

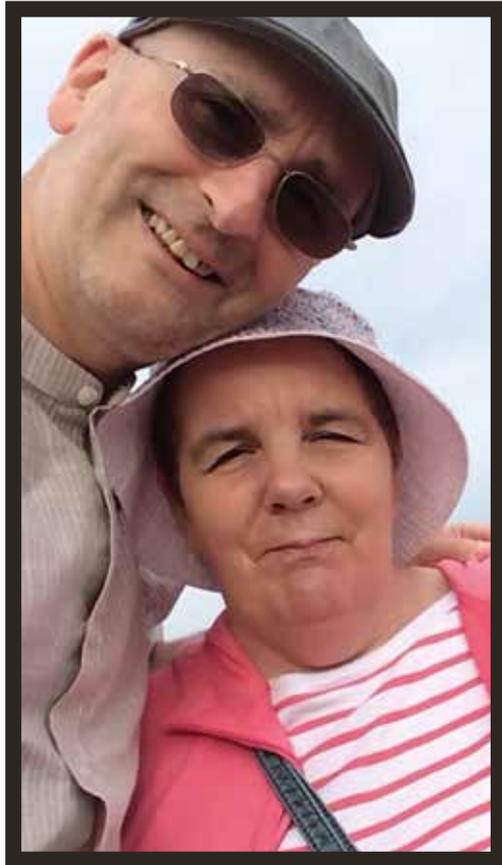
# To Know Me

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](http://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.

ISBN: 978-0-9934188-1-5

UK £5