PRINCIPLES OF CAREGIVING:
AGING AND PHYSICAL DISABILITIES

CHAPTER 2 – PHYSICAL DISABILITIES AND CONDITIONS: THE BRAIN AND NERVOUS SYSTEM

CONTENTS

A. Basic Principles
B. Physical Disabilities and Conditions
   1. Spinal Cord Injuries (SCI)
   2. Traumatic Brain Injuries (TBI)
   3. Strokes
   4. Multiple Sclerosis (MS)
   5. Amyotrophic Lateral Sclerosis (ALS)
   6. Parkinson’s Disease
   7. Seizures
OBJECTIVES

1. Identify the basic principles of care for a person with a disability.

2. Identify common physical disabilities and conditions involving the brain and nervous system and the therapeutic interventions used.

3. Explain effective techniques that can be used in providing care for these conditions.

KEY TERMS

<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Aphasia</td>
<td>Plegia</td>
</tr>
<tr>
<td>Autonomic dysreflexia</td>
<td>Seizure</td>
</tr>
<tr>
<td>Exacerbation</td>
<td>Spinal cord injury (SCI)</td>
</tr>
<tr>
<td>Paralysis</td>
<td>Traumatic brain injury (TBI)</td>
</tr>
</tbody>
</table>
A. BASIC PRINCIPLES

Individuals have individual needs
As with any condition, an individual with a disability is unique with unique strengths and challenges. People with the same disability will have different needs. For example, a person with multiple sclerosis may or may not be incontinent. You must check the service plan or ask the supervisor to determine the interventions that are to be used with each person.

Therapeutic interventions
Therapeutic interventions for persons with physical disabilities will be unique to each individual. Therapeutic interventions can include range of motion (ROM) exercises, durable medical equipment (DME), physical therapy (PT), occupational therapy (OT), speech therapy (ST), proper diet, etc. These interventions can be crucial to maintaining or improving the health and welfare of a person with a physical disability.

Paralysis
Paralysis is the inability to move a body part or even the whole body. There is loss of feeling, usually as a result of injury to the nervous system or spinal cord. Conditions involving the brain and nervous system may or may not cause paralysis.

B. PHYSICAL DISABILITIES AND CONDITIONS

1. Spinal Cord Injuries (SCI)

The spinal cord is a long, rope-like cord about the width of your little finger that extends from the brain to the lower back, where it fans out like a horse’s tail. It is protected by bones called vertebrae. Between the vertebrae are disks which act as cushions. The spinal cord is the second most protected organ in your body, next to the brain.

The spinal cord can be damaged easily. Some spinal cord injuries (SCI) are the result of something going into the spine, for example, a gunshot wound. Another type of injury can be something that causes pressure within the spinal column. An example would be a tumor inside the spinal column. Another type of injury can occur from actually breaking the vertebra, which can then cut the cord.

Types of injuries
Complete: All the nerves at the level of injury are damaged. There will be no voluntary movement or sensation below the level of injury.
Incomplete: Partial damage to the nerves at the level of injury. There may be some movement and/or sensation.

The Spinal Column and the Body Parts/
Muscles Involved at These Levels of Injury

- **CERVICAL (Quadriplegia)**
  - C4 - Diaphragm (Breathing)
  - C5 - Shoulders
  - C6 - Wrist
  - C8 - Hand

- **THORACIC (Paraplegia with Varying Upper Body Strength)**
  - T2 to T7 - Chest Muscles
  - T9 to T12 - Abdominal Muscles

- **LUMBAR (Paraplegia)**
  - L1 to L5 - Leg Muscles

- **SACRAL (Tailbone) - Elimination**
  - S2 and below - Bowel and Bladder
Types of plegias or paralysis
This diagram illustrates the types of paralysis (plegias). Different areas of the human body are paralyzed in each specific category of plegia. Hemiplegia is most often associated with a stroke.

Autonomic dysreflexia (hyperreflexia)
Autonomic dysreflexia (AD) is an emergency medical condition. It causes extremely high blood pressure as a result of a stimulus below the level of injury. This can lead to a stroke! It generally occurs in individuals who have an injury at T-6 or above.

Why this happens
When a stimulus occurs in the non-injured body, blood vessels dilate and the blood pressure rises. Messages are sent from the brain to lower the blood pressure to keep the body in balance. In a person with an SCI, those messages cannot pass through the level of injury. The blood pressure then rises uncontrollably. This rise in blood pressure will cause signs and symptoms that something is wrong.

Symptoms
- Pounding headache.
- Profuse sweating (above the level of injury).
- Nasal congestion and pupil constriction.
- Goose bumps/chills.
- Slow heart rate (brain’s response to high BP).
- Vision changes (seeing spots, blurry vision).
- Anxiety, apprehension.
- Flushing of skin (above level of injury).
Causes
The causes of AD are varied. Basically it is any stimulus below the level of injury. Although this is not a complete list, following are some of the causes:

- Full, distended or infected bladder (check the catheter tubing for blockage).
- Blocked bowels (constipation).
- Pressure ulcers.
- Broken bones, severe cuts.
- Labor pains, menstrual cramps.
- Extreme temperatures, sunburns.
- Tight clothes.
- Stress.
- Ingrown toenail.

What to do
- Have the person immediately sit up or raise head to 90 degrees. This will reduce the blood pressure.
- Determine the cause.
- If you can’t determine the cause, GET HELP!! Call or go to the hospital. Be aware that not all health providers will be familiar with AD. It is a good idea to carry an ID card, which explains it.

Persons who are paralyzed can CARRY A CARD! It may save a life!

Below is an example of a card a person can cut out and carry in a wallet. Put the person’s name in the space below “FOR AUTONOMIC DYSREFLEXIA.” Let health care team members and contact people know this person has this card. Use it with medical staff for instructions in emergency care.
**MEDICAL ALERT FOR AUTONOMIC DYSREFLEXIA**

Name: ____________________________

is subject to the above syndrome. This is a serious medical problem that can occur in people with a spinal cord injury above the 6th thoracic level. The symptom of autonomic dysreflexia (AD) can be caused by many types of stimuli below the level of the spinal cord injury, but the most common emergency causes are: (1) full or spastic bladder or (2) bowel distention (usually from stool in the rectum). Severe AD is a medical emergency which if not properly treated can result in cerebral vascular hemorrhage (stroke).

**Symptoms:**
- Pounding headache
- Flushing of skin and sweating above the level of injury
- Increased blood pressure (as high as 250/150), slow pulse
- Apprehension/anxiety
- Vision changes, blurring, spots before the eyes
- “Goose bumps”

**Medical Treatment:**

1. If the AD episode is not resolving after the above measures, medical treatment is necessary. Ask the patient if he has his own supply of any of the AD medications. If not, transport patient to an emergency room as soon as possible.
2. If the AD episode is not resolving and/or the blood pressure reaches 160 systolic, give the patient Nifedipine 10 mg sublingual. Instruct patient to bite through the capsule and hold it beneath his tongue. May repeat Nifedipine dosage after 15 minutes if blood pressure has not responded.
3. Continue to look for causes of AD by checking the patient’s entire body. Other causes include fractures, sores and tight clothing.
4. Alternative treatments (if Nifedipine is not available or does not work):
   a. Nitroglycerine ointment: 1 inch to upper chest or back. If no resolution in 15 minutes add additional 1 inch.
   b. Markedly elevated blood pressure not responding to the above measures should be treated with IV Apresoline (20 mg/1cc). Inject 0.5cc SLOWLY. May repeat dosage after 15 seconds of no response.
5. Blood pressure may be safely lowered to 90/60, which is typical of quadriplegics in the sitting position.
6. After an episode of AD, it is not uncommon for a second episode or rebound to occur, so blood pressure should be checked every 30-60 minutes for the next 4-5 hours.

**What To Do: (First Aid) (Most of these measures are for emergency personnel)**

1. Place patient in a sitting position
2. Drain the bladder.
   a. If catheter is in place, check for kinking. If catheter is plugged, do not try to irrigate. Change foley using Lidocaine jelly for lubrication.
   b. If no catheter is present, insert a catheter using Lidocaine jelly for lubrication. Do not crede (push on) the bladder.
3. If emptying the bladder has not decreased the blood pressure and there is stool in the rectum, apply Lidocaine jelly to the anal sphincter and wait three minutes. Then, using a Lidocaine-lubricated gloved finger, gently remove stool from the rectum.
Living With a Spinal Cord Injury

My name is Gregg and back in 1993 I became a quadriplegic from a car accident. After ten months in the hospital, I went to an independent living center in Minneapolis. There I learned how to live as independently as I could before moving back into the mainstream of life. The rehab program involved physical therapy to build up my strength, and occupational therapy to find adaptive devices for me to do routine tasks such as, writing, typing, shaving, cooking, unlocking doors, and other activities of daily living. After seven months of rehab I moved into an apartment where I had a live-in aide, but a couple years later I started living on my own and have ever since. I graduated from college, and then moved to Arizona in 2002. I currently receive my attendant care under Arizona Long Term Care System.

I try to maintain my independence as much as possible, but there are things someone has to help me do or do for me. A typical day starts out with my attendant arriving to get me out of bed. She comes into my apartment and opens the curtains, and after giving me a minute or two to clear the gunk out of my eyes, we begin the processes: range of motion on my legs / replace and clean a night bag with a daytime leg bag / transfer to shower chair and move into bathroom / bowel care program / shower / transfer back to bed / dress / transfer back to wheelchair / breakfast and food prep / laundry some days. My bowel care program is every other day, so on the other days I get dressed right away and transfer to my wheelchair not having to shower. During my bowel care program (approximately 50 minutes), my attendant does household chores: vacuuming, dusting, emptying the dishwasher, making the bed/changing sheets, and other tasks as needed. I do my own shaving and brushing teeth, but my attendant sets the items up for me, and then cleans and puts them away when I am finished. Now it is time to plan/prepare food and water for the day. I have three jugs of water filled for my easy access. I like to cook, but slicing, dicing, and chopping isn’t easy for me, so my attendant preps whatever items I need. If I wanted to cook a hamburger in my George Foreman grill, for instance, my attendant slices tomato, onion, and lettuce, placing them in a container in the fridge, along with a hamburger patty. All I have to do fry the hamburger, and put together a complete sandwich. And let us not forget that somewhere in amongst doing all this, some days I have to have my laundry washed and dried.

At night someone has to put me to bed. My attendant transfers me to bed, undresses me, connects the night drain bag and cleans the day leg bag, does range of motion on my legs, tucks me in, and if I’m lucky maybe a goodnight song/story.

My attendant is a VERY IMPORTANT person. I rely 100% that he or she will be here to get me out of bed in the morning. If no one shows up or is late, then I am stuck in bed, waiting. So, I have to trust my attendant WILL be here when I expect them to be. It’s the same thing at night when I go to bed. If no one shows up or is late, then I am stuck sitting up in my wheelchair.

Gregg, a Person with Quadriplegia
Psychological adjustment
A person with an SCI will go through a physical adjustment and a psychological adjustment. There is no set length for this process; nor is there a specific pattern as to how the person will handle it. Often you will see the individual experience the phases of the grieving process. Your role as the assistant is a vital one. Be as supportive as possible. Be honest with the person. It is good for the individual to look into the future, but remind them to focus on where they are now, both physically and emotionally.

Remember, an individual with an SCI still has talents and abilities to offer. Using adaptive equipment, modifying the environment, etc., will assist individuals with SCIs to utilize the abilities they have. To have your body’s physical ability change often creates the idea that you no longer have anything to offer. It’s all a process of the individual learning how to express him/herself again.

Bowel care and bladder management
The goal for a bowel care program is to establish emptying the bowel at regular times, and prevent embarrassing accidental bowel movements. A bowel care program usually consists of inserting a suppository followed by a digital stimulation routine. A bowel care program is usually established three times a week, but does vary from client to client.

Note: Most agencies do not allow DCWs to insert a suppository or perform digital stimulation. Check with your supervisor to determine your job responsibilities. DCWs can perform the clean-up after a qualified person does the suppository and stimulation.

a. Bladder control and care

*Intermittent catheter:* Catheter inserted every 2-4 hours directly into the bladder through the urethra allowing the bladder to drain.

*Indwelling catheter:* Catheter inserted into the bladder through the urethra and remains inside the bladder.

*Supra-pubic catheter:* Catheter is inserted through the lower abdomen into the bladder.

*External catheter:* Also known as a condom, Texas, or buffalo catheter.
- Change every day (easier to change if penis is somewhat erect).
- Wash skin well to remove glue and old urine.
- Dry skin thoroughly.
- Clip hair that may get caught in the adhesive on catheter.
2. **Traumatic Brain Injuries (TBI)**

A traumatic brain injury may occur when a force severely impacts the brain. Brain trauma can be caused not only by the force of the injury, but also by increased pressure in the brain from swelling that happens after an injury. TBI is a major cause of death and disability worldwide, especially in children and young adults. Causes include falls, vehicle accidents and violence. Preventative measures include use of such things as seat belts and sports or motorcycle helmets. Programs to reduce the number of accidents such as safety education programs and enforcement of traffic laws also promote prevention.

TBI can cause multiple physical and mental problems. The severity and type depends on location of the injury and the amount of brain involvement. The outcomes can range from complete recovery to permanent disability or death. A brain injury can affect not only the movement of the body but also all the functions that the brain controls, such as judgment and speech.

3. **Strokes**

Strokes, also known as cerebrovascular accidents (CVA) or brain attacks, can be caused by blocked arteries or bleeding within the brain. Brain damage occurs when blood flow to or within the brain is interrupted. Without oxygen, the brain cells die. The location of these damaged cells will determine the symptoms and severity of the stroke.

Signs and symptoms of a stroke include drooping of one side of the face, slurred speech, visual disturbances, lack of coordination or paralysis of extremities.

There are two types of strokes:
- Blood vessels can leak blood into the surrounding tissue. This can be caused by a weakened artery wall (aneurysm) or by trauma
- There is a blockage of blood flow due to a clot or plaque formation

If the cause is due to a blockage, a medication can be given within the first three hours (per American Heart Association guidelines) that will greatly reduce the effects of the stroke. If the cause is due to blood leaking, that same medication can cause further bleeding and possibly death.

**It is very important the individual be taken to the emergency room for treatment within two hours of the beginning of symptoms.** It has been proven that severe damage can be lessened or even reversed if treatment is received within the 2-hour window.
Possible effects of a stroke
- Paralysis.
- Memory loss.
- Impaired judgment.
- Aphasia (difficulty expressing oneself).
- Depression.
- Emotional instability.
- Seizures.

Following a stroke, it is important that the individual get rehabilitative therapy as soon as possible to lessen the effects of the impairment, and to learn how to manage ADLs with the impairment. The caregiver can assist in making sure therapy arrangements are being made and followed.

The caregiver can also help by allowing the person to be as independent as possible, and to allow plenty of time for independent function. This will help decrease depression.

4. Multiple Sclerosis (MS)
Multiple sclerosis is the most common central nervous system disease among young adults in the United States. The central nervous system acts like a switchboard, sending electrical messages along the nerves to various parts of the body. These messages control all our conscious and unconscious movements. Most healthy nerve fibers are insulated by a myelin sheath, a fatty substance that aids the flow of messages. In MS, the myelin breaks down and is replaced by sclera, or scar tissue (sclerosis). This distorts or even blocks the flow of messages for vision, walking, talking, etc. Multiple sclerosis is not a mental illness, contagious, preventable or curable. The disease is progressive, although damage to the central nervous system occurs at different rates in different people.

Symptoms
- Seeing double or uncontrolled eye movements.
- Partial or complete paralysis in any part of the body.
- Shaking of the hands.
- Loss of bladder or bowel control.
- Staggering or loss of balance.
- Speech problems such as slurring.
- Weakness or unusual tiredness.
- Loss of coordination.
- Numbness or prickly sensations.
- Obvious dragging of feet.
Causes

- **Virus attack**: MS might be caused by some slow-acting viruses or it might be a delayed reaction to a common virus.

- **Immune reaction**: MS might involve an autoimmune reaction in which the body attacks its own tissues by mistake.

- **Combination**: When viruses invade the body, they take over body cells. The body’s defense system might become confused because some viruses take over parts of cells and it might attack both body cells and virus cells.

There is much not known about MS, and the possibility of developing the disease cannot be predicted. However, there is a pattern in who is more likely to develop it:

- **Young adults**: Symptoms usually appear between ages 20 and 40.

- **Women**: Slightly more women than men develop MS.

- **People in areas with high standards of sanitation**: Perhaps children in these areas are not exposed to some factor that would help build immunity to MS.

Exacerbation (flare-up)

This term is often associated with MS, meaning the client is having a flare-up. *Relapsing-remitting multiple sclerosis* is a form of MS in which symptoms randomly flare up (relapse) and then improve or fade. This relapsing-remitting pattern emerges with the onset of the disease and may last for many years.

For more information contact: National Multiple Sclerosis Society, Arizona Chapter: (480) 968-2488.

5. **Amyotrophic lateral sclerosis (ALS)**

   Also known as *Lou Gehrig’s disease*, ALS is a progressive wasting away of certain nerve cells of the brain and spinal column called *motor neurons*. The motor neurons control the voluntary muscles, which are the muscles that allow movement. The cause for ALS is unknown. Symptoms of ALS in the beginning are weakness of one leg, one hand, the face, or the tongue.

   ALS is a progressive, disabling disease. ALS affects walking, speaking, eating, swallowing, breathing, and other basic functions. These problems can lead to injury, illness (for example, pneumonia) and other complications. A person diagnosed with ALS will need to make decisions on treatment or lack of treatment as the disease progresses. Treatment in the early stages can include the use of a cane, shower chair, physical therapy, occupational therapy, speech therapy, and medication. As the disease progresses, breathing assistance with a ventilator and tube feeding will be necessary.

6. **Parkinson’s disease**

   Parkinson’s disease is related to a chemical imbalance in the brain. Cells that make a brain chemical called dopamine, which helps control muscle movements, are slowly
destroyed. Symptoms may include rigid movements (freezing), tremors, loss of balance and coordination, and loss of facial control (blank affect). Medications may help control the symptoms, but the disease gets worse over time.

- The individual may have problems chewing, swallowing, or speaking.
- Can lead to dementia.
- Do not mistake blank affect for lack of comprehension.

7. **Seizures**

Seizures are caused by sudden, abnormal electrical signals in the brain. Most people think of seizures as uncontrollable shaking of the body, with the person not knowing what is happening. After a seizure, the person is generally confused, tired and sometimes has muscle soreness from the spasms. There may have been some injuries due to falling, hitting objects or biting the tongue or cheeks.

There are two types of seizures:

- **Focal:** A seizure in one side of the brain, causing mild spasms of the brain. The client may seem to stare into space, not respond when spoken to or touched, or eyes may seem to not focus or may close.

- **Generalized:** Abnormal signals affect both sides of the brain. Usually, with this type of seizure the person will become rigid with jerking movements, then become relaxed but unresponsive. The person will gradually become more responsive but will need reassurance as to what happened. The person may also lose bladder control.

Both types of seizures usually last between 30 seconds and 1 minute. Clients experiencing seizures should be allowed free movement. Do not attempt to hold or restrain them in any way, or put anything in their mouths. The caregiver should protect the person’s head from banging on a hard floor and move objects away from the person’s body that may cause harm.

Seizures lasting more than five minutes, multiple seizures (several episodes in a row) or clients that do not awake afterwards are cause for immediate medical attention.
Providing Care for My Son, Corey, who has a Traumatic Brain Injury

When a personal attendant has the opportunity to work for a consumer who has intense care needs, it may be helpful to know several things in advance.

Our son, Corey, is one of those consumers with intense needs. Corey was in a car accident that left him with a severe traumatic brain injury (TBI). Corey is completely dependent for all of his needs. Corey cannot talk, but he can blink his eyelids for “yes” and “no”. Corey understands everything going on around him. Corey has a wheelchair and relies on the attendant to reposition and move him.

Taking care of someone like Corey who understands everything, cannot verbally communicate, and who is completely dependent on someone else can not only be very physically, mentally, and emotionally draining on the attendant, it can be challenging. It is wise for an attendant to care for someone like Corey part time and have a verbal consumer for the rest of the week. A good example is having a consumer who is verbally interactive in the mornings and having an intense care consumer, like Corey in the afternoon, (or vice versa). This way the attendant does not get “burned out”, nor mentally and emotionally exhausted, nor feel “isolated”. This arrangement is also good for the consumer who is in Corey’s situation, because these intense care consumers need stimulation and variety in their lives since they are less likely to get out among lots of people and tend to feel isolated themselves.

There are several things to consider about the household/families in which these intense care consumers live. One, there is probably a lot of stress because of the high needs of the consumer. The family will be sleep deprived because of getting up all night long to care for their loved one. There may be moodiness and emotional times for the family because of what has happened to their loved one and how now they have to manage their loved one’s care (medical needs, etc.). Another source of stress for the family is that they may have some loss of income now that they must stay home with the loved one. Also, now the family has to have extra non-family members in their home. The attendant should never take any of the moodiness personal. Those things are the result of what the family experiences.

The attendant needs to be aware that if the family is busy, whether working or tending to household tasks, they are not ignoring their loved one. While the attendant is there, that is the only time the family can work, and do everything that needs to be done, because when the attendant is gone the family is back on full time care with the consumer, their loved one.

Further, the attendant should try not to interrupt the family members (with chit chat or their own personal goings on), unless the consumer needs something that can’t wait or it’s time for family to administer medical needs, tube feeding, etc.

The attendant needs to have the ability to talk to the consumer all the time despite the fact that the consumer cannot respond verbally. As the attendant and consumer get to know each other, the attendant will understand other forms of communication the consumer uses, but still needs to talk all the time. I would suggest that an attendant ask their self, “Can I handle this consumer situation? Can I handle not hearing my consumer speak to me?” If the attendant can’t, don’t take the job. Training new attendants is very time consuming for the family and emotionally hard on the consumer because the consumer becomes very attached to the attendant.

It takes a special person to do this job. Those that take this type of intensely emotional job are a blessing to these consumers and their families. We pray every day that the attendants are blessed.

Theresa Buhr, mother of Corey