

CADASIL

About the condition

CADASIL is the most common genetic cause of stroke and vascular dementia in adults.

The name CADASIL is short for: Cerebral autosomal dominant arteriopathy with subcortical infarcts and leukoencephalopathy.

Each part of the name relates to the cause or effect of the condition. Cerebral refers to the brain; Autosomal Dominant refers to the way in which it is inherited.

CADASIL is an inherited disorder caused by changes (mutations) in a gene called Notch 3.

Strokes are the main feature of CADASIL and often occur repeatedly. Strokes may lead to severe disability, such as an inability to walk and urinary incontinence. The average age of a person when strokes first appear is 46 years.

Changes that might happen

CADASIL usually causes a slow decline in thought processes and approximately 75% of affected individuals eventually develop dementia.

Strokes that occur can:

- affect a person's thinking, reasoning and planning abilities
- cause changes in mood
- affect how a person walks.

Other changes that may happen include:

- migraines with aura occur in about 35% of individuals with CADASIL
- 30% percent of individuals with CADASIL experience psychiatric issues, varying

from personality changes to severe depression

- epilepsy is present in 10% of individuals with CADASIL and usually occurs in middle age.

Things to consider and strategies to cope

Tell people how the condition can affect you. From your appearance and physical condition, it may be fairly clear what the condition is doing to you. Chances are, however, that a lot more is going on than what people can see. Some rare conditions cause "invisible disabilities" and, to someone unfamiliar with it, the person looks perfectly fine. CADASIL is one of those.

Carry cards about your condition. Online printers offer custom business cards for a low cost. A small image along with a brief explanation of the disease and a list of symptoms can fit on one side. Keep a card in your wallet or purse as well as contact details for CADASIL Association (www.cadasilassociation.org), so someone interested can find out more.

Useful information

<http://www.cadasil.sgu.ac.uk/> (CADASIL Website)

http://www.alzscot.org/services_and_support/search/1945_glasgow_younger_persons_support_services (Alzheimer Scotland Support Services for Younger People with Dementia)

<http://www.cadasilfoundation.org/experiences.html>

<http://www.cadasilassociation.org/cadasil-info>

<https://globalgenes.org/raredaily/the-stigma-of-rare-disease-how-do-you-tell-people-about-your-condition/>



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