



Dementia-friendly emergency services guide

A practical guide for police, fire and
ambulance services to supporting people
affected by dementia



Document purpose

This is a practical guide for emergency service organisations outlining and encouraging best practice when working and interacting with people affected by dementia. This guide offers support to assist the emergency services to understand the impact of dementia and how to support employees, volunteers, staff, officers and the general public through awareness and training, processes and the physical environment. It demonstrates that small changes can go a long way in supporting people affected by dementia.

Title

Dementia-friendly emergency services guide: A practical guide for police, fire and ambulance services to supporting people affected by dementia

Publication date

November 2019

Target audience

Frontline employees, volunteers, staff or officers and those who are contacted by or come into contact with the public.

Acknowledgements

We are very grateful to colleagues from the following organisations that have voluntarily input into this guide or provided case studies:

Alzheimer's Society Dementia Helpline and dementia support workers, Avon Fire and Rescue Service, Bedfordshire Police, East England Ambulance Service, Cleveland Police, County Durham and Darlington Fire Rescue Service, Kent Fire Rescue and Service, Greater Manchester Police, Greater Manchester Fire and Rescue Service, ITV News, Lancashire Fire Rescue Service, National Fire Chiefs' Council, Association of Ambulance Chief Executives, National Police Chiefs' Council, North East Ambulance Service, North West Ambulance Service, Nottinghamshire Fire and Rescue, South Central Ambulance Service, South East Coast Ambulance Service, Welsh Ambulance Service and Yorkshire Ambulance Service.

Special thanks to Paula Breeze, Sean Bone-Knell, Ged Devereux, Steve Irving, Dominika Kimber, Matt Peskett, Sue Putman and Lynne Woodward.

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Publisher

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This report uses the term 'people affected by dementia' to include people with dementia and those important to them, which may include friends or family members (including family carers).



Contact

Alzheimer's Society Programme Partnerships team at programmepartnership@alzheimers.org.uk

Web

There are a number of resources and case studies mentioned throughout this guide. For details of how to access these go to alzheimers.org.uk/emergencyservices



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Foreword from Alzheimer's Society

Dementia is one of the greatest challenges we face in society today. One in three babies born in 2015 will develop dementia and people caring for someone with dementia make up many of the one in eight people in the UK with caring responsibilities. It isn't a challenge that is going away and it is one that emergency services are coming into contact with every single day.

Dementia can affect every aspect of an individual's life, often preventing them from doing the things that many of us take for granted and sometimes putting people's lives at risk leading to interactions with the services. Getting out in our communities can improve quality of life and reduce the risk of social isolation.

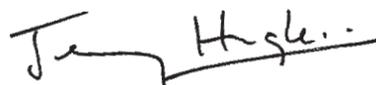
In 2017 we were delighted to see over 28 regional services and key national associations including the Association of Ambulance Chief Executives, National Fire Chiefs' Council and National Police Chiefs' Council sign up to an Emergency services strategic commitment on dementia. This committed emergency services to becoming dementia friendly through greater awareness and understanding and by providing support to every person living with dementia – whether they were members of the public in the community or employees. This will make a huge difference to those affected by dementia and their quality of life.

We need to ensure that emergency services train their employees to be aware of the impact of dementia, and consider environments and processes to safeguard and support people to continue to live safely in their community.

The public want services that value their communities. This will only be achieved with greater awareness, understanding and support for the public and members of the services affected by dementia. This guide highlights the many ways a service can transform itself to continue to support people affected by dementia, so they can live and participate in their local communities. With numbers of people with dementia in the UK set to increase to over a million by 2025 and over two million by 2050, it has never been timelier to take action and improve the lives of people with dementia.

I know that numerous trusts and services have done some amazing work, including producing dementia strategies and engaging with local people affected by dementia. Thank you for all you have done to date and you will find a number of these case studies on our webpages.

Services are seeing the positive impact that becoming dementia friendly has on the communities they serve. Defeating dementia won't just happen in a lab or in a care setting – we need a whole society response. We need a big change in the way people think, talk and act about the condition, and all of society has a role to play in this.



Jeremy Hughes
CEO, Alzheimer's Society



Introduction

The Prime Minister's Challenge on Dementia was launched to make the UK the first dementia-friendly nation.

The challenge set out three key commitments:

- in research to look for treatment and a cure
- to improve health and social care
- to develop dementia-friendly communities.

The ambition for the third commitment, dementia-friendly communities, is to support people with dementia to continue to be active and to enable them to continue doing everyday activities for as long as possible.

This guide will form one of the key deliverables of the Prime Minister's Challenge which calls on all sectors to explore ways in which they can provide a more dementia-friendly approach and produce guidance and share best practice across business and sectors.

Emergency services strategic commitment on dementia

In 2017 emergency services came together and launched the Emergency services strategic commitment on dementia. The commitment exists for all emergency services providers and has been signed by The National Police Chiefs' Council, The National Fire Chiefs' Council and The Association of Ambulance Chief Executives.

The strategic commitment is made up of the following parts.

Commitment 1

We will work towards being dementia-friendly employers with suitable employment policies and procedures in place to allow us to support colleagues who become carers or those who themselves develop dementia.

Commitment 2

We will ensure employees, volunteers, staff or officers have the necessary awareness, skills and understanding to recognise and support people living with dementia before, during and after an emergency incident.

Commitment 3

We will work together and with our local partners to maintain and improve the general safety of people living with dementia, their families and carers.



Commitment 4

We will support Alzheimer's Society in its quest to develop more dementia-friendly communities and Dementia Friends in line with the Prime Minister's challenge on dementia and the subsequent duty on all public services.

This guide will focus on the four areas in the Strategic Commitment and identify practical steps that emergency services can take.



Has your service signed up?

Find out more visit

alzheimers.org.uk/emergencyservices



The scale of the challenge

Dementia affects large numbers of people, so it's likely you'll regularly come into contact with people living with or caring for someone with the condition.

The following numbers show how many people are affected.



Over 850,000 people are living with dementia. There will be 1 million in 2025 and 2 million by 2051.



Over 1,800,000 people in 2019 are caring for someone living with dementia (CEBR, 2019)



1 in 6 people over the age of 80 have dementia.



Dementia is the leading cause of death in England and Wales (ONS, 2016).



Over 42,000 younger people (under the age of 65) have dementia.



Two-thirds of people with dementia live in the community while a third live in care homes.



Over the next 20 years the population aged 65–84 will rise by 40% and the population of those over 85 will rise by 106% (The Kings Fund, 2013)

The statistics above are from (Alzheimer’s Society, 2014), unless specified otherwise.

What is dementia?

The word ‘dementia’ describes a group of symptoms that may include memory loss, difficulties with thinking, problem-solving or language, and often changes in mood, perception or behaviour.

Dementia occurs when the brain is damaged by diseases, such as Alzheimer’s disease or a series of strokes. It is not a natural part of the ageing process. There are different types of dementia, including Alzheimer’s disease (which is the most common), vascular dementia, frontotemporal dementia and dementia with Lewy bodies.

Dementia is a progressive condition, which means it can begin with mild symptoms that get worse over time. Different types of dementia can affect people in very different ways, especially in the early stages. Dementia is one of the main causes of disability in later life, ahead of cancer, cardiovascular disease and stroke.

People with progressive conditions can be classed as disabled under the Equality Act 2010, if they have a physical or mental impairment which has a substantial, long term and adverse impact on their ability to carry out day to day activities.

Symptoms of dementia

Everyone experiences dementia in their own way. Different types of dementia can also affect people in different ways. However there are some common symptoms that people might have.

- **Memory loss** – which may include problems recalling things that happened recently (such as what they had for breakfast) and repeating things (such as asking the same question over and over).

- **Difficulty thinking things through and planning** – for instance, struggling with problem solving, grasping new ideas or following a series of steps. A person might also have problems with familiar everyday tasks such as managing bank accounts or paying bills.
- **Problems with language** – difficulty finding the right word or struggling to follow a conversation.
- **Being confused about time or place** – losing track of the time or date or getting lost even in familiar places.
- **Difficulties with sight and perception** – problems judging distances (for example, on stairs), seeing objects in 3D (three dimensions) or misinterpreting things in the environment (such as patterns and reflections).
- **Changes in mood or difficulties controlling emotions** – becoming unusually anxious, sad, frightened or more easily annoyed, or losing interest in things and becoming withdrawn (for example around friends or family).

Some of the symptoms of dementia are also symptoms of other conditions, disabilities and impairments. Supporting people with dementia can therefore also help you to support people with a range of conditions.





Why does this matter to emergency services?

There are a number of aspects to think about when people with dementia come into contact with your service.

Keeping safe and well is important to everyone, but it may be more of a concern if a person has dementia. People with dementia may find it harder to manage everyday risks as a result of the condition.

They may:

- forget to turn things off such as the oven or gas
- have difficulties getting around safely, for example going up and down stairs
- become confused about how things work or where they are.

Fires

Research has shown that impairments, disability, ageing and dementia are substantial factors in increasing someone's risk of injury or death from a fire in the home. During 2012/13, people over the age of 60 were 10 times more likely to die in a fire than those aged 17–24. People with dementia may have a higher risk of being involved in a fire, for example, if they forget they are cooking or don't remember to put out a cigarette.

Scams or fraud

People with dementia may be vulnerable to scams and fraud. Some people may direct these at older people and people with dementia because they may be seen as an 'easy target'. People with dementia may be less able to recognise a scam and less able to report it. Sometimes friends or family members who support a person with dementia may subject them to financial abuse, such as taking money out of their bank account without them realising.

Trips and falls

People with dementia can be up to eight times more likely to fall than people without dementia (Allan et al, 2009). If they have dementia with Lewy bodies or Parkinson's disease dementia they are at an even greater risk. People with dementia are at an increased risk because they:

- are more likely to have problems with mobility, balance and muscle weakness
- may have difficulties processing what they see
- can have problems finding their way around.

They may also have other health conditions, not related to dementia, that increase the likelihood of falls.

Inconsistent hospital recording of the numbers of people with dementia who have fallen means this data was only available for a quarter of hospitals, but even in this small sample size of from 38 trusts, 6,834 falls were reported in 2015. In these hospitals an average of 28.3% of people aged over 65 who had a fall were people with dementia, but these numbers were as high as 52.2% to 70.6% in some hospitals (Alzheimer's Society, 2016). Services should be aware how to provide falls prevention advice and reduce the risk of people with dementia falling.



For information on key organisations which can support both people affected by dementia and the services visit our Emergency Services webpages at alzheimers.org.uk/emergencyservices



Hot or cold weather

In addition to the normal reduction in our ability to regulate our body temperature as we age, people with dementia generally have greater difficulty regulating their body temperature. A person with dementia may prefer a warmer environment and be at higher risk in cold weather (Van Hoof, 2008). In hot weather they may be more likely to get dehydrated, or to wear too many clothes (which may be linked to them generally feeling colder). The services should provide outreach and support to people affected by dementia in periods of adverse weather.

Emergency admissions

People with dementia can often end up in hospital. An Alzheimer's Society investigation in 2018 has discovered tens of thousands of people with dementia each year are being admitted to Accident and Emergency because inadequate social care is leaving them unprotected from falls and infections. Emergency admissions have

increased rapidly for older people, by 58.9% since 2006/07 for people aged 85 years or older. These trends are challenging for hospitals and ambulance services to manage, as patients with more conditions spend longer in hospital once admitted.

People going missing

People with dementia can be at increased risk of getting lost, even in familiar settings, due to problems with their memory and orientation.

The average cost of investigating a missing person case is £1,325 – £2,415 (Centre for Missing Persons Studies, 2012). Data from Sussex suggests that one in fifteen missing person enquiries are for people with dementia. Prevention of people going missing, through awareness and schemes like the Herbert Protocol, are better for services and for people with dementia – see **page 24** for more information.





Commitments





Commitment 1

Working towards becoming dementia-friendly employers

We will work towards being dementia-friendly employers with suitable employment policies and procedures in place to allow us to support colleagues who become carers or those who themselves develop dementia.

With an ageing population organisations and businesses can benefit from supporting their employees to continue working for as long as they can. This includes people who are living with dementia, or caring for someone with the condition.

Employers have a legal duty to consider reasonable adjustments to help a person continue working and not doing this is damaging to employers and the wider economy. Consider other ways to support employees with a diagnosis, or those with caring responsibilities, such as introducing a carer's policy and promoting flexible or part-time working.

Supporting staff and volunteers who are living with dementia

There are 42,000 people under the age of 65 with young-onset dementia. The Centre for Economics and Business Research estimate that there are approximately 47,000 people working with dementia in 2019 (CEBR 2019).

If a staff member or volunteer has a dementia diagnosis it does not necessarily mean that the employee can no longer do their job. However, their needs may change as their condition progresses and they will require different support from their employers at different stages of their journey. Ongoing support for an employee with dementia in the workplace may include:

- ✓ creating an environment where employees with dementia feel they are a part of a team and are making a valuable contribution
- ✓ creating a culture where employees with dementia feel comfortable to talk about their condition and to ask for help
- ✓ making reasonable adjustments to their working environment, which could include making changes to their role or working pattern, accessible training, supervision and day-to-day support
- ✓ having a supportive manager who can offer practical and emotional support
- ✓ arranging regular reviews to establish their needs and support or adjustments which would help them continue to do their job.



Supporting staff and volunteers who are caring for someone with dementia

As of 2019 there are 1.8 million people who provide some form of care for people with dementia (CEBR, 2019). The number of people who combine work with caring responsibilities is likely to increase because of an ageing population.

There are a number of ways to support people who are caring for someone with dementia, including the following:

Identify carers

Many employees who have caring responsibilities do not identify themselves as carers to their employers. They may not consider themselves carers see opposite page or they may be worried about how their employers will react to this. For instance because caring responsibilities can be unpredictable and difficult to balance with their work responsibilities they may be worried that their employer will question their commitment to their job.

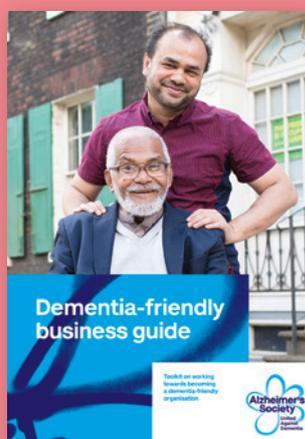
It is important to identify carers and engage with them to establish their needs and the support they require. The support that employers can offer employees with caring responsibilities will differ. The needs of employees caring for older people or those with disabilities, including people with dementia, should be distinguished from the needs of those with childcare responsibilities.

Develop internal policies and processes to address the needs of carers

As well as identifying carers it's important to develop specific policies for carers in order to help staff recognise and support their needs. Policies should cover the support available to carers – such as flexible or special leave arrangements or the ability to work remotely – and how it can be accessed. When producing this policy, ask carers about the support and provisions that would be helpful for them.

Are you able to offer:

- ✓ **support for carers to manage their own health** – this could include online tools and training, the use of occupational health assessments, as well as access to counselling or employee assistance programmes
- ✓ **training for managers** – to support them to understand some of the difficulties that caring may involve, and help them overcome their own concerns about managing employees with caring responsibilities
- ✓ **carers contracts or passports** – a communication tool, which enables an informal conversation between employees with caring responsibilities and their line managers about their caring circumstances
- ✓ **an internal support network** – a workplace network or support group offering the opportunity to link with other employees in a similar situation to exchange experiences
- ✓ **signposting to external information and support** – to relevant sources of information and support on dementia available both nationally and locally.



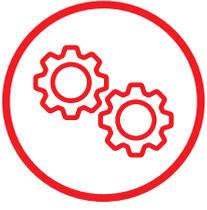
For more information and guidance on support your employees, volunteers, staff or officers affected by dementia please see our **Dementia-friendly business guide** – go to alzheimers.org.uk/business



‘Do you look after someone?’

Carers UK found that some people with caring responsibilities do not see themselves as carers (Carers UK, 2016). Instead they see themselves either as a partner, friend or family member, doing what they have always done or just ‘keeping an eye out’. When identifying colleagues who may be carers, instead of using the term carer, it may be more helpful to ask a question such as ‘Do you look after someone?’

It’s also important to note that caring is different for everyone. While for some people it’s full time, for others it can be a few hours a week, in their home or travelling to the home of the person with dementia. More and more people are caring for young children and elderly parents at the same time. They are likely to need support to continue working and caring.



Commitment 2

Ensuring awareness, skills and understanding

We will ensure employees, volunteers, staff or officers have the necessary awareness, skills and understanding to recognise and support people with dementia before, during and after an emergency incident.

There are a number of initiatives and ways of helping staff and volunteers to understand much more about dementia and how to support people affected by the condition.

Dementia Friends

Alzheimer's Society's Dementia Friends programme is the biggest ever initiative to change people's perceptions of dementia. It aims to transform the way the nation thinks, acts and talks about the condition.

Dementia Friends enables people to learn about what it might be like to live with dementia and then turn that understanding into action.

Anyone, at any level of an organisation can become a Dementia Friend. It's free and can be done through a range of different methods of different durations to best suit your organisation's needs.

Formats to deliver Dementia Friends include videos, e-learning, face to face sessions or a presentation. These need to be embedded within organisational procedures such as employee inductions or refresher training, and signposting to online course bookings, to ensure sustainability.

Dementia Friends Champions

Some Dementia Friends go on to become Dementia Friends champions. These people volunteer to encourage others to make a positive difference to people living with dementia in their community. They do this by giving them information about the personal impact of dementia and what they can do to help.



To find out more information about Dementia Friends or register your organisation go to dementiafriends.org.uk/orginfo This gives you access to a dashboard to view how many of your employees and volunteers have become Dementia Friends, as well as accessing resources such as videos or ordering badges.

For more information please contact programmepartnership@alzheimers.org.uk for a conversation about rolling out Dementia Friends for your employers, officers, staff and volunteers.



On the phone

For employees who often take calls from the public, helping them with queries.

[Transcript](#)



Getting around

For employees who work on public transport and help passengers get from A to B.

[Transcript](#)



Paying for things

For employees who regularly take payment from customers, particularly in a retail environment.



Reading & writing

For employees who provide forms and accept forms from the public.

In a Champions training day, you will learn how to run Dementia Friends Information Sessions to inspire other people to become Dementia Friends and help to create dementia-friendly communities. You will also get lots of information and resources to help you understand how to answer people's questions about dementia and the sources of further information and support you can direct them to.



For more information, look at Alzheimer's Society's **Dementia-friendly business guide** or go to dementiafriends.org.uk

Training

Further dementia awareness training is available through Alzheimer's Society and other organisations, for Continued Professional Development (CPD) accredited courses and qualifications. These can be tailored to your industry or employee groups. We recommend that any community-facing employees, volunteers, staff or officers take part in the Dementia Friends programme as well as further training appropriate to their specific role.



For examples of best practice training and support materials available please go to alzheimers.org.uk/emergencyservices

Communicating

Communicating our needs, wishes and feelings is important for everyone, including people with dementia. It can help with our quality of life, as well as keeping individuality and a sense of identity.

Dementia can cause challenges in communication. People with dementia may:

- have trouble finding the right word or phrase
- repeat words
- have difficulties following a conversation
- struggle to understand what people are saying to them
- need longer to respond
- eventually struggle to communicate verbally.

These difficulties can make communication challenging, and may be made worse by stressful situations. However, there are things that can support communication with people with dementia, including non-verbal communication.

5 things everyone should know about dementia

There are five key messages about dementia that all staff can learn as part of the Dementia Friends programme.

- 1 Dementia is not a natural part of ageing.
- 2 Dementia is caused by diseases of the brain.
- 3 Dementia is not just about losing your memory.
- 4 People can still live well with dementia.
- 5 There is more to a person than their dementia.



For more information see Alzheimer's Society's booklet **5 things you should know about dementia**.

Tips for communicating with people with dementia

- ✓ Ask the person or someone close to them about the best way to communicate with them.
- ✓ Try to make sure the environment is as quiet as possible and try to reduce distractions, or take the person somewhere quiet to talk.
- ✓ Where possible make sure you have the person's full attention before you start.
- ✓ Make sure you give the person as much time as possible.
- ✓ Speak clearly and calmly.
- ✓ Use short, simple sentences with clear instructions.
- ✓ Give the person time to process what has been said and respond.
- ✓ Try to communicate in a conversational way, and not question after question.
- ✓ Try to stick to one idea or point at a time. It can help to break things down into smaller bits of information.
- ✓ Focus on key points and find easy ways to explain what they are doing – simplifying where they are and what the service is trying to do.
- ✓ If the person doesn't understand what you are saying, rephrase it rather than just repeating it.
- ✓ Check if the person has any other conditions that may impact how they communicate. For example, if they have hearing loss and use a hearing aid, check that it is on and working.
- ✓ Try to find a common ground – this could be mentioning a family member or friend (if appropriate) or find out a bit about the person to initiate conversation.
- ✓ Think about non-verbal communication and use this to support you and the person with dementia.

Control rooms

Staff in control rooms will sometimes be the first point of contact for people living with dementia. It is important that the control room staff or call handlers become Dementia Friends and can assist callers in the most appropriate way to gain the right information as quickly as possible with as little stress to the caller. Through becoming Dementia Friends these staff will know what dementia is, how it might affect someone and what they can do to support people.

Some examples of good practice include:

- ensure all call centre staff understand dementia and sign up to become Dementia Friends
- speak slowly and clearly, check the person has understood each point and recap if necessary
- train call handlers to listen and show patience, not to talk too fast or give too many instructions
- rephrase the question instead of repeating it.



Non-verbal communication

Non-verbal communication is very important for people with dementia, and as their condition progresses it will become one of the main ways the person communicates. It's important to look for other ways that a person in the later stages of dementia may be trying to communicate with you. For example, if they are grimacing or clenching their teeth it may be a sign they are in pain.

It is also important to think about your body language, facial expression and gestures, because the person may react to these. Consider using pictures as visual aids or other communication aids to help people with dementia to understand.

In any situation, it is important to make sure that you have explained what it is you might need the person to do and what you are going to do to support them. You should make them feel reassured and you should not rush anything. Break down any actions into smaller segments to make things easy and offer encouragement where you can.

Safeguarding concerns

It can be hard to know what to do if you're concerned about someone's wellbeing. This could be the case whether or not they have dementia, though you might have particular worries if they do. There are a number of other signs of possible abuse or neglect that could be reasons to raise a safeguarding concern with social services, including:

- self-neglect – where a person isn't looking after themselves as well as they should be. This can get worse and lead to many problems
- noticing signs of financial abuse – for example, the person lacks money for basics like heating or for other things they'd usually spend it on, they're befriended by someone new who may be taking advantage of them, or they're receiving excess letters and packages as this may be an indication that they are being targeted or repeatedly buying items from sales callers
- spotting bruising, cuts, burns or other marks on the person
- witnessing or hearing arguments that appear more severe than you'd expect, for example including verbal or physical abuse
- not seeing someone for a long time – especially if you'd usually expect to see them, or if they miss something they regularly go to. For example, you might notice their bins not being put out or post not being picked up.

If you believe that someone is in any immediate danger, you should of course call 999. In other cases, a call to social services to raise a safeguarding concern could lead to them finding out what can be done to help.

Documents to support communication and understanding

Communication is important to ensure a person with dementia gets the right care and support, whether at home, in hospital or any other care setting. If you're visiting a person with dementia it may help to leave a short note for any carers, friends or family members, as well as having a written record of your visit for services systems. Keep an eye out for care plans or the Lions Club 'Message in a Bottle' schemes which could help you support the person you're visiting, by understanding what other support they are getting or who to contact. Encourage families to keep medical information (for example Do Not Attempt CPR, advance care plans, Herbert Protocol together and readily available for services, particularly ambulance services.



My visitors book (code 923)

This is an resource for people with dementia to use so they can keep track of the professionals who visit them in their home. **My visitors book** is available online at alzhaimers.org.uk/publications or call **0300 593 3333**.



This is me (code 1553)

Alzheimer's Society produces a document called '**This is me**' to support people with communication difficulties. It can give health and social care staff information about a person, including their preferences, likes and dislikes. It is available to download at alzhaimers.org.uk/thisisme or you can order packs of 25 via Alzheimer's Society's online shop at alzhaimers.org.uk/shop



Commitment 3

Working together and with local partners

We will work together and with our local partners to maintain and improve the general safety of people living with dementia, their families and carers.

Working with local partners

To help people with dementia to stay safe, you can work with different organisations and people in your local area on various different initiatives. Working with local specialist organisations including Age UK, Alzheimer's Society and carer providers will ensure people living with or affected by dementia are aware of the support you offer. Also working in partnership with key aspects of the community, for example transport hubs, housing providers and retailers.



‘They took my husband to hospital. The ambulance men told the staff I had dementia. They told me not to worry. By this point I was starting to get very confused. And I was anxious. They talked me through what was happening. Because they told them I had dementia, they arranged for a taxi to take me home. They rang the night staff here (we live in extra care housing) to tell them what happened. They could not have done enough working with our housing provider.’

Shelagh, living with dementia

Working with retailers

Dementia can change the way people think. For example they may forget things or have difficulty concentrating or making decisions. Some people with dementia may lack inhibitions or become prone to compulsions or behaviours which are ‘out of character’ for them.

It cannot be assumed that every person with dementia will experience these changes. However, if someone is making an effort to hide items to take them out of the store, it could be a result of these compulsions or behaviours. They may have forgotten to pay, been confused about where they were (especially in a big or unfamiliar shop) or have picked up items and forgotten what to do next. If the person's thinking or behaviour has changed because of their dementia it may not be possible to hold them accountable. It can still be a distressing and embarrassing experience for everybody involved.

Police should work with retailers and their security staff to make them aware of support available for people with dementia.

What can you do?

- ✓ Try to identify why the incident may have happened.
- ✓ Avoid using overly-accusatory statements or rushing to accuse someone of theft.
- ✓ Take the person to a quiet space to have a conversation away from the public.
- ✓ Work with family and friends of the person with dementia to put systems in place to support them to continuing shopping. This might include allowing people to take items back with or without the receipt, prepaid accounts or gift cards or creating a tab so a note can be made of what has been taken and it can be paid for at another time.



LEMSIP MAX
COLD & FLU relief
Phenylephrine Hydrochloride,
Paracetamol
FEVER
SORE THROAT
BODY ACHES
SNEEZY NOSE
SORE EYES
Contains Paracetamol

Safe and well visits

Fire rescue services undertake brief 30 minutes – 1 hour safe and well visits in communities to reduce risks and make positive interventions.

During the visit they may cover:

- Personal escape plan – what to do in the event of fire (different scenarios), calling the fire service
- Fire risk assessment in the home
- Identify appropriate fire safety devices for example:
 - Smoke alarm
 - Carbon Monoxide alarm
 - Cooker shut off valve
 - Vibrating pillow linked to smoke alarm
 - Flashing light linked to smoke alarm
 - Fire proof letterboxes
 - Fixed ash trays
 - Safer smoking devices
 - Fire proof bedding
 - Fire proof blankets

- Slips trips and falls – providing advice and in some areas equipment
- Discussion around key areas including:
 - Use of emollient creams
 - Smoking
 - Heating systems and methods
 - Hoarding advice
 - General health & wellbeing
 - Security
 - Advice on scammers and fraudsters
 - Advice on priority register for utility services

Home Safety Officers also conduct White Goods Checks for products in the home to ensure that there have been no product recalls on equipment such as fridge-freezers, dishwashers and cookers.



For examples of Safe and well visits supporting people with dementia please see case studies on our Emergency Services resource hub go to alzheimers.org.uk/emergencyservices





How you can help support people with dementia

If you're involved in home fire safety or 'safe and well' visits as part of your fire service, consider how you can help support people with dementia. An important part of this is looking at a person's care plan and making sure they've recorded which carers, friends or family members can be contacted in an emergency. It should also include when the next safe and well visit should be and other services they're being referred to.

Work with local Alzheimer's Society, Age UK and housing providers to let them know about the support available from your organisation, such as the Herbert Protocol (see page 24) or home fire safety/safe and well visits. Try putting advertisements in local newspapers, an article in a local lifestyle magazine or sending leaflets to doctor's surgeries, pharmacies or local shops.

Missing persons

When responding to a case of a person with dementia who has gone missing, there are certain things to consider.

Walking about

There are times when most people want to walk about, either at home or outside. People with dementia are no different.

If a person with dementia is walking about and is reported as missing, it may help to think about where they may have gone or why they are walking about. Walking is not a problem in itself – it can help to relieve stress and boredom and is a good form of exercise. However, as with all changes in the behaviour of a person with dementia, walking about could be a sign that they have an unmet need.

Understanding what this is and finding a solution could help to maintain the person's wellbeing.

A person with dementia might walk about for a number of reasons. These include:

- **memory loss** – a person may begin a journey with a particular goal in mind but then, due to short-term memory loss, forget where they were going and become lost
- **confusion about the time** – a person may, for example, wake up in the middle of the night, get dressed and leave the house
- **relieving pain and discomfort** – a person may be trying to ease their discomfort or 'escape' their pain



- **restlessness** – a person may be agitated, for instance as a symptom of dementia or a side effect of medication
- **boredom or lack of activity** – a person may have less to do than they used to, or have more energy to spare if they're not doing as much physical activity
- **continuing a habit or interest** – a person may walk about at the time of day they used to be out, such as when they would've walked the dog or collected their children from school
- **searching for someone or something from the past** – for instance, a person may be looking for someone as they don't remember that that person had moved or died.

Sometimes when a person with dementia walks about, others refer to it as 'wandering'. However, this term is not accurate – because there is usually a reason for a person walking about, rather than simply being aimlessly walking.

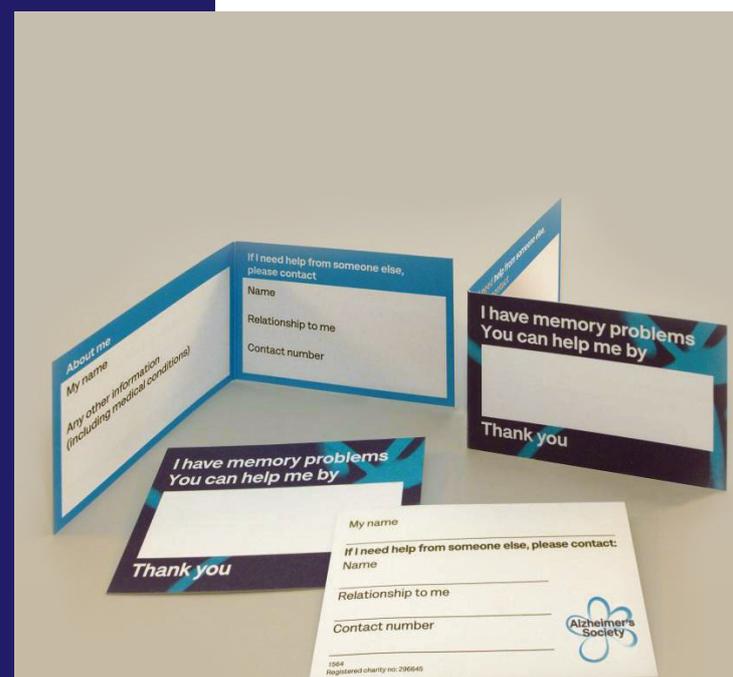


To find out more about supporting a person with dementia who walks about see Alzheimer's Society factsheet 501, **Walking about** at alzheimers.org.uk/publications



Tips

- ✓ Make links with any local volunteer schemes, such as Neighbourhood Return, in your area that help return home people with dementia.
- ✓ Encourage people with dementia and their carers to carry some form of identification or the name and phone number of someone who can be contacted if they get lost.
- ✓ If the person uses a mobile phone, encourage people with dementia and their carers to ensure that the phone number of the primary carer is stored and is easily accessible. If the mobile phone is switched on it may be possible to trace the person if they go missing.
- ✓ Helpcards are a great tool to help a person with dementia maintain their independence. Helpcards are available to order at alzheimers.org.uk/publications or call **0300 593 3333**



The Herbert Protocol

The Herbert Protocol is a risk reduction tool for people and their families living with dementia. In some areas this is called an 'At risk of going missing' form. It's a simple form designed to make sure that, in the event of someone going missing, the police can get access to important information about that person as quickly as possible. It can also help relieve the pressure on a person's friends or family as they don't have to try remembering lots of information at an already distressing time.

Police forces around England, Wales and Northern Ireland are implementing the Herbert Protocol, but in order for it to be effective it needs to be promoted to people living with dementia and their carers and families. Families can register people who are at risk of going missing by getting in touch with their local police force. You fill out a Person details and life history form, which allows the creation of a draft missing persons report. In the event that the person does go missing, the police already have most of the information they need, saving a lot of time and effort.



It is hard to bring information to mind quickly when you are really worried. People might be daunted by the form but it is reassuring to know you have all the information when it's most needed.'

Margaret, living with her husband who has dementia

Coordinated response to missing persons

As with any missing persons inquiry, it's best to use a coordinated response as soon as possible. Working with other emergency services, local search and rescue teams, and the wider community can help when trying to find vulnerable people. As well as collaborative working, where possible use search assistance through thermal imaging, drones and other assistive equipment.

Assistive technology and wearable devices

There is a wide range of assistive technology available to support people with dementia to continue to live independently, while still being as safe as possible. You may find that some people use this technology, which can include a range of devices such as remote alarms, sensors, automated prompts and cooker locking valves.

Some people choose to use GPS devices to support people who might go missing if they walk about. Most GPS devices are worn either on the wrist, like a watch, or around the neck on a lanyard, and they send various kinds of alerts notifying someone has gone outside of a certain boundary. As long as the person with dementia is in an area with a mobile signal, alerts can be sent to specified people, or to a monitoring centre. Devices usually have a panic or emergency button that can be pressed if the individual needs help. Many can also be set up so that a specified person can find out where the person is any time you want to check.

People with dementia and those supporting them must think carefully about whether they want to use GPS devices, as there are lots of questions to consider. It's important that they have these conversations early on to make informed decisions when a person with dementia has the mental capacity to do so.



For more information see Alzheimer's Society factsheet 439, **Using technology to help with everyday life.**



Case study Bedfordshire Police Herbert Protocol

Every year 100 people living with dementia are reported as missing in Bedfordshire (in addition to people who are reported as missing more than once). This puts people at risk of harm and is distressing for those around them. We launched the Herbert Protocol so that any person is able to refer to us if they are worried about a person with dementia or memory problems and they are worried that they might go missing.

We visit all people that refer in to the Protocol so we can offer personal safety advice including assistive technology while obtaining information that can help if a person goes missing, such as descriptions, information about places they frequently visit and a photograph. We also arrange for Bedfordshire Fire and Rescue to conduct a follow up visit to provide fire safety advice and support. We are therefore able to prevent people from going missing in the first place, and if someone is reported as missing we have the necessary information to locate them as quickly as possible.



We hope, by forming this partnership, that people living with dementia in Bedfordshire are able to remain independent and safe for as long as possible, to be able to continue with activities they enjoy and to provide some peace of mind for the person concerned and their family and friends. If successful, it will reduce the time taken between a person being reported as missing and the mobilisation of emergency services resources, shortening the time before the person is found and maybe reduce the number of times any individual actually goes missing.'

Catherine Bishop, Dementia Support Worker in Cambridgeshire and Bedfordshire



We secured funding for a Dementia Support Worker from Alzheimer's Society to work with our Missing Person Team for two days a week, to support people who have been reported as missing in the past. Their role involves receiving referrals and then working with the family to explore ways to prevent someone with dementia from going missing again. The objective is to reduce the number of people going missing from home and reduce the number of repeat missing persons to keep people safe.



Commitment 4

Developing more dementia-friendly communities

We will support Alzheimer's Society to develop more dementia-friendly communities and Dementia Friends in line with the Prime Minister's Challenge on Dementia and the subsequent duty on all public services.

Across England, Wales and Northern Ireland the Dementia Friendly Communities programme encourages everyone to share responsibility for ensuring that people with dementia feel understood, valued and able to contribute to their community.

These communities bring together organisations and individuals who are committed to transforming the lives of people with dementia and their carers. Local organisations can join the dementia-friendly movement by engaging with any recognised dementia-friendly community in their area, as well as encouraging other organisations to join up.



To find your local dementia friendly community go to alzheimers.org.uk/dementia-friendly-communities or email dementiafriendlycomm@alzheimers.org.uk

Recognition

Get in touch with Alzheimer's Society to find out more about opportunities to be recognised for your efforts to support people affected by dementia. These include applying for our Dementia Friendly Awards, raising awareness of your work in the local press and recognition through joining your local dementia-friendly community.



To join your local dementia-friendly community contact dementiafriendlycomm@alzheimers.org.uk

To get in touch with our Regional Press Team contact regionalpress@alzheimers.org.uk

Emergency services strategic commitment on dementia



Has your service signed up? Visit alzheimers.org.uk/emergencyservices to find out more

Environments

We would encourage working with people with dementia to ensure the range of environments, vehicles, equipment, processes and procedures to help improve people's experience when interacting with the services. Services could consider: familiarisation visits, audits of physical premises or vehicles, developing tools like reminiscence photobooks of local areas, having twiddle mits, cannula sleeves or other equipment available.

User Involvement

Work in partnership with people living with and affected by dementia to help develop your local work, training and programmes. Their stories and experiences will help to shape the work delivered and promote dementia awareness.

Useful Alzheimer's Society resources

Information

We produce a wide range of information for people with dementia and their carers, family and friends. You can read and order this information at alzheimers.org.uk/publications or call **0300 303 5933**

Dementia Directory

Find local support services for people with dementia and their carers in England, Wales, and Northern Ireland, using a simple postcode search. Go to alzheimers.org.uk/dementiadirctory

Dementia Helpline

For information, support or advice about dementia call our helpline on **0300 222 1122**. For up to date opening hours go to alzheimers.org.uk/helpline

Talking Point Online Community

Dementia Talking Point is an online community for people with dementia, their carers, family and friends. It's a place where people can ask questions, share experiences and get information and practical tips on living with dementia. Go to alzheimers.org.uk/talkingpoint

Emergency services resource hub

Our Emergency Services resource hub has case studies, further best practice guidance and detailed information. See alzheimers.org.uk/emergencyservices

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**Alzheimer's Society is the UK's leading dementia charity.
We provide information and support, improve care, fund research,
and create lasting change for people affected by dementia.**

If you have any concerns about Alzheimer's disease or any other form of dementia, visit **alzheimers.org.uk** or call **Alzheimer's Society** on **0333 155 3456**. (Interpreters are available in any language. Calls may be recorded or monitored for training and evaluation purposes.)

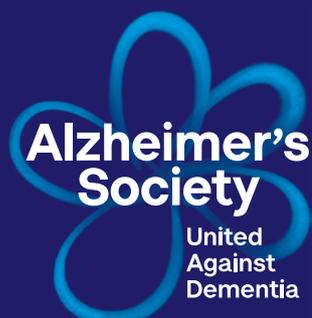
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Registered charity no. 296645. A company limited by guarantee and registered in England no. 2115499. Alzheimer's Society operates in England, Wales and Northern Ireland.