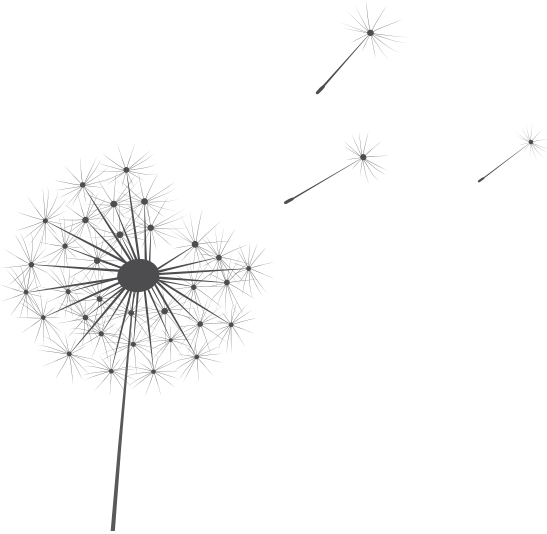
Shaken but not stirred

Living life with Parkinson's disease

Jovo Ćirković



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Living life with Parkinson's disease

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Author's note:

On August 10, 2011

I was diagnosed with Parkinson's disease … which I decided to call Parky. As with most things in my life, when faced with adversity, I looked to find a positive.

Step one is acceptance. Until you accept your fate, you simply can't move on.

I did what most people do; look on the Internet to find out more about this disease …

What I found, gave me an outlook of a future which was not very positive, so I decided there and then, that I will fight Parky and in the end I will win.

This book of poems, is my way of expressing the various stages that I've gone through, and hope that you gain some inspiration from my words.

The human mind is a powerful tool; we use less than 10% of its full potential, I will dedicate my time finding ways of tapping into the 90%.

My message to Parky … Watch out, your days are numbered!

By the way … What was the positive I found, you might ask.

I got reacquainted with my true self, found words to write poems.

Poems which previously, I would not have written.

In a way Parky helped me find myself.

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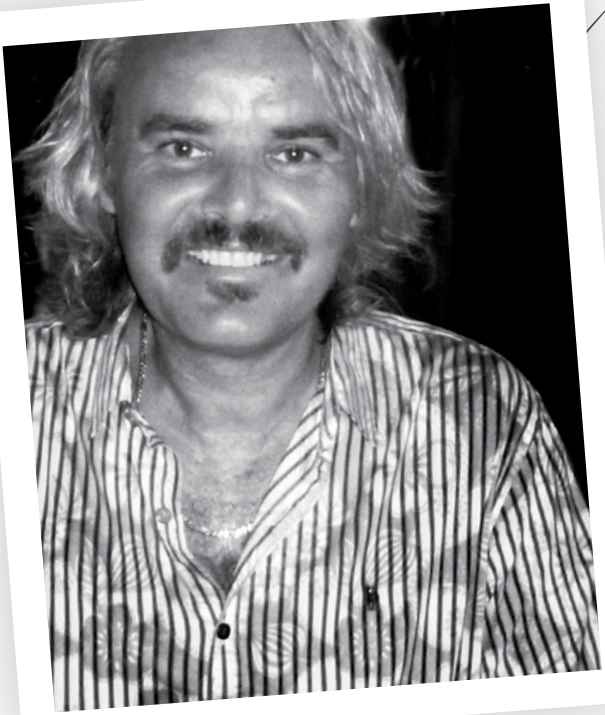

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"I think that most diseases show symptoms long before we acknowledge them. Especially the male species, we tend to go with the old "she'll be right mate" attitude. Listen to your body … It has to look after you for the rest of your life."

Big river in Egypt – Denial

When I lost my sense of smell
It's just due to stress … I'd say
Very sure of myself I was
It will return again some day

My left shoulder is always tight
From typing on my PC
A massage I'm sure will make it better
There's nothing wrong with me

I toss and turn when in my bed
Struggle to find a slumber peace
Must be the mattress … I'll get it changed
That will bring my body back to ease

I sweat at night my bed's awash
My room it's just too warm
Change the bedding, open window
My body will be back to norm

I get tired by mid afternoon
Require a Nanna-nap
My body feels fatigue, lethargic
Gee getting old is crap

My left arm has become lazy
It won't swing when I walk
I call it Gammy when it begins to shake
To my doctor I must talk

Series of tests walk and reflex
Touch my finger to my nose
You have Parkinson's disease young man
My Neurologist did propose

It all makes sense now the sleep, fatigue
Why my face has lost its smile
The signs have been there all along
But I was living in denial

This is probably the most difficult
conversation I've ever had.
The father is always meant to be
there for his sons.
They both saw my symptoms and
they did question me,
I guess I really was living in denial.
Telling your family is
very important.
As they say, a problem shared
is a problem halved.

Introducing Parky to my sons

How do I talk of Parky to my sons?
Must deal with it in stealth
For a dad's supposed to always be there
In strength and in good health

But unfair to say nothing
For I'm sure that they can see
As time goes by they notice changes
And a different me

At dinner table with food in belly
I start a serious talk
Slowly I reveal my journey
As my tongue turns into chalk

The big round eyes and attentive stare
Shows maturity beyond their age
One son leans in – hangs on each word
Whilst the other hides his rage

Tis hard for a son that dad's not well
But they take it in their stride
Hanging hopes on my positive attitude
Lessons well learnt they confide

The fear in their eyes betrays
The strength they try to show
We hug each other and deep inside
I am glad that they now know

Together we make light of Parky
My shaking left hand they tease
Hold my drink in your right they say
And give a gentle squeeze

When I take a bath they say
Throw some washing in and shake
Save on power and sell the washer
Of Parky such jokes we make

As hard as I thought in my own mind
That telling them would be
They seem to have grown up overnight
A big relief to me

For I know that deep in my heart
They will be my strength
To be there for me … to ease my pain
They will go to any length

When I was diagnosed, and
Parky came into my life,
everything was about me.
My partner Eileen also suffered,
but as I was busy … It was
hard for me to see.
This poem and the next, were
written by me, whilst I was
trying to understand how she felt.

Where is my man?

The spontaneous man that I so love
He seems to be no more
Lost in thought, in vague confusion
A bottle cast out on the shore

From outside he looks the same
His features strong, his spirit free
But inside there a battle rages
Which only I can see

The quick wit gone it has been replaced
With a stare which seems to scream
What's wrong with you, I am still the same
But it's whispered from a dream

The voice is soft and hard to hear
But to say so may offend
I find it hard to decipher which I am
Nurse or his best friend

I catch myself in my pity and anger
Makes me want to scream and kick
Why am I feeling so selfish?
When he's the one who's sick

I pull myself together
Muster up my strength and poise
Try to focus on good thoughts
And cut through my minds noise

Today's been tough but it will pass
For tomorrow I live in hope
That we shall have a better day
On a positive upward slope

For my love for him is stronger today
Than all my yesterdays to care
And when I look into his hollow eyes
I see his spirit is strong in there

Come back to me from medicated state
And let our spirits dance once more
For my heart it awaits your embrace
As it did before

Let's speed up time and maybe then
We can break this trend
And you'll return to me whole once more
I miss you my best friend

Fallen leaves upon the grass

Medicated I must walk through life
Not sure of the benefit that shall pass
One thing I know which hurts my love
A loss of spontaneity … fallen leaves upon the grass

The quick wit gone … intelligence blurred
It's hard to watch unfold
Where is my man she asks again?
The one I used to love and hold

Why do doctors medicate
Knowing nothing of our dreams
The cold isolation that meds can bring
Lack of caring or so it seems

The simple things matter the most
Like a twinkle in the eye
The touch of skin the electric charge
Seem in the past … tis hard to say goodbye

From inside I can't see the difference
Which you see … looking in
Maybe I should reduce my meds
And rekindle where we've been

Alas your words of wisdom
They seem to prevail and hold
Wait until the next Doctors meeting
And see what we are told

Parky you're a pain in the ass
But you won't beat me you know
For I am stronger than you think
And in the end … it will show

"Anger is the natural part of the cycle.
I found it easier to deal with by focusing
my anger at Parky.
Sometimes the anger can be turned
against the doctors, who prescribe
medication,
without really understanding anything
about you and your life."

A Ninja feeding on my sanity

Oh Parky here we are again
Creating in me rage
Affecting memory … wrong words selected
Yet you are centre stage

At what point, what time exactly
Do I get the old me back?
Or do you plan eternal possession
Never yielding me any slack

I try to live as if you're not there
And most days I succeed
Then like a ninja you creep back in
And on my sanity you feed

But I see you for what you are
A parasite in search of host
Go ahead and shake my arm
That's the best you'll ever boast

For I am stronger than you may think
And I'll beat you … in the end
I'll pick myself up from the deck each time
With the help of … my best friend

Again anger pops its head up, causing me to ask questions blaming ancestry and outside forces. The reality is there is no correlation between Parky and genetics … from my understanding anyway.

Leaving anger and regret

What in hell did I do wrong?
To deserve the hand that I've been given
Isn't Parky an old people's disease?
Affecting people … almost done with living

At 47 my life was planned
My future … bright and set
That has now been flushed away
Leaving anger and regret

Was this passed on genetically?
Did my ancestors sin so much?
That through a draw in the lottery of life
An evil claw should grip me in its clutch

At times I think this is a cruel joke
Played by some alien being on me
Designed to test my human strength
On some alien reality TV

If only the hands on the clock of time
Could be wound back to a time before
I'd barricade myself in safety
And lock Parky outside my door

Then he can come and knock away
But he would never reach
Into my being … my very core
Never attach to me like a leech

Parky is not always heavy. Special days and special moments still need to be cherished … This was one of them.

Yesterday … Parky was asleep

Yesterday was one rare day
When Parky was asleep
My lady's birthday … such good times had
Left no room for him to creep

Holding hands and taking walks
Not a care to bother us … you see
63 days spent relaxing in Thailand
Has set both our spirits free

Dreams rekindled … goals re-set
Bright our future it will be
One vision when it's shared by two
In photos so clear our friends can see

Sometimes it pays to remember
What is important I must see
My focus must be balanced
Between Parky, you and me

The magic that we felt before
Is still strong and it is true
Whilst Parky sleeps I'll make the most
Sharing my moments just with you

Home we go with slightly heavy heart
That's how life ebbs and flows
Even Parky can't dampen my mood
In my smile my spirit shows

Losing my ability to play guitar
was very hard.
I was never an Eric Clapton
… but I found great joy from
being able to sing and play a
love song for Eileen.
Now I offer to jam with bands
on holidays in Thailand.

While my guitar gently weeps

The soft tune of Cat Stevens
Singing "Father and Son" as tears fall
The velvet tones of Rhonan Keating
Singing "When you say nothing at all"

Enrique Iglesias and "Hero"
Eric Clapton's "Wonderful tonight"
Even my mate Neil Diamond "Sweet Caroline"
Just don't come out right

My left hand … my gammy arm
The chords it just won't find
Unable to play Sarah McLachlan's "Angel"
Now that is just unkind

Parky has decided that
Forever gone are my guitar days
As sad as that makes me feel
It brings me hope in other ways

My voice still as true as ever
Bellow out a song I can
Even if I'll never be known as
The Melbourne "Guitar Man"

"I have always believed that things happen for a reason.

Although difficult, a critical illness can focus you on the things that are most important to you. Working for me was second nature, and giving it up was difficult. Parky has forced me to refocus and re-prioritise my life."

Parky and the workaholic

When Parky and a workaholic meet
At once your life is changed
It may take some time for you
To get your priorities re-arranged

Your 60 hour working weeks
Could be relegated to the past
Your body now has a parasite
Its endurance you must outlast

Add to that your new medicine
With side effects galore
Finding strength to go to work
Might walk right out the door

A failure you may think you are
Because a provider you've always been
Turn your efforts to a new cause
Only then a new world is seen

Reasons unknown things happen to us
Strength we must source from inside
Although your path may not be clear right now
You must take life in your stride

So make a choice and write a list
What's most important for your health
Set new goals and you will see
How your visions can turn to wealth

This poem and the next relate to the dark
dog … depression.
Unfortunately depression is unavoidable.
It's important to acknowledge how
you feel but also realise, the entity watching
you whilst you feel is your true self.
Your true self does not feel depression
or any emotion, it just is.

Sapping strength from my true being

I see darkness before my eyes
Be they closed … or be they seeing
Life seems to have slipped from my grasp
Sapping strength from my true being

All my dreams … and all my plans
What good are they I ask?
I don't see a future beyond Parky
I am afraid of this unwanted task

There is no cure my doctor states
But most people learn to cope
Parky's with me for my remaining days
I'm like a puppet on his rope

Struggling when they try to walk
Every old person that I see
Their shaky hands give them away
Is that the future for me?

The pain I feel can be lived with
But it does constantly remind
Parky has my muscles at molecule level
His experiments can be unkind

Easy to judge when you're not sick
Infected by disease and pain
A clear future … I just don't see
Whilst the darkness consumes my brain

Occasionally I feel like stone

My arm shakes my back is sore
I feel my face is blank
Occasionally I feel like stone
A mossy rock on river bank

I see people holding on to frames
They shuffle … and walk by
Is it Parky who has control of them?
If that's my destiny … I'll cry

I sometimes hesitate before I walk
Is that a sign of freezing?
The dizzy spells when I stand up
Then there's my constant sneezing

Reduced meds give me clearer mind
My recollections … better today
The offset is the pain I feel
But it is worth it I must say

My whole life is now an act
Of balance … find my centre
Adjusting food, exercise, meds
A new life phase I must enter

As worrying as my future may be
Have to take it one day at a time
For to give in to Parky I will have lost
I guess the choice is always mine

It's hard to feel sorry for yourself,
when you see young people
affected by what seems to be much
worse diseases than your own.
It really puts things into perspective,
and made me realise just
how lucky I am.

Young teen boys living life in strife

Yesterday I found myself
Relaxing in a spa
Contemplating destiny
Where I'm at thus far

A sight in the spa helped me
To take stock of my life
Image of two young teen boys
Living theirs in strife

Autism or some similar
Disease obvious they both had
Hearing grunting noises from them
Made me feel so sad

At least I had 46 years
Of normal life before
My new companion Parky
Came knocking on my door

These young men seen to have
Much more strength than I
I wonder if down deep inside
Their soul and spirits cry

Next time I feel sad
Sorry for cards I've been dealt
I will remember those two boys
Get my strength from sadness felt

"I know that everyone's disease is different, and I don't judge. I only looked at Parky blogs one time, and won't be looking again. I would rather focus my efforts in finding ways to be better and eventually beat this disease."

Accepting destiny and fate

How many people out there
Have Parky as room mate
Have you conceded to your new life?
Accepting destiny and fate

Today I read some Parky blogs
And many comments say
That since Parky paid his visit
They see only darkness in their day

It's like they've lost their faith
That life can ever be
As good or maybe even better
In the future Parky free

Degenerative Parky well may be
But power to manifest you've been given
A better life than what's been foretold
You can choose now to be livin

Only 10% of the full potential
We access of our mind
Who knows what still lies dormant
What power to heal you'll find

It's only when you can accept
That we choose our own disease
At that time you can finally
Put your mind at ease

Right now take a deep breath
A life decision you must make
Who controls your destiny?
From Parky your future you must take

I have found through physical exercise my body and more importantly my mind are becoming stronger.
I see Parky as an adversary in a sporting match, my previous martial arts training gives me the mental strength to win.
This poem and the next two are all examples of my winning attitude.

Giving Parky his "What For"

I wake up in the morning
From restless sleep I'm tight
My shoulders sore my backs in pain
I've tossed and turned all night

My pillows wet, my bed awash
As I wake from another dream
Why can't Parky go away?
Leave me alone … I scream

To sit in pity for myself
Although tempting it may be
It achieves Parky's evil plan
Which he's written just for me

So out of bed I lift myself
As my reminder chimes its tone
The first of three daily Pillock O'clocks
Set in my calendar on my mobile phone

Determined face I dress for gym
Find the treadmill waiting there
Jog my five k's … sweat pours down
My arm shakes but I don't care

I sit and stretch my muscles tight
It's through exertion I must pay
To drop my guard and become lazy
Parky wins the day

I get home my muscles ache
My daily tasks I complete
Pretty soon time for a nanna nap
Rejuvenate from head to feet

Bed comes early for Parky waits
To disturb my sleep some more
I close my eyes with smiling face
In the morning he'll get his "What For"

Oh how simple life was

I sit here and am thinking
Just how my life has changed
If only I had more notice given
I can have things rearranged

When Parky came into my life
I was not ready … ill-prepared
But he came and just took over
As if he never cared

Oh how simple life was
Before losing my control
But play the hand we're given
It's onward we must roll

To give into despair and anger
That simply will not do
Time to seek strength deep inside
And refresh my strength anew

I still count myself as lucky
To have legs to help me walk
Strong arms I use to carry
And my mouth through which I talk

Together me and Parky
Coexist in one body … we may
But as long as I breathe and am able
I will kick his ass one day

Where is the rest of you?

With headphones plugged into my ears
The sweat on my body glistens
8 kg lighter and a few to go
Whilst my subconscious listens

The goals I set … The plans I make
They are with me every day
"Where is the rest of you?" When you see me
Those magic words … I hear you say

It's what we tell ourselves that matters
For our subconscious doesn't know
The difference between reality and fantasy
But the end result will show

It's important to have a mental game
It doesn't have to be real grand
Parky will always tag along
And lend his shaky hand

What exactly are you waiting for?
Get off your butt … be real
Experience the wonder that is your life
A fantastic internal joy … you'll feel

With the determination I have learnt fighting Parky,

I have started to use it in other parts of my life. Whether you believe in manifestation or not, does not a matter, the universe will deliver … Fail to plan - plan to fail.

Bringing clarity from smokescreen

Some people say I'm crazy
Because I choose to manifest my life
They don't know the power it can bring
Whilst avoiding daily strife

When you see your future clearly
If you believe with all your being
What seems like miracles can occur
Bringing clarity from smokescreen

Most people choose not to believe
Blame things on simple chance
I wouldn't be with the girl I love
Had I not asked her for a dance

No need to understand the workings
Just choose to believe right now
Universe will deliver … Just ask it
Might just blow your mind somehow

I'm not talking about Parky
Now you may think I'm strange
Choose other parts of life to manifest
Try something new for a change

Living with a partner suffering from Parky

You may feel it is your job to cure them. This is their journey … they need to learn their own lessons from Parky. Your lesson is to accept what is and encourage your partner to feel they are still the same person.

"Hakuna Matata"

"Don't worry … be Happy"
I think you know the song
Or the phrase "Hakuna Matata"
The Lion King can't be wrong

We are both right this minute
Presented with a test
Mine is how to live with Parky
Yours how to accept

Your worry is quite futile
It really is unkind
For all it does is mess around
The thoughts within your mind

Takes your energy away
From what you can control
Hurts the person you love most
And wounds your very soul

You can't fix me Eily
No matter how you try
Until a cure is found
Parky's with me till I die

I have come to accepted my fate
As I believe in destiny
As much as it hurts at times
This lesson is just for me

Although you are part of my life
This is one chance that you get
To learn to accept WHAT IS
Live YOUR life with no regret

The shine has tarnished on my armour
For it's been quite a while I stress
That a damsel has been in need of saving
This causes me distress

For I've lived my life being needed
By my lovers and my friends
If that role is also taken
Then my existence is at an end

So pull yourself together
Just let the journey be
ACCEPT every moment presented
And please come back to me

I hope you enjoy reading my poems, and if you are suffering any kind of illness … I hope they give you strength.

That's just how life goes

Yesterday I found myself
Reading poems that I've written
About the day since meeting Parky
You'd think that I was smitten

Who'd have thought six months ago?
I'd be writing … off such woes
A crystal ball … nobody has
That's just how life goes

They say when I was diagnosed
I'll go through different stages
Denial, anxiety, fear, depression
And the anger which just rages

As time passes … it has been written
A state of acceptance I will reach
Come to terms with my new life
Pass strength to others … Teach

Some days the bravery is just not there
To giving up … my thoughts are turned
I sit and daydream of a past no more
And simply wish it was returned

But then again here I am
Many poems I have penned
How many people … will they help?
How many will they offend?

I guess in life it does not matter
For our own reality we choose
The power truly lies inside
If you leave it dormant … you will lose

This is a poem for my little friends at the
Chiang Mai Orphanage.
These children are so happy …
They are well fed well clothed, but what
they miss most of all are the hugs and kisses that our
children were brought up with.
If you enjoyed "Shaken but not stirred" all I ask in
return is that you visit my foundation called
"Happy Hands Foundation" and make a donation
to help my little friends.

www.happyhandsfoundation.com

What I'd give for a bedside story read to me by Mum or dad

When I wake up in the morning
I look around and something's just not there
No mommy … No daddy to wake me up
It really isn't fair

I have 60 friends to share my time
And there are my carers too
Sometimes we get volunteers
For excursions at the zoo

My clothes are all packed away
Inside my slide-out draw
My shoes are stacked up in a row
With 59 others … at the door

I have food in my belly
Bath twice a day … it's really not so bad
But what I'd give for a bedside story
Read to me by Mum or dad

At least I am healthy
Unlike some children … Who have HIV
Sometimes they cry out late at night
I'm glad it's them not me

What did I do that is so wrong?
What have I done so bad?
That I should have to live my life
Without both mum and dad

I have lived here since I was one
That was five years ago
Sometimes life just flashes by
But some days it goes real slow

I wake up often in my sleep
I'm afraid to lose my toys
When I turn seven … Is time to move
To live with 175 older boys

No more girls to play with
I won't be the big boy any more
I've heard from other boys who've moved
I'm afraid of what's in store

For 10 more years I need to wait
Until the day that I'm set free
When I can finally leave this orphanage
And rely just on me

I promise that when I have children
I will be there … To take care
To tuck them in to bed at night
And let them know I'm there

If you can share some of your wealth
For a better future is my goal
Knowing your money is helping orphans
Will be like feeding your own soul

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