

UNDERSTANDING THE DIAGNOSIS

Major Vascular Neurocognitive Disorder

Major neurocognitive disorder was previously known as *dementia* and the primary feature of all neurocognitive disorders is an acquired cognitive decline in one or more cognitive domains. The cognitive decline must not just be a sense of a loss of cognitive abilities, but observable by others, as well as tested by a cognitive assessment (such as a neuropsychological test battery).

Vascular neurocognitive disorder is a common form of dementia. It is diagnosed in 15-30% of all people who are diagnosed with dementia. Other names for this disorder include vascular dementia, vascular cognitive impairment and multi-infarct dementia. The term "multi-infarct" is used because in advanced stages, vascular disease produces many empty spaces or infarcts in the brain. Because the majority of people that develop dementia are senior citizens, many of them display the effects of vascular disease in their brain even if they are diagnosed with other forms of dementia. The term mixed dementia is used when a person with dementia has more than one type of potential cause of dementia such as having vascular disease in the brain and Alzheimer's disease.

The degree of impairment associated with vascular neurocognitive disorder can vary considerably. Some affected individuals retain enough mental function to maintain their everyday lives, while others lose much of their mental function and become dependent on some form of assistance for their daily well-being.

Understanding Major Vascular Neurocognitive Disorder:

The "vascular" in vascular neurocognitive disorder refers to the body's system of blood vessels, known medically as the vascular system. The condition gets this name because the impairments it produces stem from some sort of reduction or blockage in the supply of blood that normally passes through the blood vessels called arteries and into the brain's tissues.

As a rule, people with mild vascular neurocognitive disorder have impairments in their conscious brain functions that are prominent enough to produce testing results lower than those found in people unaffected by a vascular disorder, but not prominent enough to produce serious life disruption. In contrast, individuals with major vascular neurocognitive disorder produce test results that are considerably lower than those produced by individuals with the mild form of the disorder, and have impairments that at least partially eliminate their ability to live successfully without some form of outside care.

Causes:

The cause of major vascular neurocognitive disorder is a blockage or disruption of the flow of blood in the brain. Areas of the brain that receive less blood get less nutrients and oxygen. This can damage tissue or even result in cell death in the area. Several vascular conditions can contribute to vascular neurocognitive disorder:

- Cerebral Vascular Accident (CVA) is the technical name for what most people refer to as a stroke. This is a major disruption of blood flow in the brain due to either a vein or artery breaking (a hemorrhage) or because of a major blockage.
- **Ischemia** is a term for damage to an organ that occurs as a result of loss of blood flow.

- Transient Ischemic Attacks (TIAs), often referred to as "mini strokes" or silent strokes, are very small strokes that individually may not produce significant effects. However, over time happen in many areas of the brain. This can produce problems with thinking, moving, etc.
- Aneurysms are weak areas of veins or arteries in the brain that form sacks that cause the blood flow to be disrupted. This can lead to ischemic damage. These blockages are not often major blockages like those that happen during a stroke. However, over time they can cause damage to the brain. They can also break and result in a stroke.
- Narrowed or chronically damaged brain blood vessels. Conditions that narrow or inflict long-term damage on your brain blood vessels also can lead to vascular dementia. These conditions include the wear and tear associated with aging, high blood pressure, abnormal aging of blood vessels (atherosclerosis), diabetes, and brain hemorrhage.

Risk factors:

The factors that can result in an increased risk of developing vascular neurocognitive disorder are the same types of factors that result in an increased risk of developing heart disease. These include:

- **Increasing age.** Your risk of vascular dementia rises as you grow older. The disorder is rare before age 65, and the risk rises substantially by your 90s.
- **History of heart attack, strokes or mini strokes.** If you've had a heart attack, you may be at increased risk of having blood vessel problems in your brain. The brain damage that occurs with a stroke or a mini stroke (transient ischemic attack) may increase your risk of developing dementia.
- **Abnormal aging of blood vessels (atherosclerosis).** This condition occurs when deposits of cholesterol and other substances (plaques) build up in your arteries and narrow your blood vessels. Atherosclerosis can increase your risk of vascular dementia by reducing the flow of blood that nourishes your brain.
- **High cholesterol.** Elevated levels of low-density lipoprotein (LDL), the "bad" cholesterol, are associated with an increased risk of vascular dementia.
- **High blood pressure.** When your blood pressure is too high, it puts extra stress on blood vessels everywhere in your body, including your brain. This increases the risk of vascular problems in the brain.
- **Diabetes.** High glucose levels damage blood vessels throughout your body. Damage in brain blood vessels can increase your risk of stroke and vascular dementia.
- **Smoking.** Smoking directly damages your blood vessels, increasing your risk of atherosclerosis and other circulatory diseases, including vascular dementia.
- **Obesity.** Being overweight is a well-known risk factor for vascular diseases in general, and therefore, presumably increases your risk of vascular dementia.
- Atrial fibrillation. In this abnormal heart rhythm, the upper chambers of your heart begin to beat rapidly and irregularly, out of coordination with your heart's lower chambers. Atrial fibrillation increases your risk of stroke because it causes blood clots to form in the heart that can break off and go to the brain blood vessels.

Specific Symptoms:

The symptoms of vascular neurocognitive disorder depend on what area of the brain has been affected. Some people may display a few symptoms such as problems with forgetfulness, weakness on one side of the body, and problems with attention. Others may display problems in several different areas, often referred to as a "patchy" presentation.

The symptoms of vascular neurocognitive disorder typically develop in a stepwise fashion, meaning that an individual experiences a rather sudden decrease in one or more areas of functioning that will then level off for a period of time. This is followed by a later decrease in functioning that levels off for a period of time, etc. This pattern is different from Alzheimer's disease because Alzheimer's disease most often produces a slow and steady decline in functioning.

Vascular dementia signs and symptoms include:

- Confusion
- Trouble paying attention and concentrating
- Reduced ability to organize thoughts or actions
- Decline in ability to analyze a situation, develop an effective plan and communicate that plan to others
- Difficulty deciding what to do next
- Problems with memory
- Restlessness and agitation
- Unsteady gait
- Sudden or frequent urge to urinate or inability to control passing urine
- Depression or apathy

Vascular dementia symptoms may be most clear-cut when they occur suddenly following a stroke. When changes in your thinking and reasoning seem clearly linked to a stroke, this condition is sometimes called post-stroke dementia.

Sometimes a characteristic pattern of vascular dementia symptoms follows a series of strokes or mini strokes. Changes in your thought processes occur in noticeable steps downward from your previous level of function, unlike the gradual, steady decline that typically occurs in Alzheimer's disease dementia.

But vascular dementia can also develop very gradually, just like Alzheimer's disease dementia. What's more, vascular disease and Alzheimer's disease often occur together.

Studies show that many people with dementia and evidence of brain vascular disease also have Alzheimer's disease.

Prevention:

The health of your brain's blood vessels is closely linked to your overall heart health. Taking these steps to keep your heart healthy may also help reduce your risk of vascular dementia:

- **Maintain a healthy blood pressure.** Keeping your blood pressure in the normal range may help prevent both vascular dementia and Alzheimer's disease.
- **Prevent or control diabetes.** Avoiding the onset of type 2 diabetes, with diet and exercise, is another possible way to decrease your risk of dementia. If you already have diabetes, controlling your glucose levels may help protect your brain blood vessels from damage.
- Quit smoking. Smoking tobacco damages blood vessels everywhere in your body.
- **Get physical exercise.** Regular physical activity should be a key part of everyone's wellness plan. In addition to all of its other benefits, exercise may help you avoid vascular dementia.
- **Keep your cholesterol in check.** A healthy, low-fat diet and cholesterol-lowering medications if you need them may reduce your risk of strokes and heart attacks that could lead to vascular dementia, probably by reducing the amount of plaque deposits building up inside your brain's arteries.

Treatment:

There are no drugs approved by the FDA to treat vascular neurocognitive disorder. Drugs used to treat Alzheimer's disease may or may not be helpful. The general approaches to treating people with suspected vascular neurocognitive disorder are the same as those used to treat high blood pressure, heart attacks, etc. Most often the use of medications for these conditions, dietary changes, and if possible, use of an exercise program are the standard forms of treatment. If the vascular condition can be controlled with medications and lifestyle changes,

the outcome may be relatively good depending on when treatment began. However, it is possible for the condition to progress if the vascular condition is not treated adequately.

Coping with Major Vascular Neurocognitive Disorder:

Major cognitive impairment can make you feel frustrated. To cope with the frustration, try some of the techniques listed below to help compensate for any cognitive decline that interferes with your enjoyment of life, your effectiveness at work and at home, your relationships, and your goals for the future.

- Be patient with yourself and ask your family to be patient with you. Understand that you may feel frustrated, anxious, or sad at the loss of some abilities. Slowing down can sometimes make it easier to remember or complete a task.
- Learn more about major neurocognitive disorder and share that knowledge with those around you. This will enable them to better understand the changes that are affecting you.
- Find constructive ways to release anger and frustration you may feel. Exercise, talk with a close friend or a counselor, and consider joining a support group for people with cognitive losses. It will help to talk to others going through the same experience, or one that is similar. Encourage your family members to seek out counseling and support to meet their needs.
- Continue to explore ways to fulfill your needs for intimacy and closeness. Participate in family events as you are able, and keep in touch with friends. The desire for close relationships with others continues throughout life.
- Ask your physician for an exercise program that best fits your needs. Exercise contributes to good physical health, can reduce stress, and helps keep your brain as healthy as possible.
- Use visible and/or accessible reminders. Useful strategies include writing notes to yourself, posting a large calendar to track appointments, leaving messages to yourself on your answering machine, using an automatic dispensing pill box, and setting the alarm on a mobile device to remind you of upcoming events.
- Document your personal story by creating a scrapbook, recording your autobiography, or keeping a journal. This is a wonderful way to reflect upon your life and share yourself with those close to you. Your children and grandchildren will treasure these keepsakes.
- Keep your mind active doing things that you enjoy: Work on puzzles, read the newspaper, play cards, listen to music, write in a journal, learn about something new.
- Celebrate the many and varied personal attributes that you possess.
- Increase your awareness of major neurocognitive disorder research projects and clinical trials of new medications. Participate in medication trials if your physician thinks they might be helpful.
- Complete an Advance Healthcare Directive, a Durable Power of Attorney, and Durable Power of Attorney for Finances. These documents will help your loved ones provide you with the type of care you want and need in the future should you be unable to state those preferences. Meet with a lawyer knowledgeable about estate planning to draft a will, set up a trust, or handle other related legal matters.
- Focus on your present abilities and avoid worrying about what might happen in the future. Know that there are many ways to live an active and productive life. Focus on what you can do, not on what you can't.

Here are some additional tips to help you enhance your memory, health, and well-being:

- Take good care of your body. Keep hydrated by drinking plenty of water. Eat a low-fat, healthy diet, with plenty of fruits and vegetables.
- Maintain an updated list of your medications and contact information (doctors and family). Keep it with you at all times.
- Reduce clutter at home; enlist a friend to help organize and label important files, documents, and medications.
- Decrease your consumption of alcohol; it can have a negative effect on your mental abilities.
- Don't smoke.
- Continue to engage in social activities with friends and family.
- Never stop learning. Read a book, enroll in a class, attend a concert or play.
- Talk with friends or a trained counselor about your feelings.

Transitions:

It may be necessary to change your daily routine due to major neurocognitive disorder. Although a time may come when you must rely more on others for assistance with some tasks, you will want to stay involved in making decisions that affect your life as much as possible. The goal is to find a balance in your life: ensuring your safety while maintaining a reasonable degree of independence.

The following may require adjustments in your life:

Driving: If you drive, ongoing evaluation of your driving abilities and consultation with your physician are essential. It's also wise to pay attention to the suggestions of those close to you, as they might recognize changes in your driving ability before you do.

Home responsibilities: Household management may be difficult for you. Tasks such as cooking and taking medications may pose safety risks. You might, for example, forget to turn off the stove or forget to take a dose of medication. However, it's possible to continue to participate in household activities with a little help from another person or with the aid of technology (electronic medication reminders, etc.). You might choose to have family or friends assist in certain areas, or you might hire outside help. This is a good time to start discussing options with those close to you should you no longer be able to manage these tasks in the future.

Financial responsibilities: Complex tasks like balancing a checkbook, dealing with insurance, and paying bills may become frustrating and overwhelming. Consider enlisting a trusted family member or friend to help. Work with an attorney to draw up a Power of Attorney for Finances. This will allow a trusted person to act on your behalf if you aren't able to do so. Be sure to include this person early in the process so that he or she has time to learn what needs to be done. Like driving, managing your own finances is a sign of independence. It can be difficult to allow someone else to do this for you, but there is no embarrassment in admitting you need help. The people who are close to you may recognize your need for help before you do.

Health care: Complete an Advance Health Care Directive (sometimes known as a Durable Power of Attorney for Health Care or a Living Will), to ensure that your family members know your health care choices. It is important to have a conversation about end-of-life care as well, and to complete the appropriate forms documenting your preferences.

Key Community Resources:

The Eldercare Locator is a free service that will connect you with your local Area Agency on Aging or other sources of help.

Family Caregiver Alliance's National Center on Caregiving (800-445-8106, <u>www.caregiver.org</u>) offers help in locating services in your community.

Alzheimer's, senior service, and health organizations: Several organizations, both local and national, help people with cognitive impairment or dementia and their family caregivers. Many offer support groups, advice lines, and services at no cost to you.

Support groups and counseling services: Support groups for those with memory loss can be primarily discussion-oriented or can offer a variety of creative activities including planned outings. Caregiver support groups and education programs are also available in the community for family members or friends who are assisting you.

Volunteer programs: Volunteer opportunities for persons with major neurocognitive disorder are available in some areas. You may enjoy the chance to contribute your time and talent to your community.

Artistic programs: Expressing yourself through drawing, painting, clay, or photography, for example, can be beneficial and provide you wonderful opportunities for self-expression.

Structured day programs: Adult day programs include activities such as art, music, gardening, exercise, discussion groups, field trips, and assistance with physical health needs.

Professional assistance: Take advantage of professionals who assist with maintaining your physical strength and coordination, such as personal trainers, occupational therapists, and physical therapists. Hired attendants can also help with household chores and errands.

Resources:

Family Caregiver Alliance National Center on Caregiving (415) 434-3388 | (800) 445-8106

Website: www.caregiver.org
Email: info@caregiver.org

FCA CareJourney: www.caregiver.org/carejourney

Family Care Navigator: www.caregiver.org/family-care-navigator

Alzheimer's Association

www.alz.org

Alzheimer's Disease Education and Referral Center (ADEAR) www.nia.nih.gov

BrightFocus Foundation

www.brightfocus.org

Eldercare Locator

eldercare.acl.gov

Well Spouse Association

www.wellspouse.org

Palliative Dementia Care Resources

www.pdcronline.org

Administration on Aging

www.aoa.gov

Power of Attorney Documents

www.caringinfo.org