

# ***HEALTH MECHANICS: B&B EDITION***



***Tools for the Self-Management of  
Neurogenic Bowel and Bladder for  
Individuals with Spinal Cord Injury***

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## **About Health Mechanics**

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***Health Mechanics:  
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## **Introduction to the Program**

***Health Mechanics* is a program designed to teach individuals with Spinal Cord Injury (SCI) the skills that will help them to keep their bodies healthy and to manage their life given their physical impairments.** Just like you need to maintain a car if you want to keep it running, so too, must you learn to manage both your health and your environment to maintain or create a good quality of life.

This program is designed to teach you the skills and principles of self-management so that you can develop a toolbox that can be used to handle any situation. While the program will help you to manage health and medical information and apply it to your specific situation, it should not be taken as medical advice. We advise that you work in partnership with your physician and other health care providers and consult with them about the changes you are considering making in your life.

### **What is self-management?**

Self-management refers to the ability of an individual with a chronic condition to manage their health and its physical, psychological and social consequences [1]. A key component of this process is the ability to make decisions and lifestyle choices that will optimize functioning and allow for greater participation in family, social, community and vocational roles and environments[2].

This program is based on the assumption that **you** – as the person with the impairment or disability - are the primary person managing your medical condition while still trying to create and enjoy a full life. You are the one who must schedule and go to doctors' appointments, perform pressure relief for your skin and take care of your bowel and bladder. You have to figure out how to negotiate your way through the physical world, and do all the self-care tasks involved in everyday life with SCI. You must also learn to partner with your physician, caregivers and other health care professionals so that you can prevent secondary complications and deal with those that do occur. More importantly, though, you are the one who has to integrate these things into your life so that they do not take all your time and energy. An individual with SCI can and should expect to be able to form relationships, be part of their community and engage in activities that are fulfilling and meaningful. However, for this to really work, first you need the skills to manage your health and its consequences.

This program will help you learn basic skills or tools to find and use information, communicate and work effectively with others. In learning these skills, you will develop confidence in your ability to take an active role in managing your health and your life.

### **What does it involve?**

The basic skills or tools that are taught in this program are attitude, self-monitoring, problem-solving, communication, organization, and stress management. These skills will allow you to effectively apply the knowledge you have gained from your health care providers, from books (such as the *Yes You Can!* Guide), and from other people living with a disability.

### **Why is this important?**

When living with SCI, your health impacts what you can do and how much energy you have to do it. While there is currently no cure for SCI, there are ways to manage your condition and optimize your functioning. One key is to prevent secondary conditions, such as pressure sores, respiratory infections, bowel problems, pain and others that can make you less independent, cost you more in medical bills and cause you to have more hospital stays. In other words, they can prevent you from getting on with your life.

The good news is that many secondary conditions can be prevented or lessened by managing them using health maintenance steps (like performing pressure reliefs to prevent skin problems) and other strategies. While physicians and other health care professionals can provide information, medication and treatments, ultimately your health is based on your ability to perform behaviors consistently. You are the one who must learn to manage your impairment and your environment. To do so you **MUST** be an active participant in your health to an extent far beyond people with other chronic conditions.

There is plenty of information out there to tell you what you need to do but knowing is not enough. You have to figure out how this information applies to you, think about how to begin to work it into your life, and feel comfortable doing it. This program will help you start. Congratulations on taking this step toward developing skills that will last a lifetime!

## **How to use this Manual**

**This program is written to be used either independently by individuals with SCI or with the assistance of a health coach or facilitator.** This particular version of the program is designed to focus on management of neurogenic bowels and bladder. The guide starts with a brief overview of the recommendations and guidelines for bowel and bladder management after SCI and, from there, discusses each skill in depth. However, the skills that you learn now can be applied to managing many different aspects of life with SCI – from weight management to improving community participation.

At the beginning of each module or skill, a series of screening questions are provided. These questions allow you to consider the degree that you already know and apply that particular skill. If you can answer these questions quickly and easily, it may be that you can spend less time reviewing that skill or module. On the other hand, if it is more difficult to answer the questions, or if it is hard to see how those questions relate to managing your SCI, then it might benefit you to spend more time going through the module and associated homework exercises.

## **Levels of Self-Management Competency**

Even after you have had the opportunity to read and go through this program, you will not automatically acquire these skills. Developing and applying self-management skills takes practice and can be helped by discussion with and feedback from others. Just as car owners vary in the ability to maintain their car (from novice to master mechanic), so individuals with SCI vary in their ability to manage their condition and its physical, psychological and social consequences.

Many things influence level of self-management skills and competency. Age, education and cognitive capacity all have a role. Experience in using the skills also contributes to the current level. Finally, degree of adjustment and mental health status influence both ability and motivation to take on the responsibility of actively managing your health.



## SCI Specific Guidelines with a Focus on Bowel and Bladder Management



Below are specific guidelines for managing your health that have been recommended by health care providers and professional associations.[3-17] You may notice that there are a lot of recommendations; however we have tried to highlight those most associated with managing neurogenic bowel and bladder. SCI can impact almost every body system, so it may be that you will need to monitor the ways that these systems now work and look for any problems.

When people think about SCI, they can become overwhelmed with the number and different types of actions that should be performed and recommendations that should be adhered to. It will be important to work with your health care providers to figure out what recommendations and systems are most important to focus on right now.

### Three key factors are critical here:

- **Do you know what it is suggested that individuals with SCI (as a group) do to manage their health?**
- **How important is each recommendation to your health, considering your personal risk factors, values, and history?**
- **Are you having any problems or concerns in these areas?**

### Bowel Management

- Goals: Prevent bowel accidents; Produce bowel movements at regular and predictable times; Minimize bowel-related complications
- Self-Monitoring: Exercise; Effectiveness of Medications; Level and impact of emotional stress; Diet and fluid intake; Productivity and time requirements of bowel program
- Behaviors for Bowel Care: the scheduled process of starting and assisting your body to have a bowel movement
  - Regular Timing (Establish a regular time that will fit into your daily schedule; Allow 1-3 hours; Perform 3- to 45 minutes after a meal or hot drink; Perform bladder management first)
  - Positioning (Commode/toilet; Bed; Have supplies within reach)
  - Stimulate peristalsis (Rectal suppository; Mini-enema; Digital stimulation)
  - Other: Diet (Eat a well-balanced diet with high-fiber foods); Exercise; Fluid – drink as much liquid as your bladder management will allow; Medication; Scheduled bowel care; Use abdominal binder

## **Bladder Management**

- **Goals:** Have acceptable bladder volumes; Have low bladder pressure; Avoid infections; Keep your skin dry
- **Self-Monitoring:** Fluid intake (Maintain constant fluid intake to avoid infections); Cath / void volume (In general keep between 300-500 ml/cath); Signs of infection (smell and color of urine)
- **Behaviors:**
  - Routinely empty bladder (Use established catheterization technique; Maintain supplies/equipment)
  - Voiding (At least 4 times a day; Use sterile or clean catheterization techniques; Adjust frequency and interval of catheterizations as needed for fluid intake, diuretics (caffeinated or diet drinks, alcohol intake); Adjust fluid intake as needed; Minimum urine output should be 1500 cc/day (1.5 liters or about 1.5 quarts))
  - Take medications as directed
  - Wear appropriate gear/appliances to keep skin dry
  - Change clothes as soon as they are wet

## **Other SCI-Specific Recommendations**

### **Skin Care**

- **Goals:** Prevent Breakdown; Keep skin clean and dry
- **Self-Monitoring:** Skin inspection twice a day to look for red spots or pressure sores beginning to form; Be aware of how close your body parts are to possible hazards; Watch with transfers; Monitor spasms
- **Behaviors:** Positioning in bed (Change position according to skin tolerance; Initially, every 2 hours is recommended); Positioning in wheelchair (Pressure releases every 15 minutes; Check posture); Use of Well-maintained cushion; If wet, change clothes and dry skin
- **Other:** Eat balanced diet, with special attention to protein, vitamins and minerals; Weight control; Basic hygiene

## **Circulation**

- Goals: Control swelling; Prevent infection; Maximize sitting tolerance
- Self-monitoring: Blood pressure; For edema (swelling); For blood clots; Decreased heart rate
- Behaviors: Wear stockings (and possibly abdominal binder) routinely; Perform range of motion exercises daily; Move your legs from one position to another every 2-3 hours; Take medications – anticoagulants
- Other recommendations: Don't smoke; Sufficient fluid intake; Avoid excessive salt intake; Avoid weight gain

## **Respiratory**

- Goals: Avoid colds and infections; Optimize breathing and oxygenation of blood
- Self-Monitoring: Breathing; Cold and infections; Sleep apnea; Blood oxygenation using pulse-ox monitor
- Behaviors: Do breathing exercises (for those with cervical or high thoracic injuries); Quad cough/Chest percussion; If sleep apnea, stop all use of alcohol or sleep medications, lose weight, sleep on side, and use mask/c-pap
- General: Stop smoking; Stay away from known pollutants; Yearly flu shot; Pneumovax

## **Range of Motion**

- Goals: Maintain full range of motion in all joints; Prevent contractures; Improved spasticity management
- Self-monitoring: Tightness of ligaments, tendons, muscles and joint capsules surrounding joints; Posture; Signs of contractures
- Behaviors: Daily stretches: Stretch muscles counter to shortening caused by positioning, either through self-stretching or Assisted Range of Motion

## **General Health**

### **Nutrition**

- Goals: Eat a variety of foods; Maintain ideal body weight; Avoid too much fat, saturated fat and cholesterol; Eat foods with adequate starch and fiber; Avoid too many sweets; Avoid too much sodium; Only drink alcoholic beverages in moderation
- Self-Monitoring: Weight; Caloric intake; Portion size; Types of food; Association between eating and stress
- Behaviors: Eat breakfast; Limit portion sizes; Plan meals
- Other Recommendations / Considerations: Increase fiber to promote better bowel functioning; Increase protein to optimize healing

## Exercise

- Goals: Incorporate exercise as part of your daily routine; Optimize health, physical functioning and independence
- Self-Monitoring: When do you exercise; How do you feel when exercise; What keeps you from exercising;
- Behaviors: Muscular Strength and endurance training; Cardio respiratory or aerobic conditioning; Stretching; Balance

## Pain

- Goals: To reduce or prevent pain; To limit or eliminate pain's interference in daily activities
- Self-monitoring: When do you experience pain; What do you tell yourself when you experience pain; Actions/behaviors you perform when you experience pain; Things you avoid doing in order to avoid pain; Amount of medications that you take and their impact; Type(s) of Pain; Duration of pain
- Behaviors:
  - Develop action plan depending on type or level of pain
  - **Acute or sudden onset severe pain may indicate a medical emergency\*\***
  - Mild to moderate pain lasting days to weeks is often muscle, bone or tendon pain and will usually resolve on its own
  - Muscle, bone or tendon pain often results from injury associated with overuse, overstretching or falls and often feels aching, grinding or gnawing; it is worse with activity but relieved by rest
  - Nerve Pain is caused by pressure, irritation or stretching of a nerve and results in aching, heaviness, tingling or numbness
  - Spinal Cord Pain/Central Pain/Neuropathic pain originates in the spinal cord or brain and may be felt at the level of the SCI as a band around the body – one that is hypersensitive to touch or may tingle or burn
  - Internal Organ Pain (Visceral pain) from internal organs (i.e., stomach, intestines or bladder) results from being overstretched and may occur if organs lose their blood flow
  - Headache pain of autonomic dysreflexia occurs in individuals with T6 SCI and above and occurs when blood pressure rises rapidly in response to bladder over distension or other pain stimulus below the level of SCI
  - Get assessments as needed (x-rays, imaging studies or blood tests); Initiate pain management procedures (medication, heat/ice, massage, etc.)



## **Medication**

- Goals: Know what medications you take and why; Take medication as directed
- Self-monitoring: Problems with adherence; Side effects
- Behaviors: Organize medications; Develop regular habits

## **Managing emotional/mental health (Psychosocial Adjustment)**

- Goals: Prevent depression; Optimize problem solving, social skills and communication; Maximize wellness
- Self-monitoring: Emotions, mood; Cognitions (memory, ability to pay attention)
- Behaviors: Develop coping skills; Develop problem solving skills; Engage in activities that allow you to feel good about yourself (give you a sense of purpose and accomplishment)

## **Preventative health care**

- Goal: Maintain health and wellness
- Self-Monitor: Symptoms, upcoming visits
- Behaviors: Regular check-ups; Flu and pneumonia shots; Health screenings (prostate cancer; Mammography; pap smears; colorectal cancer; heart disease: blood pressure, blood sugar, cholesterol, EKG)

## **Community-Reintegration**

### **Managing the Environment**

- Goal: To create an environment that optimizes independence and health; To feel comfortable going out into the community
- Self-monitoring: Perceived barriers for independence; Level of activity; Home accessibility
- Behaviors: Organize home environment to optimize accessibility; Learn attendant management skills; Learn communication and self-advocacy skills

### **Negotiating the Physical Environment**

- Goal: To feel comfortable going out into the community
- Self-Monitoring: Perceived barriers
- Behaviors: Reach out to other individuals with disabilities to learn from them; Self-advocacy skills

### **Negotiating the Health Care Environment**

- Goal: Become empowered to manage your health; know your resources for when you need them; Communicate effectively with health care providers
- Self-Monitor: Comprehension; Feelings of being listened to/understood; Ability to comply with recommended health behaviors
- Behaviors: Write down goals for appointments; Go in with lists of questions; Follow-up to clarify instructions;
  - Keep a list of your doctor's and their contact numbers
  - Keep a list of your medications
  - Make follow-up appointments well in advance to ensure timely visits
  - Prudent use of the internet for health related information: Know the sites you are going to for information → Ask your health providers for advice



# Module 1: Attitude and Expectations

## Screening Questions

- How would you describe your attitude or approach to life and challenges?
- What motivates you to get up each day and get things done?
- What role do you think attitude has in managing your health and life?

## Attitude

Attitude (how you look at things) is a factor that most people feel is important, but few talk about. Success or failure in living with spinal cord injury [18] begins with your **attitude**. A positive attitude is a necessary part of starting to take charge of your health and life.

So what do I mean by **attitude**? I don't mean mouthing off, being stuck-up or acting like a jerk. This is not **attitude** in the way someone might say "man, that person needs to get over their **attitude**!" The attitude I am talking about it is not a problem. Instead it is part of the answer.

So when I say **attitude**, I am talking about your approach to life, your situation and the future. The right attitude – in living with SCI or any condition – is **proactive**. **Proactive** means that it is up to you to make things happen. Also, you accept that no matter what led you to have SCI, you need to take control of your health to stay well. And staying well lets you do what you enjoy the most. Healing a pressure sore can require days or weeks on bed rest. That can keep you from going out, seeing friends, working or just spending time the way you want.

## Different Attitudes

Of course, you may have a different opinion or a different type of attitude. Maybe you feel it's your right to be unhappy, crabby, rude or bossy. Or you might just be drifting along and believe that you are a helpless victim. You might think that your actions (or lack of them) have no impact at all on your life.

Well that is both true and false. First, you are not the center of the universe. Many things happen in life that you cannot control. In fact, your injury may have been one of those things. You may have gotten an SCI just because of bad luck or chance. Things happen that you can't always plan for or prevent.

When it comes to managing your health though, there is **plenty** that you can plan for and prevent. And really—if you can't plan for it, who can? If you don't tell others what you need,

how can they know that you need help? Only when you let them know what is happening with you can they offer their know-how or assistance.

Think about this: would you expect a plumber to call the house once a week just to make sure that you haven't sprung any leaks? Do you expect your insurance company to call you and ask if you need to file a claim? In general, people expect you to start communicating with them, tell them about a problem you have or begin to come up with solutions.

At a yearly check-up, a doctor or nurse may ask about issues that have not come up yet. They may review body systems (skin, heart, etc.) asking if you have noted any changes or problems. Still, you have to be responsible for answering their questions and bringing up your concerns.

You need to be the one most interested and invested in your own health. If the therapist or nurse is more concerned about your health than you are, that is a problem! They are not going with you to whisper in your ear to take medicine, exercise or eat well. They may tell you these things at the visit. But, after you leave they are not going to stand over you with a whip to make you do them.



## Attitudes about health

The right attitude toward health is one that is proactive and takes responsibility for making changes. Of course, I have the point of view of a researcher and health care provider. As I see it, the “**right attitude**” is the one that has been shown, over and over again, in personal stories and research, to be linked to better health. That means fewer health problems (like pressure sores or infections); less pain and fewer unplanned hospital or ER visits. And this is about **more than health**. Having this attitude can mean less depression, a better chance of having a job, more relationships and maybe even greater happiness.

Because this factor is so important, it is worthwhile to look a little deeper into its components.

Attitude has five basic parts:

- Expectations: how you think or believe that people should act
- Assumptions: beliefs that you accept as facts without proof
- Outlook: the way you look at things or view the world
- Responsibility: what you are going to be in charge of
- Actions: what you do

## Expectations

**Expectations** are **beliefs that people should behave a certain way**. You may expect that all mothers should be caring, all judges should be fair or that all umpires have good eyesight. These expectations are shaped by what you have learned about people or roles, sometimes through experience, or watching others. In turn, your expectations change how you behave. Different people or cultures have different expectations for people.

*Here’s an example of two different expectations for teachers.*

One group of people believes that most teachers are hard working professionals who are kind, caring and want the best for their students. Parents who believe this are likely to trust a teacher’s judgment about their child’s behavior or ability in school. These parents will often follow a teacher’s advice. But, if they find out a teacher did not live up to their expectations, they might feel angry, hurt and betrayed.

Other parents don’t think teachers are experts. Instead they think teachers are just people who give lectures and homework. They don’t believe a teacher really knows what is best for their child. These parents may feel that the teacher isn’t as smart or capable as they themselves are.

So, this parent is more likely to challenge the teacher’s opinions and advice. They may not get angry when a teacher doesn’t seem intelligent or lacks skill in managing children. However, this parent may be offended if the teacher speaks to them in a way that they feel is improper for a public servant.

This describes a single role—that of teacher. But it also describes two types of parents who have very different views which could result in very different approaches and behavior toward a teacher.

The same thing happens in relationships. If you expect people to ignore you, you are unlikely to get mad when they do. However, if they put you in the spotlight, you may become anxious or worried. In contrast, there are folks who expect to be the center of attention and enjoy the spotlight. It is when they are ignored that they may become upset or angry.

Take a minute and think about the expectations you may have for various people in your life:

- Your mother
- Your social worker
- Your physician
- Your friends
- Your brother or sister
- Your significant other

*Have your expectations for these people changed since you had your spinal cord injury?*

### **Assumptions**

**Assumptions** are beliefs that you accept as facts without proof. You may assume that everyone knows the earth is round and that people will look both ways before crossing the street. Or, you assume that when you talk to someone, they will both listen to what you say and remember it. Of course, you can't actually **know** these things. How do you know if others view the world as you do or think the same way? Assumptions can get you in a lot of trouble.

*What assumptions do you think people make about you?*

Before you can change your behavior and develop healthy attitudes and lifestyle though, you need to figure out what assumptions may be holding you back. These may not only keep you from fully taking charge of your health, but from enjoying your life. You have to know what these assumptions are before you can challenge them.

## Outlook

Your outlook is the way you look at things or view the world. It is your overall approach to life.

### *Which of the following do you agree with?*

- People are generally nice and helpful.
- People are all selfish and just out for themselves.
- Everything that can go wrong, will (and at the worst possible time)
- As long as I am prepared, things will work out in the end.
- There is nothing I can do to change things, so why try?
- If I don't do something, no one will.
- It's all about control and power.



What you see or notice depends on your outlook. If you have on “rose colored glasses”, then you may see everything as bright and happy. If you live with depression, then everything may seem negative, against us, or pointless.

People who are successful in living with SCI seem to agree that you need to have a positive outlook. This doesn't mean that everything will necessarily turn out okay, but that there is still a point to it all and life is worth living. If you don't have this outlook, you should consider finding out how to develop it.

If you have problems being able to develop a positive outlook, here are some things you might try:

- Seek treatment from a counselor or

## **Responsibility**

The idea of responsibility is critical when you live with SCI.

*Who do you feel is ultimately in charge of taking care of your condition and your life?*

Is it your doctor? Your partner? Your mother? Your care-giver? Yourself? Or some combination of these?

If you are going to be in charge, you have to take responsibility for your health. This means learning about and understanding your care. And, you need to decide which health concerns are most important and decide the order in which to address them. This step is called **prioritizing**. You have a key role in the process. You do not have to know everything, but you have to be willing to look for information and resources and to work with those who can assist you.

Other people can be a source of information, support or help in some way with your health. They may write prescriptions for medication or therapy, provide advice about your diet, or help you get ready in the morning. But, even if you rely on them, you don't have to hand over responsibility for your well-being.

Remember – no one should have more invested in your health than you. If you do not put in the effort to be healthy, can you ask anyone else to do it for you?

## **Actions**

Actions are what you do. Every action that you take or don't take is a decision that will affect the course ahead. You have to decide in which direction you want to go and figure out how to get there.

*What type of actions are you willing to do to reach your goals?*

- Are you willing to be a partner with your health care provider?
- Are you willing to compromise on what you think you should do?
- Are you willing to get a job to make money?
- Are you willing to educate those who are ignorant about disability?

Sometimes it helps to think about what you are or are not willing to do ahead of time. You can do this by considering your abilities, beliefs and values, and priorities.



### **Attitude and interacting with health care providers**

When dealing with health care providers, think about how you want to appear. You want to be confident but not aggressive. You need to make sure that you understand what the provider says and how it applies to your particular situation, but you don't want to attack them.

Presumably, you are seeing the provider because of their expertise. They know or can provide you with information, referrals or prescriptions that are supposed to help you manage your health. You should approach the relationship with a sense of **guarded respect**. They have worked hard to gather specialized knowledge and expertise that most other people don't have. They are also a critical entry point to other services within the health care system.

Please realize that **you do not have to work with this person**. If you don't want to make an appointment or refuse their suggestions, that is your right; however, deciding not to do something will likely have consequences. **It is also important to recognize that the provider does not have to work with you**. They can refer your care to someone else if they believe you are a "problem personality".

*Consider the expectations that health care providers may have for you, as a patient.*

*Do you have the same ones?*

- I will arrive on time to appointments
- If I am late, people will understand because it is so hard for me to get around
- I will call if I am unable to attend an appointment or if I am going to be late
- I will express my concerns about barriers
- I will ask questions
- I will contact providers when there are problems/concerns/changes
- I will be involved in my own care
- I will be honest with my health care provider and speak up if I cannot follow their recommendations or disagree with them
- I need to be invested in the process
- It is up to me to know everything about my care and my condition
- I will follow the rules
- I will prioritize therapy
- I will prioritize my health
- I am the one who is ultimately responsible for my health
- I will be open and communicate
- If I say "no" to doing something, I will suggest an alternative
- I am responsible for my health
- If I get angry or frustrated, it is okay if I yell at people and take my anger out on them.

## **Attitude and the Management of Neurogenic Bowel and Bladder**

Many people who acquire a spinal cord injury report the change that they experience in their bowel and bladder functioning as the one that is the most significant and distressing. Not only do you now have to pay attention to something that you always took for granted, but you are expected to discuss and analyze areas of bodily functioning that were never considered within the realm of acceptable conversation. Not only that, but you either have to take specific actions to manage them, such as cathing or performing a bowel program or digital stimulation) or you have to instruct others about how to do it. You then have to have the patience to work with them to find to become comfortable with the process.

In order to manage your SCI and maintain wellness, it is critical that you adopt a pro-active approach to bowel and bladder management and that YOU accept responsibility for finding ways to optimize these areas of functioning. You will not be doing it alone – your physician, physiatrist, urologist or health care providers will be there to assist you. But it needs to start with you. In almost every situation, it is in YOUR best interest to prevent a bowel accident, constipation or overly full bladder as it is YOU who will have to deal with the consequences.

Think through how attitude may impact the management of your neurogenic bowel and / or bladder:

- What **expectations** do you have for yourself in dealing with the changes in your bowel and bladder functioning?
- Are there any **assumptions** that you are making about the impaired bowel and / or bladder functioning or your ability to manage it? Do you think if you do not do anything, that everything will get better?
- What are your concerns about being able to deal with this changed functioning? Does it stop you from doing things or going out into the community?
- What aspects of managing your bowel and bladder health do you think are within your control? What are you able to do? Do you know how to direct care providers to assist you?
- What are you willing to do to address problems with bowel and bladder management? Are there times when doing nothing may be the best solution?

## **Summary**

**Being proactive allows you to:**

- Be in charge of making things happen
- Take control of your health
- Stay well so that you can do the things you enjoy

**Attitude has five basic parts:**

- Expectations: how you think or believe that people should act
- Assumptions: beliefs that you accept as facts without proof
- Outlook: the way you look at things or view the world
- Responsibility: what you are going to be in charge of
- Actions: what you do

### **Homework**

This homework assignment is designed to help identify what kinds of expectations and assumptions you have about yourself and others. If you agree with the statement, check it off. After you have completed it, go back and review your responses. It might be helpful to discuss some of these with your healthcare provider.





## Module 2: Self-Monitoring

### Screening Questions

- What kinds of things do you currently keep track of with regard to your health?
- How do you keep track of this information?
- How does keeping track of this information help you?

### Self-Monitoring

To **monitor** something means to observe and record what goes on. If you keep track of something about yourself, such as your emotions or your body's responses, you are **self-monitoring**. The information you track can be used to improve your health.

Learning to keep track of what you experience is useful for many reasons. Once you are able to identify a symptom, you can begin asking: “**How strong was that?**”, or, “**what was going on at the time?**” This may lead you to understand **why you experienced what you did**.

There are many different things you can monitor—your blood pressure, how often you breathe or the foods that you eat every day. You can keep track of the number of times that you blink your eyes or say “ummm” in a sentence, but if you focus on that too long it can become crazy. So, you want to monitor enough to provide you with information about what is going on but limit the amount of time you spend on the activity, so it does not take up all your time.

Devices like a heart rate monitor or a blood pressure cuff can help you monitor your body. Both of these devices give you information you can then use to make decisions, such as whether or not you need to see a healthcare provider about your high blood pressure or keep exercising as hard.

### Collecting Information

Self-monitoring is skill that will allow you to take more control of your life because it allows you to see connections and relationships that may exist between two distinct events or a behavior and a reaction or consequence.

However, it is **very important** that you DO NOT just rely on your memory. Our memories are not perfect and what you remember at any given time is influenced by how you are feeling, what you just heard or a host of other factors. ***It is critical that you record the information when or soon after it occurs.***

If you do not record information consistently and accurately, then the conclusions you draw about the relationship (or lack of relationship) between two events may not be correct.

There is also a social expectation that may impact our report (and memory of events). In US culture, when someone asks you “how are you doing?” the socially expected response is “fine – and you?” While this is what your neighbor may expect, this is NOT what your health provider is looking for and this response will NOT provide them with any useful information about your current situation.

The two key factors to consider when collecting information is

- What information to collect or monitor; and
- How to record or track that information

Because there may be many choices about what to monitor, you might want to check with your health care provider about what information would help them get a better picture of what is going on with your health and the particular issue of concern.

For bowel and bladder management, the following are some possible options:

- **Bowel Management:** Exercise; Effectiveness of Medications; Level and impact of emotional stress; Diet and fluid intake; Productivity and time requirements of bowel program
- **Bladder Management:** Fluid intake (Maintain constant fluid intake to avoid infections); Cath / void volume (In general keep between 300-500 ml/cath); Signs of infection (smell and color of urine)

The type of information that you gather should help with making the best possible decisions about your care, treatment and health. Or, it can be information that will allow you to make informed decisions and changes in the way you manage things. You can collect information based on time (like daily records of how you feel or how many times something happened.) Or, you can record information only when something occurs.

### **Recording / tracking information**

The second part of the self-monitoring process is recording or tracking information that you have identified as important or useful. As previously stated, it is important to do this in an accurate and consistent manner for a set period of time. Depending on the issue and level of detail required, you may only need to record information once a day; other issues may require recording every few hours or just after the occurrence of a trigger event or problem.

It works better if you develop or decide on the method you will use to track or record information prior to beginning to process. Once again, DO NOT rely on your memory.

An easy way to keep track of what you monitor is to write it on a calendar. A journal or self-monitoring forms can also be good tools for recording information. If you have a smart phone or are comfortable with technology, there are many applications for smart phones and tablets that are available for download which may also be of assistance.

### **Mobile Apps for Self-Monitoring**

#### **General Health**

*Health Manager*

*T2 Mood tracker* Apple app to monitor mood:

*My Fitness Pal:* Apple app to monitor diet and exercise

*BGluMon:* Apple app to monitor daily blood glucose levels

**Example**

One example that many people are familiar with is monitoring their diet. You can keep track of what you eat, how much you eat, when you eat, your mood was. By recording this information, you can begin to see your eating habits and food choices. If you are particularly accurate with your recording, you may be able to see a relationship between state (such as feeling bored or angry) and quantity of food that you



and what patterns in or honest emotional consume.

Using this example of monitoring diet, try this practice exercise. space below and write down your responses.

Use the

- 1) Let's start with today. What have you eaten so far? About what time did you eat it?  
\*\* Write "not applicable" or put an "x" if you did not eat that meal

Meal	Time	What Eaten
Breakfast		
Snack		
Lunch		
Snack		
Dinner		
Snack		
Other:		



- 2) Okay, now do the same thing with the last 2 days. Write down what you ate yesterday and the day before and about what time you ate.

Yesterday: \_\_\_\_\_

\*\* Write "not applicable" or put an "x" if you did not eat that meal

Meal	Time	What Eaten
Breakfast		
Snack		
Lunch		
Snack		
Dinner		
Snack		
Other:		

2 Days ago: \_\_\_\_\_

\*\* Write "not applicable" or put an "x" if you did not eat that meal

Meal	Time	What Eaten
Breakfast		
Snack		
Lunch		
Snack		
Dinner		
Snack		
Other:		

- 3) Let's look over your responses. Do you see any patterns in what you ate or what time you ate? Did the types of food that you ate vary?

Also consider your ability to remember. Was it harder to remember what you ate two days ago than today? What about if you were asked to add a little more information – such as your portion size or how you were feeling at the time? How much more difficult would that have been to recall after 2 days?



Most people become less accurate and less sure of exactly what happened as time passes. Even if we remember the general details of an event – such as what or where we ate – we may forget other aspects (like how we ate or what we were feeling at the time. Alternatively, our response may begin to blur and so we unconsciously combine events or feelings from several days into one general response.

It is for this reason that it is SO IMPORTANT to record what happened close to the time it occurred. This may mean writing it on a calendar or recording it on a tape or phone for later review. Not doing so greatly decreases the effectiveness of this habit and the information that you can learn from it. For example, after eating, you may want to write down what and possibly how much you ate. Depending on the purpose, you might also record the type of food it was or how many calories it had. You are using one type of information to see how what you eat changes your bowel program and the other to track energy and help you to manage your weight.

### **Information Processing and Evaluation**

So now you have collected information—but what do you do with it? First, just by noticing what you do and think, you may begin to change your behavior. By comparing what you are doing with what you **should** be doing, you may adjust your behavior to be more in line with those expectations.

Second, once you begin monitoring your body and behavior, you can look at the relationship between different types of information. In doing this, you will begin to notice patterns. For instance, you may notice that you are more likely to exercise at the beginning of the day than the end. Or that you tend to snack on junk food when dinner is scheduled for 7:00 pm rather than 5:30 pm. This information then helps you to plan and organize your day better.

Finally, each time you try a new behavior, medication or treatment, you can track how well it works for you. Let's say that you were prescribed a medication for depression and are told that 2 to 4 weeks will pass before you notice a difference in your mood (if you take it as prescribed). You may then want to begin to keep track of how you feel—maybe rating your level of happiness or sadness twice per day for the next 6 weeks. You would also keep track of if and when you took the medication. If you don't feel better in 6 weeks—and you know that you took the

medication correctly—then you may be able to conclude that this medication, at this dose, is not reducing your symptoms or feelings of depression.

## **Self-monitoring and the health care system**

With regard to your interactions with the health care system, self-monitoring is a way of collecting data to allow both you and your health care providers to make more informed decisions. When you want to make a change in your behavior or your life, it is first important to be able to accurately describe what is currently going on. You should track when something happens and what is going on at the same time—both in the external environment as well as social and internal environments (in other words, what you are thinking about at the time).

### **For example:**

Your physician or nurse suggests that you inspect your feet daily for signs of skin problems, such as redness or swelling. Last month you had a skin ulcer that turned into an infection. But, it is hard for you to remember to do this task every day, especially since you have to have another person help you look at some parts of your feet. You wonder if this is worthwhile, but decide to give it a try.

**Monitoring:** For two or three weeks, you look at your feet after showering and ask your partner to inspect the places you can't see, such as the bottom of your feet.

**Processing and evaluation:** During this time, you found an area on your foot that was a little red. So, you made sure that your shoes were not rubbing on the part of your foot where the skin was red or had broken down before. This may have prevented another pressure sore.

**Decision making:** Because inspecting your feet didn't take too much time and prevented a problem, you decided that it was something you needed to include in your daily routine.

**Action:** You now look at your feet (asking your partner's or caregivers help when needed) every day.

**Self-reaction:** You have avoided the foot infections that you used to have every few months. Since looking at your feet after showering was both easy to do and helpful, you decide to keep doing daily foot inspections. And, you feel pleased that you may have even prevented a skin problem from getting worse. Last year it landed you in the hospital.

This is just an example of how trying a new skill and then deciding how well it worked can pay off. There may be times that carrying out the skill may be more difficult or doesn't have the results you wanted. Then, you can tell your health provider about it. They may suggest something else to try or you can come up with an idea yourself.



## **Summary**

### **Self-Monitoring**

- It means that you are keeping track of something about yourself, such as your thoughts or your body's responses. The information you track can be used to improve your health.
- Monitoring yourself is important because all other self-management skills depend on it. The information you gather can help you prevent a health problem or decide whether or not you should pay attention to a symptom
- You can record things every day or just every now and then / when a problem occurs.

## **Homework**

**Your homework is to** monitor both bladder or bowel management activities and your diet. Try to record at least two days of your activities. Use the self-monitoring forms in the appendix and consider the following issues:

- What is the goal of managing this area of functioning?
- What do you currently keep track of related to this?
- What kinds of information would be helpful to monitor?
- How would you collect and keep track of that information?
- What kinds of relationships or patterns might you look for?
- What other methods might you use to keep track of this information? *Texts? Phone apps? E-mails? Memos to self?*

### **Follow-up to Homework**

Now that you've recorded at least 2 days of your activities...

1. For Bladder management
  - How often did you cath on each day?
  - In general, were your cath volumes high? Low? Or did they vary?
  - If they varied, did they seem to do so in a specific way? For example, were cath volumes more likely to be high in the morning or at night?
  
2. For Bowel Management
  - Did you have any accidents over the time you monitored?
  - What time did you conduct your bowel program?
  - What type of results did it produce?
  - How long did it take?
  - What methods did you use?
  
3. For Food tracking
  - Was your pattern of eating regular? What was it effected by?
  - Did you notice a pattern with moods and when or what you ate?
  - How balanced is your diet? What are some steps you can take to improve your diet?
  
4. Advanced: Integrating monitoring activities
  - If you tracked both your diet and your bowel management activities, you may be able to look for relationships between the two. That is, you can begin to see if eating certain types of food led you to have more or less problems with your bowels.
    - Overlay the two tables.
    - Remember that sometimes food has an immediate impact on your system, and sometimes it takes a little longer.
    - Do you notice any relationships?

Even if you see something, it may just be a one-time occurrence or associated with other events rather than being a causal link. So, if you wound up eating chili and having a bowel accident an hour later, it may be that the chili caused bowel disruptions, it may be that it was that PARTICULAR chili that was a problem, or it may be that something else that you did (or did not do) that was associated with the issues.

The more data you have – that is, the more often that you do monitor – the more able you are to both see connections and eliminate chance occurrences.





## Module 3a: Problem-Solving

### Screening Questions

- What steps do you take to deal with a new challenge or a problem?
- When you don't have an answer or don't immediately know what to do next, how do you handle it?

Very few people have all the answers. Most of us have to learn how to solve problems in order to get through the day. We try and apply the information and skills we already have to figure out what we should do or how to reach a particular result.

Problem solving allows you to deal with the world by clearly identifying and defining what the problem is, generating different solutions (called brain-storming) and weighing the pros and cons for each. This allows you to stay flexible and try different approaches to various situations.

### Steps to Problem Solving

Problem solving involves six basic steps: (1) stating the problem; (2) outlining the problem with all relevant details; (3) coming up with ideas to solve the problem (possible solutions); (4) figuring out the pros and cons of each solution; (5) ranking, combining and applying the best solution; and (6) evaluating how well the solution worked.

Let's look at each step in more detail:

**State the problem.** Off the top of your head, say what your problem is. You can write a brief statement about a problem you have now or have had in the past; perhaps related to SCI or perhaps connected to something else going on in your life. The problem does not have to be well thought out. At this stage, even if you recognize that this **is** a problem, you may not have a clear idea of exactly what the problem involves.

**Outline the problem.** Describe the problem in detail. The exact nature of the problem will become clearer to you as you write about it. Provide as much detail as you can. Figure out which factors make the situation a problem. Consider all facts, expectations and assumptions.

**List possible solutions:** After outlining the problem, come up with as many possible solutions as you can. This is known as **brainstorming**. Be as creative as you want without worrying about how good the solutions are, yet. You may want to question some of the facts or challenge some of the assumptions that you have made. Don't throw out any solutions right away, no matter

how nutty they may seem. Come up with at least three solutions. Later, you can improve ideas by combining two or more.

Look for solutions anywhere you can. Find out how other people, such as friends, family or other people you know, have solved a similar problem. Or, you can go to the library and find a book on that type of problem. Or, you could look on the internet (try [www.wikihow.com](http://www.wikihow.com) or [www.ehow.com](http://www.ehow.com)) or Care Cure Forum, for instance, if it is related to SCI. Or, you could call a group or agency that is an expert on that subject.

**View the possible consequences (results) of each solution.** Weigh each solution by listing its pros and cons. Consider what it would mean if one of your facts was not true? What would happen if you changed a behavior? How do you think others would react if you took a particular action?

**Rank solutions then use the one you rate as best.** Rank your solutions in order from best to worst. The solution you ranked as the best needs to be one you are willing to try and is likely to have an outcome you want. Try it! Give this one your best effort. Carefully track what happens as a result. Be persistent with the chosen solution before moving on to the next step. If you don't really try the solution, you may underestimate how useful it is and give up on something that might work.

**Determine how effective the solution was.** Did the solution lead to the desired result? See if the original problem is solved, either in part or fully. How does the result compare to what you expected? If the solution worked—great! Remember to reward yourself for your successful effort. Go over what you tried and figure out when it helped and when/how it didn't. Often, one solution works best in certain situations or with certain people (i.e., with your friends, but not your boss).

You might need several possible solutions to use for different situations. If it did not work at all, you could try again or move on to something else. Use what you learned from trying out this first option to help you refine the problem solving experience. Remember, experience is only wasted if you don't learn from it!



## Problem Solving Example 1

<b>State the problem:</b> My friend is always late		
<b>Outline the problem:</b> I always have to wait more than ½ hour for my friend. I get irritated when waiting. I know that she is busy, but my time is valuable too My friend works and I don't – I have no right to be angry		
<b>Possible Solutions</b>	<b>Pros &amp; Cons (Consequences)</b>	<b>Rank</b>
Always give a time a ½ hour before you actually want to meet	<b>Pros:</b> I won't have to wait; and she may find out what it is like to wait for me;  <b>Cons:</b> if, by some chance she shows up on time, she may get angry at me; it may get confusing	
Have her call you when she is finally on her way	<b>Pros:</b> I can get other things done  <b>Cons:</b> I still have to wait – just at someplace else; she might forget to call me	<b>2</b>
Bring a book and be prepared to wait	<b>Pros:</b> I can use the time to do something I enjoy; If I just expect her to be late, I won't get as irritated  <b>Cons:</b> Seems like I'm a doormat	<b>3</b>
Begin the activity and have her meet me when she gets the chance	<b>Pros:</b> I don't miss the event or activity  <b>Cons:</b> I miss her company	
I can explain how I feel when she is consistently late	<b>Pros:</b> I'll feel more in control  <b>Cons:</b> She may get mad at me	<b>1</b>
<b>Use &amp; Evaluate your solution</b> I'll let her know how I feel when she is late, then suggest that she call before she leaves so we can arrive at the same time and I know when to expect her.		

## Problem Solving Example 2

Read the following information and fill in the form as appropriate.

Sally has a T-3 complete SCI and uses a manual wheelchair to get around. She likes to go out to the mall with friends, but finds it very tiring. While her friends are able to use the most direct routes, the paths that include ramps are often out of the way and may include barriers. Sally also feels that the distance between the stores or between stores and parking is long.

<b>State the problem</b>		
<b>Outline the problem</b>		
<b>Possible Solutions</b>	<b>Pros &amp; Cons (Consequences)</b>	<b>Rank</b>
	<b>Pros:</b>  <b>Cons:</b>	
	<b>Pros:</b>  <b>Cons:</b>	
	<b>Pros:</b>  <b>Cons:</b>	
	<b>Pros:</b>  <b>Cons:</b>	
<b>Try your solution</b>		
<b>Evaluate if your solution was effective</b>		

*Example 2 Sample Solution*

<b>State the problem:</b> Sally enjoys going to the mall with friends, but gets tired when doing so.		
<b>Outline the problem:</b> Going to the mall takes a lot of energy. A place like the mall means a lot of wheeling around between stores and between the stores and the parking lot. While there are ramps, they are often out of the way or have barriers. People can also be barriers.		
<b>Possible Solutions</b>	<b>Pros &amp; Cons (Consequences)</b>	<b>Rank</b>
Don't go. Ask someone else to get you what you need.	<b>Pros:</b> Will save energy and still get what I need.  <b>Cons:</b> Sally enjoys going to the mall. It's a chance to spend time with friends. Also, she gets to pick out her own stuff. Plus, I can see friends when I go to the mall.	
Sally can ask someone to push her wheelchair at times.	<b>Pros:</b> It saves Sally's energy. She still gets to spend time with friends and have them close.  <b>Cons:</b> Sally may feel less independent. When a friend is behind the chair pushing her, she cannot see their face and it makes it harder to talk.	
Sally can start with shorter trips and work her way up to spending more time at the mall.	<b>Pros:</b> Sally still gets to go out to the mall with friends. She begins to build up endurance and learn how to deal with barriers.  <b>Cons:</b> The process will take longer. Any individual trip will give her less time out.	
<b>Use &amp; Evaluate your solution</b> Sally decides that it is important to her to continue to go to the mall with friends. While she works at slowly improving her endurance, she decides that she will also ask friends to push her if she is getting really tired.		

### Example 3

Say your bowel program is not working and you are beginning to be worried about leaving home for fear that you will have a bowel accident. You currently do your bowel program every other day in the evening and have for the past year. In addition, your diet is not the best, and your doctor has suggested that you eat more fiber and avoid fried foods.

<b>State the problem</b>		
<b>Outline the problem</b>		
<b>Possible Solutions</b>	<b>Pros &amp; Cons (Consequences)</b>	<b>Rank</b>
	<b>Pros:</b>	
	<b>Cons:</b>	
	<b>Pros:</b>	
	<b>Cons:</b>	
	<b>Pros:</b>	
	<b>Cons:</b>	
	<b>Pros:</b>	
	<b>Cons:</b>	
<b>Try your solution</b>		
<b>Evaluate if your solution was effective</b>		

Example 3 Sample Solution

<b>State the problem:</b> I'm having bowel accidents		
<b>Outline the problem:</b> My bowel program isn't working I can't leave home for very long for fear of having an accident Sometimes I don't even know I had an accident until others point it out to me.		
<b>Possible Solutions</b>	<b>Pros &amp; Cons (Consequences)</b>	<b>Rank</b>
Monitor my diet to make sure I'm eating less greasy foods and plenty of fiber	<p><b>Pros:</b> I may have fewer bowel accidents. I may also lose weight.</p> <p><b>Cons:</b> I don't like food with fiber and it can take a lot of time to cook. Fast food is easy to get and tastes good.</p>	
Change bowel program	<p><b>Pros:</b> I can create a program that works better with my schedule and needs</p> <p><b>Cons:</b> Figuring out what to change in my bowel program can be difficult. The doctor has put me on certain medications and I should contact them before not taking them.</p>	<b>3</b>
Doing a bowel program more frequently or at a different time of day.	<p><b>Pros:</b> If I change my bowel program to the morning or every day, then I will have less stool in my body and may be less likely to have a bowel accident. I won't have to worry about accidents or a bowel program</p> <p><b>Cons:</b> Changing my program to the morning means getting up earlier. In addition, as I sometimes need help, it may mean having someone else get up earlier and be there with me as well.</p>	<b>2</b>
<b>Use &amp; Evaluate your solution</b> I'll first try to improve my diet, and then maybe try a daily bowel program. If that doesn't, I will consider doing a morning program and contacting my physician.		





## Module 3b - Emotional Problem-Solving

### Screening Questions

- How do you deal with uncomfortable or feelings?
- When it comes to tough decisions, how big of feelings play?

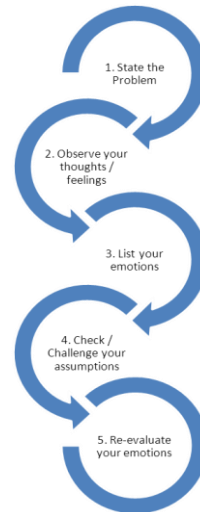
**We've talked about problem solving** when it comes around, bowel issues and pain management. These solving steps can also be used to deal with emotional may feel down, anxious or angry. Working to identify those feelings can help you reframe the issue and thinking about it.

Coping with your emotions is a special form of problem-solving; this technique is sometimes called cognitive reframing. It is just standard problem-solving, with a couple of slight changes:

**State the problem:** Once again, you start by stating the problem—in this case, what you feel and why.

For example, say that you are feeling worried about cooking Thanksgiving dinner for your spouse's family.

In most cases, your problem will be the emotional distress that you are feeling. Few people think that being too happy is something that they need to solve or fix.



unwanted  
a role do your  
to getting  
problem  
issues. You  
the source of  
adjust your

**Outlining the problem with all relevant details:** Start providing details about the situation and the event or events that may have come before it. As you outline the issue, make sure that you include **why** you feel this way. If you don't really know what you feel, go through the list of feelings in Appendix A and see if any of them fit. From there, consider what facts, information or assumptions are leading to these feelings? Observe and/or write down your thoughts. If you pay attention to your thoughts, you can become aware of a constant stream of messages. These messages are referred to as self-talk. List the messages that pop into your mind.

In continuing your example, you may say:

- *I am worried about cooking Thanksgiving dinner.*
- My spouse's mother will be there and she is very critical of me.
- I really like it when people enjoy what I cook for them.
- What I have cooked has NEVER been good enough for my mother-in-law. She always finds fault with it and with me.



**Figuring out how you feel**

Sometimes just deciding how you feel can be difficult. You are used to being a happy person, and can't really tell the difference between

**Come up with ideas to solve the problem (solutions):** For emotional problem-solving, focus on different ways of thinking about or dealing with your problem (feelings of emotional distress) rather than specifically finding solutions. To do this, you have to take a look at the details of the problem and challenge them; you might question the reality of the facts and assumptions that you are working from. Once you have done that, you can work on changing your thinking by focusing on positive statements. It is helpful to start with the facts. Turn your thinking to ways you can cope with the situation. Include the ways you have coped with the same kinds of situations in the past, focusing on the factors of the situation.

With emotions, it is not about challenging them, but recognizing and respecting them. You hurt. You may grieve for the changes and losses in your life. That is okay and normal. What is left is



knowing that these feelings will not always be this strong and that, if you allow them to be, they can be replaced by others—better and more positive emotions and feelings.

- *I am worried about cooking Thanksgiving dinner for my in-laws.*
  - Response: *It's not all my in-laws I worry about – it's my mother in law. I am fine with everyone else – they LIKE my cooking. Why do I worry so much about one person?*
- *My spouse's mother will be there and she is very critical of me.*
  - Response: *My mother-in-law is critical of everyone. It is not just me. Trying harder does not help.*
- *I really like it when people enjoy what I cook for them.*
  - Response: *Yes, I enjoy cooking and I enjoy making people happy. I am a good cook and most people like what I cook. If I focus on enjoying the process of creating a meal and a warm, welcoming then I will enjoy Thanksgiving and so will my spouse and my in-laws (at least most of them).*
- *What I have cooked has NEVER been good enough for my mother-in-law. She always finds fault with it and with me.*
  - Response: *My mother-in-law is just a critical person. I have to stop trying so hard though I will remain respectful and polite. I am going to switch my focus to creating a warm home and making my spouse happy and leave it at that.*

**Figuring out the pros and cons of each solution and then ranking them in order:** In dealing with emotions, you have to look at your concerns and challenges as a whole. How many of them reflect your own feelings about yourself? How many of them come from actual feedback from others? Is there really something that you can do about the underlying issue? Or do you just have to deal with the emotion?

When “solving” emotions, the two choices usually come down to either changing the situation or finding another way to think about it. Of course, a combination of the two may also work. So, what concerns, assumptions or expectations are you willing to try and change? Which situations are flexible? What changes can you or are you willing to make in your life?

**Rank solutions then apply the best:** Consider which assumptions and emotions seem most open to change. Then, it is time to apply that solution. It is hard to change the way that you think and act; doing so can take a lot of encouragement from others. You may need to practice it a few times before it feels right; trying it once is not enough. You really have to give it a fair chance. Think of it as a treasure hunt—are you using the solution systematically? Would you be willing to bet that no one using the same technique or procedure would be able to find treasure given the same situation? If not, then you may not have applied the technique effectively. If you are going to try to make a change, really give it your all. If you are not going to—for whatever reasons—do not kid yourself and everyone else.

*Okay, there are a couple different things I can do here. First, I am going to start by concentrating on enjoying the day and creating a meal that I like to cook. My next priority will be my spouse. From there, I'm not going to sweat it.*

**Evaluate how well the solution worked.** So, now is the time to figure out how effective the solution was for you. If you can truly say that you gave it your best shot, begin to monitor the situation. This may mean keeping track of your feelings or your thoughts. Were you able to influence your emotions at all? Have you changed the situation? How about how you feel or think about the situation? Observe the changes in your thoughts.

### **Thought traps / Cognitive Distortions**

- **Mind-reading:** Assuming what others are thinking without knowing the facts.
- **Over-generalizing:** Broadly applying a conclusion based on an event that happens once or twice.
- **Blaming:** Blaming ourselves or someone else when something goes totally wrong.
- **Awfulizing:** Deciding that something that happened is the worst thing that could happen.
- **Filtering:** Noticing the one thing that goes wrong while ignoring all else that goes well.

### **Do you tend to fall into any of these traps?**

If so, you may notice that negative thoughts can color your feelings and outlooks.

Using the emotional coping technique is not just trying to think cheery thoughts. Instead, it is a way of putting a different spin on events or taking another point of view. For instance, a real estate agent sometimes calls a dreary swamp a “possible pond site” or a tiny kitchen as a “step saver” in order to make a house sound as attractive as possible. Your health provider might use the word “discomfort” instead of “pain” as it has a much stronger and more negative word. How you talk about something can change how you think. And, how you think can change how you feel.

### **Example #2**

**State the problem:** Once again, you start by stating the problem—in this case, what you feel and why. It may be something like, *‘I am very worried that no one will find me attractive again.’* In most cases, your problem will be the emotional distress that you are feeling. Few people think that being too happy is something that they need to solve or fix.

**Outlining the problem with all relevant details:** Start providing details about the situation and the event or events that may have come before it. As you outline the issue, make sure that you include **why** you feel this way. If you don’t really know what you feel, go through the list of feelings in Appendix A and see if any of them fit. From there, consider what facts, information

or assumptions are leading to these feelings? Observe and/or write down your thoughts. If you pay attention to your thoughts, you can become aware of a constant stream of messages. These messages are referred to as self-talk. List the messages that pop into your mind.

In continuing your example, you may say:

- *I am worried that no one will find me attractive*
- *Why would anyone look at me? I am in a wheelchair.*
- *Everyone knows that people who use wheelchairs are just useless cripples.*
- *If no one finds me attractive, no one will want to date me or spend time with me; I will be all alone.*
- *I don't want to be alone, I want a family and to find love.*
- *I feel incredibly sad at the thought of being alone for the rest of my life.*
- *How can someone love me now?*
- *I am so angry that this happened! Why me! Why did this have to happen to me!*

**Come up with ideas to solve the problem (solutions):** For emotional problem-solving, focus on different ways of thinking about or dealing with your problem (feelings of emotional distress) rather than specifically finding solutions. To do this, you have to take a look at the details of the problem and challenge them; you might question the reality of the facts and assumptions that you are working from. Once you have done that, you can work on changing your thinking by focusing on positive statements. It is helpful to start with the facts. Turn your thinking to ways you can cope with the situation. Include the ways you have coped with the same kinds of situations in the past, focusing on the factors of the situation.

Sometimes, with emotions though, it is not so much challenging them as recognizing and respecting them. You hurt. You may grieve for the changes and losses in your life. That is okay and normal. What is left is knowing that these feelings will not always be this strong and that, if you allow them to be, they can be replaced by others—better and more positive emotions and feelings.

- *I am worried that no one will find me attractive*
  - Response: What do I mean by attractive? Pretty? Handsome? Desirable? Interesting? Pleasant? So many of these things are subjective.
- *Why would anyone look at me? I am in a wheelchair.*
  - Response: Actually, the wheelchair attracts attention and a lot of people wind up looking at me. I just have to feel comfortable looking back and maybe using it as an opportunity to flirt.
- *Everyone knows that people who use wheelchairs are just useless cripples*
  - Response: Where did I come up with this one? I know that I am not worthless and know a lot of people who use chairs who live full and active lives.
- *If no one finds me attractive, no one will want to date me or spend time with me; I will be all alone.*

- Response: Slow down. Yes there is a connection between dating and marriage and sexual relationships. Attraction is part of the process, but that is influenced by many things—like self-confidence and common values and goals. Also, just because I don't have a “significant other” right now does not mean that I am going to be alone forever.
- *I don't want to be alone, I want a family and to find love*
  - Response: Okay. Good to have a goal. I thought I would have this by now. Maybe I have to take a more active approach.
- *I feel incredibly sad at the thought of being alone for the rest of my life*
  - Response: That sounds sad, and heart-wrenchingly painful. But would it be better to be with anyone than to be alone? Would you want to spend your life with your 7<sup>th</sup> grade chemistry teacher? What about a smarmy car salesman? What about someone who called you names and treated you badly? Being alone may be a better option. But you don't have to be alone; you don't have to shut the door on all the life and love and possibilities that are out there. In order to connect with others, you have to be open to others. This is something you have control of—not anyone else.
- *How can someone love me now?*
  - Response: I don't feel lovable. But love is a funny thing. Getting love is connected with giving love and being loved can come in all shapes and forms. But true love is based on respect and appreciation. Maybe I have to figure out how to be someone that I can respect and appreciate, and then other people will be able to love me.
- *I am so angry that this happened! Why me! Why did this have to happen to me!*
  - Response: Nope, not fair. It's normal to feel angry and sad and hurt. But do I want my life to be wallowing in these emotions all my life? Do I just want to feel pain and anger and sadness? Or can I let them go and begin to look for other ones?

**Figuring out the pros and cons of each solution and then ranking them in order:** In dealing with emotions, you have to look at your concerns and challenges as a whole. How many of them reflect your own feelings about yourself? How many of them come from actual feedback from others? Is there really something that you can do about the underlying issue? Or do you just have to deal with the emotion?

When “solving” emotions, the two choices usually come down to either changing the situation or finding another way to think about it. Of course, a combination of the two may also work. So, what concerns, assumptions or expectations are you willing to try and change? Which situations are flexible? What changes can you or are you willing to make in your life?

*Okay, there are a couple different things I can do here. First, I can get more comfortable with myself and who I am. I also can adjust my attitude and assumptions about disability – maybe by meeting more people with SCI or getting involved in a disability organization. I also just need to get out and meet people and hopefully make friends. That may be one option, but I may also look into internet dating—it may allow me to meet more people and at least some of them will be confident enough in themselves to date a man with a disability.*

**Rank solutions then apply the best.** Consider which assumptions and emotions seem most open to change. Then, it is time to apply that solution. It is hard to change the way that you think and act; doing so can take a lot of encouragement from others. You may need to practice it a few times before it feels right; trying it once is not enough. You really have to give it a fair chance. Think of it as a treasure hunt—are you using the solution systematically? Would you be willing to bet that no one using the same technique or procedure would be able to find treasure given the same situation? If not, then you may not have applied the technique effectively. If you are going to try to make a change, really give it your all. If you are not going to—for whatever reasons—do not kid yourself and everyone else.

**Attitude adjustment first.** Maybe talking it out with a friend or counselor would help. Meet new people second—maybe by trying out for that co-ed wheelchair basketball team and then by signing up for a knitting class. As for the internet dating, I want to get some more information first.

**Evaluate how well the solution worked.** So, now is the time to figure out how effective the solution was for you. If you can truly say that you gave it your best shot, begin to monitor the situation. This may mean keeping track of your feelings or your thoughts. Were you able to influence your emotions at all? Have you changed the situation? How about how you feel or think about the situation? Observe the changes in your feelings. Developing a positive coping attitude can have a strong impact on feelings such as hopelessness or fear. If you notice little or no emotional relief, go back to the last step and continue to work on positive coping self-statements.

**Let's try to apply the steps.** First you **state the problem**, for example, *"I am very worried that no one will find me attractive again."* Once you've stated the problem, begin to provide details about why you feel this way and consider what assumptions you might be making. For example:

*[I am worried that no one will find me attractive]*

- *Why would anyone look at me? I am in a wheelchair.*
- *Everyone knows that people who use wheelchairs are just useless cripples.*
- *If no one finds me attractive, no one will want to date me or spend time with me; I will be all alone.*
- *I don't want to be alone, I want a family and to find love.*
- *I feel incredibly sad at the thought of being alone for the rest of my life.*
- *I am so angry that this happened! Why me! Why did this have to happen to me!*

These kinds of messages are referred to as self-talk and can be destructive. Think about the patterns of self-talk you tend to fall into. If you catch yourself in this kind of pattern, stop and question the reality of the facts and assumptions that you are working from. Let's take this pattern and break it down into parts and do some reality checking:

<p><b>State the problem</b>          "I am worried that no one will find me attractive"</p>
<p><b>Observe your thoughts</b>          I don't want to be alone; I want a family, but how can anyone love me now?          I feel incredibly sad at the thought of being alone for the rest of my life</p>
<p><b>List your emotions</b>          Sad, Lonely</p>
<p><b>Q. Any others?</b></p>
<p><b>Check / Challenge your assumptions</b>          "Everyone knows that people who use wheelchairs are just useless cripples"  <ul style="list-style-type: none"> <li>• I wasn't useless before the accident and I'm not useless now</li> </ul>         "If no one finds me attractive, no one will want to date me or spend time with me. I'll be all alone."  <ul style="list-style-type: none"> <li>• "What does it mean to be attractive? It's all subjective.</li> <li>• Also, just because I don't have someone right now doesn't mean I will always be alone.</li> </ul> </p>
<p><b>Re-evaluate your emotions</b>          I'm still me. If I really want to date someone, giving up and thinking low of myself certainly won't help me meet people.</p>

## Identifying Emotions

Labeling our emotions or admitting what we are feeling can be hard for many people. Review the list of words below, and see if you can identify with each. You will notice that words are grouped in general categories, with each word reflecting different shades or intensities of emotions involved. Consider the differences between two words in the same category.

## Feeling Words

### Happy

Contented  
Satisfied  
Serene  
Comfortable  
Peaceful  
Tranquil  
Joyous  
Enthusiastic  
Ecstatic  
Glad  
Pleased  
Cheerful  
Sunny  
Lighthearted  
High-spirited  
Animated  
Merry  
Sparkling  
Hilarious  
Exhilarated  
Playful  
Close  
Warm  
Grateful  
Thankful  
Silly  
Giddy

### Eager

Anxious  
Earnest  
Intent  
Avid  
Fervent  
Itchy

### Doubtful

Skeptical  
Distrustful  
Unbelieving  
Suspicious  
Uncertain

### Fearless

Brave  
Courageous  
Confident  
Independent  
Secure  
Bold  
Daring  
Strong  
Heroic  
Determined  
Firm  
Certain  
Calm

### Angry

Resentful  
Irritated  
Engaged  
Furious  
Annoyed  
Provoked  
Offended  
Bitter  
Contemptuous  
Boiling  
Fuming  
Defiant

### Interested

Concerned  
Affected  
Fascinated  
Engrossed  
Intrigued  
Absorbed  
Curious  
Excited  
Nosy  
Inquisitive

### Sad

Sorrowful  
Downcast  
Dejected  
Unhappy  
Depressed  
Gloomy  
Cheerless  
Somber  
Dismal  
Joyless  
Quiet  
Dark  
Mournful  
Dreadful  
Flat  
Deflated  
Dull  
Sullen  
Discontented  
Moody  
Hollow  
Sympathetic

### Hurt

Injured  
Grieved  
Offended  
Distressed  
Worried  
Pathetic  
Tortured  
Aching  
Embarrassed

### Afraid

Frightened  
Timid  
Chicken  
Lazy  
Shaky  
Apprehensive  
Restless  
Terrified  
Panicky  
Hysterical  
Shocked  
Horrorified  
Insecure  
Anxious  
Worried  
Doubtful  
Suspicious  
Awed  
Dismayed  
Sheepish  
Scared  
Shy  
Cowardly  
Threatened  
Cautious  
Fearful

## Emotional Problem Solving Example 1

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### State the problem:

People seem to look at me a lot when I am out in public

### Observe your thoughts:

I don't want people to stare at me.  
People look at me and think that I am a helpless gimp.  
People look at me with pity. I feel embarrassed.  
I hate needing and using this wheelchair.

### List your emotions:

I get angry and feel helpless and inferior.

### Check/challenge your assumptions and automatic thoughts:

I have a right to go out—in fact this is what I need to do to improve my life and be a part of the world. While some people may look at me with pity, most are just busy with their own thoughts and problems. If anything, they may just have questions, wonder what happened, or if they should offer to help in some way. Besides, maybe they are not staring at me because they feel sorry for me. Maybe they are just bowled over by my coolness.

### Re-evaluate your emotions:

Wow. If I can just get that people who stare at me need to be educated, I feel a lot better. Their staring is their problem—not mine. I am doing what I need to do for my physical and emotional health—I have a life. They may still need to get one.

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## Emotional Problem Solving Example 2

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### State the problem:

An old friend didn't visit me as we had planned.

### Observe your thoughts:

People avoid me since I had my SCI. I don't think that I'll ever have as many friends as I did before. There are so many people who I just no longer see.

### List your emotions:

Angry at the people who aren't around anymore, sad, frustrated, etc.

### Check/challenge your assumptions:

The friend who missed his visit has been one of my closest friends—even more so since my accident. Maybe something came up for him that has nothing to do with me or our friendship. I'll talk to him before I let this bother me anymore.

### Re-evaluate your emotions:

I need to avoid lumping everyone in my life together; they don't all react or feel the same way. The friends that I have right now care about me whether or not I have a disability. I guess I value the friends I do have; it wouldn't hurt to cut them some slack now and then.

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## **Summary**

6 steps to basic problem solving

- 1) State the problem
- 2) Describe what makes it a problem
- 3) Generate possible solutions
- 4) Describe possible outcomes for each solution
- 5) Rank solutions
- 6) After trying a solution, evaluate what worked and what didn't

5 Steps to emotional problem solving:

- 1) State problem
- 2) Observe your thoughts / feelings
- 3) List your emotions
- 4) Check / Challenge your assumptions
- 5) Re-evaluate your emotions

Thought traps often get us stuck. We first need to recognize that we are in a thought trap. Only then can we find our way out of it.

## **Homework**

Use the problem solving sheets in the Homework section to work your way through something that has been giving you trouble in your life. Start with a simple problem and then move on to a problem that is connected to your emotions.





## Module 4: Communication

### Screening Questions

- Who do you need to communicate with to manage your health?
- How do you communicate with your health care provider? What methods do you use and what are your goals and strategies?
- How do you communicate with family and friends? Do your goals and the methods you use with this group differ from how you interact and communicate with healthcare providers?
- In your experience, what types of things hinder or limit your ability to communicate and work with someone towards shared goals?
- How do you take a proactive strategy with regard to communicating?

### Introduction to communication

Another critical skill for everyone – but especially for people with SCI—is being able to communicate clearly and effectively.

**Communication** can be defined as the process of transferring information from one source to another. In general, communication is thought of as a two-way process in which there is an exchange of thoughts, feelings or ideas towards a mutually accepted goal. In this process, information is articulated by the individual who is talking and interpreted by the individual listening or receiving the information. Of course, what the receiver perceives to be the message may not be what the sender tried to convey.

These days, there are many ways to communicate, but how you do it usually comes down to Verbal and Visual.

- **Verbal Communication** – Communication via sounds; such as spoken language or music
- **Visual communication** is information relayed through signs or visual aids; ideas and information are transmitted in forms that can be read or looked at such as in books or on the internet. For example, there is a lot of information available on-line. The organization or person who posted the information is the sender (or speaker). You, as someone looking at the webpage, would be the receiver.
- **In face-to-face interaction**, communication is made up of body language (about 55% of the impact), tone of voice (38%), and the actual contents or words (about 7% of the impact).

## **Basics of communicating**

Here are a few basic rules to help you communicate better:

### **1. Decide what the goal of the conversation or exchange is:**

Do you want to get something? Share something? Find out something? Get someone to treat you better? Do you want to build a stronger connection with the person who you are talking to or do you just want to get done as soon as possible? How you approach the interaction and the conversation should be based on a realistic assessment of what you want to get out of it paired with a strategic plan for the best way of doing that.

### **2. Determine the most effective way to achieve your goal**

This is the strategic plan. Is the conversation about a person or an action? Is the person you are interacting with someone you are never going to see again or are they likely to be important to you in the future? Your strategy is based on your assessment of this person and how to get what you want from them.

There are two types of questions you can use to get information—open and closed.

**Open questions** are those that require some explanation from the person answering. Examples of open questions include: “How does this medication work?” and “Why do I have to turn in bed every 2 hours?” Open questions are most useful when you want to understand something.

**Closed questions** ask for specific information, and are short and to the point. Examples of closed questions include “How many times a day do I take this medication?” and “How long will you be on vacation?” Closed questions are helpful for learning specific information quickly.

When the goal of communication is sharing information, make sure that the listener understands. One way to be certain is to ask them to repeat your message back in their own words. This method is called **reflective listening**. When you want to be sure you understand what others have said, you can repeat what they said to see if this is what they meant. Reflective listening is important when communicating with your physician; but it is also helpful to avoid misunderstandings with family and friends.

Sometimes your goal may simply be to talk about a problem. If this is your goal, you can find someone who will listen without offering advice or trying to change your mind. Venting your feelings is often very effective in helping you feel better emotionally even if it does not change what was bothering you in the first place. However you can follow up with problem-solving steps.

### **3. Accept responsibility for your own feelings.**

This is often difficult to do but it is critical for good communication and for coping with feelings. If you blame others for your feelings, your listener may become defensive. When

someone is defensive, they become concerned with protecting themselves and may not hear what you have to say, thus preventing effective communication. Express feelings only if they are important to accomplishing your goals.

To avoid making people defensive when you talk about your feelings, start your sentences with “I” (which are known as “I” statements). You might say, “I get angry when I get different information from different doctors”, or “I feel depressed when I’m not included in my friends’ plans.” As you can see, the basic format for these statements is:

*I feel \_\_\_\_\_ when you do \_\_\_\_\_.*

If instead you said “You make me angry when you give me different information than other doctors,” or “You make me depressed when you don’t include me in your plans,” your listeners might have a different response. In these statements, you are blaming someone else for your feelings, rather than simply stating how you feel. Which do you think would lead to better communication?

Taking responsibility for your feelings is also necessary if you hope to deal with them successfully. If you say that other people “make you” feel a certain way, you believe they control your emotions. If that was so, you wouldn’t have much power over your feelings. You might feel helpless to change them. If, on the other hand, you believe that you are responsible for your feelings, you can do something about them.

#### 4. **Give and accept feedback with an open mind and non-defensive manner**

Communication—as opposed to just giving directions—is a two way street. There is more than one person involved, and so there is likely more than one perspective and goal. You want something from the other person or people and they want something from you. These goals are usually pretty harmless—you want the other person’s approval or recognition or maybe information from them. They want to share information, or to demonstrate their understanding, or to just be able to maintain a positive mood.

When communicating with people, **feedback** is a method to let the speaker know how well he or she is getting their point across. People are often unaware of how they come across to others. By listening to what others say about how you are communicating, you can decide if you are communicating the way you want to and, make needed changes. You don’t have to agree with their feedback, but be sure to give it proper consideration rather than just dismiss it.

**Assertiveness is the ability to proactively address issues in direct ways that remain respectful of the other person and their point of view.** Being assertive means honestly and directly expressing your thoughts and feelings without violating the rights of others. Assertiveness and boundaries go hand-in-hand. When you are assertive, people know your opinions without being scared of them and will usually behave accordingly. In becoming assertive, you will learn empathy (knowing how others feel, their opinions and attitudes), and you’ll be able to consider what other people think are good boundaries or goals.

## **Examples of Communication**

Communication can be very simple and straight-forward or complex and very involved. For example, just asking someone for assistance....

**Goal:** *I need assistance from someone to help me get something from a high shelf.*

**Determine most effective way to achieve goal:** *First, I have to get someone's attention and engage them, and then I can politely ask for help. **Accept responsibility for your own feelings:** I don't like asking for help, but people generally seem okay with it and appear very willing to help out.*

**Give and accept feedback:** *I'll make sure I thank them for their help.*

## **Communicating with your health care team**

While research suggests that there are steps that your health care provider can take to improve their relationship with you as a patient, there are also things that you can do! You are not helpless! By being pro-active and working at the relationship, you can improve both your satisfaction with healthcare and the treatment you receive from providers.

A study by Clarke and colleagues identified 10 basic communication strategies and showed how physician compliance with these recommendations can increase patient's satisfaction and outcomes.[19-21] We have revised and added to these so that they apply to you, the individual with SCI:

- Practice non-verbal attentiveness.
- Allow the provider to see you as a person.
- Admit underlying fears.
- Address immediate concerns.
- Provide positive feedback when you receive reassuring messages.
- Take an active role in the conversation.
- Tailor the regimen.
- Ask for assistance that will allow you to plan for decision making.
- Set short-term goals for treatment.
- Set goals with the long-term treatment plan.
- Use non-verbal encouragement and verbal praise.



**Non-verbal attentiveness** refers to how you position your body and behave in relation to the provider. Using good non-verbal signals such as eye contact, smiling, handshakes and appropriate social gestures, listening without interrupting, and leaning forward slightly when you listen to the provider will signal that you care and are paying attention.

**Allow the provider to see you as a person** means that you present yourself as someone whom the provider can connect with and relate to. Many providers do not know what they can really expect someone with a SCI to do. By giving providers glimpses into your life—particularly those aspects that defy stereotypes about disability—you are allowing them to understand that your life consists of more than just managing this condition and that management needs to support those areas of your life.

**Admit underlying fears** refers to talking about your and your family members’ concerns and worries about your condition or the treatment options. Describing your current understanding as well as your concerns can help the provider target which areas to address. Try statements like: “I understand that exercise is important, but I don’t know what types of exercises will help me lose weight. I am also concerned about being able to afford gym membership or high-tech devices.”

**Address immediate concerns—don’t wait!** You can do this by acknowledging that the provider may be worried by issues such as following recommendations or that some requests may be seen as demanding or “drug-seeking”. If you feel that the provider might have a concern, you can ask about it in an open, non-defensive manner.

**Respond to reassuring messages** to help the provider know that you appreciate their attempts to reduce your anxiety. Identifying shared priorities and goals lets the provider know that their recommendations are being heard and can go a long way in building the relationship.

**Take an active role in the conversation** is important because it allows you and your family to say what you know or think you know. Saying what you have heard or what you think may be effective solutions will allow you to get feedback about its accuracy. Don’t be afraid that you have the “wrong answer”. Instead, provide the information and assumptions that you are basing your decisions on so you know if you are going in the right direction. It is very important to let the provider know when you do not understand them. You can ask them to rephrase it, or tell them what you **thought** you heard and ask if you were right.

**Tailor the regimen** refers to having the treatment and the provider's recommendations fit into the lifestyle and routines of you and your family. Provide information about your priorities and daily routines and ask the provider how their recommendations can be fit into that schedule. This may require that you plan ahead and establish set patterns of behavior.

**Plan for decision-making** by asking advice about what you and your family should do in a given situation. The section on problem-solving goes into this in more depth. Basically, you are simply asking the provider to help you identify what signs to look for and what to do if they occur.

**Restate short-term goals for treatment** to increase your understanding of how the provider's recommendations fit with your immediate concerns and priorities. By tying their input to what is important to you, you increase the likelihood that you will pay attention and take recommendations seriously.

**Restate goals with the long-term treatment plan** to help you partner with the provider to manage your health and prevent secondary conditions. Your long-term goal may be to go sailing with your family, return to work, or spend more time without pain. Once you have agreed upon a goal, you can negotiate different steps that may help you reach that outcome. The provider may initially feel that you should be doing as much as possible to regain functioning. This is the time when it is important to help them see your personal goals and priorities.

**Using nonverbal encouragement and verbal praise** is important for building rapport and reinforcing the steps that the provider is taking to assist you. Health care providers generally enter the field to help people; they like to know that what they are doing makes a difference in your life. Always remember to thank them for their efforts and for spending the time to help you manage your condition and get on with your life.

### **Electronic Communication**

Electronic communication strategies open up both possibilities and challenges when it comes to communicating effectively. While your comfort with these methods may vary, you should recognize their opportunities they provide and use them strategically.

**Email:** Allows you to communicate with one or more people at the same time. It allows people to respond to your communication at a time that is convenient for them. However, it can be difficult to convey or interpret emotions that are imbedded in e-mails. E-mails can also create a traceable record of a conversation – which is important to remember and consider when writing to someone.

**Texting:** Texting has the benefit of immediacy. Limited amounts of information are presumably conveyed to a person's cell phone so that they can see and respond to it within a short amount of time or in environments when responding to a phone call may not be possible. However, it may be difficult to convey emotion (beyond using emoticons) through texts. In addition, you cannot be assured if the person receives the text, let alone when they may see and respond to it.



**Facebook and other Social Media:** These mediums provide the opportunity to connect with large numbers of people and can be very effective when used strategically. All types of messages can be included, from text to pictures to videos. Others can then respond to that information, showing support or providing comments. At its best, Facebook can be used as a way to share select events in your life to include and acknowledge others and through that to build a stronger network. However, it is important to remember that you no longer own what you post. Also, while privacy settings may be adjusted – both what others post and what you post are there for all to see.

**Carepages:** Per their website (carepages.com), *CarePages websites are free patient blogs that connect friends and family during a health challenge.* They can be used by explain current situations and provide updates in an efficient manner in a way that generates support and encouragement. However, this is a business, so whatever information that you provide as well as information obtained by examining how you use the website may be used by that company to target advertisements or shared with third party vendors or advertisers.

**YouTube:** YouTube can be a great place to share videos, presentations and other visual media content. You can determine who you want to be able to see and comment on those uploads – so your video can be viewed by a single person or searchable by everyone with internet access. This can be a great place to find or post tutorial on something. However, there is no assurance or monitoring about the truth or usefulness of this information – it is the users who screen and provide feedback about the usefulness of content. You can also remove the video when you want – however, if someone else has downloaded and shared it, that information may get away from your control. In addition, while you do not give away ownership to the video but “*to grant to YouTube a non-exclusive, worldwide, perpetual license to freely sub-license, re-distribute, re-publish, monetize, and whatever they may want to do with your video. They're basically requiring that you grant YouTube all of the same rights that you have with your video, short of turning over your rights to them.*” (Source: Who Owns Your YouTube Video? YouTube Copyright & Ownership Answers <http://www.reelseo.com/youtube-copyright-ownership/#ixzz2Z7kZx9SQ>)

**Web pages and Blogs:** Similar to the benefits of the above mechanisms, webpages and blogs can be used to share information, experiences and opinions with large number of people simultaneously. The problems may also be similar. To be useful, these can require a significant investment of time to promote, update and to reply to posts.

### **Other Communication Tips:**

In becoming a partner with your health care team, you must feel comfortable talking to the members and asking any questions that you have. While this may sound simple, it rarely is. People have certain expectations: that a doctor will tell you everything you need to know or that they should realize, without being told, how you feel. What you learn, however, is that you have to act **assertively** to make sure you get what you need. Being assertive makes you an active

partner in taking care of your SCI and your health. More importantly, acting assertively can prevent confusion and misunderstandings between you and your treatment team.

Few people are naturally assertive in all situations. You may find it easier to be assertive for **other people** rather than for **yourself**. Even people who find it easy to assert themselves in one situation, such as with friends, may find it hard to assert themselves in another, such as with their physician. People may act in a passive or aggressive way at times, or a little of both.

**When behaving passively, a person does not actively communicate what he or she is really thinking or feeling.** People who act passively with a physician or nurse often leave the appointment feeling disappointed, uneasy or dissatisfied. They may lack a clear understanding of the disease, medical procedure or medications that were discussed. Some people are afraid to ask questions at a visit; perhaps because they don't want to take too much of the health care professional's time.

**People who communicate in an aggressive way do let others know their thoughts, desires, and feelings, but in a rude, threatening or belittling manner.** A man who acts aggressively may lose his temper at having a long wait before a medical visit. Or he might loudly accuse the health care professional of not listening to him. The downside to this style is that people will not respond in a positive way and it may even make communication harder.

**Sometimes, a person expresses his or her thoughts, feelings or desires, but in an indirect way.** An example is someone who is frustrated with her physician after they received only a brief explanation of how to take a new medication. Or she is angry since the physician seemed to show little sympathy when the patient described some side-effects she had from the drug. A passive-aggressive response would be to stop taking the medication, but not tell the physician, having an "I'll show you" stance. Obviously, the patient is the one most apt to be hurt by this approach, rather than the physician.

The **assertive** approach is the best one to take when dealing with your health care professional. **Remember, being assertive is something that you learn. Like riding a bike or playing the piano, you must practice using skills before you improve at them.**

**To act assertively you must:**

- **know what you need, desire, think or feel AND**
- **clearly express your thoughts or feelings**

The following list of Do's and Don'ts will help you when meeting with your health care professional.

## **DO**

- Become a partner in managing your health.
- Act politely and pleasantly. No matter what your attitude is about having SCI, being respectful and assertive makes it easier to get along with physicians, family and others.
- Listen to your health care professional's suggestions and take notes of these ideas.

- Create your own list of questions. This is a necessary step to take before meeting with a health care worker. It is easy to feel confused, overwhelmed or just forget the questions if they are not written down.
- Tell your health care professional your goals, desires, and suggestions. Even if your goals are different from your physician's, you can work together to find a solution you can all accept.
- Come up with a different plan if you and your health care professional cannot agree on a goal. It can be hard to work together if you are each going in different directions.
- Be flexible. When creating your management program, keep in mind your health care team's point of view as well as your own.
- Use common sense.
- Be sure you understand what you are agreeing to and why. If you are not sure what steps you are supposed to take, ask questions until you do. This will improve your commitment and drive to manage your health.

## DON'T

- Agree to do something you know you won't do. Other solutions are sometimes possible. Unless your health care professional hears you say that a treatment plan is hard for you to carry out, she or he will not know to make other suggestions.
- Be demanding or act in an inappropriate way. When your health care provider tells you how he/she wants you to manage a health problem and you disagree, don't just demand a change. After all, your physician is using their training and expertise to help you. If you have concerns, voice them in a clear and respectful manner. Disagreements can usually be resolved when you take this stance.
- Take things personally. If your health care professional says that you are not doing everything you should do, don't take the comment as an insult. Remember that he or she only wants to see you healthy. Instead, work **with** your physician to help solve the problem.
- Direct anger at your physician, nurse, or other health care worker. Doing so won't accomplish anything. It will not only interfere with working together, it may harm your relationship with the very people who are the most concerned, besides yourself, with your health.
- Get discouraged. Taking care of any disease or condition often requires adjustment and plenty of time. Successful treatment and having your concerns resolved takes patience on everyone's part.
- Finally, keep in mind that becoming good at performing any new skills – including acting assertively – takes practice and persistence. You will probably not reach your goal of being assertive right away. And, even if you act assertively, you may not always get what you want. Nevertheless, if you continue to try to be assertive, you will find that it eventually

becomes easier to interact with others and you should find that you are more satisfied with the results.

## **Summary**

### Basics of Communicating

- Decide what the goal of the conversation or communication will be
- Remember that different people in the conversation may have different goals
- Determine the best way to reach your goal or a shared goal
- Accept responsibility for your own feelings
- Give and accept feedback with an open mind and non-defensive manner
- Be Assertive: direct, respectful yet confident, proactive

## **Homework**

The homework for this section includes a helpful sheet to take with you to your next appointment with a healthcare provider. It can be especially helpful if you have long periods of time between visits. You can put your questions on the sheet as they come to you. It also acts as a good reminder of the plan your healthcare provider and you decided on during your last visit.

The second part of the homework is working through your communication strategy for solving a bowel or bladder problem.



## Module 5: Organization

### Screening Questions

- How easy is it to find things when you need them?
- What changes have you made in your environment to make things more accessible or convenient?
- How do you approach changing things or getting organized?

### Organization

To **organize** is to put something in an orderly system to make it easier to use. An example is grouping your books by subject or author to make them easier to find. Being able to plan and organize is a very important skill for individuals with SCI to have. Once you have the skill, you can begin to consider organizing your day around your bladder management schedule or planning and gathering what supplies you may need during the day so that you have them available.

Being more organized can save time and stress. Not needing to spend your time looking for something (your keys, paperwork, clothing or whatever happens to be lost) is a thing of beauty. Most people wish they could be more organized. Organization, though, takes time and deliberate steps.

### Steps to Organization

**Decide on a goal.** Don't try to organize every area of your life. Pick one or two areas and just start somewhere.

- **Prioritize:** By deciding what is important, you are making these **a priority**. One way to decide what is a priority is to think about what would happen if they did not get done? Is it something you could live with? If it is not, that should be your priority. Another way to prioritize is to figure out what you need to do in the next few hours and then make plans to be able to best accomplish that.
- Make a plan and decide how to organize. Use your self-monitoring skills to observe what you currently do as well as strengths and potential barriers. Or, check **what** you need to organize and find out more about it.

- Define categories based on issues/goals.
- Determine if you need to do things in order and what the order is.
- Figure out how much time each action may take – remember, it is better to allow more time than less
- Create a flowchart of what will happen to items in each category.
- **Break it down.** The idea of organizing is breaking something large into smaller pieces that are easier to handle. Be realistic about how much time something will take, how much time you have in any one sitting
- Schedule when you will do the actions. (This is important; otherwise you may not do it!)

### **Take Action**

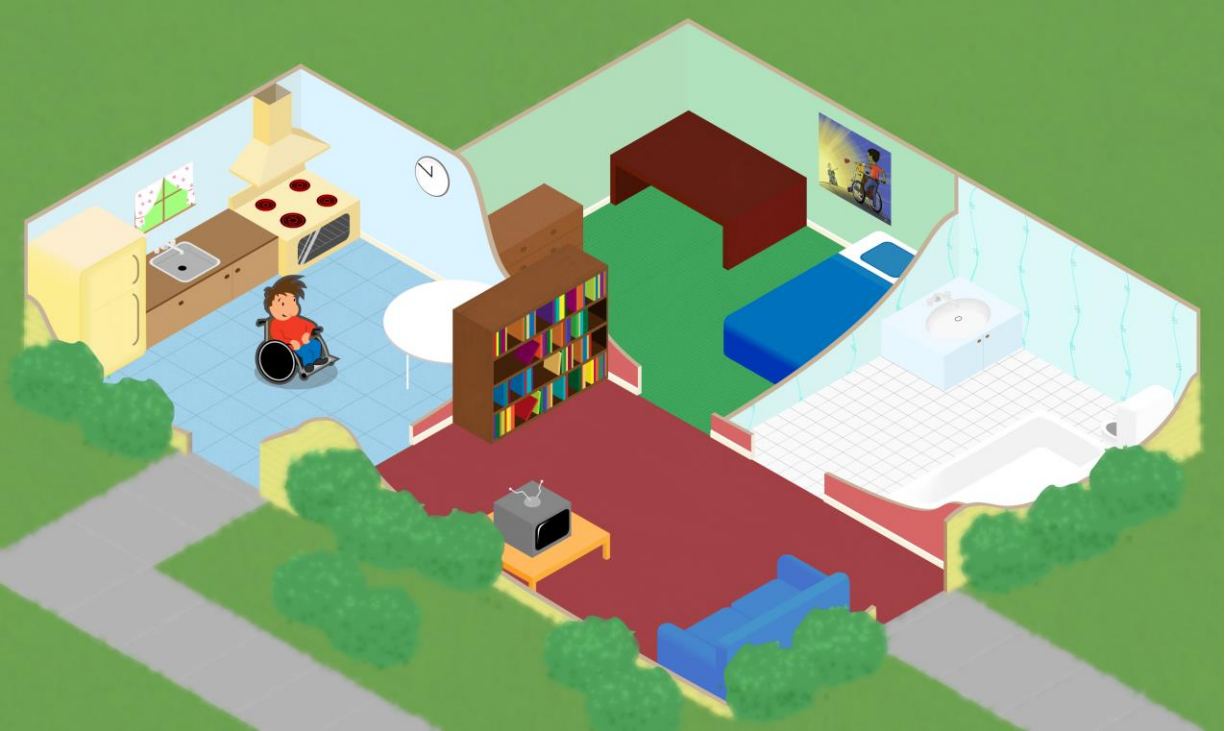
- Gather the materials you need
- Get rid of what you don't need
- Sort information/materials into categories
- Follow-through with planned action for each category

### **Maintenance:**

- Develop habits
- Deal with relapses (not keeping up your new way of organizing)
- Use the system you have developed to organize in the future (a different schedule, new information, or something else that you get.)

### **Organizing your home**

The setup of where you live is really important. You need to make the time to organize your environment so that it is accessible to you. This will save a lot of time, money, and stress down the road. Also, if your house is organized, you will be able to find your medical papers or self-monitoring diaries much more easily. Being organized can also help you prevent further injury.



- **Decide on a goal.** Don't try to organize your whole house at once. Pick one or two areas, like a room (your living room or closet). Or focus on "problem areas" that your wheelchair can't fit around.
- **Make a plan.** Spend some time thinking it through first. Consider what areas you use the most and what activities you want to or need to do in your space. Decide **how** to organize the items in a way that creates smaller units (chunks) that you can manage. Setting up an orderly system that makes sense to you is a first step and depends on what you are organizing.
- **Downsize first.** If you can **throw away** any of the items you are organizing, do so. You could throw away the old coupons or stale M & Ms in the drawer you are sorting out, get rid of clothes you don't wear from your closet or recycle the newspapers. Items can be thrown in the trash, recycled, donated to an organization, posted on Craigslist or given to a friend.
- **Gather supplies you will use.** You may want to use file folders, boxes, a marker or other items to help you sort things out. Remember, buying stuff for organizing is not the same as organizing! Extra shelves that allow you to put the supplies or stuff you need someplace you can easily reach can be a very good investment. Clear containers that you can label can also help you store things in an efficient manner.
- **Start somewhere.** Start on your plan when you have some time. You can set a timer to keep you on track or just do a small amount. Don't get distracted by the phone, TV or another project you need to do. Turn on music if that helps make it more fun. You might want to start with something like clearing pathways.

- **Keep at it.** Rome wasn't built in a day (an old saying) and you won't be organized right away either. Just keep trying to chip away at the mess a little at a time. If you schedule time regularly to work on it, before long you will make enough progress to see a difference.
- **Tweak if needed.** If the system doesn't work for you, try another. It needs to make sense to you and make your life easier.
- **Keep it up.** To stay organized, you have to build a new habit. You might want to make sure you go through the mail the day you get it, put things away after you get them out or whatever it takes to stick with your system. Realize that you will probably fall back into old habits. Rather than being hard on yourself, use your energy to go back and try again. Changing behavior is not easy!

### **Organize your schedule**

**Decide on a goal.** Planning ahead allows you to accomplish the stuff you need to do and set aside time for the things you enjoy.

**Break it down.** First, decide which appointments or tasks are most important to you – maybe spending time with your friends or children or your job. These are your priorities.

**Use the best tool for the job.** Figure out the best way to keep your schedule – it may be a wall calendar, planner, cell phone or other device that will be easy to update and check.

**Write them down.** Record the most important items on the day and time they need to happen. Then, add other things to your schedule. You can add things that happen at a certain time every day, appointments or a caregiver's hours, or time you set up to meet friends. Remember to allow some time for getting ready to leave the house and get to where you need to go.

**Combine things.** Allow some time in between events if you can. You can also chunk shorter or related things together, such as a trip to the post office, grocery store and a government office. This way you won't have to get transportation for each errand separately.

**Get rid of what you don't need.** Leave out or cancel activities that don't seem worth your time.

**Add anything else.** What else do you need to put in a schedule? Scheduling something can make it more likely you will get it done. This can be activities you enjoy (lifting weights, getting outside, time with your family or a TV show) or ones that feel like more of an obligation (exercise, homework or time with your family.)

**Check it twice.** Be sure that you check your schedule both in the morning and at night. That way you won't overlook something that was planned.



The benefit of organizing your schedule is that you can make the most of the time you have available. You don't have to be perfect, but knowing what you have to do each day and not forgetting it can make life both easier and simpler.

## **Summary**

### Steps to Organizing

- Decide on a goal
- Prioritize
- Make a plan
- Break it down
- Schedule when you will do the actions
- Action
- Maintenance

Good organization skills can be critical for an individual with SCI remaining healthy.

## **Homework**

Choose 2 of the 3 homework assignments that are in the *Homework* section.

- Organize your day in detail all the way down to pressure reliefs.
- Describe your current bowel or bladder management routine. Put the steps in order and don't forget to include critical steps such as washing your hands. If someone else assists you with part or all of the process, you should review your understanding of the process with whoever that assists you.
- Make up a packing list for a weekend away from home. What things will you need to take with you? What items could you not easily replace if you forgot them?





## Module 6: Stress Management

### Screening Questions

- What things cause you to feel stress?
- How do you experience stress in your body?
- How do you deal with stress and tension when you can't change the situation?

### Introduction to Stress Management

Sometimes it's hard to recognize that you are feeling "stressed out" or having a problem that may be related to stress. In these cases, you may just feel tense or irritable. These may be signs that you are feeling the effects of stress. Other signs of stress include headaches and fatigue (feeling tired). Because many symptoms of stress can also be signs of physical problems, it is important to consider possible physical causes before relating your symptoms to stress. If your symptoms are the result of physical illness (such as a UTI), you will most likely have other symptoms as well.

When you have strong emotions, you have to do something with them. If they get trapped in your body, they can affect your health. Anger and feelings of helplessness have been associated with heart conditions and poorer health management.

Once you decide your symptoms are stress-related, the first step in self-management is to **identify what the problems is**. Once that is done, your choices consist of solving the problem, changing the situation, or changing the way you feel about situation.

Problem-solving is the skill that helps you figure out how to change or take action in a given situation. Stress management, though, is more associated with releasing the emotion that is built up inside of us. The primary ways of doing this include **relaxation, reframing, distraction, prayer, exercise, and communicating effectively with others**. These are focused around one or a combination of the following:

- Relaxing the body: actually relaxing muscles
- Calming the mind: slowing or gaining control of thoughts
- Refocusing attention: shifting energy to different directions
- Soothing the soul: tapping into religion, spirituality, or comforting and life-affirming beliefs
- Building on strengths and supports: finding ways to feel good about ourselves

**In addition, make sure that you avoid the following [22]:**

- Not getting enough sleep
- Allowing your physical environment to become too chaotic with many distractions and a lot of noise; allowing the environment to remain inaccessible
- Not finishing what you start
- Letting everything catch your interest and distract you from what really needs to be done
- Allowing other people to set (and keep re-setting) your goals and priorities

## **Relaxation / Stress-management strategies**

### *General Guidelines / Preparation*

There are several guidelines to follow when preparing to practice relaxation:

- Practice relaxation in a quiet, dimly lit place. The setting should provide little distraction and promote concentration. It is best to be away from other family members, and to have the radio, television, and other distracting devices turned off.
- Get in a comfortable position. Recline your chair or lay on a bed or other surface that fully supports your body. Remove contact lenses or glasses. It is best to close your eyes while practicing deep muscle relaxation. Remove any gum or candy from your mouth as it may serve as a distraction.
- Allow yourself at least 15 minutes to complete these relaxation exercises, although more time may be needed during the first few practice sessions.
- A stressful situation is not the time to practice this technique – that is the time to apply a skill. In order to develop the skill, you will need to have trained your body/muscles and made relaxation a habit.

## **Deep breathing**

Deep breathing involves refocusing attention to calm the mind and relax the body. When you direct attention to your breathing, other thoughts are left to drift to the back of your consciousness. The method of deep breathing you will be taught includes a technique called **pursed lip breathing**. Pursed lip breathing is a way of breathing out that helps remove air trapped in your lungs. Let's review the steps involved in deep breathing and pursed lip breathing.

- If you can, put one hand on your chest and the other hand on your stomach.
- Close your eyes and turn your attention towards your breathing, letting the sights and sounds of the room fade away. Focus your attention on the feeling of the air as it rushes in, cool and crisp, and rushes out, warm and moist.

- Breathe in through your nose and push your stomach out, making it round like a ball. Try to keep your chest still as you breathe in.
- Then slowly blow all the air out through your mouth with your lips puckered. Use the hand on your stomach to help push all the air out. Your stomach should be flat after you have exhaled all the air you can.
- Make breathing out last for the same amount of time or longer than breathing in. For example, try breathing in for 3 seconds and breathing out for 4 seconds. Count to yourself as you both inhale (1, 2, 3) and exhale (1, 2, 3, 4).
- Try to keep your chest still, breathing in through your nose and breathing out slowly through puckered lips.
- Breathe deeper and slower with each breath. Imagine your lungs are balloons that inflate and deflate. Try to breathe out a little more air with each breath.

Slowly practice the deep breathing exercise ten or more times before moving on to the deep muscle relaxation. Continue deep breathing until your breathing has slowed down and you begin to feel more relaxed. This can take from 30 seconds to 5 minutes. The more you practice the technique, the more quickly you will be able to slow down your breathing and feel relaxed.

## **Imagery**

Have you ever found yourself lost in a daydream or fantasy? If you have, then you know the power of imagery. It combines relaxing the body, calming the mind, refocusing attention and, depending on the scene or image, soothing the soul. The use of imagery as a relaxation method starts with thinking about a pleasant image or scene. You might imagine yourself on a beach on a warm summer day or in a pine forest in the springtime. Whatever image you chose should be calming and soothing and of a place where you can feel safe and relaxed. Your relaxing scene will be different than anyone else's. You may wish to have other people with you in your daydream or you may wish to be alone. Think about any image that helps you feel relaxed.

Focus on a relaxing scene for several minutes. If you cannot think of a relaxing scene at first, use the imagery described here. Notice the detailed description of the scene. Try to imagine such details in any relaxing scene you choose. Enjoy the image with all your senses: sight, sound, touch, smell, as well as other physical and emotional sensations.

*You now feel relaxed in all the muscles in your body. Focus on the warmth that comes with this relaxation. As you become swept away in these soothing feelings, begin to imagine a beach on a tropical island. It is a warm day, but not too hot. There is a soft breeze blowing. It is late morning. You wander down to the beach after waking slowly and leisurely.*

*The palm trees sway gently overhead. The sand is clean and white. The sea is calm and bright blue-green as far as you can see.*

*You can hear the soft sounds of the surf and the gentle rush of the wind through the palms. The sun shines gently upon you, warming your face, your neck, your chest and your legs. Soak up the soothing rays of the sun as it caresses your skin. Feel the warm sand beneath you. Wiggle your feet, feel the sand between your toes – soft and smooth.*

*Inhale deeply and fill your lungs with the warm, moist ocean air. What a wonderful feeling – at peace. Feelings of relaxation flow over you as the waves gently wash over the sand.*

Continue with any other related images that will complete the scene for you and make it relaxing.

*Okay, now it's time to end this session. Do this slowly. Allow your eyes to remain closed. Slowly count to four. As you do, you will become more alert and aware of the room around you, but you will also continue to feel relaxed. One, softly move your hands and arms around to wake them up. Feel the fabric beneath them. Two, gently move your feet and legs around, feel the floor (or bed or chair) beneath them. Three, slowly move your head and neck. Allow the sounds of the room to come back to you. Four, open your eyes and sit up slowly. Allow yourself to adjust to the lights in the room. Notice that even as you become alert, the feelings of relaxation are still with you. To the extent possible, move around and gently stretch.*

## **Distraction**

Distraction is a means of refocusing or redirecting attention by putting something else in its place. In order to be considered a stress-management technique, though, what you use to distract you should be something relaxing and enjoyable. You also want to make sure that taking your mind off the situation and letting your body unwind a little will make things better and not worse. Typical things used for distraction may include:

- Music
- Video-games
- Reading
- Conversation
- Laughter
- Television / movies
- Writing
- Playing

## **Soothing the soul**

**Prayer:** For many people, prayer (usually addressed to *God* - whomever they perceive that to be - or a higher power) is what brings relief. Sometimes the prayer is for a cure; sometimes it is for strength. Almost always, it is about asking for assistance in dealing or changing the current situation. To the extent that prayer is a way of giving up worries or handing them over, it can be

a wonderful method of reducing stress. However, for this to work requires trust and faith that someone is listening and that s/he cares and will help in some way. Prayer can be performed alone or as part of a group or community.

**Meditation** is a group of practices done by an individual for the purpose of self-transformation[23] or to gain serenity. In general, meditation involves connecting with your pattern of breathing and freeing the mind to just **be** in the moment. By letting go of plans, worries about the day or what you have to do next, or any thoughts of being judged or pressured, you can begin to allow yourself to become re-centered. Many use this as a way of connecting to



their higher power or re-connecting to themselves. If you are interested in learning meditation techniques, you can look for a class. Try looking on-line for information. Instruction in meditation is often found in churches, martial arts and yoga studios and at medical centers.

**Rituals** are defined as a set of actions, performed mainly for their symbolic value, which are prescribed by a religion or by the traditions of a community.[24] People are often taught the meaning and steps to rituals that are important in their family, culture or religion. The rituals then become associated with a sense of identity, emotional or spiritual connection or rite of passage. Common rituals within U.S. culture include the graduation ceremony, getting a drivers' license or singing the Star Spangled Banner at the start of a baseball game.

When you have a SCI or other impairment, rituals can become a way to re-establish a sense of connection. This connection can be relating the person you are now with the one you were prior to your injury, or it can reinforce your connection with your family, your church or your society. Performing the steps of the ritual go beyond carrying out a routine and allow you to connect – often on an emotional or spiritual level – with something beyond yourself and the moment. Rituals can provide reassurance and a sense of identify and support. Because of that, they are classified as a method of stress management that helps *soothe the soul*.

### **Building on strengths and supports**

**Nothing feels quite as good as succeeding.** By doing things that you are good at, you get a sense of accomplishment and well-being that does a lot to reduce stress and improve your sense of self-worth. Other activities that make a difference are those that help other people. So volunteer. Make time for things you are good at.

**What do you think you can teach yourself?** This may have changed since your injury, but learning how to do some things for yourself provides a sense of independence and strength. If your goal is something physical, this is exactly where the healthcare system comes into play. Both physical and occupational therapists have a goal of helping you to improve functioning, and s/he will teach you how to teach yourself.

## **Building a Supportive Network**

**Everyone needs people in their life.** How *many* people really depends on your personality. Individuals who are introverts may need less people around – they get their energy and enjoyment from an internal world and just feel comfortable and relaxed around a small group of individuals. Those who are extroverts may do better with lots of people. For them, life is about relating to people and reinforcement and enjoyment is gotten by interacting with other people.

**It is important that you recognize the different roles that people play in your life.** Nobody is good at everything and no one person can give you everything you need with regard to support, assistance or affirmation. Some people may be good at listening and providing emotional support; others at practical activities. Still other people may be great at distracting you and helping you get along better with others.

If you are looking to build the most supportive network of people you can in order to help you deal with your injury, it's worthwhile to consider what you are good at and what other people are good at. This way, you'll be able to split things up so nobody is too overwhelmed.

Some questions to consider: (hint: the answer could be you for one or two of these things!)

- Who is good at helping out around the house?
- Who is good at organizing medical information/understanding doctors?
- Who is a good person to get advice from?
- Who is the best listener?
- Who is the best to just chat with or go out and have a good time with?
- Who has the most free time in the morning / afternoon / evening / weekend
- Who has a really specific, helpful skill?
- Who could I count on in an emergency?

## **Resilience**

Everyone has tough times in their lives; some, more than others. Even if you have an unsupportive family, there are still ways to build a supportive network of people. According to current studies, even people who grow up neglected or abused can still have good lives and supportive networks if they have these three critical things [25]:

- Caring Relationships: The people with whom you develop supportive relationships can be family members, but they can also be friends, significant others, neighbors or people who act as role models, such as a coach or a teacher. These individuals help you grow and show respect and appreciation for the person you are. If someone makes you feel like you matter, maybe by including you in social events at accessible places, that person is likely an important part of your support system.



- High Expectations: Most people need help figuring out what they want from life and need people who will believe in them and give them (or help them find) a structure in which they can learn, make mistakes, and try again. For example, those people who expect you to be able to figure out how to continue to be a father, employee or spouse after your SCI may be helping you develop resilience. It is not that they do not recognize the challenges involved, but they are reaffirming an expectation and a goal that you will continue to actively contribute to relationships and that you will find new ways to do things if needed. Too often in our society, expectations associated with disability are negative and people's attempts at encouragement and support are limited to "I know that you will be able to walk again" and/or "return to normal soon". In this situation, though, true resilience involves establishing a new "normal", reprioritizing, and moving forward to be involved and find (and fulfill) a purpose.
- Opportunities for Participation and Contribution: People have the chance to participate in their own lives (instead of just observing others and following rules) and contribute to the community. Creative outlets can do this, as can participation in community organizations that do something relevant to you. A person who cares about you and believes in you can (and likely, will) help you find an activity that you like and helps you feel connected. Having a sense of purpose and responsibility – be it a job or volunteer work or a pet that needs care– gives you a reason to wake up in the morning. It also justifies the amount of energy and planning that is required to get yourself together and moving.

This is a three-part recipe that is really hard to carry out, but the first question in building support network is: *Who makes me feel like I matter?*

## **Gratitude Journal**

Gratitude is another way of saying thanks. One of the common "threads" among the world's major religions is a belief that gratitude is very important. And gratitude doesn't have to have a religious basis, either. Just being happy for what you have is a great start. Research shows that noticing what you're thankful for can benefit both your physical and emotional health. Some newer studies in psychology have shown that "counting your blessings" and being thankful can actually have positive health effects [26, 27].

So what is gratitude? It is a sense of thankfulness and joy in response to receiving a "gift". That gift can be an actual object or a good thing that happened, like a pretty day that you got to spend outside. And gratitude invites more gratitude. The more you try to notice your blessings, the more of them you notice, and the more thankful you are.

Even though injuries and chronic conditions are very difficult, there is probably at least something you can be grateful for. Feel free to start small. Little things mean a lot. If you were happy to have a friend visit you in the hospital that is a start. If you're really stuck, you may want to ask a friend or family member something like "was there anyone who worked at the hospital back when I was there that was really nice to me and good at their job?"

Another way you can find out what your blessings are is to think of what you are good at. Are you honest, accepting, and willing to try new things? There are many other good traits out there. How have these traits helped you? Have they gotten you through tough times? What is your family good at? That is something to be thankful for as well.

A gratitude journal is a method of stress management. After experiencing something stressful, thinking about what is good in your life is a great way of distracting yourself and making yourself stronger for the next hard things that may come your way. Counting your blessings works ahead of time.

Finally, feel free to combine gratitude journaling/recording with other stress management tips. If you are exercising to combat stress, you can of course be thankful for your progress in exercise and fitness. If you belong to a house of worship, they probably talk about gratitude a lot, and you can thank them for giving you a jump start on some ideas!

### **Summary**

It is important to take time out each day to relieve the mental, emotional, and physical stress that builds up. You will need to find what methods of stress release work best for you and practice! Some of these techniques take time to develop. On the flipside, make sure you aren't bringing unnecessary stress into your life.

### **Homework**

Try out a stress management technique that you have never done before. Discover what works best and always seek out new ways to safely manage stress.

# Homework

## ATTITUDE HOMEWORK

This homework assignment is designed to help identify what kinds of expectations and assumptions you have about yourself and others. Building a proactive approach to managing your health begins by making sure your expectations are reasonable. Becoming aware of assumptions that you may be making is a good step—be sure you check them against reality.

### Check which assumptions you make about disability or people who have a disability:

- Anyone who uses a wheelchair is broken and not whole
- People who cannot walk are helpless and worthless
- People with disabilities learn creative ways of accomplishing their goals.
- People with disabilities are powerless
- If you can't walk, you can't do anything
- Things take more time when you are paralyzed
- People in wheelchairs are not sexually active
- A man who uses a wheelchair is no longer a complete man
- It is better to be dead than disabled
- People in wheelchairs are just people who travel through life sitting down.
- Life is not worth living if you have a disability
- Women with disabilities cannot get pregnant or bear children.
- If you have a disability, you shouldn't have to work.
- People with disabilities make bad parents.
- Life is more challenging with a disability
- If you have a disability, others have to help you
- People with disabilities are inferior
- People with disabilities are freeloaders
- If you can't walk, you are just a burden to friends and family
- All people in wheelchairs are mentally ill
- You can't really make assumptions since every person is different

### Check which assumptions you make about your health care provider

- If my provider says he/she will do something, he/she will always follow through
- If my provider calls me after an appointment, something must be wrong
- Physicians are like parents
- Health care people are service providers – they work for and answer to me
- My physician can fix / cure me
- Everything that the physician prescribes will work right away
- Health care providers have unlimited time to spend answering all of my questions
- Physicians can tell how much pain I have
- The first medicine I am given will almost always work
- Physicians can be reached at any time; or if not right away, then within an hour.

<b>Bladder Management Records</b>						
<b>Date</b> / /		<b>Date</b> / /		<b>Date</b> / /		
<b>Time</b> : v AM PM		<b>Time</b> : v AM PM		<b>Time</b> : v AM PM		
<b>Amount</b>	<b>Color</b>	<b>Amount</b>	<b>Color</b>	<b>Amount</b>	<b>Color</b>	
Low	Light	Low	Light	Low	Light	
Normal	Normal	Normal	Normal	Normal	Normal	
High	Dark	High	Dark	High	Dark	
<b>Odor</b>		<b>Odor</b>		<b>Odor</b>		
Normal	Bad	Normal	Bad	Normal	Bad	
<b>Date</b> / /		<b>Date</b> / /		<b>Date</b> / /		
<b>Time</b> : v AM PM		<b>Time</b> : v AM PM		<b>Time</b> : v AM PM		
<b>Amount</b>	<b>Color</b>	<b>Amount</b>	<b>Color</b>	<b>Amount</b>	<b>Color</b>	
Low	Light	Low	Light	Low	Light	
Normal	Normal	Normal	Normal	Normal	Normal	
High	Dark	High	Dark	High	Dark	
<b>Odor</b>		<b>Odor</b>		<b>Odor</b>		
Normal	Bad	Normal	Bad	Normal	Bad	

# Bowel Management Record

Date	/	/	
Time	•	•	AM PM
Productive	Yes		No
Consistency	Loose	Normal	Hard
Amount	Low	Average	A Lot
Changes to Diet?			None
IF accident(s), what time?			AM PM
	•	•	AM PM
Changes to Bowel Program?			N/A

### **Food / Meal Tracking**

\*\* Put NA (not applicable) if you did not eat that meal

Day / Date:

Meal	Time	What Eaten	Mood Before Eating
Breakfast			
Snack			
Lunch			
Snack			
Dinner			
Snack			
Other:			

Day / Date:

Meal	Time	What Eaten	Mood Before Eating
Breakfast			
Snack			
Lunch			
Snack			
Dinner			
Snack			
Other:			

Day / Date: \_\_\_\_\_

Meal	Time	What Eaten	Mood Before Eating
Breakfast			
Snack			
Lunch			
Snack			
Dinner			
Snack			
Other:			

Day / Date: \_\_\_\_\_

Meal	Time	What Eaten	Mood Before Eating
Breakfast			
Snack			
Lunch			
Snack			
Dinner			
Snack			
Other:			



# Problem Solving Homework

Choose a problem from your life and work through the steps. You should choose a problem that you don't already have an answer for!

**State the problem**

**Outline the problem**

Possible Solutions	Pros & Cons (Consequences)	Rank
	Pros:	
	Cons:	
	Pros:	
	Cons:	
	Pros:	
	Cons:	
	Pros:	
	Cons:	

**Try your solution**

**Evaluate if your solution was effective**

## **Practice Emotional Problem-Solving**

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**State the problem**

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**Observe your thoughts**

---

**List your emotions**

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**Check / Challenge your assumptions**

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**Re-evaluate your emotions**

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# Appointment with Healthcare Provider

**Date:**  
**Place:**

**Time:**

**Items to bring to appointment:**

- self-monitoring forms
- questions
- medications
- other:

**Primary goal/purpose of visit:**

**To be completed by patient prior to appointment:**

**Patient concerns:**

- |                                      |  |   |
|--------------------------------------|--|---|
| <input type="checkbox"/> Pain        | <input type="checkbox"/> Bowel         | <input type="checkbox"/> Bladder              |
| <input type="checkbox"/> Medications | <input type="checkbox"/> Skin          | <input type="checkbox"/> Physical Functioning |
| <input type="checkbox"/> Exercise    | <input type="checkbox"/> Recreation    | <input type="checkbox"/> Prevention           |
| <input type="checkbox"/> Sexuality   | <input type="checkbox"/> Relationships | <input type="checkbox"/> Mood / Emotions      |
| <input type="checkbox"/> Employment  | <input type="checkbox"/> Insurance     | <input type="checkbox"/> Sleep                |
| <input type="checkbox"/> Other:      | <input type="checkbox"/>               | <input type="checkbox"/> Diet                 |

Additional details/comments:

**Questions for provider**

- 1.
- 2.
- 3.

**Information Needed**

**To be completed with provider**

**Action plan (Negotiated between provider and patient)**

- Long term goal:
  
- Short-term goal:
  
- Trial period
  
- Signs to monitor:
  
- When to call / contact provider:

**Potential barriers and solutions brainstormed:**

**Confidence that patient will be able to follow plan**

(1=not at all confident; 5= somewhat confident; 10=very confident that will be able to follow action plan):

1      2      3      4      5      6      7      8      9      10

**Take home points (To be summarized by patient if they are able and reviewed by provider)**

**What is my main problem?**

**What do I need to do?**

**Why is it important for me to do this?**

## Communicating to Solve a Bowel / Bladder Management Problem

**Problem you are trying to resolve:**

**Who will you be communicating with?**

**What is the goal or point that you want to get across?**

**How are you feeling about this issue? How does this feeling affect the way you might communicate?**

**What do you think the other person's goal might be?**

**What factors need to be considered? Are there things you need to do or avoid doing to keep this person connected and engaged?**

**What might be one way to reach your goal or shared goals?**

**Are there other ways?**

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## **Organizing Your Bowel / Bladder Management Routine**

Outline the steps of your routine

**Before:**

**During:**

**After:**

# Organizing for a Day Trip

What things do I need to take with me?

## **Bowel**

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## **Bladder**

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## **Mobility**

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## **Medicine**

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## **Clothing**

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## Sample Schedule for Bowel Management and Intermittent Catheterization

Time Frame	Required Cares / Activity	Equipment or Assistance needed
Midnight- 12:30am	Cath (ISC)	Catheter; gloves; urinal
12:30am – 1am		
1am – 1:30am		
1:30am – 2am		
2:am – 2:30am		
2:30am-3am		
3am – 3:30am		
3:30am – 4am		
4am-4:30am	Cath (ISC)	Catheter; gloves; urinal
4:30am – 5am		
5am – 5:30am		
5:30am-6am		
6am-6:30am		
6:30am-7am		
7am - 7:30am		
7:30am – 8am	Wake up	
8am-8:30am	Cath (ISC);	Catheter; gloves; urinal
8:30am-9am	Take medications; Eat breakfast	Medications
9am – 9:30am	Perform bowel program	Assistance to transfer to commode; gloves; suppositories
9:30am – 10am	Bowel program (continued)	
10am-10:30am		
10:30am-11am		
11am-11:30am		
11:30am-noon		
noon- 12:30pm	Cath (ISC)	Catheter; gloves; urinal
12: 30pm – 1pm		
1pm – 1: 30pm	I	
1: 30pm – 2pm		
2:pm – 2: 30pm		
2: 30pm -3pm		
3pm – 3: 30pm		
3: 30pm – 4pm		
4pm-4: 30pm	Cath (ISC)	Catheter; gloves; urinal
4: 30pm – 5pm		
5pm – 5: 30pm		
5: 30pm -6pm		
6pm-6: 30pm		
6: 30pm -7pm		
7pm - 7: 30pm		
7: 30pm – 8pm		
8pm-8: 30pm	Cath (ISC)	Catheter; gloves; urinal
8:30pm -9pm		
9pm – 9: 30pm		
9:30pm – 10pm		
10pm-10: 30pm		
10:30pm -11pm		
11pm-11: 30pm		
11: 30pm -midnight		



## Fill in the Schedule with Your Activities

Time Frame	Required Cares / Activity	Equipment or Assistance needed
Midnight- 12:30am		
12:30am – 1am		
1am – 1:30am		
1:30am – 2am		
2:am – 2:30am		
2:30am-3am		
3am – 3:30am		
3:30am – 4am		
4am-4:30am		
4:30am – 5am		
5am – 5:30am		
5:30am-6am		
6am-6:30am		
6:30am-7am		
7am - 7:30am		
7:30am – 8am		
8am-8:30am		
8:30am-9am		
9am – 9:30am		
9:30am – 10am		
10am-10:30am		
10:30am-11am		
11am-11:30am		
11:30am-noon		
noon- 12:30pm		
12: 30pm – 1pm		
1pm – 1: 30pm	I	
1: 30pm – 2pm		
2:pm – 2: 30pm		
2: 30pm -3pm		
3pm – 3: 30pm		
3: 30pm – 4pm		
4pm-4: 30pm		
4: 30pm – 5pm		
5pm – 5: 30pm		
5: 30pm -6pm		
6pm-6: 30pm		
6: 30pm -7pm		
7pm - 7: 30pm		
7: 30pm – 8pm		
8pm-8: 30pm		
8:30pm -9pm		
9pm – 9: 30pm		
9:30pm – 10pm		
10pm-10: 30pm		
10:30pm -11pm		
11pm-11: 30pm		
11: 30pm -midnight		



## References

1. Barlow, J., et al., *Self-management approaches for people with chronic conditions: A review*. Patient Educ Couns, 2002. **48**: p. 177-87.
2. Creer, T.L. and K.A. Holroyd, *Self-management of chronic conditions: the legacy of Sir William Osler*. Chronic Illness, 2006. **2**: p. 7-14.
3. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Acute management of autonomic dysreflexia : adults with spinal cord injury presenting to health-care facilities*. 1997, Washington, DC (801 Eighteenth St., NW, Washington, D.C. 20006): Paralyzed Veterans of America. viii, 19 p.
4. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Prevention of thromboembolism in spinal cord injury*. 1997, Washington, DC (801 Eighteenth St., NW, Washington, D.C. 20006): Paralyzed Veterans of America. vi, 20 p.
5. Paralyzed Veterans of America., *An introduction to spinal cord injury : understanding the changes*. 3rd ed. 1997, Washington, DC: Paralyzed Veterans of America. 26 p.
6. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Autonomic dysreflexia : what you should know : a guide for people with spinal cord injury*. 1997, Washington, D.C.: Consortium for Spinal Cord Medicine, Paralyzed Veterans of America. ii, 14 p.
7. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America. *Neurogenic bowel management in adults with spinal cord injury*. 1998; x, 39 p.].
8. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Depression following spinal cord injury : a clinical practice guideline for primary care physicians*. Clinical practice guidelines, spinal cord medicine. 1998, Washington, DC: Consortium for Spinal Cord Medicine. xi, 35 p.
9. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Outcomes following traumatic spinal cord injury : clinical practice guidelines for health-care professionals*. Clinical practice guidelines. 1999, Washington, DC: Paralyzed Veterans of America. xii, 32 p.
10. Paralyzed Veterans of America. and Consortium for Spinal Cord Medicine., *Depression : what you should know : a guide for people with spinal cord injury*. Clinical practice guidelines. 1999, Washington, DC (801 Eighteenth St. NW, Washington, DC 20006-3517): Paralyzed Veterans of America. iii, 19 p.
11. Paralyzed Veterans of America. and Consortium for Spinal Cord Medicine., *Neurogenic bowel : what you should know : a guide for people with spinal cord injury*. Clinical practice guidelines. 1999, Washington, DC (801 Eighteenth St., NW, Washington, DC 20006-3517): Paralyzed Veterans of America. 51 p.
12. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Pressure ulcer prevention and treatment following spinal cord injury : a clinical practice guideline for health-care professionals*. Clinical practice guideline. 2000, Washington, DC (801 Eighteenth St., NW, Washington, D.C. 20006): Paralyzed Veterans of America. xiii, 80 p.

13. Hammond, M.C., S.C. Burns, and Paralyzed Veterans of America., *Yes, you can! : a guide to self-care for persons with spinal cord injury*. 3rd ed. 2000, Washington, D.C.: Paralyzed Veterans of America. vii, 235 p.
14. Consortium for Spinal Cord Medicine. and Paralyzed Veterans of America., *Acute management of autonomic dysreflexia : individuals with spinal cord injury presenting to health-care facilities*. 2001, Washington, DC (801 Eighteenth St., NW, Washington, D.C. 20006): Paralyzed Veterans of America. xv,26 p.
15. Paralyzed Veterans of America. and Consortium for Spinal Cord Medicine., *Expected outcomes : what you should know*. Clinical practice guidelines. 2002, Washington, DC (801 18th St. NW, Washington, DC 20006-3517): Paralyzed Veterans of America.
16. Paralyzed Veterans of America. and Consortium for Spinal Cord Medicine., *Expected outcomes : what you should know : a guide for people with C7-8 spinal cord injury*. 2002, Washington, DC: Consortium for Spinal Cord Medicine, Clinical Practice Guidelines. 19 p. (loose-leaf).
17. Burns, S.F. and M.C. Hammond, eds. *Yes, You Can! A Guide to Self-Care for Persons with Spinal Cord Injury*. fourth edition ed., ed. P.V.o. America. 2009.
18. NSCISC (2009) *Spinal Cord Injury Facts and Figures at a Glance*.
19. Cabana, M.D., et al., *Impact of physician asthma care education on patient outcomes*. *Pediatrics*, 2006. **117**(6): p. 2149-57.
20. Clark, N.M., et al., *Impact of education for physicians on patient outcomes*. *Pediatrics*, 1998. **101**(5): p. 831-6.
21. Clarke, N. *Physican Asthma Care Education Program*. 2006 [cited 2009 September 15, 2009.]; Available from: <http://www.nhlbi.nih.gov/health/prof/lung/asthma/pace/evidence.htm>.
22. Davidson, J., *The Complete Idiot's Guide to Managing Stress*. Complete Idiot's Guide. 1999: Alpha Books.
23. Wikipedia. *Meditation*. Wikipedia, the free encyclopedia 2009 [cited 2009 November 23]; Available from: <http://en.wikipedia.org/wiki/Meditation>.
24. Wikipedia. *Ritual*. [cited 2009 November 23]; Available from: <http://en.wikipedia.org/wiki/Ritual>.
25. Benard, B., ed. *Using Strengths-Based Practice to Rapt the Resilience of Families*. Strengths Perspective in Social Work Practice, ed. D. Saleebey. Vol. 4/e. 2006, Allyn & Bacon: Boston, MA. pp. 197-220.
26. Emmons, R.A. and M.E. McCullough, *Counting Blessings versus Burdens: An Experimental Investigation of Gratitude and Subjective Well-Being in Daily Life*. *Journal of Personality and Social Psychology*, 2003.
27. Froh, J.J., W.J. Sefnick, and R. Emmons, *Counting Blessings in Early Adolescents: An Experimental Study of Gratitude and Subjective Well-Being*. *Journal of School Psychology*, 2007.