



**The Victory Summit® Virtual Event: How to Live Well with Parkinson's  
“Nurturing Resilience Through Poetry”**

Recorded on April 2, 2021  
Davis Phinney Foundation

Kat Hill (Davis Phinney Foundation Ambassador, YOPD Council Leader, and YOPD Women's Council Leader):

I am so tickled to introduce today to you, Wayne Gilbert.

Wayne is a retired teacher and professor of English and educational psychology, and he was diagnosed with Parkinson's disease in 2005, excuse me. And over the last 16 years has taken refuge in poetry, having written hundreds of Parkie poems which he refers to as metaphor medicine. Oh, I love that.

Thank you so much for being here today with us Wayne, it's really an honor to introduce you, and I'm gonna let take it from here.

Wayne Gilbert (Poet, Retired Professor of English and Educational Psychology):  
I'm really happy to be here. I'm very, very pleased. And I want to thank everyone has the Davis Phinney Foundation and the incredible staff for setting up this fabulous occasion.

I'm just going to jump right in. I've written, since I was 17. I filled boxes of journals, stories, and occasional poems, but I didn't get serious about poetry until I was nearly 50 years old.

That summer of 2000, I met a brilliant saxophonist, and we spent every Saturday morning improvising poems and music. We jammed and performed regularly for five years.

16 years ago, this month, I was diagnosed with Parkinson's. I wasn't quite 55. And the first thing I did was go home and write a poem, because I needed the answers to two questions.

The first, what's happening to me? And the second, what does it mean?

Poetry is the way I answered these questions and metaphors are the heart and soul of poetry. Furthermore, metaphors really matter. I listened carefully this morning, and I heard some metaphors along the way.

One of Davis's favorites, small victories. Well, that sounds like it's descriptive. It is, but it's also a metaphor. The communication session opened with a wonderful metaphor,

one of my favorites of all time and that's, dance. It's a metaphor. There was also in there that the loop, the communication loop. Loop's a metaphor, there's not a real loop happening. That's a metaphor, that's a way of talking about what happens between us, or even within us, because I remember Pete saying, without input, a metaphor, you will just hunker down into yourself. Also, a metaphor you don't literally disappear into yourself, but it feels that way that's the way the experience is best described. It was Allen, who said in the exercise session, looking internally when thinking about exercise and exploring, where am I? How can I go a little bit further? Well, I don't literally go internally, it's not open-heart surgery. This is a metaphorical way of speaking about being in relationship to myself and to my own possibilities.

During the nutrition session, food is medicine. Oh yeah, food as medicine you better believe food is medicine no doubt about that. In a literal way, but also in a metaphorical way. And then, juggling act. Life is not a juggling act for real. I mean literally no one is out there, throwing up those bowling pins. It's a metaphor for how difficult the dance is. Now I'm mixing metaphors.

Metaphors matter because the metaphors we choose to use and develop, determine how we will live well or better or not so well with this disease. That's why, poetry, like food is medicine, the metaphors we use in conversations with ourselves and others must be as rich and varied as our experiences. And those metaphors must evolve and adapt to the progression of our disease, and the developments of our lives.

Now the language and imagery of war dominates the landscape of metaphors across our culture, but especially in communities of chronic illness disease and disability. The language and imagery of war is everywhere. It's deep seated. Sometimes it's even hard for us to think of alternative metaphors, when we talk about our experience with illness, disease, and disability.

But war metaphors, make me an enemy to myself. They are about violent oppositions and dualities. Some still say fight, battle, be a soldier and never give up. I say, my body will never be a war zone. I say show compassion, I say surrender, breathe. I say, jazz, jazz, you say, jazz, you can just whisper it if you want to. You don't want to be embarrassed by anybody in the room.

Jazz. Jazz is a metaphor for a resilient life with Parkinson's, to which I return again and again.

Those two questions. What's happening to me? And what does it mean? are never answered once and for all time. Right? Clearly not. One must keep asking, again and again because Parkinson's is not one symptom, or set of symptoms once and for all, but constantly shifts and changes unexpectedly and unpredictably. We'll never get over it.

There's no cure. Nobody is finally finished learning, adjusting, adapting, and improvising.

Every treatment is an experimental trial. It's damn hard to get really good at living with Parkinson's. You have to practice and practice and practice. Musicians call that wood shedding. That's resilience. That's jazz.

Some days I've got Parkinson's, some days, it's got me. Either way, every day, I make a poem, a poem, makes me, our jazz, our word jam, we brew our medicine, man we brew it. Take it however it comes, play it back however blue it sounds, straight up all the way, straight ahead.

Regardless, jazz.

I love that since early on, of looking internally, I think it was, Judith, I'm looking at my notes here, Judith said, my body talks to me and I listened. Like, really?

There's other medication for that too, right? No no no no, it's a metaphorical way of talking about our relationship to ourselves. And one of our experiences with Parkinson's, of course, is this seeming distance that increases.

My outward self from my inward self. And sometimes they can't make contact with one another.

This is a poem called "Lousy Reception, But Perfect Music".

*Calls from inner space are not coming through  
Reception is intermittent without the usual rhythms of speech.  
I can feel myself trying to reach myself, the urge of something wants to be said but  
Nothing I've tried clears up the link*

*Finally, this fluid chaos, perfect music, jazz burst into my head,  
Restore the link to myself, who was lost in a dead zone.  
We're talking again.*

So, I'm sort of working two metaphors there I hope you can hear. One is this notion of a link, which comes from the internet and zoom and all these ways we are linked to one another in cyberspace.

There's also this sense of hearing my deepest inner music. And finally, connecting my brain and my deepest inner music and discovering in that link for at least a moment. Some kind of, if not harmony, at least, music, and we're communicating again.

You know the problem with Parkinson's is, “dum, dum, dum, dum....” The bass player is completely unreliable. There's no one to hold it all together, nothing to hold down the improvisation. So, if you know anything about jazz, jazz must almost always have a drummer and a bass player, and it's their job to sort of hold it all down and hold it together while the soloists take off and go different places, but I think it's ultimately the bass player who is like the center of that gravity place. And the problem with Parkinson's is the bass player is completely unreliable, the jam falls apart and each instrument collapses in a heap and flies wildly off with little reference to the others, churning random tremors, locked below the frozen surface, making pointless noise.

The bass player is too wasted to drive it all towards music. Sinemet sits in. But brings weaker chops. The problem with Parkinson's is the bass player isn't completely reliable.

So, poems are ways we can explore metaphors and metaphors are the ways we can examine our inner lives. The inner aspects of our experience, our feelings.

“Noisy Coffee Shop Mindfulness,” obviously, a pre pandemic poem.

*The black tea steeps in its plain ceramic pot  
I settle on the barstool, poke in both earbuds  
Today it's Dexter Gordon, boo doo doo doo doo doo doo doo.  
Willow weep for me, the heavy white cup waits on its heavy white saucer  
Two cheap napkins flutter from its drips  
I pinch my black pen  
I open my journal reveal clean creamy pages  
Chew on the pen clicker  
My tremors settle down, poised for the silence from which sorrow shapes  
My micro calligraphy, micrographia, micro calligraphy  
I pour the tea before it comes becomes bitter  
I sip between stances  
I float like a yogi  
Dexter's onto body and soul*

Poetry invites. Especially, making poems invites a kind of mindfulness, that allows us to settle down. Experience something at least more peaceful. More contemplative. Then, before, and maybe then, after, and out of that comes something really creative and probably beautiful, but it's not always happy.

I have a friend named Allison. We were Facebook friends, and she disappeared a while back, but before she disappeared from Facebook at any rate, she said something about, I gotta get off this train.

So, I wrote this “Parkie Blues,” for Allison.

*Doo, doo, doo, doo,  
Tell the engineer  
He gotta stop this train  
I said tell the engineer  
He gotta stop this train  
Right now, I want to get off  
I'll find some shade  
I'll wait there  
For some other ride to come along  
I said stop, stop  
I said stop, stop  
I want to get it off  
Right now. I wanna get off  
This ride has gone on too long  
I've gotta get off  
Give me a beer  
I'll climb it this train  
Lay me down by a tree  
I'll wait for something better to come along  
A smoother ride  
I said stop  
I wanna get off  
Stop this train  
I wanna get off  
I said stop this train  
Right now.*

Trains are beautiful. Trains show us a lot for a country that really doesn't take the train much anymore, there's still a lot of blues and country songs that include trains I think it's really interesting.

It's all jazz. It's all jazz. Jazz is resilience. Jazz is a metaphor for resilience. Resilience is nothing but jazz. It's all jazz. Improvise, listen. Incorporate and integrate. Improvise. Listen. Feel deeply. Play. Listen. Feel further in, further down. Play that. Listen. Improvise. Feel each note. Each space between each note. Each space, feel. Feel. The way notes run together. I said the way notes, run together.

Make a phrase, I said make a phrase. Anticipate. Improvise. Incorporate, integrate. Listen. I said, listen. Play. Play. Listen. Anticipate.

There are no wrong notes in jazz. There are no wrong notes in jazz. Resilience. Only new moments. Resilience. Opportunities. Resilience. To listen and improvise. Trust.



Trust your heart, trust your ears, trust your voice, trust your deepest affection, trust your emotions, questions, celebrations, fears, trust, feel without thinking. Flow the way water always flows toward free. Free expression, free feeling, free spirit.

No matter the pain, play that. No matter the suffering, play that. No matter the despair anxiety, depression, death, play that. All the ways you hurt, play that. All the little things that bring you pleasure and joy, play that. Feel it all.

Improvise, incorporate. Listen, play. You are the instrument, you are the instrumentalist, you are the source of the sound, the rhythm and flow. You are the music itself. It's all jazz man, it's all jazz woman, there's only this one night at this particular club, and we call it Earth. So, play, freely play. Put it all out there on the stand for all to hear, leave space for your bandmates too because it's all best when the jam is cooking for everybody.

I'm telling you, people, it's all jazz.

Take some time to be alone and write. Take some time to open, mindfully.

Be curious, whatever comes up, write it down.

Have courage. Get it out, get it down, and then share it.

I invite you to a very simple writing practice. Don't make it complicated. Just grab a pen and some paper or a phone with a recording device, or this writing software on your computer or ask your care partner to sit and listen and write it down, simple statements. Explore. Feel. Play. You can do it.

Thank you.

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