study

- A peer-based, facilitated, letter writing program designed to provide feelings of social connectedness and moments of positivity to reduce loneliness and social isolation in persons with SCI/D.
- Monthly letters over 6 months
- Will enroll Veterans with chronic SCI/D, >1 year post injury
- Outcomes to be evaluated:
 - Loneliness
 - Social Isolation
 - Social Contact (frequency)
 - Satisfaction with the intervention



What can YOU do to prevent social isolation?

- Nurture existing relationships – invite people over for coffee, call to suggest a trip to the movies or mall.
- Schedule a daily call with a friend or loved one.
- Get to know your neighbors.
- Use social media to stay connected with friends and others.
- Take a class – learn something new, meet new people
- Take up a hobby – connect with others who share your interest
- Volunteer – creates a sense of purpose as well as social connections
- Join a community club or peer group.



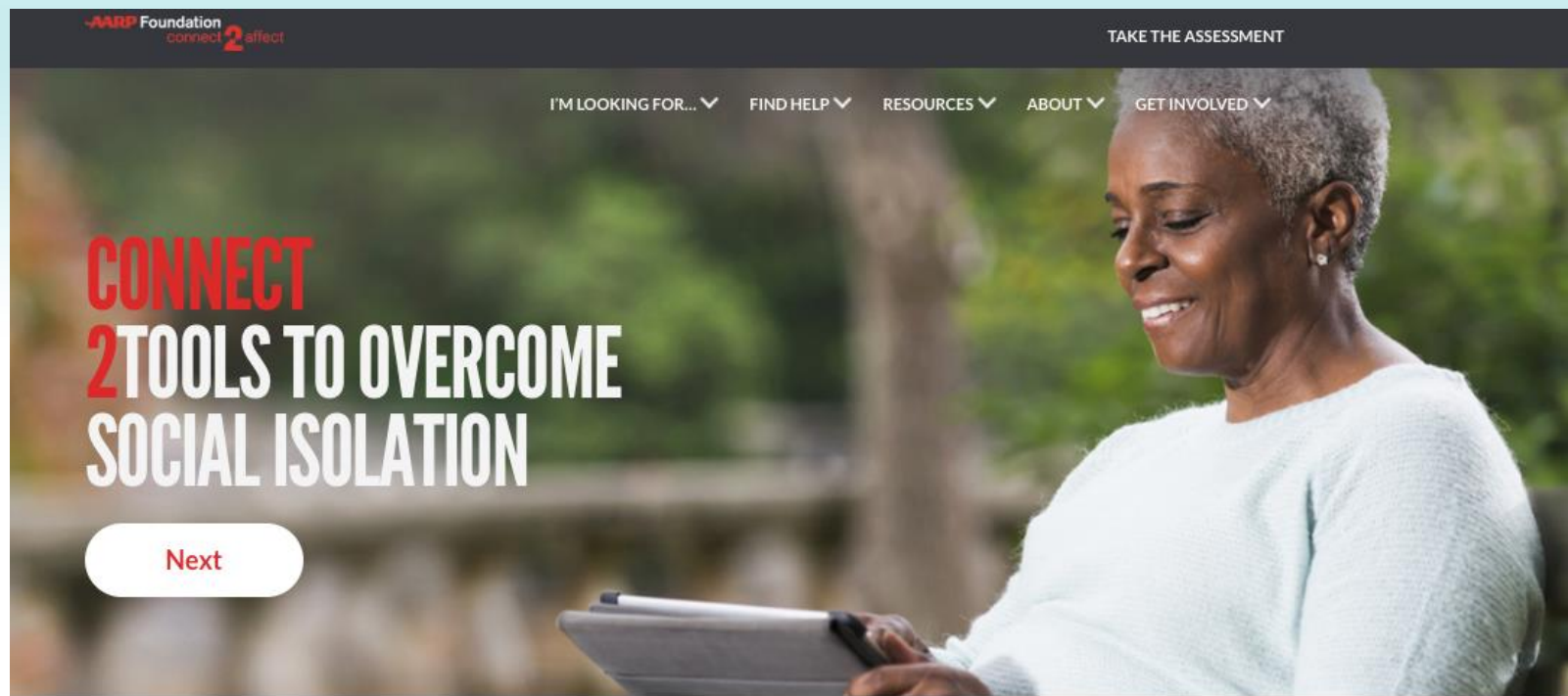
If you are feeling lonely and isolated now...

- Reach out to your family, friends, and neighbors.
- Seek out opportunities to participate in activities with people you enjoy.
- Discuss how you feel with your healthcare provider.
- Recognizing that you feel lonely and isolated is the first step to improving your quality of life.
- Explore online resources designed to help connect you with others and reduce isolation.



CONNECT2AFFECT

- supported by AARP
 - Online resource with tools to evaluate your isolation risk and information on resources in your local area
- <https://connect2affect.org/>



Social Isolation Is More Than Feeling Lonely

How connected are you?

Social isolation has reached epidemic proportions and has a negative impact on our emotional and physical health.

Are you or a loved one at risk for social isolation? Take this assessment to find out if you are at risk.

TAKE THE ASSESSMENT



17%
of adults age 65 and older
are isolated



26%
increased risk of early
death due to subjective
feeling of loneliness



46%
of women age 75 and older
live alone



Commit to Connect

- Supported by Administration on Community Living
- The aim is to connect people living with isolation with programs and resources to build the social connections they need to thrive.

<https://acl.gov/CommitToConnect/networks>



Commit to Connect Materials

- [Social Isolation: An Overview](#). A summary of key facts and links to technical assistance and resources related to addressing social isolation.
- [Getting Started: Resources & Technical Assistance](#). Strategies, programs, action steps, and tools to support social engagement and related programs.
- [Measuring Social Isolation](#). Tips, recommendations, and lessons learned from collecting and analyzing data on social isolation.

Other Resources

Customizable Materials & Tools

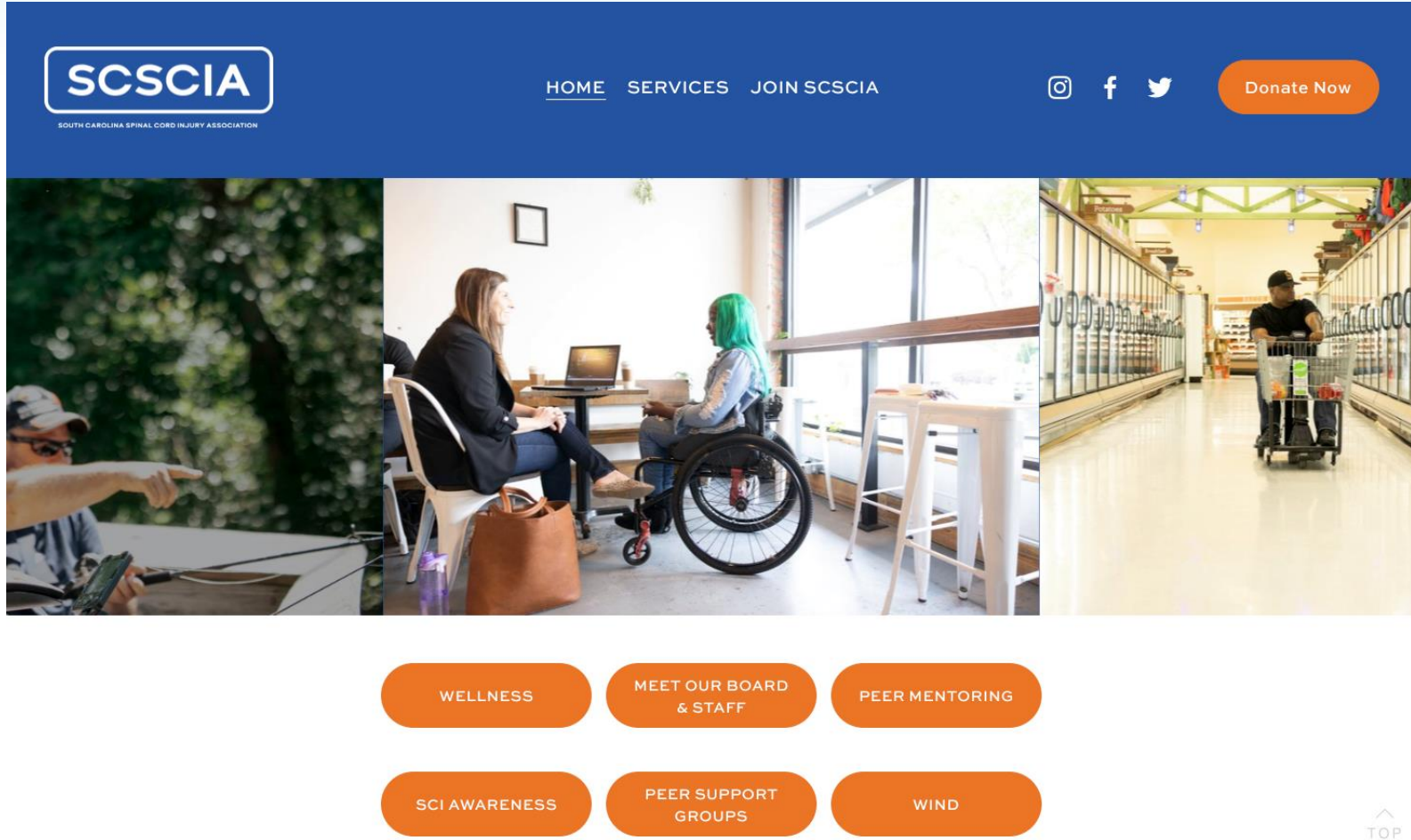
- [AARP Livable Communities](#).[☞] AARP. Toolkits, how-to guides, and to easy-to-use materials that promote livable communities for people of all ages.
- [Engaged and Connected Blog Posts](#).[☞] *engAGED National Resource Center*. A six-part series of grab-and-go posts on older adults staying engaged during COVID-19.
- [Social Connectedness and Engagement Technology Tool](#).[☞] *LeadingAge*. Hands-on resources to help organizations use technology to connect and engage with older adults.

Promising Practices & Examples

- [Addressing Social Isolation for Older Adults During the COVID-19 Crisis](#).[☞] *Advancing States*. Creative and thoughtful approaches for addressing social isolation and loneliness in older adults.
- [Care for Wellbeing of Older Adults During COVID-19: Connecting While Social Distancing](#).[☞] *Humanitarian Disaster Institute*. Suggestions from the faith-based academic disaster research center at Wheaton College.
- [Pandemic Playbook](#).[☞] *LeadingAge*. Interactive collection of insights and critical lessons learned serving older adults during COVID-19.



South Carolina Spinal Cord Injury Association



- Breeze Groups
 - In person & Virtual
- Peer Mentoring Program
- <https://www.scspinalcord.org/>



CHALLENGE

Get the contact information - phone number or email - of someone new you met today.

Make a plan to get in touch in a few weeks.

Make a plan to keep in regular contact.



In conclusion...

- People with SCI are at risk for social isolation.
 - › SCI adds additional unique risk factors for social isolation
- The seemingly protective nature of time since injury on post injury social health, warrants further investigation of the effects of aging, time since injury, and long-term adjustment on social isolation.
 - › More longitudinal studies and intervention studies are needed.
- There are growing numbers of resources to help address social isolation.



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Thank you!



Questions?