

Hospice Guidance Notes

These notes set out to guide Hospices on why and how they can improve the lives of people living with dementia, their carers and families. It also provides guidance on how you can join a local Dementia Action Alliance and publically state your commitment through developing an Action Plan about how you intend to work towards becoming dementia friendly.

Why is dementia important to you?

Dementia is important to Hospices because:

- There are over 850,000 people living with dementia in the UK and this figure is set to rise. 225,000 people develop dementia every year, roughly one person every three minutes. (Alzheimer's Society 2014)
- Dementia is now acknowledged as a life-limiting illness, often existing alongside other chronic conditions which can, and should, benefit from palliative care
- It is estimated that there are 66,000 deaths per year in the UK attributable to dementia (Dept. of Health). This is predicted to rise substantially in the next 10 years. Hospices can make a significant contribution in providing support to people affected by dementia, which is one of the biggest health challenges we face.
- Most people with dementia die in an institutional setting. The majority die inappropriately in hospital and currently only 1% die in a Hospice. Around 70% of people say they want to die at home but only 18% of people with dementia do so.
- There are strong moral and legal reasons why Hospices should make their services equitable for people with dementia their family and carers. The Equality Act 2010 recognises dementia as a disability. Organisations need to make reasonable adjustments to avoid discrimination so that people with dementia and their carers have access to good hospice care.

What can you do?

Join the Dementia Action Alliance

Organisations join the Dementia Action Alliance by implementing a short Action Plan outlining the actions they will take to improve the lives of people living with dementia.

Dementia Action Alliance members from the Hospice sector include:

- East Cheshire Hospice, Cheshire
http://www.dementiaaction.org.uk/members_and_action_plans/4638-east_cheshire_hospice
- St Giles Hospice, West Midlands
http://www.dementiaaction.org.uk/members_and_action_plans/3057-st_giles_hospice

- Douglas Macmillan Hospice, West Midlands
http://www.dementiaaction.org.uk/members_and_action_plans/3374-douglas_macmillan_hospice
- Saint Francis Hospice, London
http://www.dementiaaction.org.uk/members_and_action_plans/2533-saint_francis_hospice

What steps can you take to become more Dementia Friendly?

Ensure staff and volunteers are trained and dementia aware

- Provide general dementia awareness training for staff and volunteers and identify further training at the right level for staff supporting with people with dementia and their carers
- Organise dementia awareness sessions for all staff, volunteers and trustee's across all settings, including retail outlets. Include it in induction training and make it mandatory for all staff and volunteers. Offering Dementia Friends Sessions is a good way to meet this need but also consider having your own Dementia Friends Champions within the hospice.
- Identify high quality dementia training beyond awareness so that appropriate staff have the right skills in the right place at the right time. The Dementia Core Skills Education and Training Framework 3 tier structure, the Six Steps Programme and the Gold Standard Framework (CSF) for people nearing the end of life, all provide more information on qualifications and training

Ensure your environment is dementia friendly

- Review the hospice environment including any retail outlets, is it dementia friendly?
- Check elements such as signage, colours, contrasts and noise against dementia friendly criteria. Are there sufficient visual cues to guide patients and visitors with dementia around your environments? Is the purpose, and contents, of rooms clear and signed?
- Get feedback from patients, family and carers about the environment and any challenges they face by inviting them to walk round the hospice and give you feedback. Alternatively, carry out surveys or set up focus groups.

Develop local partnerships and raise awareness of your services

- Make links with key local partners and dementia services so they are aware of the support you can provide.
- Identify established local groups you could join e.g. Dementia Strategy Groups, Carers groups, local Dementia Action Alliances and research institutions.
- Make links with other hospices in your area to share practice - join forces and set up a peer networking group. For example there has been some discussion about setting up a Greater Manchester Hospice Network.

Next Steps

A. Become a DAA member by using the following template to create and implement an Action Plan

- Download and complete the form found here:
http://www.dementiaaction.org.uk/assets/0001/0762/DAA_Local_Membership_Form_090614.docx
- If you prefer, request a form to complete and email it to us:
dementiaactionalliance@alzheimers.org.uk
- Use the action plan guidance below to create your action plan:

Answering the three questions in the form will complete your Action Plan. By completing an Action Plan your organisation will sign up to the National Dementia Declaration and become a member of the Dementia Action Alliance.

The National Dementia Declaration

The National Dementia Declaration lists seven outcomes that all businesses, charities and public bodies can collectively work towards to improve the lives of people with dementia and their carers.

By signing up to the Declaration you will be joining an Alliance of more than 600 organisations to state publically that people can live well with dementia and that all society has a responsibility for ensuring that this happens.

To read about the history of the Declaration and download a full copy, go to:
<http://www.dementiaaction.org.uk/nationaldementiadeclaration>

Examples of Action Points from Hospices working to become dementia friendly

- Staff awareness through [Dementia Friends](#) sessions and enhanced dementia training
- Adequate signage and environmental considerations
- Offering services to support care givers and people with dementia
- Developing partnerships and communications

Search under Local Alliances and Hospices for more examples of action plans here:
http://www.dementiaaction.org.uk/members_and_action_plans

B. Join your local Dementia Action Alliance (LDAA). Once you have joined, you can take part in local alliance activities. Local DAAs are organisations working together to make their community more dementia friendly.

To find your local alliance, contact us or visit: http://www.dementiaaction.org.uk/local_alliances

If there is no local alliance in your area you can help create one by contacting your DAA regional lead. Find your regional lead using the link below.

Contact details

Contact us for help or guidance when writing your action plan, or to get involved with your Local Dementia Action Alliance.

National team: dementiaactionalliance@alzheimers.org.uk

Regional leads: http://www.dementiaaction.org.uk/contact/regional_leads

Useful Resources

Sector case studies and blogs

- Willow Wood Hospice: Tackling the disadvantaged experienced by people dying with dementia <http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/12157/>
- St. Giles Hospice: Developing hospice services for people living with dementia <http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/14503/language/en-GB/View.aspx>
- St. Cuthbert's Hospice: Admiral Nursing in a Hospice <http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/14477/>
- St. Christopher's Hospice: Living or Existing - the Namaste Care Programme for people with advanced dementia <http://www.ehospice.com/uk/articleview/tabid/10697/articleid/12114/language/en-gb/living-or-existing-the-namaste-care-programme-for-people-with-advanced-dementia.aspx>
- Putting Memory First: Specialised services to the patients door <http://www.ehospice.com/uk/Default/tabid/10697/ArticleId/10594/>
- St Ann's Hospice: Educate helps hospice to become dementia friendly <http://www.ehospice.com/uk/ArticleView/tabid/10697/ArticleId/14971/language/en-GB/View.aspx>

Information, guidance and tools

- Hospice Enabled Dementia Care – The first steps, a guide to help hospices establish care for people with dementia, their carers and family <file:///C:/Users/theclubgamenet/Downloads/hospice-enabled-dementia-care---the-first-steps.pdf>
- Hospice Enabled Dementia Care – First steps, a checklist to enable hospice leaders assess their organisational readiness to support hospice enabled dementia care <http://www.hospiceuk.org/what-we-offer/clinical-and-care-support/hospice-enabled-dementia-care?page=2>
- My life until the end - Dying well with dementia factsheets (Alzheimer's Society) https://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=1537
- Achieving a good death for people with dementia <http://www.ncpc.org.uk/dementia>
- What should I know, what should I do? - A guide to help someone in pain or distress (The National Council for Palliative Care) <http://www.ncpc.org.uk/news/how-would-i-know-what-can-i-do>
- Nameste model of end of life care <http://www.namastecare.com/>
- Carer support needs at end of life care – carer specific support tool <http://csnat.org/files/2012/07/CSNAT-approach-October-2015.pdf>
- **THIS IS ME** – a booklet to capture details of the person with dementia. To support care in all contexts and decisions made in best interest. (Alzheimer's Society) <https://www.alzheimers.org.uk/thisisme>

Environment

- Dementia Friendly Environment checklist (Dementia Action Alliance)
http://www.dementiaaction.org.uk/resources/5031_dementia_friendly_environments_checklist
- Good practice in the design of homes and living spaces for people with dementia and sight loss (University of Stirling) <http://dementia.stir.ac.uk/design/good-practice-design-dementia-and-sight-loss>

Training

- E-Learning for Health Care: Dementia Open Access e-learning <http://www.e-lfh.org.uk/programmes/dementia/open-access-sessions/>
- Social Care Institute for Excellence (SCIE): Open Dementia e-learning Programme <http://www.scie.org.uk/assets/elearning/dementia/dementia01/resource/flash/index.html>
- A guide to workforce development for end of life care – Skills for care www.skillsforcare.org.uk
- About Dementia – A-Z of Dementia (Alzheimer's Society) <https://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200360>

Videos

- Dying Matters – promotional video `Time to talk doc?` a training film aimed at building confidence of palliative nurses broaching end of life conversations affecting people with dementia www.youtube.com/watch?v=MeTvIKhhAFU
- End of Life Video (Social Care Institute for excellence (SCIE)) <https://www.youtube.com/watch?v=DfZ6nmDtyBY>