DISABILITY GUIDE

Preparing for, and assisting those with disabilities in a time of emergency

An Administrative & Personal Guide
Internet Link

WWW

Click with your mouse over the red boxes in the document to activate the link to an internet site

Disclaimer: The author neither endorses nor accepts financial gain or support from any of the listed websites. All websites were chosen by random and do not reflect the views of the author.
THIS GUIDE HAS BEEN PRODUCED IN SIZE 14 FONT

Individuals with disabilities helped in producing this guide
Table of Contents

CHAPTER 1  
Using this guide  
Defining disability  
Perceptions  
Types of disability

CHAPTER 2  
Natural and manmade emergencies and disasters  
Assessing your surroundings  
Who can help?  
Formulating your plan

CHAPTER 3  
If the worst should happen

CHAPTER 4  
Evacuation and location aids  
Techniques for moving individuals

CHAPTER 5  
Example planning document

CHAPTER 6  
Bibliography
ACKNOWLEDGEMENTS

The author would like to take this opportunity to acknowledge the guidance, wisdom and support in the creation of this guide from the following:

**Jill Elkins** (Management & Training Corporation) for giving me the opportunity and drive to create this document.

**Liz Prendergast** (LPN) for her wonderful work in identifying the types of disabilities and associated symptoms. Her ‘Enlightenment’ guide was a tremendous source of inspiration and benchmark to achieve in the production of this guide.

**Joyce Phelps** (Project Coordinator for the Work Incentive Grant) Oregon Department of Human Services, her support, enthusiasm, and helping me to get it completed on time.

**The North West ADA** for the great training and disability awareness that they have given to MTC employees.

**Tillamook County Residents** for being a great community to be part of.

**The North Oregon Coast** an inspiration to anyone that may take the time to come see it.

**The British Airborne Forces** With whom I served for many years. “*Knowledge Dispels Fear*”
Chapter 1
Chapter 1

Using this guide

This guide can be used by individuals or organizations in the evaluation, planning, and the execution of emergency procedures of persons with disabilities.

The aim of the guide is to stimulate thought and measures to facilitate in the safe evacuation of individuals with disabilities in an emergency situation, be it at home or in the workplace. The guide hopes to empower employers to have a greater understanding of considerations that might affect those individuals, give disabled persons a stake in the planning and development of emergency concerns, and help challenged individuals to plan for emergencies outside of the workplace where they may be the sole occupier of a residence.

There have been many such documents written on this subject and although this guide may include some of what may have already been written, its goals are also to look at the subject as a holistic approach which not only includes giving disabled persons a stake in the planning phase, but also to include location devices, evacuation techniques using specialty equipment, and less conventional means, an assessment and planning guide, the types of disabilities, and what that can mean to an individual and to those that formulate the plan.
Defining Disability

The American with Disabilities Act defines an individual with a disability as a ‘Person with a physical or mental impairment that substantially limits one or more life activity’.

“Substantially” means “in comparison with the general population.”

The EEOC defines major life activities as:

“Those activities that the average person in the general population can perform with little or no difficulty.”

According to the U. S. Census Bureau, about 53 million Americans have a disability, which includes people of all ages. About two-thirds of these individuals have a severe disability. Unfortunately the general perception of a disability is often restricted to physical disabilities that the so called able bodied population can see. There is often little consideration for those that have hidden or not such obvious disabilities. At times there may be reluctance for some individuals to inform their employers of certain disabilities because they feel there may be no reason to share such personal information with them. There is also an argument to state that ‘able bodied’ people can only imagine what it means to have a disability and that they may never understand what it truly means to have a disability even for such obvious cases that they might see or know of.

Disabilities come in many different ways. There are 88 types of disabilities listed in this guide that can affect people. This may not be by any means the definitive list.

When planning for emergency evacuation and situations it is important for employers to not only plan for those people that are known to have disabilities, but also give consideration during planning to those that might have silent or hidden concerns. Although time may be of the essence to evacuate a building or reacting to an emergency it is important that at least some thought is given to situations that might occur in this fashion and to be prepared for those situations. The list is designed to educate employers of the symptoms and affects of those that may be affected in some way by one or more disabilities.
Perceptions

There is quite often a perception that the public has of disabilities, and in particular that most if not all are visible in some way. As already mentioned there are many ‘hidden disabilities’ that are not readily visible or visible at all. Therefore those with disabilities must make a conscious decision as to whether they will make their employer aware of their disability and how they might then help them to achieve a satisfactory evacuation plan.

“Emergency plans often leave out disabled people, increasing the risk that when disaster strikes they will be left behind or won't have information that could save their lives.”

*Source - Siobhan McDonough, Associated Press*

Statement - Employees with disabilities have a higher absentee rate than employees without disabilities.

Answer - False

Statement - Chronic illness and terminal illness are essentially the same.

Answer - False

Statement - There are 54 million Americans with Disabilities.

Answer - True

Statement - Considerable expense is necessary to accommodate employees with disabilities.

Answer – False

Source: http://www.conillinst.org/ChronicQuiz.html

*A list of common disabilities follows:*
TYPES OF DISABILITY
ADDISON’ S DISEASE

DESCRIPTION
Addison’s disease is a disorder that causes the destruction of the adrenal glands over time, rendering the body unable to produce hormones essential to many life-sustaining processes. The cause is usually unknown although it can be a result of TB or cancer. It is believed to be an autoimmune disorder leading to the shutdown of the body’s functions and tissue destruction.

SIGNS AND SYMPTOMS
- Weakness, dizziness
- Pain
- Loss of appetite
- Weight loss
- Darkening of the skin
- Indigestion
- Nausea
- Diarrhea
- GI problems including renal failure

EMOTIONAL IMPLICATIONS
The availability of hormone replacement drugs has dramatically changed the outlook for consumers with Addison’s disease. If diagnosed in early stages, medication should enable the consumer to live a normal life. If diagnosis is delayed, symptoms become more serious and often irreversible. If untreated, it will lead to renal failure or death.
AGORAPHOBIA

DESCRIPTION
Agoraphobia is a fear of being in open, crowded or public places. Onset is usually between 18 and 35 years. In mild cases a person avoids going to places alone, speaking publicly or using public transportation. In extreme cases, it can make the sufferer a virtual prisoner of their home, unable to leave or even answer the phone.

SIGNS AND SYMPTOMS
- Apprehension and fear
- Jittering, twitching and tics
- Sweating, palpitations, clammy hands
- Insomnia and nightmares
- Difficulty breathing
- Upset stomach, diarrhea and dry mouth
- Inability to concentrate

EMOTIONAL IMPLICATIONS
Many agoraphobics have gone undiagnosed, until recently, labeled by doctors as hypochondriacs. Delay in treatment can increase problems. Treatments include anti-anxiety medications, therapy and counseling. In extreme cases the ailment can be debilitating, leaving the client unable to work, shop, or perform other basic tasks of living. Often, family and friends become hostile and unsupportive leaving the consumer severely depressed and isolated. Medical treatment should be sought at onset of any symptoms. Sufferers may find their lives significantly impaired by these attacks. Medication and relaxation techniques may help. Therapy is usually required.
AIDS – HIV

DESCRIPTION
AIDS (Acquired Immune Deficiency Syndrome) is characterized by progressive weakening of T-cell immunity, which makes the person susceptible to opportunistic infections and unusual cancers. Transmission is by sexual contact, blood transfusions, contaminated needles, and prenatal mother to child.

SIGNS AND SYMPTOMS
These often preceded complications.
- Fatigue
- Weight loss
- Afternoon fevers
- Diarrhea
- Night sweats
- Cough

A person may have these signs and symptoms but may be otherwise asymptomatic until abrupt onset of complications.

EMOTIONAL IMPLICATIONS
The diagnosis of AIDS is an emotional experience because of the social impact and discouraging prognosis of the disease. The person may face the loss of their job, financial security, as well as the support of family and friends. Coping with altered body image and emotional burden of untimely death may also overwhelm the person.

FACT – AIDS is often on the rise in younger population as well as the older generation.
**DESCRIPTION**
Alcohol addiction is a chronic disorder marked by uncontrolled intake of alcoholic beverages that interferes with physical or mental health, social and family relationships, and occupational responsibilities. Alcohol addiction cuts across all social and economic groups, involves both sexes, and occurs at all stages of the life cycle, beginning as early as elementary school age. It has no cure.

**SIGNS AND SYMPTOMS**
- Need for daily or episodic use of alcohol to function
- Inability to discontinue or reduce alcohol intake
- Episodes of amnesia during intoxication
- Interferes with social and familiar relationships and occupational responsibilities
- May have episodes of violence during intoxication
- Unexplained traumatic injuries
- Unresponsive to sedatives
- Unexplained mood swings
- Poor personal hygiene
- Secretive behavior (possibly an attempt to hide disease or alcohol supply)
- Consumption of any form of alcohol if deprived of usual supply
- Hostility when confronted about addiction

**EMOTIONAL IMPLICATIONS**
Total abstinence is the only effective treatment. Supportive programs that offer detoxification, rehabilitation and aftercare (including continued involvement in AA) produce the best long – term results.
**ALLERGIC RHINITIS**

**DESCRIPTION**
All rhinitis is a reaction to airborne (inhaled) allergens. Depending on the allergen, the resulting rhinitis and conjunctivitis may be seasonal (hay fever) or occur year round. This disorder most commonly affects young children and adolescents but can affect all age groups.

**SIGNS AND SYMPTOMS**
- Sneezing spasms
- Profuse, watery nose
- Nasal obstruction or congestion
- Red eye lids
- Headache or sinus pain
- Dark circles under eyes
- Occasional itching throat
- Fever

**EMOTIONAL IMPLICATIONS**
Persons suffering from severe allergies can find it difficult to function in day to day activities. They may be irritable and depressed.
ALPORT’S SYNDROME

DESCRIPTION
In Alport’s syndrome, red blood cells and protein are present in the urine, deafness frequently develops, and progressive loss of renal function occurs.

SIGNS AND SYMPTOMS
- A decrease in renal blood flow may be secondary to primary (pre-renal) events
- A reduced cardiac output (such as a heart failure)
- A decreased blood volume (hemorrhage or dehydration), decreased blood pressure, or hypertension (as in shock from severe infection)
- Renal vein thrombosis may also cause renal failure, if clots are extensive
- Obstruction of the urine outflow

EMOTIONAL IMPLICATIONS
If untreated, consumers may die from such complications as infections, hemorrhage, resistant congestive heart failure, and hypertension.
ALZHEIMER’S DISEASE

DESCRIPTION
Alzheimer’s disease is a pre-senile dementia that accounts for over half of all dementias. The prognosis is poor.

INITIAL SIGNS AND SYMPTOMS
- Forgetfulness
- Recent memory loss
- Difficulty learning and remembering new information
- Deterioration in personal hygiene
- Inability to cope

LATER SIGNS AND SYMPTOMS
- Difficulty with abstract thinking and activities that requires judgment
- Progressive difficulty in communication
- Severe deterioration in memory language and motor functions, resulting in coordination loss and inability to speak and/or write.
- Repetitive actions (a key sign)
- Restlessness and irritability
- Nighttime awakenings
- Susceptibility to infection (often cause of death)
- Possible twitching and seizures (late stages)
- Urinary or fecal incontinence (common in final stages)
- Disorientation

EMOTIONAL IMPLICATIONS
Overall care is focused on supporting the consumers’ abilities and compensating for abilities lost, protection from injury by providing a safe, structured environment, and encouraging exercise to help maintain mobility. Refer the family and caregivers to support groups.
**DESCRIPTION**
Amputation is the loss of limb, usually a finger, toe, arm, or leg. In complete amputation, the member is totally severed; in partial amputation, some soft tissue connection remains.

**EMOTIONAL IMPLICATIONS**
Consumer suffers severely from altered body image. Frustration occurs trying to find a prosthesis that fits comfortably. Phantom limb (physiologic reaction of the nerves in the stump causing an unpleasant feeling that the limb is still there) is quite common for a consumer who has lost a limb. This sensation can cause intense unpleasant pain.
AMYOTROPHIC LATERAL SCLEROSIS
(ALS)
(Commonly called LOU GEHRIG’S DISEASE)

DESCRIPTION
ALS is the most common motor neuron disease of muscular atrophy and progressive bulbar palsy. In inherited ALS (approximately 10% of cases), men and women are affected equally. In non-inherited ALS, incident is highest among persons whose occupation requires strenuous physical labor. Generally, onset occurs between ages 40 and 70. ALS is fatal within 3 – 10 years after onset, usually because of aspiration pneumonia or respiratory failure. Acute deterioration factors include trauma, viral infections and physical exhaustion.

SIGNS AND SYMPTOMS
- Atrophy (wasting away) and weakness, especially in the muscles of the forearms and the hands
- Impaired speech
- Normal mental status
- Difficulty chewing and swallowing
- Possible choking and excessive drooling
- Difficulty breathing

EMOTIONAL IMPLICATIONS
This cruel, demeaning neurological disease challenges the person and his caregivers’ ability to cope. Since mental status remains intact while progressive physical degeneration takes place, the consumer acutely perceives every change.
ANEMIA

DESCRIPTION
Anemia is caused by a deficiency of vitamin B12 and the body’s inability to absorb vitamin B12 and folic acid. These are essential to make red blood cells. Anemia is sometimes caused by a strict vegetarian diet, so a change in diet to compensate may help. Other people simply lack the substance known as the intrinsic factor known to metabolize these substances.

SIGNS AND SYMPTOMS
- Fatigue
- Weight loss
- Pallor
- Burning tongue
- Constipation and/or diarrhea
- Enlarged liver and spleen
- Trouble with balance, dizziness
- Muscle twitches and spasms
- Tingling sensations

EMOTIONAL IMPLICATIONS
Consumer should not attempt to self-treat by taking increased vitamin supplements, which can be dangerous. Folic acid supplements must be administrated by a physician and blood tests followed closely. Prognosis may require lifelong treatment, but beyond a period of fatigue and lethargy the consumer should respond to treatment and continue their life.
ANKYLOSING SPONDYLITIS

DESCRIPTION
Ankylosing Spondylitis (AS) is a painful progressive disease that usually strikes young adults (17-35 years). This inflammatory condition affects many parts of the body, but primarily the spine, causing intense back pain and possibly deformity in severe cases. AS also affects the joints of the extremities such as shoulders, hips and knees.

SIGNS AND SYMPTOMS
- Intermittent low back pain, usually, most severe in the morning or after a period of inactivity
- Stiffness and limited motion of the lumbar spine
- Pain and limited expansion of the chest
- Peripheral arthritis involving shoulders, hips and knees
- Hip deformity and associated limited range of motion
- Tenderness over sites of inflammation
- Mild fatigue, fever, anorexia or weight loss
- Occasional iritis

EMOTIONAL IMPLICATIONS
Most AS consumers are able to manage the disease well. They are able to continue to work, go to school, raise children and lead a typically productive and active life. Some may need to seek vocational counseling if work requires standing or prolonged sitting at a desk. Support groups are Arthritis Foundation and AS Association.
ANOREXIA NERVOSA

DESCRIPTION
Anorexia nervosa is a disorder mostly affecting young female adolescents and adults of normal weight. It is characterized by excessive weight loss, refusal to eat and obsessively exercising. Despite evidence to the contrary, consumers view themselves as fat. Death occurs more often with this disorder than any other psychiatric ailment.

SIGNS AND SYMPTOMS
- 25% or more weight loss
- Obsessions with food and/or preparation
- Ritualistic exercises
- Secretive behavior
- Changes in personality
- Irritability, mood swings, low self-esteem, depression, despair, guilt
- Binge eating/vomiting during starvation

EMOTIONAL IMPLICATIONS
Early diagnosis offers the best chance of recovery. Hospitalization or enrollment at a clinic may be required. Treatment time may be required two weeks to 2 years. Psychological problems appear to be the cause and consumers suffer great anxiety, fear, anger and depression. Support groups are available and should be encouraged.
**ANXIETY DISORDER / PANIC ATTACKS**

**DESCRIPTION**
Anxiety to danger is a natural body response releasing hormones and insulin into the bloodstream enabling us to escape the situation. However, though some anxiety is normal and beneficial, exaggerated feeling of anxiety when no danger or stresses are present can produce unpleasant feeling and overwhelming fear. Panic attacks are sudden and severe episodes of anxiety producing physical symptoms such as rapid heartbeat, dizziness, and shortness of breath. Stress may trigger some of these attacks, although they may occur without provocation.

**SIGNS AND SYMPTOMS**
- Apprehension and fear
- Jittering, twitching, and tics
- Sweating, palpitations, clammy hands
- Insomnia and nightmares
- Difficulty breathing
- Upset stomach, diarrhea and dry mouth
- Inability to concentrate

**EMOTIONAL IMPLICATIONS**
Anxiety can cause feeling of dread, doom, and a fear of loosing control or going crazy. At times anxiety lasts for months and years and can make normal life impossible. Relaxation techniques, and a short course of mild tranquilizers combined with counseling can help. Sufferers may find their lives significantly impaired by these attacks. It can be a terrifying experience for them.
ARACHNOIDITIS

DESCRIPTION
Arachnoiditis is a progressive inflammatory disorder affecting the middle membrane surrounding the spinal cord and brain. Either the spinal cord or the brain may be involved; in some cases both are affected. The disorder can be associated with Meningitis. The condition may be caused by foreign solutions such as anesthesia, drugs or dyes injected into the spine or arachnoid membrane.

SIGNS AND SYMPTOMS
- When the brain is involved, symptoms include severe headaches, vision strife, dizziness, nausea, and vomiting
- When the spine is affected, symptoms include pain, and unusual sensations; weakness and paralysis can develop
- Usually begins unexpectedly with a great loss of sensations and movement in the lower back and legs
- Inflammation, muscle atrophy (wasting away), weakness, and involuntary twitching of muscles
- In severe cases, loss of vision or paralysis may develop
- Fibrous tissue may thicken the arachnoid membrane, which can harden or ossify

EMOTIONAL IMPLICATIONS
The relentless and progressive pain of this disease is taxing to the consumer’s morale. In many instances doctor’s and relatives fail to realize that the pain can be as bad as terminal cancer …without the prospect of death to end the suffering. Compassion for consumer is important. Refer to Arachnoiditis Information and Support Network.
**ARTHRITIS**

**DESCRIPTION**
Arthritis is a joint inflammation. This can be anything from a sore swollen joint, which gets better in a few days to a long-term (chronic) disease. It is usually classified as inflammatory or non-inflammatory.

**SIGNS AND SYMPTOMS**
- Swelling in one or more joints
- Early morning stiffness
- Obvious redness and warmth in a joint
- Unexplained weight loss, fever, or weakness combined with joint pain
- Symptoms such as these that last for more than two weeks

**EMOTIONAL IMPLICATIONS**
Living and coping with arthritis can be difficult at times, for many it is a mild case and only slightly affects their activities and emotions. But for others, there are times when the pain and discomfort leads to periods of depression, anger and frustration. The Arthritis Foundation holds classes on self-care and group meetings.
ASTHMA

DESCRIPTION
Asthma is a chronic reactive airway disorder that produces episodic, reversible airway obstruction via bronchia spasms, increased mucus secretion and mucosal edema. The disorder is caused from external allergens such as, pollen, animal dander, house dust, and food additives or internal non-allergenic (irritants).

SIGNS AND SYMPTOMS
- Sudden trouble breathing
- Wheezing
- Tightness of chest
- Cough with thick, yellow sputum
- Feeling of suffocation
- Inability to speak more than a few words without pausing for breath
- Fast heartbeat
- Profuse perspiration
- Cyanosis (bluish skin)
- Confusion and lethargy

EMOTIONAL IMPLICATIONS
Loss of breath is terrifying to a person. They need calm support.
Autism is a severe lifelong disability, which usually appears during the first three years of life. Evidence shows it is associated with abnormalities in brain structure and function. Persons with autism have severe communication and social interaction deficit. They show an unevenness of development, which may allow them to be talented in a limited area such as music or mathematics while being severely deficient in ordinary living and survival skills. People with autism may have other impairments such as retardation or seizure disorders.

**SIGNS AND SYMPTOMS**

- Slow development of physical, social and learning skills
- Immature rhythms of speech, limited understanding of ideas, and use of words without attachment of common meaning
- Abnormal response to sensation. Sight, hearing, touch, pain, balance, smell, taste, posture of body, any or several of these responses may be affected.
- Abnormal ways of relating to people, objects, events

**EMOTIONAL IMPLICATIONS**

With appropriate training and support, many autistic adults can live and work in the community. All autistic persons can achieve incrementally higher development of independent living skills. Structured home planning and programming is a lifelong requirement for virtually all persons with autism. With support, the family may grow stronger and more cohesive. Services may include respite, support groups, siblings groups and counseling.
**BELL’S PALSY**

**DESCRIPTION**
Bell’s Palsy is a disorder of a facial nerve resulting in partial or complete paralysis of one side of the face. It is usually temporary, though in rare cases is permanent. It may or may not be accompanied by pain.

**SIGNS AND SYMPTOMS**
- Sudden numbness on one side of the face with inability to shut that eye
- Pain on the affected side of the face or ear
- Decrease in saliva and tears
- Sharper hearing
- Drooling, chewing, difficulties
- Facial skin drooping

**EMOTIONAL IMPLICATIONS**
Although not a serious condition in itself it can result in temporary or permanent disfigurement with accompanying psychological problems. The problem may be helpful by surgery to widen the nerve canal if improvement is not seen. Physical therapy may be helpful.
**BIPOLAR AFFECTIVE DISORDER**

**DESCRIPTION**
The sufferer experiences severe mood swings from euphoria to sadness. The cyclic (bipolar) form consists of separate episodes of elation and depression. Bipolar disorder recurs in 80% of consumers. As they age, the attacks come more frequently and last longer. Lifelong medication may help keep symptoms minimal.

**SIGNS AND SYMPTOMS**
- Episodes of elation and giddiness alternate with severe depression
- Taking on many projects which become overwhelming and stressful
- Often outgoing and creative when manic
- Tendency to stay out of social circles when suffering depressive periods
- Inability to cope with everyday tasks with any consistency
- Either unstoppably enthusiastic, or can’t find a reason to get out of bed
- Depression often associated with suicide

**EMOTIONAL IMPLICATIONS**
Mental illness is still stigmatized by the public and media. The consumer may possess extraordinary creative and mental abilities, but due to unpredictable episodes of depression and mania, they tend to avoid dealing with people. A person who appears capable and very talented can be unable to hold a job or cope with life due to recurring episodes of depression. Manic episodes also lead to situations where poor judgment can result in trouble with the law. They tend to be thought of as unreliable, due to mood swings, which prevent them from keeping appointments or being able to regulate the consistency of their concentration. They may be outspoken at times and then retreat into a shell where paranoia and delusions can accompany depression. Although new medications continue to be developed, containing the illness can be quite difficult. Those with less severe cases sometimes prove to be extraordinary in their accomplishments and with treatment can be functional.
**BREAST CANCER**

**DESCRIPTION**
This disorder ranks second only to lung cancer as the leading cause of death in women aged 35-54. It occurs in men, but very rarely. Thanks to earlier diagnosis and expanded treatment options, the five-year survival rate has improved significantly. The cause remains unknown, although a family history of breast cancer is a factor. Many chemicals, from hair dye to household cleaning products have been examined as a cause, with non-conclusive results.

**SIGNS AND SYMPTOMS**
- A lump or mass in the breast
- A hard, stony mass is usually malignant
- Changes in breast symmetry or size
- Thickening of breast skin, itching, burning, erosion or irritation of nipples
- Any sign of discharge in a non-lactating woman

**EMOTIONAL IMPLICATIONS**
For women who have breast cancer, the emotional implications are devastating. Although there are options of breast reconstruction, often times, insurance companies only pay for mastectomies, or removal of the tumor, with no concern for the after effects to the consumer. Body image can be very distorted, sexual image may be negative. The consumer may feel disfigured and angry. Counseling and support groups can be very helpful.
BULIMIA

DESCRIPTION
Consumers with this complaint go on repeated eating binges, followed by periods of regurgitation and/or the overuse of laxatives. It can vary in severity from episodes stretching weeks apart to those who repeat the ritual several times a day. Vigorous exercise and strict diets usually follow.

SIGNS AND SYMPTOMS
- Preoccupation with food and eating
- Periods of strict starvation diets (anorexia)
- Excessive exercise
- Disappearance of the individual after meals
- Use of breath sprays, etc. to cover up the smell of vomit
- Cyclical weight loss and weight gain

EMOTIONAL IMPLICATIONS
Consumer often becomes afraid of losing control over their eating binges, leaving them depressed and in despair. Since there is no known cause to specifically pinpoint this syndrome, treatments are available via hospitalization and therapy. Consumer has often been in this state for sometime prior to contacting anyone for help, and may resist efforts to interfere, as it appears to them that this is another area of control they may lose.
BURNS

DESCRIPTION
Injury to tissue caused by the contact with heat, flame, chemicals, electricity or radiation.

SIGNS AND SYMPTOMS
First degree burns show redness
Second degree show vesication (blisters)
Third degree show necrosis (cell death) through entire skin

EMOTIONAL IMPLICATIONS
A major burn is a horrifying injury, necessitating painful treatment and a long period of rehabilitation. It is often fatal or permanently disfiguring and incapacitating.
CANCER

DESCRIPTION
Cancer is an umbrella term for a group of disorders in which certain cells grow and multiply uncontrollably, eventually forming tumors (masses of tissue). About 100 different kinds of cancer are known. Cancer is caused by external (chemicals, radiation, and viruses) and internal (hormones, immune conditions and inherited mutations) factors. Ten or more years often pass between exposure and detectable cancer. Skin cancer is the most common type of cancer. Basal cell and squamous cell skin cancers tend to develop in sun exposed areas. Malignant melanomas can be fatal and should be treated promptly.

WARNING SIGNS
- Change in bowel or bladder habits
- A sore that does not heal
- Unusual bleeding or discharge
- Thickening or lump in breast or elsewhere
- Indigestion or difficulty in swallowing
- Obvious change in wart or mole
- Nagging cough or hoarseness

A, B, C’S OF SKIN CANCER
- Asymmetrical shape
- Border irregular
- Color varied
- Diameter larger than a pencil eraser

EMOTIONAL IMPLICATIONS
With medical progress producing longer survival periods for many cancer consumers, concerns are expanding to include not only consumer’s physical well being but also their psychosocial needs. Hospice is an excellent resource.
CARPAL TUNNEL SYNDROME (CTS)

DESCRIPTION
CTS may be caused by arthritis, pregnancy, or drugs that cause the body to retain fluids. It may also occur as a repetitive motion disorder, in persons whose occupations require repetitious or prolonged flexing or extending of the wrist, such as musicians, data process and athletes. In mild cases, treatment may consist of resting the hand or varying its movements more often during the day. Consumers may also be given anti-inflammatory drugs or injections of cortisone to reduce swelling. If these treatments are ineffective, surgery may become necessary

SIGNS AND SYMPTOMS
- A prickling or numbness in the hand
- Burning pain
- Decreased hand dexterity
- In severe cases, paralysis

EMOTIONAL IMPLICATIONS
Cases vary, but chronic pain, inability to function at work and carry out daily tasks can force unwanted career decisions and depression.
CEREBRAL PALSY

DESCRIPTION
Cerebral palsy comprises a group of neuromuscular disorders resulting from perinatal CNS damage. Although non-progressive, these disorders may become more obvious as an infant grows older. Three major types of cerebral palsy occur: spastic (spasms), athetoid (repetitive writhing motions), and ataxic (lack of muscle coordination). Motor impairment may be minimal or severely disabling. Common associated defects include seizures, speech disorders and mental retardation. With mild impairment, proper treatment may make a near normal life possible. However, many have normal intelligence.

SIGNS AND SYMPTOMS
- Has difficulty sucking of keeping the nipple or food in their mouths
- Seldom moves voluntary, or has arm or leg tremors with voluntary movement
- Crosses legs when lifted from behind rather than pulling them up or “bicycling” like a normal infant.
- Has legs that are hard to separate, making diaper changing difficult
- Persistently uses only one hand or, as they get older, uses hands well but no legs

EMOTIONAL IMPLICATIONS
Parents may feel unreasonable guilt about their child’s disability and may need psychological counseling. Parents may be over-protective. As they become an adult the parents and the consumer need to work with realistic goals, based on understanding of normal growth and development. Refer to United Cerebral Palsy Association.
CHRONIC FATIGUE SYNDROME

DESCRIPTION
Chronic fatigue syndrome (CFS) is now a recognized medical condition, which can last for years. At one time CFS was known as the “yuppie flu” because it was initially identified most commonly among young professional persons. During the 1980’s many physicians were dismissive of consumer’s complaints. The Epstein-Barr herpes virus is often present in CFS, though the cause remains unknown.

SIGNS AND SYMPTOMS
- Severe fatigue and weakness
- Fever and sore throat
- Swollen lymph nodes
- Confusion, depression, and a reduced ability to concentrate

EMOTIONAL IMPLICATIONS
Because skepticism in the medical community still exists, diagnosis is often overlooked. Lack of support from family and friends can add to feelings of isolation and despair. Recently, a drug called nifedpine, used primarily to treat migraine headaches and hypertension, greatly improves a consumer’s mental outlook.
CHRONIC OBSTRUCTION PULMONARY DISEASE (COPD)

DESCRIPTION
COPD is chronic airways obstruction that usually results from emphysema, chronic bronchitis, asthma or any combination of these disorders. It does not always produce symptoms and causes only minimal disabilities in many consumers. However COPD tends to worsen with time.

SIGN AND SYMPTOMS
Typical consumer has no symptoms until middle age, when ability to exercise or do strenuous work gradually start to decline, and they begin to develop a productive cough. Eventually the consumer develops dyspnea (trouble breathing) on minimal exertion.

EMOTIONAL IMPLICATIONS
Consumer and their family need help to adjust their lifestyles to accommodate the limitations imposed by this debilitating chronic disease. Encouraged daily rest periods and exercise. Consumer needs to express their fears.
CROHN’S DISEASE

DESCRIPTION
An inflammatory disorder affecting any part of the GI tract. (Usually the terminal ileum) and extending through the layers of the intestinal wall. Lymph nodes may also be involved. Possible causes include allergies, immune disorders, infection and genetic factors. Usually striking adults ages 20 to 40. Surgery is often warranted.

SIGNS AND SYMPTOMS
- Right lower abdominal pain
- Cramping
- Tenderness
- Flatulence (gas) and diarrhea
- Nausea, fever
- Mild or severe bleeding in stool

EMOTIONAL IMPLICATIONS
Remember that ileostomy changes the consumer’s body image. Offer reassurance and emotional support. Refer to appropriate support groups. Emphasize the need for strict diet changes and plenty of rest. Identify foods that cause distress and situations likely to add stress to the consumer.
CUSHING’S DISEASE

DESCRIPTION
Cushing’s disease is a disorder that causes the adrenal glands to produce excessive amounts of steroid hormones. It can also be brought on by the chronic use of steroids. The underlying reason may be a tumor of the pituitary, a tiny gland near the brain.

SIGNS AND SYMPTOMS
- Muscle weakness
- Weight gain and redistribution of fat to the trunk and to a “buffalo hump” on the upper back while lower legs and arms become spindly and thin
- Cessation of growth in children
- Menstrual irregularities
- Stretch marks
- High blood pressure
- Bone loss
- Mood swings, depression, irritability
- Hair loss on scalp or growth of body hair

EMOTIONAL IMPLICATIONS
Immediate examination by a physician will determine if cortisol levels are normal. Unchecked it can progress to a serious state. Psychological evaluation may be advised.
**CYSTIC FIBROSIS**

**DESCRIPTION**
Cystic fibrosis is the most serious disease affecting children’s lungs and digestion. Both parents carry a defective gene, which may produce the disease in their offspring. The sweat glands of cystic fibrosis consumers produce unusually salty sweat. Other glands function improperly and secrete as abnormal, thick gluey mucus. This mucus clogs the lungs, causing breathing difficulties and infection that may permanently damage the lungs. The mucus interferes with digestion into the small intestine.

**SIGNS AND SYMPTOMS**
- Sweat gland dysfunction (salty tasting skin)
- Muscular weakness, twitching
- Trouble breathing, wheezing and/or dry, nonproductive cough
- Fast heart rate
- Barrel chest and/or abdominal distension
- Cyanosis (bluish skin)
- Clubbing of finger and toes
- Vomiting
- Malabsorption of fat and protein
- Stools are frequent, bulky, foul smelling and pale
- Poor weight gain but ravenous appetite
- Poor growth
- Sallow skin

**EMOTIONAL IMPLICATIONS**
Since cystic fibrosis has no cure, the aim is to help the child lead a life as normal as possible. The child’s family needs instruction about the disease and its complications. The child’s diet should be low in fat but high in protein and calories, and include supplements of water-miscible, fat-soluble vitamins (A, D, E, and K).
**DESCRIPTION**
Major depression is more severe than grief of the “blues” and lasts longer than normal depression. It is a serious illness tending to interfere with a person’s ability to function. It is most common serious psychiatric illness, affecting 5% of all American adults.

**SIGNS AND SYMPTOMS**
A diagnosis should include at least 5 of these signs every day for two weeks or more:
- Depressed mood
- Irritability
- No interest in activities, including sex
- Insomnia or excessive sleeping
- Agitation
- Fatigue or loss of energy
- Feeling of worthlessness and guilt
- Inability to concentrate or make decisions
- Thoughts of death, suicide or attempted suicide

**EMOTIONAL IMPLICATIONS**
Persons with major depression are at a high risk of suicide and require medication and psychological treatment immediately.
DEVELOPMENTALLY DELAYED CONGNITIVE DISABILITY
(Formally called MENTAL RETARDATION)

DESCRIPTION
Developmentally Delayed is defined as significantly below average general intellectual function coexisting with deficits in adaptive behavior and manifested during the developmental period (before 18).

SIGNS AND SYMPTOMS
Deviations from normal adaptive behaviors.

EMOTIONAL IMPLICATIONS
Developing the consumers’ strengths and adaptive social skills helps them function as normally as possible. Many mentally retarded consumers become productive members of society.
**DIABETES MELLITUS**

**DESCRIPTION**
Diabetes is a chronic insulin deficiency or resistance. It is characterized by disturbances in carbohydrate, protein, and fat metabolism. The condition occurs in two forms: **insulin dependent** (Type I or juvenile-onset diabetes) and the most prevalent **non-insulin-dependent** (Type II or maturity-onset diabetes). Type I usually occurs before age 30 (although it may occur at any age); the consumer is usually thin and will require insulin and dietary management to achieve control. Type II usually occurs in obese adults over 40 and is most frequently treated with diet and exercise.

**SIGNS AND SYMPTOMS**
- Fatigue
- Polyuria (excessive urination)
- Thirst
- Dry mouth membranes and poor skin turgor

**EMOTIONAL IMPLICATIONS**
Consumers most often give their own insulin injections. Many are on a strict prescribed program with their diet. A diabetic consumer has to be very aware of some of the acute complications of diabetes and their treatments. Refer to Juvenile Diabetes Foundation and American Diabetes Association.
**DIVERTICULAR DISEASE**

**DESCRIPTION**
Diverticular disease is caused by fecal matter seeping through the thin walled diverticular, which causes a bulging pouch-like inflammation in the GI wall of the large intestine. Mild and moderate attacks are treated with bed rest and antibiotics. Severe attacks require surgery. An opening between the colon and body surface is created to rest the bowl for about 6 months.

**SIGNS AND SYMPTOMS**
- Constipation and diarrhea alternate
- Mild nausea and gas
- Low-grade fever
- Recurrent left lower abdominal pain is relieved by defecation or flatus

**EMOTIONAL IMPLICATIONS**
In most cases, distress can be managed with medications and dietary changes. Consumer must understand the importance of additional dietary fiber. If needed, arrange for lessons in colostomy care.
**DOWN’S SYNDROME**

**DESCRIPTION**
Down’s syndrome is a congenital condition (chromosome 21) characterized by varying degrees of mental retardation and multiple defects. Up to one third die before they are 10 years old.

**SIGNS AND SYMPTOMS**
- Diminished tone of skeletal muscles
- Mental retardation (IQ 30-50)
- Abnormal craniofacial structure
- Short stature
- Short extremities with broad, flat and squarish hands and feet
- Small inward-curving little figure
- Wide space between first and second toe
- Abnormal fingerprints and footprints
- Impaired reflex development, posture, coordination and balance
- Delayed puberty
- High susceptibility to acute and chronic infections

**EMOTIONAL IMPLICATIONS**
Support of the parents of a child with Down’s syndrome is vital. Parents need to know the importance of diet as many times the child has difficulty with sucking and may be less demanding and seem less eager to eat than normal babies. The child needs to be held and nurtured even though their first reaction is to reject. Exercise and mental stimulation is important. Parents need assistance in setting realistic goals for the child. Finally parents need to be warned not to overlook the emotional needs of other children or the family.
DYSLEXIA

DESCRIPTION
Dyslexia, also known as congenital word blindness, is a sequencing disorder of the brain, causing an inability to solve problems with multiple steps. There is also language dysfunction, characterized by poor reading comprehension.

SIGNS AND SYMPTOMS
- Inability to read, despite normal or above average intelligence
- Difficulty in spelling
- Handwriting abnormalities, especially reversing letters
- Poor hand-eye coordination

EMOTIONAL IMPLICATIONS
Much support is needed for consumers with this common disorder. Feeling of helplessness, inability and stupidity are common. Adults often show little patience with children who have this disorder, deducing poor study habits and bad behavior as the cause.
EHLERS-DANLOS SYNDROME

DESCRIPTION
A rare genetic disease, it is sometimes called “Loose Jointedness”. Usually beginning in childhood, the consumer can dislocate, contort and maneuver the joints of the body with no pain or effort. It is looked on by others as a special “ability” it often goes undiagnosed until later in life. It is an abnormality of the body’s collagen and connective tissues. Sometimes this results in a mere increased flexibility, but in other forms, the disease can devastate the inner organs of the body, including heart, lungs, kidneys, etc.

SIGNS AND SYMPTOMS
Abnormal flexibility
Looseness of the skin
Popping joints
Varicose veins at an early age
Easy bruising and scarring

EMOTIONAL IMPLICATIONS
The emotional implications can vary in consumers. Those with milder forms that have not attacked their inner organs may find slight adjustments in lifestyle will suffice, such as not running or taxing already lax joints. Others must undergo surgery for the problem. The disorder tends to make the consumer look as if he is aging prematurely, and can be depressing.
EPILEPSY

DESCRIPTION
Epilepsy is a chronic medical condition produced by sudden changes in the electrical function of the brain. A generalized seizure (when all brain cells are involved) is a convulsion, with complete loss of consciousness. A partial seizure (electrical changes limited to one part of the brain) involves involuntary movements or temporary changes in the way things look, taste, feel, or smell.

SIGNS AND SYMPTOMS
- Periods of blackout or confused memory
- Distorted perceptions, episodic feelings of fear or apprehensions that cannot be explained
- “Fainting spells” with incontinence followed by excessive fatigue
- Episodes of starving children; unexplained periods of unresponsiveness in a child
- Episodes of blinking or chewing at inappropriate times
- Involuntary movements of arms and legs
- Any convulsion with or without fear

EMOTIONAL IMPLICATIONS
Epilepsy can be treated with medications. Consumers with epilepsy face misunderstanding and hostility in many areas of their lives, dating back hundreds of years when they were persecuted or isolated because of myths and superstition surrounding the condition. Refer to Epilepsy Foundation of America.
FIBROMYALGIA

DESCRIPTION
Fibromyalgia indicates pain in fibrous tissues, muscles, tendons, ligaments and other “white” connective tissues. This condition occurs mainly in females. It may be induced or intensified by physical or mental stress, poor sleep, trauma, exposure to dampness or cold, and occasionally by a systemic, usually a Rheumatic, disorder.

SIGNS AND SYMPTOMS
- Stiffness and pain frequently are gradual, diffused
- Pain aggravated by straining or overuse
- Symptoms can be sudden and acute
- May be local tightness or muscle spasms
- Irritable bowl symptoms

EMOTIONAL IMPLICATIONS
Symptoms can be exacerbated by environmental or emotional stress, or by a physician who does not give proper credence to the consumer’s concerns and discharge the matter as “all in the head.” Fibromyalgia is particularly likely to occur in healthy young women who tend to be stressed, tense, depressed, anxious and striving. It also can occur in adolescents (particularly girls) and older adults. Relief may be obtained from important supportive measures, such as reassurance and explanation of the benign nature of the syndrome measures, as well as stretching exercises, improved sleep and local application of heat and gentle massage.
GUILLIAN-BARRE SYNDROME

DESCRIPTION
(Pronounced ghee yan-bah ray) This is an acute nerve disease damaging nerves throughout the body resulting in weakness, numbness and sensory loss in extremities, and finally paralysis. Onset of illness sometimes follows a small viral infection, sore throat, or flu. Symptoms become apparent in 1 to 3 weeks. It is usually temporary but can result in respiratory failure and death or permanent paralysis. No cause is known.

SIGNS AND SYMPTOMS
- Tingling and numbness in extremities
- Rapidly progressive muscular weakness
- Impaired eating and swallowing
- Difficultly breathing
- Paralysis of affected muscles

EMOTIONAL IMPLICATIONS
Hospital admission is usually required. Mechanical ventilation may be required. Paralysis usually peaks in 2 to 3 weeks. Extended rehabilitation is usually required and some consumers must relearn tasks like walking, eating, and cooking. About 10% of consumers continue to have chronic problems.
GRAVE’S DISEASE

DESCRIPTION
Grave’s disease is a metabolic imbalance resulting from excessive thyroid hormone. The most common form, results in enlargement of the thyroid gland (goiter). An acute exacerbation of hyperthyroidism is considered life threatening and an emergency.

SIGNS AND SYMPTOMS
- Enlarged thyroid
- Nervousness
- Heat intolerance
- Weight loss, despite increased appetite
- Sweating
- Diarrhea
- Palpitations
- Shaky handwriting

EMOTIONAL IMPLICATIONS
Since Grave’s disease involves such a wide range of physical complications, including nervousness and pain, the consumer may suffer from a sense of helplessness. The consumer may choose to isolate themselves at their home rather than to deal with the onset of symptoms in a social situation. Strong support from family and friends can be highly beneficial. Loss of sleep may lead to depression and might require treatment by a physician or psychologist.
DESCRIPTION
Hearing loss, results from mechanical or nervous system impediment to the transmission of sound waves. It is classified as conductive, sensorineural, or mixed. In conductive loss, transmission of sound impulses from the external ear to the junction of the stapes and oval window is interrupted. In sensor neural loss, impaired cochlear or acoustic (eighth cranial) nerve function prevents transmission of sound impulse within the inner ear or brain. In mixed hearing loss, conductive and sensor neural transmission dysfunction combine.

EMOTIONAL IMPLICATIONS
Deafness does not reflect one’s intellect. Persons with a hearing impairment are not “deaf and dumb”. Many deaf persons speak but cannot regulate the control, the tone and the volume of their voices. Because some deaf individuals have received negative reactions to their voices, they choose not to use their voice. Very few deaf people read lips well enough to carry on everyday communication or obtain information and knowledge. Half of the sounds of the English language look just like some other sound on the lips (bump-pump). Most deaf people can communicate effectively by writing notes and using sign language.
HEART DISEASE

DESCRIPTION
The most common heart diseases are hypertension, coronary, rheumatic, cerbrovascular accident, and congestive heart failure.

SIGNS AND SYMPTOMS
- Dyspnea (difficulty breathing)
- Chest pain
- Edema
- Palpitation (rapid, forceful or irregular)
- Hemoptysis (coughing up blood)
- Fatigue
- Fainting
- Cyanosis (bluish skin)
- Abdominal pain or discomfort
- Distension of neck veins
- Clubbing of fingers

EMOTIONAL IMPLICATIONS
The consumer with heart disease sees a tremendous alteration in their lifestyle. Inability due to the extent of disease, fear, or lack of knowledge can cause overprotection by spouses, family members, and friends and loss of autonomy and independence. Restriction on cigarettes, alcohols, or food can make a consumer feel even more deprived. In many instances, these alterations isolate them from friends and family at the time when they need companionship most.
HEMOCHROMATOSIS
(IRON OVERLOAD)

DESCRIPTION
This condition occurs when a person suffers from too much iron in the blood and tissues. It usually results from a liver disorder, such as cirrhosis or liver cancer. Cardiac arrhythmia’s often develops as a result. When the body cannot utilize the iron and begins to store it, the resulting damage to organs can be irreversible.

SIGNS AND SYMPTOMS
- Abdominal swelling and tenderness
- Darkening of the skin
- Weight loss, poor appetite
- Arthritis-like joint pain
- Possible congestive heart failure
- Diabetes
- Lethargy

EMOTIONAL IMPLICATIONS
Treatment for Hemochromatosis is bloodletting, or removing 500 milliliters (15oz.) once or twice a week until iron levels return to normal.
HEMOPHILIA

DESCRIPTION
Hemophilia is an inherited disorder of blood clotting. A person with hemophilia has less clotting factor than usual. They do not bleed any faster than normal but will have prolonged bleeding because they cannot make a firm clot. It affects males almost exclusively and is passed on by women who usually have no bleeding or clotting problems. In the early 1980’s the blood supply was heavily contaminated with the HIV virus. As a result, over 90% of people with hemophilia contracted the HIV virus from transfusions received during that time.

SIGNS AND SYMPTOMS
- Skin bruises and bleeding in toddlers from bumps and falls
- Hemorrhages may involve muscles and joints with painful swelling or a lack of movement of an arm or leg
- Any abnormal bleeding
- Bleeding into the bowels and urine

EMOTIONAL IMPLICATIONS
Because hemophilia has no cure, it has lifelong implications on the consumer’s life. Regular visits to the same healthcare provider are important. Family planning is strongly suggested because this is an inherited condition. Even though early treatment of bleeding has resulted in less complications, and better quality of life, hemophilia can still be a painful illness and produce considerable family stress.
HEPATITIS

DESCRIPTION
Hepatitis is a condition of liver inflammation most often due to a virus or the complication of another disease such as mononucleosis. There are 3 different viruses causing it. Hepatitis A is the most infectious. It causes epidemics and is usually due to fecal contaminated food, water, or raw shellfish. Hepatitis B is transmitted by direct contact with blood from an infected person. Hepatitis C is also spread through blood contact.

SIGNS AND SYMPTOMS
- Appetite loss and nausea
- Fever, chills, and sweating
- Weakness
- Abdominal swelling and tenderness
- Jaundice (yellow eyes and skin)
- Darkened urine and light stools

EMOTIONAL IMPLICATIONS
Support from family and friends during recovery can ease feelings of isolation and depression. Scrupulous hygiene is required along with plenty of rest and avoidance of stress.
HERPES ZOSTER (SHINGLES)

DESCRIPTION
An inflammation of the nerves, the disorder usually appears in adults over age 40, resulting in skin lesions confined to the skin, and severe neuralgic pain in other areas. It is a skin condition caused by the same V-Z herpes virus that causes chicken pox.

SIGNS AND SYMPTOMS
- Fever
- Malaise
- Deep pain
- Unusual sensitivity
- Numbness in arms, legs and trunk
- Lesions become scabs several days after appearance
- Pain continues
- Small red modular skin lesions

EMOTIONAL IMPLICATIONS
Shingles can radically alter the lifestyle of the consumer, causing severe pain, an inability to be touched or even clothed. Consumers need to remain comfortable and hygiene must be emphasized. Neuralgic pain will require analgesics. Sometimes consumers experience such horrible pain that they can no longer continue regular activity. The disease may go into remission, with recurring episodes. Terrible pain makes the consumer irritable, isolated and often terrified.
HODGKIN’S DISEASE

DESCRIPTION
A lymphatic cancer marked by painless, progressive enlargement of lymph nodes, spleen and other lymph tissue. Left untreated, Hodgkin’s follows a relentless and ultimately fatal course. Although the exact cause is unknown, recent breakthroughs make it highly treatable with 90% five-year survival rate.

SIGNS AND SYMPTOMS
- Painless swelling in one of the lymph nodes
- Persistent fever
- Night sweats
- Fatigue
- Weight loss
- General malaise and depression

EMOTIONAL IMPLICATIONS
Because the consumer with Hodgkin’s is usually healthy when therapy begins, he may be especially distressed. They should be provided emotional support. Ease anxiety by sharing your optimism about his prognosis. The consumer must understand and comply with the self-care regimen for radiation and chemotherapy. He must familiarize himself with the adverse affects of treatment and notify his doctor. Make sure both the consumer and his family knows that local chapters of the ACS and Leukemia Society of America are available for information, financial assistance and supportive counseling.
HORNER'S SYNDROME

DESCRIPTION
Horner’s syndrome is not a disease in itself, but rather a collection of physical abnormalities that appear together as the result of an underlying medical problem. The condition typically affects one side of the face, particularly the eye. The eyeball sinks in, the upper eyelid droops, and one side of the face becomes slack, producing little or no perspiration.

SIGNS AND SYMPTOMS
- The pupil of one eye becomes smaller than the other
- One side of the face is flushed red and does not sweat
- The upper eyelid of the affected eye droops and the eye appears sunken.

EMOTIONAL IMPLICATIONS
While Horner’s disease in itself is not life threatening, its cause may be a serious underlying condition. Its diagnosis will require a physical examination with particular emphasis on the eye and spinal cord as soon as possible.
**DESCRIPTION**

Huntington’s disease (formally called Chorea) is an inherited brain and nerve disorder. Symptoms are progressive and ultimately lead to death. Mild symptoms usually show up at ages 35 to 45. The disease destroys brain cells and leads to tics, twitches, slurred speech and irritability. Over 20-30 years will eventually include violent muscle spasms, dementia, paralysis and death.

**SIGNS AND SYMPTOMS**

- Tics, twitches and muscle spasms
- Irritability, depression, change of personality
- Outburst or unexplained anger
- Fidgety movements
- Unsteadiness of walk and hand movements
- Slurred speech, swallowing difficulties
- Dementia, which may be mild at first, eventually severely disrupts the personality
- Ultimately, musculoskeletal control is lost

**EMOTIONAL IMPLICATIONS**

Since Huntington’s disease is hereditary, those who are at risk are usually on the lookout for any symptoms heralding its onset. Drug treatment may improve some symptoms, both emotional and physical therapy may be useful. Because of speech problems, the consumer will need extra time to express themselves. They feel very frustrated, depressed, out of control and may be suicidal. Many times they will have to be put in an institution because of mental deterioration. For information contact the National Huntington’s Disease Association.
HYPERTENSION

DESCRIPTION
Hypertension is an intermittent or sustained elevation in diastolic or systolic blood pressure. It represents a major cause of cerebrovascular accident, cardiac disease, and renal failure. Since high blood pressure can occur with or without symptoms, certain risk factors have been identified.

RISK FACTORS AND SIGNS
- Family history of hypertension
- Race (more common in African – American)
- Stress
- Obesity
- Dietary intake of saturated fats and sodium
- Tobacco use
- Using oral contraceptives
- Secondary life-style

EMOTIONAL IMPLICATIONS
Although hypertension has no cure, modification in diet and life-style as well as drug therapy can control it. Offer support with diet and weight management.
DESCRIPTION
When the thyroid gland produces too much hormone, it causes the body’s metabolism to speed up, inducing weight and hair loss, rapid heartbeat, heightened body temperature and other symptoms related to an overactive nervous system.

SIGNS AND SYMPTOMS
- Irritability and nervousness
- Weight loss in spite of ravenous appetite
- Fatigue and weakness
- Hair loss
- Intolerance to heat
- Frequent, loose bowel movements
- Thinning of the skin, especially on the face
- Swelling of the neck
- Bulging eyes

EMOTIONAL IMPLICATIONS
Nervousness, fatigue and irritability often result in depression. Radioactive iodine or surgery and lifelong hormone treatment will improve outlook and symptoms.
IRRITABLE BOWEL SYNDROME

DESCRIPTION
The common syndrome is marked by chronic or periodic diarrhea, alternating with constipation, and cramps. Because this disease resembles several others, a careful history must be taken to rule out psychological factors such as stress, or a more serious gastrointestinal disorder. Prognosis is good. Supportive treatment and avoidance of known irritants often relieves symptoms.

SIGNS AND SYMPTOMS
- Lower abdominal pain, sometimes relieved by defecation or passage of gas
- Constipation and diarrhea, usually within the same day
- Small stools that contain visible mucus
- Heartburn
- Abdominal distention and bloating

EMOTIONAL IMPLICATIONS
Therapy is used to relieve symptoms and should include counseling to help the consumer understand the relationship between stress and their condition. If the cause of illnesses chronic laxative abuse, bowel training may help.
LUPUS

DESCRIPTION
Lupus is a chronic autoimmune disease, which causes an inflammation of various parts of the body, especially the skin, joints, blood and kidneys. There are three types of lupus: discoid, systemic and drug-induced. Discoid lupus is always limited to skin. It is identified by a rash with raised, red, scaly area most commonly on face, neck and scalp. In approximately 10 percent of consumers, discoid lupus can evolve into the systemic form of the disease. Systemic lupus is more severe and can affect almost any organ or system of the body.

SIGNS AND SYMPTOMS
- Achy joints
- Fever over 100 degrees F
- Arthritis (swollen joints)
- Prolonged fatigue
- Skin rashes
- Anemia
- Kidney involvement
- Chest pain on deep breathing
- Butterfly-shaped rash across the cheeks and nose
- Sun or light sensitivity
- Hair loss
- Raynaud’s phenomenon (fingers turn white or blue in cold)
- Seizures
- Mouth or nose ulcers

EMOTIONAL IMPLICATIONS
There is a lack of understanding about the impact that the lupus has on consumers’ lives, because it is a life-long, persistent, ever-present illness. Many times it is hard for the consumer to hold down a job as there are periods of remission and then other times when the disease flares up. Also because of the consumers susceptibility they have to be aware of colds or infections when they are around other people.
**LYME DISEASE**

**DESCRIPTION**
Lyme disease is an infection of the bacteria *Borelia burgdorferi*. It is carried by the species of tick that feeds on mice, deer, birds and other animals. It is contracted by attachment of a tick to a human, usually while hiking or participating in outdoor activities.

**SIGNS AND SYMPTOMS**
- A red, raised, circular rash at the site of the tick bite
- Flu-like symptoms often follow
- Months later, additional symptoms such as arthritis, heart block and nerve problems can develop.

**EMOTIONAL IMPLICATIONS**
Since many consumers are not aware of a tick bite, the disease may develop for some time before being treated. Oral antibiotics are used first, and in most cases symptoms begin to clear up in about a month. In tough cases, intravenous antibiotics are required along with hospitalized supervision. Depression may develop as the disease can take up to a year or more to cure.
MARFAN SYNDROME

DESCRIPTION
The Marfan syndrome is a heritable disorder of the connective tissue that affects many organ systems, including the skeleton, the lungs, the eyes, heart and blood vessels.

SIGNS AND SYMPTOMS
- Tall, thin stature with disproportionately long arms
- Unusually long lower half of body
- Long, double-jointed fingers, including an elongated thumb
- Curvature of the spine
- Chest bone that curves either inward or outward
- Flatfeet
- Backward curve of the legs at the knee
- Nearsightedness (lens of the eye are prone to dislocation)
- Abnormal heart sounds

EMOTIONAL IMPLICATIONS
The parents of a child suffer guilt because it is inherited. Consumers with the syndrome have to avoid strenuous exercise and contact sports because of the risk of injury to the aorta. Parents need to encourage normal adolescent development rather than having unrealistic expectations for the child because he is tall and looks older then he is. Refer to Marfan National Foundation.
MENIERE’S DISEASE

DESCRIPTION
Meniere’s is a disease of the inner ear with periods of dizziness (vertigo), nerve deafness, and buzzing or ringing in the ear. The cause is not known. Sudden movements often worsen dizziness. The person should have help while walking. Attacks can last from a few minutes to several hours. In severe cases, surgery on the nerve linked to balance may be required.

SIGNS AND SYMPTOMS
- Vertigo, dizziness
- Pressure in one or both ears
- Mild to severe hearing impairment
- Ringing in the ears

EMOTIONAL IMPLICATIONS
Although a variety of medications have been developed for use, recurring episodes can occur every few days, weeks, or months. Consumers who suffer frequent attacks usually have less severe symptoms but suffer greater long term hearing loss. This can result in depression, confusion and irritability. Rehabilitation may be useful.
MIGRAINE HEADACHES

DESCRIPTION
Migraine headaches, although common, indicate an underlying intracranial, systematic or psychological problem. Throbbing, vascular headaches affect up to 10% of Americans. They usually begin in childhood and recur throughout adulthood. More females are affected than men.

SIGNS AND SYMPTOMS
- Fatigue, nausea, vomiting and fluid imbalance sometimes occurring about a day before the headache
- Sensitivity to light and noise
- Aching and throbbing headaches

EMOTIONAL IMPLICATIONS
Help the consumer understand the reason for headaches so they can avoid exacerbating factors. Keeping a log of headaches will be useful. During an attack it is important that consumer retire to a dark, quite room. Medications have become increasingly effective in both treatment and prevention of migraines.
**MULTIPLE MYELOMA**

**DESCRIPTION**
Cancerous marrow plasma cells invade the bone causing lesions throughout the skeleton. This is followed by infiltration of the liver, spleen, lymph nodes, lungs, adrenal glands, kidneys and skin. Prognosis is poor due to the fact the disease has usually done extensive damage prior to its diagnosis.

**SIGNS AND SYMPTOMS**
- Constant severe back pain increasing with exercise is the earliest sign
- Swelling and aching in joints
- Tenderness
- Fever

**ADVANCED SYMPTOMS**
- Anemia
- Weight loss
- Deformities
- Obvious loss of height

**EMOTIONAL IMPLICATIONS**
Provisions need to be made for the consumer and their family’s emotional support. It may help relieve anxiety by truthfully informing them about diagnostic tests, including painful procedures such as bone marrow and biopsy treatment. Refer them to a support group or community resource.
MULTIPLE PERSONALITY DISORDER

DESCRIPTION
This is a medical condition defined as when there are two or more distinct personalities coexisting in a single person. Many cases have been portrayed in movies and the news, but most cases the differences in personalities are less obvious and go unrecognized for years. Only one personality is expressed at a given time and change from one to the other is usually dramatic. Despite the increased public awareness of the disease, it remains rare.

SIGNS AND SYMPTOMS
- A person displays two or more personalities that alternate repeatedly
- Memory lapses or “black outs” for periods of time
- Headaches

EMOTIONAL IMPLICATIONS
While a few people manage to function in society, most find life rather difficult to deal with and have trouble functioning on a normal level. The treatment of this disorder is complex and lengthy; though it can be successful in some cases. The consumer, aware that they suffer from this disorder is often stigmatized by the others as “crazy” and can suffer from isolation and depression. Untreated, it often leads to suicide, criminal behavior and transient lifestyle.
MULTIPLE SCLEROSIS

DESCRIPTION
A major cause of chronic disability in young adults, multiple sclerosis (MS) results from progressive demyelination of the white matter of the brain and spinal cord.

SIGNS AND SYMPTOMS
- Visual disturbances
- Sensory impairment such as paresthesias (morbid or perverted sensation)
- Muscular dysfunction (monoplegia to quadriplegia)
- Urinary disturbances
- Mood swings
- Poor articulation
- Difficulty swallowing

EMOTIONAL IMPLICATIONS
Most consumers lead active productive lives with prolonged remissions. Consumers must try to avoid stress, infections and fatigue and to maintain independence by developing new ways of performing daily activities.
MUNCHAUSEN SYNDROME
MUNCHAUSEN SYNDROME BY PROXY

DESCRIPTION
Consumers with Munchausen’s syndrome feign, exaggerate, or actually self-induce illness. In Munchausen’s Syndrome by Proxy, an individual makes another person sick. Tragically, this is a form of abuse in which children are the usual victims and the perpetrators are almost always a parent or parent substitute. They deliberately mislead others into thinking they (or their children) have serious medical or psychological problems, often resulting in extraordinary medication trials, diagnostic tests, hospitalizations, and even surgery that they know are not needed.

SIGNS AND SYMPTOMS
- Pathological lying
- Moving from place to place
- Feigned or simulated illness
- Antisocial personality traits
- Unusually calm during diagnostic procedures, treatments or operations
- Evidence of self-induced physical signs
- Knowledge of or experience in a medical field
- Multiple hospitalizations
- Multiple scars
- A child who does not respond to treatment or who has an unusual cause that is persistent, and unexplained
- Laboratory findings that do not match history or are clinically impossible
- Leaving the hospital against medical advice
- A parent who is reluctant to leave their child’s side and the signs and symptoms of the illness do not occur in the parent’s absence
- A parent, who is angry, demands further intervention, more procedures, second opinions, and often transfers to other more sophisticated facilities
- A parent who is medically knowledgeable and/or fascinated with medical details and hospital gossip, and appears to enjoy the hospital environment
EMOTIONAL IMPLICATIONS
Although Munchausen’s syndrome has not received the attention or advocacy among professionals as more common disorders like depression, it is a disorder that can be every bit as disabling. Further public and professional education is vital. Ethical and legal issues regarding the measures that may have to be used for establishing the diagnosis of a Munchausen’s disorder complex.

The prognosis remains poor as most of the consumers disappear before treatment can be initiated. Those who have been studied have all had an unhappy, unloving childhood. Their early home life is often abusive and neglectful. As adults they seek nurturing for what they lacked in childhood. They have usually had some experience in a hospital in which they were able to trick or manipulate the medical staff, which seems to satisfy their need for attention, even if this behavior puts them at risk.
MUSCULAR DYSTROPHY

DESCRIPTION
Muscular dystrophy includes over 40 inherited conditions distinguished by the type of inheritance factors such as dominant or recessive genes; the age of onset ranging from birth to 50+ adulthood; the types of symptoms that develop and the rate of progression, and life expectancy may be only 2 years to early 20’s. Other types have slow progression that has little impact on life span. Mechanical or non-invasive ventilation is sometimes required. Some of the more common types are Duchene’s, Becker’s, Limb-Girdle, Facioscapulohumeral, and Spinal Muscular Atrophy. ALS and Myasthenia Gravis are also forms of Muscular Dystrophy. A muscle biopsy is the primary test used to confirm the diagnosis.

SIGNS AND SYMPTOMS (Varies with each diagnosis)
“Floppy” arms and legs of babies; weak cry
Delayed muscle skills
Delay in walking
Frequent falling; “waddling” gait; poor balance
Problems swallowing and chewing
Skeletal and / or muscle deformities
Wasting (atrophy) of muscle tissue
Progressive muscle weakness
Joint contractors
Sensation is usually normal
Muscle pain and cramping
Respiratory complications
Cardiac complications
Intellectual retardation in some forms, other types may have increased mental abilities

EMOTIONAL IMPLICATIONS
There is no known cure for Muscular Dystrophy. Treatment is aimed at controlling symptoms to maximize the quality of life. Physical therapy may be helpful to maintain muscle strength and functioning. Emotional support is needed to deal with continual changes in body images. Emotional and practical support at home and at school are vital to the well being of a person living with a neuromuscular disease. Family members need to communicate because of the strain of this disease. A child with any form of Muscular Dystrophy needs peer relationships. Children need to realize their intellectual potential through school and social activities. Joining support groups where members share common experiences and problems can often help the stress of Muscular Dystrophy for the consumer and family members. Contact the Muscular Dystrophy Association for more information. www.mdausa.org
**MYASTHENIA GRAVIS**

**DESCRIPTION**
Myasthenia gravis is a chronic neuromuscular disease that produces weakness and rapid fatigue of voluntary muscles. Various skeletal muscles are involved, especially those controlling the eyes, face, neck, throat, and limbs. Onset can be any age from youth adulthood and is twice as common in women. It is an autoimmune disorder in which the body’s immune system, normally a protection against bacteria and illness, generates an attack against its own skeletal muscles. It has been linked to drug reactions and organ transplants.

**SIGNS AND SYMPTOMS**
- Weakness and dropping of eye muscles or eyelids
- Blurred or double vision
- Chewing and swallowing problems
- Difficulty talking
- Weakness in arms, hands, and fingers
- Difficulty breathing
- Difficulty standing and walking

**EMOTIONAL IMPLICATIONS**
Although it can be fatal if muscle weakness interferes with respiration, it is more commonly a chronic progressive disease. Drug therapy and / or removal of the thymus gland often are effective. Even when treated, it can be psychologically disturbing. The consumer never knows when a symptom will worsen. Limited co-ordination can render some consumers unable to work or care for themselves.
OBSESSIVE-COMPULSIVE DISORDER

DESCRIPTION
This is a mood disorder consisting of obsessive thoughts and compulsive behaviors thought to represent efforts to control overwhelming anxiety. Obsession is the recurrent idea and compulsive the ritual behavior repetitive and involuntary. Compulsive behaviors are repeated because they reduce the anxiety associated with the obsession.

SIGNS AND SYMPTOMS
- Repetitive touching
- Doing and undoing things
- Rearranging things
- Checking to be sure tragedies have not occurred

EMOTIONAL IMPLICATIONS
Obsessions and compulsions cause significant distress in consumers and may severely impair occupational and social functioning. This disorder is usually chronic, with remissions and flare-ups. Prognosis is better than average when symptoms are defined early and treated.
OSTEOPOROSIS

DESCRIPTION
Osteoporosis is a metabolic bone disease in which the rate of bone resorption accelerates while rate of bone formation slows down causing a loss of bone mass. It is a condition that affects 25% of women over the age 60, and is much less common and not as severe in men. It is more common after menopause, when estrogen levels decline. Bones weakened by osteoporosis are easily broken.

RISK FACTORS
- Thin body frame
- Asian or Caucasian race
- Family history
- Inactivity
- Women who smoke or drink

SIGNS AND SYMPTOMS
- Symptoms may occur suddenly when an elderly person stoops down to lift something and hears a sudden snapping sound and feels pain in the lower back
- Hip or lower back pain
- Painful swelling of a wrist after a fall
- Loss of height
- Markedly aged appearance

EMOTIONAL IMPLICATIONS
Consumer has to be very careful about falling as fractures happen quite often and they can be prevented.
DESCRIPTION
Parkinson’s disease is a common disorder of the brain caused by damage to a part of the brain that controls the muscles, which control posture, balance, and walking. It is a chronic disease. Untreated, the disorder progresses to total disability, accompanied by general deterioration of all brain functions and may result in an early death. There is no known cure so treatment is aimed at controlling the symptoms. Many of the medications can cause severe side effects, so monitoring and follow-up are very important.

SIGNS AND SYMPTOMS
- Earliest signs may be nonspecific and include weakness, and fatigue.
- Tremor of resting hands; finger-thumb rubbing (pill-rolling tremor)
- Difficulty walking
- Muscle rigidity
- Slow, low-volume, monotone voice
- Drooling
- “Mask-like” facial expression
- Walks with body bent forward
- Trouble eating and swallowing
- Inability to open eyelids, or to keep them open

EMOTIONAL IMPLICATIONS
The consumer has problems with their activities of daily living, as the disease has a profound impact on their lifestyle. They need long and short term goals and need intellectual stimulation and diversions. Depression occurs in half of people with Parkinson’s. Refer to the American Parkinson’s Disease Association.
**PORPHRIA**

**DESCRIPTION**
Often considered an undiagnosed disease, porphyria is a neurological disorder brought on by many cases, including reactions to toxins and chemicals, including prescription drugs which include antidepressants, antibiotics, or environmental toxins such as pesticides, household cleaners, and smog, make up and detergents. It can take on many forms and can also be inherited by a parent with the disease. Treatment usually involves removing the consumer from the irritants that cause these symptoms, which is often difficult to do. It is actually caused by the inability of the liver to synthesize drugs and toxins. The disease is actually a set of related diseases, including respiratory problems, skin conditions, gastrointestinal complications, and problems with ear, nose and throat disorders. It sometimes leads to MS or other serious diseases and complications. This disease is not understood fully by the medical community, and many doctors remain uneducated on the disease, its symptoms and the treatment. Sometimes other drugs are prescribed which actually exacerbate the problems.

**SIGNS AND SYMPTOMS**
- Gastric pain with no apparent cause
- Skin rashes and sensitivity to sunlight
- Inability to digest food
- Diarrhea
- Nerve pain
- Upper respiratory infections
- Malaise
- Depression

**EMOTIONAL IMPLICATIONS**
The consumer often goes from doctor to doctor, usually beginning with gastric pain, and after doctors find no obvious underlying cause, they refer the consumer to psychiatrists and psychologists, or prescribe drugs which increase the pain and add new symptoms. The average consumer with porphyria is someone who has obviously been dealing with a long drawn out set of illnesses.

The lack of sensitivity to this condition in the medical community leads many people with severe symptoms to question their sanity, or become frustrated, depressed and sometimes suicidal. Treatment of this illness has improved, but many doctors remain uneducated, as the disease strikes more and more people.
Considered an age-old disease, inherited in Europe in past centuries, many suffers have inherited it through European lineage. With the increase in environmental toxins, other ethnic groups are now vulnerable to it as well. It is important to reassure the consumer about their sanity, and to let them know that the symptoms are not a delusion. Support groups are forming, and information on this disease is becoming readily available through sources such as the internet. Consumers may contact others suffering and access further information about their illness and its many forms through the newly formed Porphyria Foundation.
**POST POLIO SYNDROME**

**DESCRIPTION**
1.6 million Individuals were affected by polio during the epidemics of the 1940’s and 50’s with 640,000 living in the U.S. today. Approximately 40% will develop effects of Post Polio Syndrome. It generally occurs 30 to 40 years after the initial onset, affecting individuals who, during their acute attack, were hospitalized; were at least 10 years old; had more than two limbs affected; and required the use of a ventilator. The progressive muscular weakness is thought to result from further dysfunction or death of motor units.

**SIGNS AND SYMPTOMS**
- Difficulty swallowing
- Muscle and joint pain
- Weakness in muscles previously affected by polio
- Weakness in muscles previously thought to be unaffected by polio
- Breathing problems
- Fatigue

**EMOTIONAL IMPLICATIONS**
Because these individuals felt they had “beaten” polio, re-experiencing the pain and weakness is traumatic. They may feel like they are “crazy” reliving the fear and anxiety associated with the initial attack. Many polio survivors who have lived full and productive lives for 30+ years may have to return to using canes, crutches, or wheelchairs. Others who had been weaned from mechanical ventilation during the acute stage of polio now find it necessary to use a ventilator while sleeping. The changes require psychological flexibility and an open mind dealing with their emotions.
POST – TRAUMATIC STRESS DISORDER

DESCRIPTION
War is one common cause of this disorder, although any survivor of a natural disaster, accident or close brush with death can develop the disorder. Abused children often suffer as adults, along with victims of rape or other violent crimes.

SIGNS AND SYMPTOMS
- Recurrent recollections of dreams of a traumatic experience
- Avoidance of thoughts or places associated with the event
- Detachment from others
- Lack of interest or normal activity
- Sleep problems, nightmares
- Irrational or compulsive behavior
- Impaired memory, amnesia
- Violent outbursts or extreme startling responses
- Guilt for survival

EMOTIONAL IMPLICATIONS
Although it can be overcome, and the majority of people do have remission from this behavior after counseling, and time has passed, some are so traumatized that they end up harming themselves or others. In these instances the syndrome can be extremely dangerous. Counseling and support groups may be helpful, especially in the case of war trauma, rape victims and witnesses to murder or other violence.
REITER’S SYNDROME

DESCRIPTION
Reiter’s syndrome is an immunologic disorder that sometimes follows infection with a sexually transmitted organism such as Chlamydia. 1 to 3% of consumers experience this change in the immune system from these infections. Often incurable, symptoms can go into remission.

SIGNS AND SYMPTOMS
- Signs of a sexually transmitted disease, such as discharge or genital sores
- Arthritic type symptoms, pain in joints, hands, knees
- Rashes, redness or scaly patches of skin
- Chronic pain and soreness

EMOTIONAL IMPLICATIONS
Since Reiter’s syndrome usually follows a sexually transmitted disease, some embarrassment and stigma are bound to be felt by the consumer. Particular attention to a healthy lifestyle can lessen the duration of symptoms.
**RESPIRATORY FAILURE, ACUTE**

**DESCRIPTION**
This acute disorder occurs when the lungs no longer meet the body’s metabolic needs. It is not easy to diagnose because it has so many causes and variable symptoms. Oxygen blood level tests are usually required to assess this disease. Low oxygen blood levels make it difficult for medications and enzymes to function.

**SIGNS AND SYMPTOMS**
- Difficulty breathing
- Shortness of breath during mild activity
- Dizziness
- Pain when breathing
- Passing out
- Chest pain
- Wheezing and whistling noises when breathing

**EMOTIONAL IMPLICATIONS**
Acute respiratory failure may be caused by many different initial conditions, such as smoking, bronchial infections, tuberculosis, use of sedatives, or pneumonia. Supplemental oxygen is often required; therefore, mobility of the consumer decreases radically. Lifestyle changes, and lack of activity may cause the consumer emotional problems. Restlessness, confusion and loss of concentration can render the consumer very depressed. There are often secondary conditions such as Cardiac problems involved. Specialists in these fields should see the consumer as well.
RHEUMATOID ARTHRITIS

DESCRIPTION
Rheumatoid arthritis is a chronic, inflammatory, systemic disease, which primarily attacks peripheral joints and surrounding muscles, tendons, ligaments, and blood vessels. Rheumatoid arthritis usually requires lifelong treatment and sometimes surgery. In most consumers, the disease follows an intermittent course and allows normal activity, although 10% suffer total disability from severe articular deformity or associated extra-articular symptoms, or both.

SIGNS AND SYMPTOMS
Initially, fatigue, body discomfort, anorexia, persistent low-grade fever, weight loss and enlarged lymph glands
Later, joint pain, tenderness, warmth and swelling
Morning stiffness
Possible numbness in hands and feet
Possible stiff, weak or painful muscles
Rheumatoid nodules
Advanced joint deformities and diminished joint function

EMOTIONAL IMPLICATIONS
The consumer experiences a lot of pain. They have to learn to pace daily activities, resting for 5 – 10 minutes out of each hour and alternate sitting and standing tasks. They need to use dressing aids such as long handled shoehorn, reacher and zipper pulls. Refer to the Arthritis Foundation.
**SCHIZOPHRENIA**

**DESCRIPTION**
This disorder is marked mainly by withdrawal into self and failure to distinguish reality from fantasy. There are five types of schizophrenia: catatonic, paranoid, disorganized, undifferentiated and residual. Schizophrenia has these essential features: presence of psychotic features during the acute phase; deterioration from previous levels of functioning; onset before age 45; and presence of symptoms for at least 6 months, with deterioration in occupational functioning, social relations, or self care.

**SIGNS AND SYMPTOMS**
- **Catatonic**
  - Possible inability to take care of personal needs
  - Diminished sensitivity to painful stimuli
  - Negativism, rigidity, posturing
  - Rapid mood swings between excitement and stupor
  - Extreme psychomotor agitation, incoherent shouting or talking
  - Increased destructive, violent behavior

- **Paranoid**
  - Persecutory or grandiose delusional thought content
  - Stilted formality or intensity in interactions with others
  - Possibly unfocused anxiety, anger, argumentativeness and violence
  - Gender identity problems

**EMOTIONAL IMPLICATIONS**
The consumer is acutely aware of his environment even though he seems not to be. Your presence can be reassuring and supportive. The consumer needs to be told directly, specifically and concisely what needs to be done. Emphasize reality in all contacts to reduce distorted perceptions. Don’t crowd the consumer as they may strike out. You should always approach the consumer in a calm and unhurried manner. Build trust, be honest and dependable and do not try to combat the consumers’ delusions with logic.
SCLERODERMA

DESCRIPTION
Scleroderma is a diffuse connective tissue disease characterized by fibrotic, degenerative, and inflammatory changes in the skin, blood vessels, skeletal muscles, and internal organs. Scleroderma comes from two words: “sclero” meaning hard, and “derma” meaning skin. The cause is unknown. The course and severity of the disease varies widely in those affected. Excess collagen deposits in the skin and other organs produce the symptoms. There are several forms that the disease may take. Scleroderma can develop and is found in any age group from infants to the elderly, but its onset is most frequent between the ages of 25 and 55. Risk factors are occupational exposure to silica dust and polyvinyl chloride. There are two major classifications of scleroderma: localized and systemic. Localized is relatively mild. The internal organs are usually not affected. Systemic may affect the connective tissue in many parts of the body. It can involve the skin, esophagus, gastrointestinal tract, lungs, kidneys, blood vessels, muscles, and joints.

SIGNS AND SYMPTOMS
- Disturbance in circulation of blood causes a series of color changes in the skin
  - White: blanched or pale
  - Red: flushed as blood flow returns
  - Blue: affected part loses oxygen
- Skin thickening, and shiny hands and forearm
- Joint contractures, esophageal dysfunction
- Swallowing difficulties, diarrhea, constipation
- Oral, facial and dental problems

EMOTIONAL IMPLICATIONS
A person newly diagnosed as having scleroderma may feel alone and uncertain about where to turn for help. They may experience a number of other feelings and emotional reactions from time to time, including initial shock or disbelief, fear, anger, denial, self-blame, guilt, grief, sadness or depression. Family members may have similar feelings. Professional counseling is available to assist persons with scleroderma and their family members who are having difficulty coping with their feelings. Thinking of oneself as a total person with a full life to be led may help to keep scleroderma in perspective and enable one to maintain a positive but realistic attitude.
SOMATAFORM DISORDER

DESCRIPTION
A consumer with Somataform disorder has multiple physical complaints that suggest a physical disorder without a disease or physical basis to account for them. With this disorder there tends to be a pattern of multiple and recurrent symptoms and complaints that can involve any body system and often persist for years. The symptoms begin before the age of 30 and occur more often in females. The symptoms are severe enough to lead to visiting health care providers, taking medication or interfering with the person’s life. They often seek medical treatment from several physicians at the same time resulting in complications of the drugs and therapies are not compatible. A dependency on pain relievers or sedatives may develop. The goal of treatment is to help the consumer learn to control the symptoms.

SIGNS AND SYMPTOMS
- Gastrointestinal tract problems such as nausea, abdominal bloating, vomiting, diarrhea and food intolerance
- Pain in the arms or legs; back pain; joint pain; headaches; pain during urination
- Sexual or reproductive problems
- Neurological problems such as impaired coordination, localized weakness, and double vision
- Anxiety and depression
- Impulsive, antisocial, or suicidal
- A long list of symptoms which occur over a period of years in which the overall condition does not change

EMOTIONAL IMPLICATIONS
A consumer with Somataform disorder often lives a life associated with chaos, marital and relationship discord and social problems. Their lifestyle can be as complicated as their medical histories. People with Somataform disorder rarely acknowledge that their illness has a psychological component and will usually reject psychiatric treatment. A supportive relationship with a sympathetic health care provider is the most important aspect of treatment. Regularly scheduled appointments should be maintained to review symptoms and the person’s coping mechanisms. Acknowledgment and explanation of test results should occur. It is not helpful to tell people with this disorder that their symptoms are imaginary. A poor relationship with the health care provider seems to worsen the condition, and a greater intensity of symptoms occurs with stress. It is important to remember that consumers with this disorder become ill from the same maladies as anyone else and that a real disease may be overlooked by their health care provider because of a previous history of unfounded complaints.
**SPINA BIFIDA**

**DESCRIPTION**
Spina Bifida (myelomeningocele) is a congenital birth defect where the backbone and the spinal canal do not close before birth. The condition may cause varying degrees of paralysis on the lower limbs along with loss of bowel and bladder control. Other disorders may also be present in the child, such as hydrocephalus hip dislocation, or syringomyelia. The cause is unknown; however, folic acid deficiency could play a part in neural tube defects such as myelomeningocele. All prospective mothers should take 0.4 mg of folic acid per day for the purpose of reducing their risk of having a child affected with spina bifida as well as other birth defects.

**SIGNS AND SYMPTOMS**
- Paralysis and loss of feeling below the anatomic level of the defect
- Loss of bowel and bladder control; frequent urinary tract infections
- Hydrocephalus and sometimes learning disabilities

**EMOTIONAL IMPLICATIONS**
The goals of initial treatment are to reduce the amount of neurological damage caused by the defect, to minimize complications such as infection, and to aid the family in coping with the disorder. Surgical repair of the defect is usually recommended. With treatment, the length of life is not severely affected. Physical disabilities like Spina Bifida can have a profound effect on a child’s emotional and social development. To promote personal growth, families and teachers should encourage children, within the limits of safety and health, to be independent and to participate in activities with their non-disabled classmates.
**SPINAL CORD INJURY**

**DESCRIPTION**
Spinal cord injury is a lesion of the spinal cord that results in paralysis of certain parts of the body and corresponding loss of sensation. Paraplegia refers to paralysis from approximately the waist down. Quadriplegia refers to paralysis from approximately the shoulders down.

**SIGNS AND SYMPTOMS**
- Muscle spasms and back pain that worsen with movement
- If injury damages the spinal cord, effects range from mild paraesthesia to quadriplegia and shock

**EMOTIONAL IMPLICATIONS**
The catastrophic nature of a spinal cord injury is much more complex than the loss of feeling and inability to move. Individuals who experience damage to their spinal cord also contend with impairment of bladder, bowel and sexual function. Added to this are the psychological effects of social, economic, and emotional adjustments that must be made. Refer the consumer to National Spinal Cord Injury Association or a local support group.
**STROKE**

**DESCRIPTION**
A stroke occurs when a blocked artery or ruptured blood vessel interrupts the blood flow carrying the supply of oxygen to the brain. Deprived of oxygen, nerve cells die and the brain cannot function. When this continuous supply of blood is disrupted, a stroke results. You lose your ability to speak, walk, or even breathing can be impaired. The result is often paralysis of one side of the body. There are three major types of stroke: An **Ischemic Stroke** occurs when a blood clot blocks an artery and cuts off the brain’s blood supply. This is the most common type of stroke. A **Hemorrhagic Stroke** is caused by bleeding in the brain from a broken blood vessel. This can be caused by high blood pressure or cerebral aneurysms. A **Transient Ischemic Attack (TIA)** or “mini-stroke” is a small reversible interruption on the brain’s blood supply due to the blockage of a blood vessel. Symptoms may only last a few minutes or hours and are usually followed by full recovery.

**RISK FACTORS**
- Hypertension
- Heart disease
- Arteriosclerosis
- Previous stroke / TIA
- Smoking
- Obesity, high cholesterol, behavioral factors
- Cancer
- Infection

**SIGNS AND SYMPTOMS**
- Sudden weakness or numbness on one side of the body, face, arm, or leg
- Sudden blurred or decreased vision in one or both eyes
- Difficulty speaking or understanding even simple statements
- Dizziness and loss of balance or coordination, especially when combined with another symptom
- A sudden, unexplainable, and severe headache often referred to as the worst headache ever!

**EMOTIONAL IMPLICATIONS**
The major emphasis for stroke rehabilitation is to maximize the independence, lifestyle and dignity of the consumer and the family unit.
This effort should include a physical, behavioral, cognitive, social, vocational, adaptive and re-educational point of view. The loss of the ability to speak is devastating. The road to recovery and rehabilitation is long and frustrating. A team of professionals may be necessary for this program to be successful. Support groups are available.

**Stroke Facts**

80% of all strokes are preventable
Every minute someone suffers from a stroke
Stroke is the 3rd leading cause of death after heart disease and cancer
Each year over 700,000 Americans experience a new or recurrent stroke
160,000 people die from a stroke each year
More women die each year from stroke than from breast cancer
Stroke is on the increase for the first time in 35 years
Two-thirds of all strokes occur in people 65 and older
Stroke is the #1 cause of adult disability
TEMPOROMANDIBULAR JOINT SYNDROME “TMJ”

DESCRIPTION
TMJ is a condition of facial pain in the joints of the lower jaw. The causes are multiple and can include congenital anomalies, arthritis, fractures, dislocations, and tension relieving habits such as jaw clenching or tooth grinding. This may cause muscle spasms in the jaw and dental misalignment. In spite of this, sometimes physical examination may be normal. TMJ sufferers describe pain where the temporomandibular joint joins the lower jaw to the skull. X-rays of the jaw may show abnormalities, but can be difficult to read.

SIGNS AND SYMPTOMS
- Frequent one-sided headaches that may radiate to the neck or behind the ear
- Decreased ability to open or close the mouth
- Biting or chewing difficulty or discomfort
- Snapping or popping sound when eating
- Tenderness in the jaw muscle
- Grinding of teeth or jaw clenching

EMOTIONAL IMPLICATIONS
Understanding and sympathy are required in dealing with the consumer who has probably resorted to many remedies in search of the source of TMJ pain. An appliance worn at night to prevent grinding can lessen symptoms and short term medicinal therapy for pain can be useful.
TOURETTES SYNDROME

DESCRIPTION
Tourettes syndrome is a neurological disorder characterized by tics, which are involuntary, rapid, sudden movements that occur repeatedly in the same way. Onset is usually before the age of 21 years.

SIGNS AND SYMPTOMS
Both multiple motor and one or more vocal tics present at some time during the illness although not necessarily simultaneously.
Occurrence of tics many times a day nearly every day or intermittently throughout a span of more than one year
The periodic change in the number, frequency, type and location of the tics, and in the waxing and waning of their severity
Symptoms can even disappear for weeks or months at a time
Onset before the age of 21

EMOTIONAL IMPLICATIONS
Parents of children with Tourettes must find a balance between understanding and overprotection. They must be able to determine if the child’s actions are an expression of the syndrome or the result of poor behavior or judgment in order to respond appropriately. Refer to Tourettes Syndrome Association in Medford.
DESCRIPTION
Consumers with TBI often suffer from a variety of cognitive, physical, and behavioral disabilities. 85% of brain injuries are mild TBI. Persons with such injuries generally have had a brief (less than 20 minutes) loss of consciousness. 10% of brain injuries are moderate TBI. They are a result of a period of unconsciousness in the range of 1-24 hours. Lastly 5% of brain injuries are severe TBI. They usually have experienced 24 hours or more of unconsciousness.

SIGNS AND SYMPTOMS
- Cognitive problems
- Intellectual impairments
- Behavioral and emotional difficulties

EMOTIONAL IMPLICATIONS
A brain injured person must put the whole picture of their life back together from many jumbled pieces. The strings that connect them to their past are imposed by those who knew them. They live behind a mask that says they look OK, but this can cause a silent frustrated rage deep inside of them.
TUBERCULOSIS “TB”

DESCRIPTION
Tuberculosis (TB) is a contagious disease caused by bacteria that primarily infect the lungs. TB is spread when infected people cough or sneeze the bacteria into the air and others inhale the organisms. You cannot get TB by handling things an infected person has touched. After exposure, it can take up to two years to develop active TB. Since 1985, TB has increased in the U.S., primarily due to the increased number of people who are infected with the HIV virus. Others at high risk include IV- drug users, the homeless, and immigrants from other countries with a high rate of TB, health care workers, and older adults. Anyone at risk should be tested regularly.

SIGNS AND SYMPTOMS
- Persistent cough
- Weight loss
- Fatigue
- Fever

EMOTIONAL IMPLICATIONS
Drug treatment can cure TB but it may take from 6 to 12 months. Many consumers become discouraged and must be closely supervised to insure they do not stop their drug treatment, which increases the risk that they will spread the infection.
VISUALLY IMPAIRED – BLIND

DESCRIPTION
A person with a central visual acuity of 20/200 or less in the better eye with best possible correction is considered legally blind. A person who is partially visually impaired sees in his better eye with an aid of glasses, 20/70 or less. They can still use their vision as the chief channel of learning. The most common causes of acquired blindness are accidental trauma, diabetic retinopathy, glaucoma, and macular degeneration. Rarer causes include herpes simplex keratitis, cataracts, and retinal detachment.

SIGNS AND SYMPTOMS
- Mild aching of eyes
- Gradual loss of peripheral vision
- Seeing halos around eyes
- Reduced visual acuity especially at night
- Inflammation and pressure over eye
- Cloudy cornea
- Blurring and decreased visual acuity
- Photophobia
- Nausea and vomiting

EMOTIONAL IMPLICATIONS
Safety, the ability to dress, eat, and functioning with independence are of prime importance to a person with a visual impairment. They need to have special tools and equipment so they can continue to develop to their full potential and have a positive quality of life. Many visually impaired persons have a trained guide dog to help them with the dangers of not being able to see.
WEGENER'S GRANULOMATOSIS

DESCRIPTION
Wegener’s Granulomatosis is fairly rare disease that is often difficult to diagnose. It is a prolonged sepsis with inflammation of blood vessels scattered throughout the body. The cause remains unknown. Although the disease resembles an infection, no bacteria have been isolated. The disease can occur at any age; however it peaks in the 40’s and 50’s. 97% of all patients are Caucasian.

SIGNS AND SYMPTOMS
- Persistent runny nose
- Sinusitis
- Nasal membrane ulceration and crusting
- Inflammation of the ear
- Hearing problems
- Cough or coughing of blood
- Pleuritis (inflammation of the lining of the lung)
- Fever
- Fatigue, weakness
- Loss of appetite, weight loss
- Joint pain
- Night sweats
- Changes in the color of urine

EMOTIONAL IMPLICATIONS
It is very stressful for the consumer until a definite diagnosis is made. They need support and understanding.
WERNICKE – KORSAKOFF’S SYNDROME

DESCRIPTION
Wernicke – Korsakoff’s syndrome is a brain disorder involving loss of specific brain functions due to a thiamin (Vitamin B-1) deficiency. This is actually two disorders that may occur independently or together. Wernicke’s disease is central nervous system damage. The cause is attributed to malnutrition and a deficiency of Vitamin B–1, which commonly accompanies habitual alcohol use. Korsakoff’s psychosis is an impairment of memory and intellect/cognitive skills such as problem solving or learning along with symptoms of nerve damage. Wernicke’s encephalopathy is not only seen in alcoholics, some other common causes are prolonged vomiting (often associated with chemotherapy), eating disorders, and elderly persons living alone and not maintaining nutritional status.

SIGNS AND SYMPTOMS
- Double vision, abnormal eye movements, drooping eyelid
- Loss of muscle coordination
- Muscle contractions
- Loss of sensation in hands and feet
- Inability to tolerate cold, low body temperature
- Dry skin, swallowing difficulty, speech impairment, hoarseness, or changing voice
- Mood, emotional or behavior changes
- Profound loss of memory
- Confabulation
- Decreased ability for problem solving and to think abstractly
- Dizziness

EMOTIONAL IMPLICATIONS
This syndrome usually affects people between 40 and 80 years old. The onset is gradual. History is significant for chronic alcohol use. It should be noted that one of the most distinguishing symptoms is confabulation (fabrication) where the person makes up detailed, believable stories about experiences or situations to cover the gaps in the memory. The goals of treatment are to control symptoms as much as possible and to prevent progression of the disorder. Total abstinence from alcohol is required to prevent progressive loss of brain function and damage to peripheral nerves. A well-balanced nourishing diet is recommended. Without treatment, Wernicke-Korsakoff syndrome progresses steadily to death. With treatment, symptoms such as in-coordination and vision difficulties may be controlled and progression may be slowed. Some of the symptoms, particularly the loss of memory and intellect/cognitive skills may be permanent. There may be a need for custodial care if the loss is severe.
**WHIPPLE’S DISEASE**

**DESCRIPTION**
A digestive disorder that occurs mostly in men aged 30 to 60 years. Classified as a malabsorption (inadequate absorption of nutrients from the intestinal tract) syndrome, its detrimental effects are felt throughout the body and may mimic those of many other diseases. It affects the central nervous system, resulting in confusion, memory loss, and eye twitching.

**SIGNS AND SYMPTOMS**
- Severe malabsorption
- Nutritional deficiencies
- Anemia
- Weight loss
- Chronic low-grade fever
- Diarrhea, with passage of loose, oily stools
- Joint pain and arthritis
- Darkening of the pigmentation of the skin

**EMOTIONAL IMPLICATIONS**
Some people undergo treatment for numerous other disorders for years until the intestinal symptoms suddenly flare up. One should always investigate fever, unexplained weight loss and general malaise since these are symptoms of a number of serious disorders. It requires considerable medical detective work. Treatment includes alleviating symptoms related to these problems. You may be advised to use special nutritional supplements that provide protein, calories, and other essential nutrients without causing diarrhea and other intestinal problems.
WILSON’S DISEASE

DESCRIPTION
Wilson’s disease is a rare inherited disorder of the liver that results in an accumulation of copper in body tissues. The disease is caused by a defective gene and occurs only when a person has two copies of the faulty gene, one from each parent. The disorder is also referred to as copper storage disease or hepatolenticular degeneration.

SIGNS AND SYMPTOMS
- Trembling of hands and feet
- Muscle rigidity or spasms
- Speech impairment
- Symptoms of acute hepatitis, including jaundice, malaise, and possible abdominal bloating
- Symptoms of acute hemolytic anemia, including pallor, headaches, and shortness of breath
- Development of golden-brown or gray-green rings around the cornea
- Cessation of menstruation

EMOTIONAL IMPLICATIONS
Foods should be restricted that are rich in copper, including organ meats, shellfish, nuts, dried legumes, chocolate, and whole-grain cereals. Dietary restriction does not prevent the disease, but it reduces the amount of copper available for tissue storage. Treatment consists of devising a drug regimen to rid excessive copper from the body with minimal side effects. Treatment must be continued for life.
Chapter 2
Chapter 2

Natural and Man-made emergencies and disasters

The Oxford Compendium describes an emergency as ‘a sudden state of danger, conflict, etc., requiring immediate action.’

Much attention is spent on the prediction of, or alerting the general public to the occurrence of natural disasters. It may be true to say that large-scale natural events and disasters occur far more frequently than those that are man-made. There is quite often a far greater acceptance of natural disasters by the public and business, as man-made events create a different mindset quite often that of panic within the community with a feeling of vulnerability and what next unexpected act or event may occur.

A natural disaster may be deemed to be something such as an earthquake, a hurricane, or flood. Each of these natural events may have a devastating affect on an individual or business if no prior planning has taken place. Therefore, natural disasters should be given equal respect in planning and risk assessment as those that might be man-made, as both can have equally as much impact on business’ or individuals. Although each can happen without warning there are better systems in place for natural disasters such as tsunamis. In some parts of the world coastal cities will often have tsunami sirens to warn the community of a pending disaster.

For those individuals that may have a hearing impairment the challenge will be how they will be notified or know that the alarm has sounded! Depending on the type of natural disaster scale is also a factor. The scale of the hurricane season 2004 in Florida was far and widespread. It was not limited to a block or single building. Therefore individuals must consider evacuation beyond their immediate surroundings.
Types of disasters, emergencies and concerns:

<table>
<thead>
<tr>
<th>Localized</th>
<th>Travel</th>
<th>Natural</th>
</tr>
</thead>
<tbody>
<tr>
<td>Power outage at residence</td>
<td>Unscheduled stop or cancellation</td>
<td>Severe storms</td>
</tr>
<tr>
<td>Water &amp; Flooding</td>
<td>Vehicle breakdown</td>
<td>Earthquake</td>
</tr>
<tr>
<td>Structural damage</td>
<td></td>
<td>Tornadoes</td>
</tr>
<tr>
<td>Ventilation Systems</td>
<td></td>
<td>Winter storms</td>
</tr>
<tr>
<td>Fire</td>
<td></td>
<td>Volcanoes</td>
</tr>
<tr>
<td>Sever Illness &amp; Medical Concerns</td>
<td></td>
<td>Landslides</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Hurricanes</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Tsunamis</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Drought</td>
</tr>
<tr>
<td>Civil Unrest</td>
<td>Medical</td>
<td>Manmade</td>
</tr>
<tr>
<td>Rioting</td>
<td>At Home</td>
<td>Chem-Bio threat</td>
</tr>
<tr>
<td>Mass Evacuation</td>
<td>On the road</td>
<td>Nuclear threat</td>
</tr>
<tr>
<td>High Street crime</td>
<td>In Flight</td>
<td>Terrorism</td>
</tr>
<tr>
<td>General High threat</td>
<td>Family</td>
<td></td>
</tr>
<tr>
<td>Break down of Law Enforcement</td>
<td>Children</td>
<td></td>
</tr>
<tr>
<td>Protests</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Assessing your surroundings

All emergency and contingency planning must be considered at the lowest level. In other words, don’t rely on electricity to be available, don’t expect emergency services to be there right away, and don’t expect elevators to work. With the lowest level considered, your plan should be successful. You have to think in a survival mindset to enable yourself to succeed in your planning phase. This guide is not designed to cause panic or stress by thinking of these issues. Rather; it is designed to help individuals have a greater chance of survival through prior planning.

This guide is designed to give greater confidence through having a plan and giving consideration to such issues. Therefore, when planning, think on the most basic levels. Some considerations in your plan might be:

- What physical and psychological barriers might I encounter?
- How might I overcome those barriers?
- Will there be someone there to help or aid me, or might I be alone?
- How or where will I exit a building?
- What types of events are more likely to happen that I should plan for?
- What assets might I want to have immediately at hand?
- Is there something I may require immediately after I have left the building or area?
- Who knows where I am?
- Are there existing procedures already in place to help me with these answers? Who should I ask?
- What solutions can I have in place to prepare me for such an event?
- Where will I meet other people from my family, workforce or neighbors if disaster takes place?
- Can some of my solutions be generic to more than one emergency?

Remember: Think and prepare at the most basic level.
At night you are more likely to be disorientated and less likely to remember where you have placed something that you might need. Therefore, make a habit of placing your keys, a flashlight, your wallet, and medications etc. next to your bed each night whether at home or traveling. If an emergency should occur then you only need to go to one nearby place to grab all you might require if time permits and exit the building safely.

If traveling alone, always take the time to locate emergency exits and paint a picture in your mind as to the location and route to that exit as soon as you have arrived and placed your luggage in the room. If you require assistance in the event of an emergency then make sure you let the building owner know. Don’t be afraid to ask them what procedures or plans they have in place to help you. These days the larger chains of hotels most often have contingency management plans drawn up and should be happy to answer any concerns or questions. If you’re attending an event then ask the organizer what their plan is for emergencies.

Take time to get familiar with your surroundings, both in the immediate and wider area. In the immediate area, locate emergency tools such as fire extinguishers, emergency hammers, exit ladders and as already mentioned, emergency exits. If you need to stay in the building then consider which room affords the most protection. In the wider area consider locating rendezvous points for emergency situations, evacuation routes, emergency shelters etc.
**Who can help?**

There are currently no Federal Laws requiring evacuation plans, and this may lead employers to feel exonerated from this responsibility. The Americans with Disabilities Act (1990) does not require employers to have evacuation and emergency plans either. However, Titles I, II and III of the ADA states that employers, public services, and public accommodations and services operated by private organizations are required to modify their policies and procedures to include individuals with disabilities when a plan is created or already in existence.

The OSH Act does not require that all employers have emergency action plans; however, the Act does require that employers from particular industries have emergency action plans (e.g., metal, chemical, and grain handling facilities). Employers must check particular industry codes to see if emergency action plans are required and what elements are necessary.

**Yourself:**

What does this mean to individuals with disabilities? Don’t assume that your employer has taken your needs into account in their plan. Ask if your concerns may have been included in the plan, or ask to see the plan. If you do not feel that your concerns are contained within the plan then ask to speak with whoever devised the plan so that you might work to modify the plan. Try to judge what barriers may be of particular concern to you and help devise a solution with your employer explaining what considerations need to be taken into account. What in particular would you consider to be a barrier or challenge during an emergency? Will your needs be met on cessation of the emergency? Don’t assume your employer is aware of all of your requirements; help them to collect that information by creating a partnership with them. They will thank you; after all you are a very important part of their organization.
**The Employer:**

If you are an employer then make sure that disability considerations are included in the plan. Don’t think that you have all the right answers. Speak with those you might need to, and have them help with the plan. If someone with a disability is employed after the plans creation then modify the plan with the help of those individuals. Also consider those with hidden disabilities and how you might help them if there is an emergency. Seek guidance from professional services and organizations if you need extra help or if you might be planning evacuation for the first time. There are many non-profit organizations that will help you for free; therefore cost is not an issue.

These organizations will be happy to help in any way they can. Each individual with a disability should be ‘partnered’ with someone that will be able to assist them during an evacuation. The ‘partner’ should be aware of the individual’s needs or requirements in the event of an evacuation. Some training or education may be required. It is important that the ‘partner’ is aware of their responsibilities and is capable of carrying them out. Ensure that both parties are comfortable with the ‘partnering’. After practice evacuations encourage both parties to discuss how the evacuation went, what improvements might be made and how they might approach different situations. Ask them to give you feedback on their findings. If the plan requires amending based upon their findings then do so as soon as possible.

To help establish if an individual has a disability, when and how you might ask, and if so, how you might help them. An excellent guide can be found at the Economic Employment Opportunity Commission website, titled:

‘Fact Sheet on Obtaining and Using Employee Medical Information as Part of Emergency Evacuation Procedures’

[http://www.eeoc.gov/facts/evacuation.html](http://www.eeoc.gov/facts/evacuation.html)

**Your Fire Department:**

The local fire department may well be able to help with your plan. In particular, if you are hosting an event where a number of individuals with disabilities might be attending then let your local fire department know ahead of time so they are aware of your needs if a problem occurs.
Your Risk Management Coordinator:

Larger and well organized companies, schools, colleges and locations regularly have either a team or individual who is responsible for risk management. These people are quite often expert in knowing the surroundings and planning accordingly for emergency preparedness. They will often have a detailed plan and considerations for most, if not all types of emergencies. This should include the evacuation and consideration of individuals with disabilities. If there is someone responsible for risk management ask them if you or individuals with disabilities are included in their plan. They may have a generic or blanket plan which may include individuals with disabilities and how they might approach that situation, so don’t feel let down if they haven’t considered your particular disability. Make them aware of your challenges and ask that they consider it in their plan. After working in the risk management field, the author would expect that they are likely to be the most proactive in meeting your concerns, and once informed should be able to consider in detail your evacuation from that location. So don’t be shy about approaching them.
Formulating Your Plan

At Home

Emergency Preparedness: (Immediate)

Remember, you are your biggest asset, nobody knows your concerns better than you do, and in particular, in your own home or dwelling. Make sure to give some consideration in your planning for the possibility of short and medium term emergencies. What is your immediate plane? What is your plan if the emergency extends beyond twenty four hours? Do you have enough food, water and other potential needs taken care of? Have you looked or started at the most basic level (do you have smoke or carbon monoxide detectors at your residence)? Are they checked regularly? What is your evacuation plan if a detector gives off an alert?

For immediate considerations store emergency supplies either close to hand at home, on the back of a wheelchair, walker or other such device that you might need immediately in the event of an emergency where you may not have time to collect such items for longer term needs. Have a flashlight next to your bed incase an emergency should happen during the night. Use an LED light, as this will require less bulb replacement and lasts longer under battery use. There may be two options for a flashlight.

1. A key ring flashlight which will always be with your car keys. This option is small, compact, and you will almost always have it with you even when not at home. An example is given in the Evacuation and Location Aids Chapter at the end of the guide.

2. A headlamp. This will enable the use and freedom of a hand or both hands for other tasks. An example is given in the Evacuation and Location Aids Chapter at the end of the guide.

Having a bag or ‘go pack’ available for immediate situations will reduce the time to collect these items around the home if an emergency should occur or be imminent. It will also reduce post evacuation stress if those items that are important for your immediate health or concerns are available. A sample, but by no means definitive list is included at the end of this chapter. This ‘Go Pack’ can also be taken on your travels or to work as well! It should be small enough and lightweight to be easily carried, or attached to any device you might use without affecting it.
Consider an adjustable strap on your ‘Go Pack’ so it can be slung over a shoulder, arm of a wheel chair etc, or be strapped to a leg or ankle if you have to crawl. An example might be something like a small fanny pack, arm pack, or first aid pack.

The ‘Go Pack’ list at the end of the chapter is not definitive by any means; however it will hopefully give food for thought. Each individual will have their own perspective on what should be included and this will be based on personal needs or requirements. Try to find a tin such as an old tobacco tin, altoids tin, or small hard plastic case. Place the items in the container, and then place it inside your ‘Go Pack’.

**Emergency Preparedness 24 Hours:**

The American Red Cross currently stocks packs which can be used in an emergency and can be purchased from their website or local office. These are useful to help you. There may be items that you already poses that can go a long way to completing the Red Cross pack, so see what you might already have.

**Example Immediate ‘Go Pack’ List**

- List of important telephone numbers such as doctor, family, friends etc.
- Medication (if required)
- Money
- Sanitary wipes
- Surgical Blade*
- Tweezers*
- Needle & thread
- Cut down pencil
- Sheet of paper
- Band aids
- Cheap watch face (minus strap)
- Small LED flashlight
- Swiss army style knife (*to replace some of the above items)
- Ziplock bag
- Other medication as required (Imodium, Advil, Pepcid, Allegra)
- Dust mask
- Snacks/protein/carbohydrate drinks
- Leather gloves (if required)
- Water
Emergency Preparedness 72 Hours:

In the event that an emergency should last longer than 24 hours one must consider a number of factors:

Water, Food, Climate & Shelter

The priority of the above list will depend on what assets you might have available and which need is greatest. However, water should always be the first consideration. The average human requires 6.34 pints (or 3 liters) of water per day.

**Water**

Effects of dehydration:
1-2% - Thirst, fatigue, weakness, vague discomfort, loss of appetite.
3-4% - Impaired physical performance, dry mouth, reduction in urine, flushed skin, impatience, apathy.
5-6% - Difficulty in concentrating, headache, irritability, sleepiness, impaired temperature regulation, increased respiratory rate.
7-10% - Dizziness, convulsive muscles, loss of balance, delirium, exhaustion, collapse.

*Source: Understanding Nutrition - Whitney & Rolfes*

**Food**

The average human requires 2000 calories of food intake per day.

**Climate and Shelter** – Effects of high temperature on body systems.

<table>
<thead>
<tr>
<th>Temperature (°C/°F)</th>
<th>Symptoms</th>
</tr>
</thead>
<tbody>
<tr>
<td>28 / 82.4</td>
<td>muscle failure</td>
</tr>
<tr>
<td>30 / 86</td>
<td>loss of body temperature control</td>
</tr>
<tr>
<td>33 / 91.4</td>
<td>loss of consciousness</td>
</tr>
<tr>
<td>37 / 98.6</td>
<td>normal</td>
</tr>
<tr>
<td>42 / 107.6</td>
<td>central nervous system breakdown</td>
</tr>
<tr>
<td>44 / 111.2</td>
<td>death</td>
</tr>
</tbody>
</table>

*Source: [http://www.rwc.uc.edu/koehler/biophys/8d.html](http://www.rwc.uc.edu/koehler/biophys/8d.html)*
Chapter 3
Chapter 3

If the worst should happen

In the event of an emergency it is important to recognize what may be around you that can offer immediate protection.

Earthquakes:

In the event of an earthquake, doorframes and doorways offer more and better protection than an open room. Likewise a bath tub or underneath of a bed also offer more protection. Leave the building as soon as it is safe to do so. Remember after shocks are common and so it is important to exit the building as soon as possible and to remain outside until the authorities clear (it, or all) buildings safe to enter. In the event of an earthquake there is often danger from secondary fires from burst mains and the like.

Tsunamis:

If a Tsunami is imminent then try to seek higher ground. Have a tsunami evacuation route planned if you are entering or live in a tsunami prone area. Water may well be contaminated after a tsunami, so your priority is likely to be to find clean drinking water. If you live in an area that is tsunami prone then learn to recognize the physical warning signs, warning sirens, evacuation routes and set up a network for someone else to notify you if required. Agree on a common meeting place for your family to meet if you are separated.

Floods:

Find out if you live in a flood zone or flash flood zone. Do not try to cross any streams, rivers or roads that may be in flood. If you are caught in a flood at home then move upstairs or onto your roof if you are able to. Contact family and emergency services if you believe that a flood will occur so they might rescue you ahead of time. If flooding is forecasted, move to another location ahead of time.
Hurricanes/Tornadoes

If you are entering or live in an area that is prone to hurricanes or tornadoes, find out where the nearest shelter is. If you are in a tornado zone and one occurs without time to evacuate, lie in the bath if you have one or take shelter in an interior hallway on a lower floor, closet or small room. As a last resort, get under heavy furniture and away from windows. This may go some way to protecting you. Hurricanes can produce tornadoes. If you live in a mobile or manufactured home park, get together with other residents and the park owner/manager to designate safe shelter areas in the park or community. If an evacuation is called then make your way to the evacuation shelter. Ask someone to help (fire/police) if you need help.

Drought

Your 72 hour emergency kit should have sufficient water for 3 days. Your hot water tank at home may hold as much as 50 gallons of water. If you have a 50 gallon tank it will hold enough water for one person for 63 days at the average human rate of required daily consumption. Only use water for washing etc if absolutely required, this will help your water to last for as much as the 63 days as possible. Stay out of the sun, stay cool; this will result in less water loss from your body.

Winter Storms

Learn to recognize the effects of frost nip, frost bite and hypothermia. Dress in a number of thin to medium layers as opposed to one big layer; this is the most effective way of keeping warm if your heating is disrupted. Notify family and services if your heating is disrupted so that they can help you. Do not attempt to leave your home in severe winter storms. Protect your extremities such as fingers and toes. Do not warm them near a naked flame if they become numb; warm them with another part of your body. If possible change your clothes every few days as this will give maximum thermal retention, dirty clothing retains heat less efficiently.

Power Outage

You should include a flash light and candles in your emergency packs. If your heating is disrupted then follow the steps for winter storms. Let family members or friends know that your power has gone out. If power could be out for some time consider asking someone to collect you and move to another location where you will have company.
Civil Unrest

Stay indoors unless told to evacuate by the police. Only leave your house if absolutely necessary. Use your water wisely – no bathing. Use existing food first and in particular perishable items first. Only use your 72 hour pack if you really need to, use existing food first. Listen to radio or TV announcements to keep up to date on the current situation. Call friends or family to let them know how you are. At night turn your lights out at home not to attract any attention.

Fire

If a fire occurs, evacuate your residence immediately. Do not attempt to rescue pets, collect personal items or anything else. Smoke and toxic fumes can overcome an individual in seconds and can often be fatal. Have someone else call 911 after exiting the building. If you have inhaled any smoke then have the hospital check you over. Do not attempt to re-enter a building or room if it is on fire. Opening doors can increase the fire’s spread. Only open doors to exit the building. Ensure you have working smoke detectors and check them regularly.

Chem/Bio Threat

In the event of a chem/bio threat, stay indoors unless ordered to evacuate buy emergency services. TV and radio announcements will be made on public broadcasting channels. Follow the advice of local authorities.
Chapter 4
Chapter 4

Techniques for moving individuals

In the event of an emergency the following techniques may be useful for moving a casualty or individual with movement limitations. It is stressed that these techniques should only be used in an absolute emergency where a life threatening circumstance may take place. No attempt should be made to move an injured individual unless it is absolutely necessary. Moving a casualty or individual with movement limitations may cause further injury or harm.

The Four Hand Chair

Two people form a simple seat by gripping each others wrists. This method is only suitable for short carries of less than 50 meters or yards. It is strenuous and extremely awkward for the carriers.
Foot Drag

This can be used to move a victim that is too large to otherwise move or carry. Grasp the victim’s ankles and move backwards being aware of any obstacles or dangers. Try to pull the victim in a straight line. Be very careful not to cause damage to the injured victim’s head or cause any further injuries.

The Clothes Drag

This can be used to move a victim with a head, neck or back injury. Gather the victims clothing behind if possible and cradle the head with the victim’s clothes. You can also use a blanket using the same method.
The Two Person Seat Carry

This can be used to help a victim that is not able to walk and has no suspected head, back or neck injury. Put one arm under the victim’s thighs and one around his or her back. Interlock your arms with those of a second rescuer under the victim’s legs as well as across the victims back. Be careful when lifting the victim as the center of gravity and weight of the victim are factors to stability.

The Walking Assist

This can be used to help a victim walk to safety. Place the victims arm across your shoulders and hold it in place with one hand. Support the victim with your other hand around the victim’s waist. Move the victim to safety.
Evacuation and Location Aids

Note: The author neither endorses or receives financial gain from the following products or manufacturers. They are included in this guide merely as examples of such devices or equipment that is currently available.

The following pages list some items that may be considered for emergency purposes. The author understands that there is a cost associated with these items however; it is also the authors concern that both employers, individuals with disabilities and family members at least be aware of current equipment available to help in this area.

First Alert Radio

*First Alert WX17 NOAA Portable Emergency Alert Radio*
Cost $24.96 + shipping $4.47
Item Number H121390
www.qvc.com

Life Slider - for evacuation

www.lifeslider.com
**Wherifone - GPS Locator Phone**

Whether at work, home, or traveling, simply use the Internet or any phone to quickly identify the location of the device within feet, in about a minute. In the event of an emergency use the 911-response feature and local police will be dispatched.

**GPS Personal Locator/Watch – Adult watch available soon**

1-877-WHERIFY

www.wherify.com
Evac U8 – Emergency Escape Smoke Hood

Kapton®, polyamide hood provides heat and transient flame protection.
Nose clip prevents re-breathing exhaled air.
Mouthpiece ensures effective seal.
Air intake system reduces blockages from soot and airborne particles.
Filter is suspended in a vibration and shock-absorbing mount.
Ceramic catalyst converts carbon monoxide to carbon dioxide.
Activated carbon adsorbs toxic gases created by combustion.
N-95 grade fiber filter removes micron sized soot particles.
Photo luminous disk makes canister easier to find in the dark. Helps others find you.
Flame-retardant draw tapes pull hood snugly around
Emergency Exit Hammer

www.safehomeproducts.com
1-866-303-2364

Key-Mate (Car Key Ring LED Flashlight)

Cost $9.99

Septor Headlamp

Cost $29.99

http://www.flashlights.com/keymate.html
Tel: 1-888-544-4871/4872
Chapter 5

Example Planning Document

Employers:

The following is an example planning document for employers to include individuals with disabilities.

<table>
<thead>
<tr>
<th>Awareness</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Awareness of any individuals in the workplace with disabilities, including the symptoms and effects.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are individuals with disabilities included in your plan and has disability awareness training been carried out?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Does your current plan reflect the work area to include disabilities in the workplace?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Identification of routes, equipment, signs or alarms. Are they sufficient?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have you set up a support network (buddy system) to help evacuate those with disabilities?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Planning</th>
<th>Y</th>
<th>N</th>
</tr>
</thead>
<tbody>
<tr>
<td>Are there any physical barriers to any or all options for evacuation options from the workplace?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you require any specialized equipment for evacuation purposes?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are you prepared for persons with silent disabilities?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Has the work area been broken down into search areas, or areas of responsibility etc if time permits, to ensure no individuals are left behind?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Are visitors to your workplace included in your plan and have they been consulted.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have service animals been included in your plan (if applicable).</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Implementation</td>
<td>Y</td>
<td>N</td>
</tr>
<tr>
<td>-------------------------------------------------------------------------------</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>Management walkthrough complete.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning document complete.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Planning document agreed by higher management.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desktop exercise carried out.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Desktop exercise review completed.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disseminate plan to all employees.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Announced drill carried out.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Announced drill review complete.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unannounced drill carried out.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Unannounced drill review complete.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Develop reporting systems for new hazards and safety concerns.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Annual or twice yearly review of plan.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**Individuals with disabilities:**

The following is an example planning document for individuals with one or more disabilities.

<table>
<thead>
<tr>
<th>Action or Requirement</th>
<th>Complete</th>
</tr>
</thead>
<tbody>
<tr>
<td>Ensure your residence has smoke detectors, carbon monoxide detectors, a fire extinguisher etc.</td>
<td>□ □</td>
</tr>
<tr>
<td>Create a plan so others might warn you of potential emergencies.</td>
<td>□ □</td>
</tr>
<tr>
<td>Locate local emergency shelters and evacuation routes</td>
<td>□ □</td>
</tr>
<tr>
<td>Store needed aids in a consistent, convenient and secured location.</td>
<td>□ □</td>
</tr>
<tr>
<td>Compile emergency kit 24/72 hours.</td>
<td>□ □</td>
</tr>
<tr>
<td>Arrange and secure furniture and other items to create barrier-free passages.</td>
<td>□ □</td>
</tr>
<tr>
<td>Create a plan to include your service animal (if applicable). Or arrange for your animals safety if you are not there in an emergency</td>
<td>□ □</td>
</tr>
<tr>
<td>Create a local and out of state emergency contact list.</td>
<td>□ □</td>
</tr>
<tr>
<td>Practice using your evacuation routes with someone present.</td>
<td>□ □</td>
</tr>
<tr>
<td>Practice using alternate methods of evacuation with someone present.</td>
<td>□ □</td>
</tr>
<tr>
<td>Prepare a vehicle emergency kit if you drive. Flashlight, batteries, maps, blanket, first aid kit, shovel, tire repair kit, booster cables, pump, flares, bottled water, non-perishable foods, fire extinguisher, emergency evacuation hammer</td>
<td>□ □</td>
</tr>
<tr>
<td>Formulate a list of reputable contractors for emergency repairs.</td>
<td>□ □</td>
</tr>
<tr>
<td>Tell or give other family members a copy of your plan.</td>
<td>□ □</td>
</tr>
<tr>
<td>Know all city and regional sirens &amp; warnings.</td>
<td>□ □</td>
</tr>
</tbody>
</table>
Chapter 6
Chapter 6

Bibliography


American Red Cross, (1996) *Pets and Disasters: Get Prepared*

Federal Emergency Management Agency ‘Hazards’


Prendergast, L LPN, (2003) *Enlightenment.* South Coast Independent Living Services, P.O. Box 2338, Brookings OR, 97415


Useful Internet Links:

http://www.prepare.org/basic/foodchart.htm

http://www.fema.gov/hazards/

Accessibility website design – Web design considerations for disability access.

http://www.knowbility.org/air-interactive/?content=resources

http://www.knowbility.org/curriculum/
Information on the enclosed CD

The CD attached to the rear cover of this guide includes a copy of the guide in size 14 font in MS Word format, and PDF format. You will require a word processor that can open Microsoft Word documents to be able to open the MS Word file. You will require Adobe Acrobat Reader to open the PDF document. Adobe Reader can be found at:

http://www.adobe.com

The CD also contains a quiz of disability questions. The quiz is primarily focused to test the knowledge of management and employers about disabilities within a work related environment. The quiz was created using ‘Test Developer Pro, version 7’ and can be found at:

http://www.atrixware.com

To order a copy of the guide in electronic version, hard copy or both, contact:

Management & Training Corporation
250 36th St
Astoria
OR 97103
503 325 1156

Guide produced by Alan Smiles alansmiles@gmail.com