Wegener's Granulomatosis

Wegener's granulomatosis (also called Wegener's disease) is a rare disease of the blood vessels. The small and medium sized blood vessels become inflamed, interfering with the function of various organs. In Wegener's, inflammation primarily involves the kidneys and lungs.

CAUSES

Normally, the body's immune system is supposed to guard against foreign invaders like viruses or bacteria. In Wegener's, the immune system accidentally attacks the body's own blood vessels, causing inflammation and damage. Scientists are actively researching the cause of this disease.

SYMPTOMS

Symptoms can include:

- General:
  - Severe tiredness and weakness.
  - Decreased appetite.
  - Unintended weight loss.
  - Fever or sweats.
  - Joint or muscle pains.
- Nose:
  - Nose or face pain.
  - Runny nose.
  - Crusts or sores in the nose.
  - Nosebleeds.
- Airway and lungs:
  - Cough.
  - Chest pain.
  - Change in voice.
  - Wheezing.
  - Shortness of breath.
- Eyes:
  - Eye pain.
  - Red eyes.
  - Impaired vision.

Many other parts of the body can be involved.

DIAGNOSIS

Wegener's is a rare disease. It can be difficult to diagnose. Your caregiver (or a specialist) may suspect Wegener's based on your symptoms, or on prior lab or x-ray studies you have had done. A variety of tests may be used to diagnose Wegener's disease, including:

- Blood tests.
- Urine tests.
- Imaging studies: X-rays, CT scans, and possibly others.
- Biopsies. This is when a small sample of tissue from the nasal passages, lung, kidney, skin, or elsewhere is removed for examination in a lab.

You may need to see a specialist to determine your exact diagnosis. Wegener's can be confused with a number of other rare diseases.

TREATMENT

Wegener's can be a very dangerous disease, and can eventually cause death. With proper treatment, most people

with Wegener's can survive at least five years and often longer. Treatment usually leads to remission in a few months. Relapses can occur, and do respond to treatment.

The main treatments for Wegener's disease are medicines that calm the immune system. Frequently, you will need a combination of two strong medications. You must take these medicines exactly as prescribed. Your treatment will most likely be supervised by a specialist. Other medicines may be given as well, such as antibiotics to prevent infection, bone-building medicines, or vitamin supplements. Vaccinations against certain diseases (such as influenza or pneumonia) are important.

In severe cases, if the kidneys are badly damaged, a kidney transplant may be recommended.

HOME CARE INSTRUCTIONS

- Take any medications exactly as prescribed. Tell all of your caregivers about the medications you are taking.
- Keep your follow-up appointments and appointments for lab work or other tests. Your doses of medications may need to change in the early phases of treatment.
- Only take over-the-counter or prescription medicines for pain, discomfort or fever as directed by your caregiver.
- Although some of your treatments might affect your appetite, try to eat regular, healthy meals.
- If you develop any side effects, such as nausea, diarrhea, rash, white patches in your mouth, sore throat or difficulty swallowing, or severe fatigue, tell your caregiver. Your caregiver may need to change your treatment, or may have recommendations of things you can do to improve symptoms.

SEEK MEDICAL CARE IF YOU:

- Begin to have more (instead of fewer) symptoms.
- Feel like you are having side effects from your medications, such as nausea, diarrhea, rash, white patches in your mouth, sore throat, difficulty swallowing, or severe fatigue.
- Develop an infection while you are on your treatment medications for Wegener's.
- Have any new medical problems.

SEEK IMMEDIATE MEDICAL CARE IF YOU:

- Develop an unexplained oral temperature of 100.5° F (38.1° C) or more.
- Develop chest pains.
- Feel short of breath.
- Feel very lightheaded or pass out.
- Notice pain, swelling or redness anywhere in your legs.
- Have uncontrollable bleeding, such as blood in the urine or a nosebleed that will not stop.
- Have sudden loss of vision or hearing.
- Have decreased urination.

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