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Ymddiriedolaeth GIG
Gwasanaethau Ambiwylans Cymru
Welsh Ambulance Services
NHS Trust

Dementia

A guide to communicating with
people living with dementia

listen value respect
body language positivity
kindness patience
calmness sensitivity
communication feelings
empathy awareness

The background of the page is a teal-colored image of a field of flowers, possibly daisies, with a soft focus. The flowers are in the foreground and middle ground, creating a sense of depth. The overall tone is calm and natural.

Introduction

The number of people living with dementia in the UK is set to rise significantly. Staff and volunteers at the Welsh Ambulance Service are responding to and supporting more people who are living with dementia and their carers. It is important to remember that everyone is an individual, and the way you treat someone who is living with dementia needs sensitivity and compassion.

The term dementia describes a set of symptoms caused by diseases of the brain. People will be affected differently depending on the type of dementia they have and the stage that their dementia is at. Someone in the later stages of the disease will be more profoundly affected than someone at an early stage. People's conditions will deteriorate at different rates and some people will get days when they may seem a little better or worse than the time you last saw them.

Some people who use our services will have dementia themselves but will be seeking help for someone else. Some people may tell you that they are living with dementia, while some may prefer not to. There will be a lot of people who may not be aware that they are living with dementia.

This leaflet provides some hints and tips for communicating with someone living with dementia. It includes accounts of people with dementia and carers who have used our services, along with information about where you can learn more. The information can help you to support people with dementia and ensure that their human right to be treated with dignity and care is upheld.

About dementia

There are different things that will impact on the experiences of someone living with dementia when they access Welsh Ambulance Services. These include the environment, the situation and ourselves. We may not be able to change the environment in which we treat and care for patients, but we can improve a situation and alter our own approach.

Five things you should know about dementia

1. Dementia is not a natural part of ageing

We all forget a name or a face sometimes, especially as we get older. But dementia can also include other symptoms, such as difficulties with planning, recognising familiar people, thinking things through, and sometimes changes in mood or behaviour.

Dementia is not exclusive to older age. More than 40,000 people in the UK under the age of 65 have dementia, and Alzheimer's Society Cymru estimates that approximately 3,000 people under 65 in Wales have dementia.

2. Dementia is caused by diseases of the brain

Diseases such as Alzheimer's disease cause nerve cells to die, damaging the structure and chemistry of the brain. No two types of dementia are the same. In different types of dementia there is damage to different parts of the brain and everyone experiences dementia differently.

3. It's not just about losing your memory

When people hear the word dementia, they often think of memory loss. Dementia can also affect the way people perceive things, the way they think, speak, feel and behave.

4. People can still live well with dementia

While there is no cure, support and treatments are available to help with symptoms and managing daily life. These can allow people with dementia to lead active, purposeful lives and carry on doing the things that matter to them most.

5. There is more to a person than the dementia

In the same way that we would look at someone with cancer or diabetes and see a person first, there is more to a person than the dementia.

Alzheimer's Society (2018). Five Things You Should Know About Dementia [Online]. Available from: <https://www.alzheimers.org.uk>

Hints and tips when supporting someone living with dementia

It can be more difficult to understand, or relay information if you have dementia, especially if you are under pressure or in poor health. The following guidance can help you and the person living with dementia communicate more effectively.

Value and respect

Treat each person as an individual.

Every person living with dementia can experience symptoms differently at different times, depending on the type of dementia they have and what part of the brain is being affected.

Smile warmly, be calm, be patient, be kind.

A warm approach can help someone feel reassured in difficult times.

Show empathy. Understand and share their feelings.

Try to understand how a person might be feeling at the time.

What a person is feeling will seem very real to them.

“Respect my values, beliefs and opinions with equality and acceptance.”

“I want a nice caring voice at the end of the phone.”

“I want respect, kindness and compassion – that's the most important thing.”



Speaking

Approach the person from the front to address them. If you approach the person from the side, their peripheral vision may be poor and they may not see you.

Introduce yourself each time you meet. Say *'Hello My Name is....'*

Speak clearly, calmly and slowly.

Use simple short sentences. Avoid complicated medical terms.

Avoid overloading the person with too much information. Explain one thing at a time.

Don't ask too many questions. You may need to repeat your questions or change how you say things.

A person living with dementia may feel reassured by a friendly tone. They may also feel worried or scared by an impatient tone or a raised voice.

Try not to interrupt or finish the person's sentence, it might disrupt their train of thought.

Don't rush. Try to go at the person's pace. Give them time to understand.

Use positive and active language. Talk about what the person can or could do rather than saying something they shouldn't or can't do.

Dementia can affect someone's expressive skills, their reading, writing and communication. Think about using pictures to help communication. The Welsh Ambulance Services Pre-Hospital Communication App has pictures which can help facilitate conversation.

"I want someone who talks to you face to face, not like you're not there".

"Someone who tells you what is going on and how it is going."

"You ask too many questions."

Listening

Listen carefully to what the person has to say.

Give the person time to say what they want.

Words or sentences may not make sense.

A person living with dementia may refer to past events as if it is happening now. This can sometimes be a reflection of how the person is feeling now, rather than what is currently happening.

If the person is having difficulty, listen and look for clues as to what the person might be trying to say.

"You need to have patience with me."

Body language

Smile warmly, make eye contact.

Stay at the person's level.

Respect the person's personal space.

Communicating in a person's first language

A person's ability to use a second language often deteriorates when they have dementia. Many people living in Wales have lived with Welsh as their first language, speaking Welsh with their family and communities for most of their lives.

While they may be able to communicate very well in English, they may feel more comfortable and more able to express themselves confidently and effectively in Welsh.

A person living with dementia may start to lose their second language and communicate only in their first language. This might also mean that they understand less of what is said to them in their second language, so a first language Welsh speaker may only be able to talk and recognise Welsh.

It will be important to recognise and understand this when you support someone living with dementia. You can either speak Welsh to them or find someone who can translate for you.

As with many languages, local dialects and vocabulary can be different from place to place, so someone who knows the area that a person comes from can be really helpful.

This information can relate to any other first and second languages.

Acknowledging what the person is experiencing

What a person living with dementia experiences will be very real to them. Do not try to convince them that they are wrong.

Someone with dementia might repeat themselves and have problems recalling things that happened recently.

Circle round a sensitive issue if you need to, but try to establish and acknowledge the person's emotional needs. For example, if an older person is looking for their parents, try to think what the person might be feeling, or the kind of reassurance they may be seeking from their parents, rather than explain why it might be difficult.

“One gentleman we support became very distressed when the paramedic went to take his temperature with the handheld device in his ear. He fought in the war, we think he thought the paramedic was holding a weapon to his head.” Dementia Support Worker.

The physical environment

A person may be confused about where they are.

Make sure there is enough light for the person to see clearly. Allow natural light wherever possible.

Some people may not recognise colours, faces or objects.

A person's memory of their home may be of a house they used to live in. If you are taking someone home they may not recognise the building they currently live in.

A person's dementia may mean that they perceive things in a different way, for example:

- different lighting or shadows might make a place look unfamiliar
- reflections in mirrors might be seen as another person
- steps, rugs or mats might look like obstacles or holes in the ground
- patterned walls or carpets might appear to move

What is obvious to you might not be obvious to them.

People may have or develop problems with spatial awareness, which can mean difficulty in finding your way around.

Minimise noise as much as possible (for example, TV or radio). Some people may have difficulty filtering out different sounds. Sounds may be amplified or distorted.

It might be difficult for a person living with dementia to remember the information you need, like their date of birth, postcode or a reference number. You could ask if they have a document to hand (for example, a letter, Message in a Bottle, prescription) which may help you.

If you are assisting someone in a wheelchair and you need to talk to the person;

- stop slowly
- approach the person from the front
- come down to their level
- don't talk from behind while you are pushing them.



Carers

Carers play a vital role in caring for someone living with dementia.

The person with dementia may say they are fine but they are not. Listen to what the carer knows about the person.

Involve carers in decisions. Keep them informed of what you are doing.

Allow the carer to travel with the person for their support in the vehicle. The carer can also support at the hospital during handover.

If a person with dementia has rung for someone else, be mindful that they may find answering a lot of questions difficult.

“They were kind and considerate with my mother and very understanding of her dementia.”

Carer of someone living with dementia.

Changes in behaviour

A person might be experiencing a range of symptoms and feelings which can be very distressing.

When situations are particularly difficult, someone's behaviour may be quite challenging or out of character.

When someone is away from their familiar surroundings and support, they may find it very disorientating.

Someone might be reluctant to leave home with a stranger.

Dementia can make a person feel very anxious. This anxiety can be heightened when they are unwell or disorientated. They may look for reassurance regularly, and repeat the same questions.

People may try to phone the service back several times for reassurance or because they forget what is happening while they are waiting. It may cause further distress when we ask repetitive questions.

Waiting for long periods can be very difficult and can heighten someone's anxiety levels. Allowing a carer or someone familiar to be with the person can help, as can items that are designed to be a comfort to people at times of distress.

Local groups sometimes help make items such as knitted trauma teddies, twiddle mits and twiddle aprons.

A person might be distressed by a number of different factors that we might not be aware of. This may be caused by:

- Facial agnosia – difficulty recognising faces or seeing other faces as a blur
- Peripheral neuropathy – people living with dementia may shuffle when walking, putting them at greater risk of falling. Some people may want to sit, as it can be painful to walk
- Finger neuropathy – this can affect people's coordination in their hands and fingers



Walking

Sometimes people may walk around or walk away while you are with them. They may forget where they are or what they are doing. They may be trying to find a place that was once important to them. They may be confused and not recognise their own home.

The police are promoting the 'Herbert Protocol' which asks carers, family members and friends to complete a form, recording all vital details about their loved one. This includes information such as medication, mobile numbers, places previously located, a photograph, etc. This information can then be shared quickly with the relevant agencies should their loved one be reported as missing.

Get in touch

If you would like to find out more about the Welsh Ambulance Services Dementia Plan, and how we are working to become Dementia Friendly please contact:

Patient Experience and Community Involvement Team

Email: PECI.Team@wales.nhs.uk

Telephone: **01792 311773**

You can also visit the Dementia page on the Trust's Intranet. You will find further information and links, along with instructions on how to download the free **Pre-Hospital Communication App**.

To become a Dementia Friend, or for further information, visit www.dementiafriends.org.uk

Useful links and numbers

National Dementia Helpline:
0300 222 11 22

www.dementiafriends.org.uk

www.alzheimers.org.uk

www.alzheimers.org.uk/getsupport – Find local services

www.ageingwellinwales.com

Notes

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