

THE VEDS MOVEMENT

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Name: _____

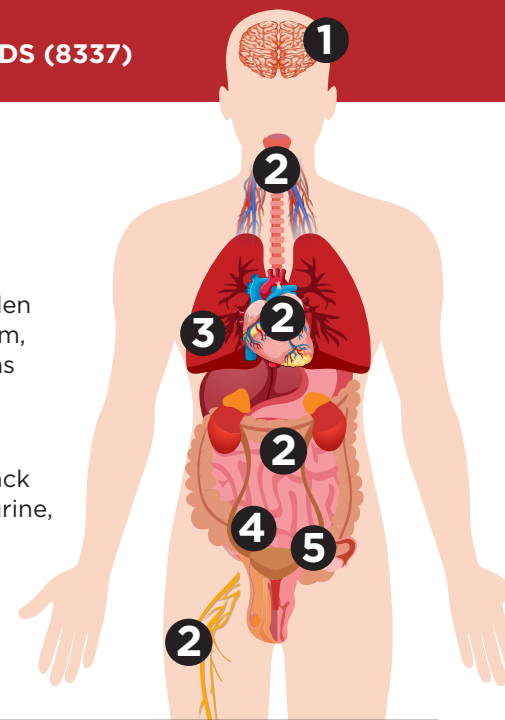
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Vascular Ehlers-Danlos Syndrome (VEDS) First Responders Quick Guide

- ▶ Vascular EDS is a rare, life threatening condition that causes fragile tissues and presents with arterial dissection or rupture, bowel rupture, and uterine rupture at the end of pregnancy.
- ▶ Life-threatening complications can occur at any age; Refer to patient's premise alert file when available.
- ▶ Patient may have a medical bracelet with doctor's direct phone number.
- ▶ The VEDS Movement Information Line for Emergency Physicians: **470-563-VEDS (8337)**

Life-Threatening Complications & Presenting Symptoms

- 1. Carotid Cavernous Sinus Fistula** – Sudden onset of swooshing sound in the head, difficulty with lateral gaze, redness of the eye, eye pain, bulging of the eye and/or rapid onset of blurred vision
- 2. Arterial Dissection & Rupture** of any artery in the body (including the aorta) – Sudden onset pain, nausea, shortness of breath, fainting, loss of pulse, abnormal heart rhythm, tingling, numbness, paralysis, rapid swelling of area and/or possible stroke symptoms
- 3. Pneumothorax/Hemothorax** – Sudden onset of chest pain, tightness in the chest, shortness of breath, rapid heart rate and breathing, cough, fatigue
- 4. Uterine Rupture** (during pregnancy) – Pain in the lower area of the belly or lower back pain (can be intermittent like contractions or ripping pain), shoulder pain, blood in urine, bloody vaginal discharge, new low blood pressure, dizziness, fainting, change in the contour/shape of belly and/or abnormalities in fetal heart rate pattern
- 5. Bowel perforation** – Common in sigmoid colon (lower left quadrant of abdomen), abdominal pain gradually increases to severe, nausea, vomiting, chills, rectal bleeding and/or fever



Management Guidance

- ▶ Transport to a **Level 1 Trauma Center only**, if possible (consider air medical for long transport).
- ▶ The fragility of all tissues means invasive procedures should be avoided, when possible.
- ▶ Defibrillation **CAN** be used on Vascular EDS patients.
- ▶ Common for veins to burst when attempting to give an IV. Expect to administer drugs or fluids from peripheral site. Intraosseous access may be more beneficial if in resuscitation scenario.
- ▶ Monitor blood pressure closely.
- ▶ Pain should be taken seriously. Treat as a **Trauma Patient**. DO NOT disregard general pain.
- ▶ If a premise alert program exists in your area, inform the patient and advocate for them to get a premise file.

Drug Interactions

- ▶ Many people with VEDS take beta-blockers. **Epinephrine** can have serious interactions with beta-blockers and should be avoided, unless in anaphylaxis or needed for immediate life-threatening scenario. Beta-blockers can mask signs of compensated shock.
- ▶ Avoid intramuscular or subcutaneous injections of **Heparin or Heparin substitutes** (blood thinners), as these can cause massive hematomas, bleeding & bruising.
- ▶ Aggressively treat nausea and vomiting in the ambulance with **PO/IV Zofran or Benadryl**.
- ▶ **Avoid fluoroquinolone** antibiotics if possible – FDA warning indicates fluoroquinolones should not be used in people with VEDS due to risk of aortic aneurysm or dissection.