Let's talk about . . .

BALANCE & DIZZINESS CANADA

PERSISTENT POSTURAL-PERCEPTUAL DIZZINESS (PPPD)

This handout is intended as a general introduction to the topic. As each person is affected differently, speak with your health care professional for individual advice.

Key points

- Say "three-P-D" or "triple-P-D".
- A common cause of long-lasting dizziness.
- May persist for three months or more.
- In some people, starts after an event that brings on dizziness or vertigo, such as another vestibular disorder.
- Instead of fully recovering, the brain stays on high alert and over-reacts.
- Anxiety often starts around things that trigger symptoms.
- Can start to interfere significantly with daily life.
- A vicious cycle starts. As anxiety increases, so do symptoms.
- Symptoms are real – NOT a mental illness.
- Treatment usually includes "retraining" the brain though a mix of vestibular rehabilitation (an exercise-based therapy), medication, and counselling.
- No quick fix, but recovery is possible with time, understanding, and the right kind of treatment.

What is PPPD?

Persistent postural-perceptual dizziness (PPPD, pronounced "three-P-D" or "triple-P-D") is a common cause of chronic (long-lasting) dizziness. It is usually treatable, especially if it is diagnosed early.

Usually, PPPD is triggered by an episode of vertigo or dizziness. After that first episode, the person continues to have feelings of movement, dizziness, unsteadiness, or light-headedness that can last for hours or days at a time. These symptoms are present nearly all the time, but they can be better or worse at times. Things like sitting or standing upright and seeing busy patterns or movement often make the symptoms worse. As a result, people with PPPD often become anxious about losing their balance or falling. They may avoid situations that make their symptoms worse, to the point where it can start to interfere with their lives.

PPPD can be very frustrating for people who have it. Many health care professionals are not very familiar with dizziness, and the symptoms of PPPD can be vague and hard to describe, so it may not be diagnosed for some time. PPPD can interfere with work, school, leisure, and family life.

PPPD was defined as a disorder in 2015. Before that, several different names were used for conditions with similar symptoms, including phobic postural vertigo (PPV), space-motion discomfort (SMD), visual vertigo (VV) and chronic subjective dizziness (CSD).

Researchers are not sure how many people have PPPD. But some studies suggest that as many as 1 in 4 people who have a vestibular problem such as vestibular neuritis, Ménière's disease or benign paroxysmal positional vertigo (BPPV) may go on to develop PPPD.

PPPD can happen at the same time as another vestibular disorder. For example, someone can have both Ménière's disease and PPPD. And some people with Ménière's disease may never develop PPPD.

PPPD seems to be more common in women, and often develops between the ages of 30 and 50.

What are the causes?

The brain's balance system combines information from many sources, including the:

- **vestibular system** (the semicircular canals and otoliths in the inner ear), which senses when your head tilts, turns or changes speed
- **visual system**, which lets you see
- **proprioceptive** system, which sends signals about position, pressure, movement and vibration from the legs and feet and the rest of the body

Normally, you don't consciously notice all these different sources of information. The balance system combines them for you in the background, and you can stand, walk, or turn your head without needing to think about keeping your balance. But with PPPD, the experience is no longer seamless. You start to notice the different signals, especially if they do not all agree with each other. This can make you feel like you are moving when you are standing still, or like you are about to fall.

If the brain thinks you might be in danger of falling, it reacts automatically to protect you. Think about how you feel when you are walking on ice or standing on a ladder: your body gets stiff, you take shorter strides, and you focus on staying upright. At the same time, the balance system uses less information from the vestibular system and more from the visual system. Normally, when the risk of falling is over, the balance system goes back to normal. But in PPPD, the brain stays in "high-risk" mode instead. This causes a vicious circle:

- you worry about falling and pay more attention to keeping your balance
- the brain stays on the alert and relies more on visual input
- visual input like busy patterns and movement suggests you might be in danger of falling

This description may make it sound as if PPPD is "all in your head," but the symptoms are real. PPPD has some things in common with anxiety disorders, but it is not a psychiatric disorder. Some studies have found differences in brain activity in people with PPPD, compared with people who do not have PPPD. These differences may make it harder for the brain to integrate different sources of information and assess threats properly.

PPPD is usually triggered by a first episode of vertigo or unsteadiness. This first episode may be caused by many different things that upset the balance system, including:

- a vestibular problem such as:
    - Ménière's disease,
    - vestibular neuritis
    - benign paroxysmal positional vertigo (BPPV)
    - isolated otolith dysfunction (iOD)
- vestibular migraine
- mild concussion

The first episode of vertigo or unsteadiness can also be caused by a psychological event, such as anxiety or a panic attack. Panic attacks and anxiety can have physical symptoms, including dizziness, light-headedness, fast heartbeat, shortness of breath, sweating, shaking, muscle tension, tiredness, or nausea.

What are the symptoms?

PPPD can cause various symptoms, including:

- **non-spinning vertigo** (feeling as if you are swaying or rocking, even though you are sitting or standing still)
- **unsteadiness** (feeling as if you are about to fall)

- **light-headedness** (feeling woozy or as if you are going to pass out)
- **mild dissociation** (feeling "spaced out" or as if you are floating)

These symptoms happen on most days for at least three months. They may last for hours at a time. They may not happen every day.

Many people with PPPD find it hard to describe their symptoms. People often feel "off" or not like themselves.

People with PPPD often feel worse when:

- they are standing or sitting upright
- they see movement, such as when they are scrolling on a phone, watching TV, looking at traffic or seeing many people walking around
- they see complex patterns, such as a busy carpet, wallpaper, or a supermarket aisle
- they are walking or riding in a car

The symptoms sometimes get worse if the person is tired or paying more attention to the symptoms and better if the person is distracted. They are usually persistent (they continue for a long time).

The pattern of symptoms may be slightly different depending on what originally caused the PPPD:

If it was caused by an acute problem (one that lasts for a short time and then goes away) or an episodic problem (one that goes away and comes back from time to time), PPPD symptoms may start as the initial problem gets better. They may come and go at first and then become persistent.

If it was caused by a chronic problem (one that does not go away), PPPD symptoms may develop slowly and gradually get worse.

People with PPPD may develop other related problems, including:

- neck stiffness
- problems with how they walk (their gait)
- fatigue (tiredness)
- fear of falling
- anxiety or avoidance about things that trigger dizziness for them, such as crowded places or even going outside

How is it diagnosed?

PPPD may be diagnosed by a primary care doctor or a specialist, such as a neurologist, an otolaryngologist, an otologist, or a psychiatrist.

There is no test that is specific for PPPD. But PPPD is not a diagnosis of exclusion, which is a diagnosis made when no other cause for the symptoms can be found. Diagnosis is based on clinical criteria.

Your doctor will ask about your symptoms. Symptoms like dizziness and vertigo are not always easy to describe. Try to be as specific as possible about your symptoms and when they get better or worse.

Your doctor will also ask about your medical history, including any medications you are taking. Side effects from medication or dose changes can sometimes cause symptoms similar to PPPD.

You may have some of the following diagnostic tests:

- general physical exam
- vestibular function tests
- balance tests
- blood tests
- imaging (CT or MRI scans)

PPPD can overlap with other vestibular disorders, such as Ménière's disease. So, your doctor will also look for signs of any related conditions, including conditions that might have triggered PPPD and problems that PPPD might have caused (also called secondary conditions).

Clinical criteria for PPPD

To be diagnosed with PPPD, a person must have all of the following:

- One or more symptoms of dizziness, unsteadiness or non-spinning vertigo on most

days for at least three months. Symptoms last for hours-long periods but may wax and wane in severity. Symptoms do not need to be present continuously throughout the entire day.

- Persistent symptoms happen without specific provocation but are exacerbated (made worse) by three factors: upright posture, active or passive motion without regard to direction or position, and exposure to moving visual stimuli or complex visual patterns.
- The disorder is triggered by events that cause vertigo, unsteadiness, dizziness, or problems with balance, including acute, episodic or chronic vestibular syndromes, other neurological or medical illnesses, and psychological distress.
- Symptoms cause significant distress or functional impairment.
- Symptoms are not better accounted for by another disease or disorder.

How is it treated and managed?

Once you have a diagnosis, the first step in treatment is helping you understand what causes PPPD and how the brain is responding to normal signals as if you were in danger. Knowing what is going on will help you feel more in control and able to take part in treatment.

Treatment for PPPD usually involves "retraining" your brain through a combination of vestibular rehabilitation, strategies to address anxiety, such as medication and cognitive-behavioural therapy (CBT).

You may also benefit from relaxation for your neck and shoulders. Ideally, you will have a treatment team of health care professionals who work together to help you.

Remember that both vestibular rehabilitation and CBT take practice and effort. Your therapists will teach you the skills you need, but you are the one who puts them to use.

Vestibular rehabilitation

Vestibular rehabilitation is an exercise-based treatment program for dizziness. Its goal is to help your brain relearn how to balance and how to respond to signals from the visual and vestibular systems. A vestibular therapist with experience in PPPD can help you set treatment goals and design a customized program to meet your needs.

Vestibular rehabilitation for PPPD may include:

- **Adaptation exercises** to coordinate the vestibular ocular reflex (VOR). A properly functioning VOR allows you to keep visual targets in focus even when your head is moving. There are several types of adaptation exercises.
- **Gaze stabilization exercises** involve moving your head while keeping your eyes focused on a target. For the exercises to work, you must move your head as quickly as you can while looking at the target. It is normal to get a little dizzy or miss the target every now and then.
- **Target shooting exercises** involve keeping your head still while moving the eyes, or vice versa.
- **Habituation exercises** designed to reset the sensitivity of the nervous system. They help your brain get used to and ignore movements or situations that make you feel dizzy. This is done through repeated, controlled exposure to signals such as complex patterns and busy environments. You may do exercises indoors and outdoors. You may go on short trips to places that trigger symptoms, such as grocery stores or shopping malls.
- **Balance retraining exercises** are done by standing on different surfaces and with increasingly narrow bases of support. They are helpful for improving steadiness to perform activities of daily living as well as to lower the risk of falling.
- **Balance exercises** done with eyes closed. These help reduce dependence on your eyes for balance by encouraging the use of the vestibular system (inner ear balance structures).

- **Strengthening exercises** to improve muscle support of your body.
- **Gait training**, for example treadmill training and learning to walk over unstable surfaces.
- **Range of motion exercises** if you have been limiting movement of your head of body to minimize dizziness.
- **Learning and practicing strategies to deal with or prevent your symptoms**.
- **Breathing and relaxation exercises**, which help to regulate the autonomic nervous system.
- **Walking and other aerobic activities**.

It is VERY important to start exercises gradually and increase them slowly and steadily. **Do not "push through" symptoms.**

Practice the exercises in a mindful, controlled way without extra muscle tension and always stop when your symptoms increase. A helpful way to judge is to rate the symptom before the exercise (dizziness = 2). Start the exercise and when the rate goes up 2 points, stop, rest, and allow the symptoms to go back to baseline before proceeding with anything else. It helps to use breathing techniques to relax and get back to baseline.

If you start doing too much, too soon, it can make the symptoms of PPPD worse. The vestibular therapist tracks your progress. The frequency, duration and complexity of the exercises is gradually increased based on your response. Treatment may last for several months.

Medication

Your doctor and you may decide to use medication in your PPPD treatment. Note that usually medication alone does not fully address PPPD symptoms. Two types of antidepressants may be used:

- SSRIs (selective serotonin reuptake inhibitors), including fluvoxamine (Luvox®), paroxetine (Paxil®) and sertraline (Zoloft®)
- SNRIs (serotonin norepinephrine reuptake inhibitors), which are usually tried if two SSRIs have not worked

These medications are used to treat depression and anxiety, but they can also help to treat PPPD. All work in slightly different ways. If the first medication does not work or if it has too many side effects, your doctor may suggest trying a different one.

It is important to start at a low dose and increase the dose gradually. Let your doctor know if you are having any side effects. It usually takes 8 to 12 weeks for medication to start working. If you find a medication that helps with your symptoms, you may need to take it for several months. Do not stop taking your medication or change your dose without talking to your doctor.

Some medications that are used to treat other forms of dizziness, including dimenhydrinate (Gravol®), betahistine (Serc®), sedatives and other antidepressants, have not been shown to be effective to treat PPPD. In fact, some of them may slow down your recovery. Be sure to discuss all medications with your doctor, including over-the-counter and natural products.

Cognitive-behavioural therapy

Cognitive-behavioural therapy (CBT) is a type of psychotherapy. It usually lasts for a relatively short time and is focused on a specific goal.

CBT is focused on the relationship between your thoughts (cognition) and behaviour. Cognition includes your conscious thoughts (which are under your control), your automatic thoughts (which may not be under your control) and your core beliefs (known as schemas). CBT teaches you how to:

- notice and identify your thoughts and beliefs
- consider your thoughts and beliefs from different viewpoints
- change your behaviour patterns

For PPPD, the goals of CBT are to help you:

- manage anxiety
- cope with symptoms when they happen
- stop avoiding situations that could trigger symptoms
- gain confidence

Some studies have found that even 3 sessions of CBT help to improve symptoms in as many as 3 in 4 PPPD patients.

Other forms of anxiety management, such as mindfulness-based stress reduction may also be beneficial in PPPD treatment.

What to expect in the future

So far, there is not much research about recovery from PPPD. Vestibular rehabilitation seems to help many people with PPPD, especially if it is combined with patient education and/or anxiety management.

PPPD may never go away completely, but the skills you learn in vestibular rehabilitation and CBT should make the symptoms better and help you go back to your normal activities.

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In addition, find information about how the balance system works, the journey from diagnosis to treatment, building a wellness toolkit, and more.

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