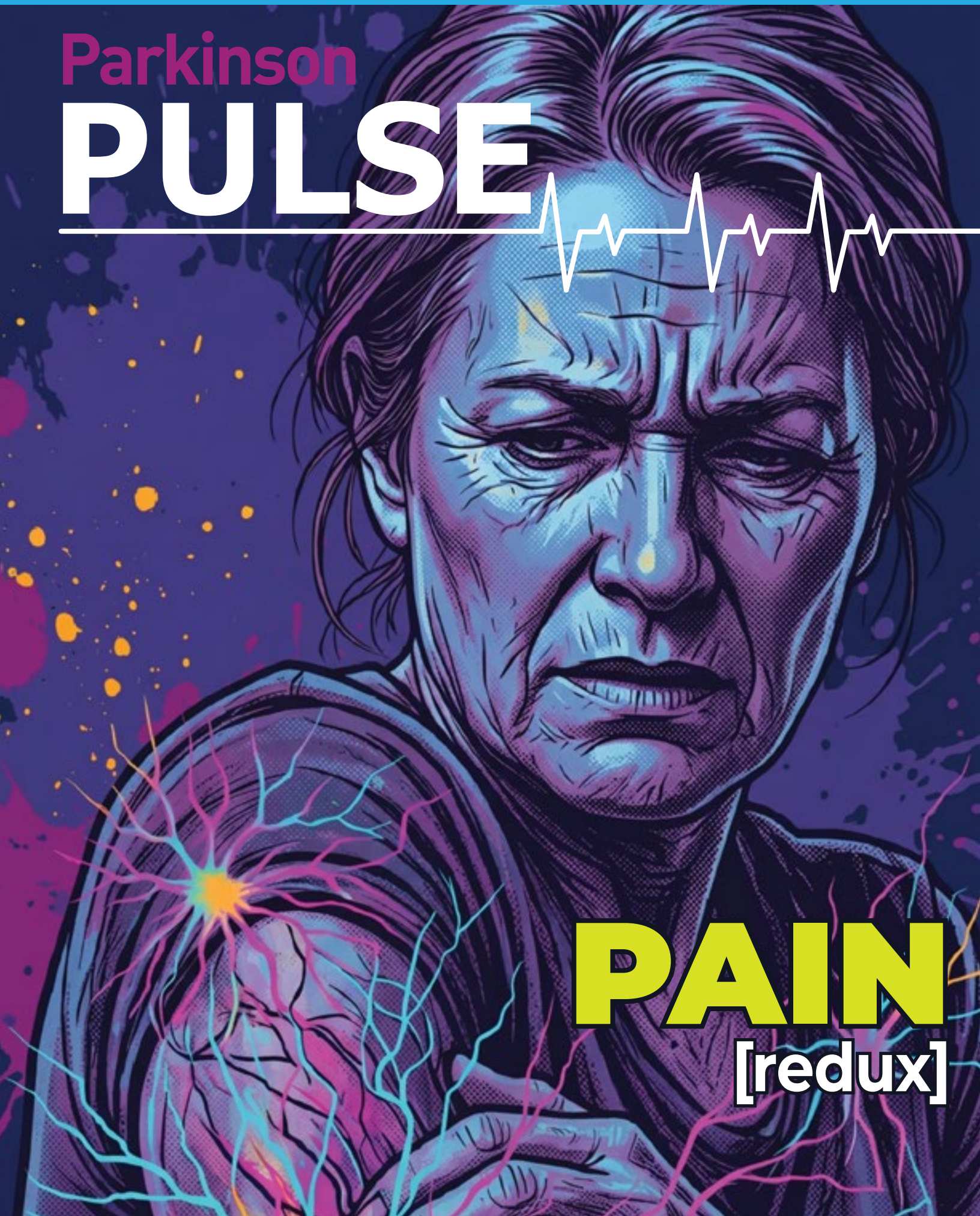
Parkinson Association of Alberta *Quarterly Magazine* Spring 2026

Parkinson PULSE



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Parkinson Association of Alberta empowers individuals and families throughout their Parkinson's journey, responding to each unique need with knowledgeable and compassionate support.

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Message from our Executive Director

Dear friends,

Can you feel it? Me neither! But I'm told spring is just around the corner. Hopefully it will feel that way as you read through your latest edition of Pulse Magazine. As is so often the case, time seems to both move slowly and fly by, but we're really excited about all the upcoming activities and events in our Parkinson's community. From new program options to our annual AGM and Brunch, we've included everything we can think of in the pages that follow. We hope to share time with you this spring and into the summer.

I'd like to take a moment once again to extend our sincere thanks for your generous support through our season of giving. We know there are so many worthwhile causes and even Parkinson's specific organizations worthy of receiving donations of your hard-earned dollars, so we are very aware how significant and special it is you continue to choose Parkinson Association of Alberta. This year's campaign earned more than $275,000, nearly twice what we traditionally see. Even our auditors were amazed! Thank you for trusting us and for your ongoing support.

This edition of Pulse is focused on an often-misunderstood aspect of Parkinson disease. I once was told by a neurologist that pain wasn't part of Parkinson disease. Um, nope. Unfortunately, pain affects as many as 90% of people with a Parkinson's diagnosis. As with most Parkinson's symptoms, how pain manifests for you and the underlying causes vary. From the processing of pain receptors to pain from rigidity, stiffness, dystonia or nervous system damage, almost everyone with PD will experience complex pain and how one manages through it varies just as much. Our team has pulled together some great information here and we're always available to talk through your specific experience and help navigate the ways in which you might work towards pain management.

I hope you find something valuable in the pages that follow and I look forward to seeing as many of you as possible through Parkinson Awareness Month and into the summer. One final note to make sure you've bought or renewed your $35 annual membership in order to vote in our upcoming AGM and help guide the future of Parkinson Association of Alberta.

Thank you for being part of our Parkinson's community and all the best!

Lana

PAIN

Written By: Brandi La Bonte

In January 2019 our Winter issue of Pulse was focused on pain. Six years later, we felt it was time to revisit that topic – reusing material that is still relevant, updating pieces that weren't, and adding in new perspectives.

Pain is …weird?!? Trust me when I say I'm not trying to make light of what is a very real, and often very terrible state to be in. However, I will ask you to humor me for a moment while I share the "Tale of Two Nails" to elaborate.

First, a medical anecdote from a 1995 British Medical Journal tells the story of a construction worker who came to the emergency department having jumped down on to a seven inch nail. As the smallest movement of the nail was so painful he was sedated so the nail could be pulled out from below.

Second, authors Dimsdale & Dantzer in 2007 share a story of another construction worker, this gentleman accidently discharged a nail gun and a four inch nail struck him in the face. Considering himself lucky with a small wound, some bruising under his chin and a toothache, he went back to work the next day.

So far it doesn't seem so weird. You've got one very unlucky guy and one very, very lucky guy. But wait, there's more.

Our sedated construction worker who jumped on the nail; well once they removed the nail, they removed his boot prepared to deal with the damage the nail did only to discover the nail had NOT touched his skin. It had miraculously gone between his toes. No wound, no blood, not even a scratch – but pain that required him to be sedated.

The other construction worker? He went back to work for six days before his toothache took him to the dentist who upon x-ray discovered the four inch nail imbedded in the man's brain. A seriously precarious situation, yet the man continued about his life pain-free.

Both incidents illustrate how pain in an interpretation of events by the brain. The first construction worker felt the nail going into his boot, saw the nail in his boot and his brain translated that as severe danger and sent signals to react. With no immediate alarming cues, the second construction worker's brain did not trigger a danger response – so no pain signals were sent.

So, pain isn't even pain until your brain decides it is!?! Yeah, pain is weird! But it can also be nagging, devastating, debilitating, and cause a lot of misery, grief, and heartache. Pain is a universal experience. It doesn't care who you are, where you live, how old you are, or how much money you make. And, in the most general of terms, pain is unavoidable; at some point each of us will experience pain, on multiple occasions, over the course of our existence.

Pain can be physical or emotional, fleeting or chronic, and, depending on its severity and duration, can adversely affect one's quality of life. Pain can feel like being wrapped in barbed wire. Where you are scared to move, speak, blink or even breathe for fear of bringing on more pain. And, even if you don't move, or speak or blink or breathe the barbs are still digging in physically and emotionally causing pain.

Being in pain (even temporarily) can wreak havoc on your daily life, social activities and even relationships.

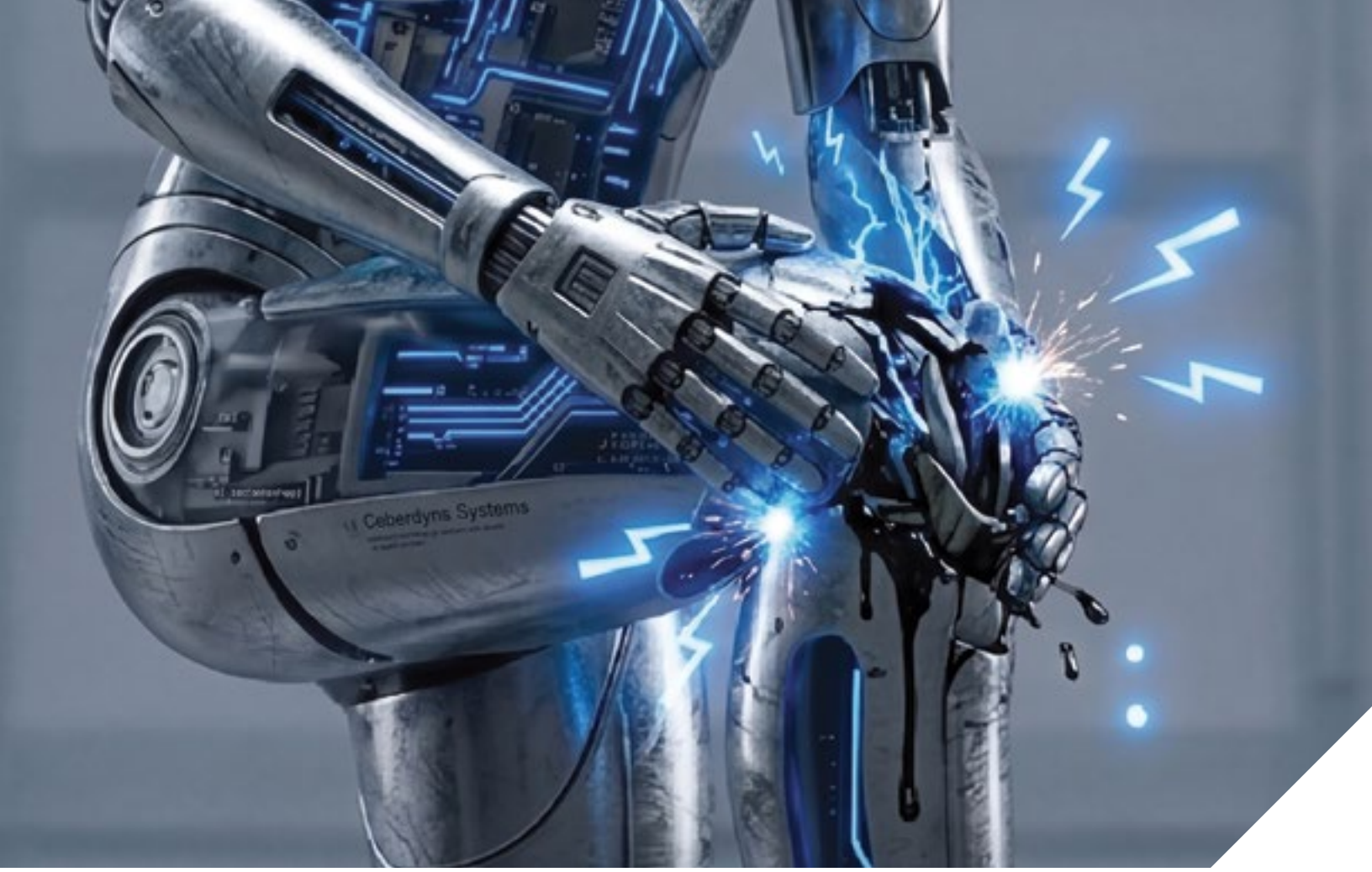
In this issue we touch on a lot of different aspects of pain – the mechanics of it, it's relationship to Parkinson's, and how to help care partners avoid it if possible. We also look at talking about pain. And believe me when I say talking about pain is very important. The statistics for under-reporting pain are high – especially among seniors, many of whom grew up in a time where "rub some dirt on it", "don't bother the doctor, it's not that bad", and "walk it off" were considered valid health advice. I'm not suggesting that one should run to the doctor or wait in an emergency room for a paper cut; however, by not reporting pain or trying to "tough it out", you can leave yourself vulnerable to significant physical, emotional, and quality of life consequences. Don't believe me?

Consider these potential consequences:

- **Minor injuries can become worse if not treated properly**
- **Ignoring pain delays medical intervention, resulting in longer recovery time**
- **Constant pain is closely linked to depression, anxiety, fear, irritability, and social isolation**
- **Untreated acute pain can turn into chronic pain which can last for months or years**
- **Favoring one arm/leg to avoid pain can overwork other muscles and joints, causing new pain**
- **Untreated chronic pain can impact cognition, causing memory loss and a decreased ability to concentrate**
- **Unmanaged pain can lead to "deconditioning," where inactivity causes muscles to weaken, further reducing mobility**
- **Chronic and unmanaged pain puts stress on your heart and veins, which can lead to hypertension, stroke, or heart attacks**
- **Unmanaged emotional pain can flood your body with stress hormones, weaken your immune system, cause fatigue, exhaustion, and cardiovascular issues**

With so many different kinds of pain, it can take some time for your healthcare team to determine not only the cause or your pain, but what to do about it. Your healthcare provider may conduct physical exams, clinical assessments, and order diagnostic tests and imaging to diagnose or rule out conditions causing or associated with pain. But first he or she is going to ask YOU about your pain. Because pain is so subjective, the only person who can describe how much pain you feel, where it hurts, or how it is impacting your life…is you. On page 18 we give you the tools to help do just that!

Pain acts as a warning signal—like a smoke detector—that alerts you to areas in your life that need attention. Dealing with physical and emotional pain, rather than avoiding it, offers significant, long-term benefits by facilitating healing, developing resilience, and improved quality of life. ■



WHAT IS PAIN?

The Mechanics of Pain

Written By: Brandi La Bonte

"By definition pain is an unpleasant physical and emotional experience."

Pain is an enigma. This very real, but very mysterious thing that is impossible to understand completely. It is both big and small, loud and quiet, short and long, a black bottomless pit, a red hot fire, and a blink and you'll miss it conundrum. It is everything and nothing all at once. And, making it even more enigmatic -- pain isn't pain until your brain decides it is! (Remember the Tale of Two Nails from the Cover Story?) Trying to understand pain is no easy feat; let's start by explaining the mechanics of it.

By definition pain is an unpleasant physical and emotional experience. It is one of the most important signals our body gives us to keep us alive and/or stay safe. A multi-stage survival mechanism designed to protect our body from damage. Pain helps us learn how to avoid harm (think slipping on ice or touching a hot stove). And alerts us to harmful changes happening to or in our body (think arthritis, migraines, or cancer). Unfortunately, there is also pain (chronic) that exists or continues with no known cause or benefit.

Like Parkinson disease, or life itself, everyone experiences pain differently, even if the cause for their pain is the same. Many factors contribute to an

individual's approach to pain, including social determinants of health which are the non-medical, environmental, and socio-economic conditions in which people are born, grow, live, work, and age. Examples of social determinants of health include housing, education, income, discrimination, and equitable access to healthcare and physical and mental health supports.

There is also an ageing factor to pain, with things becoming more painful as a person ages. Bone density decreases, metabolism slows, and we begin to lose muscle mass – as much as 3 to 5 percent per decade, beginning in our 30s, and for men, up to 30 percent of total muscle mass over a lifetime. And, thanks to the wear and tear of daily life, as well as the effects of any injuries or illnesses, we can start to feel more pain as we get older.

Types of Pain

There are various classification systems of pain. Pain is most commonly classified by duration, its cause, and/or the pathophysiology (more on this later) underlying the pain.

Let's start with duration, where the pain is named based on how long the pain lasts and its frequency.

- **Acute pain** starts suddenly and ends when its cause is treated or healed. The feeling of acute pain is usually sharp because it tends to act as a warning signal about a threat to the body from an injury, disease, overuse, or other environmental stress. Common causes for acute pain are strained muscles, broken bones, dental work, surgery, childbirth, infections, and/or burns.
- **Episodic/Transient pain** happens from time to time and may be at irregular intervals. It may be associated with a long-term medical condition, like arthritis. Painful menstrual periods and chronic migraine are examples of episodic pain. It can happen out of nowhere or may be caused by known triggers.
- **Chronic pain** lasts for longer than three months or the expected healing time. In some cases, an acute pain condition might persist and become chronic pain. In other cases, chronic pain happens for no known reason. People might experience one or more chronic pain conditions, or chronic and acute pain, at the same time.

Next up, cause. Cause or etiology refers to the origin, underlying sources, event, or condition that produces the pain. This is the physical injury, medical condition, disease, or emotional experience that is responsible for the pain. For example, bacteria that is causing a sore throat, a fall that results in a broken hip, a diagnosis of a medical condition, illness, or disease, or an emotional event like a death, breakup or other loss. By determining the "cause" of the pain (when possible) medical professionals are better able to understand if the pain is acute, episodic, chronic, or stemming from a specific injury to determine the best treatment.

The final classification in pain is **pathophysiology**. Pathophysiology examines how normal body functions (physiology) change when disease occurs. A great analogy to better understand this is to think of the cause (etiology) as the spark that starts a fire; while the pathophysiology is the way the fire spreads and causes damage. There are three main classifications of the pathophysiology of pain according to the International Association for the Study of Pain (IASP):

- **Nociceptive pain** describes pain that is caused by tissue damage and/or inflammation. This is the most common type of pain. Nociceptive pain is a nervous system response that our brains use to not only prevent injury but also recover from an injury when we rest. The sensations associated with it can be sharp, pricking, dull, or aching, depending on what caused the damage or inflammation. Examples of nociceptive pain

include pain from a paper cut, an infection, a broken bone, or osteoarthritis.

- **Neuropathic pain** describes pain that is caused by nerve damage due to an injury or disease. Neuropathic pain is very often chronic pain. Neuropathic pain sensations are often described as burning, tingling, shooting, or like electric shocks. Examples of conditions that cause neuropathic pain include diabetic neuropathy, shingles, and sciatica.
- **Nociplastic pain** – This type of pain is a term adopted by the IASP in 2017 to describe a third, distinct category of chronic pain, complementing the existing classifications of nociceptive and neuropathic pain. It bridges the gap for patients whose pain arises from altered nervous system processing rather than a clear injury, tissue damage, inflammation, or disease. The sensations related to this kind of pain vary widely. Examples of nociplastic pain include tension headaches, fibromyalgia, irritable bowel syndrome, and chronic low back pain.

The Pain Process

So, we know what pain is and how it is classified, but how does pain happen? What is the process? Think of pain as a protective alarm system designed to prevent further damage or injury. The process involves four key steps: transduction, transmission, modulation, and perception, where physical injury is converted into an electrical signal, sent to the brain, adjusted for intensity, and finally interpreted as a real world experience. Let's break it down.

- **Transduction** is a fancy word for "detecting danger" and is the very first step our body takes to feel pain. The pain process begins at the site of injury, such as touching a hot stove or falling down. The greater the stimuli (injury or potential for injury), the more likely the brain is to interpret a more severe pain. Specialized nerve endings throughout our skin, muscles, and organs, known as nociceptors, act as "danger sensors" to detect this (or any) damage. Upon injury, these nociceptors activate and initiate a process called transduction, converting the physical pain—such as extreme heat or pressure—into a tiny electrical signal.
- **Transmission** is the act of sending that electrical signal. That signal travels a distinct path along nerves from the sight of the injury, through the peripheral nervous system, to the spinal cord, and on to the brain stem and other parts of the brain.
- **Modulation** adjusts the signal. In this stage our body (specifically our nervous system) can alter the intensity of that electrical signal to either reduce or increase the pain sensation.
- **Perception** is the stage where you feel the pain. In this stage the electrical signal reaches the brain, specifically the thalamus which acts as a sorting or relay station for information – an air traffic controller for our brain if you will. It is there that the information contained within that electrical signal is distributed to other parts of the brain. The somatosensory cortex identifies the location and intensity of the pain. The limbic system processes the emotional and unpleasant experience of pain, while the frontal cortex analyzes the information, assigns meaning and determines our reaction.

Even more fascinating, the speed at which this all takes place. Pain processing is fast. Incredibly fast. Not quite instantaneous (even though it certainly feels like it is), our nervous system processes pain in a fraction of a second, often using a "reflex first, think later" approach.

What about Emotional Pain?

While emotional pain does not fall into the exact same formal medical classification system as physical pain, science increasingly recognizes that they share overlapping brain pathways and functional mechanisms. Overlapping, but not identical. The biggest differences in how the two pains are processed show up in localization and memory.

Let's start with **localization**. When it comes to pain, localization basically means "where" we feel it and if you can point to it. For example, at a doctor's appointment we may be asked to point to where it hurts on ourselves or a picture. When dealing with an emotional pain, that is certainly harder to do. In terms of localization the main difference is that physical pain has a precise, specific spot, while emotional pain feels scattered, heavy, and hard to pinpoint.

PHYSICAL PAIN		EMOTIONAL PAIN
Specific – if we burn a finger, we know exactly which finger hurts	**Location**	Widespread and abstract, with no physical location to heal
Its a sharp, burning, or throbbing feeling on the skin, muscles, or bone	**How it feels**	It may feel like a heavy weight, an empty hole, or a constant aching sensation.
Usually goes away once the injury heals	**Duration**	It can last much longer than a physical injury and often comes back when we think about the memory

And speaking of **memory**; we all have memories of both physical and emotional pain. Who among us hasn't had a papercut, or experienced other physical pain like a broken bone or childbirth? Who among us hasn't experienced the loss of a loved one, bullying, a breakup, embarrassment, etc.? These are universal life experiences that our brain stores but remembers in very different ways. The biggest difference is that we can remember physical pain without re-feeling it, but you **CAN** re-live emotional pain just by thinking about it. In short, your brain forgets the sensation of physical pain but loves to remind you of the sting of emotional pain.

PHYSICAL PAIN "It Happened" MEMORY		EMOTIONAL PAIN "It's Happening Now" Memory
No - If we broke our arm last year, we remember that it hurt, but we don't actually feel the pain in our arm again. Pain receptors are not reactivated.	**Re-Feeling/ Re-Living the pain**	Yes – Recalling a loss, a breakup, or a time we were maybe embarrassed, we may find ourselves feeling the exact same stabbing pain we felt at that moment. Memories of emotional pain can reactivate pain receptors and cause substantial pain in the present.
Physical pain memory is mostly about the "facts": *I was playing soccer, I tripped, I broke my arm, it hurt.* Once the injury is healed, the memory rarely triggers a repeat experience of the pain.	**Facts over feelings, triggers and associations**	Emotional pain leaves "echoes." For example, if a specific song was playing during a breakup, hearing that song months later can trigger the same emotional distress all over again.

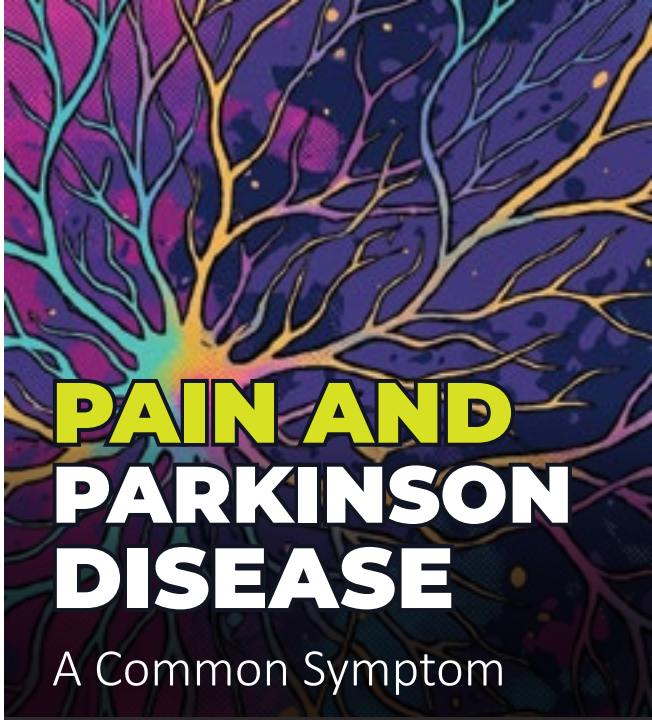
The Connection Between the Two

In addition to sharing the same brain pathways, physical and emotional pain are deeply interconnected. One of our brains' main jobs is to protect us and keeps us safe, it doesn't really distinguish between a physical and emotional pain, often treating them as nearly identical threats. This is why when we experience emotional pain, we may find ourselves also dealing with physical pain as a result – chest pains, tight shoulders, headache, stomach pains, etc. Psychological distress (can trigger stress hormones like cortisol, which can lower the pain threshold and intensify physical pain. The reverse is also true, physical pain can cause emotional pain. For example, a bad fall can cause anxiety, a medical diagnosis or illness can lead to feelings of frustration or sadness, and chronic pain can lead to feelings of hopelessness, isolation, and depression. These feelings can then intensify the perception of physical pain. Either can create what is known as a "pain loop" or chronic pain cycle where one pain (let's say emotional) triggers physical pain, which then intensifies the emotional pain, which causes more physical pain and so on and so on. It can be a very difficult cycle to break.

Dealing with Pain

There are two general approaches to dealing with pain – treatment and management. Treatment seeks to remove the pain (cure) by focusing on short-term reduction of symptoms to eliminate acute pain. Treatments often rely on medication, but can also include surgery, medical procedures or devices, massage, physiotherapy, and even the good old rest, ice compression, and elevation. The goal of pain management is to improve function and/or quality of life even if pain persists or is chronic. Management is often multidisciplinary and involves a combination of techniques including medications, physical therapy/rehabilitation, mental health support, lifestyle changes (including diet, meditation, exercise, etc).

Understanding the mechanics of pain – how the body and brain communicate – is a fundamental first step in managing both current and potential future pain. The ultimate goal of understanding pain is not to avoid it completely (which would be nice, but is highly unlikely), rather learn to be proactive in our approach to living well AND manage it so when it does happen, we have the knowledge, skills, and tools to keep it from interfering with daily life. ■



Written By: Brandi La Bonte

Did you know that, compared to the general population, people with Parkinson disease experience significantly more pain? Prevalence estimates for pain in Parkinson's is approximately twice as high as in the general population.1 In fact, pain is one of the most common issues reported by those with Parkinson disease. Clinical risk factors for pain in Parkinson's include (but are not limited to): being female, early disease (young) onset, and long disease duration.

It is important to note that not all pain is related to Parkinson disease; however, Parkinson's does affect the way your body moves both internally and externally, which can cause pain. Some of the more common types/sources of pain that people with Parkinson disease may experience include, but are not limited to:

Musculoskeletal pain is the most common, accounting for 40%–75% of reported pain in Parkinson's patients2. Caused by the muscular, joint, and postural changes that lead to decreased/limited mobility overall.

It frequently presents as muscle pain and aching in legs, lower back, neck, and "frozen" shoulder.

Dystonic pain is the second most reported pain occurring in up to 50% of people with Parkinson's; frequently experienced by those diagnosed with Young/Early Onset Parkinson's (before age 50). Dystonia is a prolonged twisting or contracting of a muscle/muscle group that can cause severe pain and cramping. It can take place in the arms, hands, feet, legs, neck, jaw and even in the muscles around the eyes. It typically will affect the more severely affected side (the side that the PD started on). This problem is due to the medication (usually levodopa) wearing off or losing its effect.

Neuropathic pain affects up to 30% of people with Parkinson's. There are typically two types of neuropathic pain:

- **peripheral neuropathy which is caused by damage to peripheral nerves and can lead to numbness or tingling in one's toes or fingertips, and**
- **central pain which is a direct result of Parkinson's affecting the central nervous system and can present as a chronic, vague, or all-over aching pain that is often accompanied by a burning sensation.**

Other types of pain:

- **Constipation occurs in a majority of people with Parkinson's, can cause painful symptoms like abdominal cramping.**
- **Bruxism – the involuntary clenching or grinding of teeth – occurs due to rigidity or spasms that can happen in the jaw when a person is asleep or awake.**
- **Burning Mouth Syndrome (BMS) is a painful, burning sensation often affecting the tongue, lips, or entire mouth**
- **Vulvodynia is similar to BMS, it is a chronic, unexplained burning pain in the vulva.**

Diagnosing the source of pain in Parkinson disease is not always easy. The first step involves distinguishing between Parkinson's and non-Parkinson's pain, then between pain caused by motor symptoms and non-motor symptoms. Once the source of the pain has been determined, actions can be taken towards relieving some or all of the symptoms. These actions can include (but are not limited to) one or more of the following: medication, physiotherapy, exercise, massage and/or counselling. By addressing pain in Parkinson disease with your healthcare provider, you are taking positive steps towards living a healthier, pain-free (or reduced pain) life. ■

References:

1 Dung Thi Hoang, Frank Xing, Daniel Truong, Characteristics of pain symptoms in Parkinson's disease, Clinical Parkinsonism & Related Disorders, Volume 13, 2025, 100404, ISSN 2590-1125,

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Parkinson Association of Alberta

APRIL IS

PARKINSON *Awareness Month*

Help us complete 500,000 together

SIT 'N STAND CHALLENGE

Participate in our Sit 'n Stand Challenge as we aim to complete 500,000 Sit 'n Stands throughout April!

STAND UP TO PARKINSON'S

Join our 3rd annual Stand Up live events for fun physical and mental activities while supporting our Sit 'n Stand goal! There will be FREE coffee & treats

SATURDAY, APRIL 11 EDMONTON 11AM - 1PM | CALGARY 1PM - 3PM

LIGHT UP FOR PARKINSON'S

Join PD Avengers in lighting the sky blue across the globe to bring awareness to Parkinson disease!

SATURDAY, APRIL 11 EVENING

LUNCH & LEARN

Register for our free noon-hour webinar, and hear the latest news on the Parkinson's research taking place right here in Alberta.

FRIDAY, APRIL 24 AT NOON

For more details and information about these events, please visit our website www.parkinsonassociation.ca

Join our Sit 'n Stand Challenge

A Sit 'n Stand is an exercise that improves mobility, balance and strength for your whole body! Doing them provides great benefits for those living with Parkinson disease and Atypical Parkinsonism

Help us complete 500,000 together

1 Grab a chair

Sit on the edge of a chair and bring your arms forward so they are parallel with the floor or across your chest. Feet should be flat on the ground hip-width apart.

Modification: Sit in front of your kitchen sink and grip the sink to help with balance.

2 Stand using lower body

Use your lower body to pull yourself up to the upright standing position.

Tip! Use momentum to power through this movement.

3 Lower back down

Sit back down without lowering your arms and hinge at the hips. Inhale on your way up. Exhale slowly on the way down. Repeat as many times as you can!

Challenge your friends or work as a team!

Send us your video and be part of our compilation!
Email us at socialmedia@parkinsonassociation.ca or tag us at @parkinsonassociationofalberta

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SIT 'N STAND CHALLENGE

Name: .....

City: .....

Goal: .....

SUN	MON	TUE	WED	THU	FRI	SAT
KEEP TRACK OF YOUR SIT 'N STANDS Help us reach our goal of 500,000			1	2	3	4
5	6	7	8	9	10	PARKINSON AWARENESS DAY 11
12	13	14	HALFWAY THERE! 15	16	17	18
19	20	21	22	23	LUNCH & LEARN 24	25
26	27	28	29	30	TOTAL # OF SIT 'N STANDS	

STAND UP TO PARKINSON'S EVENTS - EDMONTON & CALGARY

Parkinson Awareness Day - April 11th, we are determined to complete 25,000 Sit 'n Stands! Join us for free coffee and baked goods, appearances from local community leaders, fitness demonstrations and to participate LIVE in the sit 'n stand challenge!

I pledge: $ ¢ for every Sit 'n Stand .....

Log your Sit 'n Stand totals online at parkinsonassociation.ca. You can enter them daily throughout the month or submit all at once at the end.

One of a Kind

Parkinson Association of Alberta

2ND ANNUAL

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ENGAGING ACTIVITIES | EMPOWERING CLIENT STORIES

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SATURDAY, MAY 30

11.00AM - 1.00PM | EVARIO EVENT CENTRE
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PURCHASE TICKETS

$100 PER GUEST
$720 FOR TABLE OF 8

Purchase tickets and find more information online at
www.parkinsonassociation.ca or call 1-800-561-1911

TALKING TO YOUR HEALTHCARE PROVIDER ABOUT PAIN

How To Describe What's Going On

Written by: Brandi La Bonte

Talking to a healthcare professional about pain you are experiencing can seem like a daunting task. So daunting in fact, that studies have found that 25% of women and 14.6% of men under-report their pain in doctor's office settings1. Some believe that it is just a part of Parkinson disease, aging, or life in general and that they should just tough it out. Some feel guilty for "complaining" or taking up too much of their health provider's time. While others fear being labeled as "drug seekers" or being told their pain is not serious. Which leads to the next point. Unfortunately, there can also be a high prevalence of underestimation or invalidation of a person's pain by healthcare professionals. With women and people from racialized groups less likely to have their pain believed1. This can lead to disparities in pain treatment. To be fair, this does NOT mean your healthcare provider isn't on your side. Your healthcare provider wants to do what they can to help you live pain free so you can have the best possible quality of life – but they can't help you unless they know what is going on.

So, what can YOU do to ensure you are advocating for yourself or your loved one when it comes to reporting pain? The following are some questions to ask yourself (or your loved one) and actions to consider so you can be prepared to discuss with your healthcare provider. Thinking about them ahead of time and even writing down your answers can help make this discussion more effective.

Where does it hurt?

A good rule of thumb here is to be as specific as possible. For example, don't just say "my back"; instead, be as specific as possible and say "my lower back and into my right hip." Showing your healthcare provider where your pain is by either pointing or indicating on a diagram can also be helpful. If your pain moves around, be sure to state all the areas that are painful and note which ones bring the most pain.

What does the pain feel like?

This question is less about intensity and more about describing the pain sensation(s) you are experiencing. Is it a burning, tingling or stabbing sensation? Is it a dull ache or a throbbing pain? Is it a cramping or a tightness? Metaphors can also help, for example "it feels like an elephant is sitting on my chest."

Descriptive words can often offer more help to a healthcare provider because certain conditions or injuries have a very specific feeling associated with them.

How is the pain affecting your day-to-day activities?

Explain how the pain you are experiencing is affecting "normal" activities. For example, are you having trouble doing regular chores around the house or walking the dog? Have you canceled plans or not engaged in favorite activities because of the pain? Describing how the pain prevents you from doing certain activities. "I can't sit for more than 20 minutes." "I cannot sleep through the night." "It burns when I pee."

How intense is the pain?

Providing an accurate personal assessment of the intensity of your pain can help your healthcare provider understand what you are experiencing. An, while downplaying your pain is not beneficial, neither is overstating. The handy chart (Wong-Baker Faces® Pain Rating Scale) on the facing page can help you better determine and articulate the intensity of your pain.

What is the timing of your pain?

Have you been experiencing the pain for a day? A week? A couple months? How long does your pain last? Does it come and go every couple of hours or days? Is it steady throughout the day, but feels more intense in the mornings?

Your answer to these questions can help your healthcare provider determine if your pain is paroxysmal (comes on suddenly and sporadically, and leaves in the same manner) or chronic (comes on more slowly and remains present for a long time before fading away or lessening).

Does anything help or worsen the pain?

Be sure to let your healthcare provider know what you have tried to help alleviate the pain. For example, rest, ice, heat, over-the-counter pain reliever, etc. Sharing what makes the pain worse is also helpful, for example "it's painful to the touch," or "bright lights make it worse," or even stress.

Doing everything in your power to explain your pain clearly and accurately gives you the best chances of being heard and getting the help you need to manage your pain. ■

References

1Brandon L. Boring, Brandon W. Ng, Namrata Nanavaty, Vani A. Mathur, Over-Rating Pain is Overrated: A Fundamental Self-Other Bias in Pain Reporting Behavior, The Journal of Pain, Volume 23, Issue 10, 2022, Pages 1779-1789, ISSN 1526-5900, https://doi.org/10.1016/j.jpain.2022.06.002.

COMPARATIVE PAIN SCALE CHART

	Very Mild	dis-comfort	Tolerable	Distressing	Very Distressing	Intense	Very Intense	Utterly Horrible	Excrutiating Unbearable	Un-speakable Pain
Feeling Perfectly Normal	Nagging, annoying, but does not interfere with most daily living activities. Patient able to adapt to pain psychologically and with medication or devices such as cushions.			Interferes significantly with daily living activities. Requires lifestyle changes but patient remains independent. Patient unable to adapt pain.			Disabling pain; unable to perform daily living activities. Unable to engage in normal activities. Patient is disabled and unable to function independently.			

Wong-Baker Faces® Pain Rating Scale

PARKINSON Step 'n Stride

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New HISTORIC COCHRANE RANCHE
New SATURDAY, SEPT 19TH
New 9AM - 1PM

Lethbridge

HENDERSON LAKE PARK
SATURDAY, SEPT 19TH
9AM - 1PM

Lloydminster

BUD MILLER PARK
New SATURDAY, SEPT 19TH
New 1PM - 4PM

Olds

ROTARY ATHLETIC PARK
SATURDAY, SEPT 19TH
9AM - 1PM

Red Deer

CANADA 150 SQUARE
SATURDAY, SEPT 19TH
9AM - 1PM

Calgary

SOUTH GLENMORE PARK
New SUNDAY, SEPT 20TH
New 1PM - 4PM

Camrose

GRANDE DRIVE PARK & GAZEBO
SUNDAY, SEPT 20TH
1PM - 4PM

Edmonton

RUNDLE PARK, PICNIC SITE #1
New SUNDAY, SEPT 20TH
9AM - 1PM

Grande Prairie

New SOUTH BEAR CREEK PAVILION
SUNDAY, SEPT 20TH
1PM - 4PM

Yellowknife

SOMBA K'E PARK & PLAZA
New SATURDAY, SEPT 12TH
1PM - 4PM

PREVENTING PHYSICAL PAIN & INJURY FOR CARE PARTNERS

Be Aware of Your Own Safety as Well

Written by Brandi La Bonte

As a person providing care for a loved one (whatever level that may be) you are an integral part of your loved one's healthcare team and the healthcare system in general. Your commitment and actions, though loving and necessary, do not come without cost. Providing care for a loved one takes a toll on the physical, mental and emotional well-being of people providing care. A 2022 Canadian paper on Caregivers shared that "that 69% of caregivers noted a deterioration in their mental health, over half reported a deterioration in their physical health, and 16% are more likely to live with two or more long-term health conditions. 1

Providing care for a loved one can include actions such as assistance with standing up, sitting down or transferring, assisting with care-related tasks like dressing, bathing or even taking on additional household tasks like snow shoveling or laundry. And while these types of tasks are not necessarily difficult, they do require a physicality that includes repetitive movements, bending, twisting, kneeling, etc. The person you are providing care for may also be larger than you and for most, there is no prior experience in proper lifting or transferring techniques. This can lead to not only stress, but physical injury. The most common physical injuries sustained by care partners? Lower back strains/ sprains, shoulder and neck pain, wrist and hand injuries, knee pain, and chronic pain and fatigue.

What Can You Do to Help Prevent Injury?

A large number of care partner injuries are caused by improper body mechanics when it comes to lifting and/or helping a loved one up or down. These instances can occur when assisting with day-to-day tasks such as getting out of a chair, bed, or the car, getting on/off the toilet, or during more serious events like a fall. In fact, according to the Public Health Agency of Canada, falls are the leading cause of injury among older Canadians resulting in 89% of injury-related hospitalizations, 85% of hip fractures and 30% of all long-term care admissions.2

To reduce your risk of injury, learning proper techniques and methods to handle physical aspects of providing care is essential. Both physiotherapists and occupational therapists are great resources to help you, and your loved one prevent and prepare for situations that have the potential to cause injury. Below are some general guidelines that can help you provide care for your loved one, without hurting them or yourself in the process.

Smart Strategies for Your Health and Safety

- Be prepared – First, have a conversation with your loved one about the task at hand. What is needed? What role will you each have? Next, ensure the item(s) you need to assist with a specific care task are readily available/close at hand. Then keep communicating throughout the process until the task is complete. Teamwork makes any task easier!
- Ask for Help – Getting tips, tricks and "how-to's" from physio- and occupational therapists can make a significant difference. While bringing in homecare can help with some of the trickier movements involved in bathing.
- Lift smartly - Always keep the person or object you are lifting close to your body and lift with your legs, which are stronger than any other part of your body. Keep your back straight (with its natural curve) and try to avoid twisting motions that take your body out of its natural alignment.
- Get plenty of rest - Adequate rest is a critical part of managing stress, and for most people, that means around seven to eight hours of sleep a night. When you sleep, your general energy consumption is lowered as, most of the time, your body and brain is at rest. This means more energy can be used to restore your bones and muscles.
- Drink water - When you're dehydrated, the discs between your vertebrae can shrink and the nerves can become pinched, increasing pain, so drink plenty of water to help keep your muscles and discs hydrated.
- Exercise - Physical activity can strengthen muscles, reduce feelings of depression and stress, and help you improve your sleep and overall health.
- Practice or take advantage of relaxation techniques - Meditation, yoga, massage and breathing exercises are some of the easiest ways to relieve stress. Research shows that even just one hour a week can result in significant reductions in stress levels.

Helping Someone Up from a Seated Position

1. **Make sure that your feet are stable, and as close as possible to your loved one.**
2. **Face your loved one, slightly bend your knees and squat in preparation to lift. Tighten your abdominal muscles and keep your back straight (try not to curve forward). This will add lifting strength and increase power from your legs and arms.**
3. **Maintain a position as close to your loved one as possible so that excess strain is not placed on your back by leaning over.**
4. **Point your feet towards your loved one; and, if possible, place one foot in between their feet and one foot to the outside for optimal stability.**
5. **Attempt to lift using a smooth, flowing motion, pushing upward with leg muscles; keeping your shoulders and neck muscles as relaxed as possible.**

Helping Someone Up After a Fall

When it comes to helping your loved one up it is important to keep in mind that your role is to help guide them through the following steps and keep them steady, not lift their weight. Your loved one needs to be capable of doing the physical work required to get up. If they cannot do this, it may be safer to call 911.

1. **It is important to stay calm and help your loved one to remain calm. Taking slow, deep breaths can help.**
2. **Check for injuries like bruises, bleeding, swelling, possible sprains and potential broken bones.**
3. **Ask them if they are experiencing any pain, where it is located and how severe it is.**
4. **If there is any sign of serious pain or injury (ie: head injury/ broken bone) do not move them. Call 911 and keep your loved one as warm, comfortable and still as possible until help arrives.**
5. **If there is no sign of injury and your loved one feels they are able to get up, proceed slowly. Stop at any point if they become stuck, experience pain or become too tired to get all the way up.**
6. **Find two sturdy chairs and place one next to your loved ones' head and the other down by their feet.**
7. **Help your loved one roll over onto their side and support them in getting onto their hands and knees, position the chair placed by their head so that it is directly in front of them.**
8. **Have your loved one place their hands on the seat of the chair to help evenly distribute their weight.**
9. **Have them lean forward onto the seat as they gradually bring their strongest leg forward, leading with the knee to place their foot flat on the floor.**
10. **Move the second chair directly behind your loved one, then ask them to use both their arms and legs to push themselves up and sit back into the chair behind them. Use your hands to keep your loved one steady but keep your back upright and make sure they are doing the physical work to lift themselves.**
11. **Have your loved one stay seated until you and they are confident that they can stand and continue moving around without hurting themselves or falling again. There is no rush when it comes to safety!**
12. **Finally, it is important to notify their doctor that they've had a fall and keep an eye out for emerging pain and signs of injury.**

It is important to remember when providing care for a loved one to be aware of your own safety as well as theirs. If you've been on an airplane, you've heard the saying "Place the oxygen mask on yourself, BEFORE helping another person." The same adage applies to providing care – you must care for yourself, BEFORE you can care for others. Your health and safety are also a priority! ■

References

1 Canadian Centre for Caregiving Excellence. "Giving Care: An Approach to a Better Caregiving Landscape in Canada." November 7, 2022

2 Public Health Agency of Canada. Falls Among Older Adults in Canada. November 2025

EMOTIONAL PAIN

Ambiguous Loss & Grief

Written by: Brandi La Bonte

We are all familiar with physical pain. Scraped knees and paper cuts, to achy backs or migraines, to more significant things like broken bones or illness. But emotional pain? That is a lot less talked about and even less understood. You might be asking yourself why that is? Well, in the grand scheme of things physical pain is easy to understand and comprehend. If you tell someone you broke your arm, or have a headache, or were in an accident they can, even if they have not been through the same thing themselves, understand that type of pain. The understanding and comprehension is very different when it comes to emotional pain though, where this type of pain is often dismissed as less serious and/or less important than physical pain.

Emotional pain comes from common, but never-the-less painful human experiences such as being diagnosed with a serious illness, losing a loved one, loneliness or even disappointment. Emotional pain can also be caused by physical pain. And, like physical pain, managing emotional pain is as unique as the individual experiencing it with many external and internal factors playing a role. For some, it can be a minor inconvenience; but for others managing emotional pain can be one's own private hell. It can feel like you are drowning or can't breathe, in a huge black hole, a never-ending nightmare, or a swirling tornado.

And, unfortunately for many, when they try to tell others how they feel, the reactions they receive from others can be quite dismissive. People are told (or they tell themselves) to "shake it off", "suck it up", or "let it go". And, in the case of a Parkinson's diagnosis one may hear "**It's a little bit of shaking, how bad can it be?**" or "**Be grateful/Your lucky it's not (fill in some other horrible disease name here).**"

OOOF!!

When your life has been impacted by Parkinson disease or Atypical Parkinsonism – be it as the person diagnosed or a loved one – you may find yourself feeling an emotional pain that you can't quite seem to put your finger on or give a name to. It may feel like someone took a bunch of emotions – sadness, guilt, anger, embarrassment, frustration, etc. – and threw them in a blender. These feelings may seem to come and go with no rhyme or reason; but with some reflection you may notice that these feelings show up when:

- **You received the diagnosis**
- **You think about your future**
- **You watch someone do a task or activity that you can no longer do**
- **And the list goes on…**

What you're experiencing is loss and what you are likely feeling is grief. And those losses and ensuing grief can leave you feeling like you're lost in a maze of what was, what is and what could be. And it can be quite emotionally painful.

A loss that happens where there is no death (like the ending of a relationship, a soldier missing in action, the loss of an ability, loss of physical or mental health, or a life-altering diagnosis, etc.) is a unique kind of loss. One that often comes without any kind of perceived closure but retains the familiar experience of the pain, sadness, anger, etc. of a more "traditional" loss. This type of loss has a name, **ambiguous loss and grief**. It occurs when a future that was planned or anticipated does not materialize, yet the person is not able to find closure because the situation is unresolved, changing, ongoing, or ambiguous. For individuals and families, it can mean grieving the:

- **Loss of Past/Future Self:** Individuals may grieve their former identity and the future they expected for themselves before a health diagnosis, job loss, or life-altering event changed their trajectory.
    - Examples include loss of physical or cognitive ability, and loss of independence (giving up driving, decision making, or even where one lives) as well as the future they had planned (travelling, retirement, playing with grandkids, etc.)
- **Loss of Expected Plans/ Shared Future:** Spouses, adult children, and other caregivers of loved ones with dementia or chronic illness frequently grieve the future they imagined or planned together (e.g., intimate connection, traveling, retirement, sharing holidays, being more active in kids/ grandkids lives), even though the person is still physically present.
- **"Goodbye Without Leaving and Leaving Without a Goodbye":** In cases of Alzheimer's or Parkinson disease dementia, or mental illness, the person is physically there, but they may no longer recognize you, talk with you, or behave like the person you knew. So not only is the future companionship you anticipated gone; you may feel guilty and stuck between hoping they will recognize you and mourning the loss of the relationship.

Dealing with loss of any kind is painful and those making their way through a loss –including ambiguous loss -- deserve understanding and support. The ambiguity in these types of losses doesn't make it any less real or any less painful. The frustration of declining abilities or independence, the ache of stolen future plans, and the pain of saying goodbye to what was and accepting what is are just as real.

So, what can one do to help one deal with and navigate emotional pain, a light or a life raft, if you will.

Acknowledge it: Pain demands attention and, as with a physical injury, ignoring it will inevitably make it worse. The price of undealt with emotional pain can be enormous. Life can't be enjoyed, relationships suffer, self-confidence erodes, and self-imposed isolation can lead to larger issues. Give yourself the time you need to grieve and come to terms with your feelings.

Seek help for it: Help can come in many forms – rest/sleep, relaxation techniques, exercise, and/or talking to others. This could mean talking to a loved one or trusted friend, a clergy member, Elder or Client Services Coordinator. If you are having difficulty managing your emotional pain, your doctor and mental health professionals can help you by providing medication (when necessary) and psychotherapy, or a combination of both.

Learn from it: The process can, if you are open to it, provide opportunities to learn new behaviors and tools for dealing with future emotional pain. Recovering from emotional pain, though difficult, can make you stronger, wiser and more resilient.

Managing the emotional pain can be like trying to find your way in the fog. You keep moving forward, despite the stress of not knowing what lies ahead. There will be days when you will feel stronger than ever and days that will bring you back to your knees. You keep moving forward and, as with many other of life's challenges, you reach out for support and human connections to stay resilient and strong. In this you may no longer feel so alone knowing that someone is listening to your concerns, that there are others going through a similar experience and that you can learn strategies for navigating emotional pain. ■

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