Spinalis®

Food, weight and health for people with spinal cord injury

tips, questions & answers



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Introduction

The purpose of this brochure is to help you gain knowledge and awareness about the risk of developing overweight and obesity, what you can do to avoid becoming too heavy, and the general importance of diet for health and wellness.

One of the pillars of health and wellness is healthy food. This is true for everyone. The fact is that unhealthy eating habits is at the top of the list of risk factors for the most common lifestyle diseases globally: cardiovascular disease, type 2 diabetes and some forms of cancer.

This brochure is intended for those who have a spinal cord injury and answers common questions such as: What dietary guidelines apply? How should I eat to avoid extra kilos? What should I do if I want to lose weight?

Even if your background for physical impairment is not the result of a spinal cord injury, for example, you have Multiple sclerosis, Cerebral palsy, or have suffered a stroke or amputation, you can benefit greatly from the tips and advice on these pages.

We hope you get inspired!

Stockholm, June 2017 Anna-Carin Lagerström, Registered Physiotherapist MSc, Health Educator and Nutrition Counsellor

A healthier and lighter life

Research shows that it is important for persons with spinal cord injury to review their eating habits, adjust portion size and eat healthy. Even though the metabolic rate decreases due to a reduction in lean body mass and decreased physical activity, the body's need for vitamins, minerals and protein remains the same. When infections, fever and chronic wounds are present, nutritional requirements can even increase.

In short, a smaller amount of food must satisfy the body's need for nutrients and building blocks. There is little room for energy-rich "extras" like cookies, candy, soda, chips, beer, etc. When it comes to food, think *less but better!*

The most important things to keep in mind

- » Eat smaller portions
- » Vary your diet
- » Increase the proportion of vegetables
- » Avoid sugar
- » Do not skip meals

"Enjoying good food and wine is a gift and a treasure – something that those of us who have broken our necks and backs can still find joy in. We have already lost so much in this life, but there is great value in indulging with moderation. Every extra kilo that we carry increases the risk of our bodies breaking down prematurely. We are so much more vulnerable than our friends who walk around on two legs. We need to be smart early.

Read the information in this little brochure thoroughly and take all the wise advice to heart. You won't just live longer – you will also have much more fun. And above all, living will be easier."

Many gain weight

Today, nearly 30 percent of the world's population is either obese or overweight. For people with physical impairments such as spinal cord injury, the proportion is even bigger. An increase in fat around the waist is usually the first noticeable sign.

"It would have been great if I had been given proper information about the risk of gaining weight earlier. I would have eaten smaller portions and might have avoided many unnecessary extra kilos. My life would have been easier now."



Tore, age 65, living with spinal cord injury for 6 years

Overweight/obesity stresses the body, which in turn increases the risk for developing high blood pressure, type 2 diabetes, and strain injuries to the joints. Other risks include atherosclerosis, gall stones, snoring or breathing problems (sleep apnoea).

For persons with spinal cord injury, there are additional risks:

- » pressure ulcers
- » shoulder problems
- » respiratory problems abdominal obesity leads to a worsening of respiratory function, and it becomes more difficult to take deep breaths and cough up mucus
- » loss of mobility and independence
- » the wheelchair becomes too tight



"Being overweight snuck up on me slowly. Nothing was directly visible, but I felt heavier and my transfers became much more difficult. Now I've lost weight, and I feel stronger and lighter than I have in ages."

Peter, age 36, living with spinal cord injury for 13 years

Most people lose weight in the newly injured phase

Almost everyone with a spinal cord injury loses weight initially after injury. The body is fully occupied trying to repair itself, but at the same time it is has difficulties in absorbing nutrients. Muscle, bone and fat deposits break down. How large the weight loss is depends on whether the spinal cord injury is complete or incomplete, the level of injury, the person's general state of health and appetite. A weight loss of around 10 percent (5-10 kilos) is common. At this stage, it is important to increase nutritional and caloric intake to prevent the weight loss from becoming too great.

Tips for poor appetite

- Eat small meals spread out over the day.
- Boost your intake with energy-rich snacks like nuts, nutritional drinks or soups with extra cream.
- Pieces of cut fruit can increase the appetite.
- Avoid sweets, sodas and chips. These suppress hunger and your desire to eat nutritious food.

When your weight has stabilised and your appetite has returned, there is a new challenge: to not gain too much weight too quickly. Your energy intake must be adjusted. This phase usually coincides with discharge from the hospital.



Here is an example of how this might look:

What is a healthy weight?

The fact is that a healthy weight, or so called "normal weight", is lower after a spinal cord injury. This is due to a decrease in muscle mass and, to some extent, bone loss in the paralysed parts of the body, although those who can use their legs and can still walk retain more lean muscle mass and bone density.

New normal weight

- Complete paraplegia, approximately 4.5 7 kg less (or between 5-10 percent less than pre-injury normal weight)
- Complete tetraplegia, about 7 to 9 kg less (or 10-15 percent less than pre-injury normal weight)



Hidden obesity

If you have complete paraplegia or tetraplegia and weigh the same after your spinal cord injury as you did before the injury, you have more body fat. This is what we call "hidden obesity" because it is not always visible.

People with spinal cord injury carry 8-18 percent more fat than people without spinal cord injury with the same BMI. Explanation of terminology

Paraplegia: paralysis of the legs and possibly trunk but not the arms Tetraplegia: paralysis of the arms and legs

Metabolic rate decreases

Energy consumption, i.e. the metabolic rate, decreases after a spinal cord injury due to the decrease in muscle mass combined with lower levels of physical activity.

Here is a fictional person, David, to illustrate the difference in metabolic rate for one and the same person.



See the BMI table for people with spinal cord injury on page 8.

David's situation has changed. From having had a normal or high energy consumption, David is now a low energy consumer.

Body Mass Index (BMI)

BMI is a way to evaluate weight in relation to height from a health perspective. BMI is a rough measure and can be misleading as it doesn't say anything about the relationship between fatty tissue and muscle. A well-trained individual can have a high BMI without having too much body fat and vice versa.

Spinal cord injury often leads to changed body composition with a decrease in lean body mass. Adapted BMI classification tables have been developed to take into consideration the decrease in lean body mass.

Adapted BMI classifications

Columns II and III are adjusted weight classifications for persons with spinal cord injury. Persons with incomplete injuries may have greater muscle mass and hence higher weight limits than those shown in Columns II and III

Weight classifications for the general population, World Health Organization, WHOColumn I according to WHOColumn I for paraplegiaColumn I II reduced 7.5% from Column I for paraplegiaUnderweight Normal weight< 18,5< 17,1< 16,218,5 - 24,917,1 - 23,16,2 - 21,8Overweight Class I Obese $30,0 - 34,9$ $27,8 - 32,3$ $26,3 - 30,5$ Class II Obese $35,0 - 39,9$ $32,4 - 36,$ $30,6 - 34,$ Class III Obese $\geq 40,0 \geq 37,0 \geq 35,0 -$				
Underweight< 18,5< 17,1< 16,2Normal weight $18,5 - 24,9$ $17,1 - 23,$ $16,2 - 21,8$ Overweight $25,0 - 29,9$ $23,1 - 27,7$ $21,9 - 26,2$ Class I Obese $30,0 - 34,9$ $27,8 - 32,3$ $26,3 - 30,5$ Class II Obese $35,0 - 39,9$ $32,4 - 36,$ $30,6 - 34,$ Class III Obese $\geq 40,0 \geq 37,0 \geq 35,0 -$	Weight classifications for the general population, World Health Organization, WHO	Column I according to WHO	Column II reduced 7.5% from Column I for paraplegia	Column III reduced 12.5% from Column I for tetraplegia
	Underweight Normal weight Overweight Class I Obese Class II Obese Class III Obese	< 18,5 18,5 - 24,9 25,0 - 29,9 30,0 - 34,9 35,0 - 39,9 ≥ 40,0 -	< 17,1 17,1-23, 23,1-27,7 27,8-32,3 32,4-36, $\ge 37,0-$	< 16,2 16,2 - 21,8 21,9 - 26,2 26,3 - 30,5 30,6 - 34, ≥ 35,0 -

The tables above do not illustrate absolute figures.

Within the expert group NutriNord_SCI, however, there is consensus that the adjusted tables are suitable for evaluation of weight in people with spinal cord injury.

To clarify: Normal weight is for someone 174 cm tall (e.g., David):

For the general population:	56 kg-76 kg
For paraplegia:	52 kg–70 kg
For tetraplegia:	49 kg-66 kg

Personal factors should always be considered when evaluating weight. In fact, you decide whether or not you are happy with your weight.

How to calculate your BMI

Determine your weight in kilos. Then multiply your height in metres by your height in meters. Divide your weight by this number. Example: 68 kg / (1.74 m x 1.74 m) = BMI of 22.5

Tip

There are many BMI calculators on the internet. It's as simple as searching for **BMI** calculator. Otherwise, it's easy to keep track of your waist measurement (page 18).

How much do I burn?

Many factors affect your metabolic rate, i.e. how much energy (calories) you burn. Age, gender, weight, body composition, fitness level and genetics all play a role.

It is difficult to generalise about metabolic rate when individual differences, particularly in body composition (lean body mass), are so great. Bodies with a great deal of muscle mass have a greater need for energy even when the body is resting than does a body with less muscle mass.

The table below shows roughly the *differences* in metabolic rate before and after a spinal cord injury. These are estimates only.

Energy requirements/metabolic rate

Example: Here's David again, our 39-year-old male, 174 cm tall

David before his spinal cord injury Physically active, weight 68 kg, approximate daily energy expenditure 2,500 kcal calories/day			
David after his spinal cord injury:			
Functional level	Energy consumption/calories per kg of body weight (of the estimated normal weight)	Approx. normal weight as per BMI tables	Estimated daily turnover
Can use his legs	30 kcal/kg body weight	68 kg – Table I	2,040 kcal/day
Paraplegia	28 kcal/kg body weight	62 kg – Table II	1,736 kcal/day
Tetraplegia	23 kcal/kg body weight	58 kg – Table III	1,334 kcal/day
These figures are for persons who are otherwise healthy. Note: Rody weight for persons with paraplegia			

These figures are for persons who are otherwise healthy. Note: Body weight for persons with paraplegia and tetraplegia should be based on estimated "normal weight/ideal weight" (see BMI table page 8), according to Frost 1998 and Lynn Powell, Frost 2010.

Whether David weighs 80 kilos, 90 kilos or more, the metabolic rate should, in principle, be calculated according to columns II and III in the BMI table (page 8) for normal weight for paraplegia and tetraplegia.

Tip

Show this guide to your nutritionist when you discuss your diet. Then there is no risk of you getting energy requirement advice that applies to those who can walk, and who do not live with paralysis.





Physical activity and metabolic rate

Physical activity makes us stronger and more mobile, and increases our stamina and well-being. There is less strain on our joints and heart, we have better control of blood sugar, blood lipids and blood pressure, and we sleep better.

From a health perspective, it is *important to reduce the time we spend completely sedentary* as any form of physical activity increases metabolism and improves our health. Research has shown that even everyday activities such as rolling indoors at a walk rate, transfers or managing personal hygiene, all increase our metabolism compared with driving an electric wheelchair or sitting still. Household chores like making the bed, setting the table or vacuuming, increase metabolism nearly as much as shorter workouts at the gym.

Previously, there was an over-reliance on the need to increase physical activity and exercise to lose weight. This is true and false. Increased physical activity will help with weight loss but is not necessary.

For someone with paralysis of the body's largest muscles – the muscles of the thighs and buttocks – it is quite difficult to reduce body fat through increased physical activity only. The most effective way to lose weight – and this applies to all people – is to reduce energy intake. In other words, eat less.

A comparison

A person walking briskly for 30 minutes increases the amount of energy they burn by approximately 150 kcal. A wheelchair user needs 50 – 60 minutes of self-propelling outdoors to burn the same amount.

150 kcal is equivalent to the energy in 25 grams of 70% chocolate, 50 grams of chips, 1½ glasses of red wine, or two pieces of crisp bread with a sandwich topping.

Physical activity and exercise

- makes it easier to maintain your weight
- gives some "space" to eat a bit more without weight gain
- gives better appetite control
- builds strength and independence
- affects sense of well-being and motivation, which leads to better compliance with dietary recommendations and lower energy intake – which leads to weight loss

How can I lose weight?

You need to eat fewer calories than you burn to lose fat. But most people do not like counting calories. Nor is it necessary. By weighing yourself or measuring your waist, you will know if your efforts to lose weight are working.

Here are some tips from women and men with spinal cord injuries who succeeded with their weight loss goals, most of them losing 6-12 kilos, without counting calories

Our best tips

1. Smaller amounts of food

"Take a single portion, with everything laid up on your plate." "Use a smaller plate." "Eat slowly and chew your food thoroughly. Then you'll eat less." "I've cut back on all fast carbohydrates: pasta, rice, potatoes and white bread. I eat more vegetables instead." "At restaurants, I ask for a doggy-bag to take home with me. No one finds that strange anymore." "I stop eating when I feel moderately satisfied. I used to overeat because I ate too fast." "I try to focus on the food when I eat - no more eating in front of the TV."

2. Don't snack

"Three meals a day and no snacking between meals when I'm not hungry." "No more night sandwiches. I go to bed earlier instead." "A small bowl with chips for me on Friday evening. The family shares the rest of the big bag."

3. Foods that make you feel full and help control sugar cravings

"I have completely cut out sugar, cakes, white bread, sweets, juices, soft drinks, and most fast food from my diet. They give a lot of energy but you don't feel full. You just get hungry again and wind up eating even more later." "I try to stick to real food that satisfies: meat, fish, eggs, vegetables and high-fibre bread." "I used to eat a lot of fruit because I thought it was healthy. I've cut back to 1 or 2 servings of fruit per day and I've lost weight." "I eat two eggs for breakfast. Eggs are filling and low in calories."



Tip

Explain to those who offer you sweets that people with spinal cord injuries have a much slower metabolism and can't eat as much without gaining weight. Then you don't have to feel guilty for saying No thanks or for insisting on a smaller portion.

4. Stay motivated

"I keep a food diary for a few days now and then so I can see what I'm eating." "Training is important to me. It strengthens my sense of identity, and keeps my entire lifestyle on track." "I weigh myself at least once a month to see if I'm maintaining my weight or if it's creeping up." "I meet two other women with spinal cord injuries regularly. We support each other. We have fun, without the coffee and cake." "I use positive visualisation as a treat: I imagine a feeling of well-being, that I am light, and that I manage transfers on my own."

5. Plan for the long-term and avoid yo-yo dieting

"For me, losing weight wasn't just about eating less. I needed more extensive lifestyle and attitudinal changes." "I try to stay active by doing different things. I crave sugar when I'm sitting bored in the comfort of my living room." "Losing weight requires organisation, planning, and being prepared. For instance, I always have good food at home." "We prepare proper food on the days I have assistants who are good cooks, and then we freeze it in single portions."

Comment: To lower the risk of losing muscle mass, a slow weight loss (approximately 1 kg per month) is recommended for persons with spinal cord injuries.

"I sin once a week. I treat myself to something I'm really craving. It's my way of coping with eating small amounts of healthy food all the other days."

Eva, age 42, living with spinal cord injury for 8 years

Plate Method for Persons with Low Energy Expenditure

The Plate Method for Persons with Low Energy Expenditure is an easy way to remember how much persons with spinal cord injuries or other physical impairments can eat from the different food groups to maintain or lose weight.

First, choose a smaller plate. Then, imagine your plate consists of three parts: one large, which takes up half the plate and two smaller, almost equal parts.



- **1. The protein part** meat, fish, poultry, eggs or low-fat dairy products like cottage cheese. The amount should be slightly greater than the size of your palm.
- **2.The vegetable part should fill half the plate**. Fill it with warm and cold vegetables, preferably those that grow above ground, such as tomatoes, spinach, broccoli, peas and lettuce. These give you the greatest volume without unnecessary calories.
- **3. The carbohydrate part** pasta, rice, grains, potatoes or bread is the smallest part. Fibre-rich options are more filling, stabilise blood sugar levels, and decrease sugar cravings.

Fat, which is the third important nutrient along with protein and carbohydrates, usually occurs naturally in the various parts or can be added anywhere.

Note: A high carbohydrate diet increases levels of the fat-building hormone insulin which is not good from a weight loss perspective. It is particularly important to reduce "fast carbohydrates", i.e. sugar and white flour. Protein-rich foods and fat (in limited quantities) gives a greater feeling of fullness. This is positive for weight loss.

"I stick to the Plate Method. Then I don't have to think that much, and I know I'm still getting it right."

Monica, 35 years old, with congenital spinal cord injury

How much you can eat is individual. The picture should give you a rough idea about proportion and portion size. If you are not wrestling with excess weight, you can increase the protein and carbohydrate parts.

Keep track of calories.

If you still want to keep track of calories, there are many ways to do so. The British National Health Service provides an online calorie checker (http://www.nhs.uk/ Livewell/weight-loss-guide), you can download apps to your phone, or simply read the labels.

> "I counted calories and tried to stay between 900-1300 calories per day."

Lennart, 60 years old and living with spinal cord injury for 44 years, lost 39 kilos and reached his target weight after three years.

If you have normal meals three times a day and maybe a small snack, you do not need extra fuel after exercise. This is just a stubborn, counter-productive myth if you are trying to lose weight. If you are training on an elite level, other recommendations will apply.



Tip

It is not primarily fat that makes you fat if you do not exceed your "budget". Sugar and processed carbohydrates are the culprits!

Healthy food choices

How healthy is your diet? Take the test and then calculate your score.					
How often do you eat vegetables and/or root vegetables (fresh, frozen or cooked)?					
Twice per day or more often	Daily	A few times per week	Once per week or less often		
□ 3 points	2 points	1 point	🗆 0 points 🛛 🙅		
How often do you eat frui	How often do you eat fruit and/or berries (fresh, frozen or cooked)?				
Twice per day or more often	Daily	A few times per week	Once per week or less often		
□ 3 points	□ 2 points	1 point	🗆 0 points		
How often do you eat fish or seafood as a main course, in salads or on a sandwich?					
Three times per week or more often	Twice per week	Once per week	A few times per month or less often		
□ 3 points	□ 2 points	1 point	🗆 0 points		
How often do you consume sweets, chips/crisps or sweet drinks like soda/juice?					
Twice per day or more often	Daily	A few times per week	A few times per month or less		
D o points	🗆 1 point	2 points	3 points		

Source: Dietary index prepared by the Swedish National Board of Health and Welfare as per Nordic dietary recommendations.

9-12 points – Congratulations! You have healthy eating habits and for the most part follow dietary recommendations (approximately 10% of the population).

5-8 points – Most people land here (approximately 70% of the population). Lots of opportunity for improvement!

0-4 points – Very unhealthy eating habits (approximately 20% of the population).

Bonus question: How often do you eat breakfast?			
🗆 Daily	□ Almost every day	□ A few times per week	□ Once per week or less

Eat regularly, three times a day: breakfast, lunch and dinner and perhaps a little snack between meals. When your blood sugar and mood are in balance, it's easier to eat smaller portions.

Dietary advice

- Eat a varied diet that includes carbohydrates, proteins, and fats and all the vitamins and minerals that these sources of nutrition offer.
- Eat plenty of vegetables and 1 or 2 servings of fruit per day. The vitamin C in fruits and vegetables increases iron absorption.
- Choose fibre-rich whole grain breads, cereal, pasta, brown rice and whole wheat bulgur.
- Legumes, such as beans, lentils and peas, are all nutritious, particularly for those who do not eat meat, fish or eggs and need to get their protein elsewhere.
- Drink water with meals and when thirsty.
- Eat fish at least twice a week, preferably fatty fish such as salmon, mackerel and herring which contain high quality protein and essential Omega 3 fatty acids. Those who do not eat fish can find Omega 3 fatty acids in canola oil, flaxseed oil and walnuts.

Dietary supplements

If you are not a big eater - less than about 1500 kcal/day - or find it difficult to eat a varied diet, you may need supplements.

- In northern latitudes, it is difficult to get enough vitamin D during winter. We get most of our vitamin D from the sun but also from food, mainly fish. Vitamin D is synthesized when our skin is exposed to sun and is important for bone health, amongst other things. The need for supplementation is individual but for persons with spinal cord injury, extra supplements are often recommended. For the population as a whole: if you do not spend much time outdoors, have dark skin and/or are completely vegetarian, you are at increased risk of vitamin D deficiency, especially in winter.
- Multi-vitamin tablets containing iron, vitamin C and zinc are especially recommended for healing wounds.
- Those who do not eat meat may need a B-12 supplement.

To be on the safe side and avoid taking unnecessary supplements, ask your doctor or nutritionist before starting supplements. A blood test will tell if you have any deficiencies.

Weigh, measure and take control

Monitor your long-term weight trend. Weigh yourself regularly, preferably every month, and during the first year after your spinal cord injury, perhaps even more often. Write down how much you weigh. You'll see what the trend is and can do something about it. Also write down how much your wheelchair weighs and deduct this from the total if you weigh yourself on a wheelchair scale.

How much do you weigh?	
Kilos Date	Don't know □
Are you happy with your v	veight?
Yes 🗆 No 🗆 Don't know 🗆]
If no, what is a realistic we	eight goal? Kilos

Another simple way to take control of your weight is to measure your waist. Abdominal fat is unhealthy fat. If possible, measure your waist while standing; otherwise measure while lying down. Measure in the middle, approximately at the level of your navel. If your stomach is large, measure the thickest part. Most important, measure the same way each time so you can compare and monitor progress.

- Women: A waist measurement over 88 cm is defined as abdominal obesity. 80 cm or less is ideal.
- **Men**: A waist measurement over 102 cm is defined as abdominal obesity. 94 cm or less is ideal.

Maintaining your weight and being happy

If your weight is stable, you're in energy balance. This is positive even if you weigh too much. The big challenge for low energy consumers is to not continuously gain weight. If you are keeping your weight stable, you can feel proud and happy. In addition to taking control, you have reduced your risk of developing diabetes.

Weight gain and medications

Medications that can cause weight gain include some antidepressants and some pain relief preparations. Others are insulin and cortisone. Ask your doctor if there are alternatives without this side effect. If you are taking Baclofen for spasticity, your metabolic rate will drop slightly. Reduce your energy intake to prevent weight gain.

One step at a time

To achieve long-term lifestyle changes, you need to be realistic. It requires planning, time, clear goals and often a change in attitude.

Is your goal to start eating breakfast? Or to go to bed earlier to avoid bedtime snacks? Do you want to eat healthier foods and more vegetables, cut out soda, or reduce your alcohol intake?

Start with one change at a time, and give each change some time. Make your plan and stick to it for a few weeks. Your body needs time to adapt to new food with higher nutritional and fibre content. After a while, you can add a new change.

You reap the benefits in the form of increased well-being. You'll feel more alert, experience fewer cravings for sweets and sleep better. Additionally, your body is better able to fight infections. Most also experience better bowel function, and less constipation, bloating and diarrhoea.

"I gained almost 20 kilos in four years. Now, I have completely cut candy, chips and soft drinks from my diet. I drink water with meals, I've stopped having a sandwich at bedtime, and I'm starting to lose weight and feel better. And no more constipation. I'm super regular."

Liam, age 35, living with spinal cord injury for 4 years

Note

If you are underweight or border-line, you need to do something about it. Is it due to poor appetite, medication, difficulty shopping or cooking, or something else?

This booklet was developed in cooperation with the members of NutriNord_SCI™. – a Nordic initiative on patient education on nutrition for people with Spinal Cord Injury

NutriNord_SCI[™] is a Special Interest Group within NoSCoS – the Nordic Spinal Cord Society. NoSCoS is an association of professionals in the Nordic countries with special interest in rehabilitation after injuries and diseases of the spinal cord (www.nutrinord@noscos.org).

The aim of NutriNord is to strengthen the knowledge, teaching, support and guidance on nutrition and nutritional related complications after a spinal cord injury.

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Spinalis Foundation has also produced a book about health and lifestyle entitled, *The art of healthy living with physical impairments* (2014), available in a number of formats:



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