# Fact Sheet: Wernicke-Korsakoff Syndrome

#### **Definition**

Wernicke-Korsakoff Syndrome (WKS) is a neurological disorder. Wernicke's Encephalopathy and Korsakoff's Psychosis are the acute and chronic phases, respectively, of the same disease.

WKS is caused by a deficiency in the B vitamin thiamine. Thiamine plays a role in metabolizing glucose to produce energy for the brain. An absence of thiamine therefore results in an inadequate supply of energy to the brain, particularly the hypothalamus, which regulates body temperature, growth and appetite and has a role in emotional response. The hypothalamus also controls pituitary functions, including metabolism and hormones. and mammillary bodies, where neural pathways connect various parts of the brain involved in memory functions. The disease is typically associated with chronic alcoholism but may be associated with malnutrition or other conditions which cause nutritional deficiencies.

#### Overview

WKS has a relatively low prevalence (0.4% to 2.8% of reported autopsies). However, it is likely that the disease is under-reported and under-diagnosed. An estimated 25% of WKS cases were missed where the brains

were not examined microscopically. Another study found that only 20% of clinical WKS diagnoses were made correctly in life when compared to autopsy results. Moreover, WKS appears to be only one distinct disease that causes alcohol-related dementia. Based on clinical research studies, between 22% to 29% of individuals with dementia were found to be heavy drinkers or alcoholics and 9% to 23% of elderly alcoholics in alcoholism treatment were found to also have dementia.

An estimated 1.1 to 2.3 million older Americans have problems with alcohol. Medical researchers are still grappling with how to more fully define the association between heavy alcohol use and symptoms of dementia.

# **Symptoms**

WKS symptoms may be long lasting or permanent and should be distinguished from the acute affects of alcohol consumption or from a period of alcohol "withdrawal." The disease is characterized by mental confusion, amnesia (a permanent gap in memory) and impaired short-term memory. An estimated 80% of persons with WKS continue to have a chronic memory disorder. Individuals often appear apathetic and inattentive and some may experience agitation. In addition, WKS tends to impair the person's ability to learn new information or tasks.

Individuals with WKS are known to "confabulate" (make up or invent information to compensate for poor memory). Other symptoms include ataxia (weakness in limbs or lack of muscle coordination, unsteady gait), slow walking, rapid, tremor-like eye movements or paralysis of eye muscles Fine motor function (e.g., hand or finger movements) may be diminished and sense of smell also may be affected. In the advanced stages, coma can occur. Although treatable if caught early enough, the death rate from WKS is relatively high, about 10% to 20%.

### **Diagnosis**

WKS is often missed as a diagnosis. In the acute phase, a physical examination may reveal skin changes and a red "beefy" tongue. In addition, blood count, electrolytes and liver function tests should be conducted. Even in the chronic phase, an MRI may show shrunken mammillary bodies and other changes in the brain. CT scans have showed enlarged ventricles and diencephalic lesions.

It is important that a full medical history include information about the person's daily drinking habits, both present and past. Family, friends and past medical records should be consulted to obtain the most complete information possible on the person's history with alcohol. Proposed criteria for diagnosing alcoholrelated dementia (not strictly WKS) suggest that the diagnosis be made at least 60 days after the last exposure to alcohol and that a "significant" alcohol history would include an average of 35 drinks per week for men (28 for women) for at least five years. Typically, the period of significant drinking must be

within three years of the onset of dementia.

Recent medical research also suggests that the genetic marker APOE4 is a significant predictor of global intellectual deficits in people with WKS. Individuals with the ApoE genotype may experience a certain interaction with heavy alcohol use which could predispose them to WKS. Concerns about an inherited susceptibility to WKS should be discussed with a genetic counselor.

In cases of suspected non-alcohol related WKS, the physician may investigate anorexia nervosa, hypermesis gravidarum, severe malnutrition and other disorders or surgical procedures which impair intestinal absorption of thiamine.

#### **Treatment**

If caught early enough, WKS is a preventable, treatable disease. Treatment consists of thiamine replacement therapy, sometimes along with other vitamins. Dosages may vary and should be monitored closely by a physician. If alcoholic consumption stops and treatment is properly administered, individuals with early-stage WKS can expect a marked recovery and may be capable of learning simple, repetitive tasks.

However, the person's confusion may take some time to subside and even incomplete recovery of memory can take up to a year. In the later stages, if damage to the brain is irreversible, individuals are likely to have lasting problems with memory and gait (for example, lack of muscle coordination and numbness or weakness in limbs).

## **Family Issues**

Caring for a family member who has WKS or alcohol-related dementia presents multiple challenges for family caregivers. Lasting symptoms of dementia and other neurological problems are difficult conditions under even the best circumstances. Bizarre behaviors may be interpreted by the family as a continuation of "binge" drinking, even if the person has stopped drinking.

Individuals with a history of alcohol abuse have often isolated themselves from their families and loved ones. Strained relationships are common in families of alcoholics. As a caregiver, you may feel resentful of caring for a parent or spouse with a lifelong history of alcohol abuse. In addition, it may be hard to convince the impaired person to give up drinking, since most WKS-affected individuals have been long-term alcoholics. Discuss with a physician or mental health professional effective strategies for preventing a loved one from drinking. Ironically, people with WKS can be guite apathetic and seldom demand alcohol yet are likely to accept it if offered.

Families should enlist the help and support of mental health professionals or caseworkers who have experience in working with alcoholism. Family meetings or support groups also may be helpful in bringing together additional family members to assist the WKS person. A case manager or family counselor can help the family sort through issues and help arrange appropriate support services. In severe cases or when the family is unable to provide appropriate care, a residential facility may be sought. Nursing homes

that provide special dementia care should be considered for a confused WKS patient.

Research indicates that alcoholism often runs in families. Having additional family members who are alcoholic increases the burden of care. Some research has shown that a person whose parent has a history of alcoholism may have an inherited susceptibility to alcohol addiction and alcohol-related neurological problems (peripheral neuropathies). Such findings suggest that people in alcoholic families need to take special precautions to avoid excessive use of alcohol in order to reduce their own risk of alcohol-related health problems.

### Caring for the Person with WKS

It is important to ensure that the affected person continues to abstain from drinking alcohol and that the person maintains a balanced diet with adequate thiamine intake. However, even if the person stops drinking and replenishes thiamine, symptoms of the disease (e.g., problem behaviors, agitation, lack of coordination, learning deficits) may continue. In an abstinent (i.e., sober) WKS patient, these symptoms must be recognized as part of the disease caused by irreversible damage to the brain and nervous system.

Family caregivers should take precautions to ensure the safety of the person with WKS, as well as others in the household. The confused or disoriented individual should not be left alone. Supervision is required to ensure that the person does not wander away from home, leave the stove on or the water running.

Short-term memory problems mean that the confused person may repeat the same question again and again. Coping with frequent repetition often involves a trial and error approach and a combination of strategies. First, be patient and deliver responses in a calm manner. The confused person will pick up on your mood and may become more frustrated if your voice is loud or angry. In addition, place reminders in the house to help the person feel more secure. Label inside doors and drawers with words or pictures. Write notes (e.g., dinner is at 6:00 pm). Another strategy is to distract the person with another topic or activity (e.g., a short walk, reminiscing over an old photo, etc.).

If the person continues to be agitated, symptoms should be discussed with a physician, neurologist or psychiatrist. Medications may be available to help control outbursts or anxiety.

Just as important, it is essential that the caregiver get some support and time off from constant caregiving demands. Make sure you leave some time to attend to your own needs, including eating well, getting enough sleep and getting regular medical checkups. A home care worker, friend or family member may be needed to provide periodic respite assistance to help your loved one and to relieve the stress on you, the family caregiver.

#### Resources

Southern Caregiver Resource Center 3675 Ruffin Road, Suite 230 San Diego, CA 92123 (858) 268-4432 | (800) 827-1008 (in CA) E-mail: scrc@caregivercenter.org Website: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

### Family Caregiver Alliance

(415) 434-3388 | (800) 445-8106 Website: www.caregiver.org E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. FCA's National Center on Caregiving offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.

# National Organization for Rare Disorders

www.rarediseases.org

# National Institute on Alcohol and Alcohol Abuse

www.niaaa.nih.gov

# American Association for Marriage and Family Therapy

www.aamft.org

#### **Eldercare Locator**

www.eldercare.gov

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