

Supplemental Figure S2: Data Set including poems, source material and explanations of the poets' creative process

Rare Dementia Support Impact Study

This data set contains 27 completed poems from 71 participants (9 cohort groups), explanations of the poets' creative process, and source material (original words) from people living with rare dementia and carers (stakeholders) who responded to a series of three prompts over a 12 week period. Data was collected between 2021-2022 as part of the Electronic Poems Project within the Rare Dementia Support Impact Study. Survey data from healthcare professionals and students (collected between 2022-2023) is available from the corresponding author with appropriate justification for its use.

The data are organised by: Cohort group (numbered 5-13), Prompt number (1-3)/*Prompt question*. For example, immediately below, 5 refers to cohort 5 and 1 refers to prompt 1 (out of 3 prompts); 5.2 refers to cohort 1 and prompt 2, whereas 5.3 refers to cohort 5 and prompt 3. The prompts are in italics. This is followed by the poem, the poet's explanation and source material. The structure of each poem is reproduced in the same format it was sent to participants.

5.1/What is your experience of having PCA or being a family member caring for someone with PCA?

A Steep Learning Curve

A steep learning curve

Always on duty

Anxiety oh dear oh dear

Always

Challenging symptoms and behaviours

Connect with the inner spirit beyond the inabilities

Connect

Deep compassion

Exhaustion leading to chronic fatigue

Deep

Feeling of worthlessness

Feeling restricted

Frustration

Frustration navigating the health care and social care system

Feeling

I remember being mindful with my breathing as I consciously joined them in their reality

Independence lost

Remember

Lost for words

Misunderstood and fragile

Needing to cope with boredom

Words

Often there was silence in the room although their energy (a different kind of energy to when they were well) was very much still there

Silence

Remembering happier times

Stuck in a loop, repeating the same actions everyday

Time slows down and remembering to truly be in the moment

Time

Unable to make them well again

Unfinished business, unable to complete or explain

Unfinished

A steep learning curve

Learning

Poet's explanation of his process:

This is what is sometimes called a “list” poem. It works well in this situation as I did not want to leave out any of the wonderful words and phrases that the participants wrote.

The first thing I did was to alphabetise the participants' phrases.

The next step was to decide where the smaller divisions (the stanzas) might go—some of this was determined by how many phrases began with a particular letter of the alphabet, and others just seemed naturally to belong together.

The final thing was the selection of the ten indented single words that finish each stanza, that reflect upon the feeling or motion of what is just above them on the page. These also make a lovely poem when read on their own, one that “sums up” the group's work.

Source Material:

Independence lost

Lost for words

Misunderstood and fragile

Anxiety oh dear oh dear

Connect with the inner spirit beyond the inabilities

Time slows down and remembering to truly be in the moment

I remember being mindful with my breathing as I consciously joined them in their reality

Often there was silence the room although their energy (a different kind of energy to when they were well) was very much still there

Unfinished business, unable to complete or explain
 Stuck in a loop, repeating the same actions everyday
 Unable to make them well again
 Challenging symptoms and behaviour
 A steep learning curve
 Exhaustion leading to chronic fatigue
 Frustration navigating the healthcare/social care system
 Deep compassion
 Remembering happier times
 Needing to cope with boredom
 Feeling of worthlessness
 Frustration
 Always on duty
 Feeling restricted

6.1 *What is your experience of having PCA or being a family member caring for someone with PCA?*

Still Me

Reinvent yourself—

A white cloth on the table

Give me a white plate

Looks like my food is floating

A sensory overload

Unclear. Unreal. Next?

A tunnel—where does it lead?

Bright sunshine? No. Fog

Hallucinations scary

Sometimes funny, confusing

Not mad at myself
Still me and always will be
Time to have a laugh

This tunnel—will roof collapse?
Will there be rats? Will it flood?

Wading through treacle
Dark and sticky—destiny?
Forget. Reinvent

Watching and listening—no
Time to have a laugh

A man enjoys clothes
Wears pyjamas over shirt
Escapes from the house

In tracksuit bottoms, odd socks
Flat cap, carrying slippers

Light to see forward?
Starting to rely on touch
Not sight—a struggle

Reducing my confidence
Still me and always will be

Foggy day—ah, well

Amazing music, recalled

TV, film—unreal

I try not to get angry

Sometimes more successfully

Forget. Reinvent

Frustration. Fear. Overload

Will there still be light?

PCA—unclear—what next?

Still me. I will always be

Poet's explanation of his process:

Senryu is an ancient Japanese form with the same origins as haiku, but focusing on observations of human experience rather than commenting on nature. When linked into longer poems, they become what is known as renga, adapted by non-Japanese writers using a pattern with groupings of three lines in five syllables, seven syllables, and five syllables again, then two lines of seven syllables each.

This writing group produced some really wonderful images—more images than narrative, some funny, some heart-breaking, all insightful—and the senryu/renga form emphasises both the shared experiences and the unique ones. I was not able to include every single word, but I was able to bring in every image.

Source Material:

PCA can be confusing

Hallucinations can be scary or sometimes funny

Put a white table cloth on the table and give me a white plate, it looks like my food is floating on its own above the table

Bright sunshine, oh no sensory overload, personal foggy day

Watching and listening a no go

Foggy day, ah well
 Forgetting and constantly 'reinventing' yourself is a frustration
 I try not to get angry with myself, sometimes more successfully than others!
 I keep telling myself I'm still me and will always be
 Responsibilities
 Unclear
 What next
 Unreal
 Not me
 In a tunnel
 Will it flood?
 Will the roof collapse?
 Will there be rats?
 Where does it all lead?
 Will there be light to see the way forward, or are we destined to forever wade
 through a sea of darker and stickier treacle
 The man who showed me how to enjoy clothes wears a pyjama top over a shirt
 a flat cap, odd socks
 rolled up tracksuit bottoms
 And escaped from the house wearing shoes, but carrying slippers.
 Take every opportunity to have a laugh
 Amazing recall with all my music
 Reducing confidence
 Struggle with tv and film
 Starting to rely on touch instead of sight

7.1 What is your experience of having dementia or being a family member caring for someone with a dementia? [mixed rarer dementia group]

No One Would Believe Me

Do you have anxiety?
 People are so rude --
 no one would believe me: *heartbreaking,*
cruel disease, disaster, increasing difficulty

My most frustrating memory gap
 is not being able to recall ...
 I am so, so depressed
 there is no treatment to stop or slow up...

mad; furious; sad; lonely

I cannot find my wife,
she doesn't know she's lost.

Why is Mom having trouble walking?
Mom could hurt herself ...

I will not live to be an 'old' lady
I am not following the other lovely women in my family ...

They say it's good to learn new things.
Anosognosia is not one of them.

*the names of my former students and teacher colleagues
my most frustrating memory gap*

Do you have anxiety?
tiring

Learn to forgive yourself when you become exasperated.

Mom was right: what do we do?
Learn to forgive yourself when you become exasperated.
We walk holding hands again, like when I was little.
How long will this last? I still see her.

Eyes closed now.
Her laugh is still hers.

We're all ok.
*Learn to forgive yourself -
Her laugh is still hers.*

Poet's explanation of her process:

The texts from the respondents had a lot of poetry in them. I printed the texts and cut them up into useful fragments. Then I tried various arrangements and started writing down the ones that worked immediately. Whole sections of the poem were already coming together. The themes of distress and worry were balanced by the theme of caring and the individualized, resounding voices of the respondents. The condition threatens erasure but the personal, evocative voices insist on love bearing witness.

I was able to use most of the respondents' words and I was very moved by all of them.

Source Material:

Disaster; Upset; Mad; Furious; Sad; Lonely; Tiring; Mentally, Emotionally, and Physically Exhausting

My most frustrating memory gap is not being able to recall the names of my former students and teacher colleagues.

I can not find my wife,

She doesn't know she's lost.

They say its good to learn new things.

Anosognosia is not one of them.

Learn to forgive yourself when you become exasperated.

I am so, so depressed that there is no treatment to stop or slow up the progress of Primary Progressive Aphasia

I am gradually experiencing the increasing difficulty in remembering the definition of some words, how to spell some words and how to properly pronounce some words

very sad that I will not live to be an 'old' lady and will die much earlier than I expected as I am not following the other lovely women in my family

if I can assist to be part of research for PPA to help find treatment/cures (maybe those +ve results won't happen while I am alive) but I would be pleased to contribute to help others with PPA in the future.

Heartbreaking

Cruel disease

No one would believe me

1. we're all ok.

2. do you have anxiety?

3. why is mom having trouble walking?

4. shit-mom could hurt herself...

5. fuck, people are so rude

6. double fuck. mom was right. what do we do?

7. how long will this last? i still see her.

We walk holding hands again, like when I was little.
 Eyes closed now.
 Her laugh is still hers.

Cohort 8.1 *What is your experience of having dementia or being a family member caring for someone with dementia?* [mixed rarer dementia group]

Changing

I am a member of a shitty club:
 Life Changing

life changing

at the beginning I felt
 somewhat lost and cheated
 surprised and confused
 frustrated
 embarrassed
 devastated

(life changing)

I needed to fight, be more patient
 plans needed to change

I needed to find answers
 sadness
 lost memories

I needed to accept and become a better person
 with hope anything was possible
 honouring our vows
 loving you in the present moment

doing the best I can
 "in sickness and in health"

life changing

though I am a member of a shitty club
 I needed to find answers, and
 I felt at peace that I am doing the best I can

Poet's explanation of her process:

I am primarily a free verse poet, and the sound of words and poems is particularly important to me. In reading this group of responses, I was immediately struck by the prosody in what became line 1, which seemed to be trying to be a song, and therefore was looking for a refrain. "Life changing" is the underlying theme here, and became the refrain almost immediately. The responses shaped the poem into parts addressing the situation of change, looking into how it could possibly be handled, and trying to find courage while admitting that the situation is extremely difficult. The responses quite clearly were a song waiting to happen; my task was to find the song that was already there.

Source Material:

Devastated; Embarrassed; Frustrated; Surprised and confused

Sadness; Lost memories; Life changing

At the beginning I felt somewhat lost and cheated. Plans needed to change

With hope anything was possible.

I needed to accept and become a better person.

I needed to fight, be more patient and find answers - at first it was a hectic pace, as time passed I felt at peace that I am doing the best I can. I do however need to continue to work at being more patient. My spouse with FTD surprisingly is the best teacher.

member of a shitty club

honouring our vows of "in sickness and in health"

loving you in the present moment

Cohort 9.1 *What is your experience of having FTD or being a family member caring for someone with FTD?*

Eleven

1.

life changing

horizon shrinking

energy zapping doors

closing

longing for this not to be

2.

who cares for me, myself?

where did all the friends go?

nobody drops by
they have no idea of the reality
the cruellest disease you have never heard of

3.
you never know what you are going to get
I go into my own dark space
overwhelming, exhausting
this fear for the future t
this trepidation for what's to come

4.
invisible
written off
scary, sad, helpless
I fight
I know I'll lose

5.
what's being lost
hard to accept
the world shrinking
slowly taking everything away
one bit at a time

6.
Strangers in the home
In your life
Frustrating, challenging
Deep love, unconditional
These strangers become your friends

7.
roller coaster of emotions
embarrassing to forget people's names
keeping focused on preserving my own identity
a heavy burden to carry
there is no one left

8.
harrowing, destructive, relentless
soul-sucking, sadistic disease
"look after yourself" they say

“you can live well with dementia”
robbed of being, cruelly, slowly

9.
protective, vulnerable
confusion, lack of understanding, sorrow
brain giving up
the people they once knew
witness apathy, loss of empathy

10.
“life is a box of chocolates”
crazy beast continual loving care, inspiring
appreciate each stage whilst you are in it
as the next brings more loss, more sadness

11.
the challenges, the pain
reactions from friends and family
forget events in the past
forget things you have committed to
slowly fading

The poet’s explanation of his process:

As there were eleven participants in this session, and quite a lot of words produced in response to the prompt, a good deal of editing was necessary, lest the poem become overly long and unwieldy to read and absorb. I divided it into eleven stanzas of five line each, which enabled the inclusion of every person’s ideas, cut and pasted for what I hope is maximum effect. This also gave the poem its title: *Eleven*.

This session included particularly powerful, expressive, and astonishingly honest reactions—a great deal of sorrow, fear, frustration, and fury, with only the smallest glimmers of acceptance or hope. Not easy to read, but a piece, I think, that could help readers with and without dementia to understand what this group of writers is experiencing at the moment. Thank you for the opportunity to work with your words.

Source Material:

it is an embarrassment to forget people's names, events in the past and things you have committed to

Riding the roller-coaster of emotions.
 Keeping focused to preserve my own identity.
 Continual loving care for both of us.
 Horizon-shrinking,
 Energy-zapping,
 Inspiringly-Joyful..... bvFTD
 I go into my own dark space
 There is no one left
 Who cares for me myself
 UNCONDITIONALLY
 Harrowing, despicable, destructive, relentless, soul-sucking, sadistic disease. beast.
 FTD is a heavy burden to carry.
 The cruellest disease you have never heard of'.
 Life is like a box of chocolates you never know what you are going to get until
 bite into it !
 Life changing
 Crazy
 Loss of empathy and ritualistic behaviour are the first signs of this disease
 Checking out which pub the quiz is in tonight tomorrow the night after quiz quiz
 every nighthe gets to the pub at 6 pm for the quiz at 9pmhe doesn't get to do
 the quiz he just gets drunk by 9 pm I pick him up and get him home to bed"how
 many pints have you had I say "I've had two f****g pints is always the answer
 Reactions from his friends my friends and family....."look after yourself they say
 "...they never say I will take him to the pub and get him home for you to have a
 night off....they never say drop him off to my house and get your hair done "they
 just say LOOK AFTER YOURSELF
 Where did all the friends go ? No phone calls from work mates quiz mates, nobody
 drops by
 It's hard to accept carers who are strangers into your life into your homethen you
 get to realise these strangers are becoming your friends
 Overwhelming
 Exhausting
 Scary
 Sad
 Helpless
 Sorrow for what's being lost
 Fear for the future
 Trepidation for what's to come
 Longing for this not to be
 Doors closing, fading slowly. Becoming invisible and written off.
 Brain has given up on me. I fight I know I'll lose.
 Robs a loved one of their very being, slowly taking everything away, one bit at a
 time

People continue to say “ you can live well with dementia” yet they have no idea of the reality, the challenges, the pain of this cruel slow degenerative disease
 As a carer, however frustrating and challenging it is, you have to appreciate each stage, whilst you are in it, as the next brings more loss and sadness
 Feelings of protection, vulnerability and deep love for the person with dementia, as you witness their world shrinking – the confusion and lack of understanding of everything and the people they once knew.

10.1 What is your experience of having or being a family member caring for someone with a rare/young onset dementia? [mixed rarer dementia group]

Accept This Honour

Walking in a long dark tunnel --
 Struggling to understand the journey –
 Heart-wrenching to feel so helpless --
 Hopeless against this unrelenting disease --
 This train wreck happening before my eyes:

She has the function of a toddler
 with the attitude of a teenager
 with all the guilt of being my mother...

The joy of reading her her favourite poem
 and getting the same reaction
 like she hasn't heard it in
 forever...

The sister I loved so dearly
 was being taken from me
 piece by piece ...

Miss my partner
 even though he's physically still here,
 trying to be positive and know
 these moments with him won't come again...

I just hope she knows that even when I am frustrated
 I still love her so much ...

If only there was a cure or something to stop this!

The need someone who they can trust...

It's YOU...ACCEPT this honour--
 Show your patience, understanding,
 unconditional love and dependability.

Accepting the inevitable
 Tiny snippets of dappled sunlight

The poet's explanation of her process:

Responses in this group worked very well in free verse, divided into descriptions of living with the condition and accounts of individuals. The general descriptions, collected together, suggested a way to offset the individual stories like the decoupled cars of a train, and then put everything back together again with the brave stoicism several respondents voiced. The responses were very poetical, touching, and successful expressions of the challenges of this condition, and provided the energy that drives this poem.

Source Material:

Show your patience, understanding, unconditional love and dependability.
 They need someone who they can trust...it's YOU...ACCEPT this honour
 Struggling to understand the journey, the sister I loved so dearly, was being taken from me, piece by piece. Heart-wrenching to feel so helpless and hopeless against this unrelenting disease. If only there was a cure or something to stop this train wreck that was happening before my eyes.
 - She has the function of a toddler with the attitude of a teenager with all the guilt of being my mother
 - I just hope she knows that even when I am frustrated I still love her so much.
 - the joy of reading her, her favourite poem and getting the same reaction like she hasn't heard it in forever.
 isolating, especially during Covid
 miss my partner (with YOD), even though he's physically still here
 trying to be positive and know these moments with him won't come again
 Walking in a long dark tunnel
 Tiny snippets of dappled sunlight
 Accepting the inevitable

11.1 What is your experience of having PPA/FTD? [this cohort consisted only of PLwRD and no carer-partners]

When Will I No Longer Be Me?

tiredness, frustration, disorganisation

thank God for the support group

the most mundane things take the largest effort

don't be ashamed of me

I realize my personality has changed

what is the rate of my decline?

I can't remember the shock but there must have been

run away and hide

when will I no longer be me?

I have some words in a day

and then they don't come through the next day

the most mundane things take the largest effort

letter, number and word-finding difficulty

then curiosity and call to action take over

what is the rate of my decline?

perpetual grief, rapid fluctuations in mood

I don't understand this

when will I no longer be me?

Who can help me?

I often know the words in my brain

the most mundane things take the largest effort

I am energised and happy

participating in mealtime conversations with friends, I mostly listen

what is the rate of my decline?

when I have a strong opinion, I try to explain my point of view

learning about myself and a brighter side of this world ever since

when will I no longer be me?

empowerment to create understanding around dementia
 let's build that old-fashioned village again
 the most mundane things take the largest effort

my first thought was, "Thank God it's me"
 anger, emotional upset, lack of control
 what is the rate of my decline?

heard of dementia, heard of Alzheimer's
 never heard of FTD/PPA
 when will I no longer be me?

challenging—I spell a word: p-l-e-a-s-e
 then a few minutes later "please" come out
 the most mundane things take the largest effort

new friendships, love and support, acceptance and patience
 surrounding love—these people have lifted me
 what is the rate of my decline?

am I going to die soon?
 the world needs to know and see
 when will I no longer be me?

The poet's explanation of his process:

This particular prompt elicited a wide variety of heartfelt fears, questions, and fragments of personal stories, all of which have found a place in the final piece. In putting together a longer poem, such as what was needed in this instance, structure becomes particularly important. I carefully reviewed past RDS poems as well as poetry anthologies on my bookshelves before deciding on an adaptation of an old form, the *tercet*, one used by poets as diverse as Shelley in the early 19th century and William Carlos Williams in the mid-20th.

The name comes from the Latin for "third" and consists of stanzas made of three lines each. Often there is a rhyming pattern, but in this case the emphasis is on repetition—there were three lines in the source material that seemed to sum up the mood and served to group the responses into potent statements of personal

experience, with each repetition yielding a slightly different effect. The overall form features the three lines of a tercet, but the repeating lines create an additional tercet-based framework, a “super-tercet,” on which to build the poem.

Source Material:

I cant remember the shock but there must have been.
 My first thought was "thank god it's me.
 My second is, dont be ashamed of me, the world needs to know and see.
 Then curiosity and call to action took over.
 I have been learning about myself and a brighter side of this world ever since.
 I am energised and happy.
 Let's build that old fashion village again.
 perpetual grief
 surrounding love
 run away and hide
 I realized my personality has changed.
 When participating in lunch/dinner conversation with friends I mostly listen.
 When I have a strong opinion about a topic I try to explain my point of view.
 I don't understand this, never heard of FTD/PPA. Head of Dementia , heard of
 Alzheimer
 Am I going to die soon?
 Who can help me?
 Thank God for the support group, these people have lifted me
 the most mundane things take the largest effort
 what is the rate of my decline
 when will I no longer be me?
 Empowerment to create understanding around dementia
 Tiredness
 Frustration
 Acceptance and patience
 Emotional upset
 Anger
 Lack of control
 Rapid fluctuation in mood
 Disorganisation
 Challenging
 Letter, Number and word finding difficulty
 New friendships
 Love and support
 I have some words in a day and then it doesn't come through the next day. I often
 know the words in my brain and will say it as
 p-l-e-a-s-e, then a few minutes and please comes out in my brain.

12.1 What is your experience of having a rare or young onset dementia or being a family member caring for someone with a rare or young onset dementia? [mixed rarer dementia group]

Out Here in the Rain

“We are not the walking dead”

I’m stuck here with a rare disea ... eeeze

devastating

terrifying

heart breaking

frustrating

The physicians don’t have a clue, who?

very maddening

very stressful

very sad

I’d be stuck in last century

sitting here clueless

fear

stigma

You blessed me with a nursing degree

opportunity

education

support

understanding

Becoming and blossoming into something different

yet beautiful

Finding a deep sense of self

freeing

comical

Hours fly by like minutes

faces I ought to remember

no longer provide me names

I read and read about how to ease the pain

but none of the doctors can agree ... ee

leaving me out here in the rain

with all the pain

Explanation of the poet's process:

This free verse poem responds to the musical suggestion of one respondent and becomes a song, with opening lines followed by a chorus. I imagine this as the "star" singing the openers and the back-up singers doing the italics. Although the subject matter is very serious, the undercurrent of light-heartedness comes through in the arrangement. Readers get to make their own music.

Source Material:

Devastating

Terrifying

A great sadness

Becoming and blossoming into something different yet Beautiful

Finding a deep sense of self

Freeing

Heart Breaking

Frustrating

Comical

Hours fly by like minutes

And faces I ought to remember

No longer provide me names

Caring for a family member with young onset dementia is:

Very sad

Very maddening

Very stressful

Fear, understanding, education, stigma, support, opportunity and my phrase is "We are not the walking dead"

Ooooouu baby, baby,

I'm stuck here with a rare disea. eeze

and the physicians don't have a clue,

who?

Oouuu baby, baby,

You blessed me with a nursing degree ...ee

Or I'd be stuck in last century y

With sitting here clueless with my MD

Ou baby, baby,

I read and read about how to ease the pain

But none of the doctors can agree ee

Leaving me out here in the rain

With all the pain

13.1 *What is your experience of having a rare or young onset dementia or being a family member caring for someone with a rare or young onset dementia?* [mixed rarer dementia group]

How May I Help You?

Use short sentences:

LIFE IS TOO

BLEEDING

TEARS LIKE RAIN

I don't want

PAIN

risk anger FURY

I am angry.

I am trying to cope

as normal as possible

and still be able to communicate with people.

Thoughts over time after learning of the diagnosis:

confusion – frustration – patience – disbelief – skepticism – compulsive behaviours --
unknown uncharted territory -- cascading loss – isolating – endless –wrenching.

I never thought a disease could be so horrible

and have such a dramatic impact on a family:

loss, loss of myself, my essence, my work, my driver's license, my job, my body,
friends, love of husband because he feels overwhelmed by extra housework.

obey

recoiled in fear

would not

could not

cruel indifference

he lied

MENTAL HEALTH

I am sad.

Sadness is my daily companion.

People don't understand a rare form of dementia.

Even professionals seem at a loss

and are slow to respond to a 'rare' form of dementia –

they seem at a loss of what to do.

I don't want
she screamed
guilty
unclothed
FIRE
remorse

When will this end?
Our dreams are shattered
and we will never be the same again.
Scared.
Fear of the future.
Fear and uncertainty about what's coming next.
I will never get the chance to say good bye.
Sorrow for my son and granddaughter when I'll be gone.

I don't want
love
tears like rain
life is too

I try to remain in the Present,
grateful that I have notice of my condition.
Love keeps me holding on,

empathy.

We live in the second.

Everybody has been pretty good to me.

I am strong & supported.

Hope holds a spark

that beckons me.

TEARS LIKE RAIN

The poet's explanation of her process:

Responses in this group expressed the struggles of living with early onset dementia in very powerful language. The idea and instruction "use short sentences" suggested how to contrast brief comments, wrung out of pain and concern, with longer statements about the condition. The poem has bursts of words that in their incompleteness describe the difficulty of conveying meaning, and the deep grief of the suffering. The poem proves that language does have the power, albeit imperfectly, to try to describe the condition.

Source Material:

MENTAL HEALTH

LIFE IS TOO

She screamed

I don't want

I don't want

I don't want

Pain

Guilty

Unclothed

Anger

Recoiled in fear

FURY

Risk

Remorse

Obey

He lied

Would not

Could not

Love

Cruel indifference

FIRE

BLEEDING

TEARS LIKE RAIN

I am sad.

I am strong & supported.

I try to remain in the Present.

Everybody has been pretty good to me.

I am angry

I am trying to cope as normal as possible and still be able to communicate with people.

Confusion – frustration – patience – disbelief – skepticism – compulsive behaviours - empathy – unknown – scared - long history of abusive behaviour – Have the symptoms been present for over 20 years, and have expressed themselves as symptoms of various mental illness and personality disorders?

Uncharted territory

Cascading loss

Fear and uncertainty about what's coming next

Sadness is my daily companion.

Hope holds a spark that beckons me.

Love keeps me holding on. Isolating

Endless

Wrenching

* how may I help you?

* use short sentences

* when will this end?

- People don't understand a rare form of dementia.

- Even professionals seem at a loss and are slow to respond to a 'rare' form of dementia

- they seem at a loss of what to do.

Thoughts over time after learning of the diagnosis:

"disbelief, confusion, fear, anxiety, frustration"

1) We live in the second.

2) I will never get the chance to say good bye.

3) Our dreams are shattered and we will never be the same again.

4) I never thought a disease could be so horrible and have such a dramatic impact on a family.

- Loss

- Loss of myself, my essence, my work, my driver's license, my job, my body, friends, love of husband because he feels overwhelmed by extra housework.

- Fear of the future
 - Sorrow for my son and granddaughter when I'll be gone
 - Grateful that I have notice of my condition compared to someone who dies suddenly
-

5.2 How would you describe PCA to a friend or family member?

From the poet: This type of poem is known as a "foursquare," and its flexibility allows it to be read vertically, in columns, or horizontally, line by line, or even diagonally if you like.

Bewilderingly So

PCA is cruel
steals your futures

it takes your mind
steals your dreams

heart-breaking to witness
a badly shaken cocktail

a potpourri of symptoms
especially cruel

reality can't be right you're living it
frustrating, and you know it angry, helpless

the paving stone like a hole diminishing visual awareness
no handles, no keyboard the fog of dementia

rollercoaster of emotions independence and language lost
the impact as it progresses no way to retrieve it

steals the person you love everyday practical skills
bewilderingly so a few precious moments shine through

The poet's explanation of his process

When I saw that there were four participants who responded to this particular writing prompt, I started experimenting with the foursquare model of crafting a poem. It is inspired by the traditional schoolyard game of four players standing in the corners of a grid and taking turns to bounce a ball quickly amongst themselves. In this case, though, there's no rubber ball crisscrossing and ricocheting, but intense

ideas, honest emotions, and profound and insightful descriptions, arranged into groups of four and those groupings arranged into a larger foursquare shape.

Given the storytelling nature of some of the responses, it wasn't possible to include every single word of the source material, so I worked with the selection of phrases and fragments that fit together well in at least two different adjacent positions. The images harmonise or contrast differently depending on the direction one reads, altered by new juxtapositions.

Source Material:

PCA is cruel – it takes your mind ... and you know it.

You know your reality can't be right but you're living it – setting down a cup on a table that's actually two feet to the left so it falls, the paving stone that looks like a hole, the wallpaper that appears to be on the front of your husband.

And as PCA progresses, the brain becomes like a filing cabinet with no drawer handles. Or a hard drive with no keyboard. You know the data is there but you've no way to retrieve it.

Frustrating

Angry

Helpless

Steals your futures

Steals your dreams

Steals the person you love

Heartbreaking to witness the impact as it progresses

It seems especially cruel, by diminishing visual awareness and ability to speak as well as everyday practical skills, like writing

Independence and interests, including language, become lost...bewilderingly so if without a formal diagnosis... and the right support

A rare neurological condition, similar to that experienced by Terry Pratchett

A badly shaken cocktail of neurotransmitters = a potpourri of symptoms & a rollercoaster of emotions

A few precious moments when, even through the fog of dementia, her sense of humour shines through...

6.2 How would you describe PCA to a friend or family member?

Where to Begin

Where to begin?

Brain blindness

Vision is darker. That's not a rubber mat?

I can see it, but at the same time I can't see it.

Confusing, disorientating.

Good days and foggy days

Frightening

Where to begin?

Which way round does this go?

Things aren't where they appear to be

I wish you could see through my eyes

Invisible dementia

Misdiagnosed and misunderstood

Getting confused more often

How to describe something

No more words

Which way round does this go?

Why can't I find things?

I wish you could see what I see

It's a black hole

I can't do anything I used to be able to do

Eyes are okay in themselves

No more driving

Staying positive as possible

How to begin?

Why can't I find things?

Where is the top or the bottom?

When I struggle to understand

Word searching

Things aren't where they appear to be

The brain effects the eyes

Embuggerance

No more words

Misunderstood

Where is the top or the bottom?

Where is the top or the bottom?

Why can't I find things?
 Which way round does this go?
 Where to begin?

The poet's explanation of his process

Reading the group's responses, I was immediately struck by the questions—the feeling they gave of being uncertain, of wishing for answers and clarity that are never entirely provided—and I noticed that, although similar, the questions never repeated exactly word-for-word.

This became the starting point. Repetition is a key component to poetry, along with rhythm and word-play—tools used to heighten the reader's awareness of the language being used. While there are some poetic forms that rely quite heavily on repetition, like pantoums and villanelles, none of them really suited this collection of responses, so I worked at crafting a structure that would. It also felt important to make sure to include as many of the original words as possible—fragmented, juxtaposed so that no one writer's words dominate or end up next to the places where they began.

I think that this a poem that benefits very much by being read aloud. Every time a repeated line is heard, its impact changes.

Source Material:

The brain affects the eyes
 Eyes are ok in themselves
 Misdiagnosed and misunderstood condition
 Brain blindness
 "Embuggerance" (Terry Pratchett)
 Invisible dementia
 Frightening
 It means I can't do anything I used to be able to do
 Vision is darker
 No more words (reading, writing, understanding)
 Word searching!!!!!!
 No more driving!!
 I can see it, but at the same time I can't see it.
 I wish you could see through my eyes!!! and see I what I see.
 That's not a rubber mat? "IT'S A BLACK HOLE".
 Confusing, disorientating Why can't I find things?
 Things aren't where they appear be.

Which way round does this go? Where is the top or the bottom?

PCA to me, is having, good days and 'foggy' days, getting confused more often, whilst staying as positive as possible

Where to begin?

How to begin?

How to describe something, when I struggle to understand

7.2 How would you describe your or your family member's dementia diagnosis to a friend or family member? [mixed rarer dementia group]

Unwavering braveness

Brain blindness.

Extreme turmoil.

An excruciatingly slow
drip
of profound
loss.

Unwavering
braveness.

A time
when old memories
get lost
but can be found.

You easily see that she is
not the same
person you remember
but she believes
that she has not changed
that she is still
the same person
she has always been.
She may not
understand the nuance
of the situation

and say or do
something
out of place.
When you speak
to her she may not know
a word
you use.
She will ask
you
the meaning
of that word.
You often have to
repeat
a question and
her answers will
likely be slower
than before.

PPA can
progress
slowly.
As it is progressing with
me I am finding:
I have to think more about
how to pronounce words
correctly, to spell
correctly, to remember
the definition of a word.
My short term
memory is not as good
either -- so I record
a lot of things
to make sure I
remember; for example,
what to do, what has happened

I can get very sad
some days
about the progress, but then I try
to remember
how blessed my life
has been – I know
I will not be living as long

as many of my relatives/parents –
 but try to focus
 on how wonderful
 many parts of my life have been

PPA is very depressing, to know
 that, at this point,
 there is no cure/treatment
 for it. I am MOST interested
 to be involved in research
 if I can
 to help anyone who gets PPA.

The poet's explanation of her process:

Responses in this group were about the difficulties of trying to communicate about the condition, of trying to find and remember words, and make meaning for others. Therefore, I broke up the statements into smaller parts and floated them in the middle of the page to express the fragility of the attempts to communicate. I hope the result is a beautiful and delicate form, with words carrying extra emphasis from their temporary isolation from each other.

Source Material:

Disaster; Upset; Mad; Furious; Sad; Lonely; Tiring; Mentally, Emotionally, and Physically Exhausting

My most frustrating memory gap is not being able to recall the names of my former students and teacher colleagues.

I can not find my wife,

She doesn't know she's lost.

They say its good to learn new things.

Anosognosia is not one of them.

Learn to forgive yourself when you become exasperated.

I am so, so depressed that there is no treatment to stop or slow up the progress of Primary Progressive Aphasia

I am gradually experiencing the increasing difficulty in remembering the definition of some words, how to spell some words and how to properly pronounce some words

very sad that I will not live to be an 'old' lady and will die much earlier than I expected as I am not following the other lovely women in my family

if I can assist to be part of research for PPA to help find treatment/cures (maybe those +ve results won't happen while I am alive) but I would be pleased to contribute to help others with PPA in the future.

Heartbreaking

Cruel disease

No one would believe me

1. we're all ok.

2. do you have anxiety?

3. why is mom having trouble walking?

4. shit-mom could hurt herself...

5. fuck, people are so rude

6. double fuck. mom was right. what do we do?

7. how long will this last? i still see her.

We walk holding hands again, like when I was little.

Eyes closed now.

Her laugh is still hers.

8.2 *How would you describe the diagnosis to a friend or family member?* [mixed rarer dementia group]

There Is So Much I Could Say

FTD is a journey,

a terminal degenerative brain condition,

a slow and painful death I encounter each day,

a condition which steals an individual's personality.

There is so much I could say:

Frustrating when you can't remember

words

or things --

her friends no longer call as before.

There is so much I could say:

common household tasks are difficult,

worried if husband

not available to take care of

business,

taxes,

driving car,

house work.

There is so much I could say:
 PPA as changed our retirement plans,
 worried about being a bother
 or a problem at times
 or in the future.
 The chapters of our retirement will be
 different than the plans we had made.

There is so much I could say:
 it demands continuous learning.
 It requires extra sprinkles of patience
 for your loved one who has limitations
 with communication and planning.
 My husband is my best friend and soulmate.
 I am a lucky woman to have him in my life.
 He treated me like a queen for over 30 years
 and he is still my knight in shining armour.

There is so much I could say:
 Live each day as that is the only guarantee you have,
 that is how I live life now!
 There is so much I could say!

The poet's explanation of her process:

Respondents in this group reported on the difficulties and frustrations of trying to express their experience of the disease, yet they were conveying important information and illuminating their feelings. I grouped similar ideas together and worked with the theme that they were successfully doing what they felt they Couldn't do – speak to the limitations of the condition. I broke up the lines to indicate distress, and repeated “There is so much I *could* say” as meaning “There is so much I *am* saying”, with more to be said in future. The effort to communicate is working, and works in poetical space.

Source Material:

Frustrating when you can't remember words or things
 Worried about being a bother or a problem at times or in the future
 Worried if husband not available to take care of business, taxes, driving car, house work

PPA has changed our retirement plans
 her friends no longer call as before
 common household tasks are difficult
 FTD is a journey. It demands continuous learning
 It requires extra sprinkles of patience for your loved one who has limitations with
 communication and planning
 There is so much I could say
 My husband is my best friend and soulmate. I am a lucky woman to have him in my
 life. He treated me like a queen for over 30 years and he is still my knight in shining
 armour, even though the chapters of our retirement will be different than the plans
 we had made
 Live each day as that is the only guarantee you have, that is how I live life now!
 a condition which steals an individual's personality
 a terminal degenerative brain condition
 a slow and painful death I encounter each day

9.2 How would you describe FTD to a friend or family member?

Description

From the poet: "*Description*" is in a form that is sometimes called a "stack" poem, as the words are arranged as just one or two words in columns—these can be read horizontally or vertically, and the meaning and imagery changes depending on the direction. If you think of the words as coins in a stack, each one is valuable in itself and when placed with others becomes important to the total sum.

not Alzheimer's	rarer	destroyer	crazy sadness
different	altering	exasperating	changed
apathetic	empty	distressed	rituals
hypercritical	atrophy	by default	blackouts
frontal lobe	diagnosis	loss	poor judgement
destructive	illness	consuming	classic
symptoms			
no insight	aggressive	aggravating	memory loss
no control	behaviours	mutate	erode
eats away	everything	heart-breaking	soul-destroying
love	confusion	hard work	disappears
different	apathy	anger	alone

frightening	repetitive	unwell	for help
you thought	empathy	in depth	awful
you knew	concern	together	confirmed
comfort	language	personality	never heard
once-loving	memory	hides behind	own world
confusing	one knew	thoughts	perceived norms
disinhibited	suffering	devastating	lacking

The poet's explanation of his process:

The prompt, *How would you describe FTD to a friend or family member?*, elicited some extraordinarily eloquent and emotional responses, some exceedingly painful and all of them heartfelt and significant to the understanding of researchers, carers, and the general reader for the understanding of this disease.

Approaching the responses as a poet, the sheer number of words, as well as the story-telling nature of some of them, presented a challenge of condensing and arranging. In this case, I was not able to include every word that every respondent wrote, but I think that in selecting key words from each person and arranging them in this form that a unifying poem has coalesced.

Some stack poems feature columns that are fifteen or twenty words tall, but in this case I kept each stack to six, partially to intensify the effect of the responses and partially because the form echoes the oracular hexagrams of the I Ching, the ancient Chinese *Book of Changes*.

A column of six single words equates to the hexagram for "force," for instance, while one that follows the pattern of 1-1-2-2-2-1 translates as "persevering." I'm not making claims that this poem encapsulates the wisdom of the ancients, but it is interesting to consider the philosophical possibilities of fortuitous arrangements, and how the stacked words might contradict or reinforce the traditional meanings.

Here is a Wikipedia link if you would like more information about the I Ching and the sixty-four hexagrams: [https://en.wikipedia.org/wiki/Hexagram_\(I_Ching\)](https://en.wikipedia.org/wiki/Hexagram_(I_Ching))

Source material:

It's not Alzheimer's

The cruellest dementia you have never heard of.

A rarer dementia associated with personality, behaviour and language.

Repetitive behaviours and loss of empathy.

“The Destroyer of Lives”

Crazy sadness loss

Frighteningly different to what you thought you knew.

Life altering

Exasperating!

The first thing I noticed that changed in my husband was apathy, he was always a hard working man got things organised without any effort, he became towards getting ordinary chores done and would look through me empty of concern for me when I asked for help.

I was unwell and required surgery, again he looked through me when I was in pain or distressed I felt so alone in my hour of need . We had been together for over many years and always comforted each other. After I had had the surgery he was more concerned about the fact that I had moved the mode m from my bedside table shining in my face than how I was.

He had rituals getting the newspaper sitting and reading every page. Planning a night out to a quiz for as many nights of the week as he could. Going to the quiz at 6pm and the quiz started at 9pm consequently drinking for 4 hours consuming many more pints of beer per night.

He became hyper critical about different religions race and other peoples enjoyment such as football which he called mindless tribalism.

He began drawing out money from a joint account which was used for everyday bills one month drawing out £600 pound just for drink.

When he was diagnosed which was by default, after a brain scan he had when he was suffering from blackouts showed frontal lobe atrophy. I paid to see a neurologist who confirmed the diagnosis.

When I got home and look more in depth at the illness it was as if he walked out of the computer screen towards me, the loss of empathy, apathy, poor judgement, loss of organisation skills we listed as classic symptoms of this awful destructive illness. It was a relief to me that my once loving caring husband and father of my children had no insight and no control over his thoughts or behaviour.

And then the loss of memory starts to happen and your once strong loving friend and husband becomes your child.

A neurological disease that does not follow the perceived norms of Dementia of memory loss and only for the older person but far more aggressive and devastating as it affects behaviours and personalities of younger people it ways that make them disinhibited lacking empathy and insight and carry out very anti social and often unkind actions.

A disease that hides behind personality traits and and explainable behaviours at first till it begins to mutate and erodes everything you thought about that person and your relationship with them

A disease that eats away the soul of the person and everything they are or who they had wanted to be.

Devastating
 Soul destroying
 Heartbreaking
 Confusing
 Love confusion and anger as the mother one knew
 disappears into her own world

10.2 *How would you describe your family member's diagnosis to a friend or family member?* [mixed rarer dementia group]

I Know You Have Noticed

My husband is a little different this year --
 we received a diagnosis of dementia ...
 it's heartbreaking --
 the thought of this
 heart-wrenching journey
 breaks my heart in two.
 Disbelief washes over me!
 Web of words fading.

Her mind is cloudy.
 She is slowly slipping away;
 one function disappears at a time.
 She is trying to remember her day
 and the people around her,
 like when you try to remember
 a dream the details are all fuzzy.
 Emotions might be deep inside
 where you can't see them.

Safe when in his peaceful world
 emotions might be deep inside ...
 Savour every minute shared together
 as it is the memories made
 that will help
 through the darkest times.

The poet's explanation of her process:

This poem balances suggestions of two individual situations in which the difficult outside contains "emotions ... deep inside". The poem calls on onlookers to pay deep attention in their noticing, and to retain memories made by noticing for the future. By noticing, onlookers can see the universal in the individual, and retain some comfort that will be needed.

Source Material:

(To very close friends) I know you have noticed my husband is a little different this year; we received a diagnosis of dementia....

Disbelief washes over me! The thought of this heart-wrenching journey breaks my heart in two. Savour every minute shared together as it is the memories made that will help me through the darkest times.

She is slowly slipping away, one function disappears at a time. It's heartbreaking. Her mind is cloudy. She is trying to remember her day and the people around her, kinda like when you try to remember a dream the details are all fuzzy.

Web of words fading.

Safe when in his peaceful world.

Emotions might be deep inside where you can't see them.

11.2 How would you describe PPA/FTD to a friend or family member? [this cohort group only consisted of PLwRD and no carer-partners]

Tumbling, Jumbling

First of all, I have PPA

An indescribable experience

My mind plays tricks on me

I forgot the name of a shop

People's names and places we travelled to

I can understand the conversation

But I have difficulty in speaking

T U M J U M

B L E B L E

An unexpected challenge
 I thought it was just me being so busy at work
 It wasn't just one shop
 Increasing opacity between me and the world
 I get so tired just doing ordinary things
 Please give me time to respond
 To your comments and your questions

T M L J M L
 U B E U B E

it happened again—I forgot the names of animals
 I asked for an MRI brain scan
 I got the diagnosis after assessments
 Don't review the symptoms on Google
 It's so scary to see it and goodness very depressing
 My thoughts, words and actions have been put into a tumble drier
 On spin mode to jumble and mix everything up

U B E J B M
 T M L L U E

Now? Things are the same—it's just about animals and places
 I have wonderful support—groups, one-to-ones, a family
 I can drive, cook, garden, shop, walk the dogs, gym classes
 I can remember what I need to do
 But—Tumble. Jumble
 Learn to accept
 I am drifting away from you

The poet's explanation of his process:

When I first read this set of responses, two words leapt out at me and seemed to set the tone for the poem—indeed, almost giving me clear instructions that this was going to be a piece about rearranging and juxtaposing different participants’ images and emotions—the “jumble.” Additionally, I wanted to re-create the feeling of not being entirely in control—the “tumble.”

This poem incorporates aspects of “concrete” poetry—not that it’s made of cement, but a method of using the shape, size, and positioning of certain letters in order to reinforce the overall mood. In this case, I was attempting to reflect the lived experiences of the participants, and so the large-type words become more difficult to decipher each time the reader encounters them—we know what they say, but it’s harder to figure them out as the poem progresses.

Source Material:

PPA. ... An unexpected challenge
 An indescribable experience
 Learn to accept
 Sometimes it is as if my thoughts, words and actions have been put into a tumble
 drier, put on spin mode to jumble and mix everything up
 I’m drifting away from you
 My mind plays tricks on me
 I get so tired just doing ordinary things
 increasing opacity between me and the world
 I forgot the name of a shop and thought it was just me being so busy at work !
 It happened again and it wasn't just one shop , it was people's names and places
 where we travelled to.
 I then forgot the names of animals. So, I asked for an MRI brain scan. Thats when I
 got the diagnosis after assessments as well.
 Now? things are the same- it's just about animals and places. I can drive , cook,
 garden, shop, walk the dogs and do lots of Gym classes and remember what I need
 to do.
 Don't review the symptoms on Google as it's so scary to see it and goodness very
 depressing
 I have wonderful support, groups , 121's and a family.
 I would say that, first of all, I have PPA. I can understand the conversation, but I
 have difficulty in speaking.
 Please give me time to respond to your comments and questions.

12.2 How would you describe your type of dementia to a friend or family member?
 [mixed rarer dementia group]

Why I Repeat the Same Question at Random

You've been told there's something out of tune, in my muddled brain,
slow brain death, with physical appearance often not changing,
a rollercoaster ride,
confusion that overwhelms,
insidious,
heart breaking to see a vivacious intelligent person decline in this way.

Why I repeat the same question at random:

how can one word, de-ment-ia,
erase random notes on a page of a life lived in harmony, together?
Why does one, simple word change the dynamics of a life lived?

Why I repeat the same question at random:

dementia is a disease that tears at your heart;
to watch someone you love beyond words
become someone you don't know
is terrifying, sad and maddening;
you can't cope with why I can't cook, or drive;
the loneliest place I have ever been,
the longest goodbye,
the "I'm not gonna miss you "effect.
And you just don't see me anymore.

Can you see me? I am here!

Dementia = Clarity.

It's ok here,

scary but joyful,

shocking but acceptable --

I have made friends with my dementia,

can live well but must do the work:

compassion

understanding

respect

peacefulness

inner strength.

Can you see me? I am here!

still here

still alive

still able to contribute

Why does one, simple word change the dynamics

of a life lived?

The poet's explanation of her process:

The responses in this group included the idea of a random but profound question that is repeated, which became the organizing principle of the poem: asking questions that can only partially be answered by personal accounts, definitions,

further questions. The poem offers two versions of living with dementia – the puzzling, sad side, and the attempt to find some positive aspect. The poem emphasizes the essential wish of respondents to be seen and heard as they try to explain living with the condition.

Source Material:

Shocking but acceptable. Scary but joyful. Can live well but must do the work.

“You’ve been told there's something

Out of tune, in my muddled brain

But you can't cope with why I can't cook,

Or drive; why I repeat the same question

At random; confusion that overwhelms

And you just don't see me anymore

Why does one, simple word

Change the dynamics of a life lived?

How can one word, de-ment-ia,

Erase random notes on a page

Of a life lived in harmony, together?

Can you see me? I am here!”

Slow brain death, with physical appearance often not changing, the longest
goodbye, “I’m not gonna miss you “effect.

The loneliest place I have ever been

Dementia = Clarity, Peacefulness, Inner strength

It’s Ok here, I have made friends with my dementia

Thank you for the opportunity to participate

Respect understanding still able to contribute still alive still here compassion

Dementia is a disease that tears at your heart , to watch someone you love beyond
words become someone you don’t know is terrifying, sad and maddening

Insidious

Heart breaking to see a vivacious intelligent person decline in this way.

A rollercoaster ride

13.2 How would you describe your type of dementia to a friend or family member?

[mixed rarer dementia group]

Who Our Loved Ones Used To Be

Dementia doesn’t care how old you are.

No cause; no cure.

Annoying to others, devastating for us.

A death sentence, no hope, dreams shattered, live in a maze till you die.

A disease that steals the essence of who our loved ones used to be.

Our life plans are over.

It is what I thought was going on.

I am not sure if I can do this.

Dementia is a term for symptoms of a diseased and dying brain.

Degenerative.

Starts with atrophy in the visual processing and spatial part of the brain.

Symptoms differ for each patient

depending on which area of the brain is affected.

Things are not the same, but don't be afraid to talk about it.

Know the signs to watch for, but remember

they can be different and will change over time.

Dementia is a disease like any other and there are many kinds.

Learn the difference.

Memory loss is not the main loss:

choking often, falling, loss of balance;

not able to make any decisions big or small on most basic tasks;

loss of not being able to accomplish what used to be second nature;

loss of being able to organize or focus on anything;

slowness in all we do.

Eroding our spirit, our personality, our own self.

She is still the same person, but is not able

to do the things she used to do because of the disease.

That's why we encounter people who don't believe it's dementia –

it's the everyday necessary things that are not obvious to you.

I would tell them I have early onset Alzheimer's and I am not in any pain.

But still I remain grateful for what is left

(so grateful to experience the greatest joy of having a granddaughter).

Be like the Magi - the best three gifts you can give

are patience, kindness and time - they are true gifts of love.

Be willing to support.

It's okay to do the things to keep me safe

even when I don't ask.

The poet's explanation of her process:

This poem describes the essence of how dementia affects bodies and lives, and alludes to the changes in the essence of those who suffer with it. The tone is dry and impersonal as difficulties are enumerated, but becomes more tender with references to real people and their real-life experiences.

Source Material:

Degenerative

Starts with atrophy in the visual processing and spatial part of the brain

No cause; No cure

Dementia is a term for symptoms of a diseased and dying brain.

Dementia doesn't care how old you are.

Symptoms differ for each patient depending on which area of the brain is affected.

Our life plans are over.

It is what I thought was going on.

I am not sure if I can do this.

I would tell them I have early onset Alzheimer's and I am not in any pain"

A death sentence, no hope, dreams shattered, live in maze till you die

One day you are going to hug your last hug, kiss your last kiss and hear someone's voice for the last time, but you never know when the last time will be, so live every day as if it were the last time you will be with the person you love. Author unknown.

Know the signs to watch for, but remember they can be different and will change over time.

Things are not the same, but don't be afraid to talk about it.

Be willing to support and it's okay to do the things to keep me safe even when I don't ask.

Dementia is a disease like any other and there are many kinds. Learn the difference. She is still the same person, but is not able to do the things she used to do because of the disease.

Be like the 'Magi' - the best three gifts you can give are patience, kindness and time - they are true gifts of love.

Memory loss is not the main loss

That's why we encounter people who don't believe it's dementia, it's the everyday necessary things that are not obvious to you

Not able to make any decisions big or small on most basic tasks. Choking often, Falling, loss of balance

Loss of not being able to accomplish what used to be second nature

Loss of being able to organize or focus on anything

Slowness in all we do

Annoying to others, devastating for us

Eroding our spirit, our personality, our own self

But still I remain grateful for what is left

So grateful to experience the greatest joy of having a granddaughter

I would describe dementia to them as a disease that steals the essence of who our loved ones used to be.

5.3 *What does support mean to you?* [PCA cohort group]

Truth: A Fib

myself

emotional

not dismissed

both

ready

care

myself

for somebody

concerns and observations

on call

understanding

compassion

expertise

advice

being there

understanding and compassion

at practical and emotional levels

ready to help someone who's about to fall

we're not alone in this

togetherness beyond family

constructive responses

knowledge

help

unexpected

relevant

affirm decision

talking problems through

loved one

myself

longer

specific

practical

being there

not

alone

The poet's explanation of his process:

This poem is a fib—which has nothing to do with telling the truth, and everything to do with an Italian mathematician of the 11th century.

Leonardo of Pisa, also known as Fibonacci, was the first western European to explain the series of numbers that we now know as the Fibonacci sequence, although they had been identified earlier in Indian mathematics and used as early as 200 BC in Sanskrit poetry. In the sequence, each number is the sum of the two preceding ones—0, 1, 1, 2, 3, 5, 6, 13, 21, 34, 55, 89, etc—and it can be used to describe features of the natural world like the double spiral pattern of seeds growing in sunflower heads, the way that pinecones twist, and the shape of the chambered nautilus.

When using the sequence to create poetry, one can choose to count either syllables or words. I found that counting by words was more useful this time. For this poem, I first sorted the original responses into groups, so that I had a number of single words, a few less doubles and triples, only a few fives and only one that was eight words long. The poem wasn't quite working as a single long stanza, so I broke it into smaller, mirror-image fibs, each one following the pattern of small to large and back to small. Several of the single words repeat more than once—they just cried out to be heard again.

Lines – sorted by number of words: In developing the poem, I first took participant's words and sorted them into groups, seen immediately below

1.

help

care

advice

myself

expertise

knowledge

2.

the unexpected

no longer

on call

constructive responses

being there

for somebody

affirm decision

3.
 talking problems through
 my loved one
 understanding and compassion
 specific and relevant
 concerns and observations
 not being dismissed
 togetherness beyond family

5.
 a practical and emotional level
 we're not alone in this

8.
 ready to help someone who's about to fall

My impression of the original responses is that the participants have used the prompt to describe a variety of positive, satisfying experiences. It's a glimpse for the reader into a very personal set of truths—so that the pun of the title stands out.

Source Material:

Togetherness beyond family
 Understanding
 Compassion
 We are not alone in this
 Being there for somebody
 Help to affirm decisions
 Ready to help someone who is about to fall
 Specific and relevant knowledge, expertise, understanding and compassion
 constructive responses
 concerns and observations not being dismissed
 Help, care and advice, on both a practical and emotional level, for my loved one
 and... myself!
 No longer on call
 Help with the unexpected
 Talking problems through

6.3 *What does support mean to you?* [PCA cohort group]

SUPPORT

enablement, a listening ear

the spine, the confidence

the lighthouse in a storm

someone to catch you when the tsunami hits

SUPPORT SUPPORT

caring, kicking ass, holding my husband up

when I just want to talk

I'm not alone

I could not manage

SUPPORT SUPPORT SUPPORT

cathedral columns, old-fashioned underwear

when I get confused and frustrated

people willing to help when I'm lost in the woods

being there when down

being seen in a blizzard

SUPPORT SUPPORT SUPPORT SUPPORT

like being rescued, like what I get from you

meeting people in my situation, participation in many groups

accessing expert advice and information

helps me live my life independently, something I cannot give enough of

what makes me go on

S U P P O R T

The poet's explanation of his process

This poem uses elements of a type of poetry known as “concrete.” Concrete poems use space in ways that other forms of poem do not. The words are not merely descriptions or narrative tools, but dramatize the underlying meaning of the poem by the way in which they appear on the page—size, arrangement, colour, typeface. They draw attention to themselves, becoming not only something to read but something to see.

One of the first things that struck me about this group of responses, aside from the strong, evocative images, was the repeating of the word “support.” Seeing it eleven times made me think of bells chiming, each time a bit louder, and then it made me think of strong square bricks providing a foundation to a structure of images, metaphors, and emotions. The poetic lines are clustered, balanced, sometimes looking a bit fragile or likely to tip from the weight of words above them, but the underlying support structure is always there to hold them steady.

Source Material:

Support helps me live my life independently
 Support gives me the confidence to live with dementia
 Support groups shows me that I'm not alone
 Support helps me when I get confused and frustrated
 Support opens their ears, when I just want to talk

Support to me, is provided by my participation in many groups, also and most importantly by my wife, without whom I could not manage anywhere near a normal life, with PCA

Support is like being rescued, like being seen in a blizzard or knowing there's someone to catch you when the Tsunami hits. It's having people willing to help through action when you yourself feel helplessly lost in the woods.

Support means something I cannot give enough of. Nothing seems to help

Support means

enablement

kicking ass

being there when down

Support is the lighthouse in a storm

Support means caring

Something that makes me go on, like what I get from you

A listening ear

Meeting people in my situation

Accessing expert advice and information.

Old fashioned underwear

cathedral columns

The spine

Holding my husband up

7.3 What does support mean to you? [mixed rarer dementia group]

What Else Could I Try To Do

Writing/spelling, language, communication, definitions...

Take a break when you need one

Seek advice when you need it

Learn from other's experiences

Learn from others that have PPA how they are managing

Support means I can manage/operate better longer

Do the best I can for as long as I can

Do your best, but when you fail do not be hard on yourself

Support means not feeling utterly alone

I am not in this alone

It means having someone to help bear the unbearable

Sharing with others how to help me in the future

A good source for me to continue in my life

To link to the item / person that I need to speak to / use

Able to connect / talk with others that have PPA and I am able to help / support them

Appreciate being involved in any research to help finding new treatments / management for those with PPA

Helps me feel better about myself as I can help others

Support means

I am not in this alone

The poet's explanation of her process:

The form of this free verse poem is a weave of two different kinds of lines to suggest how to make a supportive environment out of various voices and ideas. The lines flow back and forth and answer each other to suggest how to create support by listening carefully to those trying to help, and to oneself.

Source Material:

Support means to me a good source for me to continue in my life.
 I am not in this alone
 Learn from other's experiences
 Do your best, but when you fail do not be hard on yourself
 Take a break when you need one
 Seek advice when you need it

Support helps me to try to do the best I can for as long as I can eg. writing/spelling, language, communication, definitions.

I am in the process of getting a new ipad and a SPL and Occupational Therapist are taking lots !!!! of pictures that I send to them of areas in my condo, friends, relatives etc. etc. and they are setting it up on my new ipad to assist me in being able to link to the item / person that I need to speak to / use. That is supportive knowing that as I can't communicate well, I have an ipad set up with lots of items on it that I can select to help me. That support means I can manage/operate better longer.

If I am able to connect / talk with others that have PPA and I am able to help / support them -- that is very helpful for me. Also helpful to learn from others that have PPA how they are managing it -- what else could I try to do.

I really appreciate being involved in any research -- to help finding new treatments / management for those with PPA -- of course right away !!!! but for those, of course, in the future. That is very supportive for me -- helps me feel better about myself as I can contribute to -- help others.

Sharing with others how to help me in the future is very supportive to me
Support means not feeling utterly alone. It means having someone to help bear the unbearable.

8.3 *What does support mean to you?* [mixed rarer dementia group]

A Journey

as we venture
through a journey
of so many unknowns
in need of understanding
advice
back-up
relief
you actually care enough
to learn about
this most wretched of diseases
you are aboard my train
and will help in any way you can
trusted lifetime friendships
that one can always rely on
for a laugh
eternally grateful
hugs, many of them

with whom you can share experiences
 experts who listen objectively
 and share their expertise

you
 you get it
 someone to talk to
 my loved one, my children

words, a journal in-waiting
 for my kids to discover who helped out

this is about me
 it's not about you
 you are aboard my train

The poet's explanation of her process:

In these responses, the idea of a journey, of movement, suggested the flow of the free verse poem, which goes gently from one thought to another and gathers all the ideas together into the theme of support.

Source Material:

Help to someone in need of understanding
 situations, problems.

Advice

Back-up

Someone to talk to

Relief

Trusted lifetime friendships that one
 can always rely on for a laugh

New friendships living the same
 story with one whom can share experiences

Subject matter experts who listen
 objectively and share their expertise

as we venture thru a journey of
 so many unknowns.

Hugs, many of them :)

support means you actually care enough to learn about this most wretched of diseases

support means you are aboard my train and will help in any way you can

support means you you get it - this is about me, my loved one, my children; it's not about you and your inability to cope with my loved one's FTD diagnosis and how it impacts YOU

Words to go along with question = eternally grateful; a journal in-waiting for my kids to discover who helped out

9.3 *What does support mean to you?* [FTD cohort group]

Acceptance, Relief, Managing

Acceptance of the dementia brain

Worldwide cohesion

Acknowledgement

Well-organised

Advice to help you understand

Valuing

Assistance

Understanding

Being listened to

Support is essentially support

Bonding with others

Subtle

Carer not isolated in their own cosmos

Strength

Close friend who knows when I'm struggling

Someone to listen

Comfort

Someone or something to lean on

Compassion

So individual

Enabling us to live life to the full

Safe

Encouragement

Relief

Forgetting problems

Reliability

Friends become strangers and strangers become friends

Reassurance when needed

Guiding community

Phone calls from children who live far away

Having time for me

Peacefully

Help is there

Passing without a bother

Helping hand

Others in the world

Holding of hands across all cultures

Opening up into a universe

Infrastructure

No judgement

Insight into dementia world

Navigating your way through

Kindness

Meeting others who are in the same place as you

Living for the moment when we sing

Many forms

Managing

Explanation of the poet's process:

When I read the heartfelt responses to this prompt, "*What does support mean to you?*" the first thing I noticed was the letter A in a number of places, plus a scattering of Bs and several Cs, and I immediately thought about an alphabet poem, where the opening words of each line are placed in alphabetical order. This, I thought, might provide a sturdy underlying structure to the topic of "support," and it has been my experience in the past that adhering to strict, almost mathematical rules of putting a poem together can work to strong effect. In this case, though, there wasn't a response for every letter of the alphabet, so the concept needed to be adapted.

As many of the responses were single words or short phrases, with others more extensive, the first thing I did was to break apart some of the longer expressions into separate images using words from all participants. I changed a few of the verb tenses and then alphabetised the list...and it didn't quite work. The simple structure of the alphabet didn't provide the proper support for a poem that needed to be all *about* the support.

And then I remembered the “mirror” poetic form that I’d encountered many years ago, where the poem can be read in a conventional manner from top to bottom, and then change direction and be read from bottom to top. When I combined this with the alphabet poem construction, I started seeing thought-provoking juxtapositions of the participants’ images and emotions. The title, “Acceptance, Relief, Managing,” derives from the first word, the word at the halfway point, and the final word.

Source Material:

Listening

Accepting

Valuing

Someone to listen

Re-assurance when needed

Comfort and encouragement

Being listened to

Reliability

Having time for me

Enabling us to live life to the full

An opening up into a universe

where others in the world

have insight into Dementia WORLD

Worldwide cohesion

Portuguese friend’s mother

Passed today without a bother

Peacefully

A holding of hands across all

CULTURES

In acceptance of the dementia brain

SO individual

CARER is not isolated in their own Cosmos

No judgement

Compassion and understanding

Support for me as I care for my husband with profound dementia comes in many forms....

the structured support from the wonderful infrastructure that has been developed in our welfare state ...yes I pay for it ...over £400 per month but it’s structured well organised and safe ...this support has enabled me to look after my husband at home Support specifically for me is more subtlephone calls from children who live away...from sisters with their own problems who live close byfrom a new but close friend who knows when I’m struggling...from my Guiding community where I

still manage to be an assistant leaderfrom a carers choir where I can forget problems and live for the moment when we sing
I have read ..."when someone gets dementia friends become strangers and strangers become friends "it's true

Relief

Acknowledgement that support is needed and help is there.

A helping hand

Someone or something to lean on

Kindness

Strength

Advise to help you understand and how to navigate your way through

Meeting others who are in the same place as you and who understand

Somewhere to form bonds with others

Support is essentially support.

10.3 *What does support mean to you?* [mixed rarer dementia group]

Help Me

It's a range of things --

compassion, understanding, love --

someone who listens ... and believes me

someone who helps when I'm down and out

someone who reaches out

and gives me another path or crutch (an option)

someone to hug me and tell me it's ok

someone who can take over when it's too much

In between

there is support that helps me see things differently

and support that just takes time

to listen and see things the way I do,

not judged by expression of my thoughts or feelings

Never tell me I'm not doing enough for my husband --

just step in to help me!

Help me, so I can help him.

Honour his wishes.

Help is a range of things.
(an option: leave cookies on our porch!)

The poet's explanation of her process:

"Help Me" is an interplay of voices commenting very personally on the human condition of living with dementia. The poem speaks to the kinds of individuals who can be helpful, gives a framework for how they can help, and references a particular case that poignantly illustrates the theme.

Source Material:

Help me, so I can help him.
Leave cookies on our porch.
Honour his wishes.
compassion, understanding, love, not judged by expression of my thoughts or feelings
Someone who listens....and believes me
Someone who helps when I'm down and out.
Someone who reaches out and gives me another path or crutch (an option)
Never tell me I'm not doing enough for my husband; just step in to help me!
It's a range of things.
From someone to hug me and tell me it's ok
To someone who can take over when it's too much
In between there is support that helps me see things differently and support that just takes time to listen and see things the way I do

11.3 What does support mean to you? [Cohort group PPA/FTD]

To Continue

I get advice
truly interested
not feeling alone
I am not on my own

non-judgemental people
creation of PPA network
my friends do talk with me
I want to hear positive things

it lifts me up in times of doubt
 giving me a degree of comfort
 listen to what I am trying to say
 it does well for me to be with them

taking time and emotion to understand me
 allowing me to continue to do the things I enjoy
 allowing me to still participate in decision making
 being there for me to continue doing the things I can

enjoy, or at least not be frustrated, having to care for me
 it allows me to move forward in a positive way with my life

The poet's explanation about his process:

In reading over the responses to this question, I was immediately struck by the contrast between the brief, concise lines and the more lyrical, sentence-like ones. Some of these longer lines I split into two pieces, and then, after changing a few verb tenses, arranged them all by length. The resulting poem places participants' responses in new configurations, highlighting the connections and contrasts between them. It also provides the visual impression of an architectural buttress, which reinforces the theme of support.

Source Material:

listens to what I am trying to say
 Non-judgemental people
 I am not on my own
 I get advice
 I want to hear positive things ...
 my friends do talk with me and it does well for me to be with them.
 It allows me to continue to do the things I enjoy.
 It lifts me up in times of doubt.
 It allows me to move forward in a positive way with my life.
 Not feeling alone
 Creation of PPA network
 It gives me a degree of comfort
 Truly interested and taking time and emotion to Understand me.
 Enjoy, at least not be frustrated in having to care for me.

Allowing me to still participate in decision making and being there for me to continue doing things I can.

12.3 *What does support mean to you?* [mixed rarer dementia group]

The Resiliency

Support feels like being wrapped in an old comfy sweater,
 the kind that I don't have to ask for it just shows up,
 neighbours and friends asking if they can lend a hand,
 family,
 family being by your side.

Someone to listen to me without judgment,
 workers willing to lend an ear,
 unconditional actions to ease the burden of care,
 companionship, less stress, stimulation,
 acceptance, acknowledgment, understanding.

joy in every day

I know you think I'm crazy sometimes
 and question my judgment
 on every decision I make
 but if you want to show me your support
 learn to accept me as I am,
 with all my faults and errors,
 don't scold me like a child,
 just cover for me and let me believe
 in the resiliency found in love.

Explanation of the poet's process:

Responses in this group included what was clearly a finished poem that wrapped up the strands of the other thoughts and became the "old comfy sweater" in itself. The responses are the yarn that knit into the final lovely resilient garment.

Source Material:

Support me by showing acceptance, acknowledgment, understanding.
 Support feels like being wrapped in an old comfy sweater
 The best support is the kind that I don't have to ask for it just shows up
 Support means to me:
 Family
 Unconditional actions to ease the burden of care
 Someone to listen to me without judgement
 I know you think I'm crazy sometimes
 And question my judgement
 On every decision I make

13.3 *What does support mean to you?* [mixed rarer dementia group]

Please Stick Around

Seeing me without judgment.

Hope that we can cope.

I feel less alone to know others understand

or have travelled this road as well.

Knowledge and strength from shared experience.

Simple yet flexible.

Encouragement.

Willingness not Reluctance

Optimism not Pessimism

Pro-action not Reaction

Action not Procrastination

I am so blessed to have such amazing supports in my life,
 a friend who texts me everyday with a nice thought,
 family members willing to help each other,
 caring, helping with visits, hugs, drives,

and professional help to educate doctors and general public.

Walk with him and listen --

support needs will change,

taking time to listen and giving time for talking,

providing support strategies that are specific to my condition.

A genuine appreciation and thankfulness for the willing,

the kind and the pleasant;

understanding what to expect allows preparing for it,

so

please, stick around.

The poet's explanation of her process:

This free-verse poem does what it describes: it is "simple yet flexible", delivering "knowledge and strength from shared experience". The poem both listens and talks, and after asking in the title that the audience stick around, explores what kind of knowledge is needed to enable those willing to "stick around" to be helpful.

Source Material:

Everything.

I am so blessed to have such amazing supports in my life.

I feel less alone to know others understand or have travelled this road as well.

Knowledge and strength from shared experience

Encouragement

Hope that we can cope

Kindness

A friend who texts me everyday with a nice thought.

Seeing me without judgement.

please stick around

walk with him and listen

simple yet flexible

As we go through this together know that:

support needs will change

understanding what to expect allows preparing for it
 being proactive is better than being reactive
 family members need to be willing to help each other
 Taking time to listen and giving time for talking
 Providing support strategies that are specific to my condition
 Willingness not Reluctance
 Optimism not Pessimism
 Proaction not Reaction
 Action not Procrastination
 A genuine Appreciation and Thankfulness for the Willing, the Kind and the Pleasant
 Support for my FTD could be listening, believing, searching the illness online to help
 us.
 Caring, helping with visits, hugs, drives and professional help to educate doctors and
 general public.
 But if you want to show me your support
 Learn to accept me as I am,
 With all my faults and errors
 Don't scold me like a child
 Just cover for me and let me believe
 In the resiliency found in love
 Support is family being by your side
 Support is neighbours and friends asking if they can lend a hand
 Support is workers willing to lend a ear
 To me support means less stress
 Always include stimulation
 Always include companionship
 Always include joy in every day

End of data set

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