

Dementia

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[Word]

Play

Home
Home

just as ever

A selection of poems and workshops to support
those living with dementia to play with words

“They were all poets they did not know it!”

Word Play

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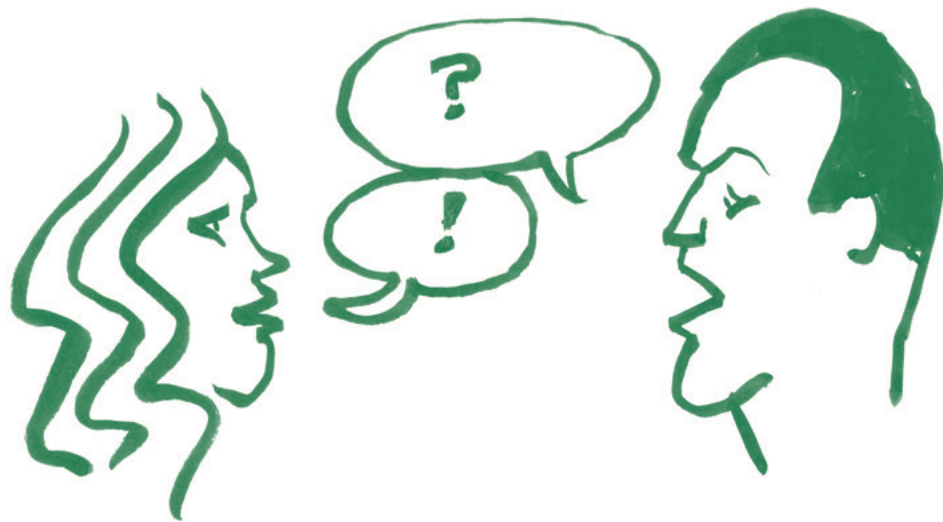
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What follows is a selection of words, phrases and poetry penned by STAND. This is accompanied by five guided workshops which allow you to enjoy word play yourself, whether living with dementia or supporting someone who is.



Introduction

An introduction to Word Play
from the members of STAND

Words from the group

I have been blessed throughout my career in health and social care settings to have experienced how the arts can significantly enhance how people live with chronic, enduring and terminal conditions. When boom saloon first approached STAND in the summer of 2020 to get involved in a creative writing project, I was determined to do all I could to make this happen. As we were emerging out of the first phase of the COVID-19 pandemic at the time, significant restrictions limited meeting face to face. As such, the first phase of this collaboration was carried out digitally – with the unexpected benefit of allowing us to engage with writers all around the world and enjoy a range of different insights and inspirations.

The flip side of this positive was that only a small number of the group were able to work digitally, and only two of the STAND members could sustain the commitment. Although small in number, the experiences of the group were so meaningful that we wanted to make sure other people could benefit from similar opportunities – hence this booklet.

It is designed to be used by individuals living with a diagnosis of dementia. If they aren't able to access it for themselves then it is laid out in such a way that their families, friends and support workers can help them to discover their inner, and quite likely

latent, creative selves. As always, when you produce something for people living with a diagnosis of dementia it is very possible that people living with other illnesses will benefit. This tool has the potential to be of value in a variety of settings and situations. It is our hope, and belief, that anyone who feels the need and desire to express their innermost thoughts and feelings about their situation could awaken a literary giant through this resource.

– Ruth McCabe

The power of the written word has long captivated and compelled us – from ancient hieroglyphics to the first printing presses to the social media so prevalent in our current world. Words have sparked global uprisings, saved lives and preserved vital learnings. They present a broad spectrum of possibility, from the simplest of communications to the sharing of complex methodologies. And yet, for so many, they can seem so daunting; few things are as intimidating as a blank page waiting to be filled.

This feeling is only exasperated when any change in functioning or loss of confidence is at play within the writer – two common experiences for those living with dementia. This presents a frustrating challenge. For most of us, language is the primary medium with which to communicate, connect and share our unique lived experience – something of vital importance to people with dementia. With this in mind, how might the written word be galvanised to share their true stories and enjoy spending time together without judgement or fear?

Including an element of play feels like a game changing consideration. Terms such as ‘poetry’ and ‘creative writing’ can often isolate and intimidate anyone not used to working in such a medium. To overcome this, we have developed this booklet to encourage a new way of thinking about words. They can be approached playfully, joyfully; without examination or editing, where there is no right or wrong.

People living with dementia can greatly benefit from enjoying time playing with words. So often written off as incapable, in truth many living with dementia can unlock new ways of playing with language due to their current experiences – breathing life and colour into the words which share these stories.

Dementia can lead people to experience things differently, seeing smells, hearing pictures and tasting sounds. The effects it can have on an individual’s understanding, and use, of language is often viewed as detrimental. Yet, might a more playful take be to consider this truly poetic? When freed from the confines of grammar or format, what new meaning might be uncovered in the play of the words of someone living with dementia?

Word Play exists to support you to discover this for yourself – whether you are living with dementia or supporting, caring for or loving anyone who is. The booklet you hold in your hands has been developed following many workshops, conversations, sessions and discussions. It highlights the need to listen and learn and celebrate. Within its pages, we hope you find joy, play and purpose alongside a sense of meaning. We have been lucky enough to see the sparks ignited when such an occurrence takes place; it is our hope that Word Play will pass this on to you to experience, too.

– Rachel Arthur

The workshops felt a bit like “therapy” as we were encouraged to explore our familiar worlds and our thoughts and feelings in response to this. I was able, in a safe and entirely supported atmosphere, to really examine some emotions I had kept hidden for too long and was able to use these emotions to drive my enthusiasm and creativity, and to pen some ideas and writing... my writing was mine, written from the heart and I am proud to have achieved what I did.

On a different level we were encouraged to travel from the familiar to the fanciful or fantastic and create a world and characters that we could explore and perhaps use to unwittingly tackle some unspoken fears. A truly liberating experience where dementia bore no influence!

Dementia is often accompanied by the anxiety of what’s next and frustration of what can no longer be done. This project brought hope, laughter, renewed self respect and a wonderful sense of collegiate working that, for me anyway, had been denied since my diagnosis. The magic of language and literacy in all its forms – fast flowing or faltering – was celebrated.

– Irene Donaldson

Through the workshops, we were encouraged to look at things, including ourselves, in a totally different light. We were allowed to express ourselves, write about how we felt, what we saw and what we thought about things. Some of the workshops were very emotional while others inspired me to write what I consider to be very good poems by a total novice.

– Gerald King

How to use this book

This book has been designed to support those living with dementia and their families, friends and carers to enjoy playing with words.

At the front, you will find a number of poems written by members of STAND. After these, you will find a series of simple workshops which will support you to enjoy playing with words yourself. Each workshop contains an explanation of how it works, a list of materials required and some top tips to make the most of each activity.

Next to each workshop, you will find an extra lined page where you can write down your poetry. On the opposite side of this page, you can write the title of your poem and any notes or drawings that you would like to include. These pages are designed to be torn out, and combined to form your own personalised word play booklet.

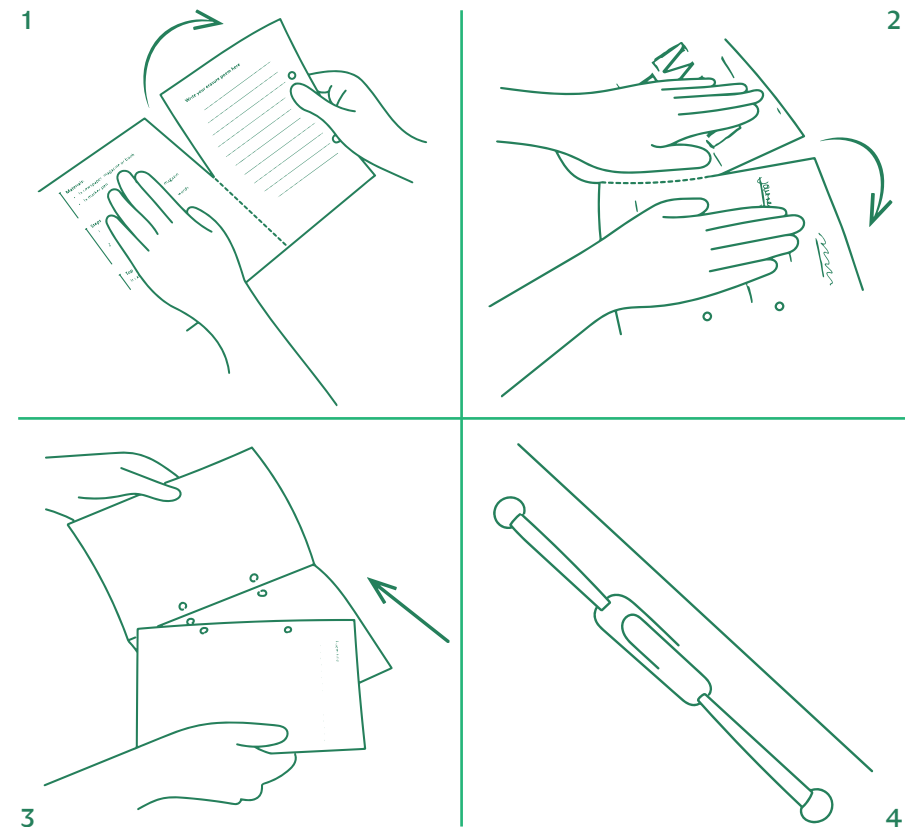
Next to the front cover, you will find an additional two pages which are also designed to be torn out. These will form the cover of your own personalised word play booklet.

To use this book, complete as many of the workshops as you like and write your finished poems on the lined

pages next to each individual workshop. Once you have done this, tear out these pages. Also tear out the additional front cover.

Place the loose pages inside the front cover and bind this together by stringing through the holes provided – you can use string, ribbon or rubber bands depending on what you have to hand and how you would like your completed booklet to look.

Once you have done this, step back and congratulate yourself – you are now a published poet!





Poetry

Selected poems
written by members of STAND

What follows are a small selection of poems written by, and with, people living with dementia. Each was penned following a particular structure, which we will go on to explain later in this workbook. They cover a broad range of topics, from the meaning of home to the life which exists just outside of our windows. None are solely about dementia, just as this is not the entirety of any person experiencing it.

I have poems in my head. I need help to
write them down on paper.

– Audrey Ross

We Remember Walking in The Hills

As collectively told to Ellen Renton by STAND

I've got my eye on you – like people do.
Pioneers like no sign of cloud and
Colours (should have gone to Specsavers).
I will have freedom and some of what
she has: oranges and lemons and very
hot sand, a camel as distressed as a shattered
community, bliss like distant dunes – life's
ups and doons, a lovely wee cottage
and trees moving in the wind. We built
this city on washday blues, but
for the criminal price of beer we could be
drinking from the ocean. Where is
the radiance? Where is the pub? Finding a way
in a human world, we cooked steaks on shovels.



home?

Rachel Arthur

sitting Before me is
the image.
the surface rises and falls – creating
a companionship and a collision

emotions dance

Opinions fly back and forth.

when the haze dissipates,
home?
and
what that means to us

– is established.

FEELINGS

Gerald King

When the grey mist descends,
Its not easy to comprehend
My heads in a vice like grip,
Slowly squeezing, applying pressure,
Numbing my senses and feelings.
Makes me want to close my eyes
And blank out the world around me.

The only ones who truly understand
Are those who dance to the same tune
Can you feel all my frustrations inside
As I hold back the flood of emotions
And look to find peace and salvation
From these demons that hold me down.

Breaking up my thoughts into a thousand
mixed up pieces, just like a jigsaw puzzle
that has lost the cover to its box which explains
Why I can no longer see the whole picture
Left in silence as language slowly leaves me
And our moments in space and time slowly slip away.

If I break down will you comfort me

Help me to remember things differently
To live for those moments and memories
That I can no longer put into words
Help me to embrace those feelings
As this disease erases all my emotions
That makes us all feel so human.

GRACE

Audrey Ross

I can't understand why
I see candlelight, Grace.
We're all going.

I do, for a moment

Mother called.
She sends the girls.
The door bursts open.
He was clearly looking for his
Sister downstairs

There is news!

Johanne is tumbling
From the bed.

Johanne! Johanne!
Is already in the room.

Johanne snatches the letter, then chuckles.
Jane

Has worms.

Shades of Green

Gerald King

Shades of green.
(Childhood playing in fields)
Numerous, bright, some short, some long,
others in untidy piles.
The smell of summer, a green carpet interspersed
with yellow buttercups,
daisies, and dandelions. And the occasional weeds.
A clear blue sky with a few streaks of white cotton,
as far as the eye can see, a contrasting backdrop
with brown and grey slates
and tiles from the roof tops.
(Calm and peaceful)
A large weather beaten tree,
in need of some pruning,
its top looking a bit bedraggled
but still shimmering in the summer sun.
(Me. How I feel at the moment)

Growth Gardens

Barbara

Gardening
Makes me feel
Useful
And
Very calm and peaceful
And
Like everything will come again.

Stamped

As told to Rachel Arthur by Ann

Stamped on my life story,
a little bit of my history.
A friend, a father, a postman.
I have, I had
no one knows how many.
11. 12. Any triangles?
Princess Di, stamped.
Winston Churchill, stamped.
Immortalised in albums of the Philadelphic Crew.
Send for special editions,
alight pages with delicate selvage.
Forever to form
this collection

of mine.



Glass Bottomed Ants

Collectively written by STAND

Caring and knowledgeable, she's incredibly kind.

Ruth is just fab!

But she owes me about £30.

One in a million, she too has a Stewart of her own.
Never sitting still, she has a glass bottom and ants
in her pants.

Ruth was an angel

When I needed one.

She always brings the tea and coffee we can't do without,
and has an incredible memory for names.

It's great to have Ruth.

She has taught me more than she will ever know,
with her caring, sharing, loving and warm heart.

Window Gazing

Collectively written by STAND

RATTLING BELL

WAVES

CHANGING

WEATHER

COLOURS

OF THE SEA

CORAL

LOCATION

BEACH

PEACE IN THE VASTNESS

PLANTS

TREES

WIND

CHANGING

TIDES

BATHTIME

Stewart McCabe

WARMTH; SUDS IN YOUR EYES; BLOWING
BUBBLES; LYING BACK DREAMING AS
THE WARM WATER WASHES AWAY THE
CARES OF THE DAY.. WRAPPED IN WARM
TOWELS - SITTING BY THE FIRE - AH
HOME AT LAST.
HOME.
OH! WE SHOULD NEVER HAVE GOT RID OF
OUR BATH!!!



Shaped by Hand

As told to Rachel Arthur by Stuart

Shaped by hand.
Shaped by hand.
Our house in France, shaped by hand.
Ruminate on our construction,
develop the skills learnt long ago.

A facet of our story,
refined and oft repeated. But
will you listen for the unheard stories,
uncover the memories anew?
As we stand together
shaped by hands.

Reach across the coast,
stretch me to Bordeaux.
A building of tolerances and foundations
that we make a home
shaped by our hands.

Be courageous, and
build this home.
Cladding – ooh! Deep breath in.
Let's be honest:
we planned for everything.
Everything except that which, now,
shapes our hands.

Together we crush rocks,
take the first jobs we can
as the opportunities flow in.
Different now, as we drill to our foundations.
Let them never waiver,
As we go,
Hand in hand.

Home With the Gang

As collectively told to David Linklater by STAND

Home is bed.

Home is where the heart is.

Home is the window.

Home is the loo.

Home is Tosh.

Home is a croft.

Home is the beach.

Home is the BBQ hut at the foot of the garden.

Home is the gin terrace, watching the sunset.

Home is the folk's kitchen.

Home is all of it.

Home is the pre-fab.

Home is safe.

Home is comfort and security.

Untitled

Barbara and Stuart

evolve

celebrate

social

memories

journey

joyfulness

wellbeing

unique

much loved



Good Advice

As told to Rachel Arthur by Stewart McCabe

A playlist for life, you say,
Rebecca? Fill mine with current
affairs and classical music –

but think twice.

For you learn when you listen: “you’ve got two ears,
two eyes and one mouth – use them in that order.”

Good advice.

Freedom, strung

Collectively written by STAND

Freedom is peace

And independence.

///

Smokehouses
exposed
the people.

///

Truth is
confirmation
of the facts.

///

Stars
Make me feel happy
And secure

When he grows up

Collectively written by STAND

“Shaikh is a very happy person.”

Happy in the garden, when it’s sunny.

“Shaikh strikes me as a quiet and particular person.”

Telling of a wonderful story, always with more to come...

“Shaikh has never had a dog”
but Eleanor has the greatest of pups.

“Shaikh will make a great GP...

when he grows up!”

An interesting past, a love of keeping nice and warm.
Always smiling, ever the intelligent man.

“Shaikh will pay later for that complement!”

Shaikh reminds me
of the wisdom

Within.

Reach for the Stars

Irene Donaldson

Aim high. Reach for the stars
And keep both feet firmly on the ground!
Always remember how you started.
A comic idea to the young girl on her dad's knee
Giggling pictures of elastic legs and arms.
Anchors for feet.
Yet his words felt safe.
And sure.
And somehow real!

As the world opened her mind grew
The stars appeared bright, promising, out of reach
Dreams and ambitions nursed and nurtured,
unspoken yet shared.
Encouragement sparkled dispersing the clouds of doubt
Love, generosity and hope propelled her forward,
rocketed her on.
The stars now within reach.

The new galaxy was beyond imagine.
Bright, bold, beautiful.
Without limit.
Wee girl comic visions faded
Sophisticated promises of profit and passion and
power took shape
Their pull strong and powerful
Promises of a better life
tearing her feet from their roots in the ground.

Sacrifices were demanded, life ties to be severed
Criticism and comparisons drawn
Prejudices and equalities battled.
Surely she thought
there's room in the galaxy for all sorts of stars?
Yet reality dawned like the sun each morning
Some stars sparkle bright
showering and sharing their beauty
Creating new hope and life in their wake
Others burn out and fall in invisible dust
loved momentarily
Then forgotten.
No roots.
No growth.
No future

The woman sits with a child on
her knee
A smile on her lips
And a heart filled with love
She knows this:
It's the heart and mind that are the stretching,
bending, flexible limbs
Folding around our hopes and dreams.
The roots of love and loyalty,
compassion and tradition
reach deep
They anchor us
Not heavy and limiting
But safely.
Securely.
Far reaching.
So she tells her child
Aim high. Reach for the stars
And keep both feet firmly on the ground.





Workshops

Five workshops to support those
living with dementia to play with words

Since the summer of 2020, we have been working with STAND to rewrite the story of dementia. We do this by working collaboratively, using words to allow those living with dementia to share their true lived experience. We listen, we talk and we write, together. There is no right or wrong – this is not school and there are no intimidating teachers to answer to, only a supportive group of peers coming together to try and spark some small positive change in our day to day lives.

To date, we have undertaken this work both digitally and in-person – never in print, until now. This booklet marks the start of a new chapter, and our hope is that it allows a whole new wave of people to benefit from our learnings to date. Together we have laughed, cried and consoled as we have undertaken the journey of unlocking great creative talents and working with words to empower them to share their stories.

No matter the level of experience or creative interest, playing with words can support all to enjoy time together and reconnect in light of the many challenges that dementia presents. We have found words to bridge the gap between those undertaking their dementia journey and those often desperately seeking to understand this, allowing them to support their loved ones with a new level of insight and empathy. We believe this to be something very special, of great importance.

As you will have seen, the previous pages share poems written by members of STAND following a number of

digital and in-person workshops. The following pages present five different workshops, drawing upon these learnings, which support those living with dementia to play with words and use them to tell their story. Each explores a different inspiration and way of working, in the hope there is something to suit all. We suggest trying them all, but experience suggests each individual will quickly find a favourite!

Each workshop includes a perforated page on which to write your poetry – once completed, these can be torn out and bound in the cover included to create a physical poetry book of your own. In this manner, this booklet provides the opportunity for those living with dementia to become published poets – challenging preconceived notions and celebrating the creativity often lurking just beneath the surface.

Workshop 1: Erasure

What?

Working with existing texts, erasure poetry is created by blacking out words to form new sentences, poems and stories from what remains.

Erasure poetry allows us to play with words without the pressure of having to think of them from scratch. Instead, we can enjoy restructuring and playing with words which already exist to tell our own stories.

Who?

This word play can be enjoyed individually by those who are comfortable working with words.

To enjoy erasure poetry with another, have one person read the existing text aloud whilst the other(s) say which words they'd like to keep and which they'd like to black out.

For anyone non-verbal, encourage physical movement such as table tapping or hand squeezing when the words they wish to keep are read aloud.

When and where?

This word play can be enjoyed anywhere at any time, but is often best enjoyed in a quiet, comfortable setting.

Materials:

- 1x newspaper, magazine or book
- 1x marker pen
- 1x piece of paper or this booklet
- 1x pen or pencil

Steps:

1. Tear out a page from a newspaper, magazine or book.
2. Use your marker pen to cross out the words surrounding those you wish to remain.
3. Once completed, read the poem you created by playing with someone else's words.

Top Tip:

It can be helpful to first underline the words you wish to remain, before then blacking out all of the others.

Write your erasure poem here

[illegible]

Use the space above for notes or doodles

Workshop 2: Window Gazing

What?

Window gazing encourages us to enjoy taking time to really look at our surroundings. It helps us to use words to appreciate the little things which might otherwise pass us by.

Window gazing requires very few materials and builds on an activity many of us enjoy every day – gazing out of our windows.

Who?

This word play can be enjoyed individually by those who are comfortable working with words.

To enjoy window gazing with another, share a conversation about what you both see out of the window, with one person writing down what is spoken aloud.

For anyone non-verbal, enjoy spending time together as you both look out of the window and you describe aloud what you notice.

When and where?

This word play can be enjoyed anywhere at any time, but is often best enjoyed from a quiet, comfortable chair.

Materials:

- 1x window
- 1x comfortable chair
- 1x piece of paper or this booklet
- 1x pen or pencil

Steps:

1. Find a comfortable seat from which to gaze out of a window.
2. Write down each thing you can see.
3. Below each word, write down something about it that you've never noticed before.
4. Below this, write a little about how this thing makes you feel.

Top Tip:

It can be enjoyable to repeat window gazing from the same window at different times of year, noting how the seasons change and our world evolves over time.

Write your window gazing poem here

[illegible]

Poem title:

Use the space above for notes or doodles

Workshop 3: List

What?

List poems are created by choosing a word that means something to you and listing the things it makes you think of or feel.

List poems can help us to tell our own stories by listing words or sentences that mean something to us. They encourage us to note these things down without having to worry about rhyme or rhythm.

Who?

This word play can be enjoyed individually by those who are comfortable working with words.

To enjoy list poetry with another, have one person scribe what the other(s) say following a conversation around what is important to them.

For anyone non-verbal, discuss what is in the room you are in and encourage physical movement such as table tapping or hand squeezing when objects of importance are mentioned. Write these down to form a list of meaningful objects.

When and where?

This word play can be enjoyed anywhere at any time, but is often best enjoyed in a quiet, comfortable setting with various visible stimuli.

Materials:

- 1x piece of paper or this booklet
- 1x pen or pencil

Steps:

1. Pick a word that means something to you and write it down.
2. List all of the things this makes you think of, or feel, and write them down.
3. Repeat as many times as you like.
4. Once completed, read the poem you created by listing things that are important to you.

Top Tip:

It can be helpful to pick a physical object that means something to you to start with. If you’re stuck for inspiration, take a look around the room you’re in and pick something you can see.

Write your list poem here

Poem title:

Use the space above for notes or doodles

Workshop 4: Countdown

What?

Countdown is a game where we string together sentences and words inspired by looking at photography.

Countdown creates the opportunity to have a conversation by reflecting on photographs. During these conversations, key sentences and words spoken are written down onto flash cards. These are then used to help construct a line of a poem.

Who?

This word play can be enjoyed individually by those who are comfortable working with words.

To enjoy countdown with another, have a shared conversation with one person writing down the key sentences, phrases and single words spoken during this conversation.

For anyone non-verbal, encourage physical movement such as table tapping or hand squeezing as the photographs are described to them in words and appropriate questions with potential answers are asked to discover more.

When and where?

This word play can be enjoyed anywhere at any time, but is often best enjoyed in a quiet, comfortable setting.

Materials:

- 1x selection of photographs
- 1x piece of paper or this booklet
- 1x pen or pencil

Steps:

1. Collect a photo and think or discuss any memories or feelings it evokes.
2. On separate pieces of paper, write down key sentences, phrases and words mentioned.
3. Seperate the paper into individual piles for sentences, phrases and single words.
4. Take a piece of paper from each of the individual piles and use these as inspiration to write a line for your poem.

Top Tip:

Don't worry if the selected sentences, phrases and single words don't make sense together; there is no right or wrong in word play! If the combination makes you feel uncomfortable, shuffle the piles to select a different combination.

Write your countdown poem here

Poem title:

Use the space above for notes or doodles

Workshop 5: Joy Writing

What?

Joy writing uses everyday objects to encourage conversation and word play about our happiest times.

In challenging times, it can be easy to focus on life’s negatives. Joy writing highlights the positives that surround us every day and enables us to write something about them.

Who?

This word play can be enjoyed individually by those who are comfortable working with words.

To enjoy joy writing with another, collect your everyday objects together before conversing about the joy they are related to, what this means to you and what it makes you feel. Have one person scribe what the other(s) say.

For anyone non-verbal, discuss what is in the room you are in and encourage physical movement such as table tapping or hand squeezing when objects of joy are mentioned. Write these down to form a list of meaningful objects.

When and where?

This word play can be enjoyed anywhere at any time, but is often best enjoyed in a quiet, comfortable setting with various visible stimuli.

Materials:

- 1x piece of paper or this booklet
- 1x pen or pencil

Steps:

1. Select a number of everyday objects you have to hand.
2. Pick them up, turn them over and feel their weight in your hands.
3. Write down a joyful activity, story or memory related to each object.
4. Write down what this joyful activity, story or memory means to you, and what it makes you feel.

Top Tip:

There is no need to overly rely on memory for this word play; each object can be discussed in relation to its present meaning and the joy it brings in this moment.

Write your joy writing poem here

Use the space above for notes or doodles

STAND is a charity which supports those living with young onset dementia and their families and friends in Fife, Scotland. It is supported by the Life Changes Trust and the National Lottery.

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dementiavoices.org.uk/group/stand-kirkcaldy
lifechangestrust.org.uk
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Amidst a landscape of promises of a cure,
sensationalised headlines and inaccessible medical
reports, we sought to tell the true story of those living
with young onset dementia, in their own words.

The poetry penned during this time speaks to the
potential of us all, fully realised when given the
support and space too often unavailable.

WARMTH

evolve

STAND

Striving Towards A New Day



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joyfulness