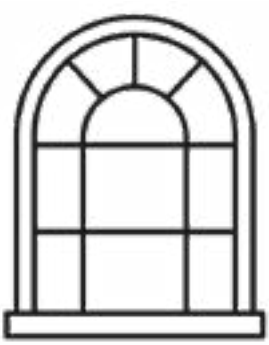
poeMS



an anthology by people living with multiple sclerosis

Alex
Claudia
Eleanor
Ellen
Memphis
Nina
Philippa
Saskia
Tilly

Edited by Georgi Gill

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EDINBURGH DIAMOND

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Foreword

Multiple sclerosis (MS) is a difficult disease to live with. It is often diagnosed in young people, meaning that people can live with the condition for more than 40 years. Multiple sclerosis can be unpredictable, variable, frustrating and frightening, is different for everyone and can result in both obvious and hidden disabilities. This is difficult for the person with MS, their families and friends but also for their clinical teams. People with multiple sclerosis can find medical appointments awkward, upsetting or simply too short to be able to share these thoughts and difficulties with their clinicians directly, but this anthology shows that they can sometimes find a voice through poems.

There is power in these voices. The reader is exposed to fact and feeling, hope and despair, humour and tears. As a neurologist especially interested in multiple sclerosis, I have looked after people with multiple sclerosis for many years, have heard their different stories, celebrated their successes, commiserated with the difficulties, laughed with them and cried with them. However, these poems took me by surprise and led me somewhere else, and I suspect they will do the same to you. These poems remind us of our patients' humanity, enhance our understanding of these poets as people and of their problems, and are a prompt to act accordingly. For me, this anthology provides a ray of hope, providing a means to maintain emotional wellbeing

and mental health of both sides of the clinician-patient relationship.

In our struggling National Health Service, where time is the most expensive commodity, these reminders are pertinent. We now recognise that 'social prescribing' of many sorts is important, timely and effective in helping people live well with their diseases. We recognise the importance of looking after mental health in both people with chronic conditions and in clinicians. Poetry is an underexplored tool in this context, and so please continue reading this anthology to explore the effect that reading these poems has on you. Who knows? You may even wish to write some of your own.

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Introduction

Language is a blunt tool. We are human and therefore we try to communicate our sensory experiences, our deepest emotions and our most complex thoughts to one another, yet so often words prove inadequate. I was diagnosed with multiple sclerosis in 2003 and found it particularly difficult to convey my lived experience to other people. My symptoms were invisible to others; I had – and still have – periods of brain fog, disrupted vision and overwhelming fatigue, but to everybody else I appear fine. For years it was difficult to express what I was experiencing. Eventually I turned to poetry, initially in an attempt to explore these peculiar sensations and emotions for myself, and later to communicate them to others.

For me, poetry worked. It worked better than prose. Culturally, we expect prose to tell sensible narratives rooted in plot; stories and memoirs are structured in beginnings, middles and endings. Yet, peering at the page through blurry eyes and a foggy brain, I did not know whether I was at the beginning of my own MS narrative or whether this had been quietly festering for years. And neither I nor my doctors could say with any certainty how things would play out. Poetry, however, gave me different possibilities for self-expression. Poems are often experimental and resonant with multiple meanings. We may relate to a poem on a profound level sensually, emotionally and instinctually before we begin

to understand what it might mean.[1] I found it liberating to write into and through my feelings and MS experiences simply as an exploration in words. To see what emerged. As time went on I began to find a language to describe what I felt and how MS had shifted my relationship with the world around me.

Ultimately these efforts led me to The University of Edinburgh and my doctoral research at the Centre for Creative-Relational Inquiry. Nine people, living in the UK, took part in the Poetry and Multiple Sclerosis study. These participants had primary progressive, relapse remitting or secondary progressive MS. They came from different backgrounds and had varying levels of previous experience with poetry. In 2020 and 2021, we met in small groups for online workshops in which we read poems together and discussed them. Then we wrote our own poems, aiming to explore and capture some of our individual MS experiences: *poeMS: an anthology* is the result of that study and showcases the participants' poems. Unlike most poetry anthologies, this is not a body of work by professional poets. I invite you to read on, not asking, *Are they good poems?* – although some of them undoubtedly are – but, *What are these poems good for?*[2] I suggest that they are more than good in their authentic representation of lives lived with MS.

For ease, the anthology is organised into five themes: 'What is MS?'; 'Being MS Bodies'; 'Being a Patient'; 'Being with Other People'; and 'Being in Time'. That said, there is crossover and some of the poems explore more than one theme. We are embodied and we exist through our bodies. The medical, public and family encounters described in this

1 Padel, R. (2007), The Poem and the Journey London: Random House.
2 Leggo, C. (2012), 'Astonishing Silence: Knowing in Poetry', in Knowles, J.G. and Cole, A. L. (Eds.), *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues* Thousand Oaks, CA: Sage.

book can only happen in and through bodies. For example, 'Out With it Then!' is about physical and cognitive problems with speech but also addresses the social awkwardness of speech problems.

The poems in 'What is MS?' use metaphor to represent MS in ways that others might be able to recognise. 'Being MS Bodies' explores MS symptoms and gives a sense of how it feels to live in a body with MS. 'Being with Doctors' is a short but mighty section that addresses the clinical experiences of MS patients. It is remarkably candid, expressing thoughts and emotions that generally are unspoken during routine medical appointments. 'Being with Other People' starts by looking at encounters with strangers, before describing social occasions with friends and then interactions with family. It considers where MS creates friction in interactions with others, and, in some cases, shows participants' strategies for easing or managing difficult encounters. Finally, 'Being in Time' explores how MS has impacted participants' identities: how did they see themselves before they became ill? Where and who are they now? How might they change or adapt further in the future? What is it to live in uncertainty?

The anthology is part of the Poems on my Mind project which is funded by the Institute of Advanced Studies in the Humanities at the University of Edinburgh, with additional support from the Binks Hub. Poems on my Mind seeks to engage the wider public with the poems and findings of the Poetry and Multiple Sclerosis study. *poeMS* will be shared with neurologists, specialist nurses and other professionals working with people with MS in order that they can gain a fuller sense of life with the condition.

Families and friends of people with MS may find much that they recognize in this anthology, and may gain some new understandings of what their loved ones are

experiencing. Certainly participants in the study found that sharing their poems with others in their lives prompted them to have illuminating conversations about the condition, in some cases clearing up misunderstandings and bringing greater clarity.

Above all, I believe the anthology can be a valuable resource for people who are themselves living with MS. As I have experienced, life with MS can be isolating. In talking, reading and writing with Alex, Claudia, Ellen, Eleanor, Memphis, Nina, Philippa, Saskia and Tilly,[3] I found others who had experienced relatable losses and anxieties. We were able to discuss these with frankness, and sometimes strong emotion or great humour. I was no longer alone with MS and will always be immensely grateful to these participants for the camaraderie which we built together. In *poeMS*, I hope that other people with MS will find a sense of shared community, perhaps even solidarity.

I believe *poeMS* is for everybody. As I write, disability, the NHS, care and welfare costs are daily features of the news cycle, hotly debated in parliament, on TV and over family dinner tables. It can be easy for chronic illness and disability to become abstract concepts, reduced to statistics and soundbites, which overshadow the actual experiences and issues that disabled and chronically ill people face. The poems in this anthology invite the reader into the lives, anxieties and hopes of real individuals with MS, giving a fuller and entirely human perspective.

I am continuing to research the potential benefits of poetry written by people living with MS. You can help this research by giving feedback on your experience of reading *poeMS: an anthology*. To get involved, please answer the short

3 All participant names used in this anthology and in the original research are pseudonyms chosen by the participants. A few poems are presented anonymously at the request of participants.

survey at:

https://app.onlinesurveys.jisc.ac.uk/s/edinburgh/poems-feedback

Georgi Gill, June 2025

What is MS?

This Pebble

Tilly

You hand me a pebble
Set it in my hand wordlessly
Fold my fingers round it
Like a fond auntie giving me a sweetie
Or a fiver

I hate you and your pebble
Don't want it
Can't give it back
If I dropped it on the carpet of your immaculately
hoovered home
You'd notice

So I sit and stare
Unclench my fist
Unfurl my fingers
Consider this pebble
Wonder how it's supposed to fit
How I'm supposed to fit in
a basketful of pebbles,
a truck load of chuckies
an avalanche of boulders
make sense
speak a language I can hear

a single, solitary pebble
smooth, soft almost
cool at first,
now warm, sweaty

heavy in my palm
isn't going to cut it

I'm filled with a sudden longing
To touch it with my tongue
taste the sharp salt-tang
Of its sea-home
To stand ankle deep in salt-water
Toes sinking into sand as the waves suck me under

The window:

Alex

I stare out, the street framed by elegant dimensions.
Familiar
Unchanging
Dull
I am bored of being by myself, the monotony of being inside
Endless.

I could go outside
It is technically possible
But thinking back to when I last tried it,
The difficulty, the fall, the embarrassment.
It is easier to stay here, to look out and observe
The old familiar life, stuck behind the glass.
Preserved in memory.

More than listening to music

Eleanor

Listening to the music is much more than that
Loud and soft, beautiful and ugly,
A mysterious and difficult thing.
Sitting in the dark I am lost.
With the players, with the audience but alone and
immersed in the music.
Distanced from the others
Confused and trapped by what I don't understand.

Banana skin

Memphis

The Banana skin of MS made me feel like my life was slip sliding away, give up walking, toil with talking, retire from work and feel like you shirk, from freedom to captivity in one step, try to keep positive, you can't lose your pep.

Frustration abounds, well that's how I feel, I think in my own mind. I am keeping it real. MS my captor ever present in life, if a cure could be found it would ease this strife, slipping and sliding in my daily routine, the banana skin of MS is dangerous even when not seen.

An icon of danger, the innocent stranger in its own way, a double-edged sword that is innocent yet deadly as time goes by, keeps me focused on surviving, we all have to try, some days I feel lucky to be alive, others it's a struggle just to survive.

Little Prick

Claudia

you ask me what MS is like.
well to be honest it's
like a bramble thorn in the garden strangling and
infringing on everything and everyone
It wraps around your legs dragging on you
ripping and tearing.
You want to move forward but frustrating it trips you
You drag up the roots pleased to have it only
for it to resurface in a new arrangement.
It's relentless in its advance
It encircles and stumbles
It is unsettling and familiar
you want to say it's ok
but it invades and smothers
all that's normal and steady
thriving in derelict wind-blown wasteland
like some sad western
and yet it produces warm and comforting blackberry
crumble
go and figure out the irony.

Hoops

Ellen

I don't understand you I never will.

My very own Olympic Hoops
Yes just for you MS
I devote these interchangeable circles
I try to keep you at an arm's length
Although I feel you, I see you.
You are so very sneaky.
Over night you can grow,
If I'm lucky you may shrink
Just in a blink.
Without warning you can put a bleak cloak around me
And I know you won't leave.
You will stay a while.

Yes you, cognition hoop, so very grey
A monster lifting its webbed feet,
Through my mind of sludge
Turning my thoughts to dust
You, I resent, more than all the other hoops
I cannot have a stick to aid
The slowness that comes on through the day
You are the biggest thief,
The one I cannot explain,
You sent my aspirations rushing down a drain
You smother my love and turn it grey.

A Plate in the Washing Machine

Philippa

It's not where one would usually find a plate
It was a shock – unexpected
Knocking around in the washing machine
The wrong machine – how did that happen?
Scooped up by accident with the bedclothes
Battered bruised – looking old now and used.

A pretty little side plate, fine china – Granny's side
Little scrolls around the edges
Little chips now too.

It's a miracle it didn't break
It must have come quite close
I can relate
To the plate
Still useful but not to be given to guests
Who wants cake from a chipped old plate?

It's ruined the whole set now!

Waves

Nina

They rolled in gently, at first, lapping against her feet,
Cold, calm, shimmering and bubbling on top of the abyss
Crashing higher and becoming intense, the waves rock her from side to side.
The ice cold water rises up,
And falls, leaving her tingling and burning
Like fire and ice against her legs
Before the tide slowly glides back into the sea
This is MS, and this is me.

Being MS Bodies

When I can't walk as far as I did before

Eleanor

When I can't walk as far
or as well as I did before,
it feels like dusk
when the light is failing
and the colours have gone.
It appears silently. Unstoppable.
I crave a place to rest,
to recover,
But I can't stop the change.
I have to remind myself
to appreciate what it is about to go

Machine

Alex

Old machinery whirring
The guarantee expired or lost.
Cogs stick and rub, movements jerk and stop.
Toes curl into tight balls unable to separate.
The engine coughs and splutters.
Limbs dead weight, blood collects in stagnant pools.
Sensations lost.

Electric

Nina

A shiver that seems unending,
It crawls and creeps across the skin.
Like the bass at a concert when it rattles through the floor and up into the feet.
Electricity sparks nerves into life, a reminder it's still there.
I feel everything and nothing at all.

Leg Tremors

Memphis

Is this really happening to me?
Control although easy to imagine has become impossible to me,
As the lightness or loss of weight sensation, an out of body experience transcends my imagination.

I detest that feeling of loss of control, although strangely the rhythmical discourse that my legs are experiencing does make me smile.
Waves lapping onto a sandy beach,
Sheets blowing in the Autumn wind, creating a rhythm to write music to.

A cascade of energy from my waist to my toes, that somehow overtakes me and leaves me in its wake,
A comfortable feeling, even enjoyable to a fashion,
Which feels like it isn't really happening to me.

Pain does not enter nor leave my body,
but is there, transfixed in the back of my mind almost as an afterthought,
can this really be happening to me?

My Legs

Claudia

encased in my head the feelings rise from the deep
black exploding firework colours
emanating from cringing frustration

my brain is firing orders to the sergeant major who barks
instructions to deaf recruits
trapped by bad wiring

my legs are a massive disappointment
it is profoundly sad
my mind races ahead soaring on warm thermal currents
quietly gliding above the patchwork squares

l am dragged back with violence to earth
struggling with the energy sapping heaviness

I'm scared of my legs
fighting a memorable battle to stop me slipping
into the quicksand l clear my head and

breathe.

Did I Boil the Kettle?

Saskia

It's Monday today.
It's probably not but hey who cares.
It's a new day which of course starts with a pot of tea.
I fill the kettle.
What now? Not sure.
Maybe I should wash the few bits in the sink.
All done. Did I boil the kettle?
It feels hot but I will boil it again.
While I am waiting I will clean the hob.
It doesn't need much cleaning as I do it most days –
After washing the few bits in the sink
It's nice and shiny now. Hang on,
Did I boil the kettle?
It feels hot but I will boil it again.
I rinse the teapot and add the tea.
I am getting there now. I think.
Did I boil the kettle? I'm sure I did but I will boil it again.
I need milk. The fridge is behind me.
I gaze inside the fridge wondering why I have opened it.
I guess I need to prepare lunch and dinner for today.
I need to check my meal planner on the computer for that.
It's not far, in fact it is on my desk next to the fridge.
As the screen opens I spot I have 3 emails.
I note on my daily planner to read the electric meter.
Planner says today is actually Wednesday –
Today I am scheduled to do the washing.
As I turn back to the kitchen counter, I spot the teapot.
You can't miss it, its bright yellow. Now did I boil the

kettle?
I must have but I will boil it again.

Being a Patient

Left side weakness in a left-handed woman with multiple sclerosis: A case study

Tilly

I don't tell my neurologist
    I am not your subject
    My life is not your case to study
I dutifully present my symptoms, in carefully curated soundbites
Digestible by medical professional and family member alike
Trim off the excess heartbreak of losing my ability to
    write shopping lists
    sign my own name
    draw doodles
    sketch faces
    knit ugly christmas jumpers
    spend just one day without pain
The physio is hopeful I'll walk again
I am appropriately upbeat about my chances
Leave out mentioning the aching void left by
    Schiehallion
    Bennachie
    Balmedie beach
    Lochnagar
    Arthur's seat
Stolen from my landscape,
filled instead with wheelchairs,
walking frames
two-minute daily standing practice

This is me

Ellen

I am not you
I stand in my shoes
be it wobbly
be it stubborn
I am free
I am not chained by my disease
be off with your drudge
I can decide, not you
They offer me poison
It may dampen the devil
but it does not discriminate
and treat me in parts
I am fond of my liver
I think it's fond of me
I'll treat it with kindness
I'm careful with the gym these days
Hey, another loss with this disease
So why is it OK for you to say,
I'm only interested in your disease
Well, I'm interested in me
all the parts of me from my webbed toes
to my tender head
I will decide how I will nurture me
I am not you
I am not a statistic
I am a partner a mother a lover
I am passionate about this world
I love the beauty of the world

I see it through my eyes
not the glazed drugged eyes
ones that I get prescribed
I am whole
Please see me this way.

The List

Alex

Filling up the page,
Preparing your approach,
Tactics
Tactics

Get through the initial small talk,
The pleasantries.
Hit them with the questions that matter.

Too soon you're waiting at the bus stop,
Watching as it comes round the corner.
You stare out the window,
Listless
Deflated

The door did not unlock
Nothing was found.

How Strange

Eleanor

It's probably just mild MS, he said.
Friendly, smooth and smiling.

Months later, in the underground room,
where two others were having eye tests
He sat opposite me and said
It was definitely MS.
The other patients heard.
The line of medical students
behind him heard.
Through the open door,
The people in the corridor waiting room heard.

How strange, I thought,
that something so human was not.

Being with Other People

Nina

Her mask glitters gold in the sunshine,
She wears it all of the time.
But not always the same one.
She tips her mask to acknowledge
Its presence, but does not remove it.
Her mask, whichever one she chooses, is her protector, her strength.
Just like her shoes, she has one for each occasion.
Sometimes, just sometimes, the mask slips.
But that's okay too.

The Invisible

Claudia

I'm the invisible person
I sit here in my chair
on a different eye line to others

confined in wheels
dependent on others' good will
I turn to talk and am facing the opposite way

left outside, foxed by mountainous steps
I face a minefield of clothes and dummies

my racetrack around confectionery and body wash
bored

all well-meaning and earnest
I am a question mark
people don't know how to answer

so I disarm with a smile and openness
honesty and lack of embarrassment
I have a reason for being here

Rude Man

Ellen

Please don't stare
I am not your property
I'm like you
I belong to nobody

I might be in a chair, but how very dare
I rise!!
I can walk! Take a look,
Integrate me with your eyes
You will not find out
What is my curse?
It is not for you to know.
I do not wish to share
I'd like to say "piss off"
And you'd think, how does she dare.

Perceptions

Memphis

What do you see when you look at me? Some will say you, others you've never changed. Are they telling me what I want to hear? Being nice or being honest, a mixture of both?

I feel a bit different, others can see, a shell of the person I used to be. My body's the same but things have changed, many not visual or even that bad, but I do miss the things that I always had.

You think I'm the same and things haven't changed, but deep inside I occasionally look for someone to blame.

People's perceptions mean the world to me, but when you look at me tell me what do you see?

Out With It Then!

Philippa

My body won't let my tongue be free
It's twisted in knots behind enamel guards
Poking a way out to be heard
Making up words by dicing and splicing
Like when it 'steezes'
And I'm jolted.
Midflow.
Discom ……..em……no it's gone!

My mouth feels stuffed full with letters
Such as you might find on an old-fashioned typewriter
All the little arms desperate to win the race to the paper
Jammed and crammed together – so tightly none can move
Tipitty tap, pittery splat, writing crap Kerching!
I've said it now.

Conversation is exhausting ……
Part of me is dealing with two squibbling toddlers
Brian and Thomas – usually so in tune
While I'm also fending off a third child
Freya who is clingy and needy
Whining in my 'hear'
Clutching at my 'loot '
Why can't I just have a simple 'chalk' for once?

Attention! Attention!!! Yes – bloody remembers that word!

Like a sleep deprived parent I cave
I lose my thread
        And the needle
                And the thumble thingy.

Such a lovely time!

Anon.

I wear my role as party guest
I put it on as I put on my dress
Over my head.
I steel myself – warm, friendly smile
I've got lots of make up on so I wait for the first,
"But you're looking so well!"
Yup, £70 worth of Touche Eclat will do that!
If I wash my face right now you'd call an ambulance.
But I'm too polite to say that
I say, "Thank you"

I am pigeon-holed – most kindly done –
With the elderly – seated in the chair near the fire
Assisted – waited on – fussed over lovingly
Everyone takes turns at keeping me company
I'm always polite – I smile
I am brought a plate from the buffet
"A little bit of everything?" *questioning head tilt*
I'm too polite to leave anything on my plate
So often I eat food I do not like but
I say, "Thank you"

In my head The Grandma turns into the Toddler!
I WANT to roam the room
I WANT to help with the dishes
Gossip in the kitchen and pour my own wine
I DO NOT want to leave early – before I get tired!!
Foot stamp – pout!!!

"I'll fetch the car to the door"
Have you got your bag? Stick? Scarf?
Politely I say, "Thank you"
And, "Goodnight"

My Pain Not Yours

Saskia

It's not like a headache or a sprain, tension or cramp
It's the constant feeling of lightning bolts rushing through my veins
It renders my arms and legs almost worthless

Nothing helps
No massage nor acupuncture procures relief
Instead I ingest chemicals to control it
But still it controls me

I may look or appear 'normal' to you
But to be unable to take the weight of my newborn granddaughter in my arms
For long is heartbreaking

You sympathise and you compare your backache
Or your sore shoulder to my pain
I scream at you inside my head

But it is perception and who am I to belittle your experience
I watch as you lift and cradle my granddaughter
I don't cry
I don't complain
I sit and feel the extra pain within my heart
And I know
It is my pain, not yours
But mine is the cruellest of all

I Say Nothing

Anon.

She's 80 and spritely
She's 80 and quick minded

She looks at me and sighs impatiently.
"You must know where you are going by now," she says.
I don't. I need help with navigating these days, as she knows.
I say nothing.

"What's taking you so long?" sounding irritated.
I can't do things as fast as I used to, as she knows.
So I say nothing.

"Are you stupid?" she asks.
I want to cry now because I'm not
But to others I may seem to be.
I say nothing.

She's my Mum and she's 80.
I know she loves me unconditionally
So I say nothing.

Ostrich

Anon.

Dear Ostrich
It does not help me to pretend that all is well
Help you it may, shield you from the pain
That I seem to be not me

Look closer, I am me
See through your pain to see mine
It is a lonely place when the ones who say they love, refuse to see your pain

I am not my illness, but it's part of me
I am not the person down the road with MS
I am not the neighbour's nephew
We share the shared diagnosis
We are each unique
As are you

Hear me, hear me, hear me
Do not change the subject when I tell you I may drown.
In sorrow, in loss, in pain and loneliness
By denying my illness you deny me
Accept and set yourself free.

It is not about you
It really is about me
Set me free

Being in Time

Journeys

Alex

My eyes flit between the different displays
Up and down the lists,
Understanding the names but then instantly forgetting their significance.

Waiting for realisation to blossom and pop.
Nothing comes.

I must have taken a decision at some point
But that memory is lost.
I stare out at the passing landscape, unsure of what I'm seeing.

The journey carries on
Hanging by a thread,
Twisting and turning in the breeze.

Dream

Philippa

I'm running now on a grassy path
Through knee high bracken
By the side of a burn
Criss crossing it – jumping from rock to stone
Sure footed as a goat.

I dream the remembered feeling of invincibility
The joyful energy of the little girl I once was
Pedalling my bike furiously
Jumping off it before I've even stopped
Running up the garden path to the house….

And then I wake.

Wistfully, tantalisingly the brief spell of my dream lingers.

Until the heart crushing truth floods back
Catching in my throat
Only truly whole in my dreams now
Cruel but wonderful

Disappointment

Ellen

A distant memory
a feeling of lightness
Weights lifted
Such brightness
a vivid blue sky
Am I flying?
Faces looking skywards…...
quizzical
I felt this too

Running bouncing leaping
Faster and faster
Higher and higher
The tallness of green trees
swaying
There was no fear of falling
No vertigo from height
Just confusion
How could this be?
I looked down
It was me
Running
On and on
Bright white trainers
the shiniest coiled springs inserted
The faces will never catch me
I will stay here
Here I am free
And light

A cloud came over
Heavy and Grey
Confusion……
I stumbled out of bed.

Tilly

Weak tired
Lockdown mired
Count the cost
Left hand lost
Paints dried out
I'm all cried out
Neighbours caring
Me despairing
Nothing doing
Just angry stewing
No more knitting
Just vacant sitting

100 days
100 days
Right hand works
Right hand plays
Makes a mark
Has a lark
Draws a face
A cat, a hand
Beavers, bears,
Dragons, hares
Hurdler, sprinter
Owls, fish
Old photographs
Elephant, flowers
Cubes, cones
Spheres, domes
A fox, a mouse

Newts, bees
My best pal's dog
Fanciful fish
A pig, a goose
A mallard duck
Magpie, snails

Post on instagram
I've got it back
Like a gift
A sudden shift
I can draw again

Saskia

Her life was as perfect as a rosebud
Ready to blossom and reveal her intricate layers
Surely, in time, she became colourful and bold
And her life was magical.
Gradually her petals began to age and she knew change was coming
But she did not expect it to change as quickly
And so painfully.
Everything she knew her life to be was changing.
As the first petal floated to the ground, a part of her was lost too.
But she was still the amazing, magical bloom she started as.
As each petal dropped and the rose changed
So did she.
She could see her life changing before her,
Tearing away possibilities and replacing them with challenges
Unlike any she had anticipated.
But she is strong and while her rose will wilt over time
She is determined to maintain her magic.

Dreams

Saskia

The walk is enchanting
Sun glows through the branches of the trees
Fluorescent greens flutter above me
Squirrels run across the leafy ground
Warmth envelops me

As I walk
I come across a choice
Do I go right or left
Along this journey of mine

I am tempted left…

I am cold
There are no colours
Only shades of grey
My legs are weak
I am tired
But I can't go back

I wake…

My journey through this life
Has taken a direction I do not care for
I must look for my inner strength
I will look for colours
For the sound of birdsong
For the furry tails of squirrels
To be enveloped with love

This my journey now
And I will walk through it
I will achieve my own dreams

Dreams can come true

Memphis

Is ambition a dream?
Do your wants and needs have an arrival or expiry date?
Where am I going and where have I been, recalling
memories of things that I have seen
There was a time when all of that was a dream
When and how did it happen? Was the plan achieved?

Can I, will I, did I, are all questions that I've asked
in a dream to take me to the future and deliver me from
the past
Dreaming of retiring early, of being financially secure
dreams from my youth that were innocent and pure.

An aspirational dream, that was well on its way, until that
fateful day
I was diagnosed with MS,
what more can you say, but life for me is not over
I have plenty things still to do and wish you health, wealth
and happiness in everything that your dreams bring to you.

Claudia

soaring towering heights
are my dreams
not ones confined to my nights
but ones that speak of hopes and
desires
that speak of yearnings of
a life past and apprehension for a
future unknown

I dream of possibilities that flow with
light that roll relentlessly in and
out as predictable as breathing

dreams keep me hopeful they are not obscure
with hidden meanings
they live with me colouring my life constantly
bright shimmering flashes that light the way

Acknowledgements

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Poetry has been a central concern at IASH for over half a century, with the very first Fellows engaging in scholarly study of Chaucer, Milton and Barthold Brockes respectively. Poets who have held IASH Fellowships include Michael Longley, Marianne Boruch, Alicia Pirmohamed, Femi Fatoba, Sumathy Sivamohan, Femi Osofisan (pen name Okinba Launko), Jeanette Lynes, Emily McGiffin, Samantha Walton and Jaspreet Kaur. The Institute published its first poetry anthology, *Our Time Is A Garden: New Nature Writing by Women and Nonbinary Writers of Colour,* edited by Alycia Pirmohamed, in 2023.

Note from Georgi:

The participants of the Poetry and Multiple Sclerosis Study hold the copyright of their poems and as such are

free and encouraged to publish them elsewhere if they choose. Therefore it is possible that they have already published some of the poems included in this anthology in other publications. Usually such first publications would be credited in the acknowledgements, however, by doing so here I would potentially breach the confidentiality of my former research participants. Instead, given the unique circumstances of *poeMS*, I thank the editors of any such publications for their understanding.

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References:

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Leggo, C. (2012), 'Astonishing Silence: Knowing in Poetry', in Knowles, J.G. and Cole, A. L. (Eds.), *Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues* Thousand Oaks, CA: Sage.

What is it like to live with multiple sclerosis (MS)?

How do we negotiate living in ill bodies while maintaining friendships, family relationships and the responsibilities of daily life?

poeMS: an anthology by people living with multiple sclerosis explores these questions in poems written during the Poetry and Multiple Sclerosis project, run by Georgi Gill at the University of Edinburgh. These poems are variously humorous, hopeful, reflective and devastatingly honest, but always powerful and accessible.

Research into the potential benefits of poetry written by people living with MS is continuing, and your feedback can help us. To tell us about your experience of reading this book, please answer this short survey:

https://app.onlinesurveys.jisc.ac.uk/s/edinburgh/poems-feedback

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