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# Health Information for Caregivers

**EXPRESSIONS**  
**OF WELLNESS I:**  
Pathways to Healthy Living





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## INTRODUCTION

The medical term for a health problem associated with the brain is *neurological impairment*. People with developmental disabilities and neurological impairments may have problems in any or all of the areas of learning, social behavior, and muscle control. Whether or not mentally retarded, some people with neurological impairments need specialized services and supports from caregivers similar to those available for other people with developmental disabilities.

## COMMON NEUROLOGICAL CONCERNS FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES

### TYPICAL BRAIN FUNCTIONING

The brain works like a computer. It collects information from various body parts, analyzes and sends back messages through the nervous system. These messages might have to do with walking, talking, seeing, hearing, remembering, learning, talking, feeling, and so on. If something happens to the brain or nervous system, it can affect some or all of the things we need to do each day. Some of the most common neurological problems experienced by people with developmental disabilities include:

#### ▶ EPILEPSY

The brain typically sends messages to the body through the nervous system in an organized pattern of small, electrical discharges. However, people with developmental disabilities who also have epilepsy produce patterns of electrical discharges that are very unorganized. These erratic patterns will cause a seizure or convulsion. This type of disability is known as *epilepsy* or *seizure disorder*. The three most common types of seizures are *grand mal*, *petit mal* and *simple or complex partial*.

#### ▶ Grand Mal

Also known as generalized tonic clonic seizures, grand mal seizures can last a few minutes or more and can occur from one or more times each day to one or more times each year. People who have a grand mal seizure lose consciousness and have convulsive body movements. Afterwards, the individual is generally confused and drowsy and may want to sleep.

#### ▶ Petit Mal

This type of seizure may occur many times per hour, but only last from 5-20 seconds. It may be accompanied by staring or twitching of the eyelids and a short loss of consciousness. Individuals are seldom aware that they have had this type of seizure.

▶ Simple or Complex Partial

These are seizures which affect only one part of the brain. A simple partial seizure may occur while someone is conscious and may cause involuntary movements of arms or legs. They may also cause unusual smells or feelings for the person having the seizure. A complex partial may include a variety of symptoms such as lipsmacking, staring, confusion, head or stomach pains, buzzing or ringing in the ears, changes in color perception, fear, anger, so on. This type of seizure may last several minutes or several hours.

▶ OTHER DISABILITY RELATED NEUROLOGICAL PROBLEMS

In addition to seizure disorders, there are other neurological problems that are associated with people with developmental disabilities.

▶ Down Syndrome

Individuals with Down Syndrome may also have two types of neurological problems. The first is a developmental problem which places them at risk for spinal cord injury and can result in partial or complete paralysis. The second is that many older individuals with Down Syndrome have been diagnosed with something very similar to Alzheimers, which is a deterioration of mental capacity.

▶ Cerebral Palsy

People with cerebral palsy have what is known as a nonprogressive neurological impairment. It is caused by an injury to the part of the brain that controls and coordinates muscles and usually happens before or at birth. In some persons, cerebral palsy may not be noticeable while others may have significant problems walking and talking.

▶ Rett's Syndrome

The cause of this syndrome is unknown and only seems to be present in females (it may be lethal for males before birth). It can result in a general lack of coordination, an unusual walk, smaller than usual head size, constant hand wringing, and behavior challenges.

▶ Microcephaly and Hydrocephaly

Individuals with smaller or larger than usual head size usually have some type of neurological problem as well. This can include mental retardation and delayed motor development.

▶ Tuberous Sclerosis

This is a hereditary disease and consists of a number of small tumors on the surface of the brain. It usually results in a decline in mental capacity and a seizure disorder.



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- ▶ **Medication**  
Individuals with developmental disabilities who use psychotropic (drugs that affect the mind) medication for long periods may contract a neurological disorder. These are typically called *movement disorders* and symptoms often include unusual movements of the face.
- ▶ **Traumatic Brain Injury**  
Injuries to the brain after birth can result in a variety of neurological problems (speech, memory, learning, walking) for people with developmental disabilities.
- ▶ **Behavior Disorders**  
Erratic behavior that gets worse over time may indicate a neurological problem. This could be a symptom of a tumor, bleeding in the brain, or migraine headaches.
- ▶ **Sleep Disorders**  
Unusual sleep patterns can also be the result of a neurological problem. The causes are varied and include night time only seizures, a mild form of sleep apnea, or something similar to a night terror.
- ▶ **Other Nerve Disorders**  
Some individuals with developmental disabilities have what is known as a peripheral nerve disorder. This is a nerve problem that affects the extremities (arms and legs), for example, carpal tunnel syndrome.
- ▶ **STROKE**  
The sudden rupture or blockage of a blood vessel in the brain which causes a loss of blood supply. A stroke can result in loss of consciousness, paralysis and other symptoms depending on the location of the rupture or blockage.

## RISK FACTORS

Individuals with developmental disabilities are at risk for neurological problems for a variety of reasons, which include:

- **Traumatic injury to the head may result in injury to the brain at any age.**
- **Trauma during birth, for example, lack of oxygen to the brain.**
- **The use of certain medications for psychiatric or other medical problems for long periods of time.**
- **Self-abusive behavior which involves the head, for example, head banging.**
- **The general aging process can include neurological problems, especially for people with Down Syndrome.**
- **Tumorous growths on any part of the brain.**
- **A number of developmental disabilities can include neurological issues, such as Down Syndrome, tuberous sclerosis, cerebral palsy, and Rett's Syndrome.**



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## PREVENTION

There are many ways to lower the risk of neurological problems for people with developmental disabilities. Suggestions for caregivers include:

- **The use of protective helmets** during certain active sports such as bicycling and baseball.
- **Monitoring of medication** for side effects such as a rapid change in behavior.
- **Behavior analysis and intervention** for self-abusive behaviors which involve the head area.
- **Observation of general behavior over time** (for example, aggression, memory loss) which may be due to specific disabilities (such as Down Syndrome), the general aging process, or growths on the brain.



# PLANNING FOR A SUCCESSFUL VISIT TO THE DOCTOR

## A TYPICAL NEUROLOGICAL EXAMINATION

As a caregiver, if you see some signs of possible neurological problems (for example, rapid changes in behavior, memory loss), it's important to make an appointment with a primary care physician as soon as possible. He or she can complete a thorough examination, provide some basic neurological screening tests and make a decision whether or not to refer to a specialist, such as a *neurologist*. The following are the major parts of a typical neurological screening test that would be used for someone with a developmental disability. They can be completed in the physician's office and are not painful.

- ▶ **Checking for Reflexes**  
The doctor will want to check for typical reflexes by tapping the knee or ankle lightly with a special, rubber-tipped hammer. He or she will also lightly touch the underside of the foot which may produce some movement in the big toe and suggest certain nervous system problems.
- ▶ **Muscle Strength and Tone**  
Checking for muscle strength and the ease of arm and leg motion can suggest the presence and location of certain nervous system problems.
- ▶ **Coordination**  
The physician may ask the individual to stand, walk or move in a certain way to see how the nervous system is controlling posture, coordination and balance.
- ▶ **Checking the Senses and Vision**  
Since the nervous system controls the senses, the doctor may also use a number of sensory tests (for example, touching the skin with something cold or warm) or may complete a vision test.
- ▶ **Mental Status**  
To check for memory loss or judgment, the physician may ask some questions of the individual (for example, *is it day or night?* or, *when is your birthday?*).

## SPECIAL NEUROLOGICAL EXAMS

If referred to a neurologist, an individual with a developmental disability may be asked to complete an *electroencephalogram* (or EEG). This is also a painless test which involves attaching a series of electrodes to the scalp. The doctor then measures the rate, height and length of the brain waves to look for possible problems.



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## PLANNING FOR A VISIT TO THE DOCTOR

Preparing someone for a visit to the doctor is important. Caregivers should consider the following suggestions:

- Before the visit, you can review the basic outline of the visit (in the Instructor's Guide at the end of this section) with the individual and ask if there are questions or concerns.
- You might talk to the doctor about any challenges he or she might face in examining the individual.
- Since neurological problems affect thinking, doctors rely on information from sources other than the individual. You should be prepared to accompany the individual and to provide information about such things as current and past behavior, medication, and sleep patterns.
- You might also be asked to start keeping a diary or log certain behaviors for a future follow-up appointment.

## ACCESS TO MEDICAL CARE

If you don't have a primary care physician, calling your local medical society is the best way to find a doctor or who can serve people with special needs . Also, ask other individuals with developmental disabilities, parents or caretakers what physicians they prefer. For individuals with developmental disabilities who do not have medical insurance, funding for medical services can be provided through:

- ▶ Supplemental Security Income (SSI)  
Social Security Administration • 800-772-1213 General Information

SSI benefits can also be used to pay for medical needs not provided by Medicare, Medicaid, or a residential institution.

- ▶ Medi-Cal  
Department of Health Services • 916/657-5173 (General Information)

Medi-Cal pays for physicians' visits and specialized testing (for example, electroencephalograms) if medically necessary.

- ▶ County Hospitals  
County hospitals can also provide emergency medical services.

- ▶ Regional Centers  
If identified in the Individual Program Plan (IPP) as needed and if not provided by another agency (e.g., Medi-Cal), a regional center may purchase such health and medical services as: *assessment, diagnosis, and evaluation; physical, occupational, and speech therapy; adaptive equipment and supplies; specialized medical and dental care; and, transportation services necessary to ensure delivery of services* (excerpted from the Lanterman Act).

## NEUROLOGY CARE RESOURCES

- ▶ INDIVIDUAL SUPPORTS AND ADAPTATIONS  
People with developmental disabilities who also have significant neurological problems will often need additional support from caregivers. This is especially true for individuals who have an onset later in life (for example, due to brain injury or the aging process). Many of the things that people were able to do independently may now take require from others. For example, bathing, dressing and eating may require extra physical support as well as careful attention for safety.



Since neurological problems can affect coordination and balance, individuals with developmental disabilities may need environmental adaptations. For example, special walkers, canes and standard accessibility features for bathrooms (grab bars, shower seats) may be needed. In addition, memory loss may require special attention to the storage of toxic household products and medication.

## ► PUBLISHED MATERIALS

You can order most books through your local bookstore or if through an on-line, Internet resource such as amazon.com.

### ***Cerebral Palsy; A Complete Guide for Caregiving***

Johns Hopkins Health Book (1995) ISBN: 0801850916

A guide for parents and caregivers of children and adults with cerebral palsy. Part I provides an overview of cerebral palsy and explains the medical and psychosocial implications of associated conditions, offering advice for caregivers as advocates. Part II contains practical information on caregiving and medical procedures and Part III defines and describes medical terms and diagnoses, surgical procedures, and assistive devices. It also includes a list of resources and recommended reading.

### ***Living Well With Epilepsy*** by Robert J. Gumnit, MD

Demos Publications

Learning to live with epilepsy requires many adjustments. Learning to live well with epilepsy requires "extra thought, good planning and realistic self-assessment." This book encourages individuals to take charge of their lives and try new experiences to enrich life. Contains chapters by leading experts in epilepsy.

### ***A Guide to Understanding and Living with Epilepsy*** by Orrin Devinsky, MD F.A.

Davis Company

Easy-to-understand resource for people with epilepsy and their families. It covers a wide range of medical, social and legal issues. Topics include explanation of seizures and epilepsy; information about medication, side effects and risks; and, getting the best medical care.

***Alzheimer's Disease and Down Syndrome*** by I. Lott (1995)  
National Down Syndrome Society. Available through the National Down Syndrome Society, 666 Broadway, New York, NY 10012 (800) 221-4602

This booklet answers some of the most commonly asked questions about Alzheimer's disease and Down syndrome. Included is information about incidence, symptoms and diagnosis of Alzheimer's disease in individuals with Down syndrome.

***Developmental Disabilities and Alzheimer's Disease...What You Should Know***  
The Arc (1995)

Available through The Arc of the United States, National Headquarters, 500 East Border Street, Suite 300, Arlington, TX 76010 (817) 261-6003. This booklet provides an introduction to the risk factors, symptoms, diagnosis, and care for Alzheimer's disease in individuals with developmental disabilities, including Down syndrome.

## ► ORGANIZATIONS

***The National Resource Center for Traumatic Brain Injury***  
P.O. Box 980542, Richmond, VA 23298-0542 (804) 828-9055

The mission of the National Resource Center for Traumatic Brain Injury is to provide relevant, practical information for professionals, persons with brain injury, and family members. This organization has more than 20 years of experience developing intervention programs, assessment tools, and investigating the special needs and problems of people with brain injury and their families.

***The National Down Syndrome Society (NDSS)***  
666 Broadway, 8th Floor, New York, NY 10012-2317 (800)221-4602

Established in 1979 to increase public awareness about Down syndrome; to assist families in addressing the needs of their children; and to sponsor and encourage scientific research. NDSS supports research seeking the causes of, and answers to, many of the medical, genetic, behavioral and learning problems associated with Down syndrome; sponsors internationally renowned scientific symposia; advocates on behalf of families and individuals; provides information and referral services through its toll-free number; and develops educational materials, many of which are distributed free of charge.



***National Tuberos Sclerosis Association (NTSA)***

8181 Professional Place, Suite 110, Landover MD 20785-2226 (800) 225-6872

The is a voluntary, national, non-profit organization, which provides support to individuals with tuberous sclerosis and their families, awards grants to researchers and offers educational information to the public and professional communities.

***The Epilepsy Foundation of America***

National Office, 4351 Garden City Drive, Landover, MD 20785-2267  
(800) EFA-1000

***Epilepsy Foundation of Northern California***

1624 Franklin St., Suite 900, Oakland, CA 94612-2124 (800) 632-3532

***Epilepsy Foundation of Los Angeles and Orange County***

3600 Wilshire Blvd, Suite 920, Los Angeles, CA 90010-2613 (800) 564-0445

An affiliation of service organizations nationwide which are committed to finding a cure for epilepsy and a positive quality of life for all those affected by seizures. The Foundation provides a number of low cost books and videos for caregivers.

► CLINICS

There are a variety of specialized neurology clinics throughout California. They are often associated with a major university or teaching hospital. You might ask your primary care physician or a local medical society for information on a clinic in your area. Here is one example:

***The Stanford Comprehensive Epilepsy Center (SCEC)***

The offers state-of-the-art medical and surgical management of epilepsy in adults and children. A full complement of advanced diagnostic tests is available for diagnosis, seizure classification, and evaluation for surgical treatment of epilepsy. For more information please contact the SCEC at (650) 725-6648 or to arrange an appointment call the clinic at (650) 723-6469.

## ▶ INTERNET

You can find the following resources on the World Wide Web:

**National Resource Center for Traumatic Brain Injury**

<http://www.neuro.pmr.vcu.edu/>

**National Down Syndrome Society**

<http://www.ndss.org/>

**National Tuberos Sclerosis Association**

<http://www.ntsaa.org/>

**Epilepsy Foundation of Northern California**

<http://www.efnc.com/index.html>

**Epilepsy Foundation**

<http://www.efa.org/indexf.htm>

**Health Plan Shopping Guide**

<http://www.healthscope.org>

If you are shopping for a health plan, California Consumer Health Scope is a shopper's guide to HMOs and other health services.



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## A QUICK REVIEW OF WHEN TO SEEK MEDICAL HELP

Signs and symptoms that indicate a need for immediate medical attention or first aid include:

**Unusual behavior (such as aggression), loss of memory, loss of ability to do things (such as self care), problems with walking or coordination, loss of muscle strength, loss of consciousness or paralysis. For any of these symptoms, it is critical to seek immediate medical care.**

### SEIZURE FIRST AID

It is important to follow these general guidelines during a seizure (adapted from the Epilepsy Foundation).

#### KEEP CALM

Seizures usually last only a few minutes and generally do not require medical attention. Remember, the individual may be unaware of their actions and may or may not hear you.

#### PROTECTION FROM FURTHER INJURY

If necessary, ease the person to the floor. Move any hard, sharp or hot objects well away. Protect the person's head and body from injury. Loosen any tight neckwear.

#### DO NOT RESTRAIN THE PERSON

#### DO NOT INSERT ANYTHING INTO THE MOUTH

The individual is not going to swallow his or her tongue and forcing open the mouth may break teeth or cause other injury. Do not put a tongue blade between the teeth.

#### AFTER THE SEIZURE SUBSIDES, ROLL THE PERSON ON THEIR SIDE

This enables saliva to flow from the mouth, helping to ensure an open air passage.

#### IF A SEIZURE LASTS LONGER THAN 10 MINUTES, OR REPEATS WITHOUT FULL RECOVERY~ SEEK MEDICAL ASSISTANCE IMMEDIATELY.

Although this rarely occurs, status epilepticus is life-threatening. It is a serious medical emergency.

#### TALK GENTLY TO THE PERSON

After any type of seizure, comfort and reassure the person to assist them in reorienting themselves. If necessary, the person should rest or sleep. If the person wanders, stay with them and talk gently to them.