

# BRIGHT AND BRILLIANT

A selection of poems for  
World Parkinson's Day



TOGETHER, WE CAN FIND A CURE

**WORLD  
PARKINSON'S  
DAY 11 APRIL**

**PARKINSON'S<sup>UK</sup>**

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Bright and brilliant

A selection of poems for  
World Parkinson's Day  
2023

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# BEING US

Thank you for choosing to pick up this selection of poems. This is a unique collection of poetry written by people who live with the world's fastest growing neurological condition, Parkinson's. Some of them have the condition themselves, others are family members, carers, supporters or professionals all using poetry to shine a light on how it feels to live with a progressive, and currently incurable neurological condition.

Since 1997, World Parkinson's Day has been marked each year on 11 April by community-led events around the world as people come together to raise awareness of Parkinson's. In recent years, Parkinson's UK's activities to mark the day have been coordinated by a core group of volunteers supported by staff.

## **Bright and Brilliant**

The theme this group chose for 2023 was Bright and Brilliant, which is how we see our amazing Parkinson's community. Activities included encouraging people to light their buildings in blue, to hold local awareness events, and to engage with the media. We also invited people to submit short poems to Parkinson's UK via an online form.

The poems we received were indeed bright and brilliant. Many of them have already been shared on more than 2,000 advertising locations across the UK including the famous lights in Piccadilly Circus. Our poets have shared everything from the silly to the serious, from their passions to their pain.

Now we have curated a selection of poems in this small selection which can be used as part of an awareness event, in individual Parkinson's advocacy, or simply for your own pleasure and insight. We will also be sharing some of the poetry on social media and in other ways in the year ahead.

## **Being with Parkinson's**

We've grouped the poems together in chapters with similar or related themes, all about what it's like to "Be" living with Parkinson's. You can choose to read the chapters that appeal to you, you can start at the beginning and read to the end, or just open the book and choose a poem at random. It's up to you.

The poems reflect many voices and experiences of Parkinson's, and we are aware that some may use words or ideas that could disturb or offend. We have kept these to a minimum but have included some of these poems because they do represent people's personal experiences.

We do hope that you find this collection of poetry as moving, insightful and enjoyable as we did. Our thanks go to all the poets and to all of the bright and brilliant Parkinson's community who continue to inspire us every day.

To learn more about Parkinson's, World Parkinson's Day and Parkinson's UK, please see the list of resources we have provided at the back of this book. If you would like to comment on this book, enquire about poetry and Parkinson's or to make any suggestions about future activities, please contact us by emailing [involvement@parkinsons.org.uk](mailto:involvement@parkinsons.org.uk).

Keep being bright and brilliant.

The Editors

### **About this project**

World Parkinson's Day takes place on 11 April every year to raise awareness of Parkinson's. World Parkinson's Day belongs to the global Parkinson's community.

For Parkinson's UK, World Parkinson's Day is an opportunity to support the community. To raise their voices. To share their experiences of living with Parkinson's. And to use our resources to back and amplify their ideas.

### **The co-production approach**

For World Parkinson's Day 2023, Parkinson's UK supported two activities created by members of our UK Parkinson's community - Poems for Parkinson's and Light Up Blue. We worked with volunteers to form a decision making group. They were central to the success of this project and lead on decisions and making things happen.

We make sure that we create a pace and environment that is accessible for those living with Parkinson's. The experience of everyone involved is as important for us as what we create and deliver together, if not more so.

### **What we did as a community in 2023**

In 2023, we encouraged the Parkinson's community to share their Parkinson's story by writing poems. We also asked the community and the public to raise awareness by lighting up blue. And our local groups and communities put on a huge variety of events to mark the day.

This is a celebration of the community's contributions with a selection of the poems submitted for World Parkinson's Day 2023 by poets from the UK and even a few from global friends.

The front cover photo was taken on World Parkinson's Day, at the Piccadilly Lights, London, 11 April 2023. The photo is courtesy of Gill Carter.

# BEING ME

*I have Parkinson's  
but it doesn't have me.*

Sometimes I am slow, can freeze and not able to call  
My face can look funny and tremor so bad, I could fall  
Most of all it's not catching, don't judge me by what you see  
Just look very closely, yes that's it  
I REALLY AM STILL ME.

**Christine, Greater Manchester**

I have Parkinson's, but it doesn't have me  
My arm has a tremor, my steps are shuffled  
My voice is quiet and sometimes muffled  
My face might be blank, but my eyes still twinkle  
I have Parkinson's and I'm still ME.

**Helen, Morayshire**

There's a person behind the label  
Parkinson's does not define me  
Don't judge me by my symptoms  
This is not how I'd choose to be.

**Clare, Staffordshire**

Who invited you? You're not welcome here  
I was doing just fine. I had nothing to fear  
But you crashed into my life when I was doing well  
And turned it on its head and made it hell

**John, Essex**

It shook me up when told the news,  
Met freezing point, stepped out of line;  
Life's pace a drag, trained journeyman,  
Deck shuffle, cards, gambolling lad.

**Stephen, Wrexham**

I want to be me for as long as I can,  
I'll have to come up with a new game plan  
What's caused this you ask  
Parkinson's I say.  
I do wish someone would take it away.

**Rita, Powys**

I do not want to be a burden  
I do not want to take up time  
I thought that I controlled my Parkinson's  
It seems control is his not mine.

**Mark, Fife**

There once was a young man from Kemble  
Who had an incurable tremble  
He'd shiver and shake  
Every moment awake  
That unfortunate young man from Kemble.

**Terence, East Dunbartonshire**

When you look at me what do you see?  
A stumbling figure with a face so still  
With shaking hands as if rolling a pill  
Yet all you see is against my will  
Because deep inside I am still me.

**Steven, Newcastle upon Tyne**

It is 3.30 in the morning and I cannot sleep.  
I lie awake all alone, from the birds not yet a cheep.  
Parky Pete creeps up, settles comfortably in my head,  
Turns off my brain connections and he takes control instead  
Heeeeelp!

**Lilian, Lancashire**

Can't make any decisions today, I fear,  
Parkinson's thought processes unfocussed, unclear.  
Feeling fragile but people can't see  
What's happening inside is not how I was or I want to be.

**Linda, Teesside**

A day trip to the country  
An unwelcome need to pee  
Grappling with button-fly trousers (early PD ignorance)  
Help!  
Where's the nearest tree?

**Peter, Kent**

For a year I've been suff'ring with Parky  
And the symptoms are making me narky.  
What with bradykinesia,  
Dystonia, amnesia...  
It's no wonder my language is sarky.

**Gaby, Hampshire**

I'd like to say it's a doddle,  
Living with PD.  
But that would be a lie,  
I think that's plain to see.

**Theresa, Kent**



From smelly, malodorous, whiffy stinks  
I smugly stay immune, but...  
My yearning is for fragrance, spice,  
Newly mown and freshly ground...  
My life once more in full bloom.

**Helen, Warwickshire**

I cannot cloak my Parkinson's –  
Determined terms that dominate  
Unless some symptoms medicate –  
The calmer quiver, further walk  
A better sleep, pills and a glass.

**Stephen, Wrexham**

For my retirement I've changed a plan or two  
It's because there are some things I can't do  
I was diagnosed with PD  
It's early stages for me  
Now I can't abseil or bungee jump too.

**Martin, Cornwall**

A bit of a tremor  
Some stiffness too  
Fatigue and dystonia  
How do you do?  
How does Parkinson's affect you?

**Clare, Staffordshire**

My mobile phone sits by my side  
Reliable news and information guide  
I face the telly and pick it up  
First of all laying down my cup...  
Press it on to start TV, lift it up to drink my tea.

**Lilian, Lancashire**

On the bowls green, my arm wouldn't swing  
Unable to understand what was going on  
As I encountered difficulty with everything  
Until my sixth sense told me how I felt in a throng  
That's when I knew there was something wrong.

**Heather, Buckinghamshire**

My voice is weak, starting to fade  
I talk to my wife's hearing aid  
With Bluetooth mic on my lapel  
We keep in touch, it works quite well  
But one thing I forgot to do  
Is turn it off when in the loo.

**Terence, East Dunbartonshire**

Which one do you see, Parkinson's or me?  
A friend, a stranger or passerby  
With my slurred speech, awkward gait and expressionless face  
Don't just stare, don't pity or judge  
It's me.

**Dee, West Midlands**

3am pen and notebook at hand.  
Trying to get the words to flow in five simple lines.  
It's Parkinson's awareness and I can't think of what to write.  
4am "Oh great, coffee's gone cold".  
5am I give up – I'm going back to bed now.

**Cath, West Lothian**

Evening; sat at the table, conversation is loud;  
Hear myself getting quieter, fading, lost in the crowd;  
Neck stiffens, can't turn my head, will I be mis-read?  
I hear you, do you hear me?  
Can you see me or the person I used to be?

**Linda, Teesside**

It's hard to explain to those not "in the know"  
How you used to be fast, but now you're so slow,  
How you struggle to dress, sleep, shower or bake,  
Or hand write a note, or stay still and not shake.  
These are some of the things that Parkinson's will take.

**Jane, Middlesex**

Weebles wobble but don't fall down so they say.  
Unfortunately for me I am not a weeble.  
So I regularly go wobbly and fall over.

**Margaret, Selkirkshire**

The new day starts and I'm feeling Low,  
Washed and dressed – I'm sort of ready?  
But hark – the alarm sounds and meds do beckon,

Lord, I do hope this day is Good, as it takes so long to have my brekkie,  
'Get it on time' and I'll Cope - I reckon?  
Freezing now so my day may go Slow!

But – Wow it's time for lunch,  
And dare I say - blast!  
Some days just go so Fast!

**Chris, Essex**

# BEING YOU

*You don't feel the same, it brings confusion and despair  
You're still my Mum, I will always love you and always care.*

His Parkinson's is a kerfuffle  
His body shakes, his feet do shuffle  
I am so glad I am his Wife  
To give him hope and make him chuckle.

**Deborah, Surrey**

That lady looks a lot like my Mum, yet she's very different.  
My Mum smiles all the time, laughs, sparkles.  
She's independent, active, walks everywhere .  
She loves to bake, is a keen gardener, meets me in town to go shopping.  
No, that lady can't be MY Mum.

**Maxine, South Yorkshire**

Once a retirement dream, now a living struggle  
Once outgoing and chatty, now quiet and withdrawn  
Once an early riser to walk in early morning sun  
Now struggling to rise before noon  
Love and care is stronger than ever, with a breaking heart for the one I love,

**Carole, South Glamorgan**



Dad I hated taking your car keys away  
I hated being embarrassed when you drove so slow  
I hated hearing when you would fall in the bus stop  
and people thought you were drunk  
I hated coming home and you were in the kitchen  
smoking with a house smelling of gas  
You didn't turn the gas hob off again  
I hated being protected by everyone, not knowing what was wrong with you  
I never realised, I was a young child, I'm sorry.

**Jacqui, Dorset**

20+ years of Parkinson's, then Dementia.  
Impaired Speech and One Look,  
Constipation, needs more Time,  
A change not just for Dad,  
Change for you, and it's mine.

**Helen, Essex**

My Pal had Parkinson's disease,  
But was given a few guarantees!  
Not to be judged,  
But immensely loved  
And enough care to help feel at ease!

**Rachel, Warwickshire**

He stands beside me every day, doing his best to find the way  
His body will ache whilst his mind is strong, searching for ways to carry on.  
In sickness and health our love was born, 56 years later we are riding the storm.  
His body will ache, I can see his pain, but for him I would do it all over again.

**Barbara, Dorset**

You were my cheeky chap with bright blue eyes and a wide broad grin.  
Robbed of the obvious: dexterity, independence, body and mind.  
Now dyskinetic and disconnected.  
Though cruelly, it's your stolen smile I miss the most.

**Becky, Staffordshire**

The call came early evening, to tell us what they knew  
They said that Anne has Parkinson's, we thought it might be true  
What next? Is all you want to ask, we don't know where to turn  
We have to find out what this means, together we will learn  
To help each other through this test, that is what we will do.

**John, Dorset**

You don't understand what's going on  
The days you moved so swiftly, long gone  
You don't feel the same, it brings confusion and despair  
You're still my mum, I'll love you always and always care.

**Nazia, Greater Manchester**

My Mum has special powers.  
See how she taps her foot to tunes that no one else can hear.  
Suddenly she freezes.  
Has the music stopped?  
The wiring must have gone wrong.

**Maxine, South Yorkshire**

I never told you.

It hurts me to watch you struggle to get out of bed every day  
You battle to accomplish the small things in life in your own special way  
I miss the days we travelled, wined and dined in London, Paris, Italy & Spain...  
I am so grateful you can still walk a little, talk, eat ... and hold me to ease my pain  
Your love, energy, and smile are forever the sunshine through the thunder and rain  
On Parkinson's day and every day...I love you, Baba

**Rima, Lebanon**

The diagnosis.

Spin, dance, sing and meditate,  
No better...no worse!

**Ruth, Cambridgeshire**

Parkinson, Parkinson, Parkinson  
A disease attributed to witchcraft in my country  
A disease which caused my patient to shrines  
Parkinson, Parkinson, Parkinson  
A disease which caused depression to my patient.

**Mugole, Uganda**

You're shaking. We can just about hear you speak  
We help you get dressed, use the toilet and eat  
There's Therapy for your speech, a Rolater to help you walk  
We wish we could do more,  
'specially for Mum, for you to talk.

**Helen, Essex**

Parkinson's. I don't have it but I know someone who has.  
Keep taking the tablets love, God bless science  
Parkinson's is so tiring ... for both of us  
Oh and by the way, who were you talking to at 4 am whilst jogging in bed?  
Keep taking the tablets love. We'll fight this to our last breath.

**David, Antrim**

A father diagnosed, and what determination we saw  
Behind his glasses, where  
he brought light and humour to those in care.  
A mother who nursed, and the burdens she bore  
Behind her twinkling eyes.

**Ben, Kent**

I wish there was a cure,  
I don't want to see him suffer anymore,  
I've learnt a lot from my hero ... my Dad,  
To remain positive and not let it make you sad.

**Zeena, London**

# BEING POSITIVE

*I'm positive that Positivity works,  
that Positivity brings its own perks.*

Keeping physically active is essential  
Whilst not neglecting matters mental  
Exercising the body and mind  
Helps my general health I find.

**Geoff, Cumbria**

He's been with me, Parkinson's, some ten years or so  
Tablets help, but they won't make the bugger go  
Exercise and laughter, the best advice I've known  
Try a laugh a day, Parkinson's UK  
We're here, you're not alone.

**Ray, Kent**

Imagine the effort it takes to get out of bed  
When my brain won't tell my feet what to do  
So as things take longer  
Silk sheets are the answer  
I just slide right through to the loo.

**Philip, Cumbria**



I serve in the RAF, I work in the NHS  
My friends call me Parky, I'd expect nothing less  
It's the humour I love, that will get me through  
The difficult times shaking when aiming at the loo  
Stay strong, we will beat it  
much love from #TheParkyParamedic

**Craig, Lincolnshire**

There once was a man who had Parky  
His words turned into malarkey.  
But he didn't concede  
To this dreadful disease  
Now he's back to talking quite sparkly.

**Ulli, Cornwall**

A diagnosis, just the start,  
Two long words, they broke my heart.  
But after that, I'll find my way  
To try to treasure, every day.

**Frank, Co Down**

I'll shake for no reason, I shuffle when I walk,  
Now I'm walking better and I found a way to talk,  
I'm walking backwards,  
I'm talking backwards too,  
I say I've got S'nosnikrap, 'cos Parkinson's won't do.

**Ray, Maidstone**

Step over here Mr Parkinson, let me tell you what I really think  
Of a condition with so many symptoms, it's enough to drive me to drink.  
But at least that would explain my imbalance and the way that I weave when I walk  
And perhaps folk wouldn't be so intolerant when I dribble every time that I talk  
I'm not drunk!

**Liz, Bedfordshire**

I'm positive that Positivity works  
That Positivity brings its own perks  
Manage your life and do what you can  
Enjoy daily activities whether woman or man.

**Geoff, Cumbria**

It's taken so much of my life away  
It weighs on me every minute  
I hate it with too much energy  
But I am loved and cherished and I live.

**Kathryn, Cumbria**

The neurologist was clear and bold,  
"You've got Parkinson's disease,  
And I wish not to displease"  
It could be worse, I have been told,  
You could have a migraine or a cold.

**Angus, Surrey**

Don't mind my slowness of movement ... I will get there...  
Being careful enough not to fall...or losing sight of my path.  
I am not shaking because I am frightened...but because I am aware...  
Of the contributions I still need to make.  
This journey of life happens...and we must continue...  
Whatever life hands us!

**Karin, Essex**

There was a young man from Belize  
Lost his grip whilst on the trapeze  
He went into shock  
When told by his Doc  
I'm sorry sir, it's Parkinson's disease.

**Martin, Cornwall**

Parkinson's changed my life  
Working with shaky hands  
Walking with dragged legs  
But determined to be positive  
Life is beautiful, enjoy it!!!

**Tincy, Cambridgeshire**

My right side, sense of smell and balance are not great.  
Handwriting has changed, get pain in legs, muscle knots and cramp.  
I do now wonder what is my fate.  
However I still smile and laugh out loud.  
The way I cope makes me feel proud.

**Joanne, Essex**

There once was boy called Parkinson  
Whose teacher told him "stop larkin' son."  
If you want to be great  
Then you must concentrate.  
He didn't. Now forgotten: this Parkinson.

**Terence, East Dunbartonshire**

Last year's feeling of despair  
The doom and gloom was barmy  
Has been replaced by hope and fun  
I've joined Amanda's Army.

A Sgt.Major in disguise  
She gets us all a moving  
To fight and change the way we feel  
With music that's a grooving.

So thank you all in Hinckley's group  
For friendship and for fun  
Once again life's feeling good  
and 'Parkie's' on the run.

**Mel, Leicestershire**

A chap went off to hospital to see  
A consultant who specialised in PD  
While he was at rest  
He did a maths test  
All he could do was 7 from 100 is 93.

**Martin, Cornwall**

Diagnosed with Parkinson's 5 years ago  
My brain is sharp my body, slow  
Paul, art and yoga keep me talking.  
A bright blue mop aids my walking  
Horse riding is my Get up and Go.

**Chris, Lancashire**

Confusion, confusion all around  
Why me? Became my refrain: I needed to gather my wits again...  
to the internet I came  
Some things were scary, other things were clear:  
“Exercise, eat well and move much more”  
I needed to take action that much was clear,  
Now exercise, eat well and move much more are what I try and strive for.

**Sarah, South Yorkshire**

As I get older I do believe  
I am becoming more naïve  
For as far as I know  
Parkinson's was a TV chat show.

**Trevor, Warwickshire**

My gaitway comes, akimbo legs,  
My turnover, silk balance sheets.  
With walking-stick, kick-boxing tricks –  
As prescribed pills, the dope all mine.

**Stephen, Wrexham**



When I was diagnosed  
At the age of 63  
With this thing they call Parkinson's  
I could barely get dressed  
I should have been depressed  
I'm laughing with Parkinson's.

So I started fighting  
And began writing  
I joined the choir  
Boy was I dire  
I'm laughing with Parkinson's.  
One day I heard a rumour  
You can beat it using humour  
Laughter they say is a way  
Of getting through the day  
I'm laughing with Parkinson's.

My hands are a shaking  
When I'm out picture taking  
My brains not in gear  
But never fear  
I'm laughing with Parkinson's.

What will tomorrow bring  
Will it be an ok sort of thing  
It could be good, it could be bad  
But above all let's be glad And not be sad  
I'm laughing with Parkinson's.

**Kevin, Leicestershire**

I'm wibbly, wobbly and weak  
Some days I can hardly speak  
Don't get me talking about walking  
And my writing is a scrawl  
But no time to bawl  
You suck PD but it's on with the living for me!

**Yvonne, Scotland**

Nobody said life would be a cabaret  
There are many challenges along the way  
But when I feel sad  
And my Parkinson's bad  
My favourite songs make it a better day.

**Deborah, Durham**

I try to do the things I did  
And wish that I was stronger  
I know I'll get there in the end  
It just takes a little bit longer.

**Terence, East Dunbartonshire**

# BEING OFF

*I want to feel the way to control  
What I cannot control.*

At this time of despair, as we join silently in prayer,  
As we look at the world, like a small child frightened and curled.  
Mankind is treated so cruel, for Parkinson's is no fool.  
It takes your smile, then your mind and you're scared all the time.  
With the shakes and shuffles and dragging of feet.  
Is that really me, is it lack of sleep, the medication or defeat?  
I'm tired all the time, is this body really mine?  
I have no energy today, will I have to go away, when my body starts to sway?  
Can I have a glass of wine, or can I still fine dine,  
when I can't cut my food or sing a rhyme?

**Ashley, South Yorkshire**

I wake in the morning feeling stiff and robotic.  
Sure, I can take a pill or a probiotic.  
That will help for a while with a few side effects.  
Exercising with gusto to improve my steps.  
Then climb into bed to find restful sleep  
With a list of PD symptoms which goes way too deep.

**Rose, Glasgow**

A lively man, now quiet  
Waiting, waiting, trying to stay patient  
Retirement dreams shattered  
A breaking heart, watching a loved one struggle  
A disease which steals happiness.

**Carole, South Glamorgan**

To have Parkinson's young is a worry  
Working's hard if your brain becomes blurry  
Then there's shaking and freezing  
Motor functions decreasing  
Why not pack up and retire from work early?

**Mark, Fife**

A bolt from the sky, a feeling of winning the jackpot,  
But, only the other end of spectrum.  
A feeling of millionaire, to nothing to share.

**Carlito, UK**

Parkinson's comes without invitation, totally screwing up your life.  
It takes away your happy cells and fills your head with strife.  
It can freeze your face, reduce your pace,  
Can make you stop suddenly with no warning.  
It robs you of any decent sleep until you see another day dawning!

**Kerry, GB**

April 11 – my birthday  
Parkinson's day  
I want to feel the way to control  
What I cannot control  
Please give me what I need.

**Bruce, UK**

I live but I can't do the things I used to.  
My days are not what I want.  
I try to be what I used to be but my efforts have no response.  
My torture is silent and no one can know.  
How much I wish this suffering would go.

**Margaret, Fermanagh**

Come inside, the house is dark;  
No sights, no sounds have left their mark.  
I do not understand at all;  
Enter, experience my brick wall.  
Open up the place for me; with your bright light I will see so much suffering  
So much pain, dealt with positively again.

**Lilian, Lancashire**

The lows are lower, the highs not as high,  
I manage my best and just about get by.  
Who asked you to visit, you pain in the a\*\*e?  
You are the devil, Parkinson's your curse.

**John, Essex**

Dad was everyone's Handyman, Black Cab Driver,  
Special Constable and Ambulance Paramedic  
This was my Dad.  
Then the diagnosis "you know you've got it" he said.  
Parkinson's then Dementia.  
Our world's changed forever.

**Helen, Essex**

Why has it happened to me?  
My life has been taken over by PD  
I shake  
I ache  
I'm only 53.

**Stuart, Dorset**

My hands shake with a tremor  
my knife and forks on the floor  
I've knocked over a chair  
As I fell in the door  
The only thing I can order  
Is risotto and coke  
Eating out for me is a really bad joke  
I hallucinate and see people  
Throughout the day and the night  
Sometimes I hear them whisper into my ear  
It frightens me so much  
I'm paralysed with fear.

**Veronica, Suffolk**

# BEING DEFIANT

*You control the way I eat and sleep  
But at least for now you can't control my soul.*

I have Parkinson's  
But I don't have to be  
A "fighter" or a "warrior"  
I can just be me.

**Phil, West Midlands**

I'm in a different world now, just not the one I planned,  
Yes Parky closed many a door, but many more have been opened by my hand.  
My magic hand can draw and paint, and my shaking forgets to shake,  
How lovely, people say in awe, how do you do it so?  
Well ..... I have adapted until I've overcome ..... But oh, how I wish it would go.

**Shelagh, Kent**

Diagnosed with Parkinson's one day  
So that's why my arm shakes, okay  
With a stiff upper lip  
I said get a grip  
Parkinson's is going to pay.

**Martin, Cornwall**

Angry, how I hate Parkinson's with all my heart  
Annoyance that my body won't play its part  
Anguish at not knowing what life has in store  
Acknowledging my limitations, whether they be big or small  
Acceptance is the dream, though it's not as easy as it seems!

**Rebecca, Staffordshire**

I have an amazing super power  
Which Parkinson's gifted me  
The ability to prove everyone wrong  
With a sprinkling of creativity!  
Parkinson's does not define me.

**Clare, Staffordshire**

Parkinson's is the grumpy old man from No 23,  
And Eileen's cousin in a wheelchair, not me!  
Shaky and weary I slowly make my way,  
Over the moon and rainbow elude me today  
I didn't see this coming, not for me, not for you  
But things like this happen every day it is true!

**Pam, Cheshire**

Out of the blue, this death sentence  
In reports, columns, memoriams  
That Parkinson's implied or bold  
The passing cause, so long battled, brave  
How dare it claim, domain its name?

**Stephen, Wrexham**

Parkinson's robs you of so many things,  
You cannot play with grandchildren, clean and cook - that's what it brings.  
Some have a tremor, some have the shakes.  
All keep battling on and wear a smile for families' sake

**Janet, Leicestershire**



My mind is frizzed with it,  
I shake, I stutter, I sleep,  
I'm shattered, something's going to get you.  
Do what you can, while you can.  
ENJOYO!!

**Andrew, UK**

You control the way I eat  
You control the way I sleep  
But at least for now  
You can't control my soul  
At least for now you can't control my soul.

**Andy, Wirral**

There's something wrong, it's just not right  
My legs don't work as once they might  
Parkinson's? Who can say?  
Old age will get you anyway.

**Terence, East Dunbartonshire**

Shakin' Steven's how I'm known,  
Slowly sliding gradients,  
Sloping like a writing desk,  
Pretending antique by design,  
Visible – who said PD?

**Stephen, Wrexham**

I live a life of humour  
I live a life of lies  
I live a life as best I can  
When Parkinson's denies

**Clare, Staffordshire**

Parkinson's doesn't define me,  
And has to put up with me.  
I show it who's boss,  
When I think there is loss,  
Because it's a big part of me!

**Rachel, Warwickshire**

My feet may make me stumble  
My hands cause me to fumble  
My lips just seem to mumble  
But I am still here  
And I will NOT disappear!!!

**Linda, Leicestershire**

I am not Parkinson's, my name it is Jan  
I am not a disease, that is not who I am  
Parkinson's is however now in all that I do  
So love me or leave me, that part's up to you...  
For I am not Parkinson's, my name it is Jan.

**Jan, Suffolk**

Don't despair or get all twisted up inside.  
Get up, get out there, take control of your life.  
Don't look at your feet, you might fall in the street.  
Walk tall, walk straight, remember your gait.  
Think loud, speak loud, show Parkinson's you're in charge.

**Cath, West Lothian**

Mr PD came again today;  
He affected me in the normal way.  
He pulled me and pushed me and made my arms shake,  
But whatever he delivers, I can take.  
Ok, there are times when you think you are winning,  
But what's that I can hear? That's me singing!  
I am not him and he is not me, there's only one person I am and that's me.  
I won again today and damn I feel chuffed,  
As far as I am concerned Mr PD "get stuffed".

**Andy, Suffolk**

# BEING SUPPORTED

*How can the lack of dopamine take all this life away?  
Let's come together to find a cure for Parkinson's one day.*

Blue is the colour  
Parkinson's is our game  
We're altogether with educating being our game  
We're altogether and curing is our aim.

**Nicola, Somerset**

Blue is the colour.  
Parkinson's is our game.  
Were altogether and exercise being our aim.

Blue is the colour.  
Parkinson's is our game.  
Were altogether and curing is our aim.

Blue is the colour.  
Parkinson's is our game.  
We're altogether in educating being our aim.

**Nicola, Somerset**

Our sister Hilary was as sharp as a tack  
She loved puzzles and such, but it took all that  
But her family had support from Parkinson's UK  
We send you our love and thanks on this special day.

**Heather, Leicestershire**

In a self-service restaurant  
You have to queue for what you want  
And when you reach the end to pay  
Get someone to help you with your tray  
But if you like meatballs in IKEA  
They use tray trollies – a good idea.

**Terence, East Dunbartonshire**

I wrote about coming to terms with Parkinson's disease  
About how the pain of loved ones is difficult to deal with  
But together we will get through it  
With this poem I want to thank my family members who are with me in this process  
Thank you, my dear ones

**Sari, Finland**

Parkinson's research is a noble quest  
To find a cure and give hope to the rest  
It means a better life for those in need  
And a brighter future for all indeed  
So let's support this cause and take the lead

**Michael, Gloucestershire**

Parkinson's is really a puzzle, with so many different forms.  
It provides lots of issues to study and research,  
But it needs volunteers to give time and material  
In order to establish the facts.  
So step up fellow sufferers and give researchers a chance.

**Roy, East Sussex**

When you talk I listen, my expression says otherwise  
I am trapped inside this body, please be patient  
Hold my hand when we go out, I may be slow  
But just remember I am still me inside  
I'm just broken, please don't let go.

**Angela, West Sussex**

There once was a Parky in Lanson  
His wife thought he looked rather handsome.  
And when the disease  
Forced his muscles to freeze  
She tickled him madly...and then some!

**Ulli, Cornwall**

Love is the anchor that secures the allyship  
As the Parkinson's storm batters and lets rip  
Symptoms rain down from the PD cloud  
Medication's side effect blows chill through crew's love  
Love is the anchor that keeps us connected.

**Jon, Cornwall**

Remember how Mam loved to dance, now can't even walk?  
Remember how we'd hear her sing, now struggle to hear her talk?  
How can the lack of dopamine take all this life away?  
Let's come together to find a cure for Parkinson's one day.

**Maxine, South Yorkshire**

Scene on Zoom, ballet screen  
Arabesque and plié stance  
Solo in my living room  
Dance for Parkinson's my stake;  
Gold mine claim where not alone.

**Stephen, Wrexham**

Parks empties my life  
Research, curing, prevention  
Donate – gives back Hope.

**Sandi, South Yorkshire**

Parkinsons, our lives you have changed,  
Plans for the future need to be rearranged.  
A new way forward is what we are after,  
Found in PD friends bringing joy and laughter,  
With love and support we are no longer estranged.

**Tina, Leicestershire**

I've got Parkinson's, what's happening to me?  
Feelings of uselessness, days that are bad  
With help, care and love I stop feeling sad.  
Help people like me with calmness and speed  
Patience not pity is just what we need

**Rita, Powys**

I wondered as D3 is allowed  
That it would fight my shakes and ills,  
When all the genes awakened crowd  
A host of gedanken pills;  
Besides the dopa, with D3 treat.

**Peter, Denbighshire**

Out last night, dyskinesia started  
People staring as though I'd just farted  
Dancing a lone dance, frustrated, downhearted  
Read of a new drug when I got up today  
Optimistic, uplifted, chase those black clouds away.

**Richard, West Yorkshire**

Researchers ask questions ... follow procedures ... interpret results  
Participants answer questions ... do tasks and read results.  
People affected by Parkinson's help make questions ... readable  
Procedures ... manageable - results understandable  
By talking with researchers through PPI.

**Anne, Surrey**

When the days seem dark, research offers light  
When the future seems uncertain, research offers hope  
That one day, help will come  
When you feel alone  
Research offers support so that you know you are not alone.

**Christine, Cumbria**

I haven't written a poem, my writing is far too small.  
You wouldn't be able to read it or even have a clue,  
Of what I want to say to you. It's up and down all over the page,  
It disappeared behind the margin, then came back again but smaller than ever,  
Well that's five lines ... let's read them together.

**Pauline, Suffolk**

Parkinson's and me – where do I start?  
Maybe a few words, straight from the heart.  
I've just been diagnosed, so much to take in,  
I want to live my best life because life is for living,  
I'll take one day at a time  
And with the help and support of Parkinson's UK,  
I know I'll be just fine.

**Vivienne, Kent**



This is surely wrong, how can it be?  
I'm far too young for this to be happening to me!  
So what now? Who to tell?  
This is the start of my living hell.  
I continue my life just like nothing is new  
But three years later I realised what I had to do.

Talk, tell, shout and cry, why make things more difficult, living this lie.

The support I received meant the world to me.  
I truly felt like I had set myself free

Be brave, be strong, talk and accept the help  
This is so unfair but it's the card you've been dealt.

The pain can be unbearable, life can be rough  
But keep the faith my friend, you've got this!  
You're tough!

**Christa, Cambridgeshire**

Beginnings-sadness, tearful, worry, acceptance is painful and learning  
Middle-disbelief, support group, family, drugs trial and error  
End- acceptance, support, spread awareness and lots of love.

**Tran, Surrey**

My arms move but it's not me  
My hands shake but it's not me  
My legs are unsteady but it's not me  
I try and open this jar, but it's not me  
I drive my car, but it's not me  
I try and concentrate on this task, but it's not me  
My brain screams silently for my body to respond, but it just doesn't hear me  
I used to have confidence in all that I do,  
But now it's someone else in charge of my body.  
IT'S JUST NOT ME  
Thank the Gods for Parkinson's UK, they see it's not me.  
My relatives and volunteers can see me and they try to find the pieces  
THAT STILL ARE ME.

**Paul, Essex**

On this, World Parkinson's Day  
We really feel we have to say  
This disease took our grandmother when we were small  
We hoped none of us would get it at all.  
  
But unfortunately it chose Hilary, our eldest sister  
She left us in November and how much we have missed her  
So many charities to donate to out there today  
But if you have a moment think of @WorldParkinsonsDay.

**Heather, Leicestershire**

My friends living so bright  
In a brand new world  
A whole new regime to create  
Their lights still shine  
Albeit with such difficulty – we simply support and see!

**Tracy, Swansea**

# BEING THANKFUL

*My dreams, my dreams  
make everything alright.*

I was diagnosed at 72  
And asked myself, what should I do ...  
When I wake up and my knees are weak  
And I can't seem to stand on my own two feet.  
When people think that I am drunk.  
I know they are talking a load of junk.  
It used to make me feel real cross.  
But these days now ... I don't give a toss  
I know I can't sing, dance or jive  
But I am so thankful for being alive.

**June, Dorset**

Very often Parkinson's makes me dream,  
Of faraway places with sea and sand and skies of blue,  
Oh my God, what shall I do?  
When with the shake of my hand  
I'm back in bed in wonderland!

**Trevor, Warwickshire**

My head shakes, my movement is slow  
My outlook is positive wherever I go.

**Erika, Tyne and Wear**

Everything is shoogly  
You, me, us  
The dreams we had for our future.  
Precarious, untimely, shoogly  
But our love stands firm.

**Kirsty, Renfrewshire**

My dreams, my dreams bring me flowers in the night  
My dreams bring me scents of such delight  
My dreams, my dreams make everything alright  
My dreams, my dreams make everything .... Alright.

**Ken, Derbyshire**

Despair  
Frustration  
Perseverance  
Support  
Hope.

**Billy, Scotland**

When they tell me I'm drunk  
I say "never felt fitter"  
Thanks to the effects  
Of Parkinson's Best  
(not to be) Bitter.

**Terence, East Dunbartonshire**

The waiter saw me scoot the slope,  
His sigh I saw, a strategy  
He knew before, with ready smile,  
Filed index nail, direction point,  
A vacant stall by toilet door.

**Stephen, Wrexham**

The man I looked up to while I grew up,  
Suddenly struggling, shuffling and shaking,  
People watching, judging not knowing,  
And finally all his symptoms eased,  
As hard as it was to lose him at last he was at peace.

**Sarah, Dyfed**

I scream into the vastness of space  
My pain begins to ease

I touch stardust with my hand  
Blowing it into the air

Love shines from behind your eyes  
I take your hand and  
we rise into the air  
Conquering the cosmos

We observe the world,  
its beauty dazzling

I gaze at your tears, streaming down from your beautiful eyes

Come here, I'm here for you

We'll fly together forevermore  
We'll reach the edge of the world

Hair filled with stardust  
I laugh, I'm happy

Here. Now. Always.

**Sari, Finland**

I am fading away  
Like an image on an old polaroid photograph  
Alpha-synuclein slowly suffocating brain cells  
So I live in the moment, unexpectedly finding  
Fireflies in the dark.

**Lesley, Perthshire**

Bits of your brain fall off,  
Memories never to be recalled.  
But new thoughts appear –  
Not influenced by what has gone before –  
These are the wonderful wild ideas of you.

**Jackie, Ceredigion**

I can still breathe  
I can still bend  
I can still laugh  
I can still love  
I can still fly

**Shiona, Dumfries and Galloway**

I was diagnosed,  
I shut out the world and kept my curtains closed,  
Three years on now though I've found  
To deal with this curse, without making it any worse.  
Is to live my life one day at a time,  
To be thankful to see the sun rise and shine,  
Cherish my wonderful family for being the best by far,  
And wish for a cure upon that star.

**Hazel, Essex**

# WITH SPECIAL THANKS

Parkinson's UK would like to thank the many volunteers and poets for sharing their poems and experiences with us.

## Resources

### Parkinson's UK

To access support or learn more about Parkinson's and Parkinson's UK, World Parkinson's Day or to make a donation, you can:

- Visit our website at [www.parkinsons.org.uk](http://www.parkinsons.org.uk)
- Email [hello@parkinsons.org.uk](mailto:hello@parkinsons.org.uk)
- Contact our helpline on 0808 800 0303.

### Poets with Parkinson's – Poets Wall

Poets with Parkinson's is a poetry collective of individuals, all poets, and all living with Parkinson's. We have an online home where we share our poetry, work together to improve our art, and provide a showcase for the work of our members.

We also hold poetry events, usually on Zoom, where we connect with our members in the UK, Ireland, Germany, USA, Italy and around the world. Please take some time to read our poetry and, if you are a poet, and touched by Parkinson's then you might consider joining our supportive, welcoming, and friendly community.

For more information see the website at [www.poetswall.com](http://www.poetswall.com) or email [team@poetswithparkinsons.com](mailto:team@poetswithparkinsons.com).

### Feedback and suggestions

If you would like to comment on this book, enquire about poetry and Parkinson's or make any suggestions about future activities, please contact us by emailing [involvement@parkinsons.org.uk](mailto:involvement@parkinsons.org.uk).