

HEALTH MECHANICS

***Tools for the Self-Management of
Spinal Cord Injury and Disease***



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Health Mechanics

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Introduction to this Program

***Health Mechanics* is a program designed to teach individuals with Spinal Cord Injury and Disease (SCI / D) 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 you have to learn to manage both your health and your environment if you want 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 develop a toolbox that you can use to handle any situation.

What is self-management?

Self-management refers to the ability of an individual with a chronic condition to manage their health and its physical and psychosocial consequences². 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 environments³.

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 every day 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/D can and should expect to have 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 other books (such as the *Yes You Can!* Guide), and from other people living with a disability.

Why is this important?

When living with SCI / D, 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. Unfortunately, **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 towards developing skills that will last a lifetime!

How to use this manual

This program is written so that it can be used either by individuals with SCI / D or individuals who are working with them to facilitate skill development. It is written as a conversation or discussion with the individual with SCI/D who is reading or using the program. However, facilitators (be they family members, health care providers, peer mentors, or others) can also use this guide, either directly quoting or paraphrasing the language and concepts in this guide.

The program starts with a brief overview of the recommendations and guidelines for managing specific body systems. From there, each skill is discussed in depth and examples are provided. At the beginning of each of these sections, a series of screening questions are provided. These questions allow individuals with SCI /D and facilitators to consider the degree that someone has already developed and applies a particular skill. If responses show good understanding of the concept, less time or attention may be need to be spent on that section. On the other hand, if answers show limited awareness of the skills or demonstrate poor integration into daily activities, more time should be spent on the explanations and examples.

Levels of Self-Management Competency

Even after you have had the opportunity to read this program, you (or the individual with SCI / D you are working with) 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 like there is a difference from the typical car owner and the master mechanic, so individuals with SCI / D will have different levels of skill or competency in managing their condition and its physical and psychosocial 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 current level. Finally, level of adjustment and mental health status influence both ability and motivation to take on the responsibility of actively managing your health.

SCI SPECIFIC INFORMATION AND CONCERNS



Below are specific guidelines for managing your health that have been recommended by health care providers and professional associations.⁴⁻¹⁸ You may notice that there are a lot of recommendations. Since almost every body system is affected by spinal cord injury, it makes sense that you may need to monitor the ways that these systems now work and look for any problems. When people think about SCI/D, 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 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 those recommendations are?**
- **How important is each to your health, considering your personal risk factors, values, and history?**
- **Are you having any problems or concerns in these areas?**

Skin Care

- Goals: Prevent Breakdown; Keep skin clean and dry
- Self-Monitoring: Skin inspection twice a day; 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

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
 - Regulars 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: Monitor fluid intake (Maintain constant fluid intake to avoid infections; Minimize fluid intake); Monitor 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

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 you experience pain; What 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; Types of Pain (musculoskeletal, nerve, Central / Neuropathic, visceral, autonomic); 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 to a nerve and results in 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) results from internal organs (i.e., stomach, intestines or bladder) resulting 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 results from blood pressure rises rapidly to high levels in response to bladder over distension or some 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: Rate of / 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
- 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; Colo-rectal 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

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



SKILL 1: ATTITUDE AND EXPECTATIONS

Screening Questions

- What is your approach to life?
- How important is your attitude in managing health and taking charge of your life?
- What type of attitude do you think is best for being healthy and well?
- What motivates you to get up each day and get things done?

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 ¹⁹ 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** 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 ones 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 towards 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 less 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
- Outlooks: 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 will result in very different approaches and behavior towards a teacher.

The same thing happens in relationships. If you expect people to ignore us, 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

Assumptions

Assumptions are things you **assume** or accept as true without any 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 you make about being disabled or about people with disabilities?

When people see someone with an SCI, they might assume that they don't have a family or a job. What assumptions have you faced from other people since you have an obvious (or not) disability? How has this affected you? What assumptions do you yourself hold about having a disability? Do you believe your quality of life is automatically less because you have a disability? Do you believe that all individuals with disability are depressed? Is there anything you now do differently because of these assumptions?

Completing the Assumption Exercise will help you identify what assumptions that you or others may have about people with disabilities. You must look at what your own assumptions to see how they affect you. If you really think that people with disabilities do not get married, then you are unlikely to ask someone out on a date. If you assume that others *have* to help someone with a disability, you may not bother being polite to them. If you think all people with disabilities are depressed, you might not seek treatment if you feel this way.

What assumptions do you have about disability or people who have a disability?

- Anyone who uses a wheelchair is broken and not whole
- People in wheelchairs are just people who travel through life sitting down.
- People who cannot walk are helpless and worthless
- People with disabilities are powerless
- If you have a disability, you are no longer the person you were
- If you can't walk, you can't do anything
- Just because an individual uses a wheelchair does not mean that they cannot walk.
- Things can take more time when you are paralyzed
- If you have a disability, life is over
- 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 then disabled
- Life is not worth living if you have a disability
- If you have a disability, you shouldn't have to work
- Life is more challenging with a disability
- People with disabilities make bad parents.
- If you have a disability, others have to help you
- People with disabilities are inferior
- People with disabilities learn creative ways of accomplishing their goals.
- People with disabilities are freeloaders
- If you can't walk, you are just a burden to your friends and family
- All people in wheelchairs are mentally ill
- You can't really make assumptions, every person is different

Before you can change your behavior and develop healthy attitudes and lifestyles, 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.

Outlooks

An outlook is the way that you look at things. It is your overall sense of the world and 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 psychologist
- Spend time with people who have positive outlooks
- Make connections with people living successfully with a SCI or other disability
- Read books about individuals who are coping and living successfully with a disability

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

Attitude and interacting with health care providers

When dealing with health care professionals, think about how you want that attitude 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, you have to realize that doing so will have consequences. **It is also important to recognize that they do not have to work with you**. They can refer your care to someone else if they believe you are a "problem personality".

Expectations are beliefs that people should behave in a certain way.

Which of the following statements reflect expectations that you have of your health care provider?

- My provider will be timely
- My provider will be competent
- My provider will be thorough
- My provider will be attentive
- My provider will be compassionate
- My provider will be honest
- My provider will be caring / interested in my care
- My provider will be want to improve my life
- My provider does not really care, they are just in it for the money
- My provider is a professional, and I value his or her advice
- My provider will give their complete attention to my problem
- My provider is an expert in treating individuals with SCI, and familiar with all the issues / concerns that I will have
- My provider will be able to help me improve functioning
- My provider will work to the best of his or her ability to help me optimize functioning

Which statements reflect expectations that you have of yourself with regard to your interaction with the health care system?

- 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.

Assumptions are things that you take for granted or accept as true without proof (i.e., suppositions).

What assumptions do you think you may make about your health care providers?

- If my provider does not ask me something, it must not be important
- If my provider says they will do something, they will
- If my provider calls me after an appointment, something is really wrong
- My physician will be disappointed in me if I come in with a problem or do not succeed in doing something that they explained
- Physicians are like parents
- I will just tell physicians what they want to hear
- Health care personnel are service providers – they are responsible and answerable to me
- My physician can fix / cure me
- Health care providers do not make mistakes
- Everything that the physician prescribes will work right away
- Health care providers have an unlimited amount of time to spend answering all of my questions
- Physicians just know how much pain I am in
- The first medicine I am prescribed will almost always work
- Physicians can be reached any time and if not immediately available, will respond within an hour

After you complete this exercise, consider showing it to your health care provider to see how your assumptions and expectations match with theirs. The closer the match, the more likely that the relationship will work smoothly.



SKILL 2: SELF-MONITORING

Screening Questions

- What things are important to keep track of?
- How do you keep track of them?
- How do you use this information to improve your decisions about health?

Self-Monitoring

To **monitor** something means to observe and record what is regularly happening. If you keep track of something about yourself, such as your emotions or your bodies' 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

Monitoring what happens to you is crucial because all other self-management skills depend on it. Good information to observe and record may involve any or all of the guidelines previously mentioned. You may be able to think of others.

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.

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.

An easy way to keep track of what you monitor is to write it on a calendar. That can also be a reminder to *keep* writing it down and tracking the information.

Appendix B contains self-monitoring forms that you can use.

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, you may want to keep monitor bladder or bowel management activities. You may start by keeping track of the time and your ability to perform your management regimen on a specific schedule. Then you can begin notice details; the self-monitoring forms in the appendices can help with this process.



Another 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 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.



SKILL 3: PROBLEM-SOLVING

Screening Questions

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

Problem Solving

For most people who did not get the *User's Guide to Life* or who don't have someone to tell them what to do all the time, learning to solve problems is what gets them through the day. They learn to use what they know and the skills that they already have to figure out how to get something done, usually with a particular result in mind.

Problem Solving allows you to deal with the world by deciding what the problem is, creating 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. No doubt you have had to problem solve at many times in your life.

There are many different formats that can be used to help you consider and work through problems. The one presented here is based on a format developed in 1991 for an Asthma Self-Management Program.²⁰

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/D 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.

If you are teaching this skill to someone else, it is critical that the individual with SCI /D identify the problem. If the issue is not important to them or not causing some emotional distress, they will not bother to change what they do.

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 question challenge some of the assumptions that you have made. Don't throw out any solutions right away, not matter how nutty they may seem. Come up with at least three solutions. Later, you could 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 or 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.

Once again, when assisting someone else in problem-solving, it is critical that they generate solutions, articulate the positive and negative effects of each, and then help rank them. The individual with SCI is the one who knows what else is going on in their life. It is their perceptions of feasibility and convenience of a solution that will impact whether or not it is carried out.

If you have solutions you think they should try, ask their permission to suggest some before stating them¹. Problem-solving is a critical skill that the individual with SCI must learn and a process they must become invested in.

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. Then 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. And, if it worked at least in part, figure out when it helped and when 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: Community Mobility



<p>State the problem: I want to go out to the mall, but I get so tired.</p>		
<p>Outline the problem: Going out into the community takes a lot of energy. Somewhere like the mall means a lot of walking. Plus there are a lot of obstacles that I have to deal with.</p>		
Possible Solutions	Pros & Cons (Consequences)	Rank
Don't go. Ask someone else to get you what you need.	<p>Pros: Will save energy and still get what need.</p> <p>Cons: Getting really tired of the house. Also, want to pick out my own stuff. Plus, I can see friends when I go to the mall.</p>	
I'll take short-cuts when possible. Use elevators or escalators if they are going to make things easier.	<p>Pros: Save a little energy. Still get to go out and see friend.</p> <p>Cons: Not taking the opportunity to practice stuff like stairs.</p>	1
I can use a wheelchair rather than my crutches.	<p>Pros: The wheelchair will make it easier to get around the mall and save energy. Will be better able to carry stuff.</p> <p>Cons: Will be hard to use escalators and get up curbs. I feel better about myself when I use the crutches.</p>	2
<p>Use & Evaluate your solution This time, I'll use the crutches and see how it goes. I'll keep the wheelchair in the car, though, in case I need it later on. I'll also use elevators – I'll be getting enough exercise just walking the mall.</p>		

Problem-solving Example 2

<p>State the problem I'm having problems with my bowel program</p>		
<p>Outline the problem My bowel program is very inconsistent. I like to get it done in the mornings, but often run out of time. I am also having more accidents in the middle of the day. This can be very embarrassing. Because I'm worried about accidents, I have avoided going out.</p>		
Possible Solutions	Pros & Cons (Consequences)	Rank
<p><i>Medications</i> I could use Docolax (a stool softener) because it makes my bowel program go faster.</p>	<p>Pros: May help. Easy. Cons: Docolax can cause bad cramping for me.</p>	
<p><i>Timing</i> I could do the bowel program in the morning.</p>	<p>Pros: It would not interrupt my social plans in the evening. Cons: If I stay up too late or oversleep a few minutes, I just don't have time.</p>	
<p><i>Diet</i> I could eat a diet that is higher in fiber, which my doctor suggested.</p>	<p>Pros: No new medicine; no need to change my schedule. Cons: I should give up eating fast food and eat more high fiber foods. But I don't want to have to give up the foods I like.</p>	1
<p>I could take Metamucil to prevent some of the loose stools I have.</p>	<p>Pros: It works. Cons: I really hate drinking that stuff!</p>	2
<p>Use & Evaluate your solution I'll try the lower fat diet with more fiber. I won't cut out the fried foods I like, but I will eat them about half as often. Also, I can get Metamucil in a capsule so I'll try it sometimes to help prevent loose stools.</p> <p>Determine if the solution is effective I have very few accidents. I've discovered some new foods that contain more veggies and aren't fried that I like to eat. I still eat some greasy stuff, but I've added some other foods for variety. I also take the Metamucil capsules.</p> <p>Combining two solutions helped me to solve most of my problem with a bowel program.</p>		

Problem-solving Example 3

<p>State the problem I'm having a lot of pain in my _____. The meds I've got for pain are not really helping- much.</p>		
<p>Outline the problem I have been stressed out due to the amount of pain I have been experiencing. I feel my doctor doesn't take me seriously.</p>		
Possible Solutions	Pros and Cons (Consequences)	Ranks
<p>Medications I'm really fed up with suffering this pain. I'm just going to demand the strongest drugs they've got.</p>	<p>Pros:</p> <p>Cons: If I get angry I may not be able to explain the situation clearly. I am also concerned about side effects (feeling sleepy and "doped up")</p>	
<p>Monitor I could try keeping track of when I have the pain each day, how high the level is and how long it lasts.</p>	<p>Pros: This gives me a record of day to day pain that I can easily record it on a calendar. This won't cause anything negative to happen.</p> <p>Cons:</p>	
<p>Other pain therapy I could explore other pain therapies to see what is available (acupuncture, meditation or something else).</p>	<p>Pros:</p> <p>Cons: I have been to a few web sites and SCI forums to learn from other people's experiences.</p>	
<p>Execute your solution I talked to my doctor and showed her records of how intense the pain is and how often I experience it. This helped her understand my issues with pain and how it was affecting me. She agreed to try another kind of pain med.</p> <p>I am also going to try meditating, which involves relaxation exercises and using imagery to cope better with the pain. I found some books and tapes at the library about this.</p>		
<p>Evaluate if your solution was effective I was given another prescription for a pain med. I'll again record my level of pain a few times a day and see whether or not it changes.</p> <p>I am learning more about relaxation and using mental images to reduce the intensity of the pain. I'm not sure how helpful this is yet, but so far it has reduced the amount of stress I usually feel.</p>		

Emotional coping

Sometimes the problem you want to solve is how you feel. You may feel down, anxious or angry. Coping with your emotions is a special form of problem-solving; this technique is sometimes called cognitive reframing. Basically, emotional problem-solving helps you give yourself an **attitude adjustment**. 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. 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!*

Figuring out how you feel

Sometimes just deciding how you feel is hard. You are used to being a happy person, and so can't really tell the difference between feeling sad or helpless. You just know you are feeling bad. On the other hand, you may be real familiar with anger, but don't know what to do about feeling worried or sad.

Because a lot of people get confused about how they feel, we are going to review some feeling words. Then I want you to draw what each one means to you and finally identify how you feel and why you feel that way. (see feeling word list – Appendix A)

Come up with ideas to solve the problem (solutions):

In this case, you should not be focused so much on solutions but rather on different ways of dealing with or addressing your problem (feelings of emotional distress). 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 will be replaced by other – 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.

- *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-wrenching painful. But would it be better to be with anyone then to be alone? Would you want to spend your life with your 7th grade chemistry teacher? What about a smarmy car salesman? What about someone who called you names and treated you bad? 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 – you, 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 woman 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 reason – 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.

Thoughts and emotions

By doing this exercise, you may notice the strong link between the way you **think** about a situation and how you **feel**. Most people find themselves falling into **thinking traps**. Such ways of thinking lead to unsettling and bad feelings. This can prevent you from coping with a situation.

For instance, you may frequently have thoughts like these to come to your mind:

“I’m useless.”
“I’ll never feel better.”
“Things don’t work out for me.”
“Nobody likes me.”
“It’s always my fault.”
“I’m not a good parent or spouse”
“I’ll never find a boyfriend/girlfriend/partner/friend.”
“I could never do that.”

These negative thoughts can color your feelings and outlook.

Here are other thinking traps:

- **Mind reading** (deciding what others are thinking without knowing all the facts)
- **Over Generalizing** (coming to a conclusion from 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)

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 call 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.

Emotional Problem Solving Examples

<p>State the problem People seem to look at me a lot when I am out in public</p>
<p>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</p>
<p>List your emotions I get angry and feel helpless and inferior</p>
<p>Check / challenge your expectations 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.</p>
<p>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.</p>

<p>State the problem An old friend didn't visit me as we had planned.</p>
<p>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.</p>
<p>List your emotions Angry at the people who aren't around anymore, sad, frustrated, etc.</p>
<p>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 any more.</p>
<p>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.</p>



SKILL 4: COMMUNICATION

Screening Questions

- Who do you need to communicate with on a daily basis?
- Who do you need to communicate with to manage your health?
- Does how you communicate depend on who you're dealing with?
- What do you want to get out of your interactions? How can you achieve those things?
- What styles or things may prevent or harm communications?

Introduction to communication

Another critical skill for everyone – but especially for people with SCI / D – 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 online. 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 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 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 figure out what other people think is a good boundary/goal.

Examples of Communication

Communication can be very simple and straight forward and complex and involved.

For example, just asking someone for assistance....



Goal: Get someone to help me get something from a high shelf.

Determine most effective way to achieve goal: Catch someone's eye. Smile. Politely ask for their 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.

Clarke and colleagues identified 10 basic communication strategies and showed how physician compliance with these recommendations can increase patient's satisfaction and outcomes.²¹⁻²³ 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 determine would do in a given situation. The section on problem-solving goes into this in more depth. Basically, though, 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 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.

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/D 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 all can 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.



SKILL 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 stacking books by their size or subject or arranging CDs by the artist so you can find them more easily. Being able to plan and organize is a very important skill for individuals with SCI/D 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 of 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 issue / 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 of flow-chart 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

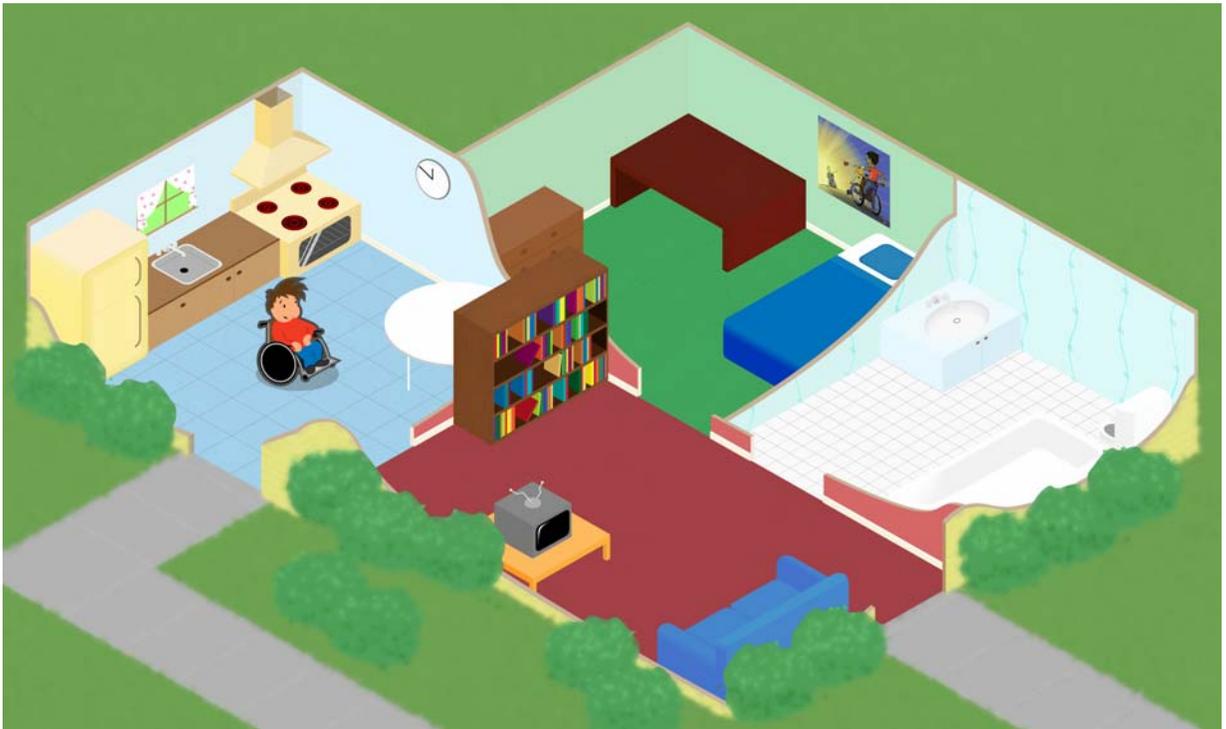
- Gather the materials you need
- Get rid of what you don't need
- Sort information / materials into categories
- Follow-through with planned action for each category

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 easier. 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 me – 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.

Sample schedule for planning skin Care, medication and intermittent catheterization

Time Frame	Required Cares / Activity	Equipment or Assistance needed
Midnight- 12:30am	Cath (ISC); If in Bed, roll & reposition (R&R)	Catheter; gloves; urinal
12:30am – 1am		
1am – 1:30am		
1:30am – 2am		
2:am – 2:30am	If in Bed, roll & reposition (R&R)	
2:30am-3am		
3am – 3:30am		
3:30am – 4am		
4am-4:30am	If in Bed, roll & reposition (R&R); Cath (ISC)	Catheter; gloves; urinal
4:30am – 5am		
5am – 5:30am		
5:30am-6am		
6am-6:30am	If in Bed, roll & reposition (R&R)	
6:30am-7am		
7am - 7:30am		
7:30am – 8am	Wake up	
8am-8:30am	Cath (ISC); If in Bed, roll & reposition (R&R) If in chair, pressure relief	Catheter; gloves; urinal
8:30am-9am	Take medications; Eat breakfast If in chair, pressure relief	Medications
9am – 9:30am	Perform bowel program If in chair, pressure relief	Assistance to transfer to commode; gloves; suppositories
9:30am – 10am	Bowel program (continued)	
10am-10:30am	Get dressed and transfer to wheelchair ; Check skin	
10:30am-11am	If in chair, pressure relief	
11am-11:30am	If in chair, pressure relief	
11:30am-noon	If in chair, pressure relief	
noon- 12:30pm	Cath (ISC); If in chair, pressure relief	Catheter; gloves; urinal
12: 30pm – 1pm	Medications and lunch If in chair, pressure relief	
1pm – 1: 30pm	If in chair, pressure relief	
1: 30pm – 2pm	If in chair, pressure relief	
2:pm – 2: 30pm	If in chair, pressure relief	
2: 30pm -3pm	If in chair, pressure relief	
3pm – 3: 30pm	If in chair, pressure relief	
3: 30pm – 4pm	If in chair, pressure relief	
4pm-4: 30pm	Cath (ISC); If in chair, pressure relief	Catheter; gloves; urinal
4: 30pm – 5pm	If in chair, pressure relief	
5pm – 5: 30pm	Begin making dinner; If in chair, pressure relief	
5: 30pm -6pm	If in chair, pressure relief	
6pm-6: 30pm	Dinner If in chair, pressure relief	
6: 30pm -7pm	If in chair, pressure relief	
7pm - 7: 30pm	If in chair, pressure relief	
7: 30pm – 8pm	If in chair, pressure relief	
8pm-8: 30pm	Cath (ISC) If in chair, pressure relief	Catheter; gloves; urinal
8:30pm -9pm	If in chair, pressure relief	
9pm – 9: 30pm	Shower	Assistance transferring to tub bench
9:30pm – 10pm	Change for bed; Check skin	
10pm-10: 30pm	Transfer to bed	
10:30pm -11pm		
11pm-11: 30pm		
11: 30pm -midnight		



SKILL 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 increased 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 ²⁴:

- 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

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.

Deep muscle relaxation

This method of relaxation is based on the idea that tensing then releasing tension in different muscles results in a deep state of relaxation. By practicing these exercises, a person can learn to relax quickly; eventually you can skip the tightening part of the exercises. To get to this advanced stage takes faithful practice; anyone who understands the general principles, however, can use the exercises to achieve relaxation. For this technique, only focus on those muscles that you are in control of. When you get to a level where you can not actively control the movement of the muscle, picture that muscle and – as you breathe in and out – picture it slowly relaxing and unwinding, becoming warm and quiet and relaxed.

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.

The following instructions will lead you through a standard deep muscle relaxation session. If the given method for tensing a muscle group does not work for you, try to discover another way to tense that particular area and substitute your own exercise.

- When you tense each muscle group, you should tighten the area until you experience tension without causing cramping or pain.
- You are to hold the tightness or tension in each muscle for 10 to 15 seconds and then let the tension go, focusing on the relaxed feelings in that muscle for at least 30 seconds.
- When you let go of the tension, try to do it all at once.

- While relaxing each muscle, concentrate on how good it feels. Just let yourself sink into a comfortable, relaxed state, focusing on the warm and heavy feeling in the relaxed muscle.
- Become aware of how different your body feels when it is tense versus when it is relaxed.

In the beginning, it is useful to practice tensing and relaxing small muscle groups, such as the hand, forearm or biceps. Once you learn how to relax individual muscles, you may wish to shorten the exercise by tensing and relaxing entire areas of the body, such as an arm, all at once.

The muscles of the body are tensed and relaxed in the following sequence:

- Hands, lower arms
- Upper arms, shoulders
- Scalp, forehead, eyes
- Eyes, nose, mid-facial muscles
- Lower facial muscles, jaw, mouth
- Neck
- Chest, shoulders, upper back
- Lower back, stomach
- Buttocks, hips
- Thighs
- Lower legs, calves
- Feet

This outline may be used as a reference for practice. Change the order or combine muscle groups to meet your needs. Develop a system that works for you and does not cause discomfort. Remember not to hold your breath during this exercise. If you can, breathe comfortably and deeply throughout the session.

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.

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.

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 palms 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 and 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 follow 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 its 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 up 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 are a group of practices done by an individual for the purpose of self-transformation²⁵ 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 recentered. 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.*²⁶ 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 / D 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, though, 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 things²⁷:

- Caring Relationships: The people who you develop supportive relationships with 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/D 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 your self 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 thankful. 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^{28, 29}.

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. Remember those college students who felt more positively about the upcoming week after using gratitude journals!

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!

APPENDICES

Appendix A: Feeling Words

<u>Happy</u>	<u>Fearless</u>	<u>Sad</u>	<u>Afraid</u>
Contented	Brave	Sorrowful	Frightened
Satisfied	Courageous	Downcast	Timid
Serene	Confident	Dejected	Chicken
Comfortable	Independent	Unhappy	Lazy
Peaceful	Secure	Depressed	Shaky
Tranquil	Bold	Gloomy	Fidgety
Joyous	Daring	Cheerless	Apprehensive
Enthusiastic	Strong	Somber	Restless
Ecstatic	Heroic	Dismal	Terrified
Glad	Determined	Joyless	Panicky
Pleased	Firm	Quiet	Hysterical
Cheerful	Certain	Dark	Alarmed
Sunny	Calm	Mournful	Shocked
Lighthearted		Dreadful	Horrorified
High-spirited	<u>Angry</u>	Flat	Insecure
Animated	Resentful	Deflated	Anxious
Merry	Irritated	Dull	Worried
Sparkling	Engaged	Sullen	Doubtful
Hilarious	Furious	Discontented	Suspicious
Exhilarated	Annoyed	Moody	Awed
Playful	Provoked	Hollow	Dismayed
Close	Offended	Sympathetic	Sheepish
Warm	Bitter		Cold
Grateful	Contemptuous		Scared
Thankful	Boiling	<u>Hurt</u>	Shy
Silly	Fuming	Injured	Cowardly
Giddy	Defiant	Grieved	Threatened
		Offended	Cautious
<u>Eager</u>		Distressed	Fearful
Anxious	<u>Interested</u>	Worried	
Earnest	Concerned	Pathetic	
Intent	Affected	Tortured	
Avid	Fascinated	Aching	
Fervent	Engrossed	Embarrassed	
Itchy	Intrigued		
	Absorbed		
<u>Doubtful</u>	Curious		
Skeptical	Excited		
Distrustful	Nosy		
Unbelieving	Inquisitive		
Suspicious			
Uncertain			

SELF-MONITORING FORMS

Day		Date:	
Time		AM	PM
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Other comments			

Day		Date:	
Time		AM	PM
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
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Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Other comments			

Day		Date:	
Time		AM	PM
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
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Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Time		Am	Pm
Amount	Normal	High	Low
Color	Normal	Light	Dark
Odor	Normal	Bad	
Other comments			

**Self-Monitoring Form:
Skin / Pressure Sore Prevention**

Guideline / Goal for Wheelchair users

- Perform Pressure Reliefs every half-hour for 30 seconds each
- When in bed, roll and reposition every 2 hours
- Keep skin clean and dry
- Prevent continual skin irritation
- Check skin 2 x's per day for redness and signs of pressure sores
- A separate sheet is available if needed for monitoring pressure reliefs

Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	

Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Date:		Where / location	
Time 1			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	
Time 2			
Redness	Yes	No	
Broken skin	Yes	No	
Rubbing	Yes	No	
Wound	Yes	No	

Bowel Program Monitoring Form

Recommendations:

- Perform Bowel Program every day or every other day at approximately the same time
- Try to perform ½ hour after meals

Personalized Action Plan

- Every day Every other day
- Mornings Evenings
- Assistance needed with set-up: yes no
- Perform: In bed On toilet / commode
- Medications required:

- Digital stimulation required: yes no

Date:				Time:	AM	PM
Productive	No	Yes				
Quality	Hard	Normal	Watery	Other:		
Amount	Low	Average	A lot	Other:		
Notes about diet	Usual diet		Changes			
Any accidents during the day?	No	Yes:	When:			
Date:				Time:	AM	PM
Productive	No	Yes				
Quality	Hard	Normal	Watery	Other:		
Amount	Low	Average	A lot	Other:		
Notes about diet	Usual diet		Changes			
Any accidents during the day?	No	Yes:	When:			
Date:				Time:	AM	PM
Productive	No	Yes				
Quality	Hard	Normal	Watery	Other:		
Amount	Low	Average	A lot	Other:		
Notes about diet	Usual diet		Changes			
Any accidents during the day?	No	Yes:	When:			

Date:		Time:	AM	PM
Productive	No	Yes		
Quality	Hard	Normal	Watery	Other:
Amount	Low	Average	A lot	Other:
Notes about diet	Usual diet	Changes		
Any accidents during the day?	No	Yes:	When:	
Date:		Time:	AM	PM
Productive	No	Yes		
Quality	Hard	Normal	Watery	Other:
Amount	Low	Average	A lot	Other:
Notes about diet	Usual diet	Changes		
Any accidents during the day?	No	Yes:	When:	
Date:		Time:	AM	PM
Productive	No	Yes		
Quality	Hard	Normal	Watery	Other:
Amount	Low	Average	A lot	Other:
Notes about diet	Usual diet	Changes		
Any accidents during the day?	No	Yes:	When:	
Date:		Time:	AM	PM
Productive	No	Yes		
Quality	Hard	Normal	Watery	Other:
Amount	Low	Average	A lot	Other:
Notes about diet	Usual diet	Changes		
Any accidents during the day?	No	Yes:	When:	

APPOINTMENT WITH HEALTH CARE PROVIDER

Date:

Time:

Place:

Things to Bring to appointment:

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

Primary goal / purpose of visit:

To be completed by patient prior to appointment:

Patient concerns

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

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 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?



SKILL REVIEW HANDOUTS



Skill 1: Attitude and Expectations

Let's talk about attitude

Success or failure in living with spinal cord injury begins with your attitude. **Attitude** and mindset are necessary parts of taking charge of your life and creating the life you want.

Pro and **active**. These words together (**proactive**) mean that you are in charge and positive about what you can do.

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

The right attitude can mean:

- Less health problems
- Less pain
- Fewer trips to the ER or hospital stays
- Better moods and less depression (feeling down)
- Many other benefits

Attitude has five basic parts:

- **Expectations:** how you think or believe that people should act
- **Assumptions:** beliefs that you accept as facts without proof
- **Outlooks:** 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.

It is important to think about what expectations you have about your health care providers. When possible, check to see if your expectations about your physician, therapist, nurse or other provider matches what they think their roles and responsibilities are. The closer the match between your expectations and theirs, the smoother the relationship will be.

Assumptions

Assumptions: the beliefs that you feel are true without checking to be sure.

Do your assumptions about disability hold you back? There are times when individuals with disabilities change their behavior and move towards being happier and healthier, but their assumptions get in the way. You have to know what your assumptions are before you can challenge them.

Outlook

Outlook is your general approach to life. Successful people with SCI tend to have a **positive** outlook.

Responsibility

Being in charge of your health means:

- Learning about and understanding your medical care
- Deciding which health problems are the most important
- Decide the order in which to address them is known as **prioritizing**.
- Be willing to find information

Other people can give you information, support or help in some way with your health. They may write prescriptions for medication, provide advice about diet or exercise, 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.

Exercises for People with SCI/D: Expectations and Assumptions

Expectations *are beliefs that people should behave in a certain way.*

Which of the following statements are true of your expectations for your health care provider?

- My provider will be on time
- My provider will be competent
- My provider will be thorough
- My provider will be attentive
- My provider will be compassionate
- My provider will be my friend
- My provider will be honest
- My provider will be caring / interested in my care
- My provider wants to improve my life
- My provider will give their complete attention to my problem
- My provider is an expert in treating people with SCI, and familiar with all the issues / concerns that they will have
- My provider will be able to help me improve my function
- My provider will work to the best of his or her ability to help me function as best as I can
- My provider will educate me about what can happen if I make lousy decisions
- My provider will return calls quickly

Can you think of other expectations you may have? Are they positive or reasonable?

Which statements reflect what you will do when you work with the health care system?

- I will arrive on time to appointments
- If I am late, people will understand because it is hard for me to get around
- I will call if I can't come or am going to be late
- I will speak up about barriers or problems
- I will ask questions
- I will contact providers when there are problems / concerns / changes in my health
- I will be involved in my own care
- I will be honest with my health care provider and tell them if I cannot follow their advice or disagree with them
- I need to be a part of the process
- I will follow the rules
- I will be my own advocate
- I will make therapy a priority
- I will make my health a priority
- I will be open and communicate freely
- If I say "no" to doing something, I will suggest another way to do it
- I am responsible for my health
- If I get angry or frustrated, I feel it is okay to yell at people and take my anger out on them

What assumptions do you think you might make about disability or people who have a disability?

- Anyone who uses a wheelchairs 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 have a disability, you are no longer the person you were
- 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
- If you have a disability, life is over
- A man who uses a wheelchair is no longer a complete man
- It is better to be dead then disabled
- People in wheelchairs are just people who travel through life sitting down.
- Life if 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 your friends and family
- All people in wheelchairs are mentally ill
- You can't really make assumptions since every person is different

What assumptions do you may make about your health care providers?

- If my provider does not ask me something, it must not matter
- If my provider says they will do something, they will always follow through
- If my provider calls me after an appointment, something must be wrong
- My physician will be disappointed in me if I come in with a problem or I could not do what they asked me to do
- Physicians are like parents
- I just tell physicians what they want to hear
- Health care people are service providers – they are work for and answer to me
- My physician can fix / cure me
- Health care providers do not make mistakes
- 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. If not right away, then within an hour



Skill 2: Self-Monitoring

To **monitor** something means to observe and record what is happening. **Self-monitoring** 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.

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.**

Collecting Information

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.

Below are some examples of self-monitoring. You may be able to think of others.

<u>Area</u>	<u>Example of what you can monitor</u>
Bladder	how often you need to cath every day
Skin	an area of your skin that is red or swollen
Sexuality	your level of interest in sex
Moods and feelings	how happy or angry you feel at any time
Other's reactions and moods	how grumpy a family member is today
Diet	how many servings of fruit you ate today
Exercise	how often you wheeled around the street

If you monitor something, you gather information that allows you learn more about what is going on with your body. This information can be collected based on either time or event. One way is to record **every day** about something that happened. The other choice is to record information only when **something happens.**

Recording and Understanding Information

- (1) Determine what information to record
- (2) Set up a routine and record information on a regular basis
- (3) Examine information to look for differences, changes, or patterns

So now you have collected information – but what do you do with it? First, just by noticing what you do and think often begins to change your behavior. By comparing what you are doing with what is best for you to do, you may decide to change to be more in line with those expectations.

Second, once you begin monitoring stuff, you may 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 at 7:00 pm rather than 5:30pm, or that you eat poorly when you are stressed. This information helps you plan and organize your day better.

An easy way to keep track of what you monitor is to write it on a calendar. That can also be a reminder to **keep** writing it down and tracking the information.

Other ways to monitor:

Keep a record on a pad of paper or in a journal
Collect information and save it in a computer file
Putting a sticker on your calendar when something happens

Monitoring and collecting information can allow you to best describe what is going on with your body or a treatment. This in turn allows you and your health care providers to make better decisions by looking at how something has changed over time.



Skill 3: Problem-Solving

Problem Solving allows you to deal with the world around you by deciding what the problem is, coming up with different solutions and weighing the pros and cons for each. It allows you to stay flexible and try ways of finding solutions.

Problem Solving Steps

Problem solving involves six basic steps:

State the problem. Briefly talk or write about a problem you have. The problem does not have to be well understood. At this stage, you may recognize that there **is** a problem, but not know exactly what is involved.

Describe the problem. Think about the details. The exact nature of the problem will become clearer as you write or talk about it. Figure out what makes this a problem. Decide which are facts and which are assumptions.

Come up with possible solutions. After laying out the problem, come up with as many possible solutions as you can. Be creative! Don't think about how well they might work, just list them all.

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 or www.ehow.com) or Care Cure Forum, which is a site related to SCI. You might also call a group or agency that is an expert on that subject.

View the possible outcome of each solution. Critically rate each solution by listing what might happen (called an outcome) both pro and con as a result of using it.

Rank the solutions and pick the best one. After listing possible outcomes from each solution, number them from best to worst. The solution you ranked as first should be one you are willing to try. It should also be likely to give you the outcome you want.

Then, carry out the best solution. Give it your full effort and take a look at what happened. Stick to this solution before moving onto the next step. Without really trying it, you may not really see how useful it is and wrongly discard it.

Decide how useful your solution was. Did the solution give you the result you wanted? Is the original problem gone or less noticeable? Compare what happened to what you expected. If the solution worked, keep using it. Remember to reward yourself for finding a solution to the problem. If the solution worked at least in part, try and determine when it helped and when it did not. It may be that you need to have several different solutions, depending on the situation. If the solution didn't work at all, either try it again or try

another solution. Use what you learned the first time to help you perfect the problem solving experience.

Problem Solving (feelings)

State the problem
Observe your thoughts
List your emotions
Check / Challenge your assumptions
Re-evaluate your emotions

Problem Solving

State the problem		
Outline the problem		
Possible Solutions	Pros & Cons (Consequences)	Rank
	Pros: Cons:	
Try your solution		
Evaluate if your solution was effective		



Skill 4: Communication

Communication is the act of moving information from one source to another. That is just a way of saying that a message is sent from one person or group to another one.

Basics of communicating

1) Decide what the goal of the conversation or communication will be

Sometimes you are seeking information, or want to let someone know how you feel or just talk with an old friend. Maybe you want to explain your opinion, or find out more about theirs.

2) Remember that different people in the conversation may have different goals

3) Determine the best way to reach your goal or a shared goal

When your goal is to share information with someone, make sure that the listener understands. One way to be sure is to ask them to repeat your message back in his/her own words. This method is called **reflective listening**.

4) Accept responsibility for your own feelings

Express feelings only if they are important to reaching your goals. You can avoid making people defensive when you talk about your feelings, by saying it this way:

“I feel _____ when you do _____.” One example is, “I feel rejected when you don’t call me.”

5) Give and accept feedback with an open mind and non-defensive manner

Good and Bad Communication Styles

People who communicate in an angry or aggressive style do let others know their thoughts, desires, and feelings, but in a rude, threatening or belittling way.

Assertive: direct, respectful yet confident, proactive

Being assertive means honestly and directly expressing your thoughts and feelings without violating the rights of others.

DO

- Act politely and pleasantly. No matter what your attitude, being respectful and assertive will make it easier to get along with physicians, family and others.
- Listen to your health care provider's suggestions and take notes of these ideas.
- Create your own list of questions before meeting with a health care provider.
- Tell your health care provider what your goals are. A "goal" might be lowering how much pain you have, increasing your energy or improving your sleep.
- 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 do.

DON'T

- Agree to do something you know you won't do. Other solutions are sometimes possible. Unless your health care provider 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 something and you disagree, don't just demand a change.
- Take things personally. If your health care provider says that you are not doing everything you should do, don't take the comment as an insult. 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 and may harm your relationship with those who are most concerned, besides yourself, with your health.
- Get discouraged. Taking care of any condition often requires plenty of time. Successful treatment and having your concerns resolved takes patience on everyone's part.



Skill 5: Organization

Organization

To **organize** is to create an orderly system to make something easier to use or do.

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.**

Make a plan. Decide how to organize

- Self-monitor to identify what you currently do as well as strengths and potential barriers; alternatively, take a survey of what you need to organize to find out more about it
- Define categories based on issue / goals
- Determine if you need to do things in order and what it is
- Figure out how much time each action may take. (Better to allow more time than less)
- Create of flow-chart 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!)

Action

- Gather the materials you need
- **Get rid of what you don't need.** This step is more important for organizing other things, such as items like clothing or an area. For a schedule it could mean leaving out activities that don't seem worth your time.
- 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.)



Building Block 6: Stress Management

How to Deal with Stress

The first step in self-management is to **identify what the problems is**. Once that is done, you can decide to solve the problem, change the situation, or change the way you feel about the situation.

Stress management is a process of releasing the emotion that is built up inside of you.

The chief ways of doing this are: **relaxation, reframing, distraction, prayer, exercise and communicating effectively with others**. These are focused around:

- Relaxing the body: relaxing the muscles
- Calming the mind: slowing or gaining control of thoughts
- Refocusing attention: shifting energy to a different direction
- Soothing the soul: using religion, spirituality, or comforting /life-affirming thoughts for soothing
- Building on strengths and supports: finding ways to feel good about ourselves

Relaxing the body

Deep breathing

Deep muscle relaxation

Calming the mind

Imagery

Refocusing attention

Distraction

Soothing the soul

Prayer

Meditation

Rituals

Building on strengths and supports

Gratitude journal

Refocusing on priorities

Positive self-statements

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