**Slide 1 Intro**

Good morning, thank you so much for inviting me today and giving me the opportunity to talk to you all about dementia.  My name is Nicki, I am the Community Fundraiser for Greater Manchester, I’ve worked for Alzheimer’s Society for just under 4 years now and have to say, last couple of years was the hardest in my career so far.

The pandemcia was difficult for everyone, especially people living with dementia.  Between March and June 2020, 1 in 4 people who died with COVID-19 had dementia.  It was reported that 95% of carers experienced a negative impact on their mental or physical health.

Overnight they were ripped from their support networks, crucial services were suspended, and many spent more than a year without being able to see or hug the ones they love.

As there is currently no cure for dementia, this was valuable time they couldn’t’ afford to lose.  It is with thanks **everyone** who has supported us that has enabled us to be there for **everyone affected by dementia.** Some of the topics we cover can be quite distressing and as much as I’m advocate for living with dementia, the reality is it’s often very difficult for people.  If you are affected by any of them please get in touch, details will be sent out after the session.

I’m not an expert in dementia so if you have a question that I can’t answer I will certainly try get the answer and I need to let you know that if you do share something that would raise concerns about a person’s safety, I can’t promise to keep it a secret. I may be required to pass this information on to the Safegurading team or Local Authority for support.

**So before we get started, I’d like everyone to have a bit of think about the first word that comes to mind when you think of dementia and pop it in the chat box.**

**NEXT SLIDE**

**Slide 2**

A bit about us - **Who we are?**

We're a vital source of support and a powerful force for change for everyone affected by dementia.

We want people living with dementia and their carers to live more fulfilled and less fearful lives, free from stigma and inequality.

**​​​​​​​**We’ll help people affected by dementia now and in the future through some of the hardest and most frightening times so we can improve their lives and avoid reaching a point of crisis wherever possible.

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**Slide 3 – What is dementia**

Few key facts that form a theme throughout this session and hopefully ones for you to take away

1. Dementia is not a natural part of ageing - Not everyone who grows old will develop dementia and not everyone who develops dementia is old. People in their 20s have been diagnosed with dementia, although this is very rare.​

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1. Dementia is caused by diseases of the brain- In the same way that any other organ can be damaged by disease (e.g., kidney disease, liver disease), dementia is caused when diseases physically damage the brain. Imagine that the brain is a collection of thousands of fairy lights, representing a memory, a skill or a function of the brain. Now imagine that dementia is causing some of those lights to **flicker dim or switch off completely.** For each person this will happen in a different order and different "lights" will be affected.​ Just like with other diseases, a healthy lifestyle that features regular exercise, a balanced diet and not smoking can help reduce your chance of developing dementia. What’s good for your heart is also good for your head!​

1. Dementia is not just about losing your memory  -

1. Motor skills – Someone with dementia might struggle with using a knife and fork or climbing up and down stairs.​​
2. Sequencing – someone with dementia might struggle with getting a task in the right order, like getting dressed in the morning.
3. Changes in inhibition – For example someone with dementia used to be a very quiet shy person and now they are outgoing.​​
4. Visual perception – Some examples of this are difficulty judging or seeing colour contrast. A shiny floor might look wet or patterns of fruit on a tablecloth may look real and someone may reach for a piece of fruit.​​ A black mat for drying your feet in front of a shop may look like a big black hole
5. Communication – A person with dementia may forget words or use the wrong words, for example calling a dog a horse.

1. It is possible to live well with dementia

1. There is more to the person than the dementia

Next slide

**Slide 4 – video**

So that’s a lot of facts to take in!  I’m often asked to describe what dementia is and what it’s like to live with and I think the best way to understand what having dementia is like is to hear from someone who has a diagnosis.  So, we’re going to watch a short video of Peter who is living with dementia. PLAY VIDEO

**Slide 6 – Spotting the signs:**

**Symptoms of dementia**

Each person is unique and will experience dementia in their own way. I’m going to explain some of the symptoms someone affected by dementia might experience.

What are the most common symptoms of dementia?

The different [types of dementia](https://www.alzheimers.org.uk/about-dementia/types-dementia) tends to affect people differently, especially in the early stages. Other factors that will affect how well someone can live with dementia include how other people respond to them and the environment around them.

A person with dementia will have cognitive symptoms (to do with thinking or memory). They will often have problems with some of the following:

* [day-to-day memory](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/memory-loss) – for example, difficulty recalling events that happened recently,
* concentrating, planning or organising – for example, difficulties making decisions, solving problems or carrying out a sequence of tasks (such as cooking a meal),
* [language](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/symptoms/dementia-and-language#content-start) – Dementia can affect how a person communicates and the language they use.  for example, difficulties following a conversation or finding the right word for something or use a related word (for example, ‘book’ instead of ‘newspaper’) or use substitutes for words (for example, ‘thing that you sit on’ instead of ‘chair’) or may not find any word at all.  They may also go back to the first language they learned as a child. For example, if they learned English as a second language, they may forget how to speak it.
* visuospatial skills – for example, problems judging distances (such as on stairs) and seeing objects in three dimensions, (train example)
* orientation – for example, losing track of the day or date, or becoming confused about where they are.
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**How does memory loss affect a person with dementia?**

People with dementia often experience memory loss. This is because dementia is caused by damage to the brain, and this damage can affect areas of the brain involved in creating and retrieving memories.

For a person with dementia, memory problems will become more persistent and will begin to affect everyday life. This can be difficult to cope with, both for the person themselves and for the people around them.

However, there are ways to help a person with dementia manage their memory problems and stay independent for longer.

A person with dementia will also often have [changes in their mood](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/apathy-depression-anxiety). For example, they may become frustrated or irritable, apathetic or withdrawn, anxious, easily upset or unusually sad.

Be aware that sometimes a person with dementia may behave in a way that appears they have depression, anxiety or apathy even though they don’t. There may instead be another reason for their behaviour – they may be reacting to their environment or how they are being treated.
For example:

* they may seem depressed because they are bored and don’t have enough stimulation
* they may seem anxious because they have an underlying unmet need
* they may seem apathetic because they are finding it difficult to choose between too many options.

With some types of dementia, the person may see things that are not really there ([visual hallucinations](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/hallucinations)) or strongly believe things that are not true ([delusions](https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/delusions#content-start)).

Some people with dementia will have hallucinations in different senses – for example:

* auditory hallucinations – hearing things that aren’t there, like voices or footsteps
* olfactory hallucinations – smelling things that aren’t there, such as smoke or perfume
* tactile hallucinations – physically feeling things that aren’t there, such as being kissed or insects crawling over their skin
* gustatory hallucinations – tasting things that aren’t there, such as a metallic taste in their mouth.

Visual hallucinations are more common in people with dementia with Lewy bodies, and often take the form of complex, vivid and very realistic hallucinations of people or animals. They often last for several minutes and happen often.

Hallucinations can be extremely distressing and can lead to the person with dementia becoming frightened and in need of support. However, some people find the hallucinations pleasant or comforting. It often depends on what they are hallucinating and how others respond.

How we respond to these and how we communicate can make all the difference.

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**Slide 7 – communication**

Dementia affects everyone differently so it's important to communicate in a way that is right for the person. Listen carefully and think about what you're going to say and how you'll say it. You can also communicate meaningfully without using spoken words.

Ways to communicate with a person with dementia

* Stand or sit where the person can see and hear you as clearly as possible – usually this will be in front of them, and with your face well-lit. Try to be at eye-level with them, rather than standing over them.
* Be as close to the person as is comfortable for you both, so that you can clearly hear each other, and make eye contact as you would with anyone.
* Communicate clearly and calmly.
* Go at a slightly slower pace than usual if the person is struggling to follow you.
* Use short, simple sentences.
* Don’t talk to the person as you would to a child – be patient and have respect for them.
* Allow time between sentences for the person to process the information and respond. These pauses might feel uncomfortable if they become quite long, but it is important to give the person time to respond.
* Try to communicate with the person in a conversational way, rather than asking question after question which may feel quite tiring or intimidating.
* Try to let the person complete their own sentences and try not to be too quick to assume you know what they are trying to say.
* Include the person in conversations with others. It is important not to speak as though they are not there. Being included can help them to keep their sense of identity and know they are valued. It can also help them to feel less excluded or isolated.
* If the person becomes tired easily, then short, regular conservations may be better.
* Prompts can help, for instance pointing at a photo of someone or encouraging the person to hold and interact with an object you are talking about.
* Try to make sure your body language is open and relaxed and avoid speaking sharply or raising your voice.
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It’s not just about how we communicate, but what we communicate as well.

What to communicate

Tips for what to say to a person with dementia

* Try to avoid asking too many questions, or asking complicated questions. The person may become frustrated or withdrawn if they can’t find the answer.
* Try to stick to one idea at a time. Giving someone a choice is important, but too many options can be confusing and frustrating.
* Phrase questions in a way that allows for a simple answer. For example, rather than asking someone what they would like to drink, ask if they would like tea or coffee. Questions with a ‘yes’ or ‘no’ answer are easier to answer.
* If the person doesn’t understand what you’re saying even after you repeat it, try saying it in a slightly different way instead.
* If the person is finding it hard to understand, consider breaking down what you’re saying into smaller chunks so that it is more manageable.
* Try to laugh together about misunderstandings and mistakes. Humour can help to relieve tension and bring you closer together. Make sure the person doesn’t feel you are laughing at them, there is more to the person than dementia.

NEXT SLIDE

**Slide 7: Dispelling myths.**

There are lots of myths around dementia.  I’m going to ask you a couple of questions about dementia– please shout out yes or no in the chat box – this isn’t a test and no right or wrong answer.

Is dementia a natural part of ageing a myth? Yes or no..  We know dementia is not part of ageing and that people living with dementia, can live well.  This does not mean that it is not challenging for everyone involved, but does mean by working together in communities, through research around supporting people living at home longer and independently we believe they can live a happy life.

Is it only old people who get dementia? Yes or no – there are 40,000 people under the age of 65 with dementia.

Is dementia hereditary? Yes or no – There is no evidence to suggest that dementia is heredity however, it can be genetic and can occur in much younger people.

Sadly, there is still a stigma attached to dementia which often prevents people from getting an earlier diagnosis, this can have an impact on the type of medication available.  Through Alzheimer’s Society initiative, Dementia Friends social action movement, we work hard to change the publics perception.

I mentioned earlier that 52% of population are affected by dementia, and again, these people are often our peers, neighbours and friends, the impact of dementia is devastating.

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**Slide 8: - video, dementia is killing me**

At Alzheimer’s Society, We’re here for everyone affected by dementia.  Last year family members provided over 92 million extra hours of unpaid care. 95% of carers we spoke to reported a negative impact on the mental and physical health.  It is often at these times when people need us most.  It is at these times we people are living behind closed doors dealing with this on their own.   Since the pandemic, thousands of people with dementia have seen a devastating deterioration in [symptoms](https://www.alzheimers.org.uk/about-dementia/dementia-symptoms-and-diagnosis) – due to lockdown causing social isolation, and health or social care service interruptions – reported by 83% of the family carers we spoke to.

This perfect storm has piled pressure on loved ones - 76% of family carers whose responsibilities had increased during lockdown said they were putting in more hours because of these worsening symptoms.

Tragically, even when putting in the exhausting extra hours, 45% of family carers felt the level of care their loved one with dementia needed was more than they could give. - Please video

We’re going to watch another short video that was used in our 2021 DAW to highlight the impact can have on loved ones and raise the issue that the social care system is broken.

PLAY VIDEO

Slide 9 – The Future

As we’re sat here this morning, 52% of the population are affected by dementia –

52% of the population will have been up early to make sure their mum or dad has had breakfast, is washed and dressed all before they head out to work.

52% of the population that are our friends, neighbours and people within our communities.  Trying to go about their daily life with the constant pressure of caring for a loved one.

Dementia is the UK’s biggest killer and there are around 900000 people with dementia in the UK, living with a disease where there is no cure. .  Can you Imagine going to see your GP and being given a dementia diagnosis, knowing there is no cure.  Knowing that dementia devastates lives. devastates lives - yet there is no formal support offered by the NHS.  So around 900,000 people living with no formal support.  This figure is set to rise to over 1million in the next few years, it could be much more as we start to realise the effects of the pandemic

We know everyone was affected in one way or another by the pandemic but people living with dementia were the hardest hit.  Between March and June 2020 1 in 4 people who died with covid had dementia and throughout the pandemic our dementia advisers and our support line colleagues heard how terrified people were after forgetting how to dress themselves and heartbreakingly, even forgetting how to speak.

We saw a huge spike in the need for support with over 110,000 people turning to us for support (and 23,000 reaching out for the first time) we had over 8.5 million visits to our website which was a 550% increase from pre-pandemic times..

Alzheimer’s Society are here to support people from day one, at a pace that suits them.  We put people living with dementia at the heart of what we do, making sure they are connected to vital services and ensuring no one has to face dementia alone.

We’ve talked through a lot of information that can be quite daunting but let’s look to the future.  By uniting against dementia we are going to make a difference  We will provide both help and hope.

We support people affected by dementia to face some of the hardest and most frightening times. Evidence shows these to be:

1. Getting a diagnosis

2. Adjusting to living with dementia

3. Needing greater support with care

4. Ending up in hospital

5. Needing an alternative home

6. At the end of life

We do this by being a source of support through practical advice, emotional support, and navigation to others who can help.

We are, and we empower people affected by dementia, to be a force for change - using research and influencing to push for breakthroughs that’ll change the lives of people affected by dementia, now and in future.

All our work is informed by a deep understanding of the reality of living with dementia, good and bad.

We’ll achieve all this by constantly demonstrating our values: we’re determined to make a difference, as a trusted expert, with compassion, and in partnership. Facing dementia, we’re always better together.

We’ll help improve the lives of people affected by dementia, avoiding points of crisis wherever possible.

Our top priorities for 2022-27

1. Grow direct reach, including to communities that rarely receive dementia support removing cultural barriers.  There is a real need for community intervention to help break these barriers down.  Cultural barriers and how communities see dementia play an active role in the ability to access a diagnosis – we can all play our part.

2. Ensure more people get an accurate diagnosis faster, and then receive a seamless transition into effective ongoing support, including our own.  There are currently over 30,000 people waiting for a dementia diagnosis

3. Increase our impact by properly understanding what makes the biggest difference to people affected by dementia.

·     continue to strengthen our understanding of the lived experience of dementia so we can show how it informs everything we do and increase how people with dementia can shape our organisation.

·     improve and grow our pre and post diagnosis dementia support services, using evidence to measure our impact, increasing our focus around the six stages of transition.

·     invest in our service capacity and in our people, with an improved digital offer and more face-to-face Dementia Advisers.

·     be a force for change by focusing our research and influencing work on improving lives and increasing choices for people living with dementia.

·     make evidence-informed decisions led by great data and insight, continually learning to improve.

Slide 10 – so what’s next.  Well, I wouldn’t be a fundraiser if I didn’t try to shoehorn an ask in would I.  There are so many ways you can help support Alzheimer’s Society and people living with dementia.  Get in touch with myself to chat about charity partnerships, ad hoc fundraising or to chat about the work we do so please do get in touch.

Slide 11

 Well, I guess all that is left to say is a massive thank you for your time and I’ll open up now for questions.