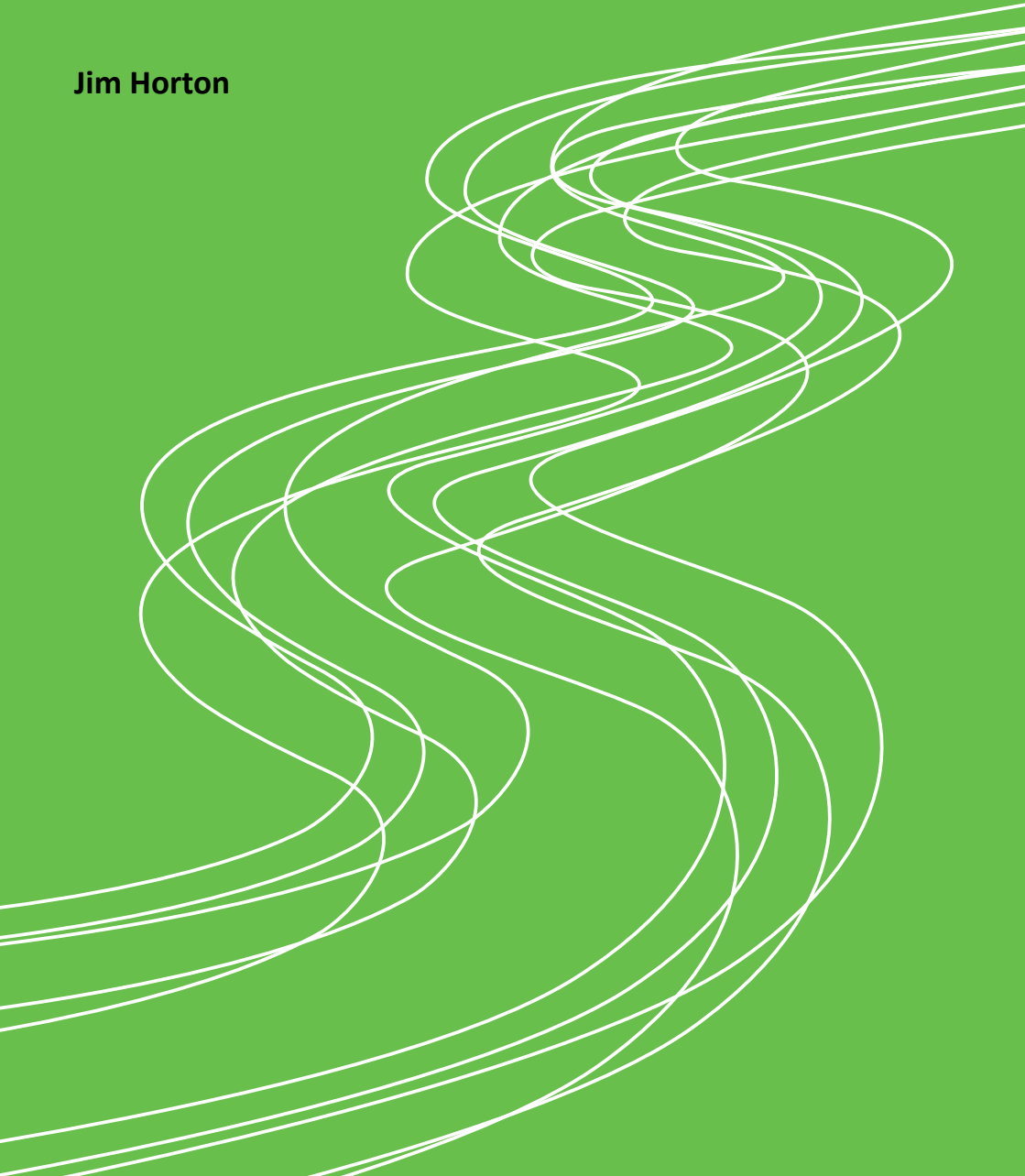


To Know Me

Our Shared Dementia Journey in Poetry

Jim Horton



*I dedicate this publication to Jane, and our daughters
Sarah, Jade, Fern and Clare. Our journey continues,
in time and in rhyme.*



To Know Me

See me, hear me,
To know me is a start.
Remember me,
I'm still me,
Know me in your heart.

Introduction

In August 2013 my partner Jane James received a preliminary diagnosis of young onset Alzheimer's, which was confirmed six months later. Like so many other people in our situation the news was devastating, yet slowly we picked ourselves up and determined we would live one day at a time, we would enjoy each precious moment together for as long as we could.

We helped to set up a young onset dementia support group in north London at the end of 2015, YoYo. We became involved in a dementia cycling project, went to fortnightly yoga sessions, engaged in music and poetry activities, participated in dance and theatre projects, and attended regular social events.

In 2016 I began writing poetry about Jane's new life, our new life. *To Know Me* brings together a selection of those poems. I do not

think my efforts warrant describing myself as a poet, but that was never the point.

I did not set out to document our dementia journey, but at each contour on the path we travelled verses demanded to be written charting the progression of Jane's illness, my attempts to understand it, and its emotional impact. Some of my poems attempt to give a voice to Jane, try to get inside her head and express her thoughts, her perceptions, which of course is impossible.

My poems inevitably reflect the sorrow we felt about our loss, but also highlight the happy moments that sustained us. Writing the poems was cathartic, helping me to adapt to the ever changing and challenging journey that is dementia.

On 29 June 2017, the day of our 30th anniversary, Jane went into residential care.

I would like to thank Barbara Stephens at Dementia Pathfinders for offering to publish my poems, and Clare Morris and Barbara Stephens for their innovative, imaginative and inspiring approach to supporting people with dementia and their carers.

My particular thanks to all the members of YoYo, Chrissie, Charles, Erica, Roger, Marion, Ian, Caroline, Mike, Rose, Keith, Michael, Yvonne, James, Maria, Geraldine, John, Valerie, Edward, Sue and John for sharing all our journeys, and helping to create memorable moments of joy in the midst of immense moments of sadness.

Jim Horton

Why Write Poems?

Why write poems,
More miss than hit?
To bear emotions which
Conflate and conflict.
To trace a journey
Otherwise left untold,
These are my poems,
More cathartic than bold.
Sadness and hope
Jostle in empty time,
Confused complications
In free style and rhyme.
Why write poems,
Day after each night?
To recount a full life lived
In the cruel dimming light.

In the Moment

Each and every day
A poignant reminder,
Remnants glimpsed
Of our shared past.
Rightly, they say
Live in the moment,
It's all we have,
But today cannot last.
Time has a way
Of revealing the essential,
And the inexorable,
Within your fragile cast.
Resolute we stay,
There's still happiness,
Safe in your new reality,
Don't progress too fast.

Its Journey to Diagnosis

It crept up on us,
Gradually.
Sneaked through an
Open window?
Or perhaps a door ajar?
There was no invite from us,
No warning from it,
No greeting!
It invaded,
Was invasive, intrusive!
At first we didn't know,
The not remembering
The conversations,
The tasks,
Deeds and events.
The whereabouts
Of familiar things
In familiar places.
We joked about it,
With no idea it was it!
The reminders,
The notes.
Notes to remind,
Notes about notes,
Reminders about reminders,
On this page,
That page,
And the next!
The lost credit card,
The lost debit card.
How count money?
How add numbers?

No more crochet,
Forgotten knitting,
But still no inkling,
Far too young,
But evidently not!
The struggle to gather thoughts,
Writing the article,
Speaking to conference,
The sympathetic audience.
It would be ignored,
Joked about,
No longer!
Just one more step,
It's proclamation,
It's confirmation,
The diagnosis!
The affirmation!

Four Years Ago

Four years ago
I wasn't there
In Clacton,
That Sunday,
To see people stare
In sympathetic
Bewilderment,
People did care.
Until that day
We'd been so
Blissfully unaware,
Four years ago!



Happy on a Bike

Happy on a bike,
Not going fast,
Riding free,
Independently.
It's not a bicycle,
Those days are gone,
It's a tricycle,
Each day to come.
Independent,
Riding freely,
Not too fast,
On a bike,
Happy as can be.

My Name, My Life

I know my name,
My first name,
My surname's in the past.
I have an age,
Time turns a page,
How old doesn't last.
I have a home,
In which I roam,
But it is where?
I have a mind,
It is still mine,
But to think is to stare.
I have a fear,
Soon forgotten dear,
Not even curious.
I have emotions,
Amid the commotions,
They make me anxious.
I suffer loss immense,
But I can still sense,
I can feel, hear and see.
I can laugh and cry,
My mind asks why,
Please don't disable me.
I have contentment,
It masks bewilderment,
I'm not defined by it.
I live my life,
It is my life,
Do you understand it?



Medley

A medley, recalling
Once played tunes,
Musical fragments,
Grieg's Morning Mood.
Treble, no bass,
Strangers in the night,
Your moment focused,
Don't lose sight.
Notes on a page,
No longer read,
Improvisation
Conducts instead.
One lost memory,
One lost song,
Hit the keys,
You can't do wrong.
A semibreve, a minim,

Hear the beat,
Crotchet, quaver,
Sounding unique.
Still playing piano,
Was once grade eight,
Watching the joy,
That's what's great.
Soon one day
It will all be gone,
Until that day
Just play our song.

I Knew Once

I did know once,
Only I've forgotten!
I knew how to do
This and that,
And what was
The other thing?
I knew how to get
To there and here,
And that other place!
Or somewhere!
I knew everything
I did know once,
Until I didn't!

Acrostic

Daily, stealthily,
Ephemeral toys with
Memory, each
Entreating the other,
Nuance by nuance,
Tangling wilfully
Into submission,
Achingly beckoning loss.

Thing!

Thing!
A very useful noun
To describe a multitude of...
Things!
As useful as... It!
A handy little pronoun,
Referring to a variety of...
Things!
As helpful as... Thing!
But what do you mean?
For you
Everything
Is a thing,
Or sometimes
It's an it.
We together
Try to discover
Which thing,
Or it,
You mean!

Once

I read a book once,
Its pages crumbled
In my hands!
I played a tune once,
Its notes shattered
At my feet!
I sang a song once,
Its words tumbled
From my mouth!
I saw a sight once,
Its image blinded
My weary eyes!
I heard a sound once,
Its noise echoed
Inside my head!
I cried a tear once,
Its drop trickled
Down my cheek!
I loved to love once,
Its sweet joy filled
A beckoning heart!
I dreamt a dream once,
Its image expired
Before I awoke!
I had dementia once,
Its journey progresses
As I live my life!

Grace The Autumn

Is this the Autumn
Of my life?
With Winter closer
Than at
Spring and Summer?

A stroll in Autumn
Once in life.
What wonderful hue,
More varied
Than season due.

The end of Autumn,
Joins seasons past.
As months splinter,
In a different age
Was it my winter?

Grace the Autumn
While it lasts.
Loss and love
Ferociously jostle
To proclaim enough!

Winter

Winter,
A season
Beckoning
All before it.
The joy and innocence
Of Spring,
The energy and hubris
Of Summer,
The hues and portents
Of Autumn.
All transient in
Life's journey
To winter's humble end.



Jane's Demo

Save our NHS!
We're on the demo yes!
We nearly didn't go,
Getting ready was slow.
We set off from home late,
Being there was great.
Singing chants that rhyme,
A tad emotional time.
At end feeling shattered,
But going really mattered.
I'll always remember the day,
Long after your memory fades.

In What Sense?

I looked,
I watched
The sight of the voice,
It was foreboding.
I listened,
I heard
The sound of the vision,
It was hopeful.
I conceived a perception,
In what sense?
I felt,
I caressed
The fragrance of flavour,
It was disorientating.
I smelt,
I tasted
The softness of touch,
It was reassuring.
I perceived a conception,
But what nonsense!

Another Piece

Seemingly
Suddenly
It happens,
Another
Piece of you
Breaks free.
Stolen,
Forever lost,
A void
Where a
Piece of you
Used to be.

I Miss

I miss freedom, independence,
The long soaks in the bath.
I miss our conversations,
The jokes and casual laugh.
I miss just dressing myself,
Preparing just one breakfast.
I miss popping out when I want,
Not arranging care cover first.
I miss the longer walks,
Not watching every step.
I miss a full night's sleep,
And teaching union reps.
I miss not feeling lonely,
And precious solitude for myself.
I miss the life I once lived,
But I miss you above all else!

Forget

Sometimes I forget
You forget,
And momentarily
We're in past moments,
A time when
I didn't have
To remember
To remember,
The moments
You now forget!

Outside the Fray

Grief is hard
When bits of her
Crumble each
Waiting day.
The loss breaks
A broken heart
More cruelly
That way.
Yet she remains
Contented,
Seemingly
Outside the fray.
Our journey
Continues
With a love
That will stay!

Jersey Beat

You tapped your feet
To the Jersey beat,
The songs, the music,
Electric and acoustic,
The smiles on your face,
Many joys to chase.
For an hour or so,
We didn't know,
Nay we ignored
A memory flawed,
As we tapped our feet
To the Jersey beat.

The Words You Said

I couldn't see the words you said,
Gentle breezes lifted it out of sight.
I couldn't hear the vision offered,
Soft whispers echoed without sound.
I couldn't feel the faltering flavours,
Sweet and bitter confounded each other.
I couldn't taste your soft touch,
Life had long forgotten love's caress.
I couldn't sense every fragrance,
But I understood the words you said.

Pensively Pondering

I wander, wondering
Where I'm now heading.
I pause, pensively
Pondering today so vast.
I roam, reminiscing,
Ruminating a lost past.
I stop, stupefied,
Seeing in sight no ending.

Shared Journey

We share its journey
Along narrowing path,
Weaving and drifting
With tears and a laugh.
You're not alone
In the diminishing light,
The broken hours,
Days lost in the night.
Hold tight my hand
Along unchosen route,
I'll not let you go
Watching time go mute.

Day Care

I left you there,
In daycare.
I waved goodbye,
You looked,
But didn't reply.
Was that delegated
To the woman
By your side?
For five hours
My mixed emotions,
Sad a life once
So full, so active,
Had come to this,
Daycare!
I returned
To collect you.
You were playing tunes
On an old piano,
Smiling,
Entertaining,
Leading the crowd.
I played too,
Grieg's Morning,
In the afternoon!
You'd enjoyed the day,
You wanted to stay,
Another milestone.
I took you home,
From daycare
To my care!

Time's Tapestry

A life wistfully woven
With moments
Captured from the start.
Our memories stitched
With thin thread
Tangled in tender hearts.
Our tapestry of time
Delicately crafted
For you and for me.
I embrace its fragile fabric,
Watching whispers
Wilfully drifting free.

Taken

When we're apart I miss
Your smile, your music,
And our dance.
I miss your contentment
Soothing my broken heart.
But when we're together
It's plain for all to see,
Everything I miss
Is already forever lost,
Taken from you and me!

Free Jazz!

I'm always behind,
Always chasing
The changing curve,
Struggling to swerve
The beckoning bumps,
Sureness strewn with uncertainty,
Emotions full and empty,
As you take me
On your jagged journey
From here to there,
Or to somewhere
Silently signposted.
At first I thought
I'd know each single step,
I'd researched it,
I'd read every bit,
But it transpires our
Pondered path
Is less rhythmic than
Free jazz!
Less melodic than our
Hummed harmonies
Hewed and hacked!
So now I must meander,
Ever behind the curve,
Chasing its changes.

I Loved Loving You

I loved loving you,
I loved caring for you,
We lived well with it,
But I must let you go,
Let others care for you now.
I still love you,
I still care about you,
I lived well with you,
My heart will never let go,
As others care for you now.
I will see you,
I will comfort you,
I'll hold your hand,
Until our time lets go,
Our love is forever, and now.

Remember What's Forgotten

You left me,
Though
You didn't mean too,
Before I left you,
Though
I didn't want to.
I'll never forget
To remember
What you've
Forgotten.

As Am I

This afternoon I strolled down
The bustling River Lea,
Where there's so much
Usually to hear and to see.
Travelling to Ferry Lane
From Stonebridge Lock,
A single mute swan grunts,
Beckoning her lost flock.
Walkers and the joggers
On towpath jostling for space,
Competing with hordes of cyclists,
Hellbent on winning a race.
Narrowboats chug along
The once calm river water,
As coots and many moorhens
Splash without fear or falter.
Gabbling Canada geese
Outnumber a Greylag pair,
While a solitary grey heron
Waits motionless for fare.
But as I journey down
The bustling River Lea,
Haunted by a walk once shared,
What do my sad eyes see?
A magpie is flying high above,
Across the grey, cloudy sky,
He's all alone without his love,
As am I!

Dropped Stitches

I've been away for so long,
I did nothing wrong.
I just lost my life
In your lost life.
Now I must let go
The threads,
The thinning threads,
Of our threadbare tapestry.
You once crocheted,
You once knitted,
Now all I see is dropped stitches,
Which no needle can repair!
So now I must weave,
Without knowing
What will be woven.
Will it go wrong?
I've been away for so long.

Still There

You're still in there,
Somewhere,
Bits of you,
Trying to get out.
You can't shout,
But you're still there,
You just don't know where.

My Poems

Will you like my poems?
I'll probably never know.
Words pour onto every page,
Not ebbing with the flow.
Will you read my poems?
My feelings are immense.
Affection floods every verse,
Where truth explains pretence.
Will you want my poems?
Time gently ticks away.
Emotions clog each stanza,
As piece by bit you stray.



You can view a larger print version of this booklet in the publications section of the Dementia Pathfinders website www.dementiopathfinders.org

All proceeds from the sale of this book will help to maintain the activities of the YOYO group, supporting people with young onset dementia and their families in north London.

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