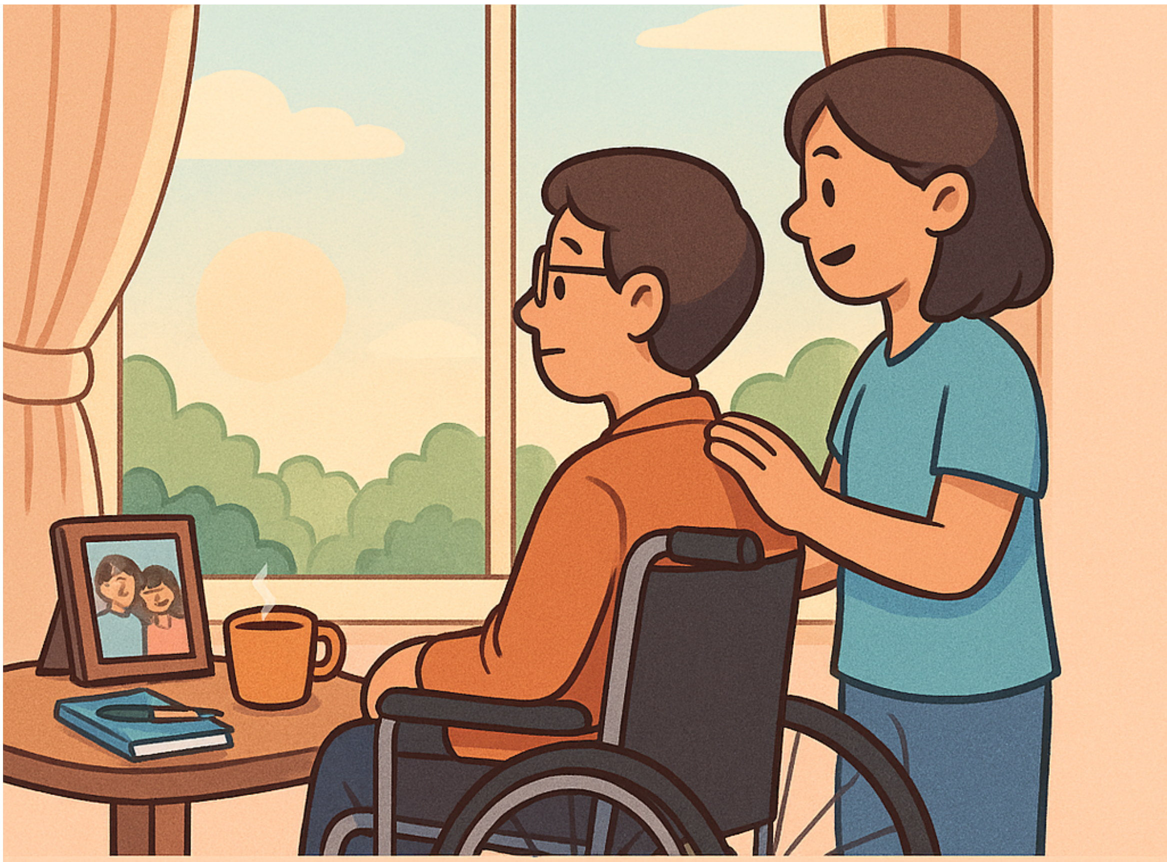

NAVIGATING A TERMINAL ILLNESS

A PATIENT’S VIEW FOR CAREGIVERS

Introduction:

We’re in this together, terminal illness impacts both of us in profound and countless ways. I experience it as the patient; you face it as the caregiver. Though we see different sides of the same coin, our journey is shared. Just as I learn a lot from caregivers, I hope my thoughts may help you understand how your loved one might be experiencing the other side of this journey.

PSP, Progressive Supranuclear Palsy, is a terminal neurological condition, often described as an extreme form of Parkinson’s Disease, with a life expectancy of 6, 10 years. I am now in Year 5. Importantly, there is currently no treatment for PSP. This booklet contains a selection of articles written in October and November 2025, originally published on my blog (www.benlazpsp.com). Each article focuses on a different aspect of how I am living and coping with PSP, my terminal illness.

Although I have learned a fair bit about the world of medicine over the past five years, I have no medical training or qualifications. This booklet takes a non-medical approach and is not surrounded by scientific facts. Rather, it is simply the view and voice of one PSP patient, a voice that, I believe, may be of some use. I believe this story is relevant to many conditions and situations beyond the world of PSP.

Caregivers have a unique responsibility. They are often thrust into their role without ever asking for it, and it places considerable demands on them. I imagine most patients are beyond grateful for the support they receive from their caregivers, even if they are unable to say so themselves.

Just as patients should be understanding and empathetic toward their caregivers, I believe caregivers may find it helpful to hear a personal view of how the patient might see things.

The structure of this booklet is designed to convey an authentic perspective on living with Progressive Supranuclear Palsy (PSP), highlighting both the ups and the downs. It also touches on the guiding principles that sustain me: faith, family, purpose, positivity, and dignity. Through honest reflections and practical advice, I hope to offer a bit of support and insight, and perhaps a sense of connection, even as choices narrow.

Lastly, this is not designed as a book about faith or religion, but it would be remiss of me not to mention the importance faith plays in my journey. I am an observant orthodox Jew living in Israel. I grew up in the UK in a traditional but non-religious household and chose to become observant at age 11. To that end, I've included one article at the end on my view of faith as a fundamental support in my journey.

I hope you find these articles useful.
With my warmest wishes for your resilience and perseverance,
Ben Lazarus, Israel, November 2025

Please note these are individual blogs, so you may have to cope with a little repetition! Enjoy.

Dedication
I want to dedicate this booklet to my family, and especially to my amazing wife Gayle, my soulmate through this journey neither of us asked for, and to my three wonderful and precious kids, each an everyday wonder and miracle my life has been blessed with.

Usage and Image Notice

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5 Goals/Shifting tactics

It's 2:30 a.m., and I find myself deep in thought after reading a blog by another PSP patient – someone slightly ahead of me in this journey. He wrote about life with a PEG feeding tube. Two weeks ago, that idea wasn't even on my radar. A week ago, my neurologist suggested it. I said NO way EVER (aka. Denial). That single conversation flipped my world upside down. I immediately changed tactics, making a 180-degree turn toward a 'no-choke' diet: thickeners, smoothies, soups – anything to keep me safe. I know this strategy will eventually fail, and I'll have to accept the feeding tube, but I hope that day is far away.

This is the reality of PSP – an absurd life where you constantly adjust. Other things loom on the horizon: accepting a carer, using diapers (there, I said it), and countless changes I never imagined facing at 50. In truth, it happens to all of us over time, each in their own way.

Time bound objectives and detailed planning are simply impossible. The saying "Man plans, and God laughs" couldn't be more true. Still, I have **goals**, and we should all have goals. A close family friend reminded me of a quote today: "If God puts a Goliath in front of you, He must believe there is a David inside of you." That line struck me deeply. It inspired me to write down my goals – not time-bound, but guiding principles to keep me grounded.

Here they are:

1. **Faith** – Maintain and grow my faith, remembering there is a greater purpose. Many have walked this path with courage and conviction, and I draw strength from that.
2. **Family First** – Whatever happens, my family comes first. I'll do everything I can to ensure they are cared for and supported. This isn't about getting enjoyment from them – that's a separate goal – but about making sure they're more than okay in all respects.

3. **Purpose** – Continue finding meaning through writing, especially about my PSP journey and thoughts on faith and other topics. If my story helps even one person, that gives me purpose. Writing has become my second career, and it connects me to others in ways I never expected (and gives me huge inspiration and pleasure).
4. **Positivity and Joy** – Enjoy each day as much as possible: time with the kids, chess, Netflix, smoothies, naps, audiobooks, yoga (yes that's here:-)), chats with friends, and, yes, blogging ϑ. These small joys matter more than ever, although the exact items and methods will shift as time progresses.
5. **Dignity** – Not luxury, but dignity. I want to be treated with respect, not as a burden or a "they."

Five *simple* goals. I've thought about setting deadlines, but I won't define my life by time-bound objectives. I plan and pray to keep writing for as long as possible, to see all my kids marry, and as many happy events as G-d will allow, and to experience many more moments. Those are plans – not goals.

I've thought about how taking ultimate precautions figures here (avoiding choking, falling and keeping up exercise and yoga). These are fundamental requirements to achieve the above, not goals themselves.

So will I ever write a book – as people often suggest? I hope to. But it's not one of my goals. Right now, it's an idea that sits under goals 1, 2, 3, and 4. If the time comes, I'll embrace it, but for now, I'm focused on living these goals every day.

What have I missed? I will of course reserve the right to rethink, but I think the point of goals is relevant to many of us as is the idea of shifting tactics and plans, without which we may just face either disappointment or massive underachievement.

Patient Dignity: Why It Matters and How to Protect It

As someone living with a terminal illness, I have come to realize that dignity is not a minor detail – it is central to how we experience care and life's final chapter. For me, a mix of British prudishness, a desire for independence, a lifelong sense of self-respect (and no doubt some psychological hang ups) makes dignity one of my highest priorities. Research confirms I am not alone: studies show that up to 80–90% of patients at the end of life consider dignity as important as pain control and family presence.

Why Dignity Matters

Personal dignity during advanced illness is often more important to patients than the length of life itself. Loss of dignity can lead to anxiety, depression, and even a desire for hastened death. It is a major contributor to quality of life and emotional well-being.

My greatest fear – despite reassurances from my family, which I trust completely – is that when I can no longer communicate, dignity will slip down the priority list. Not because it isn't valued, but because the urgency of medical tasks and my reduced responsiveness might make it seem less critical. These fears may not be rational, but they are real.

What Patients Value

If you have lived your life valuing privacy, autonomy, and respect, these principles do not vanish with illness. They become even more important. Feeling like a "person" rather than a "task" matters deeply. Minor issues – like who assists with bathing – may seem small to others but can mean the world to the patient.

In my own planning, I have made dignity explicit. For example, I do not want my children to handle intimate care tasks. This is not about love – it is about preserving roles and boundaries that matter to me. I have written this into my end-of-life documentation, right after my top priority: ensuring my wife's needs determine whether I remain at home or move to a care center.

Conversations That Matter

For those who care about dignity, early and honest conversations are essential. Topics to discuss include:

1. Advance Care Wishes – Document your preferences for medical interventions and care settings.
2. Personal Privacy and Modesty – Agree on care arrangements, use of privacy screens, and who provides intimate care.
3. Communication Protocols – Establish signals or words to indicate discomfort or boundaries.
4. Identity Preservation – Surround yourself with meaningful items like photos, books, and awards.

Caregivers play a critical role in protecting dignity. This means:

1. Respect Autonomy – Involve the patient in decisions whenever possible.
2. Preserve Privacy – Advocate for modesty during care routines.
3. Communicate Clearly – Explain procedures and respect boundaries to carers etc.

Above all, dignity is a shared responsibility. It requires teamwork between patients, families, and professionals. Research shows that dignity-conserving care reduces distress and improves quality of life. For anyone facing a terminal illness, dignity is not optional – it is essential.

If you are a patient reading this, I hope you feel supported. If you are a caregiver, know that your role in preserving dignity is as important as any medical intervention.

Beyond PSP: Lessons from an Unchosen Journey

While my journey is defined by Progressive Supranuclear Palsy (PSP), a rare and challenging condition, the lessons I'm learning extend far beyond it. Some have noted that the insights gleaned from navigating this path – totally unwanted but challenge accepted – resonate universally.

I'm not an arrogant person, at least I hope I am not, but I feel fortunate to have chosen to chart my journey from the moment of diagnosis. It didn't unfold as I imagined. I thought I'd write occasionally about the latest 10k run, new treatments for Parkinson's, and my clumsy "Ben moments" – like the time I walked into a lamppost and apologized to it. Life had other plans. PSP took center stage, and writing – my coping mechanism – accelerated as the pace of change did. Looking back, I realize these reflections aren't just about PSP.

They speak first to those facing other **terminal illnesses or serious conditions**, where families wrestle with pain, sadness, and the need for coping strategies like humor or expressive writing.

But they also touch on something broader: our general human experience. Ultimately, we all face the same end; the only difference is when. For those with conditions like PSP, that reality is stark, underscoring, for all, the importance of caring for loved ones and making our wishes – especially around end-of-life care – clear while we still can.

It also touches the kids and grandkids and wider families of those who are suffering. We may see a man or woman in a wheelchair or bed, unable to speak or articulate themselves. Yet we should know that they are far more than that. They are probably looking at you with loving tender eyes and you should know that they have a whole life of real living behind them and remembering that may unlock a very different perspective.

If I were to distill a broader message, five pillars stand out:

A Positive Attitude and Endless Resilience: Viktor Frankl said, “Everything can be taken from a man but one thing: the last of the human freedoms – to choose one’s attitude in any given set of circumstances, to choose one’s own way.” This truth rings especially clear in challenging times. It’s easy to say and much harder to live, and I don’t always succeed – but I strive.

A Nurturing Support System: The unwavering presence of family and friends has proven to be an indispensable lifeline, a critical resource that must be actively cherished. You go into battle with illness alongside those who stand with you, and having a strong squad by your side is invaluable. Invest in it all the time.

A View Outside of PSP: Each day, it gets harder. Illness can become a vortex that consumes everything. Keeping a window open to life beyond PSP is like letting in a fresh breeze – it reminds me that PSP must not be the center of the universe or of my families (despite the blog ϑ).

Keeping Grounded: Humor or at least distraction matters. For me personally, I find genuine laughter in life’s absurdities. PSP provides plenty of material (far too often in fact). Even now, as I write this in the middle of the night, struggling to see the screen, with aching neck and shoulders, confined to the downstairs of my home – my “day of work” replaced by yoga, pilates, physiotherapy, and perhaps more yogurt or a smoothie – I chuckle at the absurdity. None of this is what I would have chosen six years ago (and all of which I would have thought I would detest), but laughter lightens the load.

Faith (or a Sense of Greater Meaning): For me, faith is rooted in G-d. Others may find their anchor in philosophy, nature, or purpose. Without my belief in a Just and True G-d, who I trust guides me on a path He knows I can handle and has a reason for, I would truly struggle. This doesn’t mean I understand why these things happen – I don’t. I can’t explain why bad things unfold. But I hold onto the conviction that there is a reason, even if it’s above my pay grade.

I can genuinely say I am a happy person (I may not be in 30 minutes after Yoga or for the few moments after a fall or choke, but broadly). That happiness exists despite – and perhaps even because of – the challenging path I’m on. Trust me, I would rather a very different path because at 50, no one wants this. But life is about how we deal with the situations we are given.

This blog, initially a personal therapeutic outlet to reinforce these views, has evolved into something more. As PSP continues its unpredictable course, I hope that in some meaningful way, my reflections help others navigate their own challenges.

One final note – I have so much to learn from others, and in fact I have been fortunate to have some friends who sadly (they have not been so fortunate) to be in difficult situations and I have truly been shaped by them. This is a mutual learning process for all of us. I just happen to be on a Phd of a specific section of life at the moment.

End-of-Life Planning: The Essential and the Absurd

In PSP support groups, one question pops up daily: “What do I need to know?” The answers are empathetic, but one action stands out as non-negotiable: end-of-life planning. Do it early, and the relief starts immediately.

Planning for the end feels surreal - especially at 50. That absurdity often sparks dry humor, but here’s the truth: you can’t ignore it. The window to express your wishes is narrow. Miss it, and loved ones are left guessing - under stress, with conflicting opinions and heated arguments like “they would have wanted X.” Imagine being unable to speak, hearing those debates without a voice. Heartbreaking.

Some believe planning tempts fate. I disagree. My faith doesn’t teach us to plan on miracles. The statistics are harsh, and while I hope to beat them, I believe every parent or spouse owes it to loved ones to have these conversations. For me, that meant finding a trusted friend - a Rabbi - and a financial planner. Together with my spouse, we tackled health, wealth, and mental well-being. Yes, the control freak in me went into detail about things I won’t even be around for.

Health Decisions: Start Here

What treatments do you want - or not want? Where should care happen: home, hospice, or hospital? Do you want a caregiver, and if so, what type and when? Who will decide if you can’t?

In many countries, you can file advance directives, appoint a power of attorney, and document your wishes. In Israel, for example, you can submit an End-of-Life form to the Ministry of Health. If you have religious or cultural requirements, include them. It’s not fun, but the relief afterward is real. For a universal starting point, resources like the U.S.-based AARP Advance Directive Toolkit (adaptable internationally) can help.

Finances: Navigating the Minefield

Where are the accounts, passwords, and key documents? Who handles what if you’re gone? PSP brings financial shocks - loss of income, home modifications, caregivers, equipment. Funding exists, but it’s often means-tested and bureaucratic. I retired at 50. It was abrupt and stressful. Planning helps. Update wills, keep life insurance current, and create a household budget to weather the storm.

The Emotional Toll: Don’t Go It Alone

The change is dramatic and impacts everyone differently. Friends often don’t know what to say. Professional help is often essential. Most countries offer counseling, charities, and support groups for patients and caregivers. Some people make videos for future generations - do what feels right for you.

Yet amid the planning, remember: life is for living. Don’t let logistics eclipse quality time with loved ones. Lean on local experts and support groups so you can wrap this up efficiently - then set it aside.

Beyond the Basics: Digital and Legacy Details

What happens to your online accounts, social media, and digital assets? Document funeral and burial preferences, along with any religious or cultural requirements.

Before the End of Life

I’ve been thinking about the time before all this - when I might not be able to express my wishes - and a friend had a great idea: make a list of things you want to do. I, for example, want to watch *Friends* and *The West Wing* over and over, plus reruns of the British *Office* and, oddly, *Air Crash Investigations* on National Geographic, along with spiritual items like specific audiobooks. It’s worth considering.

Sharing the Load: Family Conversations

Finally, how and when do you share your plans with family? These conversations are hard, but they prevent confusion and conflict later. I’ve had discussions with my family - especially about power of attorney - and still have work to do on finances (though they have the spreadsheet).

As a self-admitted control freak, relinquishing the reins stings - but with PSP, choice isn’t an illusion; it’s a necessity. Planning early means less stress later. Find trusted advisors - lawyers, financial planners - and don’t delay.

I hope these discussions stay on ice for a long time, but knowing they’re largely behind us brings peace.

There is so much to say on this topic in terms of the spiritual side of life but we all have our different belief sets and I am leaving that for a diifferent time and place.

Time to decide what matters…

Life used to feel like a luxury liner – so many choices, so many options, so many things to do. Sadly, for much of that time, I wasn't looking at the beautiful sights but had my nose buried in a computer or a phone. That chapter is behind me now. Thanks to PSP.

I raised a beautiful family, traveled the world, drove fast cars, and worked like a dog for far too long. I had options and possibilities. Within the bounds of kashrut (kosher food), I could eat what I wanted, when I wanted.

Now, I'm on a lifeboat, carrying only the bare minimum, heading into turbulent, uncharted waters. My options have narrowed considerably – even down to what I can eat and drink. I'm one step away from a feeding tube (some say I'm already there) and one step away from a fall that could be fatal.

It's hard – emotionally and physically. The renovation isn't complete, so I'm still using the stairs. This morning, as has happened before, I didn't just freeze – I ground to a halt. The battery ran out. My vision blurred, my eyes closed, and I couldn't move. I slumped on the stairs – luckily with control – onto a large step where the stairs turn at 90 degrees. Sliding down gracefully on my backside, I realized how lucky I was.

And then I reminded myself, as if I needed to, that everything I truly want is right in front of me: my family and friends. Life has slimmed down in choices, but I'm okay with that. I have the right choices.

I've worked hard investing in what matters all my life, and now it's time to cash in. I've been blessed in the fifty years I've had, and now I want to enjoy the fruits – watch them grow – and have as much humor and fun in the process as possible.

It's about what matters now.

It's time to play a defensive game and take every precaution to slow the progression of PSP. There are still choices – I'm not giving up. For now, a feeding tube would compromise my quality of life too much, but I know the day will come when the trade-off is necessary. The lifeboat will narrow, but I'll cling to what matters.

Physically, it means moving downstairs as soon as the fitted accommodation is ready, resting, and eating and drinking with extreme care. It may not have the allure of fine dining, and my favorites – crispy French bread and crunchy grapes – may be gone, but priorities matter. What counts is what I have in the lifeboat.

There are moments I get frustrated that other people's lives carry on as before, but it doesn't help. The other day, I was in a funk: "I'm all alone, everyone's busy, no one has time for me…" It was pitiful, but I forced myself out of it by making a smoothie. I've learned that not forcing myself to snap out of it is a recipe for disaster – oddly, when people tell me to snap out of it, my defensiveness kicks in and I dig deeper. Stupid, I know.

I understand why so many people with PSP experience depression – around 60%, compared to 10% typically. It's obvious. And yet, statistically, most don't. I totally empathize.

Three ways I'll do my best to avoid it:

- **Spiritual:** By knowing this is G-d's plan – even though I don't know why – I accept it for what it is. I truly believe that, though it hasn't stopped the occasional funk. I wish I were at the level where it did.
- **Emotional:** I need to avoid looking back at what could have been and focus on enjoying the now – taking every moment of humor and happiness that exists in this small ship. I still have skills, and I need to use them to keep my brain engaged: music, writing, learning, chess, a little work, and yes – even audiobooks.
- **Physical:** Keep exercising and doing yoga, but take every precaution as if my life depends on it. That doesn't mean being housebound – I want to walk by the sea and get fresh air – but my window of risk must shrink.

I have to move from attack to defense and prioritize what truly matters.

Change at such a rapid pace is hard – but not as hard as I thought. I truly thought giving up the basics of good food would be unbearable, but in the scheme of things, it isn't – just don't wave a rib-eye in front of me. Or a piece of fruit.

For people with PSP: It seems to me that you have to get over this hump and be happy nonetheless. Meaning still matters. And right now, I truly have it. Honestly, in many ways, I have more clarity and calmness of thought than ever before. It will get harder and I am aware of that but I hope to carry with me the same attitude.

I appreciate feedback and your ideas – they give me the chance to discuss, share, and learn. So please, feed me your thoughts.
Have a good week, all.

Squeezing the Last Drop from End of the Toothpaste

I imagine most people love starting a new tube of toothpaste – or a fresh notebook. There's something about that feeling of freshness, of endless possibility. The middle? Well, that's pretty ordinary, routine, and run-of-the-mill – it does what it's meant to do and serves its purpose. But it's toward the end is when things start to get interesting.

For me, anyway, there's always that initial temptation to throw out the old and start fresh. But as time goes on, it becomes a little battle – a challenge to see how long I can keep squeezing, how much more I can get out of it.

I don't want to overdo the analogy, but with toothpaste – and with a well-used notebook – there's a certain nostalgia when it ends. It's usually after ups and downs: moments when you're convinced there's nothing left, and then suddenly, a surge spills out unexpectedly. That's life, isn't it? Full of surprises even when you think the tube is empty.

Right now, I feel like that toothpaste tube – in a very real and surreal sense.

As a teenager, I sometimes wondered what life would feel like toward its latter stages. I had all sorts of ideas, but the truth? It doesn't feel anything like I imagined – at least not for me, not now.

Life isn't boring. If anything, it's strangely absurd. It's not filled with as many chores (I've got a "get out of jail" card for many regular tasks), but it is filled with extremes: some sadness (not really anger for me), moments of profound happiness and gratitude as I make the most of the time I have left. And then there's the quiet – the silence that stretches out in unexpected ways.

I'm awake for long stretches, often alone – sometimes from midnight to 7 a.m. There's very little I *have* to do. I'm retired, I can't do many things, and even reading is hard. Getting around is harder still. These moments can go either way, but the truth is, I find them largely peaceful. In fact, they've become creative time for me – time to ponder, think, and imagine. In many ways, this is the most productive period of my life – ironically, absurdly – where the rate of change is unlike anything that came before.

I wouldn’t choose this disease or this route at 50. No one wants to reach the end of the toothpaste early. But from my limited perspective, it’s nothing like I expected. It’s not all darkness. It’s not all despair.

They say attitude is crucial, as is support – and I’m grateful for both. The support of family and friends gets me through the dark times and helps me beyond imagination. Still, it’s down to me to find the willpower and keep trying to see the positive in this life God has gifted me. That, I think, is key.

I’d love to go back to those days in the middle of the toothpaste. I’d try to squeeze every inch from it. But those days were good to me – they gave me the strength and skills to try to handle this end zone. Life isn’t perfect; there are things I’d do differently. But I want to keep squeezing.

I’m writing with intensity because I feel like I’m in that zone – the end of the tube. I truly wish it weren’t so. I had amazing plans for life as a grandparent and beyond. But as they say, “Man plans, and God laughs.” I trust Him. There’s a reason, even if I don’t understand it.

My natural stubbornness – thankfully for once – is helping me keep squeezing. Life is very different now (wheelchair, diet, lack of mobility, rigidity), but it’s still full of life. There’s pain, grief, and sadness – not just for me – but also humour, meaning, love, and blessing.

I woke up with this toothpaste image in my mind – I can’t say why. Like the shower chair yesterday, it’s another absurdity of life. Here I am at 4 a.m., typing a blog comparing my life to a tube of toothpaste. You can laugh or cry. I choose to laugh.

Fighting my demons – And Winning (Just)

After the Jewish Sabbath ended – during which I do not use my telephone or PC – I spent some time catching up reading updates on a few PSP Facebook support groups. One anonymous post was so raw and emotional it really hit me. It was from a daughter about her father who is getting worse. Many hours later, after a short restless sleep, I realized that last night I fought – yet again – one of my ongoing and toughest battles with PSP.

It wasn't against any of choking, vision, falling, freezing, or the pain caused by rigidity. It wasn't even against the frustration of sleeplessness or the annoyance of a puree-heavy diet that keeps me, hopefully, from the clutches of needing a feeding tube. It was the mental battle.

Not to sound overly dramatic, it was a fight against my own demons – the thoughts that whisper how hard this is. Fighting a disease that is so vicious, without any treatment or medical hope, and which progresses week by week, sometimes day by day, feels like battling impossible odds, not knowing what the next cruel instalment is but knowing it is imminent.

This, I believe, is the hardest part of PSP – and perhaps of many similar conditions – the mental battle.

It took hours of inner dialogue to recommit myself to fighting with all the energy, conviction, and yes, even noise, that I can muster. The fact that I'm writing this now means I've won last nights's round. I've always considered myself a positive person, but if I can sink this low on more than irregular occasions, then I guess most of us can – patients, caregivers, loved ones, all of us.

I need to remind myself that while PSP is truly awful – and I am genuinely scared of what's ahead – it doesn't have to take over my mind and cause even more needless damage. I will do everything I can to hold on to the good things in my life: my family, my friends, and the many happy moments still happening around me.

I’m choosing to share this bluntly because this is the real battle I think many of us are in and I want to point out that from time to time it is not as easy as a bowl of meat sauce. Churchill said it best: “When you’re going through hell, keep going.” I’m not in hell right now – not at all in fact far from it, but when my mind does wander to dark places – and I know it will continue to, it feels unpleasant and I can’t sugarcoat that.

My learning from last night is I need to push through the dark and give my faith and logic a chance to kick in.

My faith tells me there’s a reason for this, even if I don’t understand it. My logic reminds me that I have far too much good in my life, and to look forward to, to let the darkness win. I truly believe both truly. Still, it’s hard – hard to know that at 50 years old, I’m one step away from a feeding tube or worse. It just is hard.

There are people out there who seem unshaken by life’s challenges – and yes, there are those who are braver than me. I’m a person who is positive in general but also at times emotional, prone to occasional introspection, and frankly, human. But that doesn’t mean I’ll let this disease break me. I’m always looking for the upside and the opportunity, and tonight was a reminder that I have the strength to pull myself back – and I’ll keep finding ways to do it. I need to do more to avoid falling into funks and more to get out of them quicker. Ideas would be welcome – but only real ones, not the famous “why worry?” point of view, which is logical but of course not what my head is willing to hear on so many levels.

This is tough – truly tough – and I imagine it will only get harder as my ability to communicate and write diminishes. If you’re reading this and feel the same, I hope you can dig deep too. Even when the fog creeps in, we can still fight back – and that’s something worth holding on to.

Enough with PSP... Other People Have Lives Too

Living with PSP can shrink your world - and everyone else's - until it feels like the condition is the center of gravity. I've noticed this in myself, and honestly, it worries me. You start writing a blog, sharing your story, and before long, everything revolves around you. Even hitting "publish" on this post feels like feeding that cycle. But maybe acknowledging it is the first step.

Illness demands attention, but it can also pull loved ones too far into its orbit. Right now, our home is in upheaval because of renovations for my needs - a stark reminder that PSP affects everyone, not just me.

I've often written about caregivers remembering the person in the bed or wheelchair. But here's the flip side: as a patient, I need to make room for others too. Especially those closest to me. I tell my kids often: your lives must keep moving forward. You have studies, jobs, dreams, and a lifetime ahead. I don't want any of that parked for me. That's not what a father works for. I want them to be better than me, to have great futures - not to hit pause because of PSP.

My wife, my primary caregiver, is 150% committed to my needs, and I'm deeply grateful - even if I don't always show it. But I don't want PSP to dominate every conversation, every decision. I know that's a tall order, but I'm trying.

I want the same with friends and family. I want to talk about their challenges and celebrations, not just my issues. The other day, I gave a friend advice completely unrelated to PSP, and it felt amazing - a welcome break from my own reality.

I think I'm doing a reasonable job and my family are keeping me on the straight and narrow to a large extent, but the blog reminds me how easy it is to slip. In some ways, we all want our cake and to eat it too: to be cared for without impacting the lives of those we love. Reality doesn't always allow that. So here's what I remind myself:

Illness expands the void. I need to fight that temptation - for my benefit and for others. My late neurologist used to say about Parkinson’s: “Don’t let it be your life - let it be part of your life.” PSP makes that harder, but it’s just as important.

Even if I become uncommunicative, I want to make sure I never slip into “me first.” That’s my goal. It won’t be perfect, but I’ll keep trying. Professional care may help, and I’ve made sure my power of attorney knows my needs come second to my carer’s. PSP may dominate time and attention, but I don’t want it to dominate my intent or my passions. They are not PSP - and never will be.

2 Articles – “They” and “Hope”

On Behalf of “They”

What happens when the person you love slowly becomes someone you barely recognize - and sometimes even a “They”? That question haunts me more than anything else about PSP. I think awareness of the issue may offer some help or at least preparation to some, myself included.

Being part of this community has taught me something important: frustration isn’t a weakness or failure – it is a natural response to the overwhelming scale of the challenge of PSP and it must be for many other conditions like it. Every relationship has its tensions, but when life is magnified through the lens of a disease that changes both mind and body so quickly, those tensions can feel unbearable.

Under normal circumstances, some of these emotions might break relationships. But with PSP, there’s a need to double down and hold things together – and that necessity can make everything harder, causing bitter feelings of resentment, anger and probably regret.

Caregivers often see apathy, sudden rage, and the heartbreaking loss of communication and cognitive ability. It’s lonely. It’s painful. Often reading caregiver stories, it feels like the person you love is no longer the same or even there. And while I’m still navigating these early waves (albeit it is already pretty stormy), I’ve glimpsed how they impact those caring for us. I’ve had moments of apathy and rage that don’t feel like “me.” I’m slower than I used to be. And to be brutally honest, I wasn’t always easy before PSP - I was, in many ways, a pain in the backside. So now? Well, let’s just say I’m probably the premium version of that pain.

I keep coming back to one word I have seen a few times in caregiver conversations: “They.”

“Why do THEY do this?” “Why won’t THEY respond?”

It is not that I judge this in any way, I understand it but breaks my heart because that word signals something devastating – the patient has become “They,” not Dad, not Mom, not a spouse, not a friend. Just… “They.” I understand that feeling. And it terrifies me. The last thing I want is for my wife or kids to stop seeing me as “Beej” or “Dad” because my behaviour changes or I become unresponsive. Being a control freak makes that fear even worse.

I can’t speak for any other patient, only for myself: these changes are not intentional (see my posts on Apathy and Lability) They’re not deliberate. Research shows that after an outburst – what’s called emotional lability – patients often feel deep regret. I know I do. It’s painful to realize what you’ve said or done, knowing it wasn’t what you meant. Right now, I can still apologize to my wife, my kids, my friends. But I can only imagine how much harder it is when you can’t share that regret.

I don’t have generic advice (and anyway I am far from qualified – I am a retired accountant and management consultant) – just a hope for me and others for whom it is relevant: that my loved ones and I can hold on to our relationship through this journey. And if that’s not possible, then at least hold on to the understanding that the person inside is still there and doesn’t want to cause you pain. I honestly don’t know what’s worse: being so apathetic that you’re no longer present or feeling the pain of your actions. Apathy might numb the hurt, but the loss of empathy is its own tragedy.

I pray that my family – and all families facing PSP – can navigate this journey with connection intact and pain minimized. This disease is brutal, and my heart goes out to everyone living it, without judgment, only compassion. For now, I’ll savor every moment and hope the later stages stay far away. More than anything, I hope I never become a “They.”

Hope

Today has been a truly uplifting one, and I wanted to share it.

No – there is no cure or even treatment.

No – the basic realities of PSP remain unchanged, and the challenges are immense.

No – I am still the same me, a choking attack away from a feeding tube, but I just drank a glass of water with added thickener (which had been mixed in the fridge for a few hours), and it tastes like… water. But that's not why I am full of hope - just a pleasant surprise, maybe.

And no – I have had no supernatural interaction, nor am I on any hallucinogenic drug.

So Why? It is because of the responses I received to my article on "They" – from some people with PSP but mainly those caring for partners and loved ones with PSP. There were, of course, replies and comments about the awfulness of PSP and how it has impacted many patients and their carers in their connection and relationship. To all those people (and all facing PSP as a patient or caregiver or loved one), I send my deepest love and prayers because I know there are no easy answers here. It has been a tough road so far, and I know it will get harder.

So, this is not a false hope article – it is hope in the face of tremendous odds. I re-read a quote from Viktor Frankl just now in the simply amazing book "Man's Search for Meaning," which he wrote after surviving three concentration camps, including Auschwitz. He says: "Once an individual's search for meaning is successful, it not only renders him happy but also gives him the capability to cope with suffering."

Tonight, I fully believe that and it is based on four sets of responses from people:

Firstly, many of my family and friends – whom I never doubted – found different ways to triple down on the fact that I will never be a 'They,' and I believe them. It is however relevant to say that not one disagreed with the fact that I am, and always was, a pain in the back, neck and worse.

Secondly, a number of people sent incredibly touching messages, responding in a way that brought tears but real hope from people, some of whom had been through the process to the bitter end, telling me that despite all odds, they believe that until the very end, their loved ones were never ‘They.’

Thirdly, I received replies saying that in many cases, their loved ones remained present and compassionate – each in different ways, many despite terrible symptoms. Some talked about their loved ones in the past tense, and some in the present – but those who replied this way reflected that PSP has varying degrees of impact on behavior (as it does on physical and cognitive decline), and a number didn’t suffer the total loss of the ability to engage and show empathy and understanding.

Lastly, a few people reached out to thank me for raising this topic, saying it gave them a little more understanding of the journey their loved ones are going through. It helped explain that many of the symptoms they see are medical and not the patient’s fault or doing.

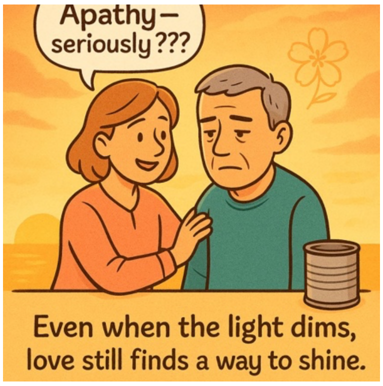
Whilst this doesn’t alter the practical realities of PSP, it gives me a much stronger sense of hope – that there is a path forward to a life with meaning and connection. And this is my biggest fear by far.

As a person of what I hope is deep faith, I shouldn’t need it – trusting in G-d should be all I need to know. But this sure helps, knowing others are living and experiencing it. That gives me more strength – and yes, hope.

To borrow a second quote from Frankl: “Everything can be taken from a man but one thing: the last of the human freedoms - to choose one’s attitude in any given set of circumstances, to choose one’s own way.”

I choose to be positive, to live life to the extent I can to the fullest, to take precautions to reduce the risks I face, to continue to try to give especially to my loved ones, and to be grateful for being able to find meaning within a community that includes truly inspiring people dealing with the most difficult of circumstances.

Apathy: “He Is Not My Husband Anymore” – A Patient’s View



Apathy seems to be a symptom discussed by caregivers more than most, and they often talk about the loneliness they feel as a result.

Yet, on first glance, I didn’t believe this could be a real symptom. It sounded made up, but as I reflect on specific instances and on my general feeling, I can sense it. And when I reflect on this, it scares me. It may however be a bit of a blessing in disguise for patients despite the pain it causes others.

According to CurePSP, “Apathy is a lack of motivation, interest, or concern. It is not the same as depression, although the two can occur together. Apathy is common in PSP and can be one of the earliest signs of the disease. It may appear as a lack of initiative, reduced emotional expression, or seeming indifference to activities or people that once mattered.”

Research indicates that apathy occurs in 50–70% of PSP cases, compared to 70–90% in Alzheimer’s patients, and less frequently in Parkinson’s disease patients during “off” periods from medication.

While PSP is not yet fully understood, it shares the TAU protein with Alzheimer’s. TAU is a protein that helps stabilize brain cells, but in PSP and Alzheimer’s, it becomes abnormal and contributes to neurodegeneration. This overlap in pathology helps explain some of the shared symptoms, including apathy.

While I initially perceived apathy as a somewhat fabricated symptom, a specific incident profoundly changed my perspective. A while ago, my wife cut herself badly in the kitchen while I was in the lounge. She called out, “I am bleeding, I have cut myself,” and I recall just sitting there, hearing it, and about 10 seconds later saying in a soft, non-interested voice – “ok.” The same thing repeated with more frustration from my wife, and then my daughter said, “Mummy has cut herself.” Eventually I think I said, “What can I do?” but it was already taken care of, and it was with a voice that implied I was not the least bit interested.

This shift is a marked departure from my usual self, someone quick to declare a national emergency and rush to a hospital in the event of a crisis. The emotional dulling I now experience contrasts sharply with my former impulsive nature. Although a friend once described me as “an empty tin can” - an American’s way of saying his British friend is emotionally reserved (understatement) - to some this may feel like the same old me with an added emptiness.

More generally, I am seeing a diminishment in my own passions, such as following my football team, the thrill of competition (I don’t mind losing at chess which is not me!), or the excitement of travel. The awareness remains, but the emotional intensity seems lessened.

Of course, this apathy could be mistaken as a convenient excuse. However, its implications are far more significant. Caregivers’ accounts on support forums are heartbreaking. Comments such as “My husband is just not my husband anymore,” and “I feel so lonely as he doesn’t engage or seem to take note of me” reveal the profound impact. The person is physically present but emotionally absent, barely recognizing, laughing, or engaging, creating a deep sense of loss for loved ones.

It is interesting how many caregivers take heart from the occasional smile of the patient when, for example, they see their grandchildren – it is a seeming resistance against apathy. I hope personally for this.

From a patient’s perspective, perhaps (this is conjecture) apathy might serve as a form of anesthetic, dulling the pain of cognitive decline, such as memory loss and the sadness in loved ones’ eyes. Without apathy it must be so painful to be aware that you are hurting those around you so much.

It might also dull the simple pain of massive changes in life and may soften the impact of the disease’s progression, offering a degree of comfort. I am not aware of any real scientific validity in that but have seen some psychological research – but as a patient going through the journey, I feel this way.

I have explained to my wife and children the likelihood of significant behavioral change. I have stressed to them that this potential change upsets me the most, alongside cognitive decline. I have asked them to try to understand that it will not be the real me and that they should hold onto their memories of me as they know me. I’d ask that my friends and other family members bare that in mind too.

Nonetheless, my heart breaks when I think this may happen to my wife as we progress, as well as to my kids.

My aim is not to dwell on apathy’s darkness but to shed light on it. By understanding this symptom, patients and caregivers can navigate challenges with more compassion. Recognizing apathy as a potential shield against pain allows me to think others can approach it with empathy, offering support and understanding instead of judgment. It’s a reminder that even as the disease progresses, the person within remains, deserving of love and connection.

Faith Is a Massive Factor for Me

One of the PSP-related charities wouldn't let me write a post about faith. The benefit of having my own blog is that I can actually write what I like, so I figured I can't leave this in the background any longer.

I'm not preaching a particular faith to anyone – that's not my place – nor do I believe that those without faith are any different. This is purely my experience.

Faith is probably the biggest single factor that keeps me positive and focused on moving forward. Family is probably the second, but they are deeply intertwined.

It's not the belief in an afterlife that drives me. I do believe in one, but I have no idea what it would look or feel like, and frankly, it's way above my pay grade. What I do believe is that I was created with a mission and a purpose by G-d, and that this challenge is something I have the capabilities to rise to. It's not out of my reach.

Whether I have a terminal illness or not, I believe I have a role to play. I am useful – and to be very honest, I see it.

In my personal opinion, I have a much greater purpose now than I did during my 28 years as a consultant. That work was important, but it doesn't compare to the time I now have to write, discuss, debate, and support people with PSP and other conditions. My writing and advocacy – for my country and about faith – have become central to my life.

I would never have chosen PSP, and I still wouldn't. It's a horrible disease. My eyes are failing (this screen is increasingly a blur), I'm slow, walking is hard, and my balance is shot. I know I'm still early in the storm. But PSP has given me so much meaning and precious time with my family – time I didn't really have before. As a partner in a big firm, I was constantly travelling or working.

I last wrote about faith in January 2025, when I still believed I had Parkinson's. After writing this post, I went back and reread that one. What strikes me is not only the similarity in tone and belief, but also how much deeper my faith and sense of meaning have become – even as the diagnosis worsened from PD to PSP, and my physical condition declined from running 5Ks to using a wheelchair. The direction has been undeniably negative, yet my spiritual clarity has only intensified.

I figure that most people have their share of good and bad times. I've had both. Wonderful years – getting married, having kids, going to university. But also dark times – poverty in my youth, family challenges (an understatement), and other difficulties I choose to keep private.

Right now, however, I am satisfied. In some ways, I'm the most content I've ever been, despite the impending further stages of PSP. The pain and discomfort are more than outweighed by this sense of purpose.

People will disagree with me – some strongly – but in my view, if I'm to be given a certain amount of sadness and suffering, I would much rather it be me than my loved ones. And if I had to choose, I'd prefer physical suffering over emotional or psychological pain.

I would never say I'm lucky. I'm not. I have PSP – an enormous challenge. But I do believe I'm blessed. Faith is the key for me.

Viktor Frankl, in his incredible book Man's Search for Meaning, wrote two quotes that inspire me deeply. He wrote this after surviving three concentration camps, including Auschwitz:

"Those who have a 'why' to live, can bear with almost any 'how'."

"Everything can be taken from a man but one thing: the last of the human freedoms – to choose one's attitude in any given set of circumstances, to choose one's own way."

With a 'why' we can bear the 'how' and attitude is something we can choose.

As I said at the beginning, this is a deeply personal blog. I thank G-d (who I believe is a universal one not limited to one faith) for the blessings He gives me and for the opportunities I have had. I need to do more to connect to Him and am working on it and I have hopefully lots more to contribute despite declining physical capabilities.

I wish everyone well.

Reference Table

Article Name	Date Published	Link to Article
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Patient Dignity: Why It Matters and How to Protect It	25 Nov 2025	https://www.benlazpsp.com/patient-dignity-why-it-matters-and-how-to-protect-it
Beyond PSP: Lessons from an Unchosen Journey	24 Nov 2025	https://www.benlazpsp.com/beyond-psp-lessons-from-an-unchosen-journey
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