



ASSOCIATION OF
AMBULANCE
CHIEF EXECUTIVES

DEMENTIA

Best Practice Guidance for Ambulance Services

Introduction

The purpose of this document is to summarise best practice aims for ambulance services with regard to people living with dementia, based on nationally recognised standards advocated by the Department of Health.

Ambulance services can use this document as guidance and consider working towards implementing the aims within their own organisations. The guidance is intended to ensure that we are all working towards improving the experience for people living with dementia using ambulance services. There is a focus on practical suggestions for ambulance staff to take into account when supporting people living with dementia.

In the appendices there are links to further information regarding dementia friendly design for ambulance services, standards for dementia training and a selection of the dementia training resources designed by or for ambulance staff.

Background

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities (NHS Choices, 2015). Dementia is a progressive condition and there is currently no cure. The Alzheimer's Society explains that each person is unique and will experience dementia in his or her own way. A person with dementia will have cognitive symptoms (problems with thinking or memory) and may also experience changes in mood. As dementia progresses, the person may develop different behaviours, for example, repeating the same question again and again, pacing, becoming restless or agitated. These behaviours can be challenging both for the person living with dementia and for other people. In the later stages of dementia, a person may have physical symptoms such as muscle weakness, weight loss, and problems with speech and swallowing (Alzheimer's Society, 2017).

There over 850,000 people in the UK with dementia, and this number is predicted to reach one million people by 2021. Dementia mainly affects people over the age of 65 (one in 14 people over the age of 65 have dementia), and the chance of developing dementia increases as we get older. However, dementia can affect younger people too. In the UK, there are more than 42,000 people aged under 65 with dementia (Alzheimer's Society, 2017).

The number of people with dementia is increasing as people are living longer (NHS Choices, 2015). One in four people in hospital have dementia (Alzheimer's Society, 2016). Approximately two thirds of care home residents are estimated to have dementia (DoH, 2013). Dementia can affect anyone regardless of their gender, ethnic group or class. People with learning disabilities are at particular risk of developing a dementia (DoH, 2009). Two-thirds of people living with dementia are female (NHS Choices, 2015). Many people living with dementia, and their carers, will come into contact with ambulance services, whether for emergency care or scheduled patient transport.

National Dementia Strategy

The UK Government have recognised dementia as a national priority. The primary aim of the UK Government's National Dementia Strategy (DoH 2009) is that people should be able to live well with dementia. The National Dementia Strategy recognises that, once a person has

dementia, the condition will worsen over time until the end of their life. However, people who have dementia can often have good quality of life for a number of years. As ambulance services, we can make a positive difference by supporting people with dementia to live as well as possible with the condition.

The National Dementia Strategy was developed following public consultation and has three key steps to improve the quality of life for people with dementia and their carers:

- Better knowledge about dementia and removal of stigma.
- Ensuring early diagnosis, support and treatment for people with dementia, their family and carers.
- Developing a range of services for people with dementia and their carers which fully meet their changing needs over time.

This guidance will now suggest five ‘best practice aims’ for Ambulance Services, reflecting the ethos of the three key steps from the National Dementia Strategy.

In response to feedback received from NHS Trust Dementia Leads, Educators and members of the National Ambulance Mental Health Leads Group, this guidance has focussed on the areas where ambulance staff could have the most impact on the everyday lives of people with dementia and their carers. Practical suggestions, along with real life examples of how other Ambulance Services and NHS Trusts are working to improve their services for people with dementia, are given after each aim.

An example of this real-world approach in action is that ambulance staff would not be diagnosing dementia. Therefore, rather than simply promoting the benefits of an early dementia diagnosis, this guidance has instead focussed on applicable and realistic advice (that ambulance staff are trained to signpost people with memory concerns to the appropriate care pathway).

Five ‘best practice aims’ for Ambulance Services:

1. Deliver person centred care that supports the patient living with dementia.
2. Develop a skilled and effective workforce able to champion compassionate person centred care and recognise the early signs of dementia.
3. Modernise our approaches to communicating by seeking and acting on feedback from people living with dementia and their carers to improve the quality of service we provide.
4. Become dementia friendly organisations with environments and processes that cause no avoidable harm to patients living with dementia.
5. Develop effective partnerships with local agencies (police, fire, health, social care, third sector) to improve care and outcomes.

Aim 1. Deliver person centred care that supports the patient living with dementia.

Consider:

- Care should be based on the needs of the individual with dementia and will maintain

their dignity and respect (see Appendix One).

- To capture the views of service users regarding the care they receive, design Patient Satisfaction Surveys specifically for people living dementia who have used ambulance services within the previous six months, considering both frontline and patient transport services.
- Actively seek out feedback from other sources, such as the Patient Experience Teams and Datix (Incident Reporting System).
- Regularly review patient and carer feedback from all sources relating to the care received by people living with dementia, and critically analyse this feedback to identify areas for improvements. Share this feedback with staff to raise awareness of good practice /areas where improvement is needed.
- Review any themes which arise in the analysis of the feedback (for example, a need for improved communication) and respond to these themes accordingly, for example by providing additional training.

Example: An ambulance service has trained clinical staff on alternative duties to support people living with dementia and their carers to complete our patient satisfaction surveys, allowing us to capture detailed responses.

Example: An Ambulance Service is exploring recording 'dementia' on the electronic patient report system as a separate box, to make future identification of the data relating to these patients and their needs more accessible.

Aim 2. Develop a skilled and effective workforce able to champion compassionate person centred care.

Consider:

- Mapping the workforce against the Dementia Core Skills Education and Training Framework (2015) to identify which ambulance staff groups will need Tier 1, Tier 2 or Tier 3 dementia training (see Appendix Three).
- Provide Tier 1 dementia awareness training to all staff, with an emphasis on care always being person centred (see Appendix Three).
- For staff who have regular contact with patients about dementia, follow up the Tier 1 dementia awareness training with Tier 2 dementia training, relevant to their role (see Appendix Three).
- Ensuring consistency of training by agreeing a Trust wide training plan.
- Using a blended approach of eLearning and face to face training to ensure training can continue to be delivered during times of peak demand.
- Incorporating dementia into induction training update to reach new staff.
- Incorporating dementia into annual training updates to reach existing staff.

- Monitoring and evaluate the implementation of the training.
- Consider introducing dementia ambassadors or champions.

Example: An Ambulance Service has incorporated (role specific) Tier 1 dementia awareness training into the mandatory induction programme, meaning all new staff receive this training before they start working with patients.

Example: An Ambulance Service has trained staff 'Dementia Champions' with an aim of one Champion per team. These Champions were the first staff in the Trust to receive Tier 2 training and are encouraged to cascade learning to colleagues.

Aim 3. Improve approaches to communicating by seeking and acting on feedback from people living with dementia and their carers to improve the quality of service we provide.

Consider:

- Explore different methods of capturing feedback from people living with dementia and their carers. The best method will vary depending on the needs and preferences of the individual. Consider all options: do they have access to the internet? Would telephone contact would be preferable? Or, if appropriate, would the person and their carer feeling more comfortable meeting a member of staff at a convenient time and place in order to communicate face to face?
- Consider establishing a focus group to gain feedback in any geographical areas which have been harder to reach. Explore people's preferred communication methods (for example, email or by post) and endeavour to provide relevant information in these formats whenever practicable.
- Ensure people living with dementia are actively invited to and can access any public facing aspects of the ambulance service, such a patient forums or participation groups. Offer any reasonable support required to enable people with dementia to attend.
- Establish links with dementia groups across the area your ambulance service covers (there are statutory groups such as Dementia Partnership Boards and voluntary groups such as Dementia Action Alliances). These groups can provide a valuable opportunity to network with colleagues from other emergency services and the health and social care sector, learn about what other organisations are doing, share your own experiences and share best practice. In addition, these groups often present an opportunity to meet participants living with dementia and their carers and may provide opportunities to receive firsthand feedback on your services.

Example: An Ambulance Service has joined at least one Dementia Action Alliance (DAA) group in each of the counties they cover. This means we can work with other services towards making the communities we serve more dementia friendly.

Example: An Ambulance Service has given a presentation at their public Patient Forums about the work they are doing to become more dementia friendly. The attendees were pleased to know that ambulance staff receive dementia awareness training.

Aim 4. Become a dementia friendly organisation with environments and processes that cause no avoidable harm to patients with dementia.

Consider:

- Appointing a Dementia Lead
- Promote the Standards for a Dementia Friendly Environment to all staff to ensure that reasonable adjustments can be made when required.
- Include dementia-friendly assessments for all new service developments and vehicle upgrades.
- Ensure that dementia-friendly aspects are included in Equality Impact Assessments for new processes and procedures.

Example: An Ambulance Service has appointed an educator to work with the Mental Health lead to head up Dementia education and strategy. This allows the Trust to have a named representative on dementia at a local and national level.

Example: Several Ambulance Services have published dementia strategies, which can assist in bringing the organisation together in a structured approach to becoming more dementia friendly. A strategy can help ambulance services put plans into action.

Aim 5. Develop effective partnerships with local agencies (police, fire, health, social care, third sector) to improve care and outcomes.

Consider:

- Review existing care pathways to improve any identified deficits to streamline care and avoid taking patients to Emergency Departments when this is not the most appropriate pathway.
- Review clinical pathways, for example of how to refer patients that have or may have dementia to appropriate local health and social care services.
- Develop partnerships with dementia health/social care providers, police and fire and rescue services (For example, by joining local Dementia Partnership Boards and Dementia Action Alliances (DAAs)).

Example: An ambulance service provides training during the Tier 1 session on 'what to do if you think a patient has an undiagnosed dementia', advising staff on the appropriate care pathways available and also on safeguarding considerations.

Example: An Ambulance Service has developed useful contacts with police, fire and health colleagues by joining DAAs across their area. This has enabled the sharing of education resources and increased understanding of local dementia care pathways.

APPENDIX ONE

Common Core Principles of Supporting People with Dementia

Principle 1.

Know the early signs of dementia.

Principle 2.

Early diagnosis of dementia helps people receive information, support and treatment at the earliest possible stage.

Principle 3.

Communicate sensitively to support meaningful interaction.

Principle 4.

Promote independence and encourage activity.

Principle 5.

Recognise the signs of distress resulting from confusion and respond by diffusing a person's anxiety and supporting their understanding of the events they experience.

Principle 6.

Family members and other carers are valued, respected and supported just like those they care for and are helped to gain access to dementia care advice.

Principle 7.

Managers need to take responsibility to ensure members of their team are trained and well supported to meet the needs of people with dementia.

Principle 8.

Work as part of a multi-agency team to support the person with dementia.

(Taken from the Department of Health (DoH) (2011) Common core principles for supporting people with dementia)

APPENDIX TWO

Standards for a Dementia Friendly Environment (suggestions for frontline and patient transport (PTS) ambulance services)

These standards are written in the first person to ensure that dementia-friendly design is understood from the perspective of the person with dementia, who may have all the impairments of old age combined with the cognitive and perceptual impairments of dementia.

I will feel calm and relaxed.

- Keep noise to a minimum. Overstimulation from noise can be very distressing for people with dementia. Consider reducing noise in whichever ways are possible.
- People with dementia often like to be able to see staff/relatives all the time so try to facilitate this whenever possible.
- Allow plenty of time to settle a person with dementia onto the ambulance. For PTS crews, try to ensure the person is able to sit in the same place for each journey as the familiarity will be reassuring for them.
- Maintain dignity and respect.

I am as safe as possible from falls.

- Using dynamic risk assessment, ensure that potential hazards are identified before moving the patient; including the patient's normal level of mobility.
- Ensure handrails and grab handles are clear and easy to grip.
- The floor is kept free of trip hazards.
- Lights are kept in good working order.
- The general light level is good.

I am as safe as possible from infection.

- Normal infection prevention processes apply.

I will be able to see as well as possible.

- There is plenty of light – both natural and artificial.

(Based on the University of Stirling's Dementia Services Development Centre Standards for Dementia-friendly Design, 2012)

APPENDIX THREE

“By 2020 we would wish to see all NHS staff having received training on dementia appropriate to their role.”

- Prime Minister’s Challenge on Dementia (Department of Health, 2015)

Dementia Core Skills Education and Training Framework

The Dementia Core Skills Education and Training Framework is a comprehensive resource to support health and social care staff, educators and carers who work with and care for people living with dementia. It sets out the essential skills and knowledge necessary for all staff involved in the dementia care pathway.

This Framework was commissioned and funded by the Department of Health and developed in collaboration by Skills for Health and Health Education England in partnership with Skills for Care. The framework structures dementia education and training in three tiers. Here is a summary of the three tiers:

Tier 1

Raising dementia awareness, in terms of knowledge, skills and attitudes for all those working in health and care settings.

Relevant to the entire health and care workforce including ancillary staff i.e. all staff including those not providing direct care and support (For ambulance services, this covers all staff roles).

Tier 2

Knowledge, skills and attitudes for roles that have regular contact with people living with dementia.

Relevant to all health and care staff in settings where they are likely to have regular contact with people affected by dementia (For ambulance services, this is likely to be all staff who have patient contact, whether in person or over the telephone).

Tier 3

Enhancing the knowledge, skills and attitudes for key staff (experts) working with people living with dementia and designed to support them to play leadership roles.

Relevant to staff working intensively with people affected by dementia including those who take a lead in decision making and developing or disseminating good practice (For ambulance services, this could be the manager(s) leading on dementia).

(Taken from the Skills for Health, Health Education England and Skills for Care (2015) Dementia Core Skills Education and Training Framework)

What does the *Dementia Core Skills Education and Training Framework* mean for Ambulance Services?

The Department of Health's Mandate to Health Education England (DoH 2015/16) states that, 'to improve the care of people with dementia, all NHS staff that look after people with dementia will go through a dementia awareness programme (Tier 1 dementia training). This programme will enable staff to spot the early symptoms of dementia, know how to interact with those with dementia, and signpost staff to the most appropriate care'.

How can we implement this in our Ambulance Service?

As a starting point, NHS ambulance services should provide Tier 1 dementia awareness training to all staff. The Framework indicates that Tier 1 training is relevant to the entire NHS workforce, not just staff providing direct care to patients.

A review of the workforce will enable identification of the staff groups who have 'regular contact with people with dementia'. These staff will require Tier 2 dementia training, in addition to the Tier 1 dementia awareness training.

Managers who are leading on dementia education, policy or strategy, should work towards Tier 3 dementia training.

A potential strategy could be to deliver Tier 1 training in year one, followed by Tier 2 training in year two for the staff groups which require this.

The Dementia Core Skills Education and Training Framework provides detailed information on suggested standards for training delivery, and the proposed frequency of refresher training, in addition to an extensive list of sources for further information and guidance.

Skills for Health, Health Education England and Skills for Care (2015) Dementia Core Skills Education and Training Framework. Available at:
<http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf>

APPENDIX FOUR

A selection of the dementia training resources available for Ambulance Services

This list is just a sample of the many dementia training resources available, with a focus on the resources of particular relevance to ambulance services.

Nationally, in association with the Dementia Academic Action Group (DAAG), Health Education England (HEE) have produced a Tier 1 dementia awareness package which is freely available on their website, in addition to links to free Tier 1 eLearning. Skills for Health and the Association for Dementia Studies at the University of Worcester have worked with local partners, including West Midlands Ambulance Service, to produce the dementia education resource 'Stand by Me', which is now available as an eLearning package with a module designed for the emergency services.

Locally, many ambulance services have produced their own dementia learning resources. This is just a selection of the resources available in a variety of formats. Although many of the ambulance services intended these documents to be shared for educational purposes, the authors' permission should always be sought before reproducing, distributing or altering their original work.

Health Education England (2016) Tier 1 dementia eLearning and Dementia Academic Action Group (DAAG) Tier 1 dementia awareness training package. Available at: <https://www.hee.nhs.uk/our-work/person-centred-care/dementia/tier-1-training> (free to access)

London Ambulance Service and Dementia Care Matters (2016) Dementia Care Matters in the Ambulance Service (DVD)

NHS Education for Scotland (2014) Scottish Ambulance Service - Dementia Learning Resource (pdf)

North West Ambulance Service (2013) CLEARvision Dementia Learning Pack (pdf)

South Central Ambulance Service NHS Foundation Trust (2015) Communicating with people living with dementia (YouTube video)

Skills for Health and the Association for Dementia Studies (2015) Stand by Me (eLearning)

West Midlands Ambulance Service (2013) Dementia and Pain (pdf)

Yorkshire Ambulance Service (2014) Dementia learning resource for ambulance staff (pdf)

References

Alzheimer's Society (2016) Fix Dementia Care: Hospitals. Available at:
<https://www.alzheimers.org.uk/site/scripts/download.php?type=downloads&fileID=2907>

Alzheimer's Society (2017) What is dementia? Available at:
https://www.alzheimers.org.uk/download/downloads/id/3416/what_is_dementia.pdf

Dementia Services Development Centre (2012) University of Stirling publications on the importance of design for people with dementia. Available at: <http://dementia.stir.ac.uk/design>

Department of Health (2009) Living Well With Dementia: a national dementia strategy. Available at:
<https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

Department of Health (DoH) (2011) Common core principles for supporting people with dementia: A guide to training the social care and health workforce.

Available at:

<https://www.gov.uk/government/publications/common-core-principles-for-supporting-people-with-dementia>

Department of Health (DoH) (2013) Dementia: A state of the nation report on dementia care and support in England. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/262139/Dementia.pdf

Department of Health (DoH) Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values.

A mandate from the Government to Health Education England: April 2015 to March 2016. Available at:

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/411200/HEE_Mandate.pdf

Department of Health (DoH) (2015) Prime Minister's Challenge on Dementia 2020. Available at:

<https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020>

NHS Choices (2015) Dementia. Available at: <http://www.nhs.uk/Conditions/dementia-guide/Pages/about-dementia.aspx>

Skills for Health, Health Education England and Skills for Care (2015) Dementia Core Skills Education and Training Framework, Available at:

<http://www.skillsforhealth.org.uk/images/projects/dementia/Dementia%20Core%20Skills%20Education%20and%20Training%20Framework.pdf>