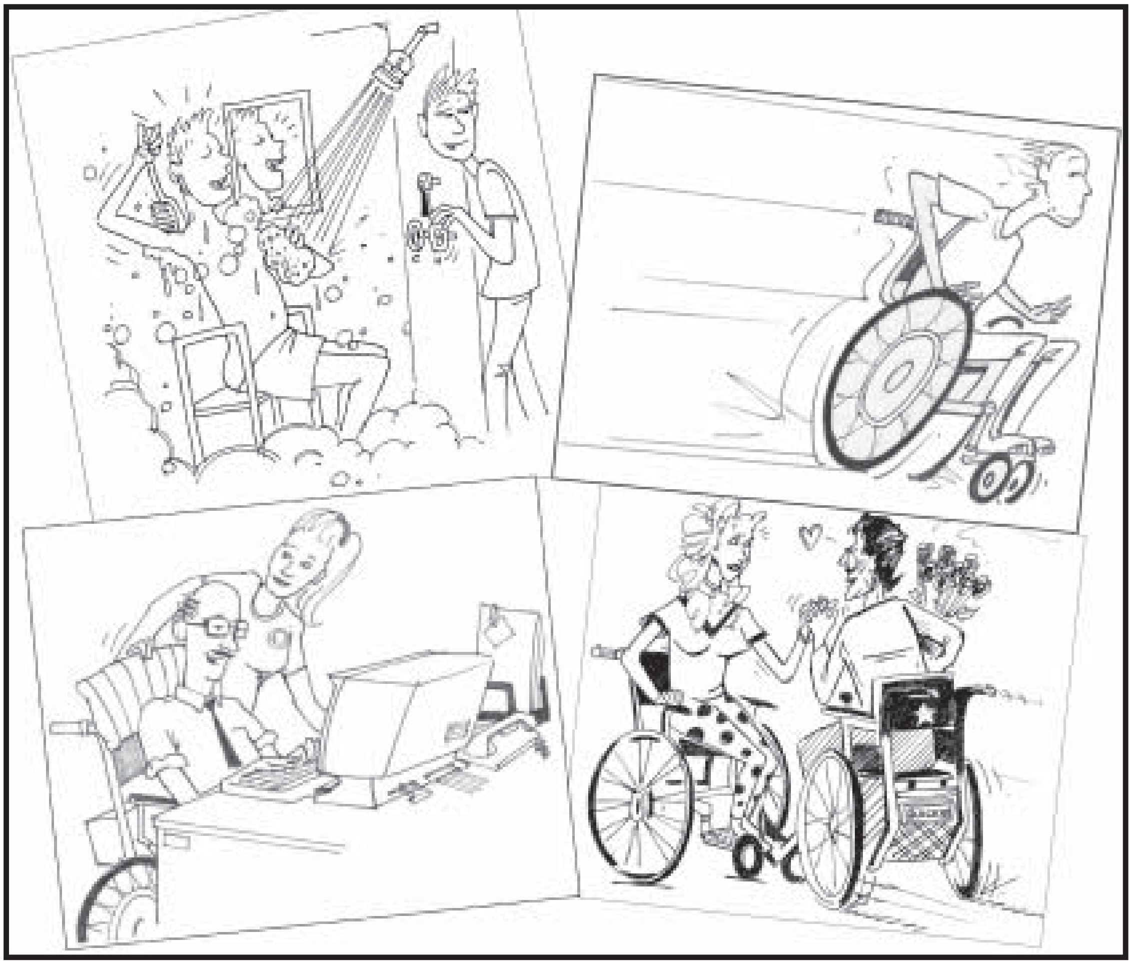
Enhancing Independence



A Personal Attendant Training Manual

A Product of Services for Independent Living
Columbia, Missouri

Enhancing Independence

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Editor/Layout Designer/Desktop Publisher
Lucille Amico Bruyneel

Coeditors
Steve Banister
Jim Umstattd

Graphic Artist/Medical Illustrator
Lance Meek

United Way
Local Dollars
Working Locally

Enhancing Independence: A Personal Attendant Training Manual
A Product of **Services for Independent Living (SIL),** Columbia, Missouri.

Editor / Layout Designer / Desktop Publisher: Lucille Amico Bruyneel
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In 2003, MOMSCIS received permission from SIL to update and re-publish the **Enhancing Independence: A Personal Attendant Training Manual** in digital format, and make it available on the Internet. This updated version of the manual is Copyright © 2003 by the University of Missouri-Columbia and SIL Productions. Update editor was Larry Nossaman, Senior Information Specialist for MOMSCIS. Special thanks to Services for Independent Living, the MOMSCIS staff, especially Michael Acuff, M.D., and Laura Schopp, Ph.D., and the MOMSCIS Advisory Board members, especially Anne Edwards, Consumer Advisory Board chair, for their help in producing this update.

Established in 1995 and located at the University of Missouri-Columbia's School of Health Professions / Department of Health Psychology, MOMSCIS is one of 16 model centers in the United States. MOMSCIS collaborates with Services for Independent Living and Rusk Rehabilitation Center in Columbia, MO. MOMSCIS is committed to developing, implementing and evaluating innovative research that promotes independent living and community integration among persons with spinal cord impairment. MOMSCIS is funded by the National Institute on Disability and Rehabilitation Research, a division of the U.S. Department of Education's Office of Special Education and Rehabilitatative Services, grant #**H133N000012**.

Dedication

Enhancing Independence: A Personal Attendant Training Manual, is dedicated to Kay Rauscher, who has been an outstanding mentor and advocate for people with disabilities, as well as an ardent supporter of the Independent Living Movement nationwide.

• • •

A book of this type cannot be put together without the help of many people. The Board and Staff of Services for Independent Living extend sincere gratitude to the following individuals for their contributions to this publication.

Special Thanks

Kristofer Hagglund, Ph.D.
Principal Investigator,
Missouri Model Spinal Cord Injury System

• • •

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Pam Messmer
Laura Meyer
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Shellie Nazarenus
Ann Osborne
Kay Rauscher
Stacey Schroeder
Benita Nease
Chris Temporal, R.N.
Jeaniene Thompson
Elisabeth Wall-Smith, R.N.
Joanne Willett

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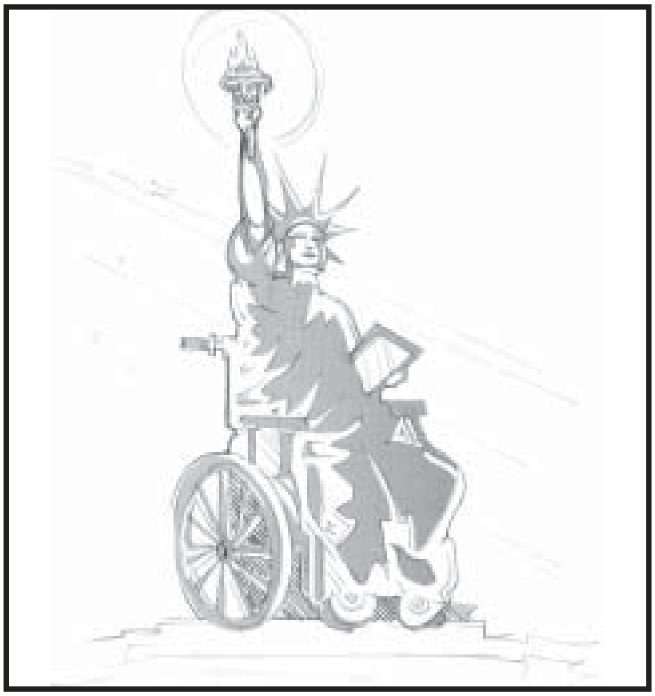
Introduction

A satisfying, fulfilling life is dependent on the ability to live independently. Autonomy to develop a unique lifestyle, to select from leisure and career opportunities, to cultivate friends and life partners is necessary to a good quality of life and happiness. The independent living movement was established on these principles and continues to succeed in applying these models to real life for people with disabilities.

Enhancing Independence: A Personal Attendant Training Manual is a testament of the success of the independent living movement and a celebration of independent living and the pursuit of happiness. This manual effectively describes how consumer-directed personal assistant services break down a significant barrier to independent living. Rejecting the medical model, the team of writers at Services for Independent Living (SIL) and their colleagues have captured the essential elements of successful consumer-directed personal assistant services. The straightforward, no-nonsense descriptions, reflections, and instructions are grounded on the independent living philosophy and make *Enhancing Independence* a truly accessible manual. By focusing on consumer direction and autonomous living, this manual improves the quality of life for all of us.

Kristofer Hagglund, Ph.D.
Principal Investigator
Missouri Model Spinal Cord Injury System

Chapter 1



Who Calls the Shots?

Independent Living

Understanding the Independent Living Philosophy

According to the Independent Living (IL) Philosophy, persons with disabilities (PWDs) are disability professionals. Based on choice, control, and change, the IL philosophy contends that persons with disabilities know their needs best and therefore have the right to direct their own lives. The concept views independence as having control of what is done, how it is done, who does it, and when. Independent living includes participating in community activities, fulfilling a wide range of social roles, and making decisions that lead to self-determination. This empowerment often fosters positive self-images and minimizes psychological or physical dependence on others.

Personal assistant (PA) services are a vital component of independent living. For many individuals with disabilities, personal assistants are the key to living independently. Personal assistants help persons with disabilities accomplish tasks that they are unable to do themselves. Because individual needs, wants, and lifestyles are so diverse, personal assistant duties vary greatly. Example PA tasks will be listed later in this chapter.

Independent Living is ...

- Having opportunities to participate in all aspects of community life.
- Making decisions and taking responsibility for one’s actions.
- Controlling and directing one’s own life.
- Taking risks and being allowed to fail.

History of the Independent Living Movement

Independent living as a movement is unique compared to existing programs and facilities serving people with disabilities. The independent living concept was rooted in Berkeley, California, by Ed Roberts. Having had polio since he was 14 years old, Roberts had first-hand knowledge of discrimination. He despised it; he viewed it as dehumanizing and segregating. His goal was to eliminate it for himself and for others with disabilities. After the University of California at Berkeley denied Roberts' enrollment because of disability issues, he became a civil rights activist. He challenged the university's denial of his enrollment and won. Then he and his peers instituted a Disabled Students' Program on campus. In a quest to give people with disabilities control over their own lives, he and his fellow students spearheaded a crusade to establish a program to replace the medical model. In 1971, Roberts and his associates organized the first Center for Independent Living (CIL).

CILs are consumer-controlled, community-based, non-residential organizations that assist people with all types of disabilities to achieve and maintain as independent a lifestyle as possible. A majority of the management, service delivery personnel, and board members are individuals with disabilities who have personal experience living independently. The four core services, which are available at no cost, are Information and Referral, Independent Living Skills Training, Peer Counseling, and Advocacy. The significant involvement of persons with disabilities, especially in providing direct services and having a specific charge to advocate, is probably the most distinguishing feature of a center setting itself apart from other service organizations. In addition to the four core services, CILs offer a variety of other services,

Independent Living Model vs. Medical Model

Traditionally, family members have taken care of the functional needs of individuals with disabilities. In the past, many people felt that persons with disabilities were incapable of doing anything, including making decisions about their personal needs.

The prevailing thought of the medical community, the main guide for so many years on issues concerning personal assistants, transformed people into patients. As part of a definition in Webster, a patient is one who is under medical care. A patient is seen as one who must depend on medical personnel to take control of a situation. The patient is seen as the problem, which must be identified and labeled as dependent to access services. The individual is perceived as being incapable of knowing what is in his / her own best interest. This is referred to as the medical model.

Combining the medical model with the long-held belief that families take care of their own creates an interesting form of discrimination. In many ways, this discrimination has been more difficult to overcome than the racism of the 1960s. The discrimination takes place when it is assumed that a person with a disability is unable to complete tasks or does not understand the process of how a task is completed. Experience shows that family members often assume the responsibility of task completion for the individual.

Within the structure of a family, values, roles, responsibilities, and obligations are learned. All members of the family learn these lessons as they grow and mature. However, when a child within the family structure is born with a disability, or becomes disabled at an early age, the focus may be placed on what the child cannot do, rather than focusing on what the individual can do. Allowing a loved one to attain independence may be difficult for family members who do not wish to see the person struggle.

Under the medical model, the person in control of services is the healthcare provider; whereas, under the independent living model, the person in control is the person with the disability or the consumer. According to the rehabilitation theory, the desired outcome of any service is maximum physical or mental functioning (or, as in vocational rehabilitation, gainful employment). In the independent living movement, however, the goal for the consumer is complete control over daily living activities, but not necessarily over physical or mental functioning. For some disability groups, obviously, complete control may not be possible, but the disability rights / independent living movement continues to work toward unlimited consumer control wherever and whenever possible.

The Personal Assistance Services (PAS) Program is rooted in the concept of employability and independence. Building on the success of the Independent Living Movement, the consumer-driven model has supplanted the medical model in PAS provision. Consumers are no longer viewed as problems to fix, but as persons seeking a system that works in their behalf. This system can help increase self-esteem, promote consumer activism, shorten hospitalizations, and allow PWDs to live longer lives after illnesses and injuries.

What is a Personal Assistant?

A personal assistant (PA) is an individual who is hired to assist persons with disabilities (also referred to as employers or consumers) to reach a level of independence based on personal choices. A personal assistant helps PWDs with routine activities of daily living. Typical tasks include getting out of bed, dressing and undressing, bathing, grooming, bowel and bladder care, eating, meal preparation, transportation, shopping, household management, and other duties (as long as they are moral and legal) essential for PWDs to maintain an independent lifestyle. Persons with disabilities direct and manage all tasks performed by PAs wherever services may be provided. PWDs are responsible for learning their limitations and for determining how much attendant care is needed to achieve their desired level of independence.

PLEASE NOTE: Because the terms attendant and assistant are often used interchangeably in the field of spinal cord injury (SCI), both are incorporated in this manual.

Qualifications for Being a Personal Assistant

- 16 years of age (Attendants working for consumers on the state PCA and TAP Programs must be 18 years of age and U.S. citizens.)
- Willing to work closely with others
- Gets along well with others
- Willing to perform tasks as each employer requests
- Looks beyond the disability to see the person
- Practices good hygiene
- Has reliable transportation
- Has own telephone

When Interviewing for a Personal Assistant Position

1. Ask for a list of job duties. If you do not understand the tasks on the list, the employer's expectations, or any procedures, ask for further explanation. It is important that you clarify what is expected of you. Be certain that you are willing to perform all job tasks. Recruiting, hiring, and training a personal assistant can be stressful for persons with disabilities.

2. Ask what the salary is for the position. Discuss the rate of pay, the possibility of extra pay for late night work or overtime, how often you will be paid (daily, weekly, monthly), and whether pay will be in cash or by check. Also, ask if you will be paid for time spent waiting for the employer. (For live-in attendants, the value of the room and board can be considered and reported as part of the PCA's salary for tax purposes.)

3. Discuss the hours of the position and scheduled time off. Ask if your employer has a back-up system if you become ill.

4. Be honest about your abilities and background. If you have never done this type of work, SAY SO. A willingness to learn can be a very high qualification.

5. List references who will vouch for your character, integrity, dependability, and credibility on your application.

Working as a Personal Assistant

- Keep all information pertaining to your employer’s personal life confidential. When working closely with people with disabilities, you may learn their “life secrets.” Do not discuss the employer outside of the job.

- Carry out assigned duties, update procedures as requested, and try to be flexible regardless of your background. Maintain your professionalism while remembering that these individuals are capable of living independently and are not patients.

- Learn as much as possible about the consumer’s disability - from the consumer and from other sources.

- Be reliable and dependable. These two attributes rank highest with an employer, perhaps even higher with an employer with a disability. They count on your help to keep them reliable and dependable to their employer.

- Learn and practice good communication skills to avoid misunderstandings. If personality conflicts occur on the job, be honest and discuss them with your employer. Because of the close contact involved in attendant work, your employer will feel the tension of an attendant who is unhappy with the working atmosphere.

Responsibilities of a Personal Assistant

- Arrives at the scheduled time ready to work.
- Completes assigned tasks in allotted time.
- Uses a time sheet to accurately record time worked.
- Notifies employer if he/she will be more than 15 minutes late.
- Schedules time off as far in advance as possible.
- Gives at least two weeks notice, preferably more, prior to resigning.
- Knows what to do if a medical emergency should occur.
- Respects the personal property of the employer.

Benefits of Being a Personal Assistant

- Experience working with people
- Opportunity for personal growth
- Extra income
- Flexible work time

Code of Ethics for Personal Assistants

- Respect an employer's / consumer's rights regardless of disability, race, religion, sexual preference, or other beliefs.

- Acknowledge that the employer / consumer is in charge of the working relationship and that the employer / consumer has the final decision concerning his / her assistance.

- Refrain from any act of abuse, neglect, or exploitation.

- Do not put personal preferences before the employer's / consumer's choice.

- Safeguard employer's / consumer's right to privacy.

- Act to safeguard the consumer and the public when home-based assistance, health care and safety are affected by the incompetent, unethical or illegal practice of any person.

- Assume responsbility and accountability for individual judgment and actions.

- Maintain competency levels in regard to home-based assistance.

- Exercise informed judgment and use individual competence and qualifications as criteria in seeking consultation and accepting responsibilities and delegating activities to others.

- Make an effort to expand knowledge of an attendant's work.

- Make an effort to establish and maintain conditions of employment conducive to high quality assistance.

- Make an effort to protect the public from misinformation and misrepresentation; maintain integrity of home-based assistance.

The Americans with Disabilities Act (ADA)

In July 1990, the United States Congress passed the most important legislation ever to affect people with disabilities. The Americans with Disabilities Act (P.L. 101-336), or ADA, gives civil rights protection to people with disabilities and prohibits discrimination on the basis of disability.

For the purposes of this overview, a disability is a physical or mental impairment that substantially limits one or more of an individual's major life activities. Major life activities include functions such as caring for one's self, walking, performing manual tasks, breathing, speaking, hearing, seeing, learning, and working.

A disability can also mean a record of an impairment, or being regarded as having an impairment. A record of an impairment means that a person has a history of an impairment or has been misclassified as having an impairment. Examples include a person who has recovered from mental illness or cancer, or a person whose school records may have misclassified him or her as having a learning disability.

Being regarded as having an impairment means that a person is perceived or treated as having an impairment, even though the impairment itself does not substantially limit major life activities. Examples include a person with controlled diabetes or high blood pressure, a person with physical disfigurement due to scarring or burns, or a person who is rumored to have tuberculosis or AIDS.

The ADA also prohibits discrimination against people without disabilities on the basis of their relationships or associations with people with disabilities. For example, an employer cannot refuse to hire someone who provides care for a spouse with a disability on the assumption that the caregiver will have a high absentee rate.

The ADA is divided into four major areas:

Title I: Employment

Title II: Public Services / Government

Title III: Public Accommodations in Commercial Facilities

Title IV: Telecommunications

TITLE I:

Employment

Private employers are prohibited from discriminating against qualified individuals with disabilities in job application procedures, hiring, termination, promotion, compensation, fringe benefits, job training, and other terms, conditions and privileges of employment. Beginning July 26, 1992, this applied to employers with 25 or more employees; as of July 26, 1994, the law applied to employers with 15 or more employees. Public service employers were required to comply as of January 26, 1992, regardless of the number of employees.

A qualified person with a disability is an individual who can meet the requirements of the position and perform the essential functions of the job, with or without reasonable accommodation.

Reasonable accommodation includes modifications in the work environment (including common areas such as lounges, cafeterias, and restrooms) and modifications in the way things are usually done. These changes are required to ensure that people with disabilities can enjoy equal employment opportunities. A person may also need reasonable accommodation during the job application process to ensure access to testing facilities or to take employment tests that relate directly to the position.

TITLE II:

Public Services/Government

Title II of the ADA is divided into two subtitles.

Subtitle A

Subtitle A prohibits discrimination on the basis of disability by state and local government in the provision of services, programs, and activities, even when they are made available by contractors. This subtitle also covers communication with the public and the public's use of public facilities. All such programs must be administered in the most integrated setting possible.

Structural changes in existing public buildings may not be required as long as all services and programs are accessible. Public entities are also required to furnish auxiliary aids and services that provide communication to people with vision, hearing, and speech impairments. This communication must be as effective as the methods provided to people without disabilities.

In addition, emergency response services, such as 911 services, must provide direct access; relay service is not adequate.

Subtitle B

Subtitle B prohibits discrimination on the basis of disability in the provision of accessible transportation services and transportation facilities. This includes rail and non-rail vehicles, such as minibuses, articulated buses, rapid-rail and light-rail cars that are purchased by public entities or private entities under contract with public entities. Transportation facilities include publicly operated depots and other stations, as well as airport passenger terminals.

TITLE III:

Public Accommodations in Commercial Facilities

Title III prohibits discrimination on the basis of disability by private entities in places of public accommodation, commercial facilities, and certain tests or courses related to professional or trade licensing certification. According to Title III, businesses open to the general public must make their products and services available to all people, regardless of disability.

Places of public accommodation include restaurants, bars, or other establishments serving food or drink; movie theaters, auditoriums, and concert halls; hotels, inns, and motels; professional offices, for example, accountants' or lawyers' offices; social service centers; retail sales or rental establishments; places of recreation; museums; and zoos. Commercial facilities include office buildings, factories, hospitals, and warehouses.

No matter what the facility, all goods and services must be provided in an integrated manner. Facilities must provide auxiliary aids and services to customers or clients with vision, hearing, or speech impairments to ensure effective communication. Structural barriers in existing facilities must be removed when removal does not require much difficulty or expense; building access is the first priority. New construction and alterations must be designed for accessibility.

TITLE IV:

Telecommunications

Title IV of the ADA ensures that people with hearing or speech impairments have equal access to universal telecommunications services. Common carriers must provide interstate and intrastate telecommunication relay services (TRS) throughout their respective service areas by July 26, 1993. The communication assistants who relay a conversation from voice to text and vice versa must be familiar with the cultures and languages of people with hearing and speech impairments. They must also be competent in the interpretation of typewritten American Sign Language (ASL).

Courtesy of the STAR (System of Technology to Achieve Results) Program, Minnesota Advisory Council on Technology of People with Disabilities, St. Paul, Minnesota.

For more information on the ADA, call the ADA Project at 1-800-949-4ADA.

NOTES

NOTES

Chapter 2

Watching Your P's and Q's

Attitudes and Etiquette

Thinking About Attitudes

This section of the manual invites you to look honestly at how you think about people with disabilities. Try to have an open mind and be willing to learn. You will be glad you did.

- What are some of the general ideas that people might have about people with disabilities?

- What is the difference between empathy and sympathy? Which should you have when working with people with disabilities?

- Do you feel uncomfortable associating with a person with a disability? If so, explain why and what type of disability is the most difficult for you.

- People with disabilities, in general, can live "normal" lives. Explain why or why not.

- Do you feel that people with disabilities should receive special

Attitudes Started It All

By taking a look at the history of how persons with disabilities were treated by various cultures, we can easily see how the movement for independent living began. From nomadic tribes to social change in the United States during the 1960s, persons with disabilities had roles to play as members of their societies and cultures. What is occurring now seems to be the dawning of a new age for persons with disabilities and their place in society.

The nomadic people considered persons with disabilities useless because they could not contribute to the wealth of the tribe. This simple reasoning caused them to leave persons with disabilities behind to die whenever the tribe moved to a new location.

The Greeks sought rational reasons for disability. Typical conclusions reached by many of these philosophers and learned men included: epilepsy was a disturbance of the mind; deaf people could not learn because communication was essential to learning.

The Christians brought a period of sympathy and pity to the way persons with disabilities were treated. Churches organized services for people with disabilities in their congregations or geographical areas. Many Christians in the early periods held superior attitudes toward persons with disabilities which resulted in a loss of autonomy to individuals with disabilities. Some were convinced that a disability represented impurity, therefore, persons having disabilities needed to be saved.

During the Middle Ages, supernaturalism was the belief of the day. This era ushered in a new attitude which focused on fear. Persons with disabilities were ridiculed (for example, the court jester) and often persecuted because society thought persons with disabilities represented manifestations of evil.

The Renaissance witnessed the beginning of medical care and treatment for persons with disabilities. Education was also brought to persons with disabilities for the first time. An enlightened approach to societal norms and dreams for the future seemed to encourage active participation by people with disabilities in their communities.

Moving from Europe to the American Colonies, the first settlers would not permit persons with disabilities to enter their towns because they believed that such persons would require financial support. Colonists enacted settlement laws to restrict immigration of many people, including those who were disabled. But by 1880, after the development of almshouses, most states and territories had programs for persons with disabilities. Most of these programs were large institutions where persons with disabilities were sent to spend the rest of their lives.

The movement westward, otherwise known as the Frontier Movement, inspired a new belief in Americans that social ills could be eradicated by local initiative. For persons with disabilities, this meant that they need not be condemned because they could not earn their own living. Community-based services began to emerge, but persons with disabilities were still segregated from society as a whole.

World War I began the concept of rehabilitation services on a broad basis. The emphasis of the first rehabilitation service program was on the veteran with a disability who was returning home. The need for training or retraining created the first federal program for persons with disabilities, a program now known nationwide as Vocational Rehabilitation.

During the social changes of the 60s, the federal government seriously considered other major services for persons with disabilities. Although the Social Security program provided benefits to those who had earned sufficient income over a long enough period of time and who had become disabled (unable to work), there was no attempt to broaden the base of services to persons with disabilities beyond the vocational approach. For the first time in America's history, advocates, professionals, and consumers of services began examining the network of services available and what was missing. Community-based programs for people with disabilities began growing throughout the nation in an attempt to deal with new needs, new technologies and new attitudes.

Adapted from an article written by Maggie Shreve from an educational supplement from The WHOLE PERSON, Inc., February 1985

Language About Disability

Language is powerful. It reflects, reinforces and shapes our perceptions of people. Words which express positive attitudes and awareness help develop positive communication.

Language about disability has been influenced by the legal, medical and political fields. Consequently, our daily language is filled with technical terms which often do not convey our intended social message and which are further complicated by personal styles and preferences. To portray people with disabilities as capable individuals, use affirming language. If you are describing someone in a wheelchair, avoid terms like victim or invalid. These terms tend to make the listener see the person as an object, not as a person. Also, this terminology promotes the helpless cripple stereotype and encourages a negative image centered on disability rather than on the human being.

Remember, when writing or speaking about persons with disabilities, emphasize the person rather than the disability.

Politically Correct Language for Persons With Disabilities

Acceptable	*Unacceptable*
Person who uses a wheelchair Wheelchair user	Confined to a wheelchair Wheelchair bound
Person with cerebral palsy	Spastic
Little person Person of short stature	Dwarf Midget
Person who is deaf Person who is hard of hearing	The deaf Stone deaf Deaf and dumb
Person with a mental or emotional disability	Mentally ill Crazy Mentally disturbed
Person with a learning disability Person with Down's Syndrome Person who is retarded	Slow Stupid Retarded
Person who is blind Person who is visually impaired	The blind Living in a world of darkness
Person with	Victim of Sufferer of
Person who is	The Handicapped Afflicted Crippled

Etiquette and Behavior for Working with Persons with Disabilities

Tips on Conversation

The most important thing to remember in any conversation with someone who has a disability is to assume nothing. If you have a question about what to do, what language or terminology to use, what assistance, if any, he/she might need, the person with the disability should be your first and best resource. Do not be afraid to ask.

When conversing with a person with a disability, focus on the fact that it is simply communication between two individuals. Keep in mind that you are talking to a person, not a disability. Be patient with the person with the disability as well as with yourself. Frustration may come from both sides of the conversation and needs to be understood and dealt with by both parties. Ultimately, it is what is communicated, not how it is communicated, that will be important.

Guidelines for Working with a Person Who Uses a Wheelchair

Things to Know

There are many reasons (not just being paralyzed) for someone to use a wheelchair.

There is a wide range of physical abilities among those who use wheelchairs. This means that the persons who use them may require different degrees of assistance or no assistance at all.

Some persons do not use wheelchairs exclusively, but may also use canes, leg braces, and in some cases, no assistive devices at all for short periods.

All wheelchairs are not the same. Different sizes and shapes meet different needs. Some wheelchairs are moved manually and others are motorized. Just because one employer could access an area in a wheelchair does not mean that everyone using a wheelchair could do so.

Things to Do:

If you are asked to fold, carry, or store a wheelchair, treat it with the same respect that you would someone's eyeglasses. They are similar in many ways. Remember that wheelchairs can break and are difficult to have repaired on short notice and weekends. It is extremely disruptive to the user when they are out of commission.

When speaking to someone who uses a wheelchair, remember to give the person a comfortable viewing angle of yourself. Looking straight up is not a comfortable viewing angle.

Things to Avoid:

Do not come up to someone who is using a wheelchair and start pushing him / her without asking.

When communicating, do not stand too close to the person in the wheelchair. Give the person some space.

Things to Consider:

It is a very common experience for persons who use wheelchairs to be told that a place is accessible when it is not. Listen carefully when anyone who uses a wheelchair tells you that an area that you thought was accessible is not.

Do not assume that the person using a wheelchair needs assistance. Ask the person if there is any help you can provide.

Etiquette

Before you help, always ask a person who uses a wheelchair or any assistive device if assistance is desired. Your help may not be needed or wanted.

- Don't hang or lean on a person's wheelchair because it is part of that person's personal body space.

- Speak directly to the person with a disability, not to someone nearby as if the person were not there.

- If conversation lasts more than a few minutes, consider sitting down or kneeling to get yourself on the same level as the person using the wheelchair.

- Don't pat a person in a wheelchair on the head. This is seen as a put-down.

- Give clear directions, including information about distance and physical obstacles that may cause difficulty.

- Don't discourage children from asking questions about disabilities. Open communication helps overcome fearful or misleading attitudes.

- When a person using an assistive device transfers to a chair, toilet, or bed, do not move the object out of reach.

- It's ok to say I've got to run to someone who cant run or See you later to someone who can't see. He/she may talk like that, too!

- Don't assume that people use wheelchairs because they can't walk. There are different reasons for using wheelchairs. Some people can walk but use wheelchairs to save energy and move about quickly.

Credo for Support

Throughout history, people with physical and mental disabilities have been abandoned at birth, banished from society, used as court jesters, drowned and burned during the Inquisition, sterilized, gassed in Nazi Germany and still continue to be segregated, sterilized, institutionalized, tortured in the name of behavior management, abused, raped, euthanized and murdered.

Now for the first time, people with disabilities are taking their rightful place as fully contributing citizens. The danger is that we will respond with remediation and condescension rather than equity and respect. And so, we offer you A CREDO FOR SUPPORT.

Do not see my disability as the problem.
Recognize that my disability is an attribute.
Do not see my disability as a deficit.
It is you who see me as deviant and helpless.
Do not try to fix me because I am not broken.
Support me. I can make my contribution in my own way.
Do not see me as your client. I am your fellow citizen.
See me as your neighbor. Remember, none of us can be self-sufficient.
Do not try to modify my behavior.
Be still and listen. What you define as inappropriate may be my attempt to communicate with you in the only way I can.
Do not try to change me. You have no right.
Help me learn what I want to know.
Do not hide your uncertainty behind “professional” distance.
Be a person who listens and does not take my struggle away from me by trying to make it all better.
Do not use theories and strategies on me.
Be with me. And when we struggle with each other, let that give rise to self-reflection.
Do not try to control me. I have a right to my power as a person. What you call non-compliance or manipulation may actually be the only way I can exert some control over my life.
Do not teach me to be obedient, submissive, and polite. I need to feel entitled to say NO if I am to protect myself.
Do not be charitable toward me. The last thing the world needs is another Jerry Lewis.
Be my ally against those who exploit me for their own gratification.

Do not try to be my friend. I deserve more than that.
Get to know me. We may become friends.
Do not help me, even if it does make you feel good.
Ask me if I need your help.
Let me show you how you can best assist me.
Do not admire me. A desire to live a full life does not warrant admiration.
Respect me, for respect presumes equity.
Listen, support, and follow.
Do not work on me. Work with me.

Written & produced by Norman Kunc & Emma Van der Klift phone (604) 723-6644 for copies of this video.

NOTES

Chapter 3

Say What?!

An Approach to Communication

People don’t get along because they fear each other.

People fear each other because they don’t know each other.

They don’t know each other because they have not properly communicated with each other.

– Martin Luther King, Jr.

A Look at Communication

The process of communication is a two-way street that produces shared responses. Communication implies a sharing, a meeting of minds, a common set of symbols, an understanding. It requires four elements: the sender, the message, the channel, and the receiver. The sender or encoder is the person who creates the message and translates a mental image into symbols (generally spoken words). The ideas that are encoded are the message that is sent through a channel, such as spoken language, written language, body language, and many others. The person who translates the symbols that are sent is the receiver or decoder.

People convey their thoughts and feelings to each other both verbally and nonverbally. The verbal channel for communication is the spoken word. Nonverbal communication includes the written language; body language such as smiles, frowns, nods, shrugs, embraces, and pushes; and modes of dress and social formalities. Information can be transmitted without moving the body in any way. For example, an erect torso with shoulders squared, chest out, and head up, says confidence and pride; a slumped posture with head down and shoulders sagged gives the opposite message. Each part of the body speaks. Foot-tapping communicates impatience. Knuckle-cracking conveys nervousness. Flexing the muscles delivers a “macho” message. Stroking the chin relays thought. The face also has many ways of revealing one's ideas, emotions, and attitudes. Eyes light up to show pleasure, open wide to indicate surprise, narrow and shift to express evasiveness, and so on.

A person begins communicating from birth by crying. This is a newborn's way of informing people that he/she is hungry, wet, or sick. With maturity and education, a person learns to use the spoken word to express needs, desires, and emotions. But this does not mean that a person has developed the communication skills necessary to communicate effectively with family, friends, or co-workers. Some people have difficulty participating in society because, though they can talk, they lack the ability to transmit understanding and respect in their messages and responses.

Good communication skills take time and experience to learn, but when mastered, they foster prosperous personal and professional relationships. For this reason, it is important for you as a personal assistant to have the ability to communicate effectively with your employer. Productive working relationships between personal assistants and employers thrive on an open, honest exchange of thoughts and opinions. Without good communication, studies show that most attendant/employer relationships are unsuccessful.

Types of Communicators

The Passive or Non-assertive Communicator

Passive or non-assertive people have difficulty expressing their opinions, beliefs, and feelings. They frequently think that others take advantage of them. Passive individuals generally inhibit honest, spontaneous reactions and typically feel hurt, anxious, and sometimes angry as a result of their own behavior. In addition, they often send mixed messages. Verbally they say, "Sure, I'll be glad to stay late," while nonverbally they have a tight face, weak voice, and indirectly communicate the opposite message.

Characteristics of the Passive Communicator:

- Exhibits shyness
- Displays anxiety and nervousness
- Has feelings of worthlessness
- Believes others' wants and needs are more important than his / her own
- Finds it difficult to make decisions for self
- Often cannot say no or feels guilty about saying no
- Assumes others will know what's best for him / her
- Keeps negative feelings inside
- Frequently sends mixed messages

The Aggressive Communicator

Aggressive communicators tend to humiliate, dominate or put others down rather than simply expressing their honest emotions or thoughts. They attack the person rather than the person’s behavior.

Characteristics of the Aggressive Communicator:

- Inappropriately expresses feelings and opinions
- Violates the rights of others
- Disparages others, often in a sarcastic way
- Makes self more important
- Is confrontational, hostile, sarcastic and blaming
- Makes decisions for others

Examples of Aggressive Behavior:

- Making threats
- Giving orders
- Name-calling, swearing, yelling
- Blaming or accusing someone
- Physically striking out at someone
- Making demands instead of asking
- Viewing own rights as superseding others’ rights
- Being disrespectful

Examples of Indirect Aggressive Behavior:

- Trying to make someone feel guilty
- Talking behind someone's back instead of directly talking with the person
- Eye-rolling, sighing, mumbling, and slouching instead of expressing feelings honestly
- Refusing to respond to another person

The Assertive Communicator

Assertive communicators express thoughts and feelings in an honest, straightforward fashion that shows respect for the other person.

Characteristics of the Assertive Communicator:

- Open and willing to take risks
- Actively engages in meeting others’ needs
- Capable of expressing both positive and negative feelings and opinions
- Sensitive to the feelings and rights of others

Examples of Assertive Behavior:

- Addressing a problem situation while it is in progress
- Objecting to specific behavior that infringes on the rights of others
- Being brief and to the point
- Avoiding bringing up the past
- Never apologizing for asserting rights
- Being assertive with the body, voice, eyes, and facial expression
- Telling people how their behavior affects others
- Being friendly and firm, initially; if necessary, asserting more authority
- Avoiding threats and aggressive behavior
- Making your needs known to others in a direct, non-threatening manner
- Talking to others with respect

Assertiveness skills enable one to stand up effectively for one's own dignity, respect and courtesy without violating the rights of others, while at the same time helping others to recognize and better obtain their rights.

Communicating with Your Employer

DO

Be flexible.

Let your employer know in advance if you have something special planned so that he or she can plan around it.

Maintain a pleasant attitude; develop a good sense of humor.

Treat your employer with respect.

Learn from past experiences; try not to repeat mistakes.

Keep your working relationship private; maintain confidentiality.

Be direct by expressing your needs clearly.

Give constructive criticism honestly, openly, and clearly.

Remember that your employer has his / her own life; you are only a small part of it.

Be sensitive to your employer's moods and feelings.

Be responsible for your own feelings.

DON'T

Don't hold a grudge. Don't stockpile feelings until they explode.

Don't take your employer's moods personally.

Don't gossip and tell others about problems and conflicts.

Don't anticipate your employer's thoughts and feelings and make judgments about them.

Don't be demanding.

Assertive communication behavior is considered to be the best way of communicating because of the ability to send and receive information clearly and accurately. Each person has his / her own level of assertiveness.

Fine Tuning Your Listening Skills

Good listening skills are essential for personal care attendants. Because you must transform your employer's requests into actions, you must understand what he / she is trying to communicate. Remember, listening does not always guarantee that you will hear or comprehend your employer's message. If you need clarification of your employer's requests, ask for it. Taking time to understand what is really wanted is worth the extra effort.

Aids to Listening

- Focus on the speaker. Face the person and keep eye contact.
- Avoid distractions.
- Ask for clarification about messages you're not sure about.
- Do not allow your personal feelings to interfere with what the speaker is saying.
- Postpone long discussions if you're tired. Listening is hard work. Heartrate quickens, respiration increases, and body temperature rises.
- Do not let your mind wander when the speaker is talking. Most people talk at a speed of about 128 words per minute. On the other hand, most people think at a speed of about 400 words per minute. Use this spare time to understand the speaker's ideas, not to think about what you want to say or ask next.

Relationship of Communication to Conflict Resolution

The difference between the expectations you have about what someone else will do, or what you want them to do, and what the person actually does, can result in conflict.

Conflict Unresolved

Lack of effective communication
results in frustration
and anger.

Frustration and anger
will tend to make you
moody and depressed.

Moodiness results
in less communication
with the other person.

Less communication will
result in even better
chance of the other
person not knowing
what is expected.

More moodiness.

You "blow up."
At this point you may
or may not tell the other
person what is bugging you.

Anger has overpowered
communication.

Relationship is unstable
and under stress.

Beliefs About Criticism

Let's look at your beliefs about criticism. If you believe that all criticism is negative and means that you are a failure, then the outcome of criticism will be a rejection of yourself and your ability, which may result in an inability to move forward, change, grow, and develop. In fact, you may stagnate, never breaking down the walls with which you have protectively surrounded yourself.

If, on the other hand, you accept and welcome criticism as a vehicle for learning, then the outcome of criticism will be much less stressful, for you are free to accept or reject it.

An irony of criticism is that the more you resist it, the more it becomes a problem. The more accepting you are of criticism, the better you can use criticism to your advantage.

Another way to explain the impact of our beliefs is to examine our self-talk. Self-talk is the stream-of-consciousness thoughts that reflect our attitude towards events in our lives. Self-talk and our beliefs often make for a self-fulfilling prophecy. Therefore, it is vital that we control what we say to ourselves.

Negative self-talk can contribute to our feeling overwhelmed and defeated by those who criticize us. If we allow someone else to determine how we feel about ourselves, we give him or her the power to control our reaction to criticism. We must realize that criticism is neither in itself negative nor positive unless we attribute meaning to it. We do possess complete control over the meaning we attribute to criticism and, therefore, how we will respond to it.

How to Express Feelings

by Elisabeth Wall-Smith, RN

Feelings come in all varieties. As a personal care attendant, you will experience many feelings related to your work. Usually we know the origin of a feeling. A flower from a neighbor child brings joy; a flat tire brings frustration; a driver pulling in front of you without signaling elicits anger, perhaps even rage. Each new encounter we go through brings on a different response, a different emotion. You will have some of these same emotions when you work for persons with disabilities.

Feelings are dangerous when unrecognized. You have probably heard the story of the man who comes home after his boss yelled at him unfairly. He goes home and fights with his wife, who in turn yells at their child, who in turn hits the dog! Feelings deserve to be noticed. By identifying our emotions, we have a choice about how and whether to respond to them. If we do not identify our feelings, they can be expressed without our control. As a personal care attendant, your employer may ask you to perform tasks that you find disagreeable or that cause you to be concerned for his or her welfare. Or you may think your employer should have you do things he or she doesn't ask you to do. For example, your employer may ask you to make him / her fried eggs every night for supper. You may think your employer should eat a more healthful diet. This can create feelings of discomfort because you want to do as asked but may not agree with your employer's judgment. This can happen with housecleaning, exercise, money, and many other life events. You must recognize your feelings of discomfort.

When you feel uneasy or uncomfortable, take note of it. Try to understand your discomfort. You may learn that you do not agree with what your employer has asked you to do, or you may think your employer is making a mistake. These realizations have enabled you to discover the basis of your feeling. You then have control over how you react to it.

When we do not recognize our feelings, things may happen that are beyond our control. We may start being late, start burning food, or start being irritated by little matters. However, when you realize that your boss is doing something differently than you would, you can choose how to react. When you identify such a conflict, there are several ways to work through your feelings:

1. Realize that you are employed by your boss to assist with daily tasks that are difficult or impossible for him / her to do. You are the arms and legs of your employer.

2. Your employer is an adult. He / she is capable of making decisions related to his / her life.

3. Discuss the issue with your employer. As in other employment, you have the responsibility to carry out your employer's requests to the best of your ability. Therefore, you need to know your boss and his or her wishes. If you have a good relationship with your boss, you may choose to address the situation.

When talking to your employer, try not to make your opinions sound like the only way of doing things. Let your employer know that you respect his / her right to be in charge of all life events, but don’t be afraid to express your feelings. For example, you can say, “I know that you have asked me to help you get out of bed now, but I'm worried that your pressure sore will get worse,” or “I don't know how to tell you this, but I'm concerned about making you eggs every day.” Expressing your concerns in this way will foster better employer / employee relations. When you take responsibility for how you feel, you are easier to be with. No one appreciates being blamed for making someone feel bad.

When you are feeling uncomfortable and choose not to talk with your employer, find a friend or another personal care attendant to talk with about the situation (but don't disclose your employer's name). At times, you may have to choose between disagreeable tasks or more agreeable employment.

Summary of Basic Human Rights

The right to consider your needs are as important as the other person's rights.

The right to make mistakes and be responsible for them.

The right to express yourself as long as you do not violate the rights of others.

The right to refuse requests without feeling guilty.

The right to offer no reasons or excuses to justify behavior.

The right to refuse responsibility for finding solutions to other people's problems.

The right to change your mind.

The right to say “I do not know.”

The right to be illogical in decision making.

The right to say “I do not understand.”

The right to say “I do not care.”

The right to be independent of the goodwill of others.

The right to judge your own behavior, thoughts, and emotions and to take responsibility for their initiation and consequences.

The right to be recognized as a capable human adult and not to be patronized.

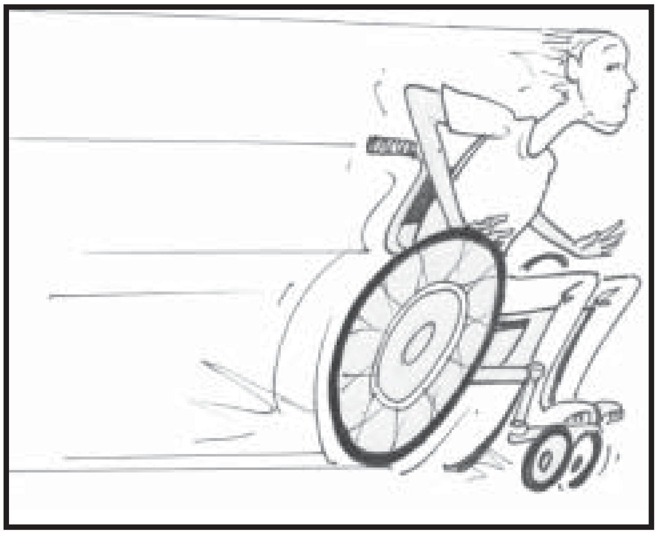
The right to demand respect and consideration for your opinions and expression of thought.

This listing was copied from the book, Bus 9 to Paradise, (Buscaglia, 1986).

> If you don’t change your beliefs, your life will be like this forever. Is that good news?
>
> – *Robert Anthony*

NOTES

Chapter 4



Movin' On

Spinal Cord Injury: Bargaining With Change

An Introduction to Spinal Cord Injury

Spinal Cord Injury (SCI) is defined as damage to the spinal cord and the associated nerves that results in loss of mobility and sensation. Though various diseases can cause SCI, most occur as a result of trauma to the vertebral column or to the spinal cord. Each injury is different and can affect the body in many ways. The level and type of injury determine which bodily functions are impaired. The higher in the spinal column an injury occurs, the more dysfunction a person will have. Usually, the nerves above the injury site continue to function normally and the nerves below the site do not.

The spinal cord, part of the central nervous system (CNS), is a group of nerves that transmits nerve impulses from the brain to the rest of the body. Nerves are cord-like structures composed of nerve fibers that control the body's communication systems. Nerves outside the CNS that direct motor and sensory functions make up the peripheral nervous system, and two other groups of nerves that control involuntary functions such as blood pressure and temperature regulation are the sympathetic and parasympathetic nervous systems.

The spinal cord is encircled by rings of bone called vertebrae. These bones, which form the vertebral or spinal column, include seven cervical vertebrae (C1-7), twelve thoracic vertebrae (T1-12), five lumbar vertebrae (L1-5), and five sacral vertebrae (S1-5). Injuries to the cervical regions generally cause loss of movement and feeling in the arms and legs or quadriplegia (tetraplegia). Thoracic injuries affect the chest and lower extremities and result in paraplegia. Lumbar and sacral area injuries generally bring about a loss of functioning in the hips and legs.

About eighteen inches long, the spinal cord extends from the brain, down the middle of the back, to the waist. The nerves that make up the spinal cord are upper motor neurons and function by carrying messages from the brain to the spinal nerves along the spinal tract. The nerves that branch out from the spinal cord and exit and enter from each vertebral level are lower motor neurons.

Complete and Incomplete Injuries

Spinal cord injuries can be classified as complete or incomplete. In a complete spinal cord injury, the spinal cord has been completely severed, and there is almost no possibility of a person regaining any motor or sensory function. In an incomplete injury, the spinal cord is partially severed or traumatically bruised, and there is a good chance that a person will regain some motor or sensory function. Incomplete injuries will differ from person to person, depending on which nerves are damaged. Some individuals may have a lot of feeling, but little movement. Others may experience some movement and little feeling.

Spinal cord injury affects many body functions. Besides losing movement and sensation, a person with SCI may experience bowel and bladder dysfunction, changes in sexual function, and loss of involuntary functions including the ability to breathe without breathing aids. SCI also may cause low blood pressure, the inability to regulate blood pressure, reduced control of body temperature, inability to sweat, and chronic pain.

Potential Complications of SCI

Autonomic Dysreflexia

Autonomic dysreflexia (AD) is a life-threatening condition that can occur in any individual with a spinal cord injury at the T6 level or above. It causes the blood pressure to rise to dangerous levels. If AD goes untreated, the body's attempt to control blood pressure will drastically decrease the heart rate. Stroke and possibly death can result. For a more detailed explanation of AD, see Chapter 8.

Cardiovascular Disease

Cardiovascular disease is a long-term risk for people with SCI. Because persons with spinal cord injuries generally have less mobility than individuals without SCI, they are more likely to develop cardiovascular disease. To help prevent this complication, exercise programs should be incorporated in the management and care of people with spinal cord injuries.

Deep Vein Thrombosis

Deep vein thrombosis (DVT), clotting of the blood in the circulatory system, or pulmonary embolism, a blockage of the circulatory system caused by a blood clot, occurs because of changes in the normal neurologic control of the blood vessels. DVT in the lower leg is common during the early stages of recovery and rehabilitation. Proximal (thigh) vein thrombosis is more serious than distal (calf) vein thrombosis, but both are important because of the potential of the blood clots to grow and to embolize. Blood clots in the leg can become dislodged and travel through the blood vessels to the lungs, possibly causing death. Measures a person with SCI may take to reduce the risk of DVT include wrapping the legs with Ace bandages and using pneumatic compression stockings.

Heterotopic Ossification

Heterotopic ossification (HO) is a condition in which there is a risk of joint stiffening and fusion. It generally occurs in large joints such as the hips and knees. If a person with SCI experiences HO, surgical release is necessary to allow range of motion.

Hormone Imbalance

Metabolic changes caused by reduced hormone levels can cause fatigue, limited strength, diminished stamina and / or decreased energy level. Other symptoms could include lightheadedness, dizziness, daytime sleepiness, weight loss, decreased appetite, dry skin, difficulty with wound healing, decreased motivation and decreased desire to be active. A simple blood test can determine whether a supplemental hormone treatment is appropriate. The most common side effect of this hormone replacement is somewhat oilier skin (and possible acne). Otherwide, side effects are minimal.

Neuropathic/Spinal Cord Pain

Neuropathic / Spinal Cord Pain refers to the pain that individuals with SCI describe. This is due to damage to the spine and soft tissues surrounding the spine. The nerve-root pain, which may be sharp, is at the left of the injury. Persons with SCI may also have phantom pain or pain that radiates from the level of the lesion. Medications and nerve block procedures are used to treat neuropathic pain.

Osteoporosis and Fractures

Osteoporosis and fractures are the direct result of persons with SCI not bearing weight on their legs. A decrease in muscle activity causes the legs to lose calcium and phosphorus and become weak and brittle. Once bones become brittle, they fracture easily. Osteoporosis generally occurs two to three years following an injury. Standing frames and electrical stimulation of the leg muscles may help reduce the risk of osteoporosis.

Pneumonia, Atelectasis, and Aspiration

Pneumonia, atelectasis, and aspiration are terms used to describe a restriction in respiratory function that persons with spinal cord injuries at the T4 level and above may develop. This condition occurs about five to ten years after an injury and can be progressive. As part of a healthcare maintenance program, individuals with tetraplegia should have pulmonary studies at yearly or biyearly intervals between five and ten years after they are injured.

Skin Breakdown

Skin breakdown occurs because of excessive pressure over the bones of the buttock. After spinal cord injury, there are shifts in the supply of blood to the skin and subcutaneous tissues. Moreover, there is a loss of normal elasticity of the tissues underneath the skin. Because of these changes, the skin's ability to withstand pressure is greatly reduced. To help prevent or reduce pressure sores, various types of air or gel cushions are used. For more information on pressure sores, see Chapter 9.

Spasticity

Spasticity or muscle spasms can occur whenever the body is stimulated below the level of injury. Pain and other sensations from the body are carried to the spinal cord. Because the nerve cells become disconnected from the brain following spinal cord injury, these feelings will cause the muscles to contract or spasm. People with SCI often cannot control these movements. Causes of spasticity include the need to eliminate waste, bladder and kidney infections, skin breakdown, infrequent range of motion exercises, and injuries to the feet and legs. For more information on spasticity, see Chapter 11.

Syringomyelia

Syringomyelia is a disorder in which a cyst forms within the spinal cord. Over time, this cyst, called a syrinx, expands and elongates, destroying the center of the spinal cord. Its primary risk is a loss of function above the level of the original spinal cord injury. An example of this complication is an individual with a thoracic-level injury who has numbness and weakness in the extremities. Syringomyelia is progressive and usually treated through surgical drainage. Approximately one to three percent of all persons with spinal cord injuries are affected by this condition.

Statistics About Spinal Cord Injury

Statistics show that approximately 450,000 people live with spinal cord injuries (SCI) in the U.S. Each year, about 10,000 individuals experience SCI, of which 82 percent are males between the ages of 16 to 30. Motor vehicle accidents are the leading cause of SCI, followed by acts of violence, falls, and recreational sporting activities. In the 90s, the proportion of injuries from acts of violence has steadily increased.

Since 1990, among those who sustained spinal cord injuries, 56.2 percent were Caucasian, 28.7 percent were African-American, 10.5 percent were Hispanic, 2.1 percent were American Indian, 0.4 percent were Asian, and 0.4 percent were unknown.

About 51.9 percent of the SCI population is tetraplegic (quadriplegic), while 46.8 percent are paraplegics. It has been noted that since 1991, the most frequent neurologic category is complete paraplegia (28.9 percent), followed by incomplete tetraplegia (28.6 percent), incomplete paraplegia (21.8), and complete tetraplegia (21.7).

It has been reported that more than half of the persons with SCI worked prior to injury. Persons with paraplegia are more successful at obtaining post-injury employment than tetraplegics. Because many persons with SCI are young adults, most are not married. For those who are married at the time of injury or marry after injury, the divorce rate is slightly higher than for persons without SCI.

Other statistics indicate that about 88.9 percent of all persons with SCI who are discharged from rehabilitation facilities return to their homes. The rest are placed in nursing homes, hospitals, and group homes.

Today persons with SCI live longer than they did in past years. However, life expectancies are still lower for individuals with SCI than for those without the disability. Persons with injuries have a higher mortality rate during the first year of injury.

Before advancements were made in urologic management, the leading cause of death for persons with SCI was renal failure. Today the causes of death for many persons with these injuries include pneumonia, pulmonary emboli, and septicemia (an infection in the blood).

This information was adapted from the National Spinal Cord Injury Database.

Movin’ On

When a person experiences a serious loss, he / she generally goes through a time of grieving. For many people, a spinal cord injury is considered a major loss. Those who have sustained spinal cord injuries mourn because they can no longer accomplish simple daily tasks. Some may grieve because they can't get out of bed, can't feed themselves, can't play sports, or can't breathe without ventilators.

They grieve for the body that once was. To cope with their new disabilities and body images, individuals often go through the five stages of grief: shock / denial, anger, depression, bargaining, and resolution / acceptance.

Please Note: Each person's reaction to having a spinal cord injury will be different.

Shock/Denial

Shock is a change which occurs too rapidly for integration. Every injury is accompanied by some degree of shock, confusion, withdrawal, or bewilderment. These feelings may last a few seconds, several months or even longer and may require support and reassurance. Denial, a refusal to admit the reality or presence of something, generally comes with shock. A person may say, “This can't be happening! This isn't real." A short period of denial can cushion the pain and prepare the person for the next stage of grief. As a personal assistant working with a newly injured individual, be truthful with a person who is coping with shock and denial. Your honesty may help him / her to deal with reality and to avoid false hopes.

Anger

After a person realizes that whatever was lost is permanent, he/she becomes angry. Individuals with new spinal cord injuries often become angry when they feel helpless and dependent. Having to rely on others to do those things that a person was fully capable of doing before the injury can turn into anger and cause the person to ask, "Why me?" Some may think that this is unfair treatment or that the injury/illness is a punishment for something. You, as a personal assistant, can be supportive during this time by being patient and by not taking anything personally. By allowing a person to express anger, you are communicating that you understand.

Depression

The chief symptom of depression is a sad, despairing mood. Other indicators of this stage are altered sleep patterns, diminished appetite, diminished motivation, crying, and feelings of hopelessness. Unlike clinical depression, it is a temporary state that eventually should be worked through. Avoid saying things like "I'd be depressed too, if . . ." Supportive reassurance may be all that is needed for a mild depression, whereas therapy and medication may be indicated for more severe depression. Once again, not everyone goes through all of these stages, so don’t assume that because a person has a spinal cord injury that he/she is depressed.

Bargaining

In this stage, a person will often try to make a deal with God. He/she will promise anything if God will take away the pain-inducing problem.

Resolution/Acceptance

When a person is in the resolution/acceptance phase, his/her mental energy is directed toward setting new goals, improving self-esteem, and reassessing values. The person is ready to accept the major changes that have occurred and to move on.

How to Support a Person Through the Grief Process

- Offer your quiet, supportive presence. Listening is important. If you don’t know what to say, don't say anything. Just be there.

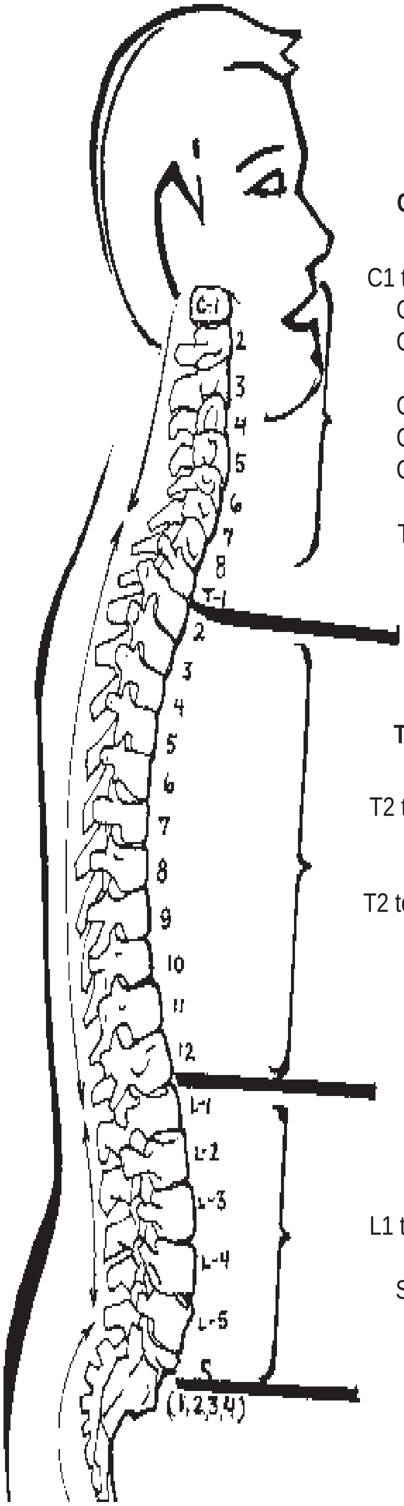
- Encourage the person to talk about the loss. Invite the person to share happy or sad memories. Listen more than talk.

- Don't be shocked by anything an individual talks about. Don't say things like, "You shouldn't say that” or “You shouldn't feel that way.”

- Encourage the individual to maintain friendships, activities, personal hygiene, and spiritual pursuits.

Spinal Cord Injury/Functional Chart

Use this chart as a general guideline, keeping in mind that everyone is unique. Goals should be set based on the person's own unique abilities and recovery.



Cervical Segments C1-T1

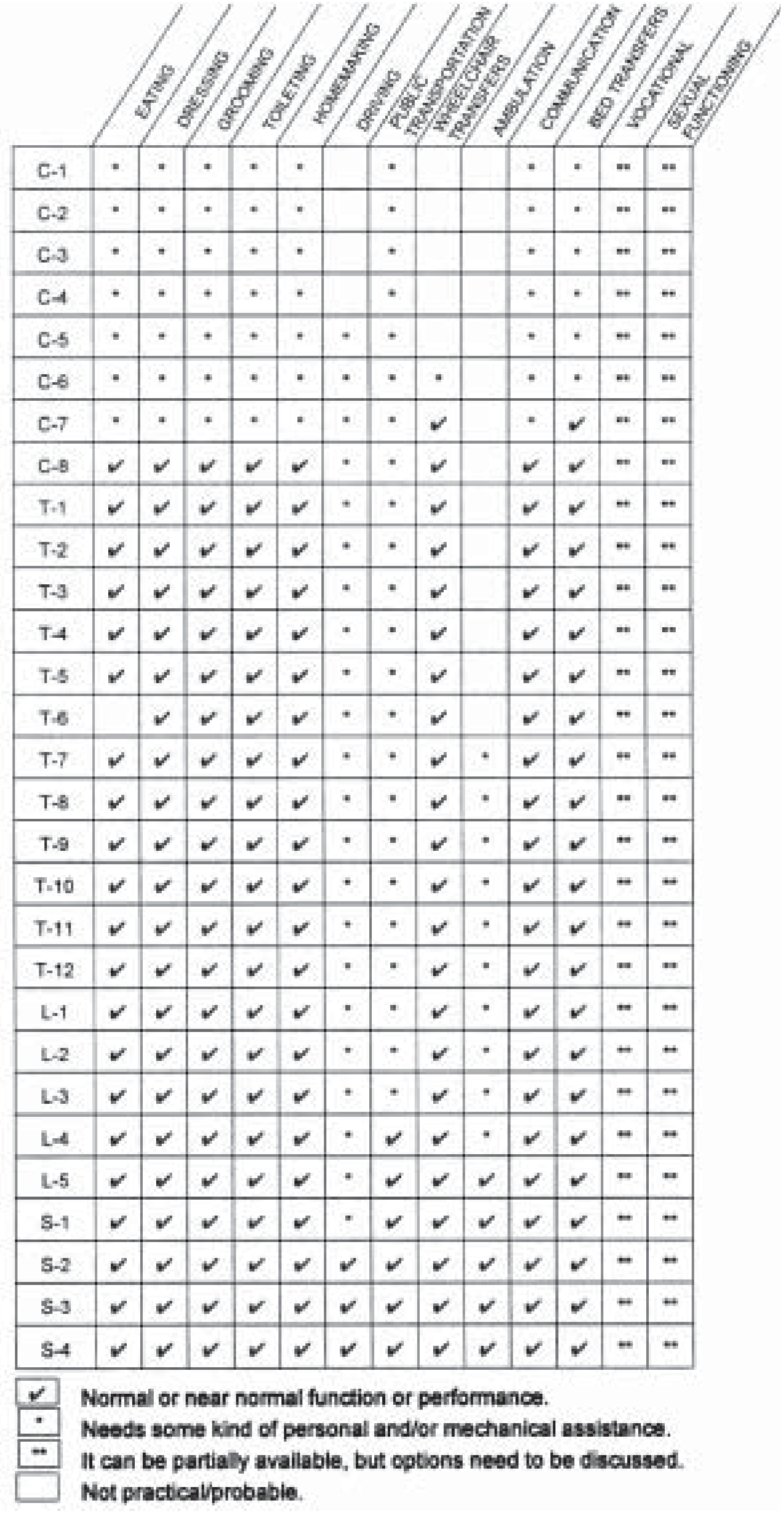
C1 to C3	Head & Neck
C4	Diaphragm
C5	Deltoid & Biceps
C6	Wrist Extensors
C7	Triceps
C8	Hand (Wrist) Flexion
T1	Hand Intrinsics

Thoracic Segments T2-T12

T2 to T7	Upper Back + Chest Muscles
T2 to T12	Lower Back + Abdominal Muscles

Lumbar & Sacral Segments

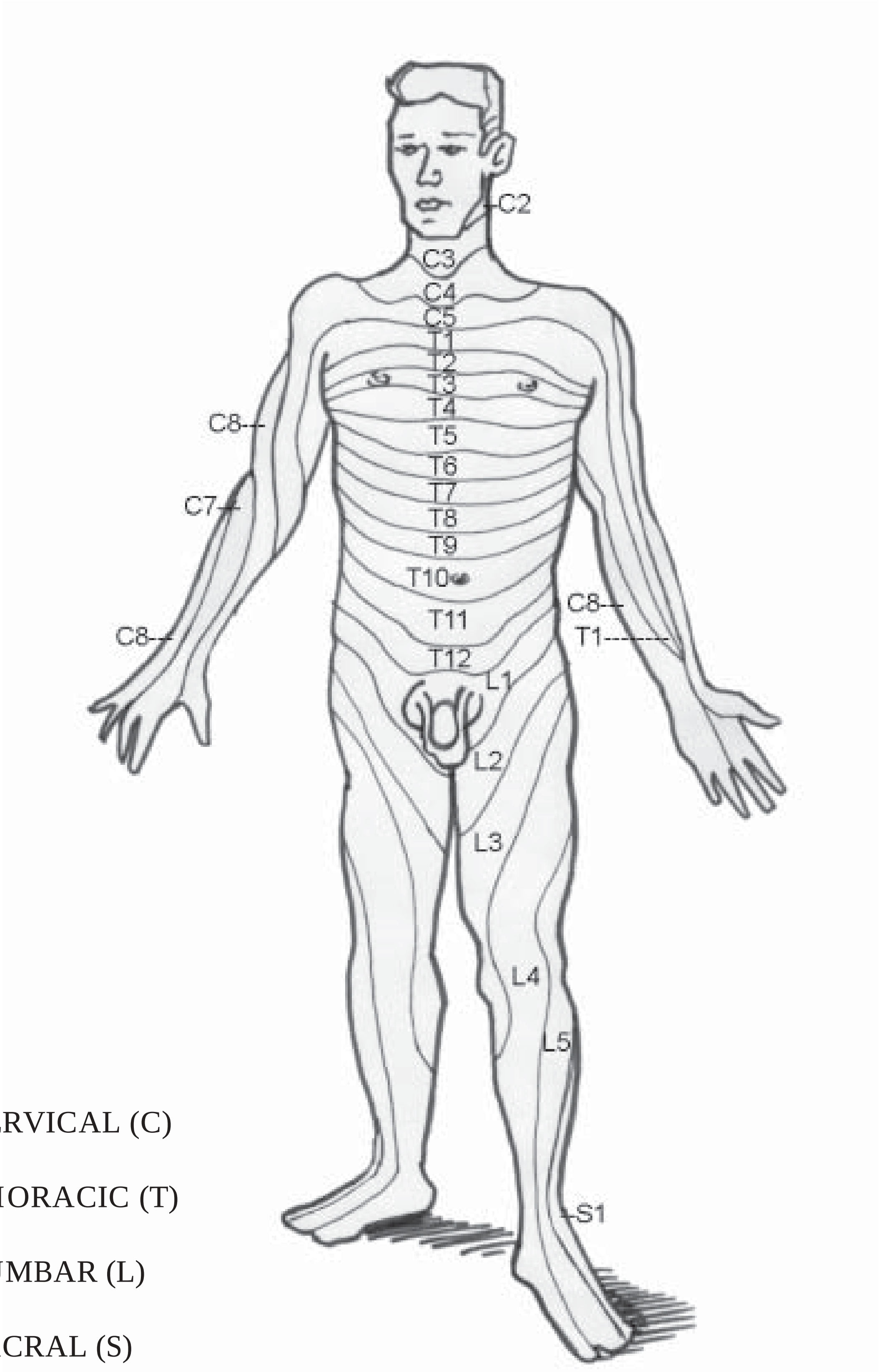
L1 to L5	Leg Muscles
S2	Below Bowel & Bladder



	EATING	DRESSING	GROOMING	TOILETING	HOMEMAKING	DRIVING	PUBLIC TRANSPORTATION	WHEELCHAIR TRANSFERS	AMBULATION	COMMUNICATION	BED TRANSFERS	VOCATIONAL	SEXUAL FUNCTIONING
C-1	*	*	*	*	*		*			*	*	**	**
C-2	*	*	*	*	*		*			*	*	**	**
C-3	*	*	*	*	*		*			*	*	**	**
C-4	*	*	*	*	*		*			*	*	**	**
C-5	*	*	*	*	*	*	*			*	*	**	**
C-6	*	*	*	*	*	*	*	*		*	*	**	**
C-7	*	*	*	*	*	*	*	✓		*	✓	**	**
C-8	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-1	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-2	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-3	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-4	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-5	✓	✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-6		✓	✓	✓	✓	*	*	✓		✓	✓	**	**
T-7	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
T-8	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
T-9	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
T-10	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
T-11	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
T-12	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
L-1	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
L-2	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
L-3	✓	✓	✓	✓	✓	*	*	✓	*	✓	✓	**	**
L-4	✓	✓	✓	✓	✓	*	✓	✓	*	✓	✓	**	**
L-5	✓	✓	✓	✓	✓	*	✓	✓	✓	✓	✓	**	**
S-1	✓	✓	✓	✓	✓	*	✓	✓	✓	✓	✓	**	**
S-2	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**	**
S-3	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**	**
S-4	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓	**	**

✓	Normal or near normal function or performance.
*	Needs some kind of personal and/or mechanical assistance.
**	It can be partially available, but options need to be discussed.
☐	Not practical/probable.

Dermatome Chart



CERVICAL (C)

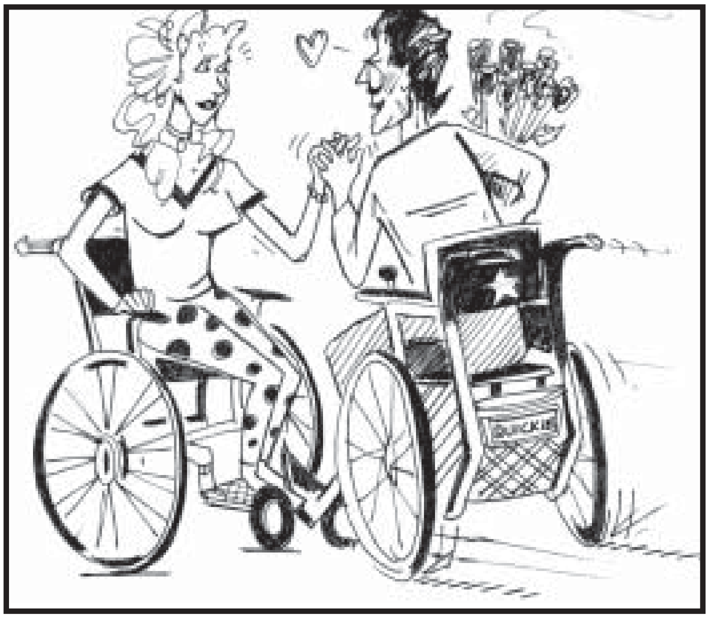
THORACIC (T)

LUMBAR (L)

SACRAL (S)

NOTES

Chapter 5



Love – What's Disability Got to Do With It?

Sexuality

Sexuality and Disability

Sexuality is more than what transpires between two people in bed. It is how individuals behave as males and females. From the moment of conception, a person begins developing a sexual identity. Shaped by biological, psychological, and social factors, sexuality is made up of an intricate set of experiences that change throughout a person's life. It is expressed in personality, movement, conversation, body image, grooming, and dress.

Though many hold the belief that people with disabilities are not interested in sexual encounters and do not have sexual thoughts or feelings, it is not true. The desire to express love in a physical, sexual way is as real for a person with a disability as it is for a person without a disability. A disability does not change a person's need to love and be loved. As a personal assistant, it is important that you respect your employer's sexuality in the same way that you expect to have your sexuality respected.

How Spinal Cord Injury Affects Sexuality

Spinal cord injury can be one of the most disruptive disabilities to sexuality. This is because sexual function in humans is controlled by parts of the central nervous system (CNS), especially the brain and the spinal cord. Therefore, an interruption to the CNS through injury to the spinal cord will impair sexual function to some extent. The degree of impairment depends on numerous factors including the level of injury, the severity of damage to the spinal cord, and whether a person is male or female.

Male Sexual Function After SCI

Sexual functioning for males after SCI is very complicated. Some men can achieve erections easily, others occasionally, and some not at all. There are two types of erection: psychogenic and reflexogenic. A psychogenic erection is caused by sexual thoughts or erotic pictures. A reflexogenic erection takes place when there is direct physical stimulation to the penis, ears, nipples, or neck. It is involuntary and can occur without any erotic images.

The nerves that control an erection are located in the sacral segments (S/2-S/4) of the spine. Men who have spinal cord injuries above these segments, T-9 or higher, generally do not have psychogenic erections. They can no longer have an erection by becoming emotionally or mentally excited. Such injuries also can affect a man's ability to ejaculate and if ejaculation occurs, it may occur with or without an orgasm.

Generally, a man with an injury above the T-12 level of the spinal cord will not have voluntary control below that level, but will have reflex activity (the knee jerk reflex). Therefore, men with injuries above T-12 may have reflexogenic erections or erections by stimulation.

Because the ejaculatory process is dependent on nerves from a number of different spinal cord levels, it is likely to be impaired by most spinal cord injuries. Also, men with spinal cord injuries often have ejaculation which goes into the bladder instead of coming out of the penis and do not have erections that last long enough for actual intercourse. Moreover, fertility is decreased in men with spinal cord injuries due to loss of body temperature control mechanisms below the level of injury.

Female Sexual Function After SCI

Because there are fewer women with spinal cord injuries, less is known about how SCI impacts female sexual functioning. However, studies have shown that females with spinal cord injuries achieve orgasm about 50 percent of the time, using genital or combined genital and breast stimulation. Also, some women with SCI have vaginal lubrication, the physiological equivalent of erection in males. Though the level of injury does not affect a woman’s sexual functioning, it may limit her sensation and her physical positions during sexual intimacy.

After SCI, menstruation may cease for 1-12 months. Though women may experience changes in sexual functioning after SCI, they are still able to conceive, carry, and give birth. Birth control is therefore necessary for women with SCI. Women with SCI who become pregnant require skilled monitoring to guard against autonomic dysreflexia (AD) and thromboembolic disease.

Autonomic dysreflexia is a life-threatening condition which is characterized by sudden increases in blood pressure, headaches, abnormal heart rate, and profuse sweating. It occurs with SCI at or above the T6 level. Sexual activity may also produce signs of AD in males.

Thromboembolic disease is a serious medical problem in which blood vessels become blocked by clots. This is caused by the coagulable state of the bloodstream during pregnancy and by the immobility produced by SCI.

Sexual sensations can also be altered after SCI. Because nerves which provided pleasurable feelings in sexual organs may not be working as they did before injury, some individuals may have diminished sexual sensations. Others may have heightened sensations in different parts of the body, the neck, earlobes, arms, or other areas of the skin.

Preparations and the Personal Assistant

As a personal assistant, you may be asked to help with preparations for your employer's physically intimate times. You may be requested to empty your employer's bowel and bladder, because sexual activity can trigger the bowel and bladder reflexes. If the consumer or their sexual partner uses a barrier method of birth control, you may be asked to assist. Again, these are merely examples of what you may be asked to do. Always follow your employer's wishes.

PLEASE NOTE: It is inappropriate for an employer to expect or request ANY sexual contact from a personal care attendant.

Sensitivity is a key element in these matters. You will want to understand your employer's needs and your role in his or her intimate times. All arrangements should be discussed openly in advance to help eliminate any misunderstandings. In a situation where both partners have a disability and each needs assistance, you, as the personal assistant, will need to exhibit a mature, sensitive attitude. This is a highly private time and should be regarded as such with respect and confidentiality.

Sexuality and Spinal Cord Injured Women

– by Karen Ricotta, MC

The losses that occur following a spinal cord injury may include loss of sensation and movement in legs and other affected areas, loss of bowel and bladder control, and complications in the sense of self and sexual identity. These losses are devastating and have many implications for the sexuality of women with SCI.

Physiologic Changes

Fertility of spinal cord injured women does not change after injury; the potential exists for a normal pregnancy and delivery. Labor and delivery may be complicated by premature or rapid labor, uterine contractions, and autonomic dysreflexia (a condition that occurs in spinal cord injuries above T6, causing increased blood pressure, flushing, and severe headaches).

The ability of a woman with SCI to reach orgasm is not altered, but the way in which she achieves it may be different after injury. Some research findings support the potential for a woman with SCI to reach orgasm by stimulating other erogenous areas or using fantasy.

Bowel and bladder control may present an issue in the active sexual functioning of a woman with SCI. The embarrassment and discomfort of incontinence may inhibit her from experiencing complete sexual arousal or orgasm. Preparation is an advisable practice to avoid embarrassing situations. As a preventive measure, bowel and bladder programs may be planned around potential sexual experience. Communicating with a partner regarding sexual concerns will also help reduce stress and increase the chance of a positive experience.

Psychological Issues

As a result of physiologic changes, several psychological issues arise. One of the most important of these is the body image, the way in which a person perceives her body.

The pre-injury sense of self is altered by several aspects of disability. Issues that influence the body image include:

- the judgment of female worth in terms of physical appearance and loss of control of bodily functions;
- the incorporation of apparatuses, including catheters and wheelchairs, into a new body image;
- the fear that disabled bodies will become the reason for sexual or social rejection.

A woman's self-concept (the mental image she has of herself) is also influenced by the injury. Some research suggests that there is a strong relationship between self-concept and sexual adjustment. Effective sexual functioning is an integral component of self-esteem. Developing realistic attitudes about yourself and your body often leads to increased sexual satisfaction. Careful preparation leads to a heightened sense of control, thereby reducing anxiety.

Sexual adjustment should begin during the rehabilitation process. Adequate sexual information for newly injured women shared in a group, in addition to individual attention, may aid in sexual adjustment. Information (such as compensatory methods) needs to be discussed. Useful sexual techniques include body massages, stimulation of alternate erogenous zones, fantasizing with your partner, and sensate focus exercises (as described by Masters and Johnson). The ability to compensate for sensory losses is an important part of overall sexual adjustment.

Interpersonal Issues

The woman with a spinal cord injury is also confronted with the societal stereotype of the disabled person as asexual (having no sex or sexual organs). Our culture emphasizes physical perfection, which places the SCI woman at a disadvantage. However, many aspects of sexuality and femininity are the same for woman with SCI as they are for the able-bodied woman. The spinal cord injury just adds another dimension to the already existing female issues: fear of rejection, fear of unwanted pregnancy and disease, and concerns regarding body image. Sexual assertiveness may be needed to deal with all of these issues.

Communication in sexual relationships becomes a practical issue due to physical limitations. A woman with SCI may not have the ability to act in accordance with her needs, so it may be necessary for her to build her verbal skills in order to fulfill her sexual desires.

In summary, the woman with SCI must deal with all the sexual issues faced by women today. In addition, she must address issues specific to her disability, including sensory losses, body image, and availability of partners. Generally, sexual satisfaction can be increased by actions that enhance control: preparation for sexual situations; exploration of alternative erogenous zones; and communication regarding sexual situations.

Karen Ricotta has been a paraplegic since a motorcycle accident in 1975. Her degrees include a bachelor of science in therapeutic recreation and a master's in counseling from Arizona State University. She is a practicing therapist in Phoenix, Arizona, focusing on sexuality counseling.

PLEASE NOTE: Men with spinal cord injuries experience similar psychological issues as discussed in the the article above.

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Chapter 6

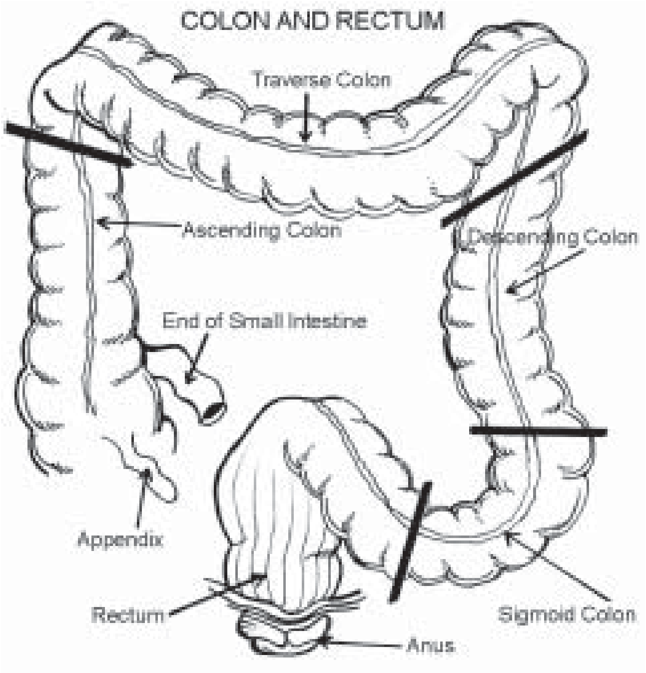
Takin' Care of Business

Bowel Management

Bowel Management

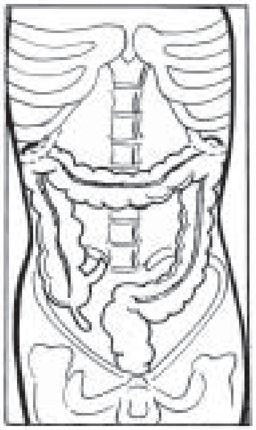
Depending on other people for bowel elimination can be a most unpleasant and degrading experience. Establishing a reliable routine is essential for the person's independence, both physically and emotionally. A regular program helps to eliminate the fear of bowel accidents which tend to create social isolation and a barrier to community integration after a spinal cord injury.

About the Bowel



The bowel, also referred to as the large intestine or colon, is part of a system called the digestive tract that extends from the mouth to the anus. The purpose of this system is to process food through the body and to eliminate waste. The undigested solid waste products are stored in the bowel until they are released from the body as stool or feces.

The way in which stool is expelled is through a bowel movement, a process controlled partly by automatic reflexes and partly by voluntary muscles. The stool is pushed down toward the rectum by peristaltic action, regular, wave-like movements of the bowel wall. After the stool has collected in the rectum (the last section of the bowel), the doughnut-shaped muscle around the anus called the anal sphincter relaxes voluntarily, pressure is placed on the abdominal muscles, and the stool is released.



With a spinal cord injury, a person may lose part or all of the voluntary control over the bowels. This occurs because nerve sensation in the rectum may be damaged, causing an inability to know when stool is present. Though sensation may be present, a person may not have control of the anal sphincter and therefore cannot hold in the stool or let it out at will. Also, because a person with SCI may not be able to push down with his or her abdominal muscles, emptying the bowels may be more difficult.

The Neurogenic Bowel

The neurogenic bowel, or bowel with abnormal nerve functioning, lacks part or all of the voluntary control over elimination. There are two types of neurogenic bowel:

Upper Motor Neuron or Reflex (Spastic) Bowel

If the injury to the spinal cord is above the T-12 level, the individual usually does not have the ability to feel when the rectum is full. There may be a recognition that a movement is coming and the reflex action occurs beyond the individuals control, however inappropriate the time or place.

Lower Motor Neuron or Flaccid Bowel

When the spinal cord injury is below the T-12 level, there may be damage to the defecation reflex, causing the anal sphincter muscle to relax. Strong abdominal muscles can assist the process of elimination by bearing down. This type of bowel problem frequently requires a daily planned evacuation attempt or manual removal of stool.

What is a Bowel Program?

A bowel program is a pattern for emptying the bowel. Its goal is twofold: (1) to help maintain regular, predictable bowel movements and (2) to prevent unplanned bowel movements, constipation, impaction, or diarrhea.

A bowel training program is first begun during a person's rehabilitation stay. By the time of discharge, the bowel routine has been established for the most part. Most bowel routines are done every day or every other day and take about five minutes to an hour or longer. The goal is for the bowel routine to regularly take no more than an hour. Routines are based on a person's prior bowel habits and his or her current lifestyle.

Remember, bowel programs vary from person to person. Working as a personal assistant, you may have more than one employer and their programs may differ according to their individual preferences and needs. Some may use suppositories, others may not. Some may prefer to do the program in bed, while others would rather sit on the toilet or on a commode chair. Keep in mind that your employer will know what works best, so follow his / her lead.

PLEASE NOTE: Any time contact is made with the area surrounding the anus, clean rubber gloves should be used. When inserting anything (i.e., suppository or fingers) into the anus, always use a water-soluble lubricant, such as K-Y® Brand Lubricating Jelly.

There are four main procedures for a bowel program which can be used in any combination. Your employer will instruct you as to which one(s) works best for him / her:

Bowel Program Procedures

1. Manual Removal

Physically removing the stool from the rectum with a scooping motion of the gloved fingers.

2. Suppository

Dulcolax® or the Magic Bullet Suppository™ (use the drug bisacodyl to stimulate the nerve endings in the rectum and cause the bowel to contract) or glycerine (puts water into the stool to help with evacuation).

3. Digital Stimulation

Digital stimulation should be done no more than once every 15 minutes or four times per hour.

A. Standard Technique. The gloved, lubricated finger makes a slight circular in and out motion in the rectum and causes the anal sphincter to relax. Using more than four digital stimulations at a time can cause trauma to the rectum and result in hemorrhoids or fissures.

B. Scissor Method. The gloved, lubricated index and middle fingers make a scissor motion in the anal canal to stretch the sphincter open and help it to relax.

4. Mini-Enema

A liquid form of the bisacodyl suppository. Stimulates evacuation by drawing water into the stool which softens and lubricates it. This is different from a regular enema, which is seen as too irritating to the bowel and should not be used on a regular basis. (Fleets, soap suds, or tap water.)

Common Bowel Problems

Constipation

Constipation is a condition in which hard, dry stool makes evacuation difficult. It can result from eating foods that tend to bind, such as bananas, white bread, white potatoes, and dairy products. The condition also can be brought on by stress, depression, medications (narcotics, iron, and certain antacids) and general inactivity. The consumer should discuss these issues with his/her health care provider. Constipation can cause muscle spasms, headaches, trouble sleeping, grouchiness, poor appetite, nausea, vomiting, hemorrhoids, and even dysreflexia. Depending on your employer's schedule, he or she may want to do a bowel program every day or even twice a day until the constipation is relieved.

Impaction

If constipation goes untreated, it can become impaction, in which a hard mass of stool gets lodged in the intestine and cannot be removed through a normal bowel program. When it appears as a scant, watery stool, it can be confused with diarrhea. However, with impaction, loose stool leaks around the hardened mass of stool in the bowel. Generally, it evacuates significantly less waste than diarrhea. If a person appears to have diarrhea after not having a bowel movement for a few days, it is likely that he or she is impacted. Using an external massage on the lower abdomen in a circular, clockwise motion from right to left helps to increase bowel activity. If this technique does not loosen the feces, the person should consult a physician.

Diarrhea

Diarrhea is an intestinal disorder in which a person has frequent, loose, watery bowel movements. Some of the causes of this condition are stress, intestinal infections, stool softeners, impaction, and diet. If a person has diarrhea for more than 24 hours, he or she should notify a physician. If untreated, diarrhea can cause serious dehydration and rob the body of vital substances.

Hemorrhoids

Hemorrhoids, or piles, are swollen blood vessels surrounding the anal sphincter. They are commonly caused by hard stool irritating the anus or by rough handling of the delicate anal tissue. Depending on whether hemorrhoids are inside or outside the sphincter, they may not be visible. Symptoms include pain in the anal sphincter region, bloody stool, swelling around the anus, and blood in the toilet. Problem hemorrhoids can be treated with nonprescription suppositories twice a day or as needed. If symptoms continue, a physician should be contacted.

Recommendations for Healthy Bowel Activity

- Eat a balanced diet that includes foods high in fiber. Fiber adds bulk to the stool, keeps stool from becoming too soft or from becoming too hard and dry. An individualized dose of a fiber supplement is recommended for most people. Fiber supplements include FiberCon® and Metamucil®.

- Drink at least 8-9 glasses of water per day. (Alcohol does not count!) Water is very important to maintaining a healthy bowel program.

- Stay on a scheduled bowel program.

- Stay active.

- Stool softeners may be recommended. Most (such as the brand name product Colace) use the drug ducosate.

- Avoid medications that can cause constipation, such as some pain

Let’s Proceed . . . Bowel Program Instructions

Your employer will explain to you which type of procedure is most comfortable, but having a working knowledge of the various components of a bowel program should help you feel more at ease and confident in this particular part of your job.

Arrange all supplies within reach before you begin. Basic supplies are:

- disposable rubber gloves
- lubricant (water soluble such as K-Y® Brand Lubricating Jelly)
- toilet paper
- Chux or protective pad
- basin of water, soap, washcloth
- suppositories (if used)

Digital stimulation has better results when sitting on the commode or toilet due to the fact that gravity helps move the stool out of the rectum. However, if your employer elects to use this procedure in bed, position him/her lying on the left side of his/her body.

Position the right leg to about a 45 degree angle or most comfortable position and place a pillow under the knee. This may vary with each employer.

Place a Chux or other protective pad under the buttocks area.

Inserting a Suppository

The purpose of inserting a suppository is to stimulate the defecation reflex, control bleeding, and relieve or diminish pain.

After you have padded the bed and put on your rubber gloves, lubricate your index finger and remove any stool that is in the anal area. The suppository will not work if it is put into the stool.

Lubricate the suppository and insert the rounded end first. Put the suppository in as far as you can, making sure that it is against the wall of the rectum.

After washing hands, put on a rubber glove, lubricate your index finger and check the rectum for stool. Using a gentle circular motion, remove the formed stool blocking the anal opening.

Apply more lubricant and insert the index finger into the rectum about 1/2 to 1 inch. Using a circular motion, rotate your finger against the anal sphincter wall for about 30 seconds. There should be a bowel movement in about 15 - 20 minutes. Once there has been a bowel movement, check the rectum once again for stool and remove manually. To empty the bowel completely and to prevent bowel accidents, do not rush through a bowel program. Be sure to wash the anal area thoroughly and dry well. Feces and moisture are two factors that can easily lead to skin breakdown.

GENTLY . . . gently . . .

With digital stimulation, manual removal, or suppository use, bleeding may occur. Inform your employer of ANY blood, swelling, rash, or redness. He or she may want to consult with a physician. Also, remember that hemorrhoids may bleed when the rectum is stimulated.

Give the suppository time to work, generally 15-20 minutes. Follow the guidelines your employer has set for this program. Digital stimulation is used in conjunction with a suppository, because this frequently stimulates the defecation reflex.

Be very thorough in washing with soap and water. Dry completely.

Watch those nails!

Long fingernails can cause bleeding and damage rectal tissue even through a rubber glove.

Perineal Care

The perineum is the external region between the vulva and anus in a female or between the scrotum and anus in a male.

Ideally, this area should be bathed at least once a day and more often if there are bowel or bladder accidents or if the woman is menstruating. Oozing feces, urine or other excretions cause skin irritation and odor as well as potentially causing skin breakdown. However, as with any procedure, follow your employer's wishes.

Assemble your supplies, which should include a clean washbasin filled about half full with warm water, 2 or 3 washcloths, towel, soap, a disposable underpad (Chux), disposable wipes or toilet tissue, and a trash bag.

Male Perineal Care

- Wash your hands and put on clean rubber gloves.

- Assist your employer onto his back and tuck a Chux or other waterproof pad under the buttocks. Spread the legs.

- Start by washing the penis first, holding the shaft with one hand and washing with the other. With each downward stroke, use a clean area of the washcloth. Rinse with a clean wet cloth. Pat dry. If he has not been circumcised, pull back the foreskin and wash and rinse thoroughly, then push the foreskin back over the head of the penis. (Drying can cause irritation when replacing the foreskin.)

- Next, gently wash the scrotum. Lift the scrotum and wash behind it, stroking toward the anus, once again using a clean area of soapy cloth with each stroke. Rinse thoroughly. Pat dry.

- Assist in turning him onto his left side. If there are feces, clean the area with toilet tissue or disposable wipes. Always wash from the scrotum toward the anus. Wash the buttocks and then the anal area. Rinse well and dry.

- Remove the protective pad and straighten the linens. See that your employer is positioned for comfort.

- Empty the washbasin and rinse. Spray with a bleach solution or use whatever your employer wishes; wipe and rinse again. Do not reuse the bath linens until they have been laundered.

Female Perineal Care

- Wash your hands and put on clean rubber gloves.
- Assist your employer onto her back and tuck a Chux or other waterproof pad under the buttocks. Spread the legs.
- Clean the outer area of the perineum first, including the area between the thighs and labia with soap and water. Rinse well and pat dry.
- Then separate the labia with one hand and with downward strokes, wash from the clitoris down to the vaginal opening toward the anal area. Remember to use a clean section of the washcloth with each stroke. Do not allow the cloth to touch the rectal area. Rinse well with a clean wet cloth to remove soap residue which can be irritating to the delicate membranes. Pat dry.
- Assist in turning her onto her left side and bend her right knee up to help separate the buttocks. If there are feces, clean the area with toilet tissue or disposable wipes. Wash the buttocks and the anal area, always wiping the anal area from front to back. Rinse with a clean cloth and dry completely.
- Remove the waterproof pad and straighten the linens. See that your employer is positioned for comfort.
- Empty the washbasin and rinse. Spray with a bleach solution or use whatever your employer wishes; wipe and rinse well. Do not reuse the bath linens until they have been laundered.

Menstruation and Perineal Care

When assisting during menses, perineal care should be done at least twice a day. Tampons or pads should be changed every four hours or more as required. But again, as with any procedure, follow your employer’s wishes.

Signs of autonomic dysreflexia (discussed in Chapter 8) can result from the uterus contracting during a menstrual period. Be familiar with the signs of autonomic dysreflexia and follow the guidelines for relieving the symptoms if your employer asks for your assistance.

Ostomy

An ostomy is a surgically-created opening in the body, usually for the discharge of wastes. Common types of ostomies include a colostomy (an opening in the abdominal wall through which digested food passes, bypassing a portion of the colon); an ileostomy (the lower portion of the small intestine is brought to an opening in the abdominal wall, bypassing all of the colon); a urostomy (the diversion of urine away from a diseased or defective bladder); and a tracheostomy (an opening in the trachea which allows a person to breathe or to be connected to a mechanical ventilator). Any of these ostomies may be temporary or permanent. A stoma is the end of the ureter, small intestine or colon which extends through the abdominal wall. Urostomies are discussed in Chapter 7, and tracheostomies are discussed in Chapter 13.

Colostomy and Ileostomy

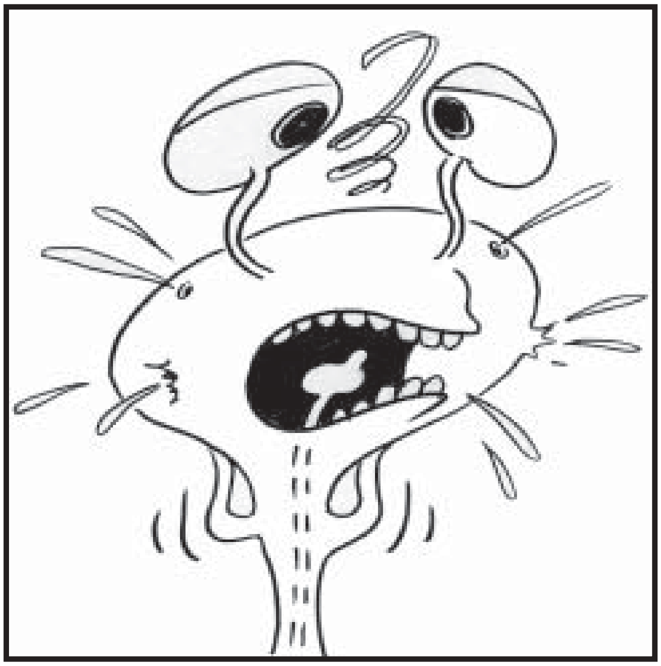
Damage from trauma or disease may require re-routing part of the colon or small intestine to discharge waste through the abdominal wall instead of the rectum. An ileostomy may involve removal of all or part of the individual's colon.

A pouch or collection bag system is used to catch the waste discharged through the stoma for either the colostomy or ileostomy. There are a wide variety of collection bag systems, and supplies are readily available. All systems employ a faceplate or flange fitted over and around the stoma. The flange is designed to collect the stoma output and to protect the surrounding skin from the output.

Some individuals with colostomies or ileostomies may be able to irrigate to clean waste directly out of the colon through the stoma. This allows for increased control over the timing of bowel movements.

NOTES

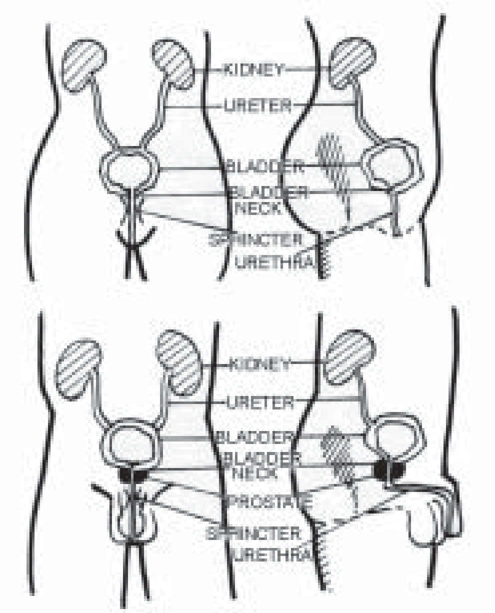
Chapter 7



Springing Leaks

Urinary Management

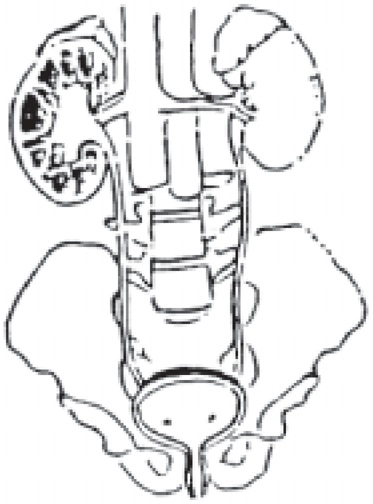
The Urinary System



The urinary system is composed of the kidneys, the ureters, the bladder, and the urethra. It works like this: the kidneys remove wastes and excess water from the bloodstream and turn them into urine. The urine then flows through the ureters (small tubes) to the bladder, a muscular sac that stretches to hold urine until a person is ready to urinate or void. With urination, the bladder contracts and the sphincter muscle opens. Urine then passes through the urethra.

Normal Urination

Urination is a coordination of the bladder and sphincter muscles which involves both voluntary and involuntary (or automatic) control by the nervous system. When the bladder becomes full, messages are sent to the sacral level of the spinal cord. Messages are then sent to the brain signalling a person that the bladder is full. At this time, a person can decide whether or not to empty his/her bladder. This is the voluntary control aspect. If a person wants to void, the brain will send nerve impulses back to the urinary system. Involuntary control involves the opening of the sphincter muscle and bladder muscle contraction.



Bladder Function After Spinal Cord Injury

After a spinal cord injury, bladder control may be limited or nonexistent, depending on the level of injury to the spinal cord. Bladder control is often affected because the pathways between the brain and bladder are interrupted; subsequently, a person cannot sense when the bladder needs emptying. This interference in function, or an abnormal nerve-functioning bladder, is known as a neurogenic bladder.

Types of Bladder Impairment

Upper Motor Neuron Bladder (Reflex or Spastic Bladder)

In this condition, the bladder tends to hold smaller volumes of urine than before SCI. The bladder muscle may spasm on its own and cause a person to have frequent, scant urination without control. This bladder type is common in most spinal cord injuries above the sacral level.

Lower Motor Neuron Bladder (Flaccid Bladder)

In this condition, the bladder muscle has lost its ability to contract and can be easily stretched. Therefore, large volumes of urine can be held by the bladder. Because the muscle cannot contract, urine leaves the bladder when it becomes too full. This bladder type is common when SCI affects the sacral level of the cord.

Diseased or Damaged Bladder (Urostomy)

A urostomy (a surgically created opening in the abdominal wall through which urine passes) may be performed when the bladder is either not functioning or has to be removed because of damage or disease. One or both ureters, which drain urine from the kidney to the bladder, are detached from the bladder. They are usually connected to a small portion of the small intestine or colon, which has been surgically removed and formed into a conduit for the urine to drain through the opening in the abdominal wall.

Pouches (either disposable or reusable) collect the urine. There are a wide variety of urostomy supplies available at medical supply outlets.

Individuals with urostomies are more prone to urinary tract infections, and should follow the recommendations for prevention and treatment of urinary tract infections later in this chapter.

Urinary Complications

Because each spinal cord injury is different, urinary management programs vary from person to person. It is best that a person remain catheter-free. However, because this is not always possible, alternative routes must be taken. Indwelling urethral, suprapubic, and external catheters will be discussed later in this chapter. Complications can occur when wearing any device. Special care should be taken in understanding and recognizing symptoms of these complications.

- Bladder calculi (stones) – These are common with a spinal cord injury. Efforts to reduce stone formation include: increasing activity of the individual; high fluid intake; restriction of dairy products; and medications to acidify the formation. Chronic urinary infection has a high association with stones. Egg shell calculi tend to form around the balloon of the catheter and can easily be seen when caring for the catheter.

- By-passing (leakage) – Individuals with indwelling catheters occasionally experience voiding around the catheter. This usually occurs in a spastic bladder which is being irritated by infections or stones. If this occurs, inserting a catheter of larger size is of no help. A small capacity bladder may cause leakage.

- Traumatic catheter changes – These may be the cause of serious problems other than infection. Forceful introduction of the catheter may lead to formation of false passages and the risk of perforation. Inflation of the balloon while the catheter tip is still in the urethra may cause hemorrhage or rupture. Always insert the catheter up to the “Y” of the catheter before inflating the balloon. (See Catheter Procedures on page 81.)

Urinary Tract Infection (UTI)

Intestinal bacteria are responsible for about 75 percent of all urinary tract infections. The most common routes of entry are the following:

- indwelling catheters

- intermittent catheters

Internal causes of urinary tract infections could be the following:

- stones

- residual urine (urine left in the bladder after attempted voiding)

- reflux (in reference to the urinary tract, refers to the passage of urine from the bladder back into the ureters toward the kidneys)

- abscesses (pockets of infection)

External causes of urinary tract infections could be the following:

- improper personal hygiene in perineal care
- poor handwashing technique and care of the catheter
- inadequate fluid intake
- pH elevation
- indwelling catheter

Signs of a UTI

- sediment in urine (cloudy / foul smelling urine)
- fever
- chills and / or sweating
- difference in voiding (more often or incontinence)
- increased frequency of spasms
- bloody urine (color will be rusty, red or pink)
- leakage around the Foley (See page 82).

PLEASE NOTE: Attendants, when changing the bedside bag to a leg bag or vice versa, DO NOT EMPTY the bag before your employer examines the urine. Your employer always needs to know if the urine is discolored or cloudy and if there is a lack of urinary output.

Symptoms of urinary tract infection may be abrupt or gradual at onset and may be one or a combination of the following:

- fever may fluctuate rapidly and may be accompanied by chills
- loss of appetite and general weakness
- nausea and vomiting
- increased spasticity in spinal cord injuries
- headache, increased blood pressure (see autonomic dysreflexia, page 76)
- sweating

Autonomic Dysreflexia

A Potential Life-Threatening Development

Autonomic Dysreflexia (AD) can be a medical emergency for an individual with spinal cord injury. This condition, often referred to as hyperreflexia, is more likely to affect persons with complete injuries above the T6 level. Because many medical professionals do not know about AD, it is essential that individuals with spinal cord injuries, family members, and personal care assistants of these persons know about this life-threatening complication.

Autonomic Dysreflexia, which happens quickly, occurs when there is an irritating stimulus to the nervous system below the level of injury. The stimulus tries to send a message to the brain via the spinal cord, but the message is blocked by the injury. The brain, therefore, cannot respond to the stimulus, so a reflex action is triggered – blood vessels tighten, and the blood pressure rises. If the blood pressure is not brought under control, seizure, stroke, and possibly death may result.

Common Warning Signs

- A pounding headache
- Heavy sweating, especially in the face, neck, and shoulders
- Flushed or reddened skin, especially in the face, neck, and shoulders
- Goose bumps
- A stuffy nose
- A feeling of tightness in the chest, flutters in the heart or chest, and trouble breathing
- Anxiety or jitters

A person experiencing AD symptoms needs to remain sitting or upright until the blood pressure is back to normal. Lying down may make the blood pressure go higher.

Early Detection & Treatment of Urinary Tract Infection

– Michael E. Acuff, M.D
Missouri Model Spinal Cord Injury System

Urinary tract infection (UTI) for people with spinal cord injury is a significant problem. Not only does UTI cause symptoms and have possible serious complications, it is also treated by a great variety of methods. Because of the nature of management of neurogenic bladder for people with spinal cord injury, urinary tract infections can be even more complicated than in the general population. For this reason, I have devised an approach that gives the major portion of decision-making power to the person with the spinal cord injury who has a significant urinary tract infection. I have also designed a treatment plan for it. Though I do believe that this is a safety net to prevent patients from becoming acutely ill with urinary tract infection, I also feel that individual autonomy is an important issue when looking at urinary tract infection in people with spinal cord injury. The following instructions are given to empower the person with spinal cord injury regarding his / her own health care.

A prescription for Chemstrip® 2LN urine test strips is given to the individual. The cost of this bottle of 100 strips is less than the cost of a course of antibiotic for urinary tract infection. The instructions are to test the urine with the test strips if a person is experiencing signs or symptoms of a bladder infection.

The instructions are easy to follow and easy to read as to whether the Leukocyte and Nitrateportions of the strip show positive. If an individual does not have signs or symptoms of a UTI, I discourage using the urine test strip to test the urine. I also encourage healthcare providers NOT to test the urine unless the patient has symptoms of UTI.

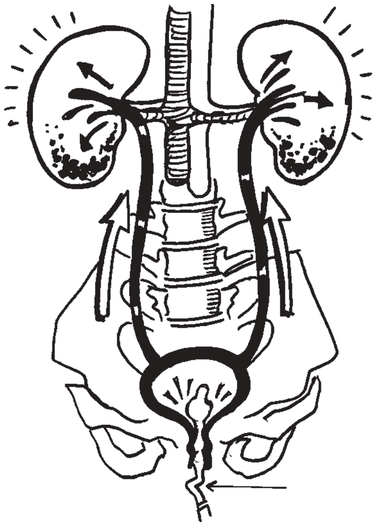
These symptoms range from increased spasms, sweating, cloudy and smelly urine along with fever and chills. If a person has these symptoms and the urine test is negative for one or both of the segments on the urine test strip, I do not consider a significant UTI to be present. I recommend that the person take Tylenol®, drink plenty of water, and watch for changes in his or her condition over the next several days. If the person's condition doesn't change by the next day, a repeat of the test strip can be performed. If both segments on the urine test strip are positive, I consider this a sign of significant UTI that needs to be treated.

Treatment can proceed in two directions at this point. The person can have an antibiotic prescription filled and take according to directions. I do not re-test the urine after the antibiotic prescription has been completed unless the person continues to have symptoms of UTI.

The other course that may be taken if the person does not feel extremely ill or have a fever is a conservative approach that involves drinking large amounts of water and taking one or two cranberry concentrate capsules twice a day. This compound, CranActin®, is not available in drug stores but can be found in or ordered from health food stores. I cannot recommend any other cranberry concentrate, because CranActin® is the only concentrate that contains the active ingredient that has been shown to prevent bladder infections or to decrease bacteria concentration in the bladder. If this condition does not show improvement with either approach within two or three days, the person should consult a physician and have a urine analysis with a culture and sensitivity check.

Hydronephrosis

A chronic reflux of urine into the kidneys is called hydronephrosis. This term means water (urine) on the kidneys and may cause severe infections of the urinary system and kidney failure. Impairment may be permanent. Taking proper care of the urinary system and preventing infections is essential to healthy kidneys.



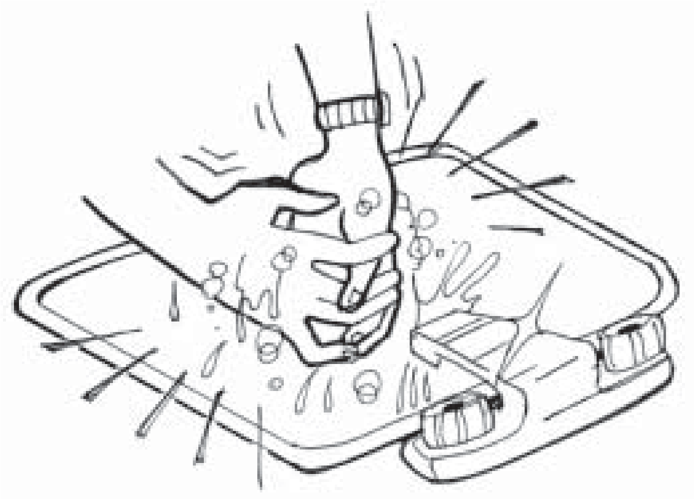
Pyelonephritis

When a bladder infection spreads into the kidneys, it causes an infection called pyelonephritis. A kidney infection may cause back pain, chills and fever, pain in the scrotum or inner thighs, nausea, and vomiting.

Prevention of pyelonephritis includes drinking at least eight glasses of water or cranberry juice per day. Water and CranActin® (or cranberry juice) help to flush the kidneys and bladder better than almost anything else. Be sure to use a clean catheter each time, washing hands and wearing gloves.

Prevention and early treatment are the keys to good health. Severe infections can damage the kidneys and cause kidney failure, which may cause death.

Hand Washing



Preventing infection and good hand-washing techniques go hand in hand. Although your hands may not look dirty, everyday activities such as petting animals, handling money, using the bathroom, taking out the garbage, and turning doorknobs can contaminate your hands with bacteria. To prevent these germs from spreading between you and your employer, wash your hands often. Beware of strong soaps; they may cause dryness and are not needed for good hygiene. Even though you may use rubber gloves, you still must wash your hands before and after wearing them. Here's how:

1. Wet your hands completely under running water while holding them in a downward position so that the water washes away the contaminants.

2. Use an antibacterial soap, preferably liquid soap. Keep the water running while you lather your hands, including the wrists. Rub your hands together vigorously on the palm side and the back side. Interlace your fingers and work the area between the fingers. With the fingers of one hand, work around and under the nails. Repeat on the opposite hand.

3. Rinse thoroughly under running water with the hands still directed downward.

4. Dry with a disposable towel. Use this towel to shut off the water, turn off the light switch, and turn the doorknob when leaving the room.

Always wear rubber gloves when you are going to touch body fluids such as:

- **Blood**
- **Urine**
- **Saliva**
- **Vomit**
- **Mucus**
- **Pus**
- **Feces**
- **Open skin wounds**

Though rubber gloves protect the hands, they do not eliminate germs. There are always germs on the skin. The warmth and moisture under rubber gloves can cause germs to grow more rapidly. After you take off rubber gloves, wash your hands well.

Always wash your hands:

- After using the bathroom

- Before eating or touching food

- Immediately after accidental contact with any body fluids

- After taking off gloves

NOTES

Catheters: Types and Procedures

Care of the Indwelling Catheter

The indwelling catheter has a bulb, or a balloon on the end to hold it in place. It is left in the bladder so that urine is constantly drained from the bladder.

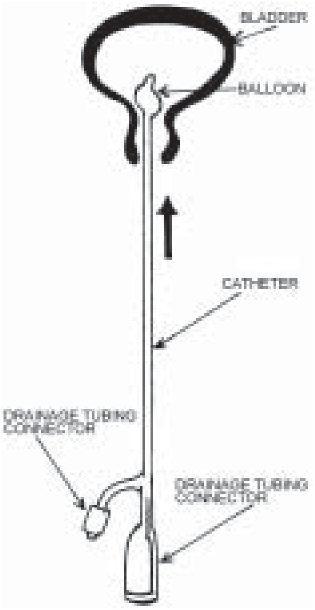
Indwelling catheters come in two balloon sizes and are used for both males and females. The balloon sizes are 5 cc (filled with 10 cc sterile water) and 30 cc (filled with 35 cc sterile water).

There are also two types of indwelling catheters:

1. The **Foley catheter** goes into the bladder through the urethra and is sometimes used by females who have a reflex bladder or who are unable to do an intermittent catheterization.

2. A suprapubic catheter goes in through the abdomen into the bladder. This catheter is used when there is a problem, such as a stricture, which makes it impossible to enter the bladder through the urethra.

The urinary system is considered to be sterile. For this reason, all tubing and other items used in caring for the catheter should be sterile.



Drainage collection bags must always be kept below the level of the bladder. Do not use tubing with kinks.

When the catheter is in place, you must take special care with the area surrounding the catheter. Soap and water and preferably an antiseptic solution will assist in preventing odor, irritation, and infection. You should avoid using creams and powders because they tend to cake, dry and further irritate the skin.

If urine output is diminished, care must be taken to ensure that the catheter is open. Inadequate intake of fluids hampers the effects of good catheter care. Sedimentation is a problem for some individuals, as well as formation of bladder stones.

The catheter may need to be changed or irrigated, whichever is indicated by the symptoms. Your employer will advise you as to which procedure to use and will be able to talk you through the irrigation or change.

Observe urine for color and content. You should report the presence of blood in the catheter or tubing to your employer immediately.

Let's Put In a Foley

- Wash your hands.

- Assemble the supplies needed. Your employer may have packages that contain all the necessary items. This is called a catheter tray. Some of the usual items in a catheter tray are rubber gloves, a lubricant, forceps, 10 cc or 30 cc syringe with sterile water, underpad, drape, and other items depending on brand name and cost. The catheter comes separately, due to varying sizes. In addition to these items, you will need a syringe to deflate the old balloon, cotton balls, an antiseptic solution or betadyne swabs, a soapy washcloth, and a wet cloth for rinsing.

- Remove the old catheter by deflating the balloon. Attach the syringe to the end of the catheter that is not attached to the drainage bag. Draw back on the plunger to remove water from the balloon. Now, gently remove the old catheter.

Male and Female

- Wash the penis or urinary opening with the soapy cloth and rinse with the wet cloth.

- Wash your hands again.

- Open the catheter tray and set up the supplies.

- Place the underpad between the legs and under the hips.

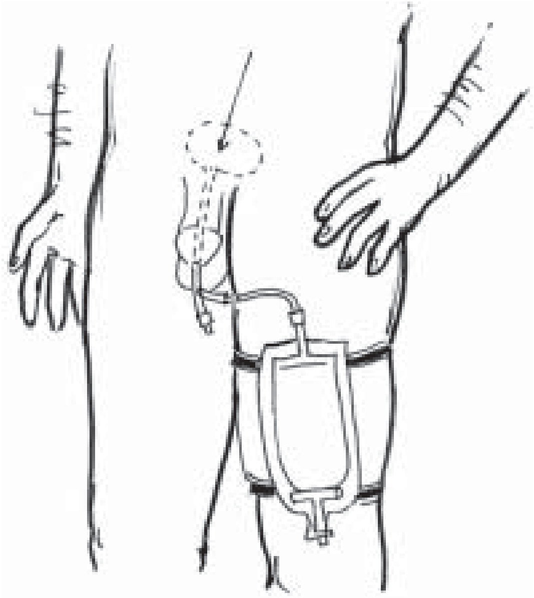
- Put on your rubber gloves.

- Wet the cotton balls with an antiseptic solution.

- Remove the plastic cover from the catheter and apply about 1 inch of K-Y® jelly onto the tip.

- Remove the rubber cap from the new syringe containing the sterile water. Connect the catheter to the drainage bag. (There should be one in the catheter tray kit.)

Male



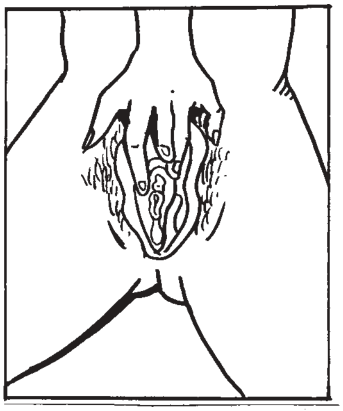
- Hold the penis with your other hand which is now dirty. Do not touch the catheter with this hand.

- Clean the urinary opening with the antiseptic cotton balls, wiping from the tip of the penis to the shaft. Use one cotton ball per wipe and NEVER REUSE the cotton ball / betadyne swab.

- Insert the catheter slowly into the urethral opening to the "Y" section of the catheter.

- When you see urine flowing from the catheter, blow up the balloon using the full 10 cc of sterile water from the syringe in the catheter tray.

Female



- Use your other hand and spread the labia using the three finger method to find the urinary opening. With one hand, spread the labia apart with your ring and index fingers. Locate the urethral opening with your middle finger. Do NOT use this hand to touch anything else.

- Clean around the urinary opening with the antiseptic cotton balls / betadyne swabs, USING EACH ONE ONLY ONCE, wiping from front to back.

- Insert the catheter slowly into the urethral opening. When urine flows into the catheter, insert for two more inches.

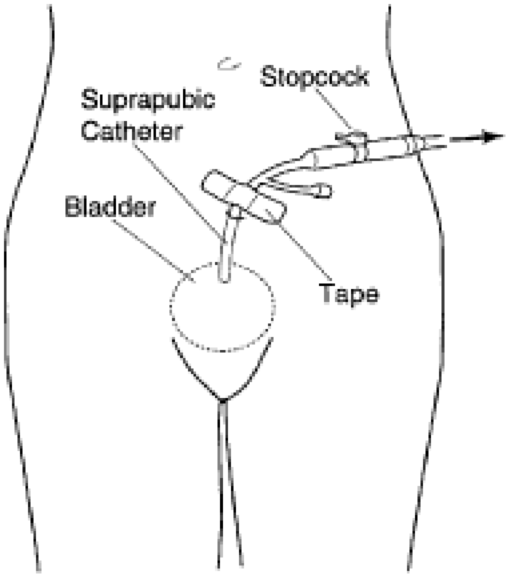
- Using the full 10 cc of sterile water, blow up the balloon AFTER you see urine flowing from the catheter tube. This means that the catheter is in the bladder.

Remember: You must begin again with a new catheter if you mistakenly insert the catheter into the vagina.

Suprapubic Indwelling Catheters

The purpose of the suprapubic indwelling catheter is to drain the bladder through a tube surgically placed in the bladder from the suprapubic area (lower abdomen), and to divert the urine from the urethra. Suprapubic drainage is considered by some individuals to be more comfortable than an indwelling catheter and some physicians feel there is less risk of bladder infection.

Care of the suprapubic catheter is essentially the same as care of other indwelling catheters with a few exceptions:



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- Hairs should be trimmed, not shaved, around the stoma (opening) to reduce bacterial contamination.

- A 4"x 4" sterile gauze pad should be placed around the stoma. This should be changed daily or more often if your employer requests.

- When you insert a suprapubic catheter, resistance is often met due to spasticity. Never force the catheter; wait until the spasticity has decreased.

When Replacing a Suprapubic Catheter

- Wash your hands.

- Assemble the supplies. Generally, this will include a 16 Fr. (French) catheter tray, a syringe to deflate the old balloon, a soapy washcloth, and a wet cloth for rinsing.

- The person should be lying flat on his or her back. The person's legs should also be flat. This allows the opening in the abdomen to align with the opening in the bladder.

- Gently remove the catheter. Do this by deflating the balloon, using the old syringe.

- Remembering how much tubing was in the bladder will help you to know how much of the new tubing to insert.

- Wash around the opening and rinse well with the wet cloth.

- Wash your hands again.

- Place the pad from the catheter tray around the opening.

- Put on your rubber gloves. Wet the cotton balls with an antiseptic and squeeze out the excess.

- Apply 1 inch of K-Y® jelly to the tip of the catheter.

- Connect the tubing of the catheter to the leg bag.

- Clean the opening with the antiseptic cotton balls and / or antiseptic swabs. Remember to use each cotton ball only once.

- Wash your hands again.

- Insert the catheter straight in about 4 inches. Hold the catheter in place and insert the syringe with the sterile water. Blow up the balloon using the full 10 cc.

- Slowly and gently, pull the catheter back until it stops. Remove any excess antiseptic from the skin as this can cause irritation to the skin.

- Wash your hands.

Suprapubic and/or Indwelling Foley Catheter Irrigation

Catheter irrigation should be done with the utmost care. A sterile or clean technique may be used for this procedure. These techniques are explained under the section called “Catheterization of the Bladder.” Again, you must respect and follow your employer's preference.

Indications for Irrigation of a Catheter

- Routine irrigations ordered by physician
- Large amount of sediment in urine
- Plugged catheter – diminished output or absence of output noted for several hours

Common Symptoms Caused by a Plugged Catheter

- Headache
- Profuse sweating
- Distended bladder
- Absence of urinary output
- Autonomic dysreflexia

Supplies and Procedures

Supplies for Sterile Technique

- Sterile, disposable syringes
- Sterile solution for irrigating. Solutions may be stored in the refrigerator between usage; however, solutions should be warmed to room temperature to prevent increased spasticity.
- Basin
- Alcohol wipes
- Towel
- Dry, sterile gauze

Supplies for Clean Technique

- Clean, dry syringe
- Fresh tap water at room temperature
- Basin
- Alcohol wipes
- Towel
- Dry, sterile gauze

Catheter Irrigation Procedure

- Wash your hands vigorously.
- Set up materials to be used.
- Place towel under catheter and pour solutions.
- Wipe your hands well with alcohol wipes.

- Wipe catheter tubing connection area well with alcohol wipes and place basin under catheter.

- Disconnect tubing (do not use fingernails) using dry gauze for each end. Cover open end of tubing with sterile gauze or sterile cap.

- Irrigate with solution; gravity is the best method. If resistance is met, do not force. Wait for bladder to relax.

- Wipe end of tubing and catheter with alcohol and reconnect.

- Wash and disinfect all equipment.

- Wash your hands vigorously.

Catheterization of the Bladder – Intermittent

Important Safety Tips and Precautions

- Lubricate the tip of the catheter using a tube of sterile lubricating jelly or water-soluble lubricant, such as K-Y® Brand Lubricating Jelly. Do not use a large container of the jelly to dip into. DO NOT use an oil-based lubricant like petroleum jelly.

- If you feel resistance when inserting a catheter, STOP. If the resistance is due to a muscle spasm, wait until the spasm passes before pushing further. If the resistance persists, a hard plastic catheter may be used. If resistance prevents the insertion of a catheter, the Crede procedure may be used to void the bladder. With the palm of your hand, apply steady and firm pressure on the abdomen directly over the bladder.

- DO NOT FORCE the insertion of a catheter. If resistance persistently interferes with catheterization, the consumer’s physician needs to evaluate the situation.

- If bright red blood is noted during or after catheterization, the consumer’s physician should be notified.

- Foley and suprapubic catheters should ALWAYS be inserted under sterile conditions.

Doing a Clean Catheterization – Male

Once again, good hand-washing is of the utmost importance in the prevention of bladder infections. Wash them vigorously!

Assemble all of your supplies on a tray or table, covered with a clean paper towel or hand towel. These will include:

- Antiseptic, cotton balls / swabs
- Latex rubber gloves
- Catheter
- K-Y® jelly
- Intermittent catheter bag, tube, or container
- Soap, water, and washcloths. If these are not available, use Handiwipes or babywipes.

Step-by-step Instructions

Open the tube of K-Y® and squeeze about 1 inch of jelly onto the tip of the catheter without allowing the tube to touch the catheter.

Wash hands and put on your rubber gloves.

Attach the end of the catheter to the bag, allowing the tip of the catheter to remain on the packaging. If you are using a container other than a collection bag, have it close at hand.

Wash the penis with a soapy cloth, disposable wipe, or antiseptic, then rinse with the wet cloth. If the man has not been circumcised, pull the foreskin back and clean the head of the penis.

Place the connecting end of the catheter in the container, then pick up the catheter just behind the jelly, about 2 or 3 inches from the tip.

With your other hand, hold the penis straight up and insert the catheter. As you are inserting the catheter, pull up on the penis, which allows the urethral passageway to the bladder to straighten out. This allows the catheter to pass more easily and also helps to prevent damage to the urethra and bladder sphincter.

If a spasm occurs while you are doing a catheterization, stop and wait for the spasm to pass before pushing the catheter any farther.

Once you begin to see the urine flow through the catheter, insert it another 2 or 3 inches. Let the penis come down while you hold the catheter in place. The urine will empty better in this position.

Pushing down on the bladder may be necessary to completely empty the bladder. Your employer may be able to do this step as you slowly begin to remove the catheter. A slow removal helps to eliminate any urine that might be remaining in the bladder which can be a cause of infection. Remove the catheter when the urine flow has stopped.

Clean the catheter well with soap and water, rinse thoroughly, air dry, and store in a paper bag. Plastic bags can cause condensation and can lead to future bladder infections.

Wash the penis with a soapy cloth, rinse well, and dry.

Empty the drainage bag or container and rinse with a bleach solution of 1 tablespoon of bleach to 1 quart of water.

Wash your hands.

Doing a Clean Catheterization – Female

Assemble all of your supplies on a tray or table, covered with a clean paper towel or hand towel, within easy reach. These will include:

- Antiseptic, cotton balls / swabs
- Latex rubber gloves
- Catheter
- K-Y® jelly
- Intermittent catheter bag, tube, or container
- Soap, water, and washcloths. If these are not available, use Handiwipes or babywipes.

Step-by-step Instructions

Open the tube of K-Y® and squeeze about 1 inch of jelly onto the tip of the catheter without the tube touching the catheter.

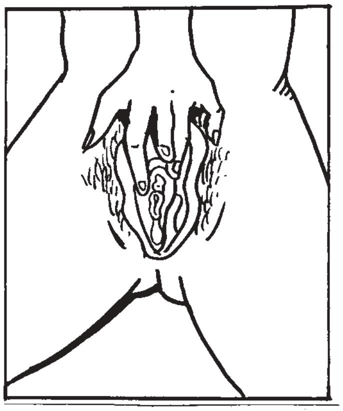
Wash hands and put on your rubber gloves.

Attach the end of the catheter to the bag, allowing the tip of the catheter to remain on the packaging. If you are using a container other than a collection bag, have it close at hand.

Wash the perineal area with a soapy cloth or disposable wipes, then rinse with the wet cloth.

Always wash from front to back to prevent germs from the rectal area entering the urethra.

With one hand, spread the labia apart with the ring and index fingers. Locate the urethral opening with the middle finger. Using antiseptic, cotton balls / swabs, clean urethra wiping downward (toward the anus).



Place the connecting end of the catheter in the container, if one is being used, then pick up the catheter just behind the jelly, about 2 or 3 inches from the tip.

Insert the catheter into the urethral opening until urine begins to flow. Now insert the catheter an additional 2 or 3 inches. Holding the catheter in place helps the bladder empty better.

Pushing down on the bladder may be necessary to completely empty the bladder. Your employer may be able to do this step as you slowly begin to remove the catheter. If not, place the palm of your hand on the bladder area and apply some pressure to help push the remainder of the urine through the catheter. When the urine flow stops, slowly begin to remove the catheter.

If the catheter is to be reused, clean it well with soap and water, rinse thoroughly, air dry, and store in a paper bag. (Some women boil the tubes and store in plastic bags in the refrigerator.)

Wash around the urethral opening with a soapy cloth, rinse well, and dry.

Empty the collection bag or container and rinse with a bleach solution of 1 tablespoon bleach to 1 quart of water.

PLEASE NOTE: The ONLY difference between the clean and sterile procedures of catheterization is that all supplies must be sterile.

Care of the Leg Bag and Bedside Drainage Bag

The items used by your employer for urine collection will vary from person to person depending on preference and / or cost. These items can be expensive. As a personal assistant, you should be aware of the different cleaning methods to help extend the life of these supplies.

The medical supply stores carry different products for cleaning or you may use soap and water. Just a drop of soap can make a lot of suds which can make it difficult to rinse. Two of the better home methods of cleaning are bleach or white vinegar.

When making a bleach or white vinegar solution, use a large container so that you have plenty on hand. It can be divided into smaller bottles for easier use. The bleach solution keeps well.

Water	2/3 c	1 1/4 c	2 1/2 c	5 c	7 1/2 c	10 c
Bleach or white vinegar	1 tsp	1/8 c	1/4 c	1/2 c	3/4 c	1 c

After you have emptied the urine out of the bag, rinse it well with water, then empty the water.

Pour 1/8 to 1/4 cup of vinegar or bleach solution into the bag and shake the bag so that all areas are rinsed.

If using vinegar, leave it in the bag for at least 10 minutes, empty, but do not rinse. If using bleach, rinsing is optional.

Condom Catheters

You will find that there are several different designs of condom catheters and that they come in small, intermediate, medium, and large. The correct size is very important.

Some condom catheter-users prefer a self-adhesive type, others secure the catheter using a stretchy tape, while still others prefer the use of a condom holder, which uses a Velcro band. A combination spray adhesive/skin conditioner is sometimes used in addition to using the tape.

If your employer uses tape, be sure not to put it on so tight that it causes swelling or redness when you remove it. The purpose of using a stretchy tape is to hold the condom in place so that if there is an erection, the blood supply to the penis is not cut off.

During urination, there is some suction created on the condom, which can cause a sore. To help prevent this, leave a space between the tip of the penis and the end of the condom.

When Putting on a Condom

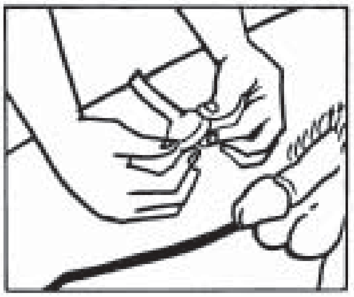
- Always wash your hands well with soap and water, and put on rubber gloves.

- When taking off the old condom, roll it, do NOT pull. (If adhesive has been used, you may need an adhesive dissolver.)

- If the hairs are caught in the tape or condom, now is a good time to clip them if your employer has no objection. Remember, DO NOT shave.

- Wash the penis well with a soapy washcloth. Pull the foreskin back and wash the head of the penis. Rinse well and pat dry. Pull the foreskin back down over the head of the penis.

- Roll the condom up to the funnel end. This will help to position the condom on the penis better. Now roll the condom over the penis.



- If using a condom holder, wrap it about one inch above the base of the penis. Make sure the strap is not too tight. Fasten the elastic strap to the Velcro.

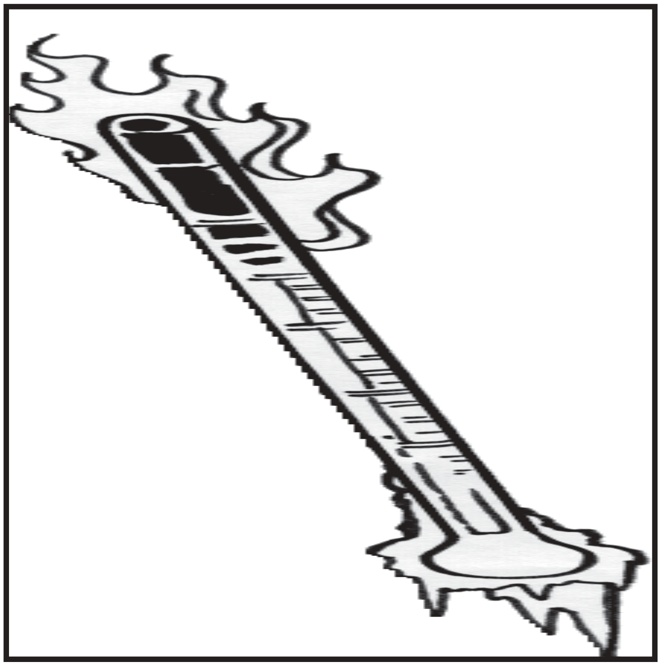
- If using a self-adhesive condom or if you have used a spray adhesive, hold your hand around the condom for about 10 seconds to help the adhesive bond.

- Position the leg bag according to your employer's instructions.

- Then connect the tubing to the catheter.

NOTES

Chapter 8



Keeping Your Cool

Thermoregulation

Regulating Body Temperature After Spinal Cord Injury

Through a self-regulatory process called thermoregulation, the body is able to maintain a consistent temperature. Core (deep tissue) temperature almost always stays steady at 98° F to 98.6° F despite changes in the skin (shell) and environmental (ambient) temperature. This procedure, highly dependent upon the center of the brain and parts of the nervous system, occurs through the tract in the spinal cord. Consequently, normal temperature control may be seriously disturbed if the spinal cord becomes injured.

The hypothalamus of the brain, the body's thermostat, keeps the body's temperature in the normal range. Containing temperature receptors that sense changes in the body's core temperature, the hypothalamus sends messages to cool the body when heat is sensed and warming messages when cooling is detected.

The spinal cord in the thoracic region sends signals to the sympathetic division of the autonomic nervous system, which controls the tone of the skin's abundant blood vessels. Generally, blood vessels are constricted to some extent. When the body's core temperature begins to rise, the hypothalamus sends messages to the nervous system through tracts in the spinal cord to expand the blood vessels, resulting in heat loss. To cause heat retention, the hypothalamus sends messages to constrict the blood vessels.

Temperature regulation is also affected by sweating and shivering. The sweat glands, which release sweat through pores in the skin, are also a component of the autonomic nervous system. Therefore, when the body's core temperature rises, the nervous system responds by producing sweat, resulting in the cooling effect of evaporation. Shivering helps to warm the body. The nervous system responds to cold temperatures by sending messages through the spinal cord to trigger the shivering mechanism.

Understanding Your Level & Degree of Injury

After a spinal cord is injured above the mid-thoracic level, the body has difficulty in regulating its temperature. The higher the injury, the more an individual takes on the surrounding temperature. Someone with a complete spinal cord injury will have more difficulty controlling body temperature than someone with an incomplete injury.

DO NOT use electric blankets or heating pads. Prolonged exposure to these heat sources can cause severe burns. Drugs and alcohol also affect the body's ability to detect and to respond to changes in temperature.

Dealing with Temperature Extremes

Heat

- When your employer is sweating above the level of injury ...
- When your employer is overheated - has a headache, dizziness, and nausea ...
- When your employer's skin feels warm to the touch ...
- When your employer is running a fever ...

What to Do (Suggest he/she)

- Stay out of the direct sun
- Drink cool fluids
- Put cool water on the armpit and groin areas
- "Mist" with a spray bottle filled with cool water
- Use a fan to circulate the air (sometimes used in addition to an air conditioner to direct the air)
- Wear hats and sunglasses
- Cooling vests are available from outdoor supply stores for use in extreme conditions

Cold

- When your employer is extremely cold and shivering ...
- When your employer has goose bumps above the level of injury ...
- When your employer's skin feels cool to the touch ...

What to Do (Suggest he/she)

- Eat or drink warm foods or beverages: soup or broth; hot teas; cocoa; hot cider
- Wear extra warm clothing such as socks, pants and gloves
- Keep the head, feet and hands warm will help to maintain body heat
- Stay indoors if possible; avoid extreme cold temperature exposure
- Use extra blankets to stay warm. If your employer is sitting in his or her wheelchair, suggest wrapping a blanket around his / her legs. (Suggest that he / she not use electric blankets or heating pads on areas with sensory impairment.)
- Warming vests are available from outdoor supply stores for use in extreme conditions

Autonomic Dysreflexia

A Potential Life-Threatening Development

Autonomic dysreflexia (AD) can be a serious complication for persons with complete injuries above the T6 level. Because many medical professionals do not know about AD, it is essential that individuals with spinal cord injuries, family members, and personal care assistants be informed about this life-threatening condition.

Autonomic dysreflexia, which happens quickly, occurs when there is an irritating stimulus to the nervous system below the level of injury. The stimulus tries to send a message to the brain via the spinal cord, but the message is blocked by the injury. The brain, therefore, cannot respond to the stimulus, so a reflex action is triggered--blood vessels tighten and the blood pressure rises. If the blood pressure is not brought under control, seizure, stroke, and possibly death may result.

Autonomic dysreflexia is characterized by a sudden, severe headache combined with an uncontrolled elevation of blood pressure. Additional signs or symptoms include:

- spots in front of eyes and blurred vision
- profuse sweating
- flushed face
- sweating above the level of injury
- blotchiness of skin above the level of injury
- pale skin below the level of injury
- goose bumps
- cool, clammy skin
- nausea
- feelings of anxiety and fear

PLEASE NOTE: For more information about autonomic dysreflexia, you can download the booklet “Autonomic Dysreflexia, What You Should Know, A Consumer Guide” from the web site of the Paralyzed Veterans of America: http://www.pva.org/NEWPVASITE/publications/cpg_pubs/AutoDys.htm

Causes and Treatments of Autonomic Dysreflexia

Causes

- **Bladder –** This is the most frequent cause. Check for kinks in the tubing, plugged connections, or a full leg bag. Your employer will probably have you do a catheterization regardless of how recently the last procedure was performed. If your employer uses an indwelling catheter, irrigate the Foley or change it if urinary drainage does not resume.

PLEASE NOTE: Empty the bladder slowly. DO NOT drain more than 500 cc at one time. Emptying too quickly can cause spasms, causing the blood pressure to rise again.

- **Bowel –** A bowel program itself or other rectal stimulation can cause AD. Your employer may use a numbing medication (xylocaine jelly) which you would apply and wait about five minutes before gently and gradually removing the stool. If the symptoms persist, stop. When symptoms subside, resume cautiously.

- **Skin –** Prolonged pressure, painful stimulus (sunburn, cuts, burns, bruises) or ingrown toenails can bring on an episode of AD. Loosen tight clothing, remove the shoes to make sure the toes are not turned under, remove sharp objects from pockets or from seat cushion.

- **Irritations –** Prolonged exposure to the elements; too long in hot or cold weather.

- **Irritations unique to men –** Pressure on the testicles or penis during sexual activity and ejaculation can be a cause of AD.

- **Irritations unique to women –** Orgasm, contractions of the uterus during menstruation or during labor and delivery may also cause AD.

- **Trauma –** Trauma in an area where the consumer has no feeling (such as a bruise or broken bone) may cause AD.

Possible Treatments

(Again, these are listed for your information. However, always follow your employer's instructions.)

- Raise the person's head to a 90 degree angle or have him or her sit up straight. This helps to lower blood pressure.
- Take off or loosen any tight clothing.
- Check catheter tubing to be sure it is not blocked or kinked; make sure urine is flowing from the bladder.
- Empty the bladder. Wash hands, put rubber gloves on, insert a catheter, and empty the urine.
- If out in public, try to get home. If your employer cannot get home quickly and symptoms continue, call 911 for emergency assistance (if employer so requests or is unresponsive).
- If your employer is at home and agrees, empty his or her bowels. Put rubber gloves on and manually remove all stool you can reach.
- If your employer is not awake or unable to participate in decision making, seek emergency assistance (911, ambulance).
- If after 20 minutes, your employer is still not feeling better and you have both explored all avenues to lower the blood pressure and to relieve other AD symptoms, emergency help may be required. There are medications which can be used to lower the blood pressure rapidly but should be administered very carefully under a doctor's supervision.

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Chapter 9

The Pressure Is On . . . and the Skin Can't Take It!

Prevention and Care of Pressure Sores

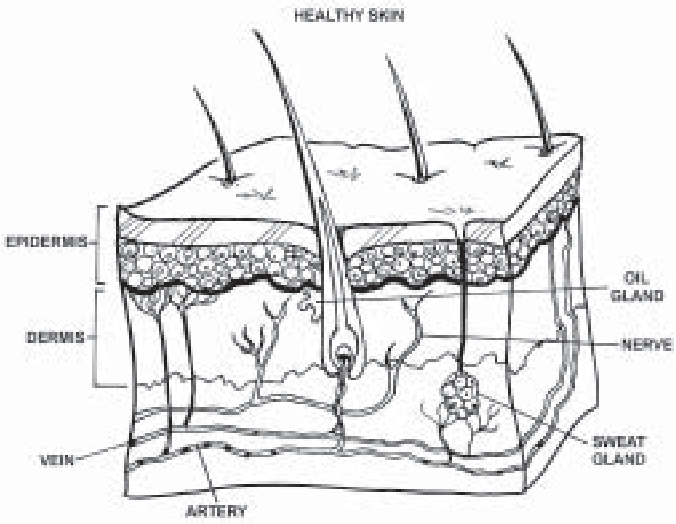
The skin destruction business generates an estimated $8.5 billion per year. Of the 3.5 million people each year who are treated for skin sores (pressure sores), about 60,000 die annually due to complications of the severity of the sore. An estimated 200,000 others will undergo restorative surgery to treat these preventable sores.

Skin represents the largest organ system of the body. Its functions include protection against injuries and parasitic invasion, regulation of body temperature, aiding body waste elimination; helping to prevent dehydration, acting as a sensory organ for the cutaneous senses, and acting as a source of vitamin D when the skin is exposed to sunlight.

Requirements for Healthy Skin

- Remove or avoid forces that cause skin breakdown (moisture, friction, pressure, shear);
- Good nutrition, with plenty of protein and a multi-vitamin;
- Drink enough water or juice;
- General cleanliness;
- No smoking of cigarettes;
- Avoid caffeine.

What is a Pressure Sore?



A pressure sore is defined as any skin opening caused by unrelieved pressure resulting in damage of underlying tissue. Pressure sores occur when blood supply to skin tissue is interrupted by prolonged pressure between a bony area, such as that next to the buttocks, and an external surface such as a wheelchair cushion or bed. The nerves send messages to the brain signaling pain and that the position needs to be changed. For a person with a spinal cord injury, that message does not reach the brain. The pressure prevents the blood from getting to the skin and the skin dies.

Complications from pressure sores include infection, dehydration, anemia, and excessive sweating. Pressure sores also may produce pain, disfigurement, lengthy periods of medical treatment, and hospitalization.

Medical treatment requires prolonged bed rest. As a result, persons with pressure sores typically have less contact with family and friends as well as interrupted employment or job loss.

Prevention of Pressure Sores

Skin sores, pressure sores, decubitus ulcers – regardless of the term you use to describe them – can be prevented. You will probably see some of your employers doing pressure reliefs every 20 to 30 minutes by shifting their body weight. Others, who cannot shift their weight independently, may ask you for assistance. This is very important for healthy skin, especially relieving the pressure over bones.

Unlike persons without disabilities who unconsciously shift positions instinctively whether sitting, lying or even sleeping, individuals with paralysis are unable to detect discomfort and sometimes even pain from weight-bearing areas starved of blood supply. For this reason, individuals must regularly shift their positions.

As a personal assistant, you will be helping to monitor changes in your employer's skin condition. Daily visual and tactile skin inspections are VITAL, especially looking at ischia (the bones on the bottom of the pelvis, used for sitting), sacrum / coccyx (bottom bones of the spinal column), trochanters (near the hip joints), and heels. Some employers will use mirrors to check themselves, but may ask you, as a personal assistant, to help. If you suspect a pressure sore is developing, inform your employer immediately. A pressure ulcer may cause a very expensive and lengthy hospitalization and even death if not treated immediately.

The Beginning of the Breakdown

The etiology (cause) of pressure ulcer development:

- **Moisture –** Caused by excessive perspiration, bowel or bladder leakage or incontinence. Certain acids and enzymes associated with diarrhea can cause chemical burns and erosion to the epidermis (the outer layer of the skin); cells fill with moisture and break with friction.

Tissue injury promotes bacterial, viral and fungal growth. Fungal rashes can be confused with pressure areas – watch this closely.

- **Friction –** Caused by rubbing of the epidermis on an external surface; the smoother the surface, the less the friction.

- **Pressure –** Any area that receives sustained external pressure, especially over bony areas, has a decrease of blood flow to that area. Healthy tissue can sustain short periods of pressure; as external pressure duration increases, the development of a pressure sore increases.

- **Shear –** Caused by pulling on the skin and blood vessels, which slows down the blood flow. For example, sitting in a slouched position can cause vertical shearing of the soft tissue that occurs with externally applied pressure. Another way to think of shear is when the skin moves in one direction and the bone moves in the opposite direction. Shear + Pressure = DANGER. The combination of shear and pressure causes more rapid skin breakdown than any outside force.

Tissue injury includes blisters, skin tears and deep tissue injury. Lateral shearing, improper handling of the extremities (poor transfer techniques) or tape stripping are associated with Stage II ulcers.

THE GREATER THE PRESSURE AND SHEAR, THE LESS TIME IT TAKES TO DEVELOP A PRESSURE SORE.

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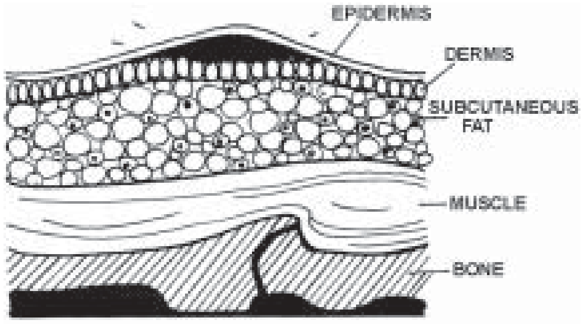
Pressure Sore Stages

Stage One



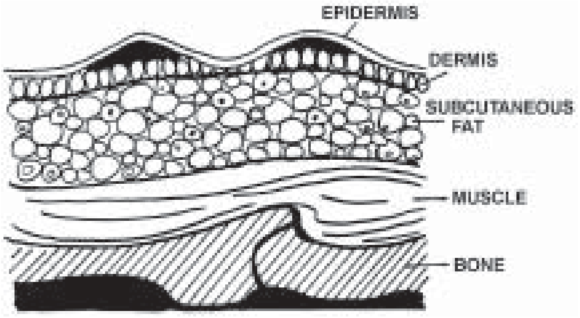
What is Stage One? The skin is not broken but is red or discolored in this beginning stage; the redness or change in color does not fade within 30 minutes after pressure is removed.

What can be done about it?

At your employer's request, be prepared to...

- position him / her to keep pressure off the sore;
- wash the sore with mild soap and water;
- rinse well, gently pat dry (DO NOT RUB directly over the wound);
- check the wheelchair cushion and the mattress;
- review your transfer and turning techniques with your employer;
- DO NOT put pressure back on the involved area until the redness is completely gone (no sitting on the area, etc.);
- inform your employer and he / she will decide what to do.

Stage Two



What is Stage Two? There is a blister or the epidermis (top layer of skin) is broken, creating a shallow open sore (partial thickness skin loss) and may not have drainage.

What can be done about it? Follow the above steps for stage one. At this point, your employer may want to consult with his / her healthcare provider who may provide the following instructions:

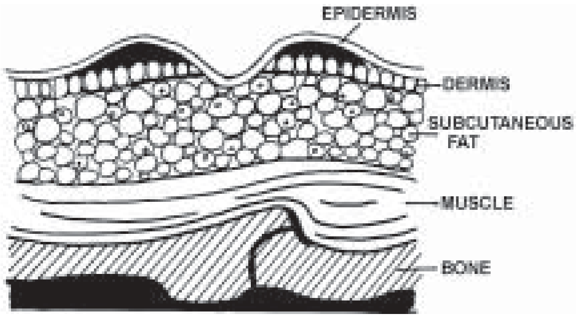
- Cleanse the wound with saline solution only. Application of a dressing or saline-dampened gauze may be prescribed. If using gauze, it will probably need to be changed twice a day and should remain damp between dressing changes.

- Check for signs of wound healing with each dressing change.

If there are signs of infection, inform your employer immediately. He/she may want to consult a healthcare provider to explore alternative wound care ideas and to review the possible causes. Signs of infection include:

- The area is hot to the touch;
- There is a white or creamy-colored drainage from the area;
- There is a foul odor around the area;
- The redness extends out into the normal skin.

Stage Three



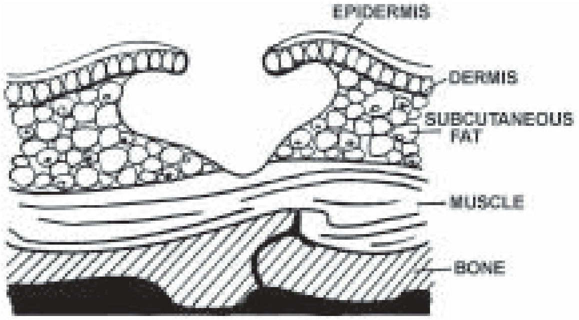
What is Stage Three? The break in the skin extends through the dermis (the second layer of skin) into the third layer of skin (subcutaneous and fat tissue). The wound is deeper than Stage Two, and there is full thickness skin loss.

What can be done about it? Follow the steps for Stage One and any additional instructions from your employer and the healthcare provider.

DO NOT let the wound dry out. "If it dries, it dies!" It is better for the wound to have a certain amount of drainage than to dry out. DO NOT use an antibiotic ointment - it slows or prevents healing.

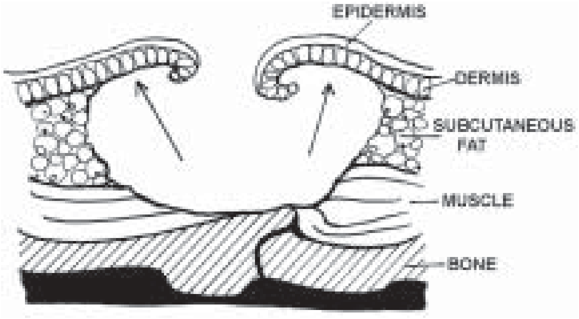
PLEASE NOTE: A wound care plan needs to be prescribed by a physician or other health care provider for the individual's needs. The wound care plan may include special cleaning agents, debriding agents, irrigations, and/or packing of the wound bed. If there is a scab present, this needs to be removed by a trained professional for proper healing. A physician may prescribe an oral antibiotic.

Stage Four



What is Stage Four? The breakdown extends into the muscle and possibly into the bone. There is usually a lot of dead tissue (full thickness skin loss) and drainage.

What can be done about it? At this stage, surgery is frequently required. Your employer's physician may prescribe protein or nutritional supplements, or other medications (such as anabolic steroids) that promote healing. Your employer should drink lots of water or juice, and discontinue any cigarette smoking.



This diagram shows the "undercutting" effect of a pressure sore.

A Stage Four pressure sore can develop within 2-4 hours, so the consumer and personal assistant must act quickly at the first signs that a pressure sore is developing.

Substance abuse can result in unwise behavior choices. These choices could lead to an increased risk for the development of pressure sores.

Do not allow your employer to sit on his/her wheelchair or other surface without a pressure relief cushion.

Indications of Healing

- wound should be healing from the inside out;
- the wound gets smaller;
- tissue along the edges of the wound turn pink;
- new tissue will be either smooth or bumpy;
- if some bleeding is present, this is a good indication that there is good blood circulation to the area which promotes healing.

Warning Indicators

- increase in the size or drainage of the sore
- redness (inflammation) increases or black areas (necrosis) begin to form
- the sore begins to smell and/or the drainage becomes a greenish color
- your employer develops a fever

Causes of Pressure Sores

- Being overweight can cause increased pressure on bony areas. The result may be a delay in healing because there are fewer blood vessels in fat tissue.

- For persons who are underweight, excess pressure over bony areas may occur because there is less muscle and fat over these surfaces. In addition, they may lack the proper nutrition to maintain healthy skin.

- Splints or braces may irritate the skin. If redness does not go away within fifteen minutes after removal, be sure to inform your employer.

- Heat sources inside the house as well as outdoors can cause skin problems. The warmth of a burning log in a fireplace can be a potential source of disaster for someone with little or no sensation.

- Wheelchair footrests and other metal areas that are close to a heat source can be conductors of heat and may cause potential burns.

- Some electric blankets and electric heating pads can cause severe burns.

- Heat vents in cars, vans, or trucks also can be dangerous for someone with a spinal cord injury. When riding in a car, suggest that your employer keep his or her feet away from the heat outlet. Before transferring your employer onto a vinyl seat, make sure it isn't too hot. If it is, place a towel over the seat and / or ask for assistance with the transfer.

- Dragging the bare skin (shearing) across fabric can result in friction burns. Never do a sliding board transfer with bare skin to board.

- Hot ashes from a cigarette dropped in the lap or other area can cause serious burns. Watch for areas of redness or possibly blisters and inform your employer immediately. Do not break the blister!

- Outside temperatures can bring on everything from sunburn and dehydration to frostbite. Time is a key element; staying out too long and / or not dressing appropriately can be dangerous.

- In the case of frostbite, which usually affects the fingers and toes first, the skin will turn pale or white and then red. Place your employer's hands or feet in lukewarm water. DO NOT RUB. Your employer may wish to call the doctor.

INFORM YOUR EMPLOYER IMMEDIATELY IF HE/SHE IS BURNED. APPLY COLD WATER FOR 30 MINUTES. DO NOT USE OINTMENTS UNLESS PRESCRIBED BY A PHYSICIAN.

- The feet and toenails are often overlooked. Because the feet are farthest from the heart, they get the least efficient circulation. This is especially true for someone with a spinal cord injury. Take preventive measures before your employer's feet turn dry and scaly. Soak them in warm water with a little bath oil, then remove the dead skin with a foot brush or pumice stone. NEVER pick off the dry skin. Massaging the feet and calves with lotion lubricates the skin and helps the circulation.

- Ingrown toenails should never be allowed to happen. This usually occurs on the large toe due to the nail having been cut too short or rounded on the corners. They should be cut straight across. If you notice redness and swelling around the toenail, possibly with some drainage, inform your employer. Tight shoes and / or poor hygiene are possible causes. This could also be the beginning of skin breakdown.

- Spasticity also can be a source of skin breakdown. Because of spasms, a person's limbs may be injured when they involuntarily move and strike or rub against something.

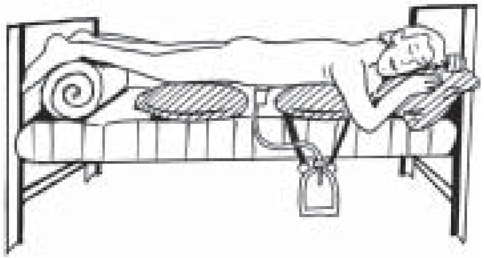
Don't miss your window of opportunity to PREVENT pressure sores!

NOTES

Turns, Positions, Pillows, Props

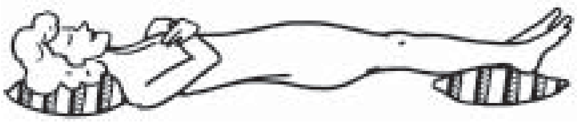
Whether your employer requires turning every two hours, four hours, or can remain in one position throughout the night, will depend largely on his or her skin tolerance. Proper positioning and the use of pillows for support will help to prevent pressure on bony areas.

Sleeping on the Stomach



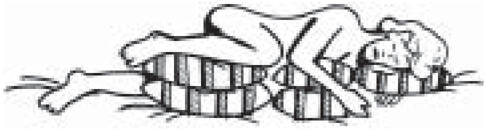
Lying on the stomach straightens the hips, prevents tightness, and helps to decrease leg spasms.

Sleeping on the Back



Check the skin of the sacrum for signs of pressure upon turning and / or rising. To prevent pressure sores on the heels, place a pillow under the ankles.

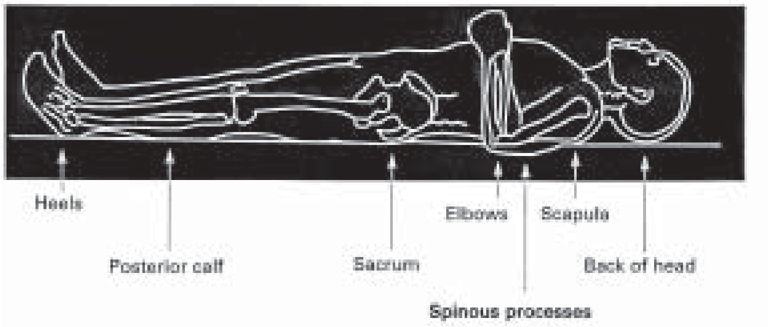
Sleeping on the Side



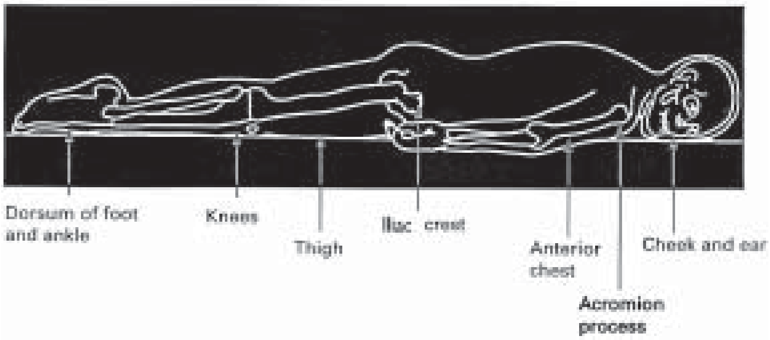
Place the top leg on a pillow to prevent pressure on the side of the knee. The bedside collection bag should be on the side of the bed that your employer is facing.

Bony Areas

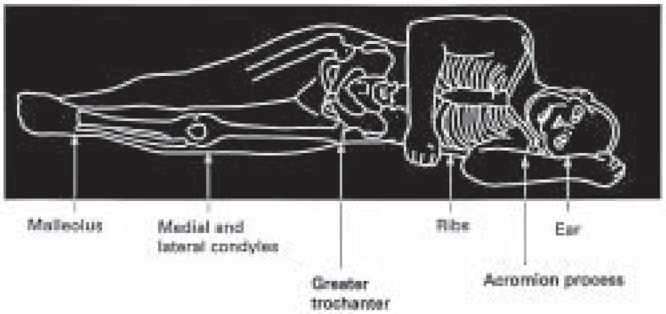
SUPINE



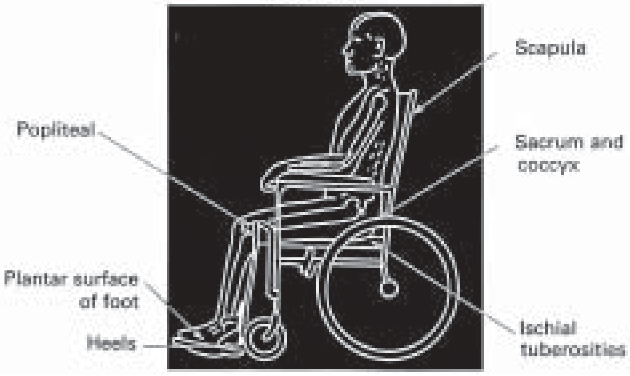
PRONE



LATERAL



SITTING



Thrombophlebitis

thrombo - combining form meaning clot of blood; a thrombus.
phleb - vein
itis - inflammation

Inflammation of a vein in conjunction with the formation of a thrombus. Usually occurs in an extremity, most frequently a leg, either in the calf or thigh.

A thrombus is a blood clot that obstructs a blood vessel or cavity of the heart. The thrombus can become an embolus, a mass of undissolved matter, that may reach the lung.

To help prevent this secondary condition, range of motion, leg exercises and avoiding prolonged pressure on the underside of the knee area will encourage circulation of blood to the lower extremities.

For people who spend most of their time in bed or use a wheelchair, thromboembolitic hosiery provides equal compression on the legs from the ankle to where the stocking ends. These stockings are commonly referred to as TED hose.

Persons who are ambulatory would use the graduated compression stockings. The majority of the pressure begins at the ankles, reduces slightly at the calves, and continues to decrease to the end of the stocking.

Warning Signs of Phlebitis

- redness
- swelling
- increased skin temperature
- pain
- low-grade fever

These signs are generally due to decreased movement and circulation. If you notice any of these warning signs, DO NOT massage or exercise the leg. Your employer may wish to call his / her healthcare provider. Like a pressure sore, this problem needs immediate attention.

AN IMPROPER TRANSFER OR POSITIONING CAN CAUSE INJURY TO A VEIN.

NOTES

Chapter 10

Lookin' Good, Feelin' Good

Activities of Daily Living

Activities of daily living (ADL's) are those self-care activities which should be accomplished each day so that your employer may participate in everyday, modern society.

The topics discussed in this chapter, as in previous chapters, are guidelines. There will be differences and variations with each set of guidelines just as there will be differences in personality with each employer. Follow your employer's instructions.

Giving a Bed Bath

Preparations

- Gather all the supplies: 2 or 3 bath towels, a hand towel, a washcloth, a bath sheet or flannel blanket, soap, a nailbrush, lotion, and a washbasin.

- Fill the basin about 2/3 full with water at 120-F. The water will cool to between 100-F and 115-F by the time it touches the body. (Hand-test the water before beginning the bath.) If the water gets too cool or dirty during the bath, replace it.

- Observe room temperature and adjust accordingly. Close doors and windows to prevent drafts. During the bath, avoid exposing the person to drafts by washing and drying one area at a time.

- Provide as much privacy as possible; close curtains or shades.

- Wash your hands. Rubber gloves must be worn when washing the perineal area or if there are open sores.

- Assist in moving your employer close to you; remove his or her clothes. Place a blanket or towel over him or her to provide privacy and warmth.

Wash the Face First

Wet the washcloth but don't add soap unless specifically directed to do so. Wash one eyelid by wiping gently from the inner corner to the outer corner. Dry the eyelid, then rinse the cloth, and wipe and dry the other eyelid. Wash the face, neck and ears with soap and water. Rinse well and pat dry.

Hands and Arms

Place a bath towel lengthwise under the far arm. Using long, smooth strokes, wipe from the hand to the underarm. Wash, rinse, and dry. Repeat these steps for the near arm. Place the hands in the basin to wash and clean the fingernails. Wash and dry one hand at a time.

Chest, Breasts, and Stomach

Place a bath towel or blanket across the chest, fold down to expose the chest and stomach. Wash chest, breasts, and stomach; rinse and dry well. Be sure to dry any creases or skin folds thoroughly.

Legs and Feet

Uncover and flex your employer's far leg and place a towel under it. Wash, rinse, and dry completely. Repeat these steps for the other leg.

Place the basin on a towel and put your employer's foot in the basin by supporting the heel; wash, rinse, and remove from the basin. Place the foot on a towel and dry. Clean the toenails as needed. Repeat these steps for the other foot.

The Back

Change the water in the basin.

Assist your employer in turning to the opposite side or abdomen. Place a bath sheet or towel on the bed along the back. Wash the entire back beginning at the neck, working across the shoulders, and down the back and buttocks and the upper thighs. Rinse and dry all areas thoroughly.

If using lotion, warm it first and apply to the back before turning.

The Perineal Area

Male – Wash the penis. If your employer has not been circumcised, pull the foreskin back and clean the head of the penis; rinse and pat dry. Remember to pull the foreskin back over the head of the penis. Next, wash the scrotum and inner thighs. Rinse well. If your employer has hemorrhoids, wash the anal area very gently. See Chapter 5 for an explanation of hemorrhoids.

Wash, rinse, and dry the anal area. Dispose of water in basin.

Female – Always wash from front to back to prevent rectal area germs from entering the urethra. Begin by washing the area between the thighs including the outer lips. Rinse well. Now wash the inner lips by spreading the outer lips and wiping one stroke at a time, each time using a clean area of cloth, cotton ball, or gauze. Be sure to rinse thoroughly and dry completely.

Wash, rinse, and dry the anal area. Dispose of basin water.

Showering

- Provide for privacy and adjust room temperature.

- Always make sure when transferring that all floor surfaces are dry. Lock all wheels. Use proper body mechanics.

- A proper shower chair has an opening in the middle of the seat to facilitate cleansing of the perineal area. Be sure to rinse thoroughly. Dry the perineal area completely. Moisture triggers skin breakdown.

- Shampooing is usually done at the same time as showering. After rinsing, cover the head with a dry towel to avoid chilling.

- After your employer has bathed as much as possible, finish the shower and rinse thoroughly. Dry him or her completely prior to transferring to another surface. Provide a towel to sit on.

- Always check the condition of the skin. Report any discoloration or skin breakdown immediately.

Feet and Nail Care

Because the feet are located farthest from the heart and because circulation is a major problem among people with disabilities, regular care is necessary. This includes prevention of dry and cracked skin on the feet and proper trimming of both toenails and fingernails to prevent ingrown nails which could result in infection. Care of the infected areas and proper cleaning are also essential to one's well being.

Nail care should be included with the bath or shower routine when possible because warm water serves as a softening agent which retards splintering or splitting of the nails. If nails are not trimmed on a regular basis, they will curl under as they grow and get thick, which will cause difficulty in their care. More importantly, untrimmed nails will rub against the shoe and could lead to ingrown toenails.

Trimming

Always trim or cut nails straight across and not too close to the quick. This will help prevent ingrown nails. Carelessness in trimming nails can create a serious problem. If the nail is trimmed too short, the quick may be cut, causing discomfort and possibly infection.

Be alert to spasms since the associated jerking motion could cause an unintended cut or scratch that could lead to infection. Use a clipper to trim the nail to the desired length. There is a small, curved nail clipper that can be used for the fingernails and the small toenails, and a heavy, straight clipper that can be used for large toenails.

Start at the side of the nail and work across the nail in a straight line. Smooth off the rough edges of the nail with an emery board or nail file. Always file away from the nail to lessen splintering, cracking, or chipping. Thick toenails are cut in short snips to prevent splintering. These must be softened before cutting. Do not trim cuticle as it is necessary to keep the nails healthy.

Care of the Infected Area

Redness and swelling around the nail can mean the beginning of ingrown nails. If redness or swelling occurs, the following procedures are recommended:

- Inform your employer.
- Keep the pressure off the toes by removing shoes and / or other articles from the feet.
- Avoid further trauma such as bumping the feet.
- Apply an antiseptic.
- Consider consulting a physician.

Lookin' Good, Feelin' Good

Daily Grooming

This is a very important part of the activities of daily living. Emotional well-being is often strongly linked to an individual's perception of how he or she looks. Simply because someone has a disability doesn't mean that they don't care about their appearance.

As a personal assistant, make every effort to insure that your employer looks his or her very best every day. This may mean spending a little extra time styling hair, trimming a beard and mustache, or applying makeup. Too many times, these tasks are rushed through or not done at all, either because no one offers to do them or time has not been available on a daily basis.

Oral Hygiene

Cleaning the mouth and gums promotes healthy tissue and may be requested at least twice a day.

First, wash your hands and put on rubber gloves. The best place for your employer to sit is in front of the sink. When brushing the teeth, always brush in the direction in which they grow. A soft-bristled toothbrush is easier on the gums and prevents irritation. One misconception is that the longer and harder you brush, the cleaner and healthier your teeth and gums will be. According to the American Dental Association, this can be abusive and can cause more harm than good.

If your employer requests you to floss his or her teeth, do so. Again, wash your hands and put on rubber gloves. If your employer has facial spasms or a tight jaw, floss with a flossing tool that allows your hands to remain outside the mouth. If using your hands, pull out about 18 inches of floss, and wrap around the first two fingers of each hand until there is about a 2-inch width between the hands. Insert the floss between two teeth at gum level. Move the floss up and down against each tooth and remove debris from under the gum. This also helps to remove the buildup of plaque that accumulates. Use a fresh section of floss for each tooth.

Dentures are very expensive and break easily. Protect them by placing them on a cloth out of harm's way until you are ready to use them. When brushing dentures, hold them in the palm of your hand. Be sure to rinse them well.

If your employer experiences “dry mouth” from medications or other conditions, chewing gum can freshen the mouth and helps to increase saliva flow. Ice, wrapped in gauze, can be placed inside the cheek to melt gradually, helping to replace saliva.

If your employer needs to remain in bed for oral hygiene, a side-lying position will keep the fluids from trickling down the windpipe.

Dressing

Proper fit of the clothing is very important. Clothing that is too loose may form wrinkles, putting pressure on the skin. Overly tight clothing can hinder circulation, not to mention the difficulty of putting it on. Again, each person will have a preference in clothing. Respect your employer’s choice.

Belts – Slide the belt through the loops before dressing. When buckling, make sure the belt is not too tight, causing pressure or irritation.

Pants – Bunch the pant leg and pull it up to the employer’s knee, then repeat on the opposite leg. Next, pull the pants up over the thigh and buttock as high as possible; repeat on the opposite side. Before slowly closing the zipper, make sure the catheter is connected to the leg bag tubing. Be sure that the skin is away from the zipper so it won’t be caught.

After the transfer has been made and your employer is sitting in the chair with hips positioned, pull the pants at the pocket/seam area to remove bunching and/or wrinkles. Adjust according to your employer's directions.

Shoes – Laces should be loosened as much as possible for ease of sliding the foot into the shoe. Do not pull the lacing tight. Allow room for expansion if your employer is prone to edema.

After the shoes are on, make sure the toes are not turned under. If you have any doubt, take the shoes off and start over. Loose shoes may cause the skin on the back of the heel to break down; close monitoring of this area is called for.

Making an Occupied Bed

- Remove all pillows.
- Loosen all bedding at the foot of the bed.
- Turn the person on his or her side with the back facing you.
- Loosen linen and tuck dirty sheets close to the back.
- Fold a sheet in half, longways.
- Place it on the bed, still folded; the hem should be even with the foot of the mattress. The fold will be running up the middle of the bed.
- Pick up the top half of the folded sheet and roll it in toward the body. Tuck it close to the back under the dirty linen.
- Tuck the clean sheet under the mattress at the head of the bed on your side and all the way to the foot of the bed.
- Turn the person toward you, rolling him or her over the linen that is gathered in the middle of the bed.
- Go to the other side of the bed and pull all the sheets toward you.
- Take the soiled linen out.
- Tuck the new bottom sheet under the mattress at the head and then tuck the rest of the sheet in all the way down the side of the bed.
- Be sure to pull the sheet tight, then arrange the top sheets.

NOTES

NOTES

Chapter 11

Bend, Stretch, Flex

Range of Motion

What is Range of Motion?

Range of Motion (ROM) is defined as the extent of movement within a given joint; motion in a joint is achieved through the action of muscles or a group of muscles.

The amount of range of motion a person needs varies and depends on the person's status of joint flexibility, spasticity, and / or painful joints. If joints do not receive their normal amount of motion each day, they begin to lose their flexibility. Contractures, a secondary condition, are the result of the muscles and tendons shortening from a lack of activity.

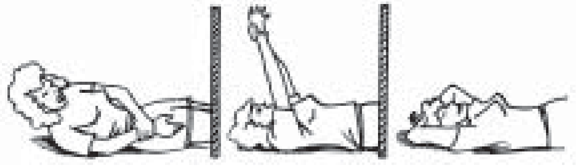
Functional exercises are of great benefit for strengthening the muscles, maintenance, and increasing overall endurance. Daily self-care tasks such as dressing, transfers, and pushing a manual wheelchair are a few exercises that help to maintain flexibility.

Purpose

The purpose of range of motion is:

- To maintain or improve joint movement while exercising the joint through its full range;
- To relax tight muscles to allow free movement of legs and arms;
- To improve circulation to the joints;
- To prevent contractures that result from a shortening of muscle or soft tissue.

Active Range of Motion



Active Range of Motion includes those exercises in which motions are performed without assistance or support, using the force of gravity in a smooth, coordinated, controlled movement. The active ROM focuses on preventing atrophy and contractures, increasing strength and circulation, and increasing ROM for functional activities.

Active Assistive Range of Motion

When someone actively does a part of the motion, the exercise is called active assistive range of motion. Range of motion can be performed with assistance if functional ability exists. Assist the person to insure slow, smooth, coordinated movements.

Active assistive ROM focuses on preventing atrophy and strengthening weak muscles, preventing soft tissue and/or muscle contractures, improving ROM of the joint, and improving coordination of movement.

Passive Range of Motion

Passive Range of Motion includes exercises that are carried out by another person without the assistance or resistance of the patient. Your employer will guide you through the series of exercises that are used for his/her individualized program.

Passive ROM focuses on preventing soft tissue and muscle contractures, increasing sensation to the joints, maintaining the normal length of the muscle, and stimulating normal reflexes.

Before performing range of motion exercises, know the reasons for doing them. It is important that you be knowledgeable about the motions that occur at each joint.

Stretching

Stretching is the procedure for lengthening a muscle or tendon when it is too short. Stretching may be done passively or actively. The goal is to increase the length of the muscle and thus increase the range of motion. Stretching will also decrease abnormal muscle tone (spasticity).

During passive stretching, the joint or extremity should be moved slowly and just to the point where resistance is felt. This will prevent any increase in abnormal tone and allow the muscle to lengthen without danger of tearing. Hold the joint or extremity in the lengthened position for about one minute unless directed otherwise by your employer. As resistance decreases, increase the stretch slightly by moving the extremity again to the point where resistance is felt. The positions of stretching are the same as those used for range of motion.

Performing ROM and stretching exercises can be exhausting for the assistant if proper body mechanics are not observed. Good body mechanics help to conserve energy and avoid unnecessary strain as well as possible injury.

Basic Standards

- Typically, the extremity is held at the joint; for example, the ankle or knee. If pain exists at the joint, the support should be above or below the joint.

- Support the extremity with your hand, keeping your hand open. DO NOT GRIP.

- These motions should be performed slowly, smoothly, and rhythmically without causing pain or exceeding the person's existing ROM. Never force a movement.

- Five repetitions are usually sufficient for each exercise using the passive range of motion unless the person requests more.

- Ask your employer to wear clothing that allows you to observe the motion and does not restrict the joint motion.

- The best time for ROM is when your employer requests it. Placing warm (not hot) towels over the extremities provides relaxation prior to the exercises.

- Range of motion is required for the shoulders, elbows, wrists, fingers, thumbs, hips, knees, ankles, and toes.

- General motions for basic ROM are up and down, in and out, and around or in a circle.

Never go beyond the point of resistance!

Spasticity . . . What Is It?

Muscles have a state of tension called muscle tone. When there is an abnormal increase in muscle tension, it is referred to as spasticity.

Standing straight and sitting up requires normal muscle tone. A high muscle tone means that muscles are so tight that movement is difficult. Abnormally high muscle tension means that the muscles are so tight that the extremity is hard to move.

Spasticity happens involuntarily and can be very bothersome for the first year or two after a spinal cord injury. For some, spasticity can be so severe that it interferes with their lives, keeping them from working, making them more susceptible to developing pressure sores, and causing them to fall out of their wheelchairs.

Spasms can be set off by a reflex action to touch, irritation to the skin, by stretching muscles, or by stress. A leg spasm may cause the knees to straighten and the toes to point, or the leg to shake. Spasms may even cause a bending of the hip and knee. Daily range of motion exercises and learning relaxation techniques can help reduce spasms. Casts or custom designed splints that can be easily removed are often used to help curtail contractures.

Range of Motion Instructions

Passive

The person's condition determines which motions need emphasis and which ones do not. In general, it is important to emphasize any motion that the person does not use. For example, if an arm is held close to the body, it is important to work on shoulder abduction (moving a limb away from the body), not adduction (moving a limb toward the body). In addition, if a person frequently moves a joint throughout the day, passive exercises are less likely to be necessary. The following section, Figures 1-1 to 1-14, illustrates passive range of motion exercises performed on the supine and prone person.

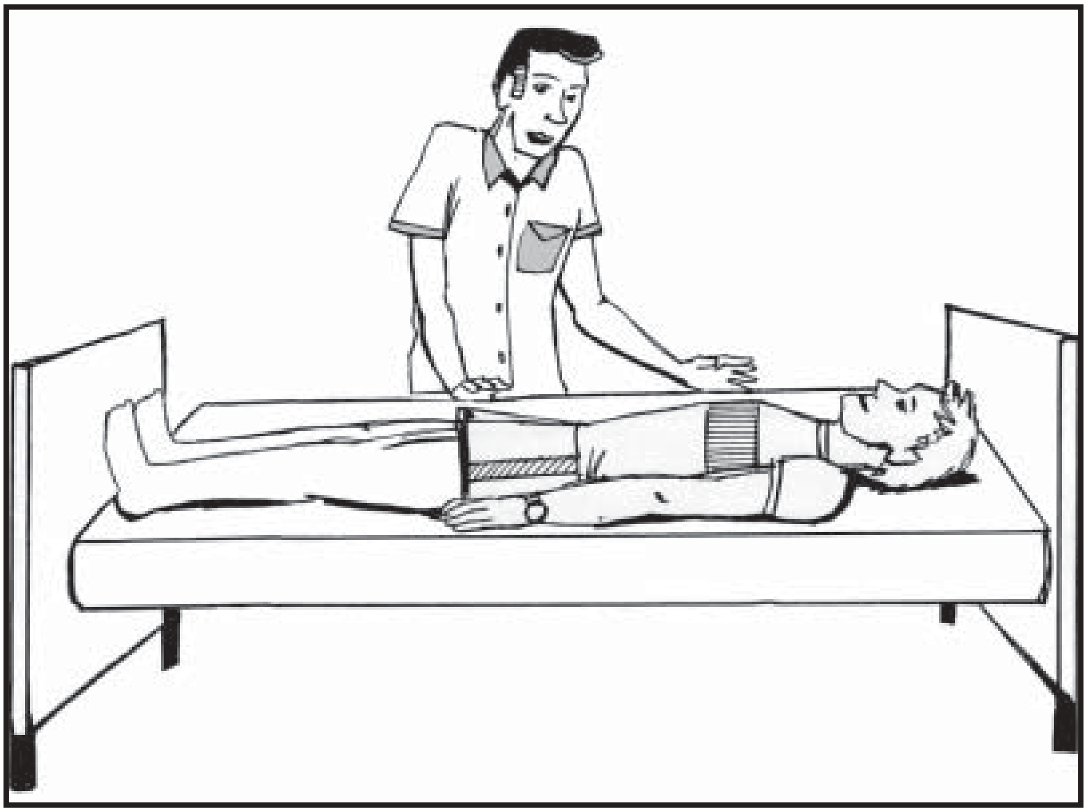


FIGURE 1-1 Proper supine position. The person is lying flat on his back in bed without a pillow under his head. His heels are together and his arms are at his sides. He is positioned close to the assistant with space around his head and feet.

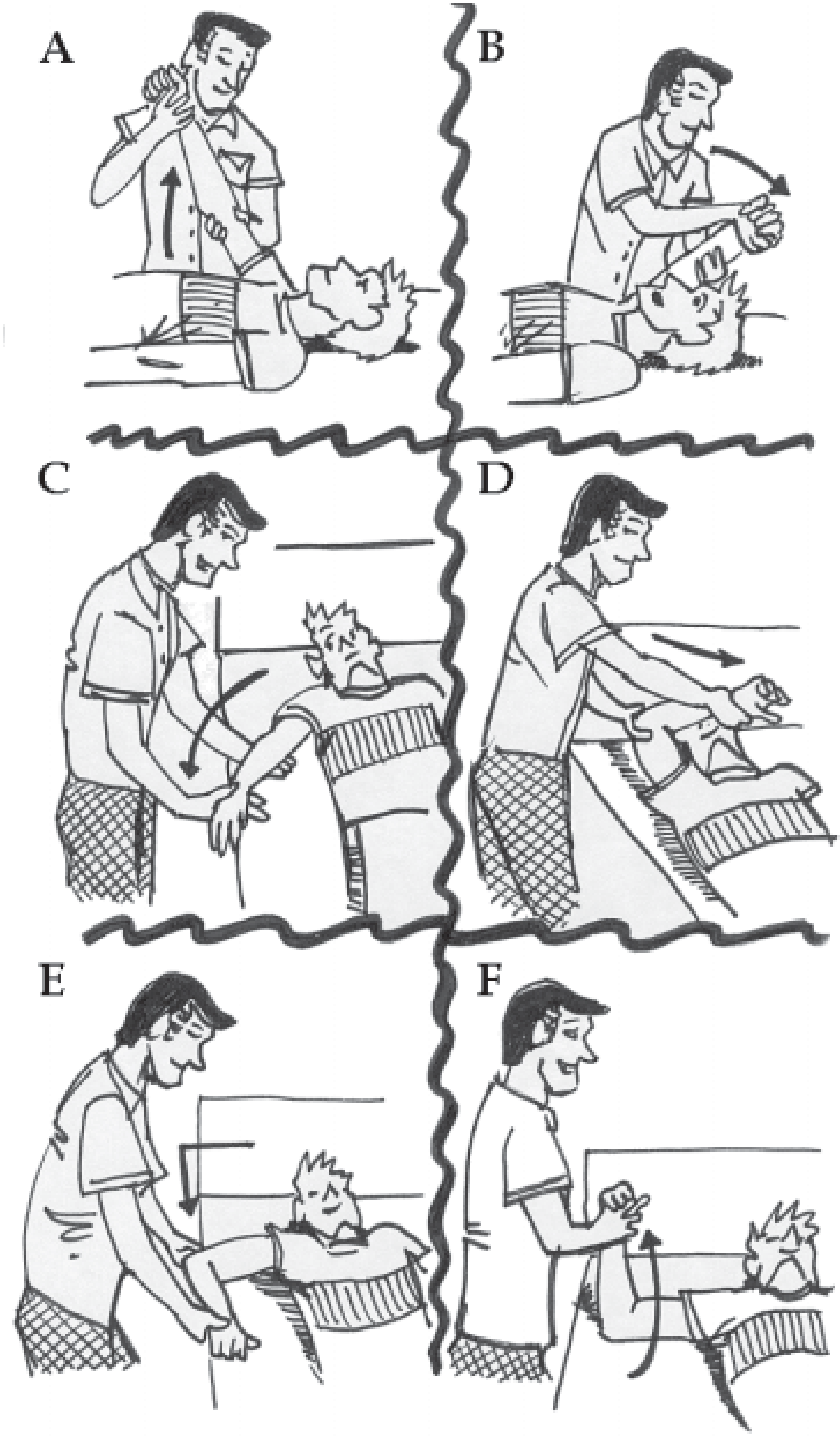


FIGURE 1-2 Shoulder exercises - Supine.

A. Lift the arm forward, reaching toward the ceiling.

B. Continue toward the head of the bed until tightness or pain occurs. Then return the arm to the person's side.

C. Bring the arm out to the side, turn palm up and then continue toward the person's head.

D. Bend his elbow to avoid the headboard. One hand may be needed on the person's shoulder to prevent it from "hiking" up toward his ear.

E. Take the arm out to the side at shoulder level and bend the elbow, so that the forearm is at a right angle to the mattress. Keeping this position, bring the forearm down so that the palm touches the bed.

F. Then bring the forearm up, so that the back of the hand touches the bed.

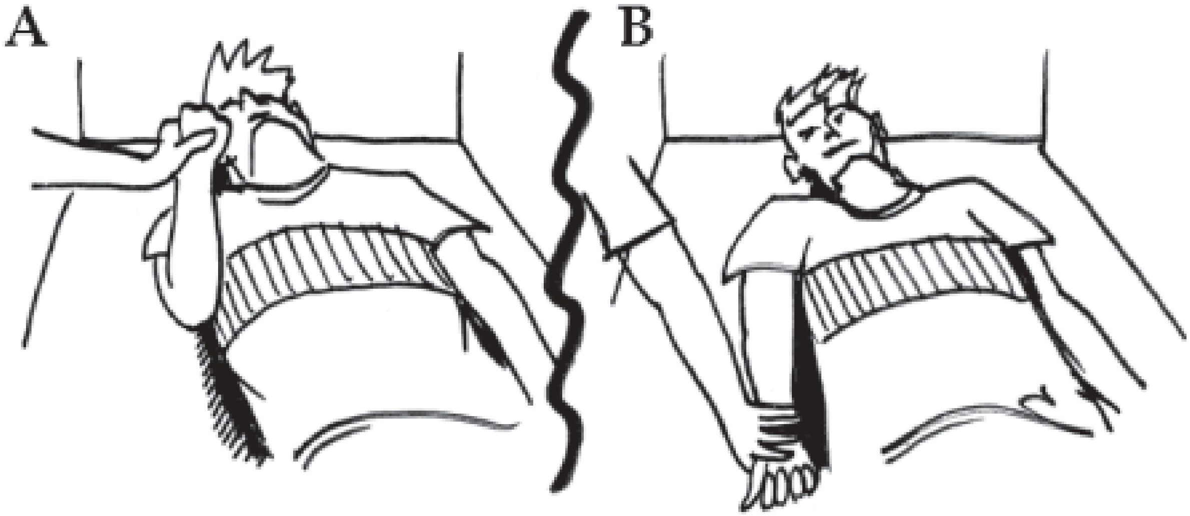


FIGURE 1-3 Elbow exercises - Supine. A. Bend the elbow, bringing the fingers toward the shoulder. B. Then, straighten the elbow.

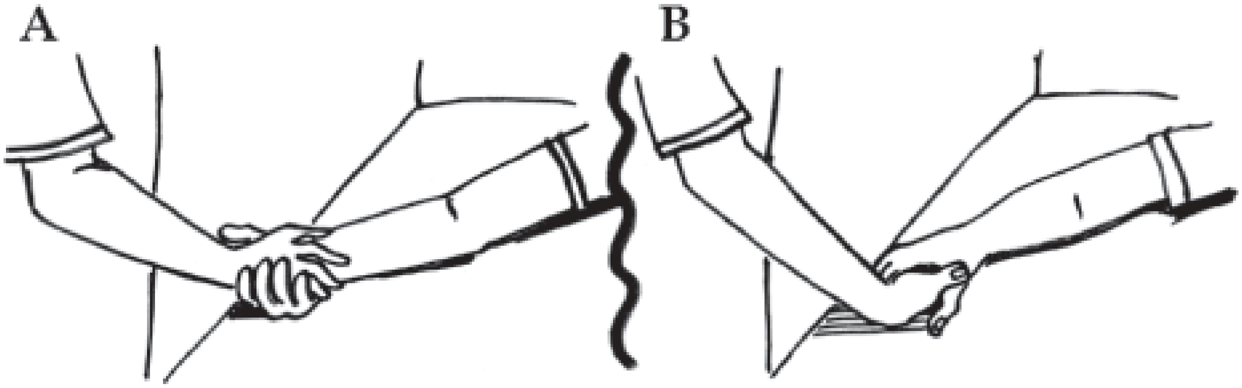


FIGURE 1-4 Forearm motions - Supine. Grasp the person's hand (as if to shake hands), support his wrist and turn his palm (A) up and (B) down. Hold elbow so motion takes place in the forearm, not the shoulder.

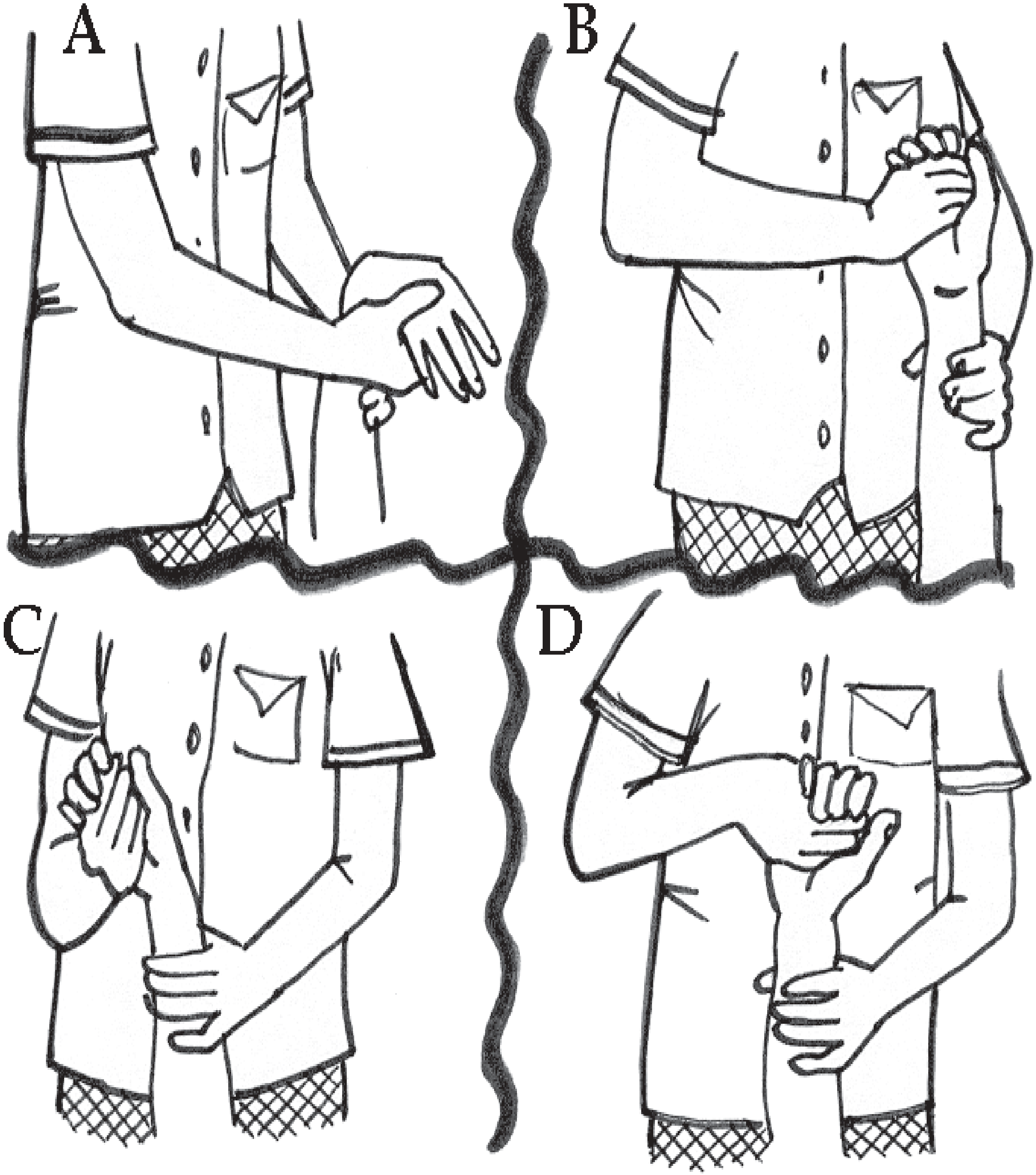


FIGURE 1-5 Wrist exercises - Supine.
(A) Bend the wrist forward. Straighten it, and then
(B) bend it backward. Support the wrist and move the hand toward
(C) the little finger side and
(D) the thumb side. Motion toward the little finger can be omitted if this is the position the wrist assumes when relaxed.

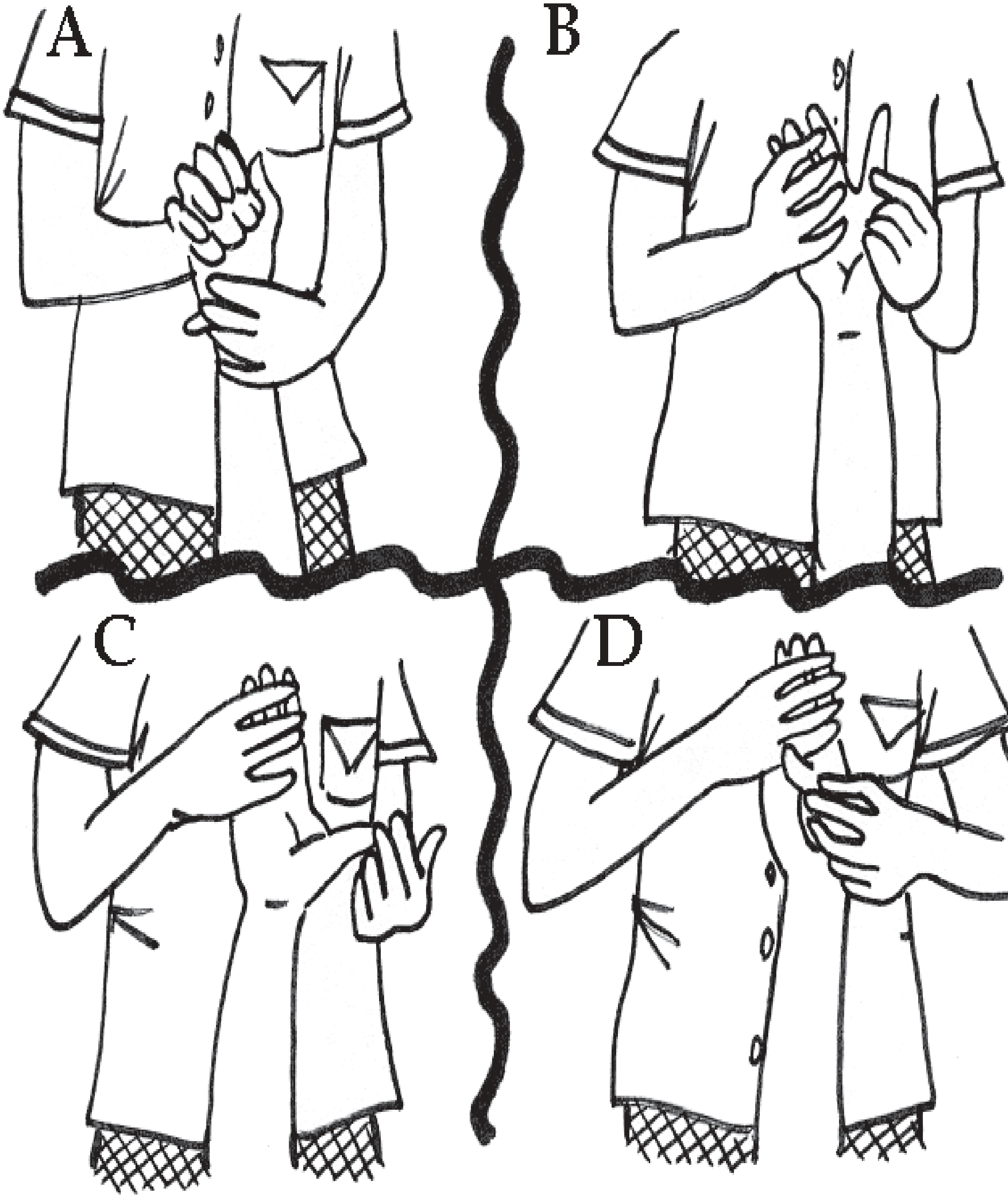


FIGURE 1-6 Exercises of fingers and thumb - Supine.

A. Bend and straighten the thumb and fingers at all joints. The wrist must be supported in a neutral position or bent backward to accomplish this motion. For the hemiplegic hand, extension is the most important motion.

B. Move the thumb and finger, in turn, away from the adjacent finger and then back. Bring the thumb (C) outward in a circling motion (D) around toward the little finger.

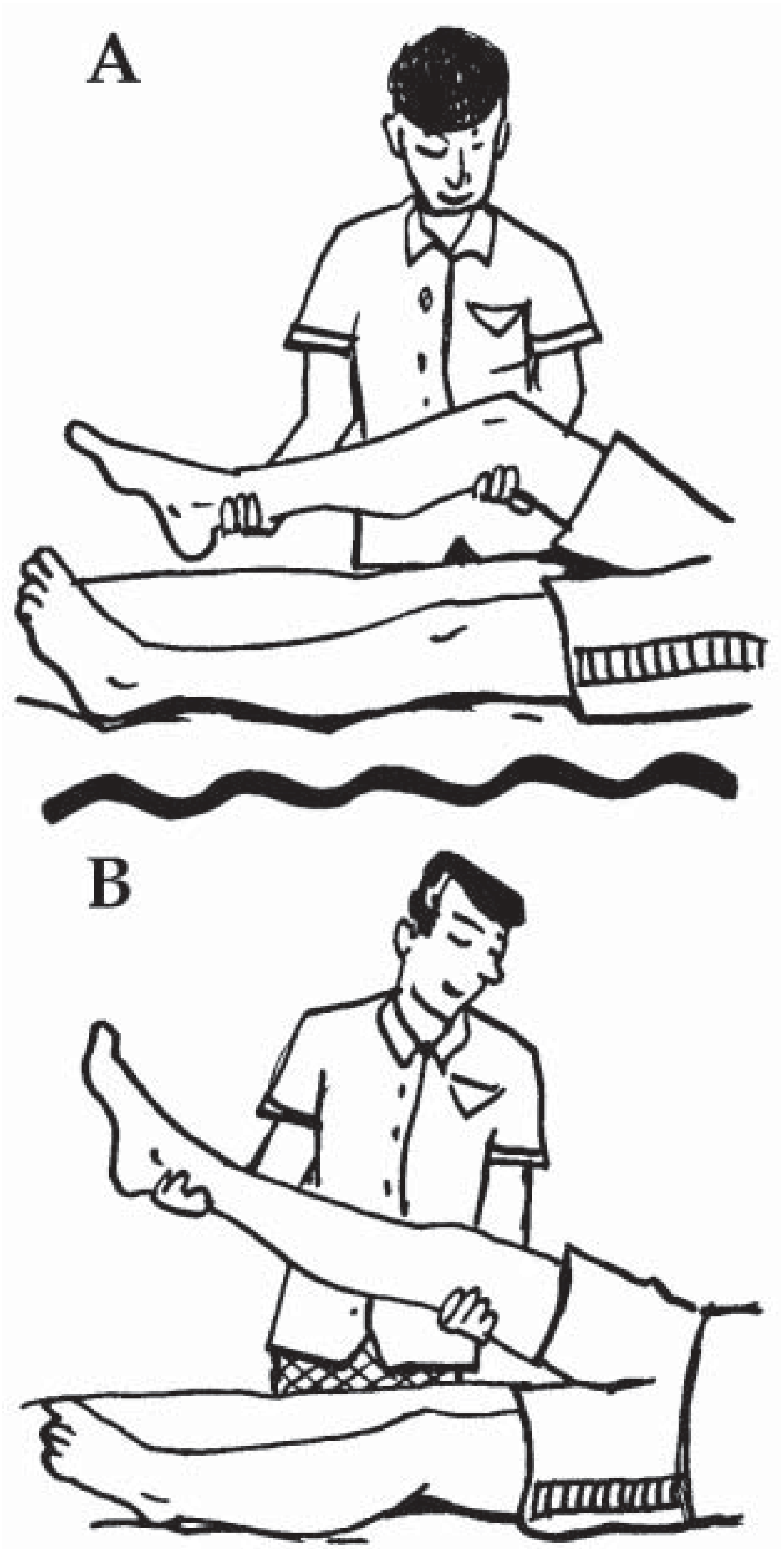


FIGURE 1-7 Knee exercises - Supine. (A) Bend the hip, and then (B) bend and straighten the knee.

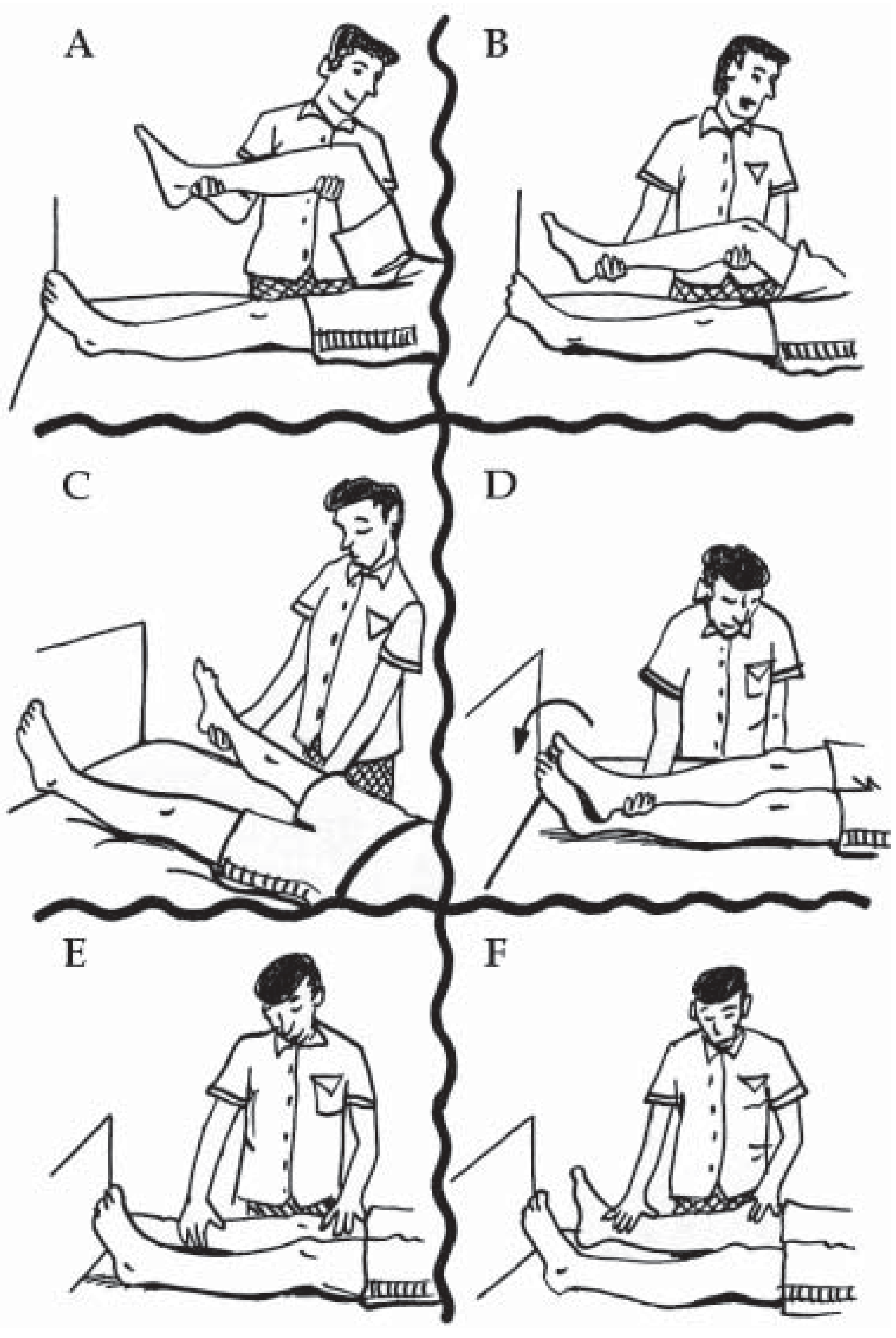


FIGURE 1-8 Hip exercises - Supine. (A) Bend the knee and raise it toward the chin. (B) Lower the leg. (C) Take the leg out to the side. (D) Return leg, continuing across the opposite leg. Caution: Do not cause pain. Keep the leg close to the bed, but avoid dragging or scraping the leg on the bedding. (E) Roll the leg inward. (F) Roll the leg outward. The outward motion may not be needed since the leg usually assumes the position when the person is supine.

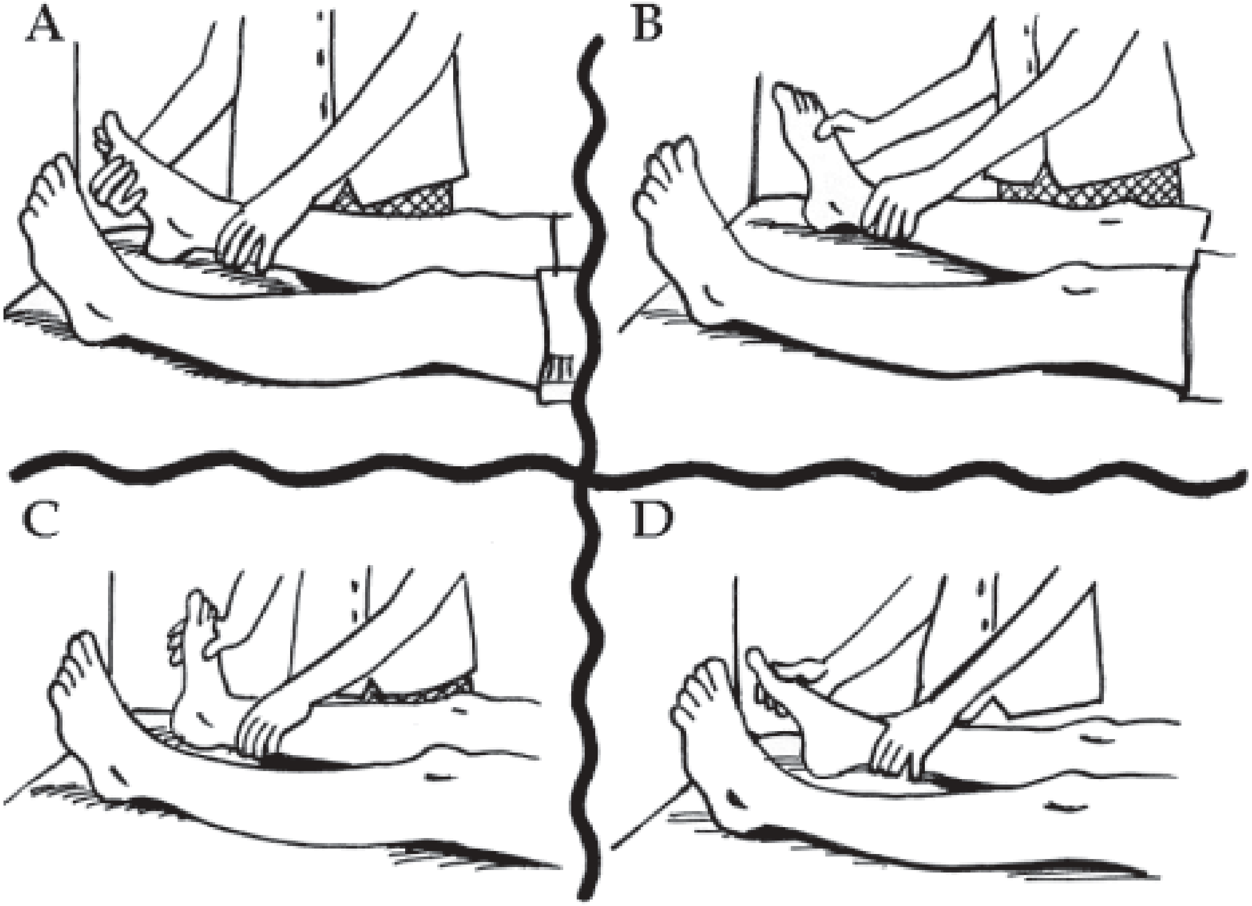


FIGURE 1-9 Ankle exercises - Supine. Turn the foot toward (A) the inside (big toe side) and (B) the outside (little toe side). (C) Bend the foot back toward the leg (upward). Caution: do not force. Being able to achieve a right angle of the ankle joint is sufficient for standing; slightly more range is needed for walking. (D) Usually it is not necessary to bend the foot down (foot drop), since the force of gravity and the weight of bedclothes encourage this position.

FIGURE 1-10 Toe motions - Supine. Bend (curl) and straighten the toes.

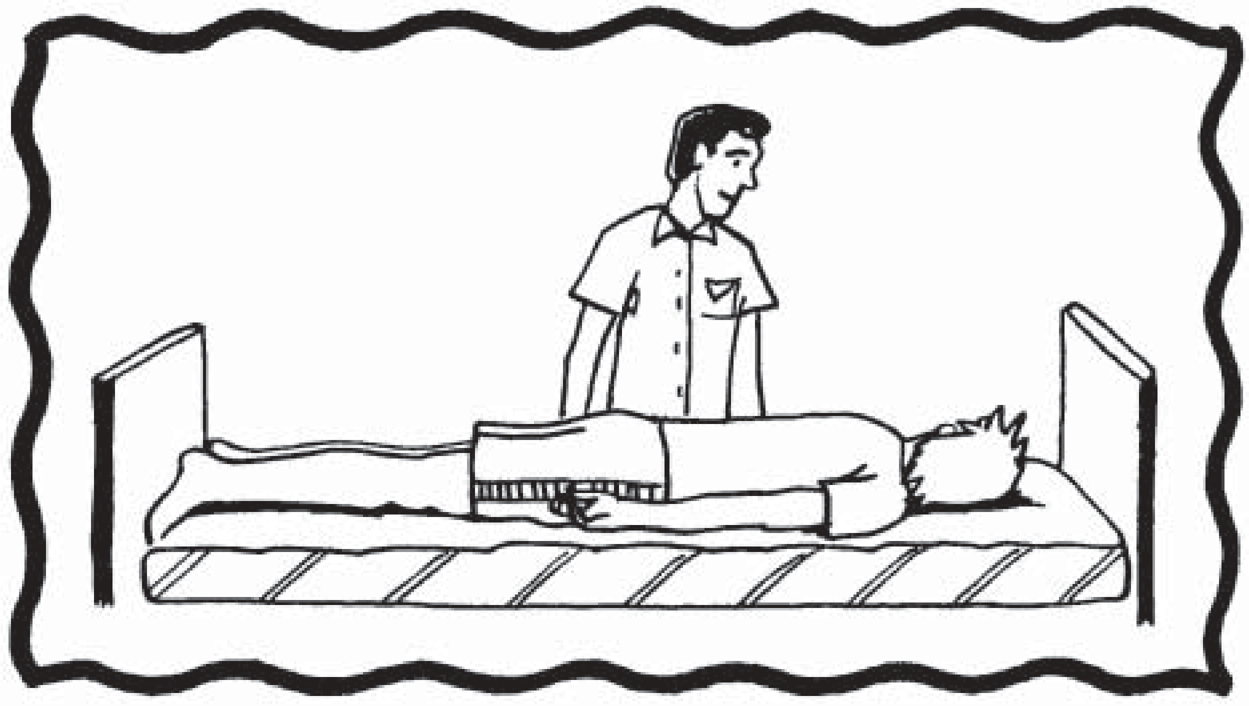


FIGURE 1-11 Proper prone position. When the person is lying prone, his toes should be over the edge of the mattress. If this is impossible, small rolls should be placed under his ankles to prevent pressure on the toes and feet. If necessitated by medical or surgical restrictions, some of the prone exercises can be done in a lateral (side-laying) position. A convenient time is when the person is being moved from his back for positioning on his side. During the exercises, the person lies on his side with the under-knee slightly bent toward the chest for balance. Additional support such as pillows and rolls may be needed.

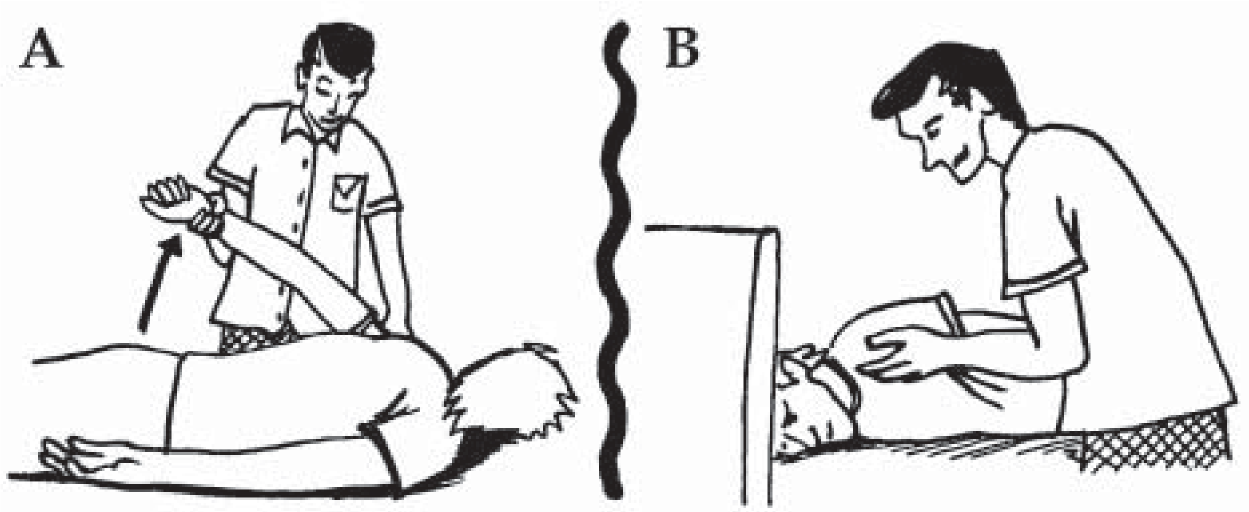


FIGURE 1-12 Shoulder exercises - Prone. (A) Bring the arm straight back. (B) With the arm at the side, lift the shoulder off the bed, as if to bring the shoulder blades together.

FIGURE 1-13 Hip exercises - Prone. Raise the leg. Hand pressure may be needed on the buttocks to prevent the hip from lifting off the bed. This exercise helps to achieve optimal hip mobility.

FIGURE 1-14 Knee exercises - Prone. Bend the knee, taking the heel toward the buttocks. Caution: Do not push beyond the point of resistance.

NOTES

Chapter 12

One, Two, Three ... Lift

Transfers

Preparing for Transfers

Moving your employer from one surface to another may involve a considerable amount of lifting and other muscular effort. If the transfer requires more than one person, everyone needs to work together so the transfer is smooth and safe. Because each person with a disability transfers differently, discuss which method of transferring the individual prefers. Before doing the transfer, you should ask your employer these questions:

1. Can you bear any weight? Where? How much? Does this ever change?
2. How have you done transfers in the past?
3. Where is it safe for me to hold on to you? (A helpful place to hold that does not cause pain).

How to Do a Transfer

- Begin the transfer when everyone is ready to move.
- Have everything ready so the person can be moved safely and comfortably.
- Place the wheelchair next to the transferring surface. Remove the wheelchair parts that may be in the way such as the removable armrests and footrests. Make sure the wheelchair is locked.
- Assist the person in moving close to the edge of the bed or chair (but not so close that he/she could slip off).
- Make the transfer quickly and smoothly but do not rush.
- When turning the person, move your feet to turn. Do not twist your body.
- When lowering the person to a sitting position, bend at the knees and lower yourself at the same time.
- Know your limits and do not try to do more than you are able to do.
- Always remember safety and good body mechanics.

PLEASE NOTE: When possible, transfer from a higher surface. For example, if your employer has an electric bed, raise the bed when doing a bed-to-chair transfer. Lower the bed when doing a chair-to-bed transfer. Also, wear a back support brace when possible.

Pivot Transfers

There are several ways to assist in transfers, with or without adaptive equipment. The easiest, fastest, and safest method is probably the pivot technique.

- Place the wheelchair next to the bed. Make sure the brakes are locked.
- Bring your employer to a sitting position on the edge of the bed with the feet flat on the floor.
- Stand in front and brace your knees against your employers knees. Remember to push your backside out and up. Place your feet on the outside of your employer's feet.
- Pull your employer as close to you as possible; stand up, pulling him or her up as you stand.
- Once your employer is in a standing position, pivot around to the chair and gently lower to a sitting position. You should bend at the knees and lower yourself also, keeping your back straight.

Your knees should be bent and your back straight, otherwise you will be using your back muscles and could injure your back.

Road Trips

Some people who use wheelchairs can be transferred into a regular automobile seat. When preparing to do this transfer, first park the car AWAY from the curb. To prevent from straining your back muscles during this transfer, place the wheelchair as close as possible to the car. Be sure to lock the brakes on the wheelchair when transferring into or out of the vehicle. Usually, it is best to place the individual in the seat next to the driver. If the person does not have adequate balance, someone may need to sit next to him / her. Be sure to adjust the seat belt properly. Be very cautious when starting and stopping to avoid unnecessary jerks.

Postural Hypotension

Postural hypotension is a sudden drop in blood pressure when changing positions. It occurs if the circulatory system has been affected by prolonged bed rest due to illness, injury or surgery, and possibly after a night's sleep.

Postural hypotension occurs when the blood vessels cannot respond to position changes as well as they did before. An example of this is when veins and arteries cannot contract and relax to govern the amount of blood supplied to the body. The blood supply begins to pool in the stomach area, and blood flow to the other areas of the body occurs at a slower rate.

Signs of Postural Hypotension

- dizziness, lightheadedness or fainting
- nausea
- sweating
- drop in blood pressure (of about 20 points)
- weak and / or rapid pulse

Although this condition often subsides after the person becomes used to getting out of the bed, it is important to understand how to completely stop or decrease the chances of postural hypotension from happening.

Moving slowly when changing positions gives the body time to adjust. If a person does get up too quickly and the blood pressure drops, you can tilt him / her into a prone position, then slowly help him / her back up. Elevating the head of the bed before transferring someone into a chair also gives the body time to adjust. A physician may prescribe elastic stockings to support veins in the legs or an abdominal binder to lend support to the arteries in the stomach to aid the body in adjusting to a change in position.

Oh, My Achin' Back

Back Safety and Body Mechanics

Remembering not to strain or stress your back muscles in any way will help to avoid injury, accidents, and even job loss.

There are quite a few things to remember when lifting objects or lifting and transferring your employer. The first and most important thing to remember is to NEVER use your back to lift anything. Your leg muscles are much more powerful than your back and spinal muscles. Using your back to lift can wrench your vertebrae out of alignment and offset your center of balance. Lifting correctly allows your spinal muscles to share the burden of weight.

- Make sure your footing is firm and you have a clear path of travel.

- Always lift and lower persons or objects by bending at the knees and thrusting the hips out. Raise and lower heavy objects by bending and then straightening the knees and hips.

- Always keep your body in direct alignment with your spine; feet, head and torso should be facing forward at all times.

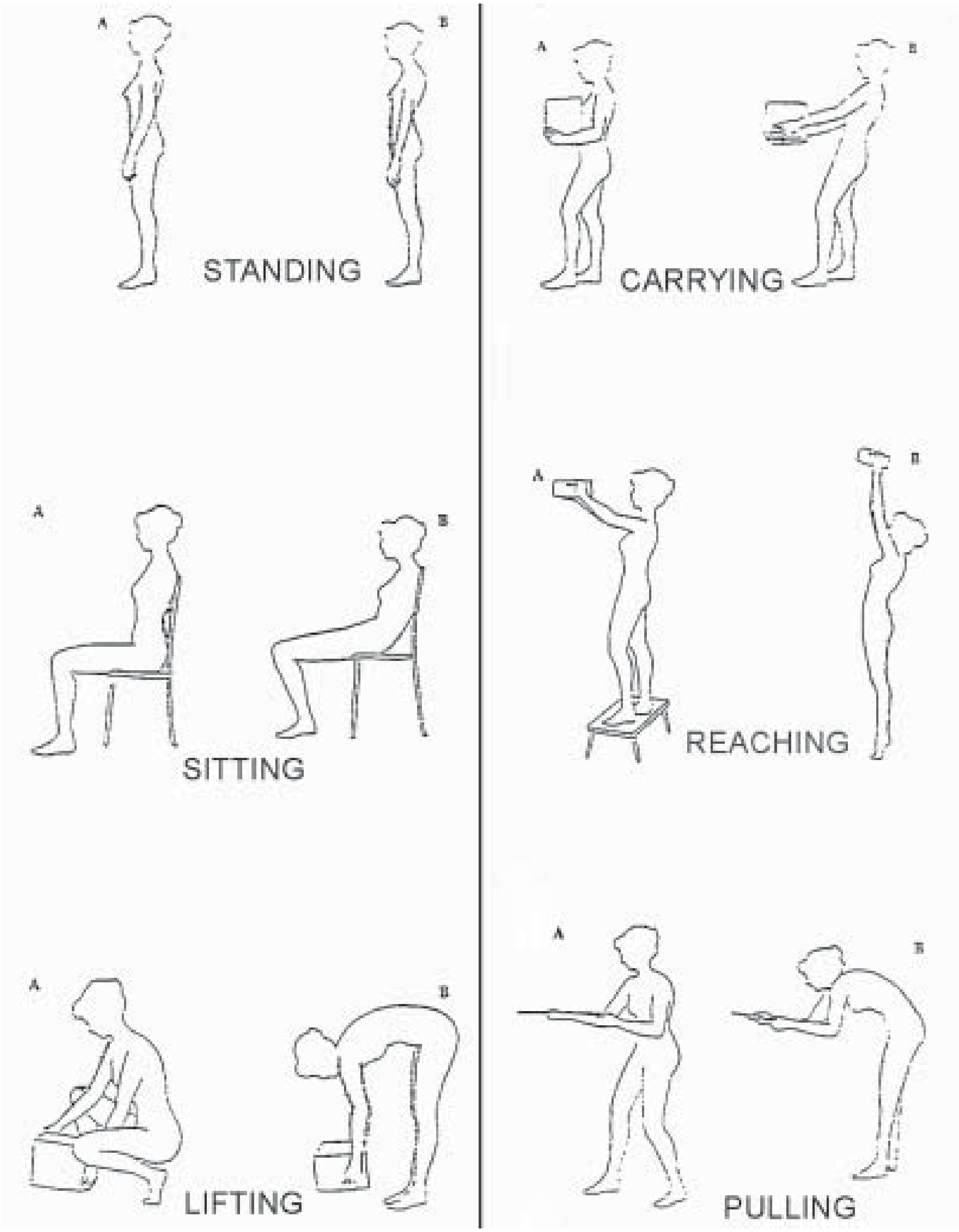
- Never rotate your spine during a transfer without moving the rest of your body. Moving the entire body at once disperses the weight among many muscles. Twisting can overload your spine and lead to serious injury. Move your feet instead.

- Allow yourself enough room in which to move.

- Holding things close to you gives you more body strength behind the lift, rather than relying on the strength of your limbs. Avoid reaching or pulling from a long distance, which gives you less muscle strength.

Posturing

Good **Bad** **Good** **Bad**



- The spine is straight.
- The head is normally aligned with the trunk and spine.
- The feet are facing the same direction as the whole body and rest flat on the floor.
- The knees are relaxed and bent slightly to absorb impact. Locked knees cut off blood flow and put a strain on the muscles and tendons.
- The chin is pointing out and head is up and facing forward.

Tools of the Trade

The Hoyer Lift

Here are some of the basic techniques when using a Hoyer Lift for transfers.

- The Hoyer may leak oil. Check for oil on the floor before proceeding.
- Position chair, brakes locked, beside the bed.
- Roll the Hoyer to the bed. Try to transfer toward the person's stronger side, if possible.
- Separate the legs of the lift.
- Roll the person onto the sling. To accommodate different disabilities, slings come in various types and sizes. Some are one-piece, some are two-piece, and each user will have his / her own system of using slings.
- Roll the lift under the bed, making sure the base of the lift is directly under the person to be lifted. If you do not, the lift will turn over when you try to hoist the person up from the side.
- Hook the chains to the top and bottom holes of the sling, making sure the hooks are facing away from the body.
- Pump the handle to raise the lift.
- Roll the person onto his / her side. Swing him / her around gently so that the legs are straddling the main post of the Hoyer.

- Always remember to give some kind of notice (such as a 1-2-3 count) before moving anyone. This prepares a person for the move or allows him / her to know when to assist you if they are able.

- Make sure you have a clear path before attempting the transfer.

- Roll the lift to the point of transfer and center the person over the chair or surface.

- When transferring, make sure your movements aren't jerky. Roll the lift gently across the floor.

- Drop the Hoyer gradually, slowly lowering the person into the chair.

- While moving, always be aware of the person’s positioning. You can push the knees back toward the chair, or use a side-to-side rocking motion to get him / her into the correct position.

- Drop the Hoyer back to the lowest position and unhook the chains.

- Make sure the person is comfortable before continuing.

Slide/Transfer Board

Slide boards, often called transfer boards, are an easy way to transfer a person to or from a wheelchair, tub, or car by making a bridge between the two surfaces.

- Try to transfer a person toward his / her stronger side if possible.

- Take the footrest and armrest off the side of the chair from which you’re transferring. Position the chair with the front wheel as near as possible to the point of transfer.

- Pull the person to the edge of the bed with the feet resting on the floor. When you are lifting, make sure that you grasp a joint area from the underside. Never grasp incisions or pressure points.

- Put a gait-belt securely around your employer’s waist if one is available. If he / she is unclothed, make sure a sheet or some other material will be between him / her and the board to aid in sliding across the board.

- Make sure the board is stable and that it won't slide to one side or the other or tip over. Place the transfer board under the mid-thigh section at an angle of about 45 degrees.

- Brace the person by clamping your knees outside of his / hers.

- With the person close to you, pull by placing your hands under the sheet near the hip area if a belt is not available. Remember to go as slowly as you need to for safety's sake.

- Make sure the person is comfortable before continuing.

The Gait Belt

The gait belt can be used to pull someone across a transfer board, but its main function is to aid in ambulation.

- Always make sure there is some sort of material between the skin and the belt. Fasten the gait-belt at the waist level, making sure it is snug enough not to crawl or slide. It is better to position the buckle in front in case the person sits down and the belt needs to be removed.

- Place your hands under the belt, holding it firmly as the person walks. Be prepared, in case the person falls, not to yank back on the belt with your back. Alternatively, you can bend one knee into a kneeling position while firmly pulling back on the belt to soften the blow of the fall.

Just Lyin' Around

Bed Mobility

It is very important to reposition someone who sits or lies for many hours at a time to allow the skin to breathe, to stimulate circulation, and to distribute weight to different areas of the body. Someone who is sitting may be able to reposition himself / herself, but if this is not possible, you need to assist him / her in changing positions every so often. Sitting or lying in one position without a change can cause many problems, such as pressure sores, which can lead to lengthy hospitalization or even death.

Always remember to bend your knees and hips rather than the back, and get a wide base of support by standing with feet slightly apart with one foot forward.

Using a Drawsheet

- Cross the person's arms over the trunk.

- Gently roll the person onto one side.You can have the person hold on to the bed rail for stability when possible.

- Fold a sheet in half long-ways, placing it the length of the person from knee to shoulder. Get it as close to the person as possible, tucking it underneath the body a little.

- Roll him/her from one side to a prone position and then onto the other side.

- Pull the sheet taut across the rest of the bed.

- Now you can return the person to a prone position, and he/she can be moved just about anywhere. Remember that when you pull, you should transfer the weight from the front to the back foot instead of bending backward.

Moving Without a Drawsheet

If you are not able to use a drawsheet, remember to lift the person before moving him/her anywhere. Dragging bare skin across material causes irritation and will probably shear the skin.

Moving to One Side

- Move the person's legs first. If possible, move the hips over a little.

- If the bed isn't too wide, you may stand on the side to which you will move the individual.

- Place one hand under the waist and the other at the elbow farthest from you.

- If possible, the person should lift his or her head off the bed during the move.

- Lift and gently pull the torso and shoulders toward you. Don't arch your back, but rather transfer the weight from the forward foot to the back foot, keeping your back straight.

- Make sure the person is comfortable before continuing.

Turning

- When turning someone, it is easier and safer to pull toward you than to push away from you. It is also necessary to pull from the center of gravity (waist) or from the thickest joint of the extremities.

- Always pull from the bottom side of the limb or the back of the torso. Pulling near incisions or pressure points can cause injury.

Turning Onto One Side

- Make sure the person's toes won't be bumped or scraped on the foot of the bed during the move.

- Put a pillow beside the head for support during the turn. Place it on the side toward which you are turning the person. Also, place a pillow beside the legs to support them during the turn.

- Take the arm nearest the side you are turning to and pull it away from the body to ensure it doesn't get trapped under or behind the trunk. You can bend the arm and place the hand behind the head for neck support.

- Bend the far knee and pull it toward you to a position over the other knee.

Turning to a Prone Position

- The most important thing to remember when someone is lying in the prone position is to make sure that pressure isn't being applied to any part of the body; for example, the hip bones, ankles, etc. Use pillows, towels or rolls liberally to make sure weight is distributed evenly.

- Again, make sure the person's feet aren't going to bump the footboard during the move. Also, make sure that the feet are positioned so that the toes don't get caught between the footboard and the mattress. You can ensure this by using a prop under the heels as the body turns.

- Take the arm nearest the side you are turning to and tuck it under the hip. The far arm crosses the torso.

- Bend your employer's knee of the far leg and cross it over the other leg; prop both on a pillow so they will be supported during the turn.

- Begin turning to the side and keep turning until he / she is lying on the stomach.

- Cushion any area that may bear pressure.

Just Sittin' Around

Positioning

Proper seating in the wheelchair can prevent many problems, such as pressure sores and autonomic dysreflexia, and provides comfort throughout the day.

Proper seating is as follows:

- Feet are flat on the footrests, pointing in the same direction as the knees, and the elbows rest on the armrests.

- Knees face forward.

- Bony places are cushioned.

- Thighs run parallel to seat.

- Allow at least a three-inch space between the seat and the back of the knees to prevent rubbing.

- Allow at least a one-half inch space between sides of the chair and hips.

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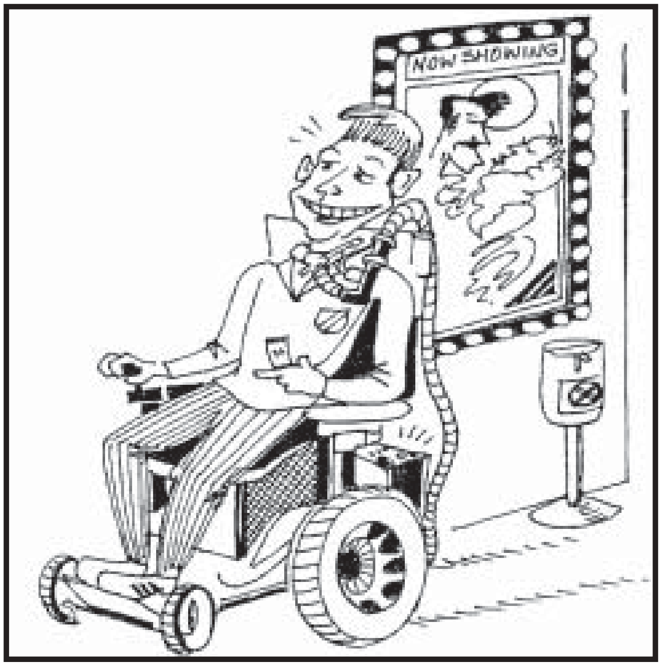
Chapter 13



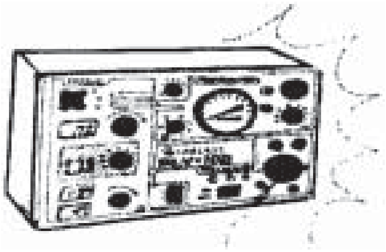
Breathing Easy

Ventilator Management

The breathing muscles are supplied by nerves that emerge from the spinal cord in various locations, from the cervical through the lumbar levels. The spinal respiratory center is located primarily at the C4 level of the cord but receives some innervation from C3 and C5. The higher the injury is on the spinal cord, the more an individual will require permanent respiratory support. Therefore, a person who has a complete, high-level cord lesion, C3 or above, will be on a ventilator. Someone who has an injury between C3 and C5 may be on a ventilator, and an individual with a C5 has a good chance of living without a ventilator.

During the acute-care phase immediately following injury, many people with cervical injuries and even some with high thoracic injuries use a ventilator at some point. Some need ventilator support only for a short time, while others require it on a long-term basis. Unfortunately, the only way to determine if a person will be able to stop using a ventilator is to simply wait and see what happens. Making the transition to independent breathing can take several months, and often there are setbacks during that period.

Mechanical Ventilation



The mechanical ventilator or respirator is one of the most important developments of modern medicine. Mechanical ventilators are pumping devices that take over the job of breathing when people with spinal cord injuries or other disabilities are too injured or ill to breathe efficiently on their own.

Today most ventilators are controlled by computers. A person's response to ventilation can be determined by a physical assessment and analyzing wave forms appearing on the computer screen. The pressure and timing of the flow of air to the lungs can be regulated as needed. If the lungs themselves are not damaged, the ventilator may deliver air to the lungs. But in most situations, the air is mixed with pure oxygen. The air can be humidified and sometimes medication can be administered through an attachment to the ventilator.

Types of Ventilators

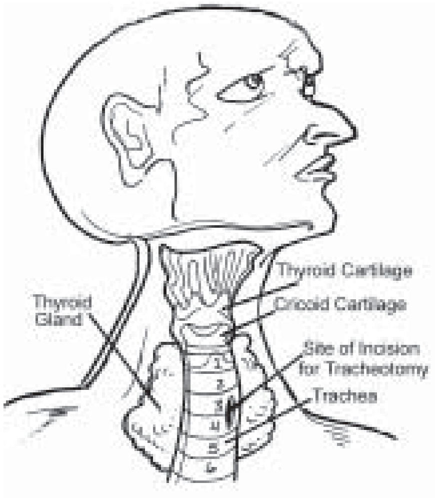
- Negative pressure ventilators, such as the well-known iron lung, create a vacuum around the outside of the chest, causing the chest to expand and suck air into the lungs.

- Positive pressure ventilators, which have been available since the 1940s, work on the opposite principle, pushing air into the lungs. Until the last five to 10 years, if you had a positive pressure ventilator, that meant you had a tracheostomy hole in the throat with a small plastic tube to which a ventilator can be attached.

- Now, however, a small face mask can be used over the nose and / or the mouth for positive pressure ventilation. Some ventilators use a cone-shaped device that is held over the nose with straps; others use a small mask that covers the lower part of the face. For people who need breathing assistance only part of the time, such non-invasive means offer a way to avoid the complications associated with tracheostomies.

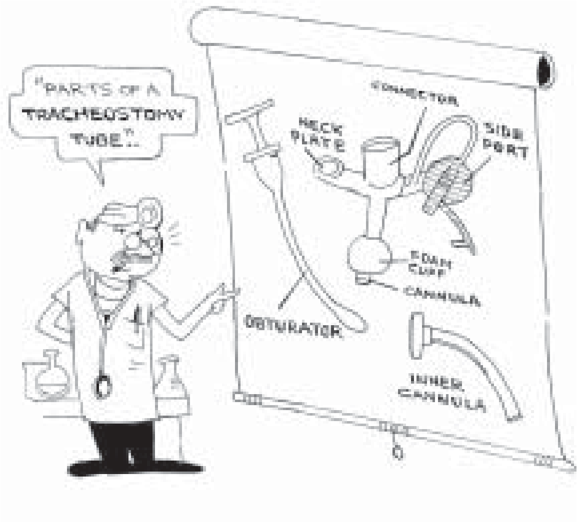
Most people who use a ventilator part of the time do so at night. They may be able to breathe but are unable to take large breaths. Over time, this can cause the lungs to partially collapse (a process called atelectasis) and allow secretions to build up, which can lead to pneumonia. This condition can be avoided by using a ventilator nightly.

What is a Tracheostomy?



A tracheotomy is an incision into the trachea to form a temporary or permanent opening which is called a tracheostomy or “trach.” The opening or hole is called a stoma. The incision is made through the second, third, forth, or fifth tracheal ring and a tube is inserted through the opening to allow the passage of air and the removal of secretions. This tube is fastened and connected to a ventilator, or possibly just an oxygen mask if the person can breathe independently.

Types of Tracheostomy Tubes



A tracheostomy tube is a curved tube that is inserted into a tracheostomy stoma. There are several different types of tubes, but all have similar parts. The main parts of a tracheostomy tube are the outer tube, the inner tube (or cannula), and the obturator. The obturator is only used to insert the outer tube and is removed once the outer tube is in place. The outer tube has ties to secure around the neck. In double-cannula tubes, the inner cannula is inserted and locked in place after the obturator is removed; it acts as a removable liner for the more permanent, outer tube. The inner cannula is withdrawn for brief periods to be cleaned. Many of the smaller plastic tubes do not have an inner tube. They are called single-cannula tubes.

Tracheostomy tubes may be made of plastic, metal, or silicone. Plastic tubes are popular because they are light-weight and have less crusting of secretions. Tracheostomy tubes come in cuffed, uncuffed and fenestrated varieties. A cuff is a soft balloon around the tube near the distal end that can be inflated to hold the tube in place. The cuffs are inflated with air or foam. There are two types of cuffs. The low volume is like a balloon and a high volume is more like a barrel shape. High volume balloons spread out the pressure, while the low volume keeps the pressure centralized. Cuffed tubes are usually only used for ventilator-assisted children.

Fenestrated tubes have an opening in the tube that allows a person to speak through the upper airway when the external opening is blocked.

PLEASE NOTE: The inner cannula is simply an inner tube for double-cannula tracheostomies. It acts as a removable liner for the outer tube.

Basic Tracheostomy Management

Daily care is needed to prevent infection and skin breakdown, especially under the tracheostomy tube and ties. Your employer will tell you how many times per day to clean his\her trach.

Supplies

- Long-ended Q-tips
- Trach gauze and unfilled gauze
- Sterile water
- Hydrogen peroxide (half-strength with sterile water)
- Trach ties and scissors if ties are to be changed
- Two sterile cups or clean disposable paper cups
- Tracheostomy cleaning kit for trachs with an inner cannula

Procedure:

- Wash hands
- Open Q-tips, trach gauze, and regular gauze
- Cut trach ties to appropriate length (if also changing ties)
- Pour half-strength hydrogen peroxide into one cup and sterile water into the other
- Clean skin around the trach tube with Q-tip soaked in half- strength hydrogen peroxide (do not allow any liquid to get into trach tube)
- Rinse area with Q-tip soaked in sterile water
- Pat dry with gauze pad
- Change trach ties if needed
- Tuck pre-cut trach gauze (4x4) around and under trach tube flush to skin
- For trachs with an inner cannula, use a trach kit, remove and wash cannula in a hydrogen peroxide solution and rinse in sterile water.

Suctioning a Tracheostomy

Suctioning is done if coughing does not effectively clear the airway. The trach tube is suctioned to remove mucus from the tube and trachea for easier breathing. There may be large amounts of mucus with a new tracheostomy. This is a normal reaction to an irritant (the tube) in the airway. Frequency of suctioning will vary from person to person and will increase with respiratory tract infections. Follow your employer's requests regarding suctioning.

PLEASE NOTE: To prevent pop-offs, many individuals tie ventilator tubing to their trachs. Except when a person is being suctioned, ventilator tubing should be connected to the tracheostomy at all times. If the tubing is off for a few seconds, an alarm will sound. Don't be surprised to hear the alarm when suctioning; this is just an indicator to let you know that the ventilator tubing is off the trach.

Management Techniques

Sterile Technique: sterile catheters and sterile gloves

Modified Sterile Technique: sterile catheters and clean gloves

Clean Technique: clean catheter and clean hands

The size of the suction catheter depends on the size of the trach tube. Your employer will have catheters that best suit his/her needs.

Signs That a Person Needs Suctioning Include:

- Rattling mucus sounds from the trach
- Fast breathing
- Bubbles of mucus in trach opening
- Dry raspy breathing or a whistling noise from trach
- Signs of respiratory distress

Equipment:

- Suction machine
- Suction connecting tubing
- Suction catheters
- Normal saline
- Sterile or clean cup
- 3cc saline bullets
- Ambu bag
- Tissues
- Latex gloves

Procedure:

- Wash hands
- Set up equipment and connect suction catheter to machine tubing
- Pour normal saline into cup
- Put on gloves
- Turn on suction machine
- Place tip of catheter into saline cup to moisten and test to see that suction is working
- Squirt normal saline with bullet if needed for thick or dry secretions. Saline may also be squirted via a syringe, which is less expensive that single dose units. The recommended amount per usage is approximately 1 cc (routine use of saline is not recommended).
- Gently insert catheter into trach tube (suction only length of trach tube, pre-measured suctioning).
- Put thumb over opening in catheter to create suction.

- Use a circular motion (twirl catheter between thumb and index finger) while withdrawing the cath so that the mucus is removed well. Avoid suctioning longer than 10 seconds because of air loss through suctioning.

- Draw saline from cup through the catheter to clear it.

- For a trach tube with cuffs, it may be necessary to deflate the cuff periodically for suctioning to prevent pooled secretions above trach cuff.

- Let the person rest and breathe, then repeat suction until the catheter is clear.

- Oxygenate as your employer instructs.

- The person's mouth or nose may also be suctioned if needed after suctioning the trach, then dispose of that catheter (do not put same catheter back into trach).

- Dispose of suction catheter, saline and gloves, turn off machine.

Other Suctioning Devices

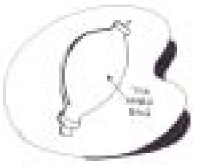
- In addition to a stationary suction machine, small portable rechargeable battery operated suction machines are available for travel. The batteries are rechargeable or the machine can be plugged into a car cigarette lighter.

- The DeLee suction trap is a small plastic suction device. The personal care attendant sucks on a tube to create a negative suction pressure. (The secretions are collected in a sputum trap and do not come in contact with the attendant.)

- Bulb syringes can be useful for removing mucus at the opening of the tube, but does not replace routine suctioning of the length of the trach tube.

- The In-Exsufflator (Cough Machine) is an alternative to traditional suctioning that is especially helpful for those with an ineffective ability to cough. The In-Exsufflator assists people in the removal of bronchial secretions from the respiratory tract. This is a new, vacuum-like, non-invasive technique that is clinically proven to be effective.

The Ambu Bag



An Ambu bag that is fitted to the tracheostomy tube size must be available at all times. This is used if your employer needs mechanical ventilation by hand.

The Downfalls of Tracheostomies

Coughing is difficult for most people with spinal cord injuries, but tracheostomy tubes make coughing almost impossible. Most of the muscles used in exhaling and in coughing, are located in the abdominal wall, and are affected even with lower thoracic injuries. Also, a tracheostomy tube partially blocks the airway, making it difficult to cough out secretions. Subsequently, ventilator users with tracheostomies must have secretions suctioned from their lungs regularly. Suctioning varies from person to person. Some require suctioning every half hour, while others need it once daily. The individual can usually tell when suctioning is needed, either by feeling secretions in the chest or hearing a change in the sound of his or her breathing.

A person with a spinal cord injury can also clear secretions through the quad cough. This is a manually assisted cough in which you push down, suddenly and repeatedly, on the upper abdomen of your employer (who is in a reclined position), helping to produce the exhalations necessary to clear the lungs.

A person must get air to the vocal cords in order to speak. Tracheostomy openings are located below the vocal cords, so the air bypasses the larynx entirely unless the tracheostomy tube is specifically designed to direct air upward during exhalation. This will permit a person to speak during regular, periodic intervals.

Because the muscles used for swallowing are located on the inside of the neck, a tracheostomy tube can interfere with swallowing and even cause the person to aspirate or inhale food into the lungs. In cases where these problems are severe, a feeding tube may be inserted through the skin into the stomach, bypassing the throat.

Infection is a major complication of tracheostomies. The tube is a foreign body in the neck, and has the potential of introducing organisms that would ordinarily be stopped by natural defense mechanisms in the nose and mouth.

What is Frog Breathing?

In the event that a ventilator fails due to power outages or other malfunctions, there is a backup breathing technique called glossopharyngeal breathing or "frog breathing." This technique involves forcing air into the trachea with the muscles of the neck, or basically swallowing air into the lungs. By using this method, a person can breathe for many hours without a ventilator.

Symptoms of Infection:

- Yellow or green secretions (may be pink tinged)
- Thicker mucus
- Increased amount of mucus
- Red inflamed skin at stoma
- Foul odor
- Elevated temperature
- Congested lung sounds
- Increased respiratory effort
- Listlessness
- Respiratory distress

Tracheostomy Complications

- Bleeding
- Possible causes of minor bleeding:
- Too frequent or vigorous suctioning
- Suction pressure that is too high
- Lack of humidity to the airway
- Trauma

If the tracheostomy is bleeding profusely, a physician should be consulted and/or a person should go directly to the emergency room. Rember, this is merely a guideline. If your employer is responsive, follow his/her instructions.

Symptoms of Respiratory Distress

- Increased respiratory rate
- Difficulty breathing, grunting, noisy breathing
- No respiration if tube has been clogged for a long time
- Whistling noise when breathing
- Pale, blue color around lips, nail beds, eyes
- Restlessness
- Sweaty clammy skin
- Retractions (sinking in of the chest)

- Frightened look
- Flared nostrils
- Change in pulse or blood pressure

PLEASE NOTE: Your employer will have his \ her procedures for responding to respiratory distress. Discuss these with him / her.

- Erosion of the trachea (rare). Innominate Artery - tracheal fistula; erosion of the artery from pressure on the tracheal wall. Hemorrhage could lead to death if not stopped.
- Tracheal stenosis - a result of scar tissue at the site of the tracheostomy tube or from excessive cuff pressure.
- Tracheoesophageal Fistula - an abnormal connection between the trachea and the esophagus resulting from pressure of the inflated tube cuff.
- Granuloma - a growth of abnormal tissue which was caused by the irritation of the tracheostomy tube in the airway.

Tracheostomy Humidification

The nose and mouth provide warmth, filtering and moisture for the air; however, the tracheostomy tube bypasses these mechanisms. Humidification must be provided to keep secretions thin and avoid mucus.

Humidity should always be delivered while sleeping. Attach the trach mask with aerosol tubing over the trach, connecting the other end to the nebulizer bottle and air compressor. Sterile water goes into the nebulizer bottle (do not over fill; note line guide).

Heated mist. This is accomplished by an electric heating rod that fits into the nebulizer bottle. Extra care should be taken to be sure that the bottle does not go dry (which could be a fire hazard). Also, more moisture will accumulate in the aerosol tubing with heated mist. Moisture that accumulates in the aerosol tubing must be removed frequently to prevent blockage of the tube and / or accidental aspiration. Disconnect tubing at the end of the tracheostomy and empty into a container and discard. Do not drain fluid into the humidifying unit. Fluid traps are helpful in preventing blockage and aspiration. These collection cups also need to be emptied frequently. Position the air compressor and tubing lower than the person to help prevent aspiration from moisture from the tubing.

Secretions can be kept thin during the day by applying a Heat Moisture Exchanger (HME) to the trach tube. A HME is a humidifying filter that fits onto the end of the trach and comes in several shapes and sizes (all fit over the standard trach tube opening). There are also HME available for portable ventilators. Bedside ventilators have built-in humidifiers. (Sterile saline drops can be squirted into the trach tube if secretions do become thick and difficult to suction.)

PLEASE NOTE: A portable ventilator is a breathing machine that allows a person who is ventilator-assisted to move from place to place while receiving the correct rate and amount of air pressure for breathing.

Room humidifiers are also helpful. However, it is vital that these machines be cleaned regularly to prevent bacterial growth. Warm mist humidifiers are even more prone to bacterial growth because bacteria, mold and mildew grow best in warm, wet, dark places. Ultrasonic humidifiers should be avoided, because they can produce white dust, which can be harmful when inhaled. The regular cool mist humidifiers are often the best choice, unless otherwise directed by the person's physician. Room humidifiers are useful, but if not carefully chosen and kept clean, they can do more harm than good.

PLEASE NOTE: The procedures detailed in this chapter are provided as a guide. However, you should always follow your employer's requests.

An organization called the International Ventilator Users Network (IVUN) exists to link ventilator users with each other and with health care professionals interested in home mechanical ventilation. The IVUN puts out a newsletter twice a year, and can be contacted at 5100 Oakland Avenue #206, St. Louis MO 63110-1406 (314-534-0475, or FAX 314-534-5070).

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Chapter 14

Protecting Yourself
While Helping Others

Safety Procedures

AIDS - Acquired Immune Deficiency Syndrome

What is HIV Infection/AIDS?

AIDS is caused by a virus known as the Human Immunodeficiency Virus, or HIV. If or when the virus enters the bloodstream, the individual may become infected. There are no symptoms and only a special blood test will reveal if a person is HIV-positive. A person may be infected for a few months or up to 10 years before any symptoms appear. If proper precautions are not taken, a person who is HIV-positive can spread the virus to others.

How is the Virus Transmitted?

HIV/AIDS is transmitted through body fluids such as blood, semen, and vaginal secretions. This is a sexually transmitted disease and is passed on by an HIV-infected partner. AIDS can also be transmitted through contaminated hypodermic needles, which is why intravenous drug users are at high risk.

The more sexual partners one has, the higher the risk of contracting the virus. If a person is HIV-positive and remains sexually active without taking precautions, he or she will keep being reinfected with the AIDS virus and could give it to others.

There is no risk of non-sexual infection in everyday situations. There is no known transmission by sharing food, eating utensils, toothbrushes, or even by kissing.

Protecting Yourself From Infection

Protection is only common sense and is suggested in all situations, because people may not know that they have the virus. To protect yourself from contracting AIDS, follow these precautions:

- Always wear latex gloves when coming in contact with blood or other body fluids, mucous membranes, or broken skin. Wash your hands immediately after removing the gloves.

- If your hands and other skin surfaces come in contact with blood or other body fluids, wash them vigorously with an antibacterial soap.

- Linens or clothing soiled with blood or body secretions should be washed in hot water with detergent and 1 cup of bleach.

- Surfaces contaminated with blood or body fluids should be cleaned with a disinfectant or a mixture of one part bleach and 9 parts water (mix 1 cup bleach with 9 cups water).

- Tissues, Band-Aids, and dressings should be discarded in a double bagging manner. Place in a leakproof garbage bag and then place in a second leakproof garbage bag.

- Needles and sharp items should be disposed of in containers which cannot be punctured such as a Sharps container or an empty detergent bottle with a cap.

Giving First Aid or CPR on the Job

First Aid and CPR courses are recommended. Contact the Red Cross and American Heart Association for further information.

The skin is a natural protective shield against viruses, including HIV, bacteria, and other germs. If the skin is broken by a cut or a sore, germs can enter the body.

Remember . . .

- Avoid direct contact with blood when practicing First Aid or CPR.

- Use a barrier such as a clean cloth, or wear disposable latex or vinyl gloves to protect yourself from any blood.

- Wash your hands with antibacterial soap and water as soon as you can after giving First Aid, whether or not you have worn gloves.

- Sterilize any items that might cause your employer to bleed, such as needles, razors, cuticle scissors, or tweezers. If you have an open sore or broken skin, wear your gloves until this has healed. This is especially important if you have sensitive skin.

- Do not touch fever blisters or cold sores (herpes simplex) around your nose or mouth; they could be transmitted to your employer.

The Lift Gone Wrong or the Fall Gone Right

If you are lifting your employer and the floor comes before the wheelchair, don't panic. If your employer is conscious and alert, ask how you can help. Follow the person's instructions if you are physically able to do so. If you cannot lift the individual from the floor to the wheelchair by yourself, suggest that you get help from a family member, a neighbor, a friend, or 911. If the person is unresponsive, call 911 immediately.

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Conclusion

It is our wish that the contents of this manual have provided you with a broader understanding of personal care for people with spinal cord injuries. Remember, the care that you are giving is “personal.” Though this manual has given many instructions and “how-to’s,” keep in mind that each of your employers is a unique individual with vastly different needs and wants. Your employers know their needs best and therefore should direct their plan of care. They have every right to be the ones “who call the shots.”

As a personal care attendant, follow the independent living philosophy. Respect your employers’ choices, allow them to control their own lives, and to experience the success or failure that accompanies change. Don’t be their caretakers; be their caregivers.

We hope that you enjoy your work as an attendant. Your service is very important. Thank you for helping people with disabilities to achieve their independence.

Most sincerely,

The Board and Staff of Services for Independent Living

SIL

Appendix A

Paraplegia. Loss of function below the cervical spinal segments while the upper body usually retains most of its function and sensation.

Autonomic dysreflexia. A potentally dangerous reaction including high blood pressure, sweating, chills, and/or headache, which may occur in persons with spinal cord injury above the fifth thoracic level.

Quadraplegia. Loss of function of any cervical spinal cord segment, affecting both arms and both legs. This term is currently being phased out and replaced with the term "tetraplegia."

What Does That Mean?

Glossary of Terms

Glossary of Terms

Accessible. A removal of barriers, both attitudinal and physical, for people with disabilities.

Acute. Critical; a sudden onset, sharp rise, and short course.

ADL. Activities of daily living: eating, dressing, grooming, etc.

Adaptive equipment. Ordinary utensils which have been changed so that persons with disabilities can function more independently.

Advocate. A person who defends the cause of another.

Ambulation. Walking with or without the aid of special equipment such as braces or crutches.

Antiseptic. Free from or cleansed of germs and other microorganisms.

Autonomic dysreflexia. A potentally dangerous reaction including high blood pressure, sweating, chills, and / or headache, which may occur in persons with spinal cord injury above the fifth thoracic level.

Augmentative and alternative communication (AAC). Forms of communication that supplement or enhance speech or writing, including electronic devices, picture boards and sign language.

Bed bag. Container for the collection of urine during sleeping or when a person needs to stay in bed.

Bladder. The expandable reservoir sac that stores the urine until it is released either by reflex or catherization.

Bladder training. Method by which the bladder is trained to empty without the use of an indwelling catheter.

Body mechanics. Moving or aligning your body in the best possible way to prevent injury.

Bottoming out. Expression used to describe inadequate support from a mattress overlay or seat cushion as determined by a hand check.

Bowel. The last part of the digestive tract, sometimes called the large intestine or colon, where the waste products of eating are stored until they are emptied from the body in the form of a bowel movement (stool, feces).

Bowel program. Establishing a specific time or habit pattern to empty the bowel to achieve regularity, assisted by the use of suppositories and / or digital stimulation. Enemas can relieve fecal impaction but are not recommended for routine use.

Catheter. A flexible rubber or plastic tube for draining or injecting fluid (see irrigation) into a cavity of the body, usually the bladder.

Condom (Texas). External sheath with an open-ended connector tip that attaches to the tubing of a leg bag or bed bag.

Cervical. The upper spine (neck) area of the vertebral column. Cervical injuries often result in quadraplegia.

Chux. Disposable plastic pads used to protect bedding.

Clapping. Applying a cupped hand in a rhythmic motion over specific chest areas to loosen mucus in the lungs.

Clean dressing. Dressing that is not sterile but is free of environmental contaminants such as water damage, dust, pest and rodent contaminants, and gross soiling.

Coccyx. A small bone at the end of the spinal column.

Congenital disability. A disability which occurs at birth.

Contract. A written, binding agreement between the employer and his/her personal assistant.

Contracture. Any body joint which has become stiffened to the point it can no longer be moved through its normal range of motion; caused by shrinking or a drawing together of the tissues that surround the joint.

Crede (cruh-day). The application of pressure applied downward and inward over the bladder to facilitate voiding.

Cystogram. X-ray taken after injecting dye into the bladder; used to check shape and function.

Cystometric examination. A procedure used to check bladder function by filling the bladder with fluid or gas and recording its activity. Used to evaluate catheterization program.

Decubitus ulcer. Medical term for pressure sore (see pressure sore).

Denial. Avoiding physical or emotional conflict or loss. To hope for functional improvement is not to deny disability.

Dislocation. The movement of a bone, such as the vertebra of the spinal column out of its normal position.

Edema. Swelling caused by an excessive amount of fluid in the body tissues. It may be localized or generalized.

Exacerbate. To make symptoms worse or more severe; to aggravate a condition.

Fecal impaction. Blockage of the bowels resulting in severe constipation.

Flaccid. When muscles are soft and limp, lacking firmness.

Fracture. A sudden breaking of the bone, possibly combined with dislocation from its normal position.

Friction. The mechanical force exerted when skin is dragged across a coarse surface such as bed linens.

Gait training. Instruction in walking with or without such equipment as braces or crutches.

Granulation tissue. The pink / red, moist tissue that contains new blood vessels, collagen, fibroblasts, and inflammatory cells, which fills an open, previously deep wound when it starts to heal.

G. U. Genito-urinary, interchangeable with Urology. Refers to the kidneys, ureters, bladder and reproductive (sex) organs.

Indwelling foley. A flexible tube that stays in the bladder for continuous urinary drainage, connected to a leg bag or other device. The catheter can enter the bladder through the urethra or through an opening in the lower abdomen (suprapubic ostomy).

Intermittent or self-catheterization. When the consumer can catheterize himself / herself to empty the bladder as needed.

Hand splint. A metal or thermoplastic support for hand, wrist, and / or fingers. Enables greater function to a disabled hand, and / or to prevent deformity.

Hematoma. A blood clot, bruise.

Hemiplegia. Unilateral paralysis of the left or right half of the body.

Hydronephrosis. Caused by urine backing up (reflux) from the bladder into the kidney; excessive reflux stretches the kidney causing functional damage to the kidney.

Incentive Spirometer. A device used to help make the breathing muscles stronger. It measures the amount of air taken into the lungs.

Incomplete injury. Maintains some sensation or control below the level of the spinal cord injury.

Incontinence. Lack of bowel and / or bladder control.

Inflammation. Localized heat, redness, swelling and pain caused by irritation, injury or infection.

Iliac Crest. The curved front part of the hip bone.

Irrigation. Cleansing or flushing by a stream of fluid, preferably saline.

Ischium. Lower portion of the hip bone.

K.U.B. X-ray of the abdomen showing the kidneys, ureters, and bladder.

Lap board. A tray which fits onto a wheelchair. It can be used as a desk, an eating surface, an exercise surface, etc.

Leg bag. A bag which is strapped to the leg for the collection of urine; connected to the condom, suprapubic or indwelling catheter.

Lesion. An injury or wound to the spinal cord.

Lumbar. The strongest part of the spine. This is the lower back immediately below the thoracic spine.

Medical Model. A relationship between a consumer and various other individuals (doctors, nurses, case managers, etc.) which focuses attention on the consumer's limitations. The relationship is usually characterized by a sense of "taking care of" the consumer. This model does not promote independence and limits consumer's choices.

Mouthstick. A wooden or plastic dowel with a rubber tip. This piece of adaptive equipment can be held in the mouth and used as a pointer, turn the pages of a book, perform keyboard / computer functions, etc.

Neurogenic. Caused by disease or abnormality of the nervous system.

Occupational Therapist (OT). The member of the rehabilitation team who helps maximize a person's independence; OT's teach daily living activities, health maintenance and self-care, and consult on equipment choices.

Ostomy. A surgically created opening in the body for the discharge of body wastes. Some types of ostomies include a colostomy (an opening of the colon), ileostomy (an opening of the small intestine), and urostomy (diversion of the urine away from a diseased or defective bladder).

Paraplegia. Loss of function below the cervical spinal segments while the upper body usually retains most of its function and sensation.

Physiatrist. A doctor whose specialty is physical medicine and rehabilitation.

Physical Therapist (PT). Also a member of the rehabilitation team; PT's examine, test, and treat persons to enhance their maximum physical ability.

Postural Hypotension. A sudden drop in blood pressure resulting in light-headedness.

Prone. Lying flat on the stomach, face down.

Quadriplegia. Loss of function of any cervical spinal cord segment, affecting both arms and both legs. This term is currently being phased out and replaced with the term "tetraplegia."

Residual urine. Urine that remains in the bladder after voiding. Excess residual urine can lead to a bladder infection.

Sacrum. The large triangular bone at the end of the spinal cord just above the coccyx.

Shearing. See “friction.”

Spasm. A sudden, involuntary contraction of a muscle that causes the person to move or jerk, uncontrollably.

Stress. When discussing healthcare, the term refers to the physical forces (injury or illness) and the psychological forces (fear, anxiety, crisis, joy) being experienced by the individual.

Stones. Hardened mineral particles which can lodge themselves in the urinary tract and block drainage of urine from the kidneys or bladder.

Straight Catheter. Similar to a Foley, except that it is removed after the urine has been drained.

Suprapubic. A tube placed in a small opening made through the abdomen and into the bladder which changes the direction of the flow of urine from the urethra.

Tetraplegia. Loss of function of any cervical spinal cord segment, affecting both arms and both legs. This term is currently replacing the term “quadriplegia.”

Thoracic. The segments between the cervical and lumbar areas.

Tracheostomy. An opening in the windpipe to facilitate breathing.

Trochanter. The bony area at the top of the thigh bone.

Urinary Tract Infection (UTI). An infection brought on by intestinal bacteria, improper handwashing, catheters not clean or sterile, poor perineal hygiene, or insufficient fluid intake.

Ureters. The passageway for urine from the kidneys to the bladder.

Urethra. The tube from the bladder which drains urine to the outside of the body.

Ventilator. A positive pressure mechanical device to facilitate breathing; usually connected to a tracheostomy. For persons who require ventilation only at night or occasionally a mask is attached to the vent instead of having a tracheostomy.

NOTES

Appendix B

Reacher. Allows a person to pick up things without bending or reaching.

Doorknob turner. A device that attaches to regular doorknobs, making gripping easier.

Communication device. An electronic device that talks or prints out words for someone who is not able to speak.

This Does What?

Glossary of Assistive Technology Devices; Bibliography

Assistive Technology Devices

An assistive technology device is any item or piece of equipment, whether acquired commercially, off the shelf, modified or customized, that is used to increase, maintain, or improve the independent functional abilities of an individual. Below is a partial list of adapted devices that are used for various activities of daily living.

Holding/Picking Things Up

Grip. Plastic that is formed so that the hand can slip into it and pick up an object without using fingers; Velcro strap that is attached to an object and wrapped around hand.

Reacher. Allows a person to pick up things without bending or reaching.

Eating

Scoop dishes. Dishes with built-up sides to make it easier to get food onto utensils.

Food guards. A plastic “wall” that slips around plate to make it easier to scoop food onto utensils.

Special cup. A cup with a cover that controls how much liquid is dispensed.

Long straw. A long straw makes it easier to reach liquid if a person cannot pick up a cup or bend over.

Bathrooms

Raised toilet seat. A device that extends toilet heights, making transfers easier.

Grab bars. Bars mounted to walls to assist with transfers and balance.

Bathing

Shower chair with arms. Helps a person keep his / her balance while bathing.

Tub transfer bench. A bench that extends out over the tub's edge to make transferring to the shower chair easier.

Hand-held shower. Gives the person control of water spray.

Bath mitt/sponge. Used instead of a washcloth

Dressing

Sock pull. Helps person pull up socks over feet.

Button hook, zipper pull. Makes it easier to button or close zippers on clothing with one hand.

Dressing stick. A stick with a small hook on one end and a larger hook on the other end that can be used to push or pull clothing.

Grooming

Hairbrush, comb, makeup brushes, razor, toothbrush. All can be modified for easier use.

Scooters

Power. Used by people who cannot walk long distances. Scooters are often available in large grocery stores for customers with disabilities.

Wheelchairs

Manual. A wheelchair that is propelled by a person's arms and / or legs.

Power. A wheelchair with rechargeable batteries that is controlled by a joystick, a head control, or by blowing into a tube.

Transfers

Hoist/Hoyer. A sling-type lift that helps with transfers.

Swing support transfer. An overhead hook that a person can hold on to to lift his/her own weight during a transfer.

Sliding board. A flat piece of wood or plastic that assists in sliding a person from one surface to another.

Opening Doors

Keyholder. A long piece of metal or plastic that holds keys. This device makes it easier to put keys into keyholes.

Doorknob turner. A device that attaches to regular doorknobs, making gripping easier.

Door pull. Rope that is attached to doors to assist with pulling doors closed.

Environmental Control

Environmental Control Unit (ECU). An environmental control unit is a means to purposefully manipulate and interact with the environment by alternately accessing one or more electrical devices via switches, voice activation, remote control, computer interface, and other technological adaptations. The purpose of an ECU is to maximize functional ability and independence in the home, school, work, and leisure environment.

Communication

Communication board. A board with pictures, words, or letters that a person can point to for expressing needs, wants, and ideas.

Communication device. An electronic device that talks or prints out words for someone who is not able to speak.

Bibliography

Adler, Ronald B. and Neil Towne, Looking Out/ Looking In, Holt, Rinehart and Winston, Inc., Fifth Edition, New York, 1987.

"Autonomic Dysreflexia: What You Should Know," Paralyzed Veterans of America, pp. 1-2. Available: http://www.pva.org/NEWPVASITE/publications/cpg_pubs/AutoDys.htm.

"Bladder Care and Management-InfoSheet #11," Spinal Cord Injury Information Network, pp. 1-8. Available: http://www.spinalcord.uab.edu/show.asp?durki=21484.

"Bladder Management," Spinal Cord Injury Notebook, pp. 1-16.

"Bowel Management," Spinal Cord Injury Notebook, pp. 1-13.

"Colostomy," a fact sheet from the United Ostomy Association, Inc. Available: http://www.uoa.org/ostomy_facts_colostomy.htm

Communication. Module 5, Sara Hunt, Consultant on Aging under contract with Louisiana Ombudsman Program, The Comprehensive Curriculum, The National Center for Long Term Ombudsman.

"Complications of SCI," The Rehabilitation Learning Center, Washington University School of Medicine, St. Louis, pp. 1-5. Available: http://www.neuro.wustl.edu/rlc/complications.html.

Crewe, Nancy M., Irving Kenneth Zola and Associates, Independent Living for Physically Disabled People, Jossey-Bass Publishers, San Francisco, 1983.

"Dealing With SCI," Charlotte Institute of Rehabilitation's Spinal Cord Injury Healthcare Information.

Epps, Roselyn Payne, M.D., M.P.H, M.A., F.A.A.P. and Stewart, Susan Cobb, M.D., F.A.C.P. (Co-editors), Guide to Sexuality, Dell Publishing, New York, 1996.

Factsheet: Spinal Cord Injury Statistics. The National Spinal Cord Injury Association's Spinal Cord.ORG, p. 1. Available: http://www.spinalcord.org/html/factsheets/spinstat.shtml, 2003.

Factsheet #3: Sexuality After Spinal Cord Injury, National Spinal Cord Injury Association, pp. 1-4.

Factsheet: Spinal Cord Injury Awareness-Understanding the Importance of Languages and Images. The National Spinal Cord Injury Association's Spinal Cord.ORG, pp. 1-2. Available: http://www.spinalcord.org/html/factsheets/sciawaren.shtml.

Factsheet: About Autonomic Dysreflexia. The National Spinal Cord Injury Association's Spinal Cord.ORG, p. 1. Available: http://www.spinalcord.org/html/factsheets/aut_dysreflexia.shtml, 2003.

"Ileostomy," a fact sheet from the United Ostomy Association, Inc. Available: http://www.uoa.org/ostomy_facts_ileostomy.htm

Information Briefs on Spinal Cord Injury, "Temperature Regulation after SCI," pp. 1-2.

Pressure Ulcer Treatment, Quick Reference Guide for Clinicians, Number 15, U.S. Department of Health and Human Services, AHCPR Publication No. 95-0653, December, 1994.

"Many Suffer From Chronic Fatigue," Spinal Cord Injury Information Network, pp. 1-5.

"Mechanical Ventilation," Health Features, pp. 1-2, Medical College of Georgia, August, 1996.

Merrill, John C. and Ralph L. Lowenstein. Media, Messages, and Men: New Perspectives in Communication, David McKay Company Inc., New York, 1971.

Pizer, Vernon, You Don't Say, G.P. Putnam's Sons, New York, 1978.

"Range of Motion," Spinal Cord Injury Notebook, pp. 1-3.

Ricotta, Karen, M.C. "Sexuality and Spinal Cord Injured Women," Paraplegia News, March 1991.

"Sexual Function and Fertility after SCI," UW Rehabilitation Medicine, Spinal Cord Injury Update, pp. 1-3. Available: http://depts.washington.edu/rehab/sci/updates/96f_sexualfunction_women.html.

"Sexuality in Males with Spinal Cord Injury," InfoSheet #3, Spinal Cord Injury Information Network.

Smith, Donald G., Joy of Negative Thinking, Delancey Press, Philadelphia, 1995.

Smith, Sandra F., RN, MS, APD and Duell, Donna J., RN, MS, ABD with Martin, Barbara, C., RN, MS, CS. "Catheterization." Clinical Nursing Skills. Connecticut: Appleton & Lange, 1996, pp. 543-559.

"Spinal Cord Injury Facts and Figures at a Glance," May, 2001, National Spinal Cord Injury Statistical Center. Available: http://www.spinalcord.uab.edu/show.asp?durki=21446.

"The Stages of Grief," Pullman Foursquare Church, pp. 1-4. Available: http://www.pullmanfoursquare.com/resources/quicktips/page45.html.

"Suctioning a Tracheostomy," pp. 1-2. Available: http://www.tracheostomy.com/suction.htm.

A Symposium on Pressure Ulcer Management: A Framework for Practice. Rik Medical Symposium Program produced in partnership with United Medical, St. Louis, 1996. Bony Areas illustrations and other information on pressure sores were taken from materials presented at this symposium.

"SCI Classifications and Terminology," The Rehabilitation Learning Center, Washington University School of Medicine, St. Louis, pp. 1-4. Available: http://www.neuro.wustl.edu/rlc/asia_class.html.

"Taking Care of Your Bowels, the Basics," UW Rehabilitation Medicine, NW Regional Spinal Cord Injury System, pp. 1-4. Available: http://depts.washington.edu/rehab/sci/pamp_bowels01.html.

"Tracheostomy Care," p. 1. Available: http://www.tracheostomy.com/care.htm.

"Types of Tracheostomy Tubes," p.1. Available: http://www.tracheostomy.com/types.htm.

"Understanding Spinal Cord Injury, Basic," Spinal Cord Injury InfoSheet No. 4, pp. 1-4. Available: http://www.spinalcord.uab.edu/show.asp?durki=22408.

University of Alabama, Spain Rehab Center – UAB InfoSheet 3: "Sexual Function for Men with Spinal Cord Injury." Available: http://www.spinalcord.uab.edu/show.asp?durki=34814&site=1021&return=21479

University of Miami and the Miami Project to Cure Paralysis: “A Guide and Resource Directory to Male Fertility Following Spinal Cord Injury/Dysfunction.” Available: http://www.scifertility.com

“Urology,” Spinal Cord Injury Notebook.

“Urostomy,” a fact sheet from the United Ostomy Association, Inc. Available: http://www.uoa.org/ostomy_facts_urostomy.htm

“Ventilatory Care on Patients with SCI,” UW Rehabilitation Medicine Spinal Cord Injury Update pp. 1-3. Available: http://depts.washington.edu/rehab/sci/updates/95f_ventilatorycare.html.

“What is a Tracheostomy,” p. 1. Available: http://www.tracheostomy.com/what.htm.

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