

Standing ^{Up} POTS

Understanding the Role of Chronic Illness in Depression, Anxiety, and Suicide Prevention

Postural Orthostatic Tachycardia Syndrome (POTS) is characterized by dysfunction of the autonomic nervous system which controls blood pressure, heart rate, blood vessel and pupil diameter, peristaltic movements of the digestive tract, and body temperature. One of the hallmark symptoms of POTS is orthostatic intolerance, in which blood pools in the lower body upon standing. As a result, a shortage of blood in the brain upon standing can cause dizziness, light-headedness, and possibly fainting.

Developing POTS is a game changer. A person with POTS uses three times more energy to stand than normal. Even minor movements around the house, including eating meals and showering, can be exhausting and increase symptoms. The quality of life of a person with POTS has been compared to those with congestive heart failure or chronic obstructive pulmonary disease. POTS can truly be debilitating.

The long term outcome for someone with POTS depends on the underlying cause of this disorder.

- For adolescents, 20% made a full recovery within 10 years, 60% had improved symptoms but still met the criteria for POTS, and the remaining 20% had maintained their level of POTS or declined further since the time of diagnosis.
- After viral infection, approximately 50% of people recover in two to five years.
- With the primary hyperadrenergic form, lifelong treatment will be required.
- For individuals with POTS secondary to another illness, treatment of the underlying disorder is critical in order to control or eliminate POTS symptoms. Diagnosing this underlying illness can be difficult.

Special Considerations when Working with the Chronically Ill

Isolation in chronic illness. The chronically ill are an often hidden segment of society because they are often partially or completely homebound. People suffering from chronic illnesses like postural orthostatic tachycardia syndrome, chronic fatigue syndrome/myalgic encephalomyelitis, and fibromyalgia have the added burden of lack of understanding by the general population. Sometimes when they venture out, they are bullied, called “fakers,” or hear other derogatory comments being made about them. Physical isolation and illness create feelings of being misunderstood and not belonging.

Feel ignored and abandoned by health professionals. For most of the population, we visit the doctor and our illness is managed or cured. This is not true for many suffering from chronic, invisible illness. Not only are people with POTS or other invisible illnesses traumatized by their illness, they are also often traumatized by their health care practitioners. Some have been told to stop fainting, bring their heart rate down, etc. because clearly they only want attention! Most physicians have never heard of POTS, and autonomic specialists who treat POTS often have waiting lists that are years long.

Disbelief of family and friends. Invisible illness can put even the strongest relationships in jeopardy. As days turn to months and then years, the constancy of chronic illness can wear on even the strongest marriage, friendship, or family relationship. Missed holidays, birthdays, and other social events leave people feeling betrayed and wondering if the ill loved one could make a little better effort to be present. Friends and family often don't believe that their loved one is sick. Some are confrontational while others are more passive aggressive. Because hair doesn't fall out with chronic fatigue syndrome, there are no skin lesions with multiple sclerosis, and no significant weight loss with POTS, it is easy to forget the internal battles being waged each day. As a counselor, it is your job to believe them! This is something a suicidal person with chronic illness is often missing – a safe place where they can be heard, validated, and comforted.

Physical Issues that may Influence Treatment

Crushing fatigue. Because of their chronic illness, routine activities can cause debilitating fatigue in those with many invisible illnesses. Standing, walking, showering, and focusing on conversation quickly tires the person with POTS. As they get more fatigued, brain fog also tends to increase.

Exercise intolerance. People with POTS or chronic fatigue syndrome get fatigued from even mild exercise. Walking across the parking lot, participating in therapeutic exercise or other activities can trigger debilitating rebound fatigue. Accommodations to the activity routine will likely be necessary.

Dehydration. People with POTS tend to have low blood volume, and symptoms are exacerbated when they don't get enough fluid and electrolytes. Allowing water or an electrolyte drink at all times is an important accommodation. Some require IV fluids to maintain their blood volume.

Anxiety can be a physical symptom of POTS. Dysregulation of the autonomic nervous system often results in the overactivity of the sympathetic nervous system. This fight or flight system can generate feelings of anxiety as a result of increased levels of norepinephrine being released into the body.

Specific sensitivities. Many people with POTS are particularly sensitive to certain foods, light, noises and smells. This is particularly true when they are flaring and POTS symptoms are out of control.

Medication intolerance. Many people with chronic illness take a myriad of medications. For many, lower doses are preferable to prevent side effects. Because dizziness, lightheadedness, fainting and brain fog are common symptoms of POTS, avoid prescribing medications that might exacerbate these problems.

Continuous monitoring of vitals for 24 hours. Monitoring their changes in heart rate and blood pressure due to POTS may help the community better understand the physical changes occurring with each change of position and allow caregivers to be more compassionate.

Coping skills to deal with POTS, and NOT necessarily related to depression/ suicidal ideation

Signs of depression in the general population may be related to symptoms of chronic illness. Coping skills to manage many chronic invisible illnesses, such as staying in bed and avoiding the shower, may not be related to depression or risk of suicide. Physical problems like surges in the sympathetic nervous system releasing norepinephrine may cause insomnia, anxiety, or panic attacks. Lack of appetite can be related to gastroparesis (paralysis of the stomach) or other digestive motility issues. It can be difficult to differentiate physical from psychological issues when working with the chronically ill. Reading and learning about their specific illness can greatly aid the therapist in making these decisions.

However, it is important to remember that persons with chronic illnesses involving functional impairment and chronic pain are at greater risk for suicide, so warning signs such as suicidal thoughts and threats, previous suicide attempts, and hopelessness must be taken seriously.