



What's Life Like?



Introduction

This book of poems has been created by the 'What's Life Like?' group in Barnsley.

We are a group of people living with dementia who have come together with one voice to tell our story. We have used poetry and visual art to help you understand what life is like for us.

The 'What's Life Like?' group is an involvement group facilitated and supported by staff and volunteers from Alzheimer's Society in Barnsley.

Looks like, sounds like, feels like

Black, black
Red, blue, purple
Yellow, at the start
Grey, green, pink.

Crackling
Radio Signal
Shriek.

Doughy, mushy
Not very nice
Sticky
Like a hand.

Bitter sweet
Sour.

'What's Life Like?' Group: 6 November 2017

A picture of me

'Who do you see?'

A stranger
Strange
There's something familiar
Is that me?

I'm waiting
Waiting for something
I like to be doing things.

Tricia: 18 September 2017

Everybody's hands are different

Our hands are unique
My hands are usable
Our hands can communicate – show friendship, – aggression, make a point
My hands are hardworking
Our hands are for eating, cleaning, washing, – cooking, being creative with, teaching
My hands bring back creative memories of being a primary school teacher
Our hands are expressive, using hands to explain things
My hands are for playing the piano
Our hands can be sign language
My hands can cradle little babies
There are two sides to hands, two sides to our personality
My hands have grown stronger over time – for gripping

Our hands, our fingertips, are our DNA
Everybody's hands are different

My hands are unique.

'What's Life Like?' Group: 30 May 2017



I prefer the yellow

One day I feel it's good
Then all of a sudden, it's back
I've lost the words
The stutter has got worse.

At the time, the black meant something
I write things down when I'm in the house
It's got to be better for me to go outside
Colours show times it's coming out.

I keep looking for things and –
It's frustrating more than anything
Sometimes it's worrying.

Clive: 20 November 2017

I'm me

I'm me
I've always been me
I don't want to be treated different
I don't want to be known for –
My dementia
I'm me.

'What's Life Like?' Group: 10 July 2017

Being part of a group

Companionship
People you can listen to
People you can talk with
Nice to get out of these four walls

Activity
Being able to get out with the camera
Laughter
Fresh air
Sense of belonging

Loss of funding
Loss of group
I get really angry
I get lonely
Withdrawn and lonely.

Alan: 27 September 2017

Loss

Photographs

If I didn't have them up there I'll forget
I'll forget about my family

I thought I was going to be ok
It's only been months when I got it bad
I can manage all that now –
Without thinking about it

I know it's bad
It seems – it's only me who's got it
And not the other people
Everyone seems to be healthy
I know it's selfish

It's my speech more than anything –
That gets bad
I don't realise I've got Alzheimer's
I'm only getting better
Cos other people, like you, are doing it for me
If you weren't here I'd be even more scared.

Clive: 11 October 2017

I always wanted to be a driver

I've always been a driver
I always wanted to be a driver
Driving buses and lorries
I'd go to my aunties on the bus
And sit and watch the driver

I taught others to drive
An advanced driver – passed with flying colours
When I got Alzheimer's –
They stopped me from driving
I'm not driving for a living

Pam can drive now
I've accepted it
And Pam drives now –
Wherever we go to – it's only local

It's not a job anymore
It's visiting people
It annoys me when I see people driving –
And reading their maps.

Dave: 25 September 2017

Protecting my family

Family, important
I don't tell them about my troubles
I don't want to trouble them
I don't want to worry them
Got their own lives to live.

Might be I want to protect them –
From worrying about me
I've got everything I need
I feel vulnerable being on my own all the time.

Jessie: 20 November 2017



Que sera sera

Que sera sera
If there's something going off
And you can't do owt about it
It's no good worrying

If you can accept what's going to happen to everybody
It just comes a bit earlier for some
I've been fortunate
Because I'm seventy one year old
Fit and healthy
Apart from memory problems

Sometimes I've got the words
But they don't come out of my mouth
It's frightening –
If you start worrying about it

If I had the choice
If they could get inside my head
And alter little switches
It would be ok.

Derek: 4 October 2017

Like living with somebody else

I am not the person I used to be
Two people –
Maybe three people sometimes –
With a different language.

I know who I am
What I want to say
But it doesn't come out like that
Sometimes, I just give up on it
Snap
The words just go anywhere
Cos I forgot what I want to say.

It's not the same anymore.

'What's Life Like?' Group: 10 July 2017

'What's Life Like?'

Sometimes I think, Yes! It's gone away
Maybe that's selfish?
Most of the day I'm fine
Sometimes, half the time I could speak
But then might have a stutter.
Anything I've lost before –
That won't come back, will it?

My job was driving in big vans
I enjoyed it
I must have done a good job
Otherwise I wouldn't have that certificate.
They must have been thinking –
Something was wrong with me then,
And I didn't know.

Reading is a bit blurry
In the past, the only thing I read is the newspaper.

I don't like it, that's for sure.
Most people will stop and speak to me
You being patient is important to me.
I go out walking, it gets me out.
There might be one or two days I get bad
I can't remember what I want to say
And I feel a wee bit down
Most of the days, I can pass it off.

It's not stopping me walking
Will that change?
At the moment I can walk
And I can run.

Sometimes I forget
I still forget things
I think, most days I'm sure I'm fine
If I do forget some things –
It's because I've been here
Not been out – I've been in the house.

Clive: 11 October 2017



When it's red, things are becoming more clear

When it's black
As the day goes along
You can't find words
Then it goes green
And things start to get better.

Grey, is not knowing my children's names
When it's red, things are becoming more clear
Yellow is a good day.

Another day it becomes black
And that's when I feel a crackle in my head
A bit like a headache, but crackly.

Joyce: 20 November 2017

Picture of me

Is that me?
An old woman
I know that's how I must look.

Looks like I'm having fun
I think it's a good photo
I see my sister in me.

It all looks like me
I just look normal
To look at me you wouldn't know.

Joyce: 12 September 2017

It is...

It's life changing
It's like someone's picked you up
Took your brain out
And put you somewhere different.

Derek and Avrel: 4 October 2017

My Life

It don't bother me at all
I just get on with it
I just get on with normal work.

Let me think...
I like to go on holidays
Different people
Different things to look at
Huskies, Whales, Bears
Dolphins, Eagles.

Family
We all go together
There's always somebody there –
If you need them
We just enjoy everything
We enjoy ourselves.

Tricia: 18 September 2017

Loneliness and Isolation

Talking to yourself all the time
I would explode.
Loneliness ...
Sometimes I sit in my chair and
Go to sleep. Sometimes I just –
Sit, and sit.
I can feel lonely in a crowd.

I wouldn't think loneliness,
Cos I've got all the family
Grandson, daughter, babysitting.
I couldn't cope with owt like that
Some people just don't want
To talk to people.
I never feel lonely; too many of us.

I'm not so sure.

'What's Life Like?' Group: 15 May 2017



It's like...

It's like fire and flames

Tricia: 4 December 2017

Seconds

If I've got to remember something
And I can't find out without asking –
It becomes a problem
Sometimes you're going happily along
If you go into a shop or something
When you want to buy something
It becomes a bit embarrassing –
Not remembering

Sometimes they're embarrassed,
You're not, they are
Some people are ok
Some are a bit more harsh
It hurts a little bit –
In different doses
People take advantage of you
Think it's funny.

Derek: 4 October 2017

Happy as I am

I'm happy as I am
I can't change what I am
I just get on with it
They say I've got dementia
You just get on with it.

I don't want all and sundry to know
Why should I –
Nothing to do with them.

I don't feel any different –
Six months on
I still do everything I normally do
I haven't got problems with owt.

You've got to keep busy – doing things
It's no good giving up – is it?
You can't let it spoil your life.

Val F: 19 September 2017

Living with memory problems

It's all to do with the memory thing
Not easy, I've to write things down
I'm lucky I've got Susan –
As she reminds me about things

It's a nuisance
It just went
I don't know why it went
I just got up one day and couldn't remember

I write things down if I want to remember things
I carry on as normal
I go out as much as I can
I like to mix with people
It's very important
I hate to be on my own

I get on with life as best as I can
It's not good
Not when you've been used to being so very different
I don't think it affects my life
I just carry on as normal
When you're on your own, you've got to

I've accepted that I've got it
You can't stop it
You can't get rid of it
You've just got to carry on the best you can
It's altered my life altogether

I had a very full life before
I was on the committee for older people
I used to give talks
Not anymore
Now, they have to tell me what to do

It annoys me
Having this 'blummin' memory problem'.

Jessie: 3 October 2017



Black and white

Black
It's dark, scary
Grey
Purple I like, because it's bright
Opposite to dark
Light hearted, happy
Enjoying doing things.

A cheerful sound
A horrible sound, black
Listening to sounds of water
Sounds nice, lifts you up.

Scary, dark sometimes –
When I don't know what to do
I feel all hemmed in when –
It's black.

Val F: 20 November 2017

The things I used to do

I built the porch
I built the walls
I made the fence –
Every panel
I built the garage
I made the door
I block paved the drive
I put the windows in
I made the cabinet
I extended the kitchen

Other people carry on as normal
People with Alzheimer's –
Can't do what they used to do

Now I go out
Now I read books
Now I belong to groups
Now it's too cold
And I watch TV.

Derek: 4 October 2017

Tips for daily living

Walking the dog
Going shopping with Pam
The gym at BIADS – treadmills, bicycles
Walking group
Keeps all your body working.

Meeting other people
Talking to them
It helps them as well
Cos a lot of them are in the same boat.

Visits to family
Looking after grandchildren
Taking photos
Eating cake
I only eat my dinner –
So I can have cake.

All these things keep me sane –
Without a lot of effort.

Dave: 25 September 2017

Other people

It's not easy to live with –
When you can't discuss it with other people
Well you can't tell everybody you've lost
your memory
They'd think you were daft

It's not an everyday thing
Losing your memory
In fact, I find it quite hard to live with

People ought to be told and informed
If people understand what it's like to lose
your memory
They would know what to say to you
And that makes me feel better.

Jessie: 3 October 2017

Like plants

We are all like plants
Because when you are born –
That's where it starts
If you don't give plants water –
They will die.

Derek: 4 December 2017

Alzheimer's at sixty

A diagnosis of Alzheimer's at sixty, sixty one,
I didn't like it.

I can remember going to the shop –
And coming back...
With nothing.
Going to the town
And not knowing where I was
I rang for Tom to come for me.
Looking for stuff –
And it's there in front of me.
Wringing my hair out.

I knew there was something not right
But you just don't say owt
Thought it were just me –
Being daft.

I thought there was somebody at the side of me –
Back then.
Even then –
I didn't let them know I didn't know em,
But I didn't know em.

I think it went on for a long time
Whether it were me that didn't want to know?

I accept it now
It's not my fault.

Joyce: 12 September 2017

Something to look forward to

New places; new people
Wonderful, wonderful Copenhagen.

A journey to the caravan.
Caravanning. For me,
It's camping; going to the pub.

My dinner. Some better weather
Tea Dance tomorrow.

Visits to the Safari Park
Family Sundays.

'What's Life Like?' Group: 15 May 2017



And then...

The yellow bit is the brain
The black bit is the bit that is all the trouble
The black bit grows,
And then...

Derek: 4 December 2017

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