

bold Creations

A Book of Creative Work

**by Dr James
McKillop, DUniv.
MBE**



Welcome

This booklet is the result of a collaborative project by James McKillop and Lorna Hill who worked together during the bold (Bringing Out Leaders in Dementia) Social Leadership Programme in 2022. This is a project between Edinburgh and Queen Margaret Universities and funded by the Life Changes Trust.

This booklet contains James' creative writing including Haiku and Pantoum poems; songs; photography and six-word stories. With special thanks to Elaine Shorthouse for her work in arranging the music to 'Jesus Saviour' and to Professor Heather Wilkinson, Dawn Irvine and Lorna Lyons from the bold team.

June 2023

About James



Dr James McKillop MBE was born in Wishaw, North Lanarkshire, in 1940. He lived in Wishaw until the age of 28 when work took him south to England where he spent time in King's Lynn, Norwich, Nottingham, London and Preston. James worked for the Ministry of Pensions and National Insurance doing clerical work, before he went to the Ministry of Health in England. He returned to Scotland in 1971 and went to Glasgow where he met his future wife Maureen at work. They married in 1973 and have two daughters, two sons and one granddaughter.

James was diagnosed with dementia in 1999, at the age of 59, and since then has been an inspiration to so many people with his activism work to raise awareness of dementia, and to eliminate, the stigma and myths, that abounded at that time. He said, you wouldn't believe the way, people with dementia were treated as, inter alia, having no insight. A diagnosis of dementia, meant an immediate loss of Human Rights, and being air brushed from society.

He has shared his own experiences of living with dementia and warmed many with his sense of humour. He says, "My sense of humour has kept me going. I have always found it's the ones that can laugh at themselves, who are the ones that last longer."

James was awarded an Honorary Doctorate from the University of Strathclyde, in 2013, for his voluntary teaching work for social work students. In 2011 he was awarded an MBE for his dementia work. In addition to his grassroots activism and wonderful sense of humour, James is a writer, musician, public speaker and photographer.

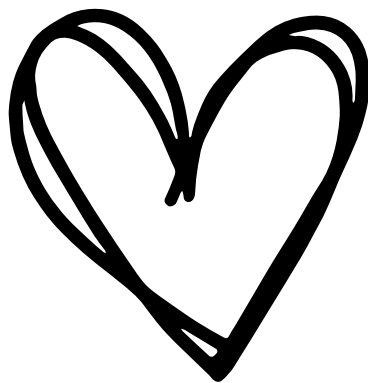
James adds, "The late Professor Tom Kitwood, who was a pioneer in the field of dementia care, always said that if you have met one person with dementia, then you have met one person with dementia. And I think that is very true. Everyone is different. We are just as diverse, as the passer-by in the street. It is vital one gets to know, the real us."

POEMS AND SIX-WORD STORIES

An Ode to My Wife

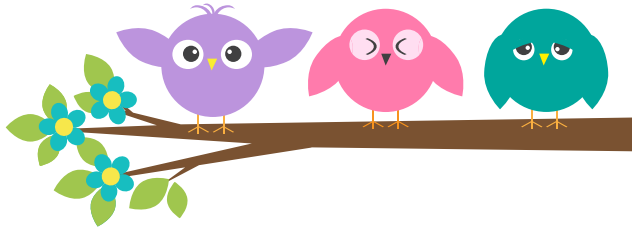
You don't owe me a thing
I did, what I, must do
I promised to love you forever
To be there when I'm needed
Love doesn't come at a cost
Love is being there for you
No matter the time of day
No matter the time of night
We had good days and bad
Some which ended up in tears
And arms reaching out to comfort
The one I held most dear
A marriage made up in Heaven
My soulmate my lovelight always there
You didn't get an easy ride
Illness followed us around for years
And in between times, some children
To share good times and tribulations
Our dreams were fulfilled, a family
To have, to love, and hold
We spent many days out walking
Taking them to the local park
Pointing out the ducks and swans
And flowers so colourful in display

The trees umbrellaing us in rain
The birds singing in tree tops
The sun shining down on us
The vapour trail of jet planes
Showing us where they have been
And where no doubt they're headed
The sky, egg blue, your colour
Loving eyes, smiling straight at me
The wind, softly sloughing your name
And even on a dreich day
The sunshine was never far away
Inside our innermost feelings and thoughts
But that's what marriage is about



The Mirror

I rose this morning, bladder bursting
I made it to the bathroom
I glanced in the oversink mirror
And recoiled backwards in sheer terror
A wizened old man looked out
Grey hair where dark had been
And wrinkles, like tramlines, etched deep
And gaps, where teeth once resided
And jowls, the size of coconuts
He too, looked shocked, seeing me
Wondering who on earth I was
I spoke, and he spoke simultaneously
He paused, when I paused too
His movements mimicked mine in synchronisation
What was he doing, mimicking me
There was something familiar about him
His eyes looked like my mother's
When she was in her prime
The face was like a version
Of how my father once looked
I stood discombobulated and quite confused
How had this ancient got indoors
And what was his true purpose
Why pick me for childish tricks
I held my ground and scowled
He did the same to me
He showed no signs of moving
And stood right where he was
I kept my stance like him
And reached an impasse like statues



It dawned on me, quite slowly
I began to realise the truth
I was no longer a youth
I was the stranger standing there
Begging understanding and clarity and truth
Where have all the years gone
Did I fulfil all my intentions
Was I someone who was selfish
Or someone one could really emulate
I heard the chorus of birds
Singing their hearts off at dawn
As I preened myself before school
My hair needed attention quite badly
A dab of Brylcream sorted that
My cheeks sprouting fluff could wait
Until I bought a Gillette razor
My teeth were pearly and white
As they were brushed with Colgate
To top it off, I smothered
My face with some Old Spice
My Sure was sure to keep
Me smelling, fresh as a daisy
So confidently I left for school
To turn all the girls' heads

Moving ahead, some fifty years on
I developed an illness called dementia
Yet I had done nothing wrong
It is no respecter of person
Or class, your gender, or wealth
You're still a human, deep down
But some treat it as contagious
Or fear they too will succumb
So they tend to ignore you
Passing by you on the street
If their luck holds, they'll swiftly
Cross to the other road side
Or quickly, reverse about and pretend
They never saw you at all
Good friends will never desert you
They're still there at the start
And through until your journey ends

Your employer may have his doubts
Which is fair enough, a consideration
Is there any way, you can
Keep working without endangering the lives
Of workmates and the general public
Your knowledge can pass to others
To keep them up to speed
I'll seek to do something new
Which benefits the whole of mankind
I'll write my story of how
A diagnosis of dementia was overcome
Staying home depressed me, too scared
To venture outside all by myself
My instinct, to preserve my pride
Deterred me from leaving the house
I feared people pointing at me
And keeping their distance from me
Some crossed the road, avoiding contact
They didn't know what to say
If only they paused and asked
How was I feeling this day
And could they help, in some way



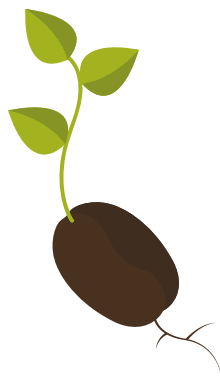
It's great, being asked, quite directly
Rather than the person beside you
I just want to be treated
The way it used to be
Treat me as normal, but note
My memory is not the same
I forget some things, each day
But feelings are still the same
I hurt when you ignore me
I cry when you rush by
With never a word of hello
It's great to see you today
Don't feel afraid to draw nigh
My illness isn't all that contagious
But sadly, is likely to impact
On your own life some day
With family and friends and colleagues
And those you socialise with daily
It strikes, at will, no concessions
To those whose lives were blameless
Who nursed and cured the sick
The mothers and fathers who raised
Their children to be good citizens

You'll find who your stalwarts are
When invites to events dry up
Or refuse the ones you offer
They weren't friends you want around
You're in a new ball park
And you'll miss them as much
As a raging pain, like toothache
It's best to have a lovelight
Who'll stand by you regardless of
The things you do or say
When something strange happens and unexpectedly
When delusional thoughts abound, be advised
The dementia is talking, not you
The spirit still dwells inside you
You are the person you were
But dementia continues unabated, so beware
Hope's the cruelest of all mistresses
The house wins in the end
So make good use of every
Minute that you have left remaining



But all isn't doom and gloom
Research is on the near horizon
To find a way to cure
But I am totally against this
I want a prevention for all
I wish future generations only hear
Of dementia, in ancient, dusty manuscripts
Wondering why it took so long
To banish dementia just like smallpox
Scientists spend their careers, frantically researching
Don't leave it up to others
You have a part to play
Your diet will mould your body
Start leading healthy lives from childhood
No smoking, exercise and alcohol consumption
Of course you must drink sensibly
It's knowing when you must stop
Alcohol makes a party go well
Its effects can be so unpredictable
You can have a good life
Moderation is best, for all
Your lifestyle will determine your future

As my life flashed before me
I began to see the truth
Those indentations, upon my aging visage
Were testaments where I did well
The good that I have done
Passes unnoticed, just as I wish
And anonymity is not the crux
It's the outcome that truly matters
I left my mark on society
Looking back, I shudder as I
Took ages getting off my mark
I hope I did someone good
I cannot live forever, so I
Planted seeds to show the way
To dispel myths and weird assumptions



We cannot do it our way
We spent too long in limbo
At the mercy of do-gooders
Reading our minds and our thoughts
Telling us how we felt inside
Well before we knew it ourselves
They proceeded without even asking us
What did we really, really want
A question or two could've established
I do like sugar in tea
With a hefty splash of milk
And when it comes to biscuits
I quite prefer plain which dip
Into tea and leave no streaks
On gnarled, arthritic fingers and lips
Being presumptive, I hope, some day
Talking to us isn't that different
From conversing, with grandad, and granny



More Six-Word Stories and Poems

Be BOLD

Be BOLD challenge the Status Quo
What's not been tried before now
Is all the more reason to
Get your thinking cap know how
You say we can't when we
Did it all those years ago
People are just realizing our worth
When they watch our ideas grow

The Wife

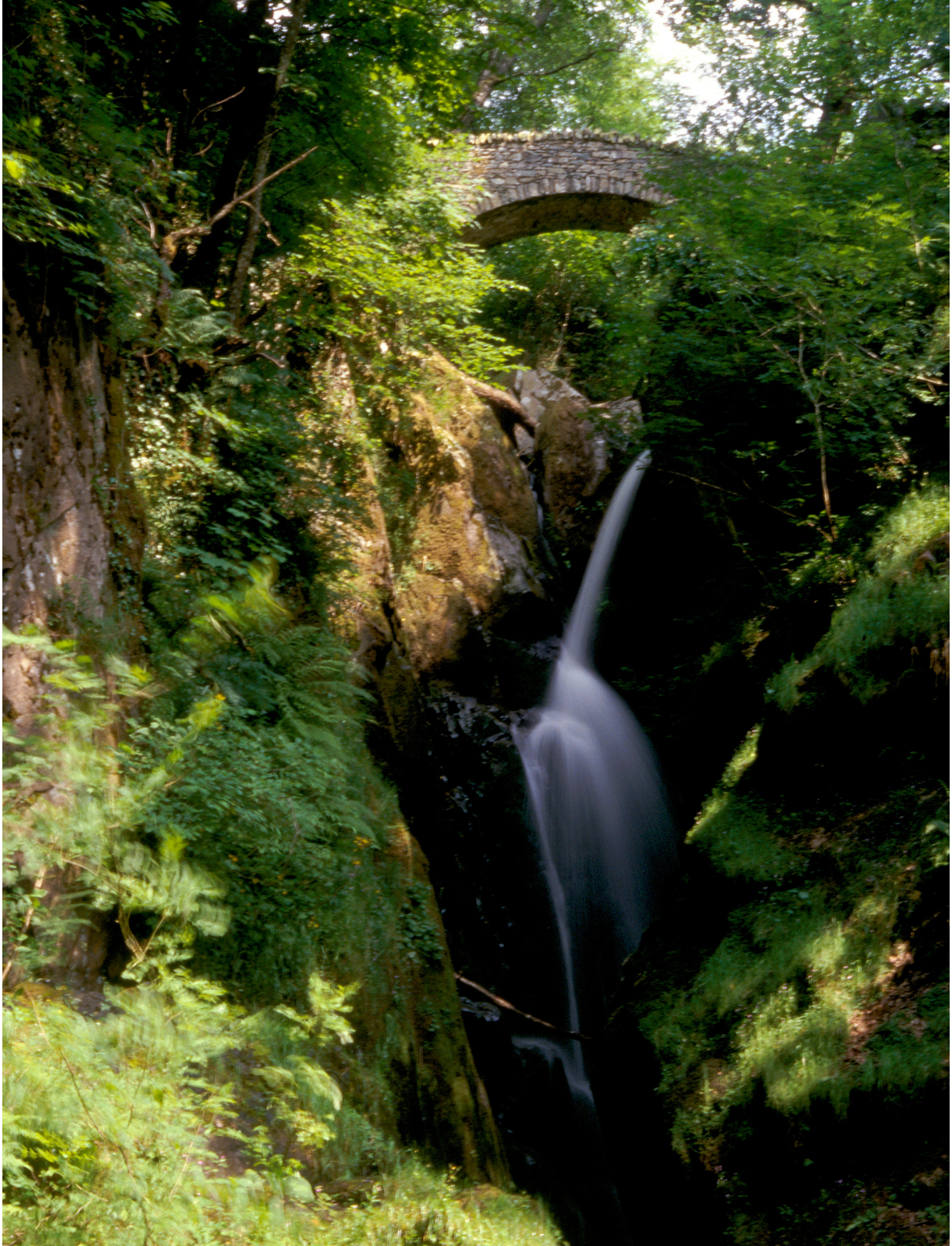
The wife is always the last
To hear of her husband's relapse
The husband, on the other hand
Doesn't mind, so long, as the
Dishes are, washed clean, and stacked

James's Photo Gallery





“My wife thought I was a bit economical with money, but she realized I was a skinflint penny pincher, when I presented her with her wedding bouquet as above.”



The scene is from a holiday in North England some years ago, perhaps in Ingleton. We had a chalet in Oasis, Penrith, and went there for the day.



HAIKU

Haiku is a short form of poetry which originated in Japan. It consists of three lines and doesn't have to rhyme. The first line has 5 syllables, the second line has 7 syllables and the third line has 5 syllables. We had great fun working on this and decided to call James's poem a Jamesku.

A note from James:

I only did this as it is part of the course. It would have been more realistic, if one did not have to keep to the 5, 7, 5 formula.

I found it both beneficial and frustrating. I used to write songs which rhymed. So this was a new venture for me. At times, I wanted to add another word, which would have improved the Haikus, but broke the pattern. At times, I had to put in an apostrophe, as I needed to lose a letter to balance the numbers.

A Jamesku

What am I to do
I cannot write a Haiku
So this is in lieu

Much to my sorrow
The last BOLD is tomorrow
What is to follow

Use my charm that thrills
Using my newly learned skills
All plain with no frills

One must take the lead
If you're wishing to succeed
Here's how to proceed

Start with your research
Some paper you have to fetch
Then you make a sketch

Now you have to find
Someone who has a like mind
Get a contract signed

So you have to seek
Someone who has great technique
Someone strong not weak

A person who shows
That people reap what one sows
And can take life's blows

Accepting command
And one who can understand
They can't be offhand

And to have no truck
With slyly passing the buck
When things go amuck

Being a leader
Means being very aware
That you have to care

For their wellbeing
And possessing a feeling
To ask anything

Covid 19

*(This was inspired by James's time on the bold programme
and written in 2022)*

I used to wander, as free as a bird
The world my oyster, with friends I could meet
Then I could travel, to faraway lands
Now I can't even, meet pals down the street

I recall the days, you could hug your friends
Now they are shrouded, hid by a face mask
They can be smiling, or hiding a tear
You can upset them, by daring to ask

You have your troubles, they have them as well
You could give comfort, by holding them close
And kissing their cheek, and smoothing their hair
Humming soothing words, and wiping their nose

Without windows and, the marvels of Zooms
We were unable, to see our loved ones
Who lived in care homes, lovingly cared for
By those who later, proved to be icons

But if you were ill, with a condition
You couldn't leave the house, for something to eat
Friends came with shopping, they left at your door
Banged your door knocker, then made a retreat

Even our grannies, a few streets away
Had no visitors, it wasn't allowed
Those with dementia, could not understand
Being left alone, abandoned and sloughed

Those living alone, out in the country,
Dwelling on islands, followed the same code
You kept your door closed, mimed through the window
Awaiting the day, when Covid plateaued

The angels of death, visited each day
Reaping their toll, of innocent folk
And up against them, angels of mercy
Risking their own lives, the minute they woke

Doctors and nurses, were at the coal face
Their heart in their mouths, with children at home
They couldn't go home, staying well away
Alas some succumbed, and died all alone

The public revealed, the debt that they felt
By standing outdoors, ev'ry Thursday night,
And clapping their hands, until they were red
Prayers were rising up, as high as a kite

But gratitude lasts, for only so long
Then it reverts to, the way it once was
The skies are silent, applause never heard
But front line workers, never had a pause

They are still risking, their lives ev'ry day
And fear bringing home, death to their dearest
But do the public, take note of the fact
That as they slumber, the virus won't rest

Nor can health workers, with plus twelve hour shifts
Fighting to save lives, while risking their own
Turning up each day, their hearts in their mouths
Making sure patients, did not die alone

How many lawyers, have saved someone's life
C.A.s at their desks, bankers at their till
When you get down to, the nitty gritty
Who would you ask for, when your child is ill

We must revalue, what a worker's worth
Those who give health care, from birth to one's death
Those who give comfort, and who hold your hand
As you slowly pass, and take your last breath

The urgency's passed, streets echo silence
Covid is not dead, you still feel its bite
Care workers remain, but feel abandoned
A pay rise is due, it's far out of sight

The gratitude shown, by the Government
Just does not extend, when danger is past
Hollow words uttered, were wiped off the map
Future promises, we knew couldn't last

Stores were shuttered tight, except essentials
Brought in on lorries, whose drivers drove on
Battling the weather, and fighting fatigue
Driving through the dusk, from moonlight to dawn

Weddings were cancelled, christenings as well
Those who had passed on, had few to come mourn
Gatherings were banned, sports events as well
Athletes were shattered, with their hopes forlorn

Nurses served you well, took it in their stride
They had their masks on, hiding their visage
You could not greet them, when out on the street
To commiserate, their poorly paid wage

Doctors worked long hours, with barely a rest
Turned into Zombies, with shifts that could kill
All hospital staff, stretched to their limits
Running on empty, relied on their skill

Some highly paid staff, confined to their homes
Continued working, still had a good wage
On the totem pole, they soon slithered down
Counting for little, on the world's new stage

The public soon found, who really mattered
When their loved ones lay, keeping death at bay
It wasn't the rich, entrenched in mansions
Who held someone's hand, as life slipped away

Their luxury cars, left in their garage
Forbidden to move, but nevertheless
Were white elephants, unless essential
They thought more of them, than staff under stress

Ghostbusters knew, whom they had to call
When panic arose, 'was their job to quell
Pandamonium, terror fright and fear
For Covid roared in, just like a bombshell

Face to face meetings, were things of the past
Aware of the risk, of spreading disease
They had to think fast, to communicate
Something was needed, to put folks at ease

Up sprang computers, alien to some
If you were older, used to handwriting
You needed to buy, the right equipment
To keep you in touch, with the best training

Teaching an old dog, to do some new tricks
Was futile at best, is that really true?
Silver heads nodded, as they came to grips
With new procedures, as confidence grew

E-ver-y cloud has, a silver lining
While confined at home, we could visit those
Who mattered the most, the ones that we loved
Grandchildren playing, and striking a pose

For those down below, distance no object
You spoke face to face, seeing each nuance
The smile when you laughed, the tears when parting
The "Zoom again" look, when you have a chance

I think back to days, five am rises
And trav'ling for hours, on cold winter dawns
Without much success, fighting to conceal
Eyelids descending, and multiple yawns

And knowing midnight, is when you get home
After a day of, presenting for thanks
You can't sleep a wink, you're too tired to rest
You have depleted, your stamina banks

With Zoom and its ilk, and phone devices
No need to travel, stay snuggled in bed
Sheets up to your chin, a pen in your hand
Noting each comment, everything that's said

If you're brave enough, the kitchen beckons
A mug in your grasp, but you must beware
Are unwashed dishes, from the night before
Clearly visible, it's one's worst nightmare

I have great memories, so pleasant to recall
But our dear grandchildren, will have nothing to tell
Days of yore are no more, Covid mangled the world
It left in its wide wake, a fore-taster of Hell

I look back today, dismay in my heart
Staff are still fighting, to get their reward
Penny pinching deals, are on the table
Miserly offers, much to be abhorred

Once promised the earth,
Adored nightly for, for the skills they possessed
Dedication and, courage ev'ry day
Fearful of dying, by just getting dressed

It's come to the point, the unthinkable
Health workers voted, to come out on strike
Burnt out medicals, voted with their feet
Gave in their notice, and went for a hike

This put the pressure, to find their equals
But this takes a while, to get up to scratch
Their legacy gone, they're yesterday's staff
Cover the fissures, with a well worn patch

For those who survived, the outcome was grim
The Status Quo stayed, at the Ground Zero
Conditions the same, desultory pay
Miniscule awards, no more the hero

Take it or leave it, politicians cry
Forgetting the past, where loved ones had died
If Covid returns, they'll turn back again
To beg the workers, to whom they had lied

Now two years later, they are in anguish
Prices are soaring, they've been forced to strike
Miserly offers, do not pay the rent
Or the food you eat, so get on your bike

Down to the foodbank, at least they do care
If you're needing help, no questions are asked
You are God's children, you have Human Rights
To eat food to do, those things you are tasked

An MP dying, alone in his bed
His colleagues absent, they are down the pub
Who cleans up his mess, and tends to his needs
The very ones whom, he'd given a snub

*N.B. The last three verses of this poem
were added by James in April, 2023.*



I am blue

Look up and see me on sunny days

And I am still there on cloudy days

**We all have things on our lives that cloud us but the sun
is always there**

I am a dog

You can depend on being ready to go out with you

I am laughter

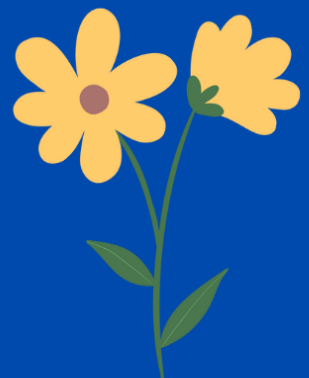
Which exits my mouth to stop you popping pills

I am spring

Dormant all winter greeting you to a show of my finery

I am James

Patient but not down



Acknowledgements

Since meeting Lorna, I have become aware that I may have a slight propensity for poetic work. This was more or less dormant, until she got her claws into me! And look at what has been created. I would never have believed it. Somewhere, there must be a massive credit to BOLD . . . bringing out . . . You have certainly done this for me. In my case “Bringing Out Latent Dexterity”. (TIC).

BOLD wants to improve the experience of those diagnosed with dementia, now the most feared illness in the UK. I want people to go away, with HOPE in their hearts. These (my) examples are not exclusive. Each person will have their own talents. I do hope this galvanizes people, to take heart, stand tall, and defy the myths.

James McKillop, DUniv. MBE

James and I began working together in 2022, during the bold online Social Leadership programme.

This booklet is a result of the work that James created during the programme and in the months that followed. I would like to thank James for sharing his work with me and for engaging in the creative writing exercise so enthusiastically. He never fails to surprise me with his beautiful words or sense of humour!.

It has been a privilege to collaborate with him on this project. James, thank you for all you have taught me.

Dr Lorna Hill



bold Bringing Out
Leaders in Dementia

For more information on **bold** and how to join the **online programme**, please visit

www.bold-scotland.org.uk



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changes
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Creating better lives.

