Faces of Dysautonomia

"But you don’t look sick."
Dysautonomia: The Invisible Illness

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Program Objectives

➢ **Awareness**
  • What is this invisible condition?

➢ **Identification**
  • What symptoms are present?
  • What can be done to identify it?

➢ **Movement**
  • How can I help the patient now? next steps, resources
Awareness:

What is dysautonomia?

- **Dysautonomia** is an umbrella term for disorders of the autonomic nervous system.

- **POTS** is a form of dysautonomia.
  - Postural Orthostatic Tachycardia Syndrome.

“invisible” does not mean “imaginary”
Awareness:
Why is this important?

- Nurses are on the front lines – often see patients first
- Chances are good that a patient you know has POTS
- 1 in 100 teens affected
- 3.5 million undiagnosed in the US; 70 million worldwide.
- *Change diagnosis from 6 years to 15 minutes*
Approximately **7-10 million** worldwide live with Parkinson's disease.

**5 million** people worldwide have a Lupus diagnosis.

**More than 70 million people worldwide suffer from dysautonomia.**

83% of patients are improperly diagnosed with anxiety or psychological disorders before POTS diagnosis.

25% of POTS patients are too disabled to attend work or school.

85% of POTS patients are female.
Christina Elizabeth Tournant
June 24, 1997 - March 5, 2015

We Will Continue Your Fight
dysautonomia
Identification:

Keys to Identification

- Top 7 signs and symptoms (p. 37)
- Orthostatic Vitals Test (p. 99, p. 220)
- Patient History is key
  - Clinical Assessment Form (p. 214)
Identification:
POTS, Dysautonomia & The ANS

POTS: Invisible Illness
KELLY FREEMAN, MSM
Identification:
Top 7 Signs & Symptoms

- Difficulty Standing Still*
- Fatigue*
- Lightheadedness
- Nausea and Other GI Symptoms
- Brain Fog or Mental Clouding
- Palpitations or Chest Discomfort
- Shortness of Breath or Difficulty Breathing
Identification:

Orthostatic Vitals Test

- Easy & Meaningful
- Takes about 15 minutes
- May support a diagnosis
- Educational video on website
- Test form on website
Protocol for Conducting an Orthostatic Vitals Test
Identification:

Patient History is Key

- Clinical Assessment Form
  - use as a guide in clinical assessment of autonomic system function
- Listen, validate
- Have dysautonomia/POTS on your radar
Identification:

Things to watch for…

Dilated pupils - first sign of a POTS flare up
Identification:
Things to watch for...

- Blood Pooling
- Trendelenburg
Movement: Next Steps

Be an informed voice in the medical community

- Become educated by reading the book
- Share the information with peers and doctor
- TDP is available as a resource online and in person
Movement:
Next Steps

Say it, write it

- Identify and advocate for patients
- “POTS”, “dysautonomia” in medical records
- Accommodations for students (hospital homebound, encourage school to be creative with learning, etc.)
Movement:
Next Steps

Consider treatment options
- increase fluids, salt intake, compression stockings, IV fluid therapy
POTS is not rare, just rarely diagnosed

The #1 Treatment is Education