

Aging Well with Post-Polio Syndrome: Don't Take Fatigue Lying Down

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Fatigue is a major problem for many people with post-polio syndrome (PPS), one that is frustrating and hard to measure. It's a symptom that can affect your ability to work, your mobility and your quality of life. People with PPS report fatigue as their most persistent and debilitating symptom.

Although most people (with or without PPS) report increases in fatigue as they grow into middle age, interestingly, they report decreases in fatigue as they transition from middle age to retirement. Middle age is a time of great stress – work responsibility, saving for retirement and preparing children for independence.

After retirement, the decrease in daily stress helps to reduce fatigue. Unfortunately, analyses from a recently completed survey study that many of the people reading this article participated in shows that people with disabilities (including PPS) do not reap the “retirement benefit” on fatigue. Instead, for people with disabilities, fatigue stays the same or gets worse as people age into the retirement years (Cook, 2011).

In our study surveying 441 people with PPS, we found individuals with disabilities are not only at greater risk to experience fatigue than people without disabilities, but this risk increases with age. Moreover, we found that fatigue in people with PPS was the *highest* of those surveyed, which also included people with multiple sclerosis, muscular dystrophy and spinal cord injury.

A 5-year longitudinal survey of people with the late-onset of sequelae of poliomyelitis done in the Netherlands showed that fatigue was associated with perceived restrictions in physical functioning, higher levels of pain and sleep problems. A task-oriented (problem-focused) coping style correlated with higher levels of fatigue. This type of coping style may be pushing survivors beyond their physical abilities and increasing levels of fatigue (Tersteeg, 2011).

There are several non-medication ways to manage fatigue:

Assistive Device/Equipment/Technology – Protect your weakened muscles – talk with your doctor or physical therapist about the best assistive devices for you, such as braces, canes, walkers or power chairs.

Self Management is defined as methods, skills and strategies that can effectively direct activities toward the achievement of a goal or objective. For people living with a chronic condition, this translates to “*overcoming the physical and emotional problems caused by the disease. The goal is to achieve the greatest possible physical capability and pleasure from life*” (Lorig et al, 2006). This idea can be applied to fatigue. You can *manage* your activity level by planning and scheduling, prioritizing, delegating or asking for help and pacing yourself. (Ghahari, 2010)

Exercise/physical activity – Historically, people with PPS were often told to minimize exercise as a way to conserve energy. Current research has shown the benefits of a *carefully tailored and gentle* exercise program designed specifically for each person depending on how PPS is affecting the body (Davidson et al, 2009). Be sure to talk with your doctor or physical therapist about starting any new exercise program.

References:

- Cook KF, Molton IR & Jensen MP. Fatigue and Aging with a Disability. *Archives of Physical Medicine and Rehabilitation* 2011; 92:1126-33.
- Tersteeg IM, Koopman FS, Stolwijk-Swüste JM, Beelen A, Nollet F, on behalf of the CARPA Study Group. A 5-year longitudinal study of fatigue in patients with late-onset sequelae of poliomyelitis. *Archives of Physical Medicine and Rehabilitation* 2011; 92:899-904.
- Ghahari S, Leigh T, et al. Effectiveness of an online fatigue self-management programme for people with chronic neurological conditions: a randomized control trial. *Clinical Rehabilitation* 2010; 24:727-744.
- Davidson AC, Auyeung V, Luff R, Holland M, Hodgkiss A, & Weinman J. (2009). Prolonged benefit in post-polio syndrome from comprehensive rehabilitation: A pilot study. *Disability & Rehabilitation*, 31(4),309-317.
- The National Center on Physical Activity and Disability (NCPAD) To Reap the Rewards of Post-Polio Exercise – www.ncpad.org/disability/fact_sheet.php?sheet=136