

HOW WE TALK ABOUT DEMENTIA

Good practice guidelines for language and images

Co-produced by a review panel of people living with dementia:

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with support from Philly Hare*

KYN

IN PARTNERSHIP WITH



Innovations
in Dementia

CONTENTS

04

Foreword from Caroline Naidoo,
Managing Director of KYN

07

Introduction

08

Talking about dementia –
how does language make us feel?

10

Talking about dementia –
what principles should we all follow?

11

Describing people with dementia

13

Describing people who support
a person with dementia

14

Diverse identities

16

Sensationalism and euphemisms

17

Slang

19

Language in a service setting

20

Portraying dementia in images

24

Panel Biographies

32

Resources

FOREWORD

Caroline Naidoo, Managing Director of KYN

I have long believed that by engaging with people and their families, we can best learn how to support and value them. I am pleased that there is now widespread recognition within health and social care of the importance and value of involving people with lived experience of dementia (people living with the condition and family carers) in audits of services and developing approaches that will help reduce inequality and stigma surrounding the condition. Care professionals and families, however, still find difficulty using the right words and images when talking about those living with dementia. As a result, they often fall back on negative stereotypes perpetuated by the media, which can, unfortunately, be offensive and disempowering.

We wanted to draw upon people's lived experiences of dementia to create a new set of guidelines that was inclusive of their views, experiences and expectations of how they are portrayed in the media. The guideline creation is an example of how including the perspectives of people affected by dementia can be successfully utilised in educating the media and broader society.

In line with KYN's value, 'Be Courageous', we believe these guidelines will challenge misconceptions, enabling everyone to find the courage to face the uncomfortable truth and circumstances and deal with things openly, honestly and with compassion for ourselves and others. The guidelines will be used to educate the KYN team at a home level and across the wider organisation and have already informed a recent review of the company website. This is another example of the meaningful involvement of people with lived experience in developing the services and activities of KYN and is part of the overall KYN approach to dementia care, where the voices of people living with dementia are at the forefront of all that we do. In early 2023, KYN invited people with lived experience to undertake a groundbreaking and innovative, dementia-friendly audit of its first care home just before it opened. The audit demonstrated that, through careful planning and preparation and good communication and support, people with lived experience of dementia can provide essential and meaningful feedback and advice on making a care home more dementia friendly.

In line with the KYN value, “Think Harder”, we realise there is always an opportunity to learn more and that everything can be improved by thinking a bit harder. The lived experience audit forms part of this open culture of learning and reviewing. The recommendations made have been acted upon and will help inform future builds.

KYN is a contemporary care home group offering an elevated approach to care: individualised journeys built around the needs and interests of its residents in beautiful surroundings, with life-enriching practices and outstanding hospitality. It aims to combine the quality of service and customer care associated with the upper end of the hospitality industry with professional, person-centred residential care for older people, including people living with dementia. The first home, KYN BICKLEY, opened in February 2023, with the second home, KYN HURLINGHAM, due to open its doors in early 2024. KYN continue to focus on central London, considering sites that may be unexpected for a care home, such as the Grade II listed building in the heart of Parsons Green.

As Head of Dementia at KYN, I bring a wealth of experience, having worked for over twenty years to improve the lives of people living with dementia and their families. I have supported and developed health, housing and social care teams through education, training, and role modelling current evidence-based best practices. As dementia is something many of us will experience, we must get this right for everybody. I hope the guidelines in this booklet will provide a helpful reference point and ensure that our everyday language no longer marginalises and stigmatises those affected by dementia.

Caroline Naidoo



INTRODUCTION

These guidelines have been created by a Review Panel of people living with dementia, working alongside Innovations in Dementia (iD). This is not about ‘policing’ language. The guidelines aim to help people portray dementia respectfully and without compromise, both in language and imagery.

The use of negative language, in care settings and wider society, to describe people living with dementia has been widely discussed since Kitwood wrote ‘Dementia Reconsidered’ in 1997. Much has been done in recent years to raise awareness about terms such as ‘dementia sufferer’ and ‘challenging behaviour’, and to promote the use instead of positive language. While interest in stories about dementia in the media continues to grow, there is much evidence to suggest that it is still considered a stigma by public and professionals alike. This is evidenced by the continued pervasive use of negative language, imagery and tone.

KYN aims to break down societal barriers around ageing and advance best practice around later life. Innovations in Dementia were commissioned to co-create a new set of guidelines for those working in media.

The work builds on the **DEEP language guide** and **film** which were co-created ten years ago, and other guidelines such as those created by Alzheimer’s Society 2018 and Alzheimer’s Australia.

Eight people living with dementia across the UK came together to form a Review Panel. They attended three Zoom workshops, facilitated by iD Director Philly Hare, in which they discussed both language and images. The use of stimuli such as actual press cuttings and media images created a lively debate, which focused particularly on how the ‘wrong’ language and images makes people feel.

Although these guidelines are aimed primarily at the media, we are confident that they will be relevant and helpful to many others – for example, to families, care services, health services, businesses, advertisers and policy makers.

TALKING ABOUT DEMENTIA – HOW DOES LANGUAGE MAKE US FEEL?

Words matter a lot. Images matter a lot.
And the Panel are clear that words
and images about dementia matter a lot too.

Sometimes it depends on how a word or image is used – the context, intent and nuance can be key. So a word or image can be ‘wrong’ in one context and ‘right’ – or at least acceptable – in another. In other cases, there is wide consensus that a particular word, phrase or way of portraying dementia is simply wrong. It may be offensive, incorrect, out-of-date, unbalanced or unhelpfully exaggerated – or all of those combined.

This is what the Panel say:

The ‘wrong’ language and imagery

- makes us feel angry
- makes us feel invisible – “no longer a person”
- makes us feel disabled and disempowered
- makes us feel excluded
- makes us feel depressed – “brings us down”
- could negatively affect diagnosis rates

The ‘right’ language and imagery

- makes us feel you are listening and taking us seriously
- helps fight stigma
- can entice readers into your article

“Not all dementia is
downbeat.”

Steve



TALKING ABOUT DEMENTIA – WHAT PRINCIPLES SHOULD WE ALL FOLLOW?

In our discussions, the Panel was in complete agreement that those directly affected by dementia can, and should, feel free to use whatever words they like.

If they want to talk about themselves as ‘sufferers’, or about caring as a ‘burden’, for example, that is their authentic experience and it is their right to describe it as such.

However, the Panel was also very clear that *the media* have a responsibility to use generic language very carefully. If they fail to do this, they can make it look as if everyone with dementia has the same experience, the same perspectives, the same trajectory. It was agreed that many people make mistakes unintentionally – they just need educating.

The Panel came up with 5 simple overarching principles:

01. Don’t stereotype, pass judgment or make assumptions. One cap doesn’t fit all.
02. Always show respect – avoid insulting, infantilising and belittling anybody.
03. See the person first, not just their dementia – value the whole of them.
04. Use neutral terms – avoid an unbalanced (usually tragic) narrative. Don’t exaggerate, sensationalise or use lazy euphemisms. *“There’s too much of the tragedy narrative. People usually forget about the humour in dementia and that we can still laugh.”* Julie
05. Don’t use headlines or images that undermine or even contradict the actual testimonies of people with dementia.

DESCRIBING PEOPLE WITH DEMENTIA

People with dementia are often upset by what they see or hear in the media. The ‘wrong’ words can make them feel angry, sad or frustrated. They also worry that these will entrench out-dated and inaccurate perceptions in the public.

The Panel call on the media to avoid using these words:

- Sufferer/suffer/suffering
- Victim
- Senility, senile or pre-senile dementia (Note: dementia is not just a condition of old age)
- Dementing/-ed (Note: this is often seen as very offensive)
- They/them (Note: as in ‘othering’; not we/us)

It is also important to describe/explain dementia in a neutral way. There is less consensus about the use of terms such as condition and disease. Perhaps dementia can be accurately framed as a neurological condition that affects the brain.

Some words which may be correctly used in specific situations should not be used *generically* to mean all people with dementia. These include:

- Service user (may be acceptable if it is used when discussing a service or services)
- Patient (may be acceptable if it is used when discussing a person in the context of a health setting/service)

Generally, the Panel preferred to be talked about as people with dementia or as people living with dementia.



DESCRIBING PEOPLE WHO SUPPORT A PERSON WITH DEMENTIA

Family members (or other care givers) are often called upon by the media to comment on dementia news stories or issues.

Care givers have of course an absolute right to tell their stories honestly and in their own words. But they sometimes use words which can feel offensive to those who have the condition.

While their perspective is of course essential and can be very moving, it is also right that we hear, at least as loudly, the voices of those who themselves have the diagnosis.

The media have a responsibility to avoid words which can be offensive. The Panel suggest that the media avoid the following words (except when directly quoting):

- Burden on (family, carer, the State etc.)
- Toll
- 'Losing' their partner

They suggest the following alternatives:

- Impact on
- Supporting/assisting a person with dementia
- Caring for a person with dementia
- Care partner
- Care giver
- Husband/wife/daughter/son etc.
- Family of choice/of origin

However, it is fair to say that there is no real consensus on the merits or otherwise of the terms carer, unpaid carer, informal carer, care partner or care giver. Many people say something along the lines of "She's not my carer, she's my wife/daughter etc."

DIVERSE IDENTITIES

People with dementia come from every section of society, and are often marginalised.

Ethnicity, gender, sex, sexuality, age, class, religion or having other medical conditions can marginalise them still further.

This means that representation of dementia in many different ways is very important. If we only show or talk about people with dementia as if they are all white, straight, elderly, married, middle-class etc., we ignore this variety, and risk alienating all those who do not fit into these boxes.

The Panel advises that the media should:

- Respect and apply preferred names, chosen pronouns, and self-identification (e.g. as a member of a particular group or category)
- Regularly assess the language used to ensure it is inclusive, respectful and current
- Sensitise others to these issues



SENSATIONALISM AND EUPHEMISMS

It is well-known that the media need to attract their audience's attention quickly, and that sensationalising an issue is a sure-fire way to do that.

But exaggerating or giving an unbalanced (i.e. usually negative) view is unethical, as it takes hope and positivity away from those affected, and makes wider society even more fearful.

For this reason, there are many words and phrases that the Panel would prefer the media to avoid using. They include:

Adjectives such as:

- Hopeless
- Life-ending
- Cruel
- Unbearable
- Pitiless/pitiful
- Impossible
- Devastating
- Incapacitating
- Sadly/unfortunately

Verbs such as:

- Crumble
- Succumb
- Erase
- Wipe out
- Fade away

Nouns such as:

- Pandemic/epidemic
- Affliction

Metaphors such as:

- Tsunami
- The long goodbye
- The dementia journey
- Long, slow death
- Empty shell

Remember: the Panel totally agrees that those directly affected by dementia can, and should, feel free to use whatever words they like. But *the media* have a responsibility to use generic language very carefully.

Alternatives include:

- Difficult
- Life-changing
- Affected by

SLANG

Few in the media would use outright slang in an article which is specifically about people with dementia.

But it is worth noting that words such as those below are often used in other scenarios – and they are found very offensive:

- Bonkers
- Not the full shilling
- Away with the fairies
- Doting
- Cuckoo
- Doo-lally
- Not as sharp
- Losing your marbles
- Not all there

Being told that “You don’t sound/look as if you’ve got dementia” or “You’re far too young to have dementia” is also often taken as very offensive. This is because there is no particular ‘look’ to a person with dementia – and it can actually affect any age.



LANGUAGE IN A SERVICE SETTING

Many of the terms still commonly used in health or care settings have the effect of othering and de-humanising the person with dementia – of putting the condition before the person.

The Panel recommends that these should be avoided:

- Feeding
- Dressing
- Toileting
- Wandering (“a wanderer”)
- Aggressive (“a shouter”)
- Challenging/difficult behaviours
- BPSD – ‘behavioural and psychological symptoms of dementia’
- Sitting service or sitter
- The ‘dementias’ (Note: as in those in our setting who have dementia)
- The dementia people (Note: as in those in our setting who have dementia)
- A dementia case (Note: this is very medical and de-humanising)

Phrases (or ways of looking at things) that are preferable include:

- Other people’s behaviours (or an environment) that the person with dementia might find difficult or upsetting
- Distressed/frustrated responses
- Supporting to:
 - eat
 - get dressed
 - walk around
 - go to the toilet
- A person who likes walking
- Unmet needs

PORTRAYING DEMENTIA IN IMAGES

The images we use to portray dementia can be just as important as the words. They stay in our heads and affect our attitudes – whether or not we realise that.

The Panel looked at a range of images, and then grouped them into 4 common categories:

Graphics

Typically these graphics/pictograms depict fuzzy brains; jigsaw pieces; mazes; light bulbs; sparks and wires; cogs; inside the brain; leaves flying away; exploding heads. Choosing graphics may avoid some of the pitfalls of using photos of real people (including asking for permissions).

Generally however the Panel was not too keen on these. They said they can hurt the eyes, be hard to understand, be depressing and look too ‘arty farty’. Some were described as ‘like a horror movie’.

Photos of people looking afraid, worried and/or confused

These photos often depict someone (who may well be a model) with their head in their hands. Overall the Panel found these images negative, depressing, stigmatising and even offensive. They said they depicted what looked like a ‘permanent nightmare’ and this simply isn’t what dementia feels like.

All of us get frightened and confused at times – but people with dementia generally have a mix of good and bad days, happy moments and sad moments.

“We all worry at times. It a part of life, not dementia, so why add to stigma and join the two.” Julie

“Representations of horror are not appropriate.” George

“It’s like everyone’s living in a nightmare.” Julie

On the other hand, there is nothing wrong with an image of a pensive or neutral face.

“I want to see just normal people leading their lives like we do. Not smiling does not equal misery. Not dancing does not mean misery.” George

The Panel feel that generally the photos used are of elderly people – they recommend they should also include younger people.

Photos of people who look happy and engaged

The Panel definitely preferred these photos. They liked the images of people in a *normal context*, doing something e.g. on a swing, in their garden, at work or with their family. They particularly liked the images of people being independent e.g. going for a walk, or volunteering.

“They lift you, they put a smile to your face” Gerry

The Panel also liked photos of people in relationship with others e.g. as part of a couple or a family. The images should be fully inclusive, showing diverse relationships and ‘family of choice’ as well as ‘family of origin’.

However, they also felt that there is no need for every image to be ‘happy clappy’, as that is not realistic either.

Photos of people in care settings

The Panel generally liked these, as long as they are positive and caring. They did point out however that they may not be a realistic image of care settings, which are currently very over-stretched (and possibly therefore not always very caring).

However, they felt such images should not be used unless the article is actually *about* people in a care or health setting. Otherwise they perpetuate the stereotype that everyone with dementia is in a care setting, or even at the end-of-life.

“That depiction has to change, otherwise nothing’s going to change.” Gerry



KEY PRINCIPLES FOR IMAGES

The Panel came up with 9 key principles for imagery in the media and other places:

01. The image should always complement the text – don't allow one to undermine the other.
02. All images should be of real people who actually have dementia. Stock images (which usually use models) are very obvious and should be avoided whenever possible (this includes the much over-used 'wrinkly hands'). *"Although I don't like negative, dismal images, nor do I think happy, modelled images, usually from USA, are appropriate. They're like adverts for retirement villages or private Medicare."* George
03. The image should always be relevant to the specific topic of the article. It's better to have no picture than the wrong one.
04. If the article is about a specific person, always try to use a photo (or ideally, more than one) of them (with their permission of course). *"A set of pictures of a real person's real life would be best if you want to illustrate dementia realistically."* George
05. Use several photos if at all possible, to show different ages, ethnicities, gender etc. *"You can't get one picture that truly depicts dementia."* Steve
06. Younger people with dementia (though they are in the minority) need to be portrayed more often – this is not exclusively a condition associated with later life.
07. Images illustrating text do not have to be of people. It all depends on the topic.
08. Icons and silhouettes can also be useful. *"You don't see the age of the person, you don't see their skin colour or anything else."* Allison. However they should not be child-like or demeaning.
09. Relentlessly negative portrayals can have a cumulative negative impact e.g. they may stop people talking to their family or seeking a diagnosis. Positive portrayals have raised diagnosis rates in other previously stigmatised conditions.

PANEL BIOGRAPHIES



ALLISON
BATCHELOR

I live in Dundonald Northern Ireland with my husband and daughter.

I was diagnosed with Young Onset Dementia (Alzheimer's) in April 2017. I was 57 at the time, and I had known for over five years that something was wrong. However, being a woman, I kept being told it was the menopause. Before my diagnosis I worked as a British Sign Language Interpreter. I absolutely loved my job, but I had stopped working a few years prior to being told I had Alzheimer's because I could no longer work smoothly or quickly between two languages. I wasn't asked to stop working, this was a decision I made myself after discussing it with my husband.

I'm an active member of Dementia NI and have worked on many awareness sessions with them. We've worked alongside Queen's University and the Ulster University on a wide range of exciting projects. I'm also involved in projects with Innovations in Dementia. Being involved in these projects stimulates my brain and, more importantly, helps me maintain my self-worth. You lose so much once you receive your diagnosis that anything that can give you something back is totally invaluable. An important thing for me is

looking at my calendar and seeing I have meetings to go to. I get depressed and stressed when I have nothing to do.

My Dementia mainly affects my sense of direction. I get very disoriented in shops. Lack of signage or poor signage is my real bugbear and I also have sensory issues, for example carpets with wild patterns or black rugs are a no-go for me. Lots of background noise can make me very unsettled and I have to get to somewhere quiet as quickly as possible or I will get agitated.

My son and his partner have two beautiful children. I simply love being a Nannie and spending as much time with my grandchildren as I can. I love all things to do with craft, particularly hand sewing or knitting. I also enjoy cooking and baking but now need to work from very detailed recipes. I make sure I have everything laid out before I start. I then use Alexa to help me with timers. This enables me to still do things I really enjoy. Given the chance I would go to the theatre daily - that obviously isn't possible, but I do go as frequently as I can. I particularly enjoy musicals. This list could go on and on. Basically I want to live the best life for as long as I can.



GEORGE
ROOK

In my working life I've been a chartered accountant, a teacher of English, and a school business manager. I was diagnosed with mixed Alzheimer's and Vascular Dementia at 64. My Dementia affects me in several ways: balance, word finding, short term memory, excess noise, brain fog, loss of awareness... These and my other medical conditions, including diabetes, kidney disease and heart disease, make life challenging to manage at times, and I have to think very carefully (long and hard) about even the simplest of tasks of everyday living.

I'm 72 now. I live in the North Shropshire countryside, surrounded by farmland, and I have a large garden and field. I've been growing flowers and vegetables all my life, and I love being outside. I have a Vizsla dog which I take out around local fields every day, to keep me reasonably exercised. I live with my wife, and I have three children and six grandchildren. So far!

I've been closely involved in the DEEP Network since my diagnosis. I started a DEEP peer support group for people living with dementia in the Shrewsbury area seven years ago, and I continue to facilitate it.

Our members have been involved in several research and consultation projects. As part of 'the Four Amigos' (all of us living with dementia) I have made over 20 films about all sorts of aspects of life with dementia. These are available on YouTube at @georgerook460. I've been increasingly involved in research about dementia, and I'm currently a co-researcher on two large studies about sleep and social prescribing respectively. I worked with the Dementia Pioneers and Innovations in Dementia to develop ways for people living with dementia to carry out their own research.

In 2021 I learned to paint in water-colour and I get huge pleasure from doing this every day. I also write a blog called 'Living with Dementia as Well as I Can'.



GERALD
KING

Everyone calls me Gerry. I'm 60 and I live in Glenrothes, Fife in Scotland with my wife Trisha and my middle son Daniel and daughter Stephanie.

I started having problems with my short-term memory at the age of 53, although my wife claims that she had noticed changes in my personality 2-3 years prior. After visiting our GP I was referred to the local psychiatrist and from there I was put into the care of a specialist team at Victoria Hospital. After approximately 18 months of prodding and testing, I was diagnosed with Young Onset Alzheimer's disease at the age of 55. I had to retire from work and surrender my driving licence. I lost work colleagues and personal friends of nearly 40 years who just stopped coming around.

But I was fortunate to meet an amazing lady from our local council, we struck up a great friendship and started to carry out Dementia Awareness presentations all over Fife. This culminated in approximately 300 local businesses becoming dementia friendly and around 3000 people Dementia Friends.

I'm also a founding member of a peer support group in Fife called STAND. This is a charity facilitated by people living with mild to moderate stage Dementia and their wives, husbands and families. We provide peer to peer support to people who are worried about Dementia, who are going through the process of diagnosis, or who are living with mild to moderate stage Dementia. Our ethos is to empower and enable people with lived experience of Dementia to be the best they can be and to live well.

I'm also a Dementia campaigner and activist. I've been involved in Dementia research with many UK wide universities including St Andrews, Edinburgh, Stirling, Northampton, Bradford, London and Nottingham. I've also been very lucky to represent people living with Dementia on a number of panels, including Age Scotland, About Dementia and the Scottish Government.



LORRAINE
DUNN

I'm 69. Born in Northern Ireland, I moved to Scotland and now live in England. I have one son and five gorgeous grandsons.

I was a primary teacher, then in special needs teaching. Although I absolutely loved it, I left teaching after 18 years - too much paperwork! I ended up as admin in Social Services, which was great.

In 2014 I noticed a substantial shift in my memory. At first I dismissed it, believing it was just normal for my age and how busy I was. But I decided to see my GP who referred me for the usual tests, which I passed. That was the end of that, or so I thought. A year later, there were other changes. I was no longer able to make quick decisions, and had difficulty processing more than one piece of information at a time. So it was back to the GP, referral for the mini mental test, and an MRI scan. You can imagine how I felt when the consultant told me the MRI showed early indications of Alzheimer's and Vascular Dementia.

I don't think I even grasped what he had said. I went home, told my husband, cried, got up the next day and said 'Stuff this! It's not going to beat me!'. I was 62 at the time.

It hasn't beaten me ... yet. But it's slowly gaining ground. In 2020 I came across the DEEP Network, joined an online group and from there have become totally involved in making a difference for people with Dementia. I facilitate an ever-growing group in Darlington, am involved in research opportunities via Innovations in Dementia, and am lead adviser for Dementia Friendly Darlington. I've never been so busy.

My diagnosis was not the beginning of the end. It was the start of a new beginning.



STEVE
KENNEDY

Originally from County Tipperary, I met my wonderful wife Carmel the very first day she came to England from Ireland. We returned home to marry in 1990 and settled back to life in a very rural part of County Fermanagh. We're still together 35 years later.

I worked as a long-distance lorry driver, travelling from Ireland and the UK to far destinations such as North Africa, Scandinavia, and the Middle East. I spoke German fluently and could also converse in French, Spanish and a wee bit of Turkish. But I started to mix up my languages and not be able to recall key words. My diagnosis of Vascular Dementia and early onset Alzheimer's in 2016 devastated both of us.

I lost my truck driver's licence the same day. Over the following 12 months I went into a very deep depression. But Carmel never gave up on me, carrying me through that traumatic time.

Luckily I came across Dementia NI. Being able to talk so freely with people of varying levels and types of Dementia gave me the huge boost I so badly needed. I completely immersed myself in everything they were doing, and now had a wonderful circle of genuine friends who understood everything I was going through.

I'm now a very active member of Dementia NI and also the DEEP Network. Being a Dementia Pioneer has given me the chance to work alongside academics as equals in research programmes.

I now see my world with completely different eyes and feel that I have a purpose in life. Through my work with Dementia NI, the DEEP Network and the Pioneers I genuinely feel that, one step at a time, I'll be able to make things a wee bit easier for those coming along behind me who receive this life-changing diagnosis. I thrive on every project, and I believe it's always worth it, even if only one person gets an easier ride through their Dementia journey.

Carmel and I have been able to turn our hobby of showing dogs into a full-time passion and we've been blessed with success, including three successive breed wins at Crufts, the world's largest dog show. I'm now a qualified show judge with the Irish Kennel Club. When I step into the showring, I always have a wee chuckle to myself, thinking "people with Dementia cannot do this!". I'll never allow Dementia to define me.



JULIE
HAYDEN

I'm from Halifax in West Yorkshire. After qualifying as a nurse at 20, I headed off to London to get better experience on my CV. I spent all my ill-gotten gains on exploring all the arts that Sin City had to offer, as I only anticipated staying for a couple of years. But life doesn't always work out like that. I met a chap, married and brought up two children, while working a variety of jobs as breadwinner of the family, including being a classroom assistant in deaf education. As my marriage was coming to an end I entered Brunel University and got my degree to become a social worker in Older People's Services, a large part of which involved supporting people with Dementia.

However, around this time my own life-impacting symptoms began. Though they were never investigated, these led to ending my career. As I was a woman of a certain age (my late 40's) it had to be the menopause - but life's not always like that.

My health fluctuated wildly over the years, but it was only after being admitted to a mental health unit that I was given a brain scan which showed cerebral atrophy. Still, the consultant psychiatrist assured me that it couldn't be Young Onset Dementia as everyone in my family had had Late Onset. I was diagnosed six months later at the age of 54.

I immediately knew I wanted to be active. I started my own peer support group and got involved in research and education through various universities. I campaign with all Dementia organisations. I'm busier now than I ever was as a paid employee. Some may think that our lives stop at diagnosis, but it's really not like that.



TERESA DAVIES
(DORY)

I was born in Mold, Flintshire in 1953. I left school at age 15 with no qualifications and I worked first of all in a cake shop. I got married, and found a job in a garden nursery, which I loved. So I went to college one day a week to study landscaping, and I worked in that area for 20 years.

I had two children but then divorced at age 40. Subsequently I was hit by a car that mounted the pavement at 80 mph. Unsurprisingly I suffered life changing injuries. Then at 59 I was diagnosed with Alzheimer's disease, and I went through a very bad time.

My life saver was the DEEP Network and Innovations in Dementia. Through them, and the peers I have met, my life has totally changed. I am a Dementia Diarist, and also one of the 'Four Amigos' – we have published many videos of our conversations.

I have also been an active member of the Dementia Enquirers programme, in which people with dementia are 'in the driving seat' of research.

I give educational talks to students at Bangor University and am also part of The Caban Group which is connected to the university. All this has helped me to live as well as I can with Dementia.

Now usually known as Dory, I still live in Flintshire and I have two adult children and three grandchildren.



RESOURCES

Useful Organisations

Age UK

Provides information and advice for older people about benefits, care and age discrimination.

www.ageuk.org.uk

Alzheimer's Society

Leading the fight against dementia.

www.alzheimers.org.uk

Alzheimer Scotland

The leading dementia organisation in Scotland. Campaigns for the rights of people with dementia and their families and provides an extensive range of innovative and personalised support services.

www.alzscot.org

Care Quality Commission

Independent regulator of health and social care in England.

www.cqc.org.uk

Dementia UK

Charity intent on improving the quality of life for people with dementia and their carers. It promotes and supports the development of Admiral Nurses, specialist nurses who support the needs of family carers and people living with dementia.

www.dementiauk.org

Dementia – NHS Choices

Provides useful information about dementia including causes, symptoms, diagnosis and treatment, with links to other resources.

www.nhs.uk/conditions/dementia

Journal of Dementia Care

The Journal of Dementia Care (JDC) is a multidisciplinary journal for all professional staff working with people with dementia in hospitals, nursing and residential care homes, day units and the community. It is available via subscription and distributed throughout the UK and internationally.

www.journalofdementiacare.co.uk

Lewy Body Society

Charity that campaigns to raise awareness of Lewy body dementia in those who need to understand the disease and its impact – people living with Lewy body dementia and those who can make a difference to their futures.

www.lewybody.org

Social Care Institute for Excellence

Social Care Institute for Excellence (SCIE) improves the lives of people of all ages by co-producing, sharing, and supporting the use of the best available knowledge and evidence about what works in social care and social work.

www.scie.org.uk

Rare Dementia Support Group

Rare Dementia Support offers specialist social, emotional and practical support services for individuals living with, or affected by, a rare dementia diagnosis. Their vision is for all individuals with, at risk of or supporting someone with one of these forms of dementia to have access to information, tailored support and guidance, and contact with others affected by similar conditions. RDS welcomes people from all areas of society affected by a rare dementia regardless of gender, age, marital or family status, race, ethnicity or sexual orientation.

www.raredementiasupport.org

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