FACILITATING HEALTH MECHANICS

A Guide for Care Providers
of Individuals with
Spinal Cord Injury and Disease

Developed by
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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 individuals with SCI/D have to learn to manage both their health and their environment in order to maintain or create a good quality of life.

This guide was developed to help you – as a health care provider, caregiver or family member – reinforce the development and use of self-management skills among individuals with SCI/D. If they are to spend any time alone, the individual with SCI/D must be able to deal with various situations that they encounter. Because SCI/D can impact every almost system in the body as well as interactions with physical, social and interpersonal environments, "success" in living with the impairment requires a high level of knowledge, skill and competency in self-monitoring, communication, planning, organizing and problem-solving. This program uses self-management as a framework you can use to present and help individuals with SCI/D conceptualize specific information, techniques and behaviors.

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 consequences [10]. A key component of this process is the ability to make decisions and lifestyle choices that will optimize functioning and allow for greater participation in family, social, community and vocational roles and environments[11].

Self-management is based on the assumption that the individual with the impairment or disability will be the primary one managing their medical condition while still trying to create and enjoy a full life. They are the one who must schedule and go to doctors' appointments, perform pressure reliefs for their skin and take care of their bowel and bladder. They have to figure out how to negotiate their way through the physical world, and do all the self-care tasks involved in every day life with SCI/D. They must also learn to partner with their physician, caregivers and other health care professionals so as to prevent secondary complications and deal with those that do occur. More importantly, though, they are the ones who have to integrate these things into their lives so that they do not take all their 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, they first need the skills to manage their health and its consequences.

*****If these assumptions do match those that you have when working with individuals with SCI/D, then it is unlikely that *Health Mechanics* or the information in this guide will be useful to you.

The Self-Management Approach

Self-management is an evidence-based approach to managing chronic illness. It provides education and skill-building related to self-monitoring, communication, problem-solving and relaxation. Self-management has been proven to be effective for improving health status and health behaviors, increasing self-efficacy, improving compliance with medication regimens, decreasing pain, and lowering health-care costs.[14-24] It provides a clear format for the acquisition and performance of skills and self-management protocols have been effectively tailored to meet the needs and concerns of minority populations.[25-31]

Self-management interventions are typically based on four theoretical constructs or techniques (either individually or combined) – social cognitive theory, the stress coping model, the transtheoretical model, and / or cognitive-behavioral therapy [24]. The health behavior model is also used to understand health behaviors and health behavior change. *Health behavior change* can be defined as the switch from risky or unhealthy behaviors to healthy or positive behaviors.[32]

- *Social cognitive theory* states that health behavior is influenced by relationships with people and the social environment, and that people's behavior also influence both of these.[33, 34] Self-efficacy, together with expectations, mediates behavior. That is, an individual will only perform an action if they are confident that they will be able to accomplish it successfully. As a result, components of self-management programs focus on acquisition of skills such as problem solving and goal-setting. With regard to rehabilitation, social cognitive theory can provide insight into empowerment, self-regulation, and understanding the relationships between people, places, and abilities. People with strong self-efficacy may perceive their disabilities as less severe.[35] It is also possible that a person can have strong self-efficacy in one area (exercise) but not another (nutrition.)

- The s*tress coping model* posits that health will be affected by an individual's ability to deal with stress associated with the conditions. Intervention components then, focus on stress management and improving coping.

- *Cognitive behavioral therapies* have influenced self-management intervention by addressing how people think about their condition and themselves and the inter-relationship between thoughts, feelings and behaviors.

- The *health belief model* discusses four key concepts- perceived susceptibility or vulnerability; perceived severity of a condition; perceived benefits of treatment; and perceived barriers – and posits that people will not change their behaviors unless they see themselves as susceptible, view the condition as sufficiently severe, and feel that taking action will make a difference. The health belief model also involves cues for action that can lead to behavior modification, such as increased pain, or increasing knowledge of a condition.[36] *Self-efficacy* is also

important; since healthy behaviors are difficult to practice, a person must believe that a healthy lifestyle is possible. [37]

- Finally, the *transtheoretical model of behavior change* is a stage theory that refers to how prepared individuals are to make changes to their behaviors; interventions focus on an individual's motivation to change, and adapt their approaches based on their stage of change. The stages of behavior change are pre-contemplation, contemplation, preparation, action and maintenance.

  - *Motivational Interviewing* (MI) is a client-centered approach designed to assist people work through their ambivalence about behavior change, and it appears to be particularly effective for people who start out not especially ready to change. [38-39] The goal of MI is to help clients think about behavior change, verbally express what they feel and link their health goals with their behaviors (or notice discrepancies). The process is nonjudgmental and encouraging. MI counselors rely on reflective listening and positive affirmations.

What does self-management involve?

There is plenty of information out there to tell individuals with SCI/D what they need to do. Unfortunately, **knowing** is not enough. Individuals with SCI/D have to figure out how the information applies to them, think about how to begin to work it into their lives, and feel comfortable performing a whole range of skills and behaviors. The basic skills or tools that allow them to do this are attitude, self-monitoring, problem-solving, communication, organization, and stress management. These are the skills taught within the *Health Mechanics* program.

Even after people are taught self-management skills, they will not automatically use them. Developing and applying self-management skills takes practice and can be supported by discussion with and feedback from others. Just as there is a difference between the typical car owner and the master mechanic, so individuals with SCI / D will have differing levels of skill or competency in managing their condition and its consequences.

Below is a guide to the five levels of self-management competency and suggestions for how providers or facilitators may want to adapt their approach based on those:

Level 0: The individual with SCI/D probably has little information or little real understanding about what a spinal cord injury is and how it may affect their life. They may feel overwhelmed and not sure of what to do, where to start or even what questions to ask. Health care providers and / or facilitators can assist by providing them with a framework for what is going on and a map of where they are, where they are heading, and the steps likely to get there.

Level 1: An individual at this level has a rough idea of what is going on and what is ahead. They may have basic information about SCI / D and know what they are supposed to do to manage their condition and achieve specific short-term goals. They are probably able to follow directions and suggestions, but their knowledge may not be well integrated and they have difficulty figuring out how to follow all the recommendations for every day life. Health care providers may want to check the patient's level of understanding then provide more details or corrective information. In addition, concrete examples and assistance with planning, organizing and integrating information into home life are generally very helpful.

Level 2: Individuals at Self-Competency Level 2 have good general knowledge about their condition / impairment. They know what they have to do and why and are able to adapt recommendations and guidelines to fit their own life or situation. Providers and facilitators need to recognize and respect this increased level of knowledge. They should work to engage the individual with SCI/D in problem solving and agenda setting.

Level 3: At level 3, individuals with SCI / D know their bodies and have a lot of information about the condition. They are familiar with recommendations, but also have a good idea of what is reasonable in different situations. Individuals at this level are able to plan ahead and consider how to manage a new environment. Competency at this level requires realistic understanding of disease process and functional limitations; in addition, a good attitude is critical. For facilitators and health care providers, it is important to remember that individuals at this level generally have the skill and judgment to successfully manage their condition. Care providers may be of most use as consultants to the person with SCI / D; providing feedback to help them modify their behavior or management strategies or deal with specific issues or problems.

Level 4: This is the expert level. The individual with SCI /D is an expert about their body and about their condition. They know what things influence their functioning and why. Individuals at this level are great self-regulators and readily adapt what they do based on feedback from their body, the environment, or from important others (spouses, health care providers, caregivers, etc). Of primary importance is the high degree of problem solving skills as well as cognitive flexibility and their ability to make adjustments when faced with new information and environments. Their attitude, adjustment and mental health are good to excellent. The individual with SCI / D is definitely managing their health as well as their environments and has learned to communicate effectively with health care providers to get what they need.

Many factors influence the level of self-management skills and competency. Age, education and cognitive capacity all have a role as does experience in using the skills. Finally, level of adjustment and mental health status influence both ability and motivation to take on the responsibility of actively managing health.

One possible way to think about levels of competency is to consider the teenager who is driven everywhere by their parent. They may know where they are going and some key landmarks, but if it came down to it, many couldn't get there themselves or provide

directions to others. Sure, they could turn on the GPS and follow the directions that are given, but they would not be able to deviate from the given route. It is only when they are encouraged to notice and grasp the relationships between distances, time and landmarks, and then have the opportunity to practice that they really begin to develop familiarity and competence with navigating.

How to use this manual

This guide is written for care providers – physicians, physical and occupational health providers, family members, and the host of individuals who work with and / or provide care to individuals with SCI/D. Its purpose is to allow you to facilitate the skill development of the individual with SCI / D within the context of your current role.

SCI SPECIFIC
INFORMATION AND CONCERNS

Traumatic SCI affects approximately 259,000 individuals in the United States, with nearly 12,000 new injuries occurring annually.[40] The damage to the spinal cord results in a loss of function, impacting the central, peripheral, and autonomic nervous systems. Direct effects include paralysis, loss of sensation, sympathetic blunting, neurogenic bowel and bladder, and thermodysregulation; the extent of impact depends on the degree (complete or incomplete) and the level of injury. A complete injury means no function exists below the level of injury (either sensation or voluntary movement); an incomplete injury means some function remains below the level of injury, sparing of sensory and / or motor ability. Level of injury determines the muscles and functions that are affected (see Table 1).

Table 1

Level of Injury	Muscles Effected	Functioning / Independence
C2-C4	No movement in upper or lower extremities Some neck muscle control. Diaphragm / phrenic nerve affected	May be ventilator dependent; assistance for all activities of daily living; can control environment / work with assistive technology
C5	Control over shoulders, deltoids and biceps but no muscle control below elbow flexors	Should be able to assist with self-care activities; modified-independent with feeding
C6	Intact wrist extension but no hand muscle function	Modified independence with most ADLs
C7-C8	Able to straighten arms but lack finger or grasping power	Independent transfers; modified independence with most activities of daily living
T1-T6	Use of hands as well as arms; no use of lower extremities. Poor trunk control as a result of lack of abdominal muscle control. Impaired sympathetic functioning.	Independent in wheel-chair accessible environment
T12	Full trunk control with good abdominal muscles. Sitting balance is good. Sympathetic functioning intact.	Can walk with extensive leg braces
L4	Use of hip flexors and quadriceps; can extend knees and raise feet.	Can ambulate using short leg braces.

Disability, though, is not limited to impairment or medical diagnosis. The ability of an individual to function within society is also influenced by environmental and psychological factors. The World Health Organization (WHO) advocates for a biopsychosocial model of disability, and articulates it through the International Classification of Functioning, Disability and Health (ICF).[41] The ICF recognizes the complexity of both individual and contextual phenomena and defines disability as the interaction between features of the individual, including their impairment and medical condition, and the context in which they live. The ICF advocates for assessment of disabilities and health with regard to the following areas: body functions and structure,

activity, participation, environmental factors, and personal factors (i.e., gender, age, coping style, education, etc).

Types of environmental factors that can facilitate or serve as barriers to functioning include products and technology, the natural and built environment, support and relationships, attitudes, and services, systems and policies. For individuals with SCI, the presence of transportation and the accessibility of the built environment have been found to be most relevant to facilitating health behaviors.

Information and website about Spinal Cord Injury are plentiful. However, it can be difficult determining which sites are really useful and worth your time. Below are some reputable resources and websites:

Spinal Cord Injury Information Network
  - http://www.spinalcord.uab.edu/

Model Spinal Cord Injury Systems Dissemination Center
  - http://www.mscisdisseminationcenter.org/

RRTC on SCI and secondary conditions
  - http://www.sci-health.org/

NIH information: NINDS Spinal Cord Injury Information Page
  - http://www.ninds.nih.gov/disorders/sci/sci.htm

Disability Organizations
  - **NSCIA: National Spinal Cord Injury Association**
    - http://www.spinalcord.org/
  - **Christopher and Dana Reeve Foundation Paralysis Resource Center**
    - -http://www.christopherreeve.org/site/pp.aspx?c=mtKZKgMWKwG&b=4451921
  - **Paralyzed Veterans of America**
    - -www.pva.org

General Disability Sites
  - www.Disaboom.com : information and resources for people with disabilities
  - www.disability.gov : site with disability related information and resources

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The realities of living with a Spinal Cord Injury / Disease

When you treat an individual with SCI/D you will rarely be treating the "ideal" patient. The mean age for individuals with SCI is 40.2 years old.[40] However, this number reflects the combined influence of two groups – those who are younger (ages 16 to 24) and those who are older (ages 60 and above).

Younger patients with traumatic SCI generally consist of males who, through participation in high-risk behaviors, become injured and need medical and rehabilitation

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care for the first time. These individuals are likely to be single (never-married) and many have a high-school education or less. There is also a subset of individuals who were injured through acts of violence. This group in particular has been found to have lower education and literacy levels and fewer resources. Many are from ethnic and racial minority backgrounds.[42]

Older individuals are generally injured as a result of falls.[43] They tend to have higher, incomplete injuries. They also are more likely to be female and have had past interactions with the medical system. If they have arthritis or degenerating discs in their spine, they may have lived with chronic pain for a while. As they are older, they are more likely to be married. Their support system may consist of adult children as well as a spouse/partner. Along with these two age groups are others who are injured in motor vehicle accidents, experienced sudden onset diseases (Guillian Barre or transverse myelitis) or who have been living with SCID for a while.

When individuals with SCI are asked about what the key issues in living with SCI are, they come up with a diverse list of items.[44] Below are some of the ones most relevant for physicians / health care providers to understand:

- ***The Economics of SCI:*** The costs associated with SCI/D are high. Estimates suggest that treatment costs range from $50-$150 K for acute care and between $250K and $4 million in lifetime costs.[40] There are many costs not covered by insurance, including co-pays, transportation costs, many mental health treatments, supplies, and some medications. In addition, most insurance programs do not cover home modifications, paid caregivers or the purchase or adaptation of vehicles. The economics of SCI include not only the cost of medical care, but also the wages lost by individuals with SCI who do not work and caregivers who give up paid employment to provide assistance. It is also important to recognize that many individuals with SCI live in poverty. In fact, many are afraid to work and improve their economic status lest they lose their health insurance. Medicaid – which many people rely on to cover medications, personal attendants, or nursing home stays – is only available to those who have less then $2000 in personal assets (not including a house and a car). Those on Medicaid cannot have retirement funds, 401Ks, savings accounts, etc.

- ***Health Literacy, Education and Understanding:*** Many individuals with SCI have not completed high school.[40, 42] In addition, the risk-taking behaviors that lead some people to incur an SCI are associated with a poor ability to plan, delay gratification or recognize the consequences of actions. Although it is important not to stereotype individuals based on their age, race or cause of injury, it is also critical to recognize that many individuals with traumatic SCI simply lack the life skills to instinctively manage their condition. That is, a provider cannot assume that patients will have the skills for monitoring, problem-solving and organizing that are vital for successful management of chronic conditions.

- ***Accessibility:*** For people with SCI /D – particularly those who rely on wheelchairs for mobility – the Americans with Disability Act (ADA) is not just a law

that mandates how many parking spaces need to be designated as handicapped. Rather, it is crucial to eliminating segregation within society. Unfortunately, the ADA is not actively enforced and many buildings (including health provider's offices) are still not physically accessible to people with disabilities.

- *Many things take a lot more time:* Care providers need to understand that it takes many individuals with SCI/D a lot more time to perform self-care activities and other every day routines. An individual whose lower body is paralyzed may take 15 minutes to get dressed rather than 2 minutes; this length of time may be 30-45 minutes if there is upper body paralysis as well. Each segment of an activity needs to be considered separately. Going out to the store for someone with paraplegia may consist of putting on a coat, transferring to a car, taking apart and storing the wheelchair, driving to the store, putting the wheelchair back together, then transferring back to the wheelchair. Of course, if they have good upper body strength actually negotiating the store may take less time. Getting ready to go in the morning may take two hours or more for some individuals with SCI/D, especially if they have to perform a bowel management routine first.

- *Little things add up:* Research suggests that little things can often cause more stress than the big stuff. So when someone has both the big stuff (i.e., paralysis, a traumatic injury) and the small stuff (i.e., inability to get into a room or house, more time needed to perform tasks, microaggressions), the frustrations can really add up fast. Trying to change their behavior on top of that may be like fighting an up hill battle.

- *Its all about attitude:* Individuals who live successfully with SCI will tell you that it is attitude that makes the difference.[44] People at some point have to make a choice:
    - Are they going to passively lie down and die?
    - Are going to be angry at the world?
    - Are they going to be content to live in poverty?
    - Are they going to blame the system or someone else for what happened to them?
    - Are they going to be grateful that they are alive?
    - Are they going to take an active interest and role in their own life?
    - Are they going to find a sense of purpose?
    - Are they going to show [x] (the doctor, their friends, whoever) that they are different and will succeed (walk again, live independently, have children, etc)?

One of the basic tenants of motivational interviewing is that the provider or therapist cannot be more invested in the patient's recovery then they are. That being said, providers need to keep switching how they tailor a message or intervention to take into the consideration the needs, strengths, concerns of a particular population or person.

- *Possibilities after SCI:* It is important that you – as a health care provider – know what is possible for individuals with SCI. Only if you believe that individuals with SCI

and other disabilities can and should have a full productive life will you make facilitating that goal part of treatment. No matter what their level of injury, a good quality of life is possible – though how people achieve this and how much assistance they require from others varies. Individuals with SCI can: have children; have sex; get married, live independently, hold jobs, be active and important members of their communities, exercise, be athletes, hold political office and make choices to enhance their health.

Be aware that while there may be limitations on the individual, relatively few will be directly related to the SCI.   If one blames everything on the SCI or other non-modifiable factors, one cannot do anything to change the situation. After all – what can be done about the level /completeness of injury, race, ethnicity, or age? Those characteristics are fixed. Only by identifying positive or problematic behaviors and attitudes which can be reinforced or altered can you impact health and quality of life.

Psychological factors are a logical target for interventions because they are potentially modifiable. This does not mean that they are *easily* modifiable – just that there is at least the potential for change.

Secondary Conditions and SCI

Rates of secondary medical conditions following acute inpatient rehabilitation are increasing for persons with spinal cord injury. [40, 45- 46] Before they can begin to think about returning to work or beginning job training programs, persons with SCI / D are developing pressure ulcers, chronic pain syndrome and other conditions that limit independence, decrease function, hinder community integration and lead to expensive treatment and rehospitalizations. There is also increasing evidence that people from racial and ethnic minority populations may be at higher risk for experiencing these complications. [42, 47-50] Among the most prevalent secondary conditions are pressure ulcers, pain, obesity, depression, diabetes, heart disease, urinary tract infections, respiratory conditions, and shoulder injuries.

Secondary conditions are not direct and necessary consequences of SCI / D. Rather, they can be prevented or minimized with appropriate management – including performance of health maintenance behaviors and compensatory strategies. [51, 52]   While you – as the health care professional - can provide information, medication and specific treatments, ultimately health is based on the individual's ability (e.g., knowledge, motivation, independence and resources) to perform behaviors (e.g., eating a healthy diet, performing pressure relief, getting out of bed and into the community) consistently.

Individuals with SCI/D (and their caregivers) must learn to manage their impairment and their environment so they can maintain health and participate in the community. In fact, they must be active participants in this process to an extent almost unimaginable to those with other chronic conditions.

Health Disparities

The high rate of secondary conditions among individuals with SCI may in part, be a reflection of the environmental conditions that lead to more negative health indicators among individuals with disabilities. In addition, because individuals from ethnic and racial minority backgrounds are over-represented among individuals with SCI, they may be a minority in two or three different respects. As such, their treatment is impacted by issues of access, biases by both individual providers and the health care system, and deficits in cultural competency.

Health Disparities vs. Health Care Disparities
Health Disparities are differences in the incidence, prevalence, mortality, and burden of diseases and other adverse health conditions that exist among specific population groups in the United States.[2, 3] These are also referred to as health inequities.

Healthcare Disparities are differences in the quality and outcomes of health services. They are a component of health disparities that is specifically focused on the workings of and interactions with the healthcare system. The primary disparities described in the research literature are those experienced by racial and ethnic minority groups. Evidence for racial and ethnic health care disparities are well documented and supported by the results of more than 600 studies conducted between 1992 and 2002.[5] Disparities experienced by individuals with disabilities are not well understood, but are a growing focus for study.

Health Recommendations

Below are specific guidelines for managing SCI / D that have been recommended by physiatrists, researchers and professional associations.[53-67] Because of the number of recommendations, providers may have to work closely with the individual with SCI / D to help them determine which should be their highest priority. They and their family can easily become overwhelmed, especially at first. They may look to a provider for guidance.

Five key factors are critical to keep in mind:

- Does the individual with SCI know what the goals and specific recommendations for each system or situation are?

- What priority should they give each area in light of their current health and personal risk factors?

- Which areas are they having problems or concerns in?

- How important does the individual with SCI think the area is for them and their life?

- How confident are they that they can perform the recommended behaviors?

Skin Care

- Goals: prevent breakdown; keep skin clean and dry
- Self-Monitoring: skin inspection twice a day; be aware of proximity of body parts 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; DVT; decreased heart rate
- Behaviors: wear stockings (and possibly abdominal binder) routinely; perform range of motion exercises daily; move leg position every 2-3 hours; take medications – anticoagulants
- Other recommendations: quit smoking, sufficient fluid intake; avoid excessive sodium, avoid weight gain

Respiratory

- Goals: avoid colds and infections; optimize breathing and oxygenation of blood
- Self-Monitoring: breathing; colds and infections; sleep apnea; blood oxygenation using pulse-ox monitor
- Behaviors: perform breathing exercises (those with cervical or high thoracic injuries); quad cough / chest percussion; if sleep apnea, stop use of alcohol or sleep medications, lose weight, sleep on side, and use mask / c-pap
- General: stop smoking; stay away from known pollutants; annual flu shot; pneumovax

Bowel Management

- Goals: prevent bowel accidents; have 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/time requirements of bowel program

- Behaviors for Bowel Care: regular timing (establish a regular time that will fit into the 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 bladder management allows, take medication, perform scheduled bowel care, use abdominal binder

Bladder Management
- Goals: maintain acceptable bladder volumes; keep bladder pressure low; avoid infections; keep skin dry
- Self-Monitoring: monitor fluid intake (maintain constant fluid intake to avoid infections; minimize fluid intake); monitor cath / void volume (In general between 300-500 ml/cath); signs of infection (color or smell of urine)
- Behaviors:
    - Routinely empty bladder (use established cath technique; maintain supplies/equipment)
    - Voiding (at least 4 times a day; use sterile/clean cath techniques) adjust frequency and interval of cathing as needed: for fluid intake, diuretics and alcohol intake adjust fluid intake as needed; minimum urine output should be 1500 cc/day, take medications as directed
    - Wear appropriate gear / appliances to keep skin dry
    - Change clothes as soon as they become wet

Range of Motion
- Goals: maintain full range of motion in all joints; prevent contractures; improve spasticity management
- Self-monitoring: tightness of ligaments, tendons, muscles and joint capsules surrounding joints; posture ; contractures
- Behaviors: Daily stretches: stretch muscles counter to shortening caused by positioning; self-stretch or assisted range of motion

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General Health

Nutrition

- <u>Goals</u>: eat a variety of foods; maintain ideal body weight; avoid excess fat, saturated fat and cholesterol; eat foods with adequate starch and fiber; avoid excess sugar and sodium; consume alcoholic beverages in moderation

- <u>Self-Monitoring</u>: weight; caloric intake; portion size; types of food; association between eating and stress

- <u>Behaviors</u>: eat breakfast; limit portion sizes; plan meals

- <u>Other Recommendations / Considerations</u>: increase fiber to promote better bowel function; increase protein to optimize healing

Exercise

- <u>Goals</u>: incorporate exercise as part of a daily routine; optimize physical functioning and independence

- <u>Self-Monitoring</u>: schedule of exercise; feelings during exercise; barriers to exercise

- <u>Behaviors</u>: muscular strengthening and endurance training; cardio respiratory or aerobic conditioning; stretching; balance

Pain

- <u>Goals</u>: to reduce or prevent pain; limit or eliminate pain's interference in daily activities

- <u>Self-monitoring</u>: timing of pain, actions / behaviors when experiencing pain; what patient does to avoid pain; pain medications taken, dosage and impact; types of pain (musculoskeletal, nerve, central / neuropathic, visceral, autonomic); duration of pain

- <u>Behaviors</u>:
    - Develop action plan depending on type / level of pain
    - Acute or sudden onset severe pain may indicate a medical emergency
    - Mild to moderate pain lasting days-weeks is often muscle, bone or tendon pain and will usually resolve on its own
    - Muscle, bone or tendon pain (associated with overuse, overstretching or falls), often feels aching, grinding or gnawing; worse with activity but relieved by rest
    - Nerve pain is caused by pressure, irritation or stretching to a nerve and results in aching, heaviness, tingling or numbness

- Spinal Cord Pain / central pain / neuropathic pain originates in the spinal cord or brain and may be felt at the level of injury as a band around the body – hypersensitive to touch or may tingle or burn

- Internal Organ Pain (visceral pain) results from internal organs being overstretched and may occur if organs lose their blood flow

- Headache pain of autonomic dysreflexia occurs in individuals with T6 SCI and above, results from rapid increases in blood pressure in response to bladder over-distension or other pain stimulus below the level of SCI

- Get assessments as needed (x-rays, imaging studies or blood tests); initiate pain management procedures (medication, heat / ice, massage, etc)

Medication

- Goals: patient knows what medications are taken and why; compliance with medication
- 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 leading to 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 vaccines, health screenings (prostate cancer; mammography; pap smears; colorectal cancer; heart disease: blood pressure, blood sugar, cholesterol, EKG)

Community-Reintegration

Managing the Environment

- Goal: to create an environment that optimizes independence and health; to feel comfortable going out into the community

- Self-monitoring: perceived barriers for independence; level of activity; home accessibility

- Behaviors: organize home environment to optimize accessibility; learn attendant management skills

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 self-manage health; increase awareness of resources; 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; prepare lists of questions; follow-up to clarify instructions;

  - Maintain list of health care providers and contact numbers

  - Maintain list of medications

  - Make follow-up appointments well in advance to ensure timely visits

  - Prudent use of the Internet for health related information: visit verified/trusted sites for information→ Ask health provider for advice

SELF-MANAGEMENT SKILLS

SKILL 1: ATTITUDE AND EXPECTATIONS

Attitude is a factor that most people feel is important, but few talk about. Success or failure in living with spinal cord injury [40] begins with the **attitude** of the individual with the condition. In particular, having a positive, proactive attitude is an important part of the individual starting to take charge of their health and life.

Proactive means that it is up to the individual with SCI/D to make things happen. They have to accept that no matter what led them to have their injury, they need to take control of their health to stay well. This type of attitude has been shown over and over again, in personal stories and research, to be linked to better health. That means fewer health problems (like pressure sores or infections), less pain and fewer hospital or ER visits as well as less depression, a better chance of having a job, more relationships and maybe even greater happiness.

<u>**Components of Attitude**</u>

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 are **beliefs that people should behave a certain way.**
These expectations are shaped by what individuals have learned, sometimes through experience or by watching others. Expectations, in turn, change how people behave. Different people or cultures have different expectations.

In U.S. culture, people have specific expectations of health care professional and family members. It is important to clarify expectations at the start of the care-giving relationship - both your own and those of the others involved. The exercises provided in Appendix A may help with this. The closer expectations match, the more likely the relationship will proceed relatively smoothly.

Assumptions are things you **assume** or accept as true without any proof. When working with individuals with SCI/D, it is important to consider both your assumptions about disability as well as those of the individuals with the impairment and their family members / significant others. Your behavior, as well as the behavior of your patients, clients and their family members, will be based on the assumptions that you make about individuals with disability. If you – or they – do not believe that something is possible, you will not consider or address it when providing care. For example, if you believe that individuals with SCI/D do not have sex, then you will not address issues of intimacy, birth control or sexual dysfunction in your treatment plan.

********Completing the Assumption Exercise will help you identify what assumptions that you or others may have about people with disabilities. You must look at your own assumptions to see how they affect you. ****************

Outlooks are the way that people look at things. It is someone's overall sense of the world and approach to life. What someone sees or notices depends on their outlook. If they have on *rose colored glasses*, then they may see everything as bright and happy. If they live with depression, then everything may seem negative 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 the individual with SCI/D you

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work with does not have this outlook, you should refer them to a psychologist, counselor, peer mentor or others who may be able to help them develop it.

Responsibility: The idea of responsibility is critical when it comes to managing SCI/D. Who does the individual with SCI/D believe is in charge of taking care of their condition and their life?

If an individual with SCI/D is going to be in charge, they have to take responsibility for their health. This means learning about and understanding their care. And, they need to decide which health concerns are most important and **prioritize them.** As a care provider, you can help facilitate the process by providing information and resources, but it is the individual with SCI/D who must take responsibility and prioritize goals.

Actions are what people do. Every action that an individual with SCI/D takes or doesn't take is a decision will affect the course ahead. The individual with SCI/D has to decide the direction they want to go and figure out how to get there. Sometimes, it helps them to consider what they are or are not willing to do ahead of time. This depends on their abilities, beliefs and values, and priorities.

SKILL 2: SELF-MONITORING

To **self-monitor** is to keep track of something about yourself, such as your emotions or your bodies' responses. The information that is tracked can then be used to improve health. Helping an individual with SCI/D learn to keep track of what they experience is useful for many reasons. Once they are able to identify a symptom, they can begin asking: "**How strong was that?",** or, **"what was going on at the time?"** This may lead them to understand **why they experienced what they did.**

The information that the individual with SCI gathers should help with making improved decisions about their care, treatment and health. Or, it can be information that will allow them to make informed decisions and changes in the way they manage things. **Appendix B** contains self-monitoring forms that can be used with SCI/D or tailored to individual regimens.

Information Processing and Evaluation

So now the person has collected information – but what will they do with it? First, just by having individuals with SCI/D notice what they do and think may begin to change their behavior. By comparing what they are doing with what they know they should be doing, individuals with SCI/D may adjust their behavior to better meet those expectations.

Second, once individuals with SCI/D begin monitoring their body and behavior, they can look at relationships between different types of information and begin to notice patterns. For instance, they may notice that they when they have a fever combined with increased spasticity, they are likely to have a bladder infection. This information can help them (and you) to plan and better organize their care.

Finally, each time the individual with SCI/D tries a new behavior, medication or treatment, they (and you) can track how well it works. Let's say that they were prescribed an anti-depressant medication and told that it may take two to four weeks before they notice a difference in their mood if the medication is taken as prescribed. You may want them to track of how they feel – maybe rating their mood twice per day for the next six weeks. They would also keep track of when they took the medication. If they don't feel better in six weeks – assuming compliance – then the person may be able to conclude that this medication, at this dose is not reducing their symptoms or feelings of depression.

Examples of Self-Monitoring

You may ask an individual with SCI/D to monitor bladder or bowel management activities.

You may start by asking them to keep track of the time and their ability to perform a management regimen on a specific schedule.

Then you can begin to ask them to include additional details about their urine or bowel movement.

The self-monitoring forms in the appendices can help with this process. The information from this process can help you work with the individual with SCI/D to find a treatment regimen that fits in with their lifestyle.

SKILL 3: PROBLEM SOLVING

Problem Solving allows people to deal with the world by deciding what the problem is, creating different solutions (**brain-storming)** and weighing the pros and cons for each. This skill allows people to stay flexible and try different approaches to various situations.

There are many different formats that can be used to help people consider and work through problems. The one presented here is based on a format developed in 1991 for an Asthma Self-Management Program.[68]

Steps to Problem Solving

Problem solving involves six basic steps: (1) Stating the problem; (2) Outlining the problem with all relevant details; Coming up with possible solutions (4) Figuring out the pros and cons of each solution; (4) Ranking, combining and applying the best solution; and (6) Evaluating the effectiveness of the solution.

State the problem. Have the individual with SCI / D identify the problem. It is critical that the problem represents their conceptualization because 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. Have the individual describe the problem in detail. The exact nature of the problem will become clearer to both of you as you discuss it. Figure out which factors make the situation a problem. Consider all facts, expectations and assumptions.

List possible solutions: After outlining the problem, work with the individual to come up with as many possible solutions as you can. Once again, it is critical that the individual with SCI/D 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. Their perceptions of a solution's feasibility and convenience will impact whether or not they will carry it out. If you have solutions you think they should try, ask their permission to suggest some before stating them.[69] Problem-solving is a critical skill that the individual with SCI must learn and a process they must become invested in.

Encourage them to be creative without worrying about how good the solutions are yet. Another method to generate solutions is to have them ask other people, such as friends or family or peers with SCI, how they have handled similar problems. They might go to the library and look for books related to the problem or look on the internet or Care Cure Forum, for instance, if it is related to SCI. Or, they might contact a group or agency that is an expert on that subject.

Encourage the person to keep all potential solutions, no matter how crazy they may seem. Together, come up with at least three solutions. Later, you can work together to improve ideas by combining two or more.

<u>View the possible consequences of each solution.</u> Have the individual weigh each solution by listings pros and cons. They need to consider the reality or truthfulness of the assumptions.

<u>Rank solutions then use the one rated highest.</u> Have the individual rank their solutions in order from best to worst. The solution they ranked as the best should be one they are willing to try and that seems likely to lead to their desired outcome. Encourage them to give the solution their best effort and track the outcome.

<u>Determine how effective the solution was</u>. 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 was expected? The person might need several possible solutions to use for different situations. If it did not work at all, they could try again or move on to something else. Encourage them to use what they learned from trying this first option to refine the problem solving experience.

General Format

State the problem		
Outline the problem		
Possible Solutions	**Pros & Cons (Consequences)**	**Rank**
	Pros: **Cons**:	
.	**Pros**: **Cons**:	
	Pros: **Cons**:	
	Pros: **Cons**:	
Use & evaluate your solution		
Determine if the solution is effective		

Problem-solving Example 1: Bladder Management

State the problem		
I'm having problems with my bowel program		

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.

Possible Solutions	**Pros & Cons (Consequences)**	**Rank**
Medications I could use Ducolax because it makes my bowel program go faster.	**Pros**: May help. Easy. **Cons**: Ducolax can cause bad cramping for me.	
Timing I could do the bowel program in the morning.	**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.	
Diet I could eat a diet that is higher in fiber, which my doctor suggested.	**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.	1
I could take Metamucil to prevent some of the loose stools I have.	**Pros**: It works. **Cons**: I really hate drinking that stuff!	2

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.

Determine if the solution is effective
I have very few accidents. I've discovered some new foods I like that contain more veggies and aren't fried. I still eat some greasy stuff, but I've added some other foods for variety. I also take the Metamucil capsules.

Combining two solutions helped me to solve most of my problem with a bowel program.

Problem-Solving Example 2: Community Mobility

State the problem:		
I want to go out to the mall, but I get so tired.		

Outline the problem:		
Going out into the community takes a lot of energy. Someplace like the mall means a lot of walking. Plus there are a lot of obstacles that I have to deal with.		

Possible Solutions	Pros & Cons (Consequences)	Rank
Don't go. Ask someone else to get you what you need.	**Pros**: Will save energy and still get what need. **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.	
I'll take short-cuts when possible. Use elevators or escalators if they are going to make things easier.	**Pros**: Save a little energy. Still get to go out and see friend. **Cons**: Not taking the opportunity to practice stuff like stairs.	1
I can use a wheelchair rather then my crutches.	**Pros**: The wheelchair will make it easier to get around the mall and save energy. Will be better able to carry stuff. **Cons**: Will be hard to use escalators and go up curbs. I feel better about myself when I use the crutches.	2

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 get enough exercise just walking the mall.		

SKILL 4: COMMUNICATION

Communication can be defined as the process of transferring information from one source to another. 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.

Basics of communicating

1. Decide what the goal of the conversation or exchange is:
How someone approaches an interaction and conversation should be based on a realistic assessment of what they 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? The communication strategy is based on the assessment of the other person in the conversation and how to get what you want from them.

3.   **Encourage the individual with SCI/D to accept responsibility for their own feelings.** Blaming other people for feelings may lead the listener to become defensive. When defensive, that person becomes concerned with protecting themselves and may not hear what was said.

To avoid making people defensive when discussing feelings, encourage the person to start their sentences with "I". They 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." The basic format for these statements is:

> *I feel _____ when you do _____.*

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 then 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 - the other person's approval or recognition or maybe just information. They want to share information, demonstrate their understanding, or 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 they are communicating, the speaker can decide if they are communicating the way they want and make needed

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changes. People need to know they don't have to agree with the feedback, but they should at least consider 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 thoughts and feelings without violating the rights of others. Assertiveness and boundaries go hand-in-hand. When people are assertive, others can hear and understand their opinions without feeling threatened.

Examples of Communication

Communication can be very simple and straight forward or 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.

SKILL 5: ORGANIZATION

To **organize** is to put something in an orderly system to make it easier to use. Being able to plan and organize is a very important skill for individuals with SCI/D to have. Once they have developed this skill, they can begin to consider how to organize their day around their bladder management schedule or plan ahead by gathering the supplies they may need during the day so that they are available.

Steps to Organization

Decide on a goal. Make sure that the individual with SCI / D does not try to organize every area of their life at the same time. Encourage them to pick one or two areas and just start somewhere.

Prioritize: People make priorities when they decide what is important and how they are going to spend their time. One way to decide what is a priority is to think about what would happen if something did not get done. Another is to figure out what needs to be done in the next few hours and then make plans to best accomplish that.

Make a plan. Decide how to organize

- Encourage the individual with SCI/D to use self-monitoring skills to observe what they currently do as well as strengths and potential barriers
- Define categories based on issue / goals
- Determine if things need to be done in a particular order
- Figure out how much time each action may take. Remember, it is better to allow more time than less
- Create a flow-chart of what will happen to items in each category
- Break down the task into small pieces that are easy to handle. Be realistic about how much time something will take and how long you have in any one sitting
- Schedule when to do the actions

Take Action

- The individual with SCI/D should gather the materials needed
- Get rid of what is not needed
- Sort information / materials into categories
- Follow-through with planned action for each category

Maintenance:

- Develop habits

- Deal with relapses

- Use the system to organize in the future (a different schedule, new information, or something else.)

Organizing the home

The setup of where an individual with SCI/D lives is very important – it can be the difference between needing a caregiver present and being independent. It will be important for the person with SCI/D to make the time to organize their environment so that it is accessible. This will save a lot of time, money, and stress down the road.
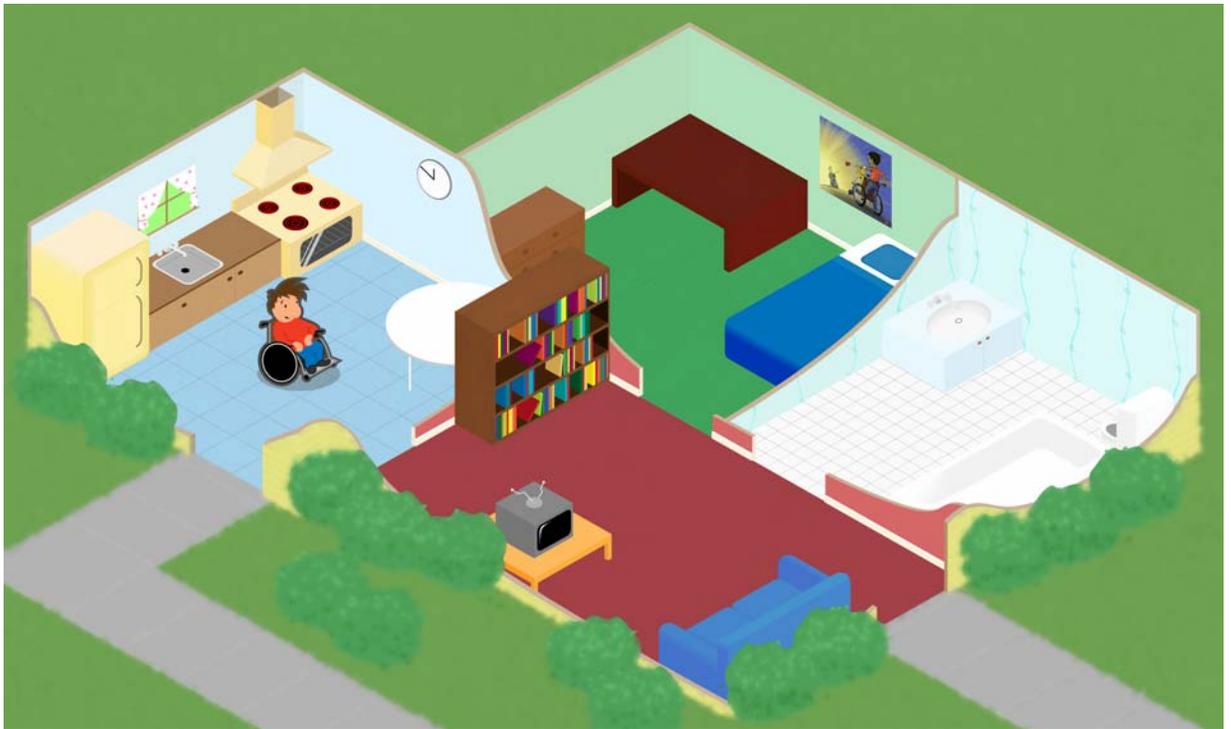
- **Decide on a goal.** The individual doesn't need to organize the whole house at once. Have them pick one or two areas, like a room or a "problem area" that their wheelchair can't fit around.

- **Make a plan.** You may want to help the person think through the organization. Have them consider what areas they use the most and what activities they want to or need to do in their space. If needed, provide assistance to help them decide **how** to organize the items in a way that creates smaller units (chunks) that they can manage.

- **Downsize first. If they can throw away** any of the items that are in the space they are organizing, they should do so first. Items can be thrown in the trash, recycled, donated to an organization, posted on Craigslist or given to a friend.

- **Gather supplies that will be used.** File folders, boxes, a marker or other items may all be helpful in sorting things out. Remember, buying stuff for organizing is not the same as organizing! Extra shelves on which supplies or stuff can be easily reached are a good investment. Clear containers that can be labeled will also be helpful in storing things in an efficient manner.

- **Start somewhere.** Help the individual you are working with start on their plan when they have some time. They can set a timer to keep them on track or just do a small amount at a time

- **Keep at it.** Provide support and encouragement. Getting organized takes time. Even working for short amounts of time will bring progress. Help the individual with SCI/D find time to use the organizational plan and before long they will make enough progress to see a difference.

- **Tweak if needed.** If the system doesn't work for them, they can revise it or try another. It needs to make sense to the individual and make their life easier.

- **Keep it up.** To stay organized, people have to build new habits. Most people will fall back into old habits at some point. Rather than allowing them to be hard on themselves, encourage them to learn from their mistakes and try again.

<u>Organizing a schedule</u>

Decide on a goal. By planning ahead, the individual is better able to accomplish what they need to and can set aside time for leisure activities.

Break it down. First, have the person identify their priorities, those appointments or tasks which are most important to them.

Use the best tool for the job. Help them figure out the best way to keep their schedule using a wall calendar, planner, cell phone or other device that will be easy to update and check.

Write them down. They can record the most important items on the day and time they need to happen and then add other things to the schedule. The person can add things that happen at a certain time every day, appointments or a caregiver's hours, or time set up to meet friends. They will need to allow time for getting ready to leave the house and get to where they need to go.

Combine things. The person should allow some time in between events. Shorter or related things can be combined together, such as grouping trips to the post office, grocery store and a government office so that transportation isn't needed for each separate errand.

Get rid of what isn't needed. Leave out or cancel activities that don't seem worth the time.

Add anything else. Scheduling something makes it more likely to get done. Plan specific time for activities that someone enjoys (weight lifting, getting outside, time with the family or a TV show) as well as those that feel like more of an obligation (exercise, homework or time with the family.)

Check it twice. The person needs to get in the habit of checking this schedule at least twice a day in order to avoid overlooking something that was planned.

The benefit of organizing a schedule is that a person can make the most of the time that is available. This doesn't need to be perfect, but knowing what has to be done each day and not forgetting it can make life easier and less stressful.

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		

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SKILL 6: STRESS MANAGEMENT

Sometimes it's hard for people to recognize that they are feeling "stressed out" or having a problem that may be related to stress. In these cases, they may just feel tense or irritable. Other signs of stress include headaches and fatigue. Because many symptoms of stress can also be signs of physical problems, it is important to consider possible physical causes before diagnosing a problem as stress-related.

When people experience strong emotions, those feelings are to go somewhere. Emotions trapped in the body can affect health. Anger and feelings of helplessness have been associated with poorer health management and more negative outcomes for people with cardiac conditions.

Once an individual with SCI/D determines they are experiencing stress-related symptoms, the first step is to **identify what the problem is**. Once that is done, their choices consist of solving the problem, changing the situation, or changing the way they feel about the situation. Problem-solving is the skill that helps people figure out how to make a change or take action in a given situation. Stress management, though, is more associated with releasing the emotion that has built up inside.

The primary methods of managing stress 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

These skills will not be discussed in this manual but more information can be found in *Health Mechanics* or through a multitude of books, classes and research programs.

In addition, the individual needs to <u>avoid</u> the following [70]:

- Not getting enough sleep

- Allowing their physical environment to become chaotic with too many distractions, too much noise or allowing the environment to remain inaccessible

- Not finishing what they start

- Letting everything catch their interest and distract them from what really needs to be done

- Allowing other people to set (and keep re-setting) goals and priorities

BUILDING THE RELATIONSHIP

Your role as a care provider

You, the health care provider, have a key role in enhancing the health and wellness of your patients or clients with SCI / D. Your treatment, counsel and encouragement can affect their health. The question becomes – how do you create a positive relationship that will help you facilitate the health of the person you provide care for? How do you encourage patients or clients to build positive health behaviors and to assist them in minimizing secondary conditions so they can optimize their quality of life?

The first step is the relationship. You can collaborate with individuals with SCI/D to enhance their health and independence, and to prevent or deal with the consequences and complications of SCI/D. To do this effectively, you will need to recognize your own expectations and assumptions. As previously mentioned, the exercises in Appendix A can assist in accomplishing this.

In the past, provider-patient relationships were paternalistic, meaning that health-care providers made decisions for the patient using their best clinical judgment. The current models emphasize the inclusion of the patient in their own care. Both the physician and patient are actively involved, share available information and work towards building consensus. Optimally, the provider and patient reach an agreement, though there can be many barriers to reaching a consensus.[71]

Regardless of whether a patient believes "the doctor knows best" or if they are prepared to take responsibility for planning their treatment regimen, research shows that patients prefer physicians who are confident, empathetic, humane, personal, forthright, respectful, and thorough. Patients want personalized attention, including the opportunity to tell their stories and feeling that their physician really listened. [72] A provider's communication style and skill in developing relationships can have a strong impact on lifestyle and behavior change by the patient. In contrast, poor provider communication skills are associated with poor patient satisfaction with services and decreased adherence to medical recommendations.

Adherence

Adherence to treatment is the extent to which a patient follows medical advice [1].
Non-adherence to any form of treatment can be traced to several factors including:

- **Complexity of treatment regimen**: Type and choice of treatment, number of treatments, and their length all affect patient compliance. Research has show that long acting treatments with simpler regimens and fewer doses may improve adherence. [4]

- **How physically tolerable the treatment is:** It is important that providers find out whether treatments have significant side effects. A high degree of side effects increases the chances of non-adherence.

- **Psychological state of the patient,** including depression, impacts motivation and performance of healthy behaviors. Individuals who are depressed are more likely to negatively evaluate a behavior's impact. They are also less likely to have an internal locus of control, and so view their own actions and behaviors as ineffectual or unimportant.

- **Social Support:** Social support is also critical in facilitating adherence. Meta-analysis of 122 studies showed that treatment adherence is 1.74 times higher in patients from "cohesive" families [6] and social support is shown to be an important factor in immune, endocrine, and cardiovascular functioning, health maintenance, and recovery from illness or injury. [7-8] Evidence also shows that support from families and friends promotes adherence by encouraging optimism, increasing self-esteem, reducing stress and serving as a source of practical assistance. [79,8] Adherence rates of patients with practical support are 3.6 times higher than those who have no practical support.[6]

- **Patient resources and finances**

- **Quality of the patient-provider relationship:** [1, 12, 13] Collaboration between patient and physician is linked to improved adherence. This appears to hold true whether the condition is chronic or acute, the patient is an adult or a child with a caregiver or the doctor is a specialist or a primary care provider. In a collaborative relationship, the doctor is the expert on the condition, and the patient is the expert on his/her own life, and decisions are made through the efforts of both parties. If a patient and physician **do** collaborate, the physician learns more about the patient's lifestyle and beliefs and can make better decisions about the best treatment plan and how to help the patient follow it.[1]

Clark and colleagues [73-75] identified ten basic communication strategies and demonstrated how health care provider compliance with these recommendations can increase patient's satisfaction and outcomes. These strategies include:

1) Nonverbal attentiveness
2) Eliciting underlying fears
3) Addressing immediate concerns
4) Reassuring messages
5) Interactive conversation
6) Tailoring the regimen
7) Planning for decision making
8) Setting short-term treatment goals
9) Making a long-term treatment plan
10) Nonverbal encouragement and verbal praise

Nonverbal attentiveness refers to how the provider positions his or her body and behaves in relation to the patient. Good nonverbal skills include eye contact, sitting at the same level as the patient to eliminate social distance, smiling, shaking hands and using appropriate social gestures. Other aspects including removing barriers between the provider and the patient (such as a desk), listening without interrupting and leaning forward slightly while listening.

Eliciting underlying fears relates to finding out about the concerns of the patient and their family members. Open ended question such as "What do you think may get in the way of you performing behavior [x]?" and "What worries do you have about managing your health?" can help identify the patient's perceived barriers.

Addressing immediate concerns is critical. This can be done by acknowledging the patient / family's key issues and addressing the most important ones. Answers to specific questions should be relayed in an open manner. If you do not know the answer, you can provide partial information and assure the listener you will look into and get back to them.

Reassuring messages help reduce emotional distress that can impede communication and compliance. Accurate identification of shared priorities and goals paired with assurance that the patient can impact their health by performing concrete, prescribed behaviors can go a long way towards reducing anxiety and improving adherence.

Interactive conversation is a communication strategy that builds on what the patient and family knows and believes. By asking questions about what patients have heard or what they think would be effective solutions, you can reinforce or correct knowledge if needed. These conversations should always be initiated in a non-judgmental and supportive atmosphere so that patients feel comfortable saying what they think and don't worry about giving the "wrong answer." This approach is more apt to elicit truthful responses. Also, it is critical that information be given at a level appropriate to the

patient's education and understanding. Overestimating a patient's ability to grasp health information can lead to a lack of understanding and compliance.

Tailoring the regimen is a matter of adjusting treatment and other recommendations to fit the life and routines of the individuals with SCI/D and their family. Ask about priorities and daily routines and reach agreement with the patient on how to best adapt the recommendations to their schedule and resources. This may require asking the patient to plan ahead and establish patterns of behavior.

Planning for decision-making will help the patient create an action plan beforehand. The section on facilitating problem-solving contains more in-depth information on this topic, as does the next chapter. Planning can reduce patient and family anxiety by instructing them on which signs to monitor and what action to take if particular symptoms arise.

Setting short-term goals for treatment translates your recommendations into interventions that are going to address the priorities and goals of the patient. By tying treatment to their goals and priorities, you increase motivation and provide a concrete benchmark for evaluating progress.

Making a long-term treatment plan allows you to partner with the patient / family to manage health and prevent secondary conditions. Long-term goals may be for the patient to return to work, or to spend more time without pain. Once you have agreed upon a goal, you can negotiate different steps that may help that patient reach that outcome. For instance, a patient may initially feel that they are increasing functioning only if they walk again, but may agree to work on improving wheelchair skills as part of a comprehensive physical therapy program.

Nonverbal encouragement and verbal praise is important for building rapport and reinforcing the steps that the patient is taking or has taken to improve their health. It is important to reinforce steps and successive approximation as well as complete compliance with recommendations. Facilitating positive self-efficacy and providing feedback about successes and tips for improving performance are valuable as well.

Using patient-oriented communication, discussing patient's expectations and behavior, having a warm, friendly demeanor and building trust with patients are provider traits that can positively influence patient behavior. Moving control from the provider to the patient is a strong factor in encouraging behavior change. [76]

Barriers to Effective Patient-Provider Communication / Relationships

Expectations and Assumptions: Earlier in this guide, we discussed how inaccurate expectations and assumptions that do not match those of the patient may be problematic. As a health care professional, it can be helpful to take the time to articulate and clarify your expectations and assumptions with patients. List your expectations and ask others to give you feedback on it. As long as you are clear up front, patients will not feel blind-

sided. It can also be useful to collect data on the reality of the situation. Try not to base your understanding on treatment or behavior on things that cannot be verified. This also is a great way to clarify any misconceptions or distortions in information.

Biases and stereotypes: One roadblock to good provider-patient interaction is a provider's own biases. Every human being has them, and they may be based on gender, age, disability, race or socioeconomic status. Research has shown that physicians are more likely to believe that women will make excessive demands on physician time compared with men, and their health complaints are more likely to be diagnosed as psychosomatic when compared to men.[77] There are also those "compassionate" biases which are positive assumptions but equally inaccurate. These may arise when dealing with the elderly. It is easy to assume that an older person is less autonomous and in greater need of support.[78]

Providers' perceptions can also be influenced by the patient's race and socioeconomic status. African-Americans and middle to low-income groups have been found to be judged more negatively than whites or the wealthy. Stereotypes included assumptions about risk behavior, ability to adhere with treatment, and assumptions about personality.[79]

Finally, there are biases associated with disability. Research conducted at three level-one trauma centers found that relatively few health care providers (only 18%) believed that they would be glad to be alive after a severe SCI (in contrast to 92% of people with SCI) and only 17% believed their quality of life would be average or above average after SCI (compared to 86% of people who already have SCI). These opinions can impact the decisions physicians make in treating SCI and also what they tell the families of injured patients about critical care decisions and options.[80]

Patient boundaries and attachment style: A person's attachment style can be secure (trusting of self and others), dismissive (high reliance on self, not others), fearful, or preoccupied (people who move back and forth, from clingy to nearly absent). The dismissive style of attachment, in particular is causally linked to lower rates of adherence to diabetes treatment.[13] Many providers find it easier to be a vehicle of "information transfer," with a patient who makes up their own mind. In contrast, a passive patient may require that the professional has to struggle to glean information and preferences as they cannot or will not communicate.[81] What attachment style you as a provider can tolerate, is based on your own history and personality.

Functional and Health Literacy: People from any background or income level can be functionally illiterate or lacking the ability to carry out the basic tasks that allow a person to function in society. The ability to read, write and speak English and perform simple calculations are the components of functional literacy. Of course, a person's level of education is related to literacy, but completing a grade level in school does not ensure the ability to read at that level.

High risk groups for functional illiteracy include people who have less than a high school education, are elderly, members of ethnic/racial minorities (African American, Hispanic

and others), recent immigrants, people born in the U.S. who speak English as a second language and those who are of lower socioeconomic status.

Health literacy is defined as "the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions."[82] Although estimates vary, a 2004 Institute of Medicine report stated that nearly half of all American adults (90 million) have difficulty reading and understanding health information.[83]

Basic, or **Level 1 literacy** is considered less than functional literacy in the US. Someone operating at this level cannot fill out a job application, read a simple story to a child or understand a food label.

About 20% of American adults read at only basic level or below, compared to 18% of people in Michigan. This percentage varies greatly from one geographic area to another and may top 50% of the population in poor urban areas. [84]

According to the Partnership for Clear Health Communication, adults reading at intermediate, basic and below basic levels would be capable of the tasks described in the following table:[85]

Literacy Level	Capabilities	Percentage of US adults with literacy level[86]
Below Basic	Searching short, basic text to find out what a patient is allowed to drink before a medical test Signing a simple form	**14%**
Basic **(Level 1)**	Reading a television guide to learn which shows are on at a particular time Learning two reasons from a clearly written flyer why someone without symptoms needs to be screened for a disease	**22%**
Intermediate	Using reference materials to determine which foods contain a particular vitamin Determining healthy weight by using the BMI chart	**53%**
Proficient	Reading a complex document to find the definition of a medical term	**12%**

As the majority of health information is written at a 10th grade level or higher[87], many people are simply not able to comprehend the materials that health providers give them.

Developing an Agenda or Treatment Plan

Developing an agenda or treatment plan in collaboration with individuals with SCI/D and their families offers them a roadmap for what is ahead. You identify the destination, or long-term goal, negotiate short-term goals that reflect the patient's concerns or priorities, and then generate an action plan that outlines how to get there; always noting that this map is fluid and may change as priorities change or complications arise. During this process, you are helping the patient or client work towards goals and break the trip into manageable steps.

Identify the Long-Term Goal

One of the key points to remember is that your priorities as a health care provider may not match the patient's priorities. They have an entire life that you do not see and values that you may or may not share. Your goal is ultimately for the person to be able to live with their condition, not have their condition be the sole focus of their life.

It is important that individuals with SCI / D and their care providers discuss the goals that each has and wants to see achieved. This may require negotiation between the two parties to determine the goals of each individual. Once the goals have been established, a contract and action plan should be developed to improve the likelihood of success.

Before you can engage a patient and convince them to change behavior, they have to identify the issue as causing a problem in their life. Begin by asking:

- *What are the priorities in your life?*
- *How does SCI/D (or a specific secondary condition?) get in the way?*

Some potential priorities are: family, including the health of other family members or the demands of children; finances; spirituality / religion; independence; employment; fitness; status / power; attractiveness; physical health; mental health; avoidance of abuse; and comfort.

Once you know what is important to the patient, you can tailor your message, your short-term goals and interventions to focus on optimizing that area.

Set Short Term Goals

Short term goals should be more immediate goals that will help the individual with SCI/D reach their long-term goals. To the extent possible, tailor the short-term goal to correspond with their priorities and concerns. It will be critical that you do not set a goal which ignores what the patient wants to do or feels ready to handle. Not doing so may lead to a break in rapport.[69]

Rollnick [69] suggests asking patients to identify how important a behavior is at this point in their life.

Ask: *How important is it right now for you to _____?*
        On a scale from 0 to 10, what number would you give yourself?
        Why are you at number [x] and not at 1?
        What would need to happen for you to get from X to (slightly higher number)?

The next step is asking about confidence to change. Readiness to change is a function of both importance of the problem and their confidence in the ability to perform needed behaviors (self-efficacy).

You may ask:

>   *If you decide to change, how confident are you that you would succeed?*
>   *On a scale from 0 to 10, what number would you give yourself?*
>   *Why are you are X and not at 1?*
>   *What would need to happen for you to get from X to (a slightly higher number)?*
>   *What would happen if you do not make a change?*

Develop Action Plan

The action plan consists of the steps necessary to accomplish the short-term goal. Although both the individual with SCI/D and the provider will have specific tasks, the majority of steps should be related to the behavior of the individual with SCI/D.

Tailor Action Plans based on patient's routine and concerns. Assist the patient with planning how your recommendations will be incorporated into their day. Be as specific as possible with what the action will involve, how long it will take, and how much assistance may be required. Simplify complex regimens and behaviors as much as possible. Self-monitoring may help an individual with SCI/D describe how they spend each day and what issues may come up when they try to perform the recommended behaviors.

Identify Barriers: Behavior change is hard. People say they will diet, and yet that intention did not take into consideration the box of chocolate and guilt that was waiting for them at home. Research has demonstrated that if someone can anticipate barriers and challenges then they can plan for them and address how to deal with them. As a health care provider, you want to ask patients about the barriers or challenges they expect to encounter as well as help them to anticipate common ones.

Ask: *So, you say you want to change your behavior to do [x], what is likely to stop you? What will you do when that happens?*

What about social support? How will your family react?

What information or skills do you need to be able to do this effectively?
Do you need practice? Feedback?
Do you have the resources you need to accomplish this?
How will you keep your motivation up? This may take a while.

Once potential problems or challenges are identified, promote the use of problem solving strategies to help address them. Encourage the individual with SCI/D to stop, think, gather information, and make informed decisions.

Decision Making Paradigms: The action plan should provide the individual with SCI/D with the information about steps that they should take should certain things occur.

For example, you may instruct them that if they notice that their urine begins to have a foul smell and becomes cloudy, they should contact the office to determine diagnosis and treatment course. Some patients may need to come in for an appointment while others can just drop off a urine sample. Still others may have a high level of knowledge and skills, such that you trust them to start taking antibiotics when they notice the signs of a urinary tract infection.

Provide Education / Information:

It is important that you help the patient / individual with SCI / D understand what is going on and what can be done to help address the condition. Explain the issue – be it a pressure sore, bowel management problems, or issues with inaccessibility – in clear, simple terms. When possible, provide pictures and diagrams to help illustrate what is happening with their body. Relate the information to the signs and symptoms that they have reported, and then have the person rephrase your words back to you.

Next, explain what you are recommending and why. Explain how your recommended treatment relates to their goal, issue or complaint. Provide information on what behaviors they will have to perform in order for the treatment to work. Assess their understanding about these recommendations and why they are supposed to work.

It is also important to address concerns that patients have and other information that they may have derived from other sources. Patients and families often try to gather information about treatment alternatives online. In addition, friends may provide advice and recommendations. For provider recommendations to be followed, they have to address how this information fits or differs from that provided from other sources and why their recommendations should be followed.

Provide frank and honest information about both side effects and potential problems with the treatment regimen and what might occur if recommendations are followed only sporadically. Sometimes, it is better to consider alternative interventions and treatments rather then rigidly focus on one that the patient has said they may not completely comply

with. It is important to listen and provide the patient with sufficient information to make an informed choice about their options.

Very few people will tell health care providers that they don't understand what they have been told, especially if it is related to a lack of reading ability. People with low literacy skills use many strategies to keep this a secret. Rather than trying to identify people who don't read well, it is better for health care providers to improve and simplify communication with patients.

There are several different approaches that can be used to ensure that all patients understand the health information they have been given.

<u>Ask Me 3 Method</u>: The Partnership for Clear Health Communication[85], a coalition of private and public health organizations, promotes "Ask Me 3" as a method to simplify key messages for patients. This involves focusing on three important questions:

1. **What is my main problem?**
2. **What do I need to do?**
3. **Why is it important for me to do this?**

A provider can use the first question, "What is my main problem?" to focus on the patient's main diagnosis and major presenting problem. The second, "What do I need to do?" pertains to specific instructions for the patient (medications, treatment or other directives) regarding their condition. Finally, the question, "Why is it important for me to do this?" relates to the importance of complying with instructions as well as the consequences of non-compliance.

<u>Teach Back Method</u>: Many health care providers already use this technique. After telling a patient about their diagnosis, treatment options and instructions, providers can say, "please tell me in your own words what we talked about." If a patient doesn't understand, the provider can rephrase and repeat the question until they do.

The physician or nurse can listen carefully to the patient's interpretation, then correct misconceptions and re-emphasize the main message. Providers might emphasize that they are doing so because of their difficulty communicating complex information, rather than on a patient's lack of comprehension. They might say, "I described your condition and treatment fairly quickly. Can you let me know what you understood about it?"

<u>Other Tips to Improve Health Communication</u>
- Repeat key information and emphasize main points.
- Slow down. Even literate patients need more time to comprehend when they are under stress or dealing with an emotional topic.
- Use visual aids (drawings, diagrams, pictures or demonstrations) to supplement the message.

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- Use plain language rather than medical terms. See Table 1 for examples. An online source is the Plain Language Thesaurus, which can be accessed at http://depts.washington.edu/respcare/public/info/Plain_Language_Thesaurus_for_Health_Communications.pdf.

Clinicians may forget that the commonplace medical terms (such as hypertension, anemia, and deficiency) may not be familiar to laypeople. They need to avoid, if possible, using words that have more than one meaning (such as dressing, stool, range and others). Complex terms need to be explained, and the term should be used consistently when communicating with the patient. Abbreviations (i.e., UTI or AT), symbols – even those for positive and negative- should be avoided.

Written materials should be chosen carefully. A number of agencies offer informational pamphlets written in plain language, including the National Cancer Institute, Center for Disease Control and Prevention (http://www.cdc.gov/DiseasesConditions/) and many others.

Table 2. Translating medical terms into plain language

Medical term	Plain language
abrasion	cut, scratch
hypertension	high blood pressure
anemia	not enough iron in your blood
adjacent	next to, nearby
contraception	birth control
occupational therapy	therapy that helps you relearn everyday activities
benign	not cancer
dilate	make larger or wider
persistent	there all the time

Facilitate the development of confidence and self-efficacy

Self-efficacy is the belief that one is capable of performing specific activities to attain certain goals. It is based on an individual's evaluation of the their ability to execute an action or series of action in various situations. Research has shown that self-efficacy is related to performance of health behaviors.

Factors that influence self-efficacy include:

- Experience and feelings of mastery: People are generally more confident about their ability to do things that they have already done. Success in performing an action increases self-efficacy while failure decreases it. An important part of mastery is knowledge. It is critical that someone know what they are supposed to do before they can do it.

- Modeling / social learning: People are more likely to feel that they can accomplish something if they see others doing it. They gain positive "vicarious experience" through watching others succeed at a task. Negative vicarious experience happens when they see others fail. The impact of modeling is mediated by social comparison between the individual observing and the model; the more similar that the observer perceives the two to be, the more the performance of the model will impact their self-efficacy.

- Social Persuasions: The messages that people receive from others in their environment can have a strong influence on their confidence that they will be able to succeed in performing a behavior. Encouragement can increase self-efficacy while negative persuasions decrease it. It is generally easier to decrease someone's self-efficacy than it is to increase it.

- Physiological factors also influence self-efficacy. When people are trying to determining how they feel and how likely they are to accomplish something, they look for cues. Signs of nervousness and distress – including shaking, upset stomache, pain, fear, etc – are often taken as evidence that they are not prepared and will not succeed. Changing the association between the response and its implications can change its ability to mediate self-efficacy.

Another way to help increase confidence and self-efficacy is to have the patient demonstrate the behavior to you. This provides them with the opportunity to practice and receive feedback about the technique or skill. Be sure to praise their success. To the extent possible, try to reinforce successive approximations. Always affirm the person and point out successes, even small ones. Reframe "failures" as intermediate successes whenever possible

Recognize and build on strengths: If you look at your patient and see only problems and weaknesses, it can be overwhelming. Many providers will "turn off" or disengage from the person who they don't know how to help or see not benefit in trying to do so.

One strategy that can help is to look at the patient and try to see an individual with strengths and potential. What has allowed them to succeed, cope or survive in the past? Do they have a good family? A good attitude? Are they intelligent or street smart? Do they take pride in their appearance or status? Are they stubborn, determined or hard-headed? Focus on whatever strengths you can and help them use those experiences, skills or personality traits in service of improving their health.

In order to promote wellness, it is important that providers work from where the patient actually is rather then from where they want them to be. Most providers do not have the luxury of limiting their practice to highly educated, disciplined people who have many resources.

Sample Form for facilitating agenda and goal setting:

APPOINTMENT WITH HEALTH CARE PROVIDER

Date: **Time:**
Place:

Things to Bring to appointment:
☐ self-monitoring forms   ☐ questions
☐ medications   ☐ other: _____

Primary goal / purpose of visit:

To be completed by patient prior to appointment:
Patient concerns

☐ Pain	☐ Medications	☐ Bowel	☐ Bladder
☐ Sexuality	☐ Skin	☐ Physical Functioning	
☐ Weight	☐ Diet	☐ Sexuality	☐ Mood / Emotions
☐ Sleep	☐ Prevention	☐ Exercise	☐ Recreation
☐ Employment	☐ Relationships	☐ Equipment	☐ 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?

Example of completed form

APPOINTMENT WITH PHYSICAL THERAPIST

Date: 8/12/2006   **Time:** 10am

Place: Physical Therapy Department

Things to Bring to appointment:
> XX self-monitoring forms   XX questions
> ☐ medications   XX other: cathing supplies, sliding board, braces

Primary goal / purpose of visit: therapy; education and practice

<u>**To be completed by patient prior to appointment:**</u>
Patient concerns

XX Pain	☐ Medications	☐ Bowel	☐ Bladder
☐ Sexuality	☐ Skin	XX Physical Functioning	
☐ Weight	☐ Diet	☐ Mood / Emotions	
☐ Sleep	☐ Prevention	☐ Exercise	☐ Recreation
☐ Employment	☐ Relationships	☐ Equipment	XX Insurance
☐ Other:			

> Additional details / comments:

Questions for provider
> 1. I'm experiencing increased pain in my shoulders with transfers, is that normal?
> 2. How much longer will I be able to attend therapy?
> 3. How are the exercises we are doing going to help me to walk?

Information Needed

<u>**To be completed with provider**</u>
Action plan (Negotiated between provider and patient)

> **Long term goal:**   Improved mobility; be able to play with children

> **Short-term goal**: Increased strength; ability to transfer independently

> **Trial period:** 3 therapy sessions per week; practice exercises twice day, every day

> 12 therapy sessions then re-evaluate plan

> **Signs to monitor:** pain in shoulder; skin integrity; strength; ease of transfers

> **When to call / contact provider:** Call office if you are unable to make an appointment

Potential Barriers and solutions brainstormed:
> Time to practice; assistance with practicing skills; transportation to therapy

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)**: 6**

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?**

APPENDICES

Exercises for Providers: Expectations and Assumptions

Which of the following statements reflect expectations that patients may have of you, the health care provider (*not always positive*)**?**

☐   I Will be *Timely*

☐   I Will be *Competent*

☐   I Will be *Thorough*

☐   I Will be *Attentive*

☐   I Will be *Compassionate*

☐   I Will be *Honest*

☐   I Will be *Caring /* interested in their care

☐   I Want to try and improve their lives

☐   I Will give my complete attention to their problem

☐   I am an expert in treating individuals with SCI, and familiar with all the issues / concerns that they will have

☐   I will be able to help them improve functioning, and give them feedback on how they're doing with that

☐   I will work to the best of my ability to help them optimize functioning

☐   I can fix / cure them

☐   They are my only patient; I can fit my schedule to them/spend as long as needed to answer questions/ignore other patients for last minute requests or questions

☐   Everything that I do will work or work right away

☐   I will know everything

☐   I am able to tell what level of pain they have

☐   The first medicine I prescribe will almost always work

☐   I work for them/ and will give them instant results or "service"

Which ones of these do you think are reasonable?

Which statements reflect expectations that you have of your patients?

☐ Patients will arrive on time to appointments

☐ Patients will call if they're unable to attend or will be late

☐ Patients will express their concerns about barriers

☐ Patients will ask questions

☐ Patients will contact providers when there are problems/concerns/changes

☐ Patients will be involved in their own care, to the extent of their ability

☐ Patients will be honest with their health care provider and say something if they cannot follow their recommendations or disagree with them

☐ Patients need to be invested in the process

☐ It is up to patients to know as much as possible (according to their ability) about their care and condition

☐ Patients will follow the rules

☐ Patients will prioritize therapy

☐ Patients will prioritize their health

☐ Patients will be open and communicate

☐ If patients say "no" to doing something, they will suggest (a) reasonable alternative(s)

☐ Patients will believe they are responsible for their own health

Do you have other expectations of patients?

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

What assumptions do you think you might make about disability or individuals with disabilities?

☐ Individuals who use wheelchairs are broken / not whole

☐ People who cannot walk are helpless

☐ Individuals 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

☐ If you have a disability, life is over

☐ A person who uses a wheelchair is no longer a complete person

☐ It is better to be dead then disabled

☐ Life if not worth living if you have a disability

☐ People with disabilities are worthless

☐ If you have a disability, you shouldn't have to work

☐ 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 individuals in wheelchairs have mental disorders

☐ You can't really make assumptions, every person is different

☐ Life is more challenging with a disability

☐ Things take more time when you are paralyzed

How have you assumptions helped or hurt you attitudes towards disability?

Some assumptions patients may have of you, the health care provider (similar to expectations listed above, again, not always positive)

☐   If I say I will do something, I will

☐   If I don't ask something, it must not be important

☐   I will be disappointed in patients who end up with complications or don't succeed in accomplishing something they tried

☐   I am like their parents and take on a parental role

☐   I want patients to tell me what I want to hear

☐   Something is very wrong if I call after an appointment

☐   I can be reached at anytime, or will respond within the hour

Are there other assumptions patients may have of health care professionals?

Exercises for Individuals 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 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

Can you think of other expectations you may have? Are they positive or reasonable? (Perhaps something like My provider will be my friend – some people do not understand the doctor is not there to be your friend i.e. sounding board –confidante – My provider will return calls in a timely fashion.   )

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 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 something else to try

☐ 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

☐ I will be my own advocate

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 if 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

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 personnel 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 am in
- ☐ The first medicine I am given will almost always work
- ☐ Physicians can be reached any time. If not right away, then within an hour

SELF-MONITORING FORMS

Bladder Management Records

Guideline / Goals: Cath every 4 hours; maintain bladder volumes below; 350 cc's; Monitor for UTI based on color and odor

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	
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
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
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
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
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
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			

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	

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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

o   Every day   Every other day

o   Mornings   Evenings

o   Assistance needed with set-up: yes   no

o   Perform: In bed   On toilet / commode

o   Medications required:

o   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:		

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:		

Sample schedule for planning skin care

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		

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		

APPOINTMENT WITH HEALTH CARE PROVIDER

Date: **Time:**

Place:

Things to Bring to appointment:
    ☐ self-monitoring forms   ☐ questions
    ☐ medications   ☐ other: _____

Primary goal / purpose of visit:

To be completed by patient prior to appointment:

Patient concerns

☐ Pain	☐ Medications	☐ Bowel	☐ Bladder
☐ Sexuality	☐ Skin	☐ Physical Functioning	
☐ Weight	☐ Diet	☐ Sexuality	☐ Mood /

Emotions

☐ Sleep	☐ Prevention	☐ Exercise	☐ Recreation
☐ Employment	☐ Relationships	☐ Equipment	☐ Insurance

    ☐ Other: _____

    Additional details / comments:

Questions for provider
    1.
    2.
    3.

Information Needed

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

<u>Attitude</u>

Let's talk about attitude
Success or failure in living with spinal cord injury [40] begins with your attitude. **Attitude** and mindset are necessary parts of taking charge of your life and creating the life you want.

<u>Pro</u> and **<u>active</u>.** 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

<u>Expectations</u>

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 match 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.

Area	Example of what you can monitor
Bladder	how often you need to cath every day
Skin	an area or 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 then 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 is 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 how what make 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:	
	Pros: Cons:	
	Pros: Cons:	
	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 demanding 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: Organizing, Prioritizing and Goal-Setting

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 <u>when</u> 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 continuing with your new organization)
- 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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