SCI Step Together

An 8-week physical activity program created for individuals with spinal cord injury who walk.



About SCI Step Together

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SCI Step Together is an 8-week program created for individuals with spinal cord injury (SCI) who walk to become more physically active. The program is also to help people have better or higher quality experiences in physical activity. The program is based on the best research evidence specifically for people with SCI who walk. SCI Step Together was developed by scientific research experts, individuals with lived experience, a SCI community organization, and Curatio (now known as RxPx Inc.).

Why We Made This

People with SCI who walk participate in much less physical activity than individuals with SCI who use manual wheelchairs. However, there has been very little research looking at physical activity for people with SCI who walk and there are no programs to help improve physical activity for this group. This is the first program to support people with SCI who walk to change their physical activity behaviour.

The Purpose

SCI Step Together was created to support people with SCI who walk to have more and better physical activity experiences. In this program, you will learn about the conditions that lead to better quality experiences in physical activity, the SCI physical activity guidelines and benefits, how to track your activity and set goals, planning for activity and how to cope with barriers that arise, how to feel more confident about yourself, skills for physical activity you might need, and resources to support your physically active lifestyle moving forward.

Adapt It

The 8-week program was originally created as a mobile application for your smartphone, and you can still access the Curatio Stronger Together app on your smartphone in the "SCI Step Together" community: <u>https://apps.apple.com/ca/app/curatio-stronger-together/id1517935369</u>. The app provides more tools like health coaching, peer support, and health and mood tracking. We decided to put the modules online so others can access the educational content on more kinds of devices. We hope that you take what you need from this program and adapt the information as you see fit.

Research References

• Developing the program:

Lawrason, S. V. C., Brown-Ganzert, L., Campeau, L., MacInnes, M., Wilkins, C. J., & Martin Ginis, K. A. (2022). mHealth physical activity intervention for individuals with spinal cord injury: Planning and development processes. JMIR Formative Research, 6(8), e34303. doi:10.2196/34303.

• Assessing the impact of the program:

Lawrason, S. V. C., & Martin Ginis, K. A. (2023). Evaluating the feasibility, acceptability, and engagement of a mHealth physical activity intervention for individuals with spinal cord injury: A randomized controlled trial. Journal of Sport and Exercise Psychology, 45(2), 61-76. doi:10.1123/jsep.2022-0087

Authors

The SCI Step Together program was created in 2021. The modules were published online in 2023. The authors of the program include:

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"SCI Step Together" – Overall 8-Week Framework:

Module 1: Quality Participation, Autonomy, and Competence	Week 1: Quality physical activity participation Week 2: Physical activity guidelines and benefits Week 3: Self-monitoring and goal setting
Module 2: Autonomy and Competence	Week 4: Action planning Week 5: Coping planning
Module 3: Competence	Week 6: Beliefs about capabilitiesWeek 7: SkillsWeek 8: Program recap and providing tools for independent use

You can find this information and more in the Curatio Stronger Together app on your smartphone in the "SCI Step Together" community: <u>https://apps.apple.com/ca/app/curatio-stronger-together/id1517935369</u>

WEEK 1 – Quality physical activity participation

1. Week 1 – Welcome & Overview

A very warm welcome to you! Each week will follow a similar format for 8 weeks.

- i. This program has been developed by the SCI Action Canada Lab at the University of British Columbia in collaboration with Curatio Networks Inc., to help you stay strong throughout your health journey. We're here to help you with the process of improving the amount and quality of your physical activity. Hopefully, you'll feel better prepared to engage in physical activity in the long-term.
- ii. In Week 1, we're going to learn about quality physical activity participation and how to have a better experience in physical activity.
- iii. You can work on this program at your own pace over the next 3 weeks. Along the way, you'll find handy resources to use, evidence-based information, interesting questions to consider and lots of positive peer support. At any time, you can reach out to us with questions, concerns, suggestions and ideas.

Let's get started!

Disclaimer: Information provided by this app is not intended to replace the advice or instruction of a professional health care provider. Contact your Family Doctor, Walk-in Clinic, Specialist, Physiotherapist, Dietician, or any other member of your health care team if you have any questions concerning your health.

You might notice that this program sometimes refers to Canadian health information and resources, such as local telephone health lines or others. If you require support in a different region, please be sure to connect with your Community Coach so we can help you find resources close by.



You can find this information and more in the Curatio Stronger Together app on your smartphone in the "SCI Step Together" community: <u>https://apps.apple.com/ca/app/curatio-stronger-together/id1517935369</u>

WEEK 1 – Quality physical activity participation

2. Week 1 – Educational Content – Quality Physical Activity Participation

This week, we're going to learn about quality physical activity participation and how to have a better experience in physical activity.

What is quality physical activity participation?

Quality physical activity participation is defined as a person's broad subjective evaluation that their physical activity involvement is (or has been) satisfying, enjoyable, and generates personally valued outcomes. Repeated quality physical activity experiences contribute to your overall sense of quality physical activity participation. **Quality experiences** are a feeling that you are satisfied and enjoy activities that fulfill one or more of your own values or needs.

What do quality experiences feel like?

Quality experiences include feelings of autonomy, belongingness, challenge, engagement, mastery, and meaning. Below are some things we have heard from peer men and women SCI ambulators. These definitions and quotes might help to better describe these feelings:

- Autonomy: Having the ability to make choices
 - **Peer example:** "With surfing, the goal is to be able to paddle myself in the waves ... Right now, it's adapting the activities I want to do to be independent in them"
- Belongingness: Being part of a group
 - **Peer example:** "The rock-climbing gym is my second family. The culture of it all is very much welcoming and supportive"
- Challenge: Being appropriately challenged
 - **Peer example:** "I like exercise that pushes me to try harder, so something that is fairly intense and working hard, sweating, and breathing heavy"

- Engagement: Feeling involved and focused
 - **Peer example:** "When everything is going really well, or I get just one good wave in that session, I am stoked, and I am smiling ear to ear"
- Mastery: Experiencing success or achieving a goal
 - **Peer example:** "I walked up a very big hill with another person. I did have support from them, but I did it all independent without any real mobility devices ... and that was a pretty big accomplishment for me"
- **Meaning:** Contributing to a personally or socially meaningful goal (e.g., doing physical activity to improve mental or physical health)
 - **Peer example:** "I feel a lot better, clearer, less anxiety ... When I am biking alone, I can listen to my book or podcast, so it feels comforting"

It's important to note that quality experiences are individual and can change over time. The feelings that are important for one person may be different for another person, and the importance of specific feelings may change for you depending on the day, time in your life, and type of activity you're doing. You also don't need to have every feeling in every physical activity experience – try to focus on experiencing a range of feelings that are meaningful and important to you.

How can I have more quality experiences in physical activity?

There are factors that can facilitate better experiences, which relate to your personal environment (e.g., pain, fatigue), social environment (e.g., group environment, harassment), program environment (e.g., sport type, safe activities), and physical environment (e.g., accessibility). We have summarized factors we have heard from other people with a SCI who walk that may influence your physical activity experience:

	Factor	Description			
Person Factors	Body functions/ structures	Secondary health implications of SCI: unpredictability of function, pain/fatigue, bladder/			
		bowel function, other secondary health conditions			
	Internalized ableism	Applying discriminatory and ableist standards onto yourself in physical activity			
	Social comparison	Comparing yourself to (a) your pre-injury ability, (b) other individuals without a SCI, or (c) others living with a SCI			
Social Factors	Physical activity-related attitudes	How individuals without disabilities perceive you in physical activity, e.g., staring			
	Harassment	Explicit harassment by others in physical activity settings, e.g., being harassed by someone for using an accessible parking spot before doing an activity			

	Group environment	Having a sense of community and knowing where you fit in with others in both able-bodied and disability communities
	Status of disability	Your disability is dismissed, underestimated, or
	Family support and	Including family members and close friends in
	integration	physical activity participation
Program Factors	Sport type	Activities are ideally suited to your needs and values,
		e.g., adapting pre-injury activities vs. trying new activities can influence social comparison
	Equipment	Access to proper equipment that suits your needs or competitive level
	Safe activities	Activities that provide you with a comfortable level of risk and limited potential for harm
	Classification	Classification for parasports should be designed to permit equal opportunity and fair competition, limiting chances for alienation so that you feel like you 'fit' somewhere in the sport system
Physical	Accessibility	Accessibility in physical activity settings is required to access a quality experience, e.g., availability of elevator, length of walk to get to activity location, bathroom availability, parking nearby

What are some benefits of quality physical activity participation?

Research shows that individuals who have better quality physical activity experiences also have better health and well-being and maintain their physical activity participation for longer.





3. Week 1 – Additional Support

Here are some reliable resources you can use to learn more about quality physical activity participation in physical activity. Don't forget, your Community Coach is here to help you if you need additional support. We also encourage you to reach out to other community members if you have questions or would like to share your experiences.

Blueprint for Quality Participation in Parasport: <u>https://cdpp.ca/sites/default/files/CDPP%20Quality%20of%20</u> <u>Participation%20Evidence%20Summary.pdf</u>

Rethinking the meaning of 'Participation' for People with Disabilities: <u>https://cdpp.ca/sites/default/files/</u> <u>CDPP%20KT%20Bulletin%20%231%20December%202017.pdf</u>



4. Week 1 – Top Takeaways

Well done! You finished the first week of the program! There is so much we can learn from each other. We would love to know what your top takeaway was this week. Did you have any AHA moments? Did you learn something new about quality physical activity participation? Until next week, we are sending you healthy wishes and warm regards.



WEEK 2 – Physical Activity Guidelines and Benefits for Individuals with SCI

1. Week 2 – Physical Activity Guidelines

One week down and two more to go for this module! This week we are going to lay a foundation of knowledge about general physical activity principles and guidelines for people living with a SCI.

Let's get started!



Before we dive deeper, let's make sure we all have a good understanding of what physical activity means.

Physical activity: Physical activity comes in all shapes and sizes! Physical activity is any bodily movement that burns energy and increases heart rate and breathing. It can also make us sweat and feel tired. Physical activity can be experienced as part of recreation and leisure (e.g., sports or planned exercise), transportation (e.g., wheeling, walking), at home (e.g., household chores), and many other parts of daily living.

While we generally know that being active is important, for people living with a SCI, finding the right information can be difficult. The Physical Activity Guidelines for Adults with SCI were developed by an international group of SCI scientists, people living with SCI, clinicians, and representatives from SCI organizations. These physical activity guidelines are based on the best scientific evidence available from exercise studies involving adults with SCI.

The guidelines have two levels: a starting level and an advanced level. Which level you choose depends on your goals, abilities, and current fitness level. If you're just starting physical activity, consider working up to the starting level and then, ideally, work up to the advanced level. If you're already physically active, you might want to begin with the advanced level.

Starting level: The starting level is the minimum level of activity needed to achieve fitness benefits.

Advanced level: The advanced level will give you additional fitness and health benefits, such as lowering your risk of developing Type 2 diabetes and heart disease.

STARTING LEVEL	ADVANCED LEVEL
AEROBIC ACTIVITY	AEROBIC ACTIVITY
20 M 2x M	30 M 3x M
STRENGTH-TRAINING ACTIVITY	STRENGTH-TRAINING ACTIVITY
3 μ 10 μ 2χ μ	3 the 10 the 2x the for each major muscle group
START MI	EET EXCEED

Let's dive into the two main types of physical activities you can do. These types of activities can be adapted to your individual abilities, and the examples we provide are only a few among the many activities you might consider doing.

1. Aerobic activities: Aerobic activities or "cardio" are physical activities that are done continuously and that increase your heart rate and breathing rate, such as walking, swimming, biking, or dancing.

2. Strength-training activities: Strength-training activities are activities that increase muscle strength, such as exercises using resistance bands, lifting weights, or exercises that use bodyweight for resistance (e.g., push-ups or sit-ups). Doing housework and gardening can count too!

Let's talk intensity! Physical activity intensity relates to the amount of physical effort you put into doing an activity. Intensity is particular to each individual – you can get a sense of the intensity level of an activity based on your heart rate, how hard you are breathing, and in some cases, whether you are sweating. However, some people with SCI cannot sweat in certain areas where their injury affects them.

There are three levels of physical activity intensity: light, moderate, and vigorous. Examples of physical activities are provided that have been suggested by others living with SCI who walk:

1. Mild: Mild intensity activities require very light physical effort. They make you feel like you are working a little bit, but you can keep doing them for a long time without getting tired. Examples include stretching or yoga, or an easy walk.

2. Moderate: Moderate intensity activities require you to work somewhat hard, but you should feel like you can keep going for a long time. You should be able to talk during these activities, but not sing your favourite song. Examples include going for a hike, biking, wheeling, and household cleaning.

3. Vigorous: Vigorous intensity activities require you to work really hard, and you can only continue them for a short time before getting tired. Examples include sports, jogging, and cross-country skiing.

Everybody is different, and the meaning of physical effort and intensity varies from one person to another. The same movement may require light physical effort for one person and moderate intensity effort for another. What matters is that you choose to do physical activities that you enjoy at various intensities, no matter what the activities are. As long as you are moving your body and getting your heart pumping, there are no other rules for what it means for you to be physically active.

Basic Safety Tips

- If you have not done exercise before, talk to your general practitioner about your intentions to exercise.
- **Be your own monitor** When you are exercising alone, you are responsible for your safety and well-being. Listening to your body is imperative. Some discomfort or muscle soreness is common. However, you should not be experiencing any sharp pain or prolonged soreness.
- Before beginning exercise, please familiarize yourself with condition specific adverse signs and symptoms. For example, if your SCI is above T6, you should monitor for signs of autonomic dysreflexia. Do not exercise when unwell. If there is dizziness, shortness of breath, chest pain, nausea or vomiting, or muscle and joint pain during exercise, stop the activity and seek medical advice as soon as possible
- Pace yourself- Try and start the program slowly, and gradually increase your intensity over each workout. This will help minimize pain you might feel and help to prevent any injuries. Set small goals for each new session.

2. Week 2 – Physical Activity Benefits

There are so many benefits you can experience by doing physical activity on a regular basis. In this section, we've described some of these benefits and some tips on how to help you be active. As you are reading through these benefits, try to think about what you could add to or change about your physical activity participation. As you are learning about the benefits of physical activity, try to think about which ones are most important to you. The benefits below are applicable to both individuals with SCI in general and people walking with SCI:

Benefits to Your Daily Activities

- Better endurance for walking longer distances
- Enhanced self-care and mobility
- More energy and less fatigue
- More social interaction opportunities
- Improved ability to play with your kids
- More time spent with family when activities are done together
- Improved cognition
- Improved sleep quality

Benefits for your Health

- Reduced cholesterol and fats in your blood, which can lower your risk of several serious chronic diseases such as cardiovascular disease
- Improved ability to regulate blood glucose, decreasing your risk for Type II diabetes
- Improved mental health and lower risk of depression
- Decreased pain intensity and interference
- Decreased spasticity
- Improved strength
- Improved cardiovascular capacity

Benefits for your Wellbeing

- Boosted self-esteem, body image, and sense of self
- Increased sense of confidence and independence
- Sense of empowerment, mastery, and accomplishment
- Enjoyable, meaningful experiences
- Sense of belonging and acceptance

Overall, physical activity of any nature can be beneficial to your health and wellbeing. Regular participation in physical activity can have a direct impact on your life. Try activities where you experience quality physical activity participation so that you enjoy and maintain participation.

1. Week 2 – Additional Support

Here are some reliable resources you can use to learn more about the SCI physical activity guidelines and the benefits of exercise for adults with a SCI who walk. We also encourage you to reach out to other community members if you have questions or would like to share your experiences!

Physical Activity Guidelines for Individuals with SCI <u>https://sciguidelines.ubc.ca/</u>

Physical Activity Among Individuals with Spinal Cord Injuries Who Walk <u>https://cdpp.ca/resources-and-publications/physical-activity-among-individuals-spinal-cord-injuries-who-walk</u>



2. Week 2 – Top Takeaways

Yippee! You've finished Week 2! What was your biggest learning moment this week? Was there something actionable you started doing this week? Do you feel you now know more about the importance of exercise and potential benefits of physical activity? Did you learn something new about the physical activity guidelines for adults living with SCI who walk? Until next week, we are sending you healthy wishes and warm regards.



WEEK 3 – Goal-Setting and Self-Monitoring Physical Activity

1. Week 3 – Goal setting (Post #1a)

Welcome to Week 3 of Physical Activity for Adults Living with SCI who Walk. We'll start off by talking about goal setting to meet physical activity guidelines. Then, we'll discuss self-monitoring your physical activity.

Let's get started!



This week we are going to focus on defining physical activity goals that are personally challenging but also achievable. For a moment, think of climbing a set of stairs as a metaphor for increasing your physical activity. While making it straight to the top on your first go may seem impossible at first - taking SMART steps, one step at a time, helps the climb to be within your reach. We are going to incorporate this stepwise approach into your physical activity goal setting. Step by step, everyone will reach the top at their own pace.

Here's a brief reminder of the physical activity guidelines for individuals living with SCI:



Remember, these guidelines are recommendations for the population, and individual variability is okay. Your current goals may not be these guidelines just yet. For example, your physical activity goal could be as simple as going for a walk around the block once a week. Don't be overwhelmed. On the other hand, you might be exceeding the advanced level activity guidelines. Don't worry – there's still room to improve! Maybe you can work towards the *World Health Organization physical activity guidelines*, which recommend **150 minutes** of moderate to vigorous physical activity per week. You could also set goals to increase your strength, learn a new skill, or move more throughout the day. Let's take a step-by-step approach to make personally relevant goals.

What is a goal, and how do we set one?

A **goal** is something that we strive to do and want to accomplish. For example, a physical activity goal could be to improve your arm strength or to increase your range of motion. But these goals are quite general, and they focus on outcomes that can take considerable time to achieve. Making specific plans of action for these broader goals can be difficult. Instead, focusing on specific goals that can be achieved in the short-term is an effective way to achieve longer-term goals.

Short-term goals must be challenging and achievable. By this we mean the short-term goal should gradually push you to meet the larger long-term goal of being more physically active. And while the short-term goal should challenge you daily, it should also be a goal that is relatively achievable based on your current situation, support available, and lifestyle. Everyone's success with their goals will come at different times, and that is okay. Goals are individually driven, and everyone can make progress at his or her own pace.

Physical Activity Goals

SMART goals are a form of goal setting that helps us make these short-term goals.

SMART goals are:

Specific (well-defined and clear) –Who is involved, what do you want to accomplish, where will the goal be achieved, and when do you want to achieve the goal. Also consider the frequency (i.e., how often, e.g., 3 x per week), intensity (how hard, i.e., mild, moderate, or heavy intensity), time (how many minutes, e.g., 10 minutes), and type (what activity, e.g., yoga).

Measurable (include specific criteria to track and measure progress) - If there are no criteria, you will not be able to determine if you are on track to reach your goal.

Attainable (not impossible to achieve) - A goal can be challenging, but it should be well defined enough that it is attainable to achieve.

Realistic (within reach and relevant) - If you are able to commit to achieving the goal, and you have the available time and resources, a goal is realistic and in reach.

Time-Based (have a clearly defined timeline) - Your goal should include a starting date and a target date. If the goal is not time-constrained, you may feel less motivated to achieve it.

Here are some tips to keep in mind when setting your goals:

Write it Down: Write out your goal so you can visually see if it hits all of the SMART criteria. For example:

"I will go for a moderate to vigorous intensity bike ride for at least 20 minutes, twice per week, every week, for one month"

- Specific The type of exercise (biking) is well-defined, it's not simply, "being active"
- **Measurable** It will be easy to keep track if the goal is being met (20-minute bike ride, twice-weekly, every week).
- Attainable / Realistic What is realistic for one person may not be realistic for another. This will depend on your history, the severity of the symptoms you are experiencing, current fitness levels and more. You can work with your team to help determine what is realistic for you.
- Time-Based The goal has an achievable end date (in this example, it is one month).

For example, a not-so-great goal for a beginner cyclist could be "I am going to do a long bike ride tomorrow". The goal is not specific – it does not say where, or how long, and most is not an attainable first step. Rather a more realistic goal would be along the lines of "tomorrow morning at 9:00am, I am going to go for a moderateintensity 15-minute bike around my neighbourhood and use my phone as a timer to track myself" Adding a little detail can go a long way. Look at the table below for a better idea of how these goals break down.

	Poor Goal	Great Goal			
	l am going to do a long bike ride tomorrow.	Tomorrow morning at 9:00am, I am going to go for a moderate-intensity 15-minute bike ride around my neighbourhood and use my phone as a timer to track myself.			
S	Bike ride (lacking intensity, location, other people, time)	Bike ride - targeting moderate intensity			
М	Long (lacking distance)	Around the block			
A	No "step-by-step approach"	15 minutes is suitable for beginners			
R	Does not detail equipment	Going to use a timer to track			
т	Sometime tomorrow?	Tomorrow morning at 9:00am			

Most importantly, focus on a goal that YOU want to achieve! Physical activity means different things to different people. Try activities that provide you with a quality physical activity experience (belongingness, autonomy, challenge, engagement, meaning, and mastery).

2. Week 3 – Self-monitoring

Self-Monitoring

Knowing your current level of physical activity participation is important for setting personally relevant goals. **Self-monitoring**, by writing down your achievements and reflections, is important to determine if your strategies for change are effective. As well, writing can help boost your confidence to meet your future goals.

Self-monitoring involves keeping track of what you are doing. The process of self-monitoring – such as tracking your physical activity in a diary or on a calendar – allows you to identify barriers that are preventing you from achieving your physical activity goals and determine solutions to overcome these barriers.

You can't change your future behaviour without knowing what your current behaviour is! Think back to last week - what physical activities did you do? What did you want to do? How did these activities make you feel? We encourage you to comment on this post or write down these reflections so you can look back at them.

How to Self-Monitor

You can self-monitor in the app or on your own. Whatever you choose. You can choose to track your physical activity immediately after you completed it (i.e., daily), or you can look back every week and track your activity. In the app, go to **"Health Tools"** near the bottom of your screen. Click on the yellow button **"Add entry+"**. Then, make sure you click on the correct day at the top of your screen. In the exercise section, you can track the intensity (low to high), time (number of minutes), and *type of activity* (e.g., yoga) by adding it to the **"Notes"** section.

Check out the worksheet we provide for self-monitoring. You can use this as a guide to self-monitor your physical activity in your own calendar (e.g., Google Cal, iCal) or diary:

Day	Mon	Tues	Wed	Thurs	Fri	Sat	Sun
Activity	Walk		Yoga			Gardening	
Intensity	Moderate to vigorous		Mild to moderate			Mild to moderate	
Minutes	30 min		20 min			60 min	
Notes	5 min mod, 25 min vigorous		10 min mild, 10 min mod			20 min mild, 40 min mod	

Remember, goal setting is thinking about what you'd like to achieve, and self-monitoring is what you've already done.



3. Week 3 – Additional Supports

Self-Monitoring

Here are some reliable resources you can use to learn more about physical activity for adults with physical disabilities.

SMART Goals: <u>https://www.healthlinkbc.ca/healthy-eating-physical-activity/being-active/smart-goal-setting#:~:text=Goals%20should%20be%20SMART%20%E2%80%93%20specific,%2C%20realistic%2C%20and%20time%20frame.&text=If%20you%20set%20yourself%20a,30%20minute%20walk%20every%20day%E2%80%9D.</u>



4. Week 3 – Top Takeaways

Congrats - you've completed Week 3! What was your top takeaway from this week? Did you have any AHA moments? Did you learn something new about setting SMART goals or self-monitoring physical activity? Do you think setting a goal will help you meet some of the physical activity guidelines we talked about in Module 1 and again this week?

