The Parkinson's Walking Marathon A POETIC WALK

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## We are all in this together we all are born and we all will die

There is an illness that we all must face It's terminal and 'life' is how its known, Its cause is 'birth', can happen any place It happens after we have lived and grown. No matter what our fate, we all will die In youth or aged our time is really short, We'll all be mourned by some, for us they'll cry As we depart with only what we brought. But now's the time whatever is our load Accept the ill that's joined us on this track, And use it to enhance the path we're showed With no regret or fear of looking back. This is our only life, our only chance Embrace it as we go, it's our last dance.

## But our adventures through life

#### are different

Our marathon won't be defined by distance Cause staminas do differ with PD, Our challenges may change within an instance We do not have a life of certainty. Our marathon won't say you're in or out Won't be the one that flags you off the track, And winning is not what it's all about It's 'turning' up, and giving it a crack. Our marathons do differ, they depend On where we've been and where we're going to, It's only us that know, we can't pretend Not just the foot, also the type of shoe. It's our own effort, its 'our' marathon, Determined mostly, by which path we're on.

# Those varied paths can be defined in many ways, and bring their own challenges, in my case it is Parkinson's Disease - (PD)

I have a disease and it's neurological

Its name is Parkinson's and with you I'll paint,

A picture broad in brush so typical

So we can catch a glimpse without much taint.

Its silence means we may not know we're caught,

Its slowness gives us hope that there's much space,

Its persistence shows that time is gold but short,

Its weakness felt but fails to leave a trace.

The arms and legs can flail - a 'social no'

Or freezing where you cannot walk at all,

The heel won't work, you're walking on your toe

Add leaning and you're heading for a fall.

But we can change the picture and the frame,

By adding our own brush, to stake our claim.

# That change can be hampered in a variety of ways and one of the main dangers lurking here is 'apathy'

It's not the disease that's deadly, 'tis apathy It tells you that you haven't got a chance, Will offer you no empathy or sympathy But takes you on quite an un-merry dance. Your motivation lacks, purpose will go Levels of energy will also fall, Your passion gone but you won't feel it so And life detachment sees no curtain call. In some I know I've seen it change its tune Where open curtains see the light once more, Their time to rise and move outside the room Assured that they will leave and close the door. Now find your passion, let it be your 'real' And live your life, that apathy did nearly steal.

# Try hard to not let other things interfere with your performance, and use your passion to override them

Disabled is a hard word to define

It conjures up a feeling of despair,

There's been a public drawing of a line

In sand that's quick and sinking - that's not fair.

The old interpretation boxed us in

A burden, it was life no longer living,

Like shredded paper filling up a bin

That takes up space, it's taking but not giving.

Today there's change with opportunities

To find your passion - move beyond your fears,

And rise above these disabilities

To live life well for many, many years.

It's tough, I know, it's easy just to say

But simply start, then take it day by day.

# One of the ways you can override those interferences is to use our natural reward characteristic

In most, it's just a very normal thing, Receiving plaudits as you strive to reach A goal, that life has helped us all to bring, To focus on, to learn and then to teach. For those who have a neuroplastic hole It's harder to believe that this is right, 'Cause they believe for them there is no goal, Why bother then, the evidence is tight. But there's a crack, that needs a dose of will, And laced with motivation there's a chance, To see the value in that task until. The pleasure and the energy enhance. That moves you further on and then toward That special goal, and dopamine reward.

# Dopamine is in short supply in people with PD so we need to use it wisely

It's not so much the size of the team in the battle For numbers don't define a win or loss, It's the battle in the team that makes them rattle Eventually showing who really is the boss. So when the odds are in the others' favour Then draw upon your wits to gain an edge, So you can earn a victory you can savour Which doesn't leave you hanging from a ledge. When diagnosed with Parkinson's Disease The loss of cells with dopamine is vast, But with intent the last few you can please Rewarding them with treasures that can last. It's best to get the most out of the few, Than mourn the loss, of those, you never knew.

# Ailments

## can also interfere with

### our progress

The cartilage in my foot - degeneration Improvement not an option so 'Doc' said, And low BP, it came from dehydration It sends you in a spin - a thing to dread. And now there is degenerative spine With osteoporosis, what a duo! Solution they once said to lay supine While others said it really is quite pseudo. My prostate disappeared in one fell swoop No semen left - at my age doesn't matter, My blood clots interfere in the whole loop With atrial fibrillation blood will scatter. Now Parkinson's has put it in perspective, Thus making me - a little more acceptive.

# There are many PD specific symptoms that can also hold you back

I've tried, it's much too hard to reach my feet And takes too long to do my buttons up, I've got PD, can't roll beneath the sheet Near empty is my saddened once full cup. I don't walk anymore because I stumble But worse than that I would guite often freeze, I stay behind my door because I mumble I'm lonely 'cause I'm very hard to please. My stare, even my doc avoids my eyes I can't control the dribble anymore, My 'flailing' hands can't wipe away the flies My muscles always seem to be so sore. But I'm not there, yet I am on that road, I'm learning though, how best reduce that load.

# Today is a walking marathon and no matter how fast and far you walk, we can all be more aware of our own body's capabilities.

Awareness is my one - 0 - one for living Like water it brings life to dying cells, For no reward it keeps forever giving It keeps you keen, no need for warning bells. So when you walk watch out for dangers lurking Some snags lie in your mind and on the ground, Awareness learnt can stay forever working Ensuring vulnerabilities aren't found. And when your body plays a different role Awareness makes you preparation-ready, So when your steady balance someone stole It gives you tools so you remain quite steady. Awareness is the lifeblood of our mind, The greatest antidote that you will find.

# We can use that awareness to make our journey safer and more satisfying

I love to walk, it makes me feel alive It gives me more than I could ever ask, Responsible for goals for which I strive Inspires me so and keeps me on my task. It doesn't need a season or a time It's ready now, and all it needs is you, Downhill, or on the flat or you can climb So easily done without too much ado. It's kind to you, and doesn't cause you pain It finds a pace to suit your own condition, It doesn't have its own private domain But a calming and an easy disposition. So humble is this exercise of walking, Out there as we speak, no need for talking.

# But there comes a time when we must talk

I'm feeling fresh, and have a wish to walk My left leg though has gone a little tense, Not certain, but I think it wants to talk We took a break and lent against the fence. "I know" it said "you want the best for me But as you know you have this sad disease, I hear your wish but automaticity Has made it hard, so help a little please". I listened as I tried another way Increased my pace and took a smaller stride, "This helps a lot", I heard my left leg say, "I thought I'd gone and then at last I cried". Back home again, we walked along as one, Excited that - another challenge won.

# You can share your walk and talk with others to make good use of what you have learnt

For a moment, once, I thought the very worst A Parky's verdict not looking very good, That moment gone, brought on a sudden thirst That 'couldn't' gone, now was only 'could'. With exercise we walked across the world With confidence I'm up to giving talks, With effort now my poetry unfurled While writing books about our many walks, Don't walk as fast but still my walks are strong Don't sleep so well, and takes a bit to rise, I shake a bit and meds don't last as long My pen still works, a bit to my surprise. So have your 'moment' - let it be your last, Then Parkinson's may slow down very fast.

# This poetry has helped me to slow down and concentrate on trying to change my brain by constructing a poem every day

To change our brain, it takes a lot of work, Some hours per day and every day we need Tense focus, it is not a job to shirk, The 'brain' - it's hunger cries for us to feed. But what's the nourishment it likes the best To ease the pain that lingers deep inside, And satiate its aching need - unrest Then wait and watch to see what will betide. It yearns no less, for us to learn and grow So its potential it can there achieve, So find your passion, let it be your flow And slowly, surely, you may then retrieve Those neurons that seemed lost for ever more, May give your brain a chance, to now restore.

This working on the brain can enhance our creativity which further helps to maintain a healthy brain

I paint and wonder how it got so deep Inside, a visual delight to ponder, A dance discovered - light upon my feet Of music I did now become much fonder. Now words did come and dance upon my lips I penned, not knowing how or what I wrote, And then they rhymed and came to me in sips A sonnet soon appeared - new words I quote. It wasn't there before my diagnosis 'Twas Parkinson's, it's been my newest guest, That's brought me life as well as this necrosis Why, cells alive! although most did go west. Those dying cells - my creativity, Have given me, a sense of liberty.

# Be in the present so as to nourish our being to ensure we are prepared for any event

There is no way that we can see the future Especially with Parkinson's Disease, In later life there's going to be some torture So move it now before you start to freeze. Now treat your love like it's a new romance And treat your diagnosis much the same, Imagine this, that it is your last dance And give it your attention not your blame. So do it while you can - regrets don't work And I mean every day - same attitude, Your duty to your life you cannot shirk Resist that ever circling PD mood. It's the present now, that I must learn to live in, Those future thoughts, encourage one to give in.

#### So the past, present and future

come together

#### with acceptance

'What was' - an opportunity gone by A waste, or were there changes for the good? Regret is dead or will eventually die No longer is there room for one word - 'should'. Acceptance is the only useful tool It's all we've got so with it we must deal, Ignoring it, the message from a fool May not be good but it's the only 'real'. And now it's time to form a new 'what is' By looking at a different 'what can be' Avoid the harm by falling in a tizz Embracing change, a latent victory. The future stems from what we've done before, So what's done now, can save our very core.

#### So let's walk

A walking revolution is what's needed It should be seen as a renewable, Becoming automatic once it's seeded We've learnt from birth that it is easily doable. So then we all do shape our marathon Like life, it can be fun, it can be tough, At times no choice but something we must act on Some different ways that we can huff and puff. So walk each day no matter how you feel You'll be surprised what difference it makes, Will keep you on a much more steady keel Your body and your mind it then awakes. It's time to walk, so get up and get going, And get the body's juices, really flowing.

# So we walk definitively into a version of Rudyard Kipling's 'lf' which I call 'When'

When you can make some sense of your disease As you try to see the forest amongst the trees, Find the hidden sunshine – feel the breeze And keep on moving lest you quickly freeze; When you can walk and make the most of walking, Improve your balance to prevent a fall, Train your chords so you can keep on talking, And focus on your core – it'll keep you tall: When you can set the bar at such a height That challenges the apathy you feel, The body, mind and soul you set to fight And treat it like it's not a massive deal; When you can use reward to motivate And train the brain to change the way it thinks, So you can keep the effort up till late Ensuring that your purpose never shrinks: When you create and never cease creating Changing ways to make a better you, Then find a passion that is stimulating A purpose that will always stay so true; When you can find a way to work this out And sift through all the options that are there, When you can earn respect so they don't shout And show it's not just them that have to care: When you can free yourself from any stress And organise your life in such a way, Suppose you do it now – avoid the mess And make the most of every single day; When you can share the things that you have learnt With those that live with Parkinson's Disease, Satisfaction with your life is what you've earned, And then you'll see the forest, and the trees.

#### And what a sight that is

This Parkinson's will not define my being It won't divert the plans that I've been hatching, It will however stop my soul from fleeing My mind and body now will take some catching. My strong belief is age should make us better So PD is my catalyst to prove it, To gain some credit, best not be a debtor To see my interest rise I'll need to 'move it'. It's not so much about the quantity About just doing lots without a thought, It's more about the depth and quality Refining features that from birth we brought. We do not have to die before our death, So try and stay alive, 'til your last breath.