

Dementia Strategy

Uniting People Together



MHA Dementia Strategy
2019-2022

Introduction

We launched a new five year strategy in April 2019 outlining how we would support people to live later life well. Our strategy has four key areas to enable us to achieve this including:

- MHA in the Community
- MHA Enhancing Later Life
- MHA People
- MHA Fit for the Future

The Dementia Strategy builds upon the content discussed in MHA's strategy to ensure we are able to support **people living with dementia and their families** to **live later life well**. The aim of the Dementia Strategy is to guide us over the next three years to ensure we achieve our **mission, values and vision**.

Mission

As a charity, our mission is to enable people to live later life well.

Our values inspired by our Methodist roots

Respect every person, treating them with dignity

Nurture mind, body and spirit

Inspire the best in each other

Our vision

By 2024 we will have increased the quality, impact and reach of our services by connecting our communities and realising our potential as One MHA.

Development of the Dementia Strategy

We were very clear from the start of this process that we wanted the strategy to be shaped by:

- People living with dementia who use our services
- Those not living with dementia who use our services
- Families and friends of people living with dementia
- Our colleagues and volunteers

To enable us to do this, feedback was sought using interviews, observations and surveys. Some of the feedback can be found in this document.

“The team always contact me if there is anything they need to discuss about my wife. When I visit and see how happy she is it makes such a difference to me and the rest of the family.”

Family member whose wife is living in an MHA care home.

“I can now sleep at night knowing that my dad is being looked after by such lovely and caring staff.”

Family member of an MHA care home resident.

“It has made such a difference to my life coming here.”

MHA resident living with dementia.

“The people here really are super, they are so friendly. You can have a real good laugh and a joke with them.”

Live at Home member living with dementia.



The feedback was then collated into **six different commitments** which form the structure of the Dementia Strategy. These commitments, to people living with dementia and their families, shows that MHA understands:

- The responsibility it has in influencing and improving services for people living with dementia.
- The importance of working together in partnership with others, including with other agencies, people living with dementia and their families.

Our commitment to enable people living with dementia and their families to live later life well.

Commitment one

We will support you to engage with your **local community**.

Commitment two

We will ensure that our colleagues and volunteers have the necessary **attributes, attitudes** and **knowledge** to support you.

Commitment three

We will work in **partnership with your family** to help them feel supported and involved.

Commitment four

We will work to recognise your **behaviour as a form of communication** and take time to respond in a supportive way.

Commitment five

We will ensure that you live in or visit an **environment** that makes you feel at home, safe and supported.

Commitment six

We will assist you to access **spiritual support, meaningful music** and **activities**.

Why does MHA need a Dementia Strategy?



There are three key reasons for this strategy:

- **To respond to the feedback gathered.**
- **Ensure services are in place to meet the need of the growing numbers of people living with dementia.** In 2015 there was an estimated 850,000 people living with dementia in the UK. This is predicted to increase to 1.2 million people by 2025, an increase of **40%** (1). The majority of people living in care homes are thought to have dementia or mild cognitive impairment (80%), however the majority of people with dementia still live in their own or relatives' homes (66%) (2).
- **To provide a unified approach in line with our MHA strategy.**

Implementing the Dementia Strategy

We acknowledge that the execution and promotion of this strategy is the key to its success. This is why we will be introducing a number of new initiatives, including:

- Our **Cherish Award** - this is an internal accreditation for our homes and schemes that achieve the six commitments. They will be required to evidence their ability to enable people living with dementia and their families to live later life well. To begin the pilot, six care homes, four retirements living schemes and four Live at Home community groups will undertake the Cherish Award. These pilot schemes will then be used as a benchmark to enable others to develop their work with those living with dementia.
- The **Dementia Strategy Implementation Group** - this will include representatives from the various directorates of MHA. The group will have overall responsibility for the implementation of the Dementia Strategy.
- **Dementia Action Teams** - working as one MHA, these local teams will help implement the commitments within their local MHA community. Once established, each of the teams' members will become **Dementia Strategy Advocates**. Their role will be to champion the dementia strategy within their own MHA scheme.
- **OST Dementia Champion** - enhancing the knowledge across OST (Operations Support Team) as well as developing a few members of the OST to become champions in dementia to support our schemes.



The Acorns & Oaks Group; a venture between our Live at Home community group in Leeds and Dementia Adventure.

Commitment one

We will support you to engage with your **local community.**

We have over 75 years' experience working with local communities, because of this we can support people living with dementia and their families to participate in their local community.

One of the key mechanisms that will enable us to continue to do this is through the **dementia friendly communities'** movement. This will involve working collaboratively with our partners on a national and local level to remove some of the barriers people living with dementia and their families face when trying to access their local community. To do this we will encourage our schemes to:

- Become part of their local **Dementia Action Alliance**
- Increase the number of staff and volunteers registered as a **Dementia Friend**

- Grow the number of **Dementia Friends Champions** so that our staff members and volunteers can deliver dementia friends sessions for staff, volunteers, families and members of the local community.

Also, in our community based Live at Home groups, we will increase the number of **befriending** services and introduce **wellbeing and friendship** groups for people living with dementia.

Finally, where suitable, we will introduce the **Herbert Protocol (England)**, **Purple Alert Scheme (Scotland)** and **Safe Haven Scheme** for people living with dementia.

"All of us have a part to play in making our communities better places in regards to those with dementia."

MHA volunteer.

"Networking with others to drive standards is so important."

MHA care home manager.

"I have run dementia friends sessions for the local school. I really enjoy it and I feel like I am giving something back."

MHA colleague.

"While he is here it gives me an opportunity to go to church. Without my faith I don't know how I would have coped over the past couple of years."

Relative of a Live at Home member.

What does the research say?

As dementia progresses the individual is more likely to withdraw from their local community due to concerns about being:

- Stigmatised by others in the community
- Faced with difficulty accessing community buildings
- Asked to complete confusing tasks for example, being asked to give the correct change to a shop keeper (3).

Withdrawing from a local community can have profound effects on a person living with dementia and their families (4).

Both memory cafés and befriending services have shown to reduce feelings of isolation both for the person living with dementia and their family carer (5&6).

Commitment two

We will ensure that our staff and volunteers have the necessary **attributes, attitudes** and **knowledge** to support you.

Key to the development of any organisation is ensuring that we have the 'right' people. What does right look like in relation to supporting people living with dementia? The evidence indicates that the quality of care given will improve if we ensure that the people we recruited have:

- The **attributes** of empathy and compassion.
- Positive **attitudes** towards people living with dementia. This relates to seeing people living with dementia as individuals rather than a homogenous group.

Currently, we do not have any validated way of measuring this in our potential candidates. Therefore, we will introduce new tools to help us do this. This includes:

- The **Dementia Attitudinal & Empathy Scale**; this examines people's perceptions about dementia and levels of empathy.



- **Dementia situational and behavioural interview questions**. These standardised questions will be introduced to present candidates with real life scenarios.

Once employed, we need to make sure that we continue to support our staff and volunteers to develop their **knowledge**. We are committed to doing this by introducing:

- A **Dementia Learning Pathway** - this will have four levels of training, starting from general learning for the all of staff members and volunteers through to specialist training.
- Our **Dementia e-Academy** - this will include interactive initiatives such as our **Dementia Education Surgery** and **Dementia Blog**. Weekly dementia news updates will also be placed on our Dementia e-Academy.

“Not everyone is cut out to work with residents with dementia. You have to have a certain way about you....I'm not quite sure how to explain it but its more than just being able to care.”

MHA colleague.

“Finding the right person is the biggest battle. It is relatively easy to find ‘carers’ but to find a person who genuinely does care can be a challenge.”

MHA manager, retirement living.

“The key to good training is getting the staff to understand how it might feel to be a resident with dementia, getting them to think about how it would feel to be sat in a chair all day or be in your bedroom by yourself waiting for your family to come and see you.”

MHA care home manager.

What does the research say?

Being able to care empathetically for people living with dementia enhances the quality of care given (7).

Quality of care is also linked to attitudes about dementia (8).

Positive attitudes amongst care staff have been linked to training, with those staff who had received training having more positive attitudes about people living with dementia (9).

Commitment three

We will **work in partnership with your family** to help them feel supported & involved.



We acknowledge that every family members' experience of dementia will be different.

However, we recognise the fundamental role families play in the support and care of people living with dementia. We also recognise that by supporting families we're also supporting people living with dementia, we will:

- Develop new **training for families**. We will pilot dementia awareness sessions for family members.
- Increase the number of **support groups**. We will build on our existing network of support groups for families.
- Publish and distribute MHA's guide for families, **'Supporting people living with dementia'**.
- Launch the **Family Buddies programme**. This will involve existing family members or colleagues/volunteers buddying up with family members who have a relative new to MHA.

"I stress to the new staff how important it is to work with the families of the residents, especially if they have dementia. By working together it means we get the best results for the residents, the families and for us."

MHA care home manager.

"Unless you have experienced caring for someone with Alzheimer's dementia then it is very hard for you to understand.

Often people feel sorry for you but they don't know how it feels. That's why I am comfortable here, the staff know my husband and they know what it is like to care for him."

Relative of an MHA resident.

What does the research say?

Strong relationships between families and staff members are more likely to be formed and maintained when families feel that their opinions are being listened to and acted on (10), they have regular opportunities for communication with the staff team (11) and they see their relative receiving positive care (12).

Families can believe that poor relationships with staff members can have a direct impact on the quality of the care given to their relative living with dementia (13).

Commitment four

We will work to recognise your **behaviour as a form of communication** and take time to respond in a supportive way.

Over the next three years, we will make sure we are responding to a person's behaviour in a supportive and empathic manner. To do this we will:

- Introduce a range of **new workshops** including the **Behaviours in Dementia programme**. These focus on behaviours as a form of communication rather than a challenge to control or manage.
- Launch **Behaviour Advisor Teams**. This will involve nominated colleagues, including music therapists and chaplains, developing psychosocial responses to a person's behaviour. Dementia Care Mapping will be one of the tools reintroduced to help with this.
- Introduce new **behaviours paperwork** which reflects the individuality of each person.
- Sign up to the **DEEP guidance** on language. Labelling language is subjective and it can

shape peoples' perceptions of people living with dementia and therefore influence the quality of care given. Documentation within MHA will be examined to ensure that it reflects this guidance.

Furthermore, we will promote alternatives to potentially harmful antipsychotic medication. We will ensure that they are only used as a last resort and in the person's best interest. To help with this we will undertake:

- An **antipsychotic audit review**. This will enable us to see if we are reducing the amount of antipsychotics given to people living with dementia in line with Government guidance.
- A **staff survey relating to antipsychotic medication**. This will give us insight into staff members understanding of antipsychotic medication.

"If my mum's routine is broken she is in bits but the staff know her routine and they stick to it."

Relative of an MHA retirement living resident.

"The right training is so important because it changes the perception of the person in a positive way because if they can only see someone as challenging then they are never going to connect."

MHA Live at Home area manager.

What does the research say?

Behaviours are the main reason as to why families move their relative with dementia from their own home into a care home (14 & 15).

The use of antipsychotic medication with people living with dementia significantly increases the risk of death (16). This risk increases the higher the dose (17) and the longer a person living with dementia remains on the medication (18). The Time for Change report estimated that in excess 1800 deaths of people living with dementia per year in the UK were attributable to the use of antipsychotics (19).

Commitment five

We will ensure that you live in or visit an environment that **makes you feel at home, safe and supported.**

Opinions about environmental design seem to be one of the most contentious elements of dementia care. This is possibly because of the difference in opinions of what the environment should look like. Luckily, we are in now in the fortunate position of having an extensive evidence base to draw upon.

We already have a number of homes and schemes with environments that support and empower people living with other disabilities, not just people with dementia. We have received a lot of positive feedback about these environments, however, there is not a consistent approach across the organisation. To ensure this happens we will:

- Publish **new environmental guides** and a new internal **dementia environmental audit** for our care homes, retirement living settings and Live at Home community

groups. The guides and audit will be based on relevant research and examines how helpful the environment is in enabling people living with dementia to find their way around, feel safe, maintain independence, dignity and have their cognitive difficulties compensated for.

- Introduce a new **workshop on dementia design** to help colleagues assess their places of work and consider areas for development. Our estates team will also undertake training relating to this area of design.
- Launch our guide to **adapting environments for worship**. This document will describe how we can adapt environments within MHA settings to create meaningful areas for worship and spiritual care for people living with dementia and their families.

“I like the fact that we have small dining areas as it allows us to provide a meaningful meal time and promotes social interaction. Large dining rooms aren’t good because they are noisy and distracting.”

MHA colleague.

“My mother’s floor is on the ground floor. It has the feeling of home from home with lovely pictures on the walls and each room giving the feel of their own flats with how the doors are decorated.”

Family member of an MHA care home resident.

“You know the number of times I come out of that thing (lift) and think where am I?”

MHA care home resident living with dementia.

What does the research say?

Having similar looking doors in a care setting can be detrimental to wayfinding (20), lead to increased anxiety and results in a greater dependency on others (21).

Environments should feel homely and familiar to people living with dementia (22).

Nostalgic decor can be particularly helpful because it creates an aesthetic that people are familiar with (23).

Commitment six

We will assist you to access **spiritual support, meaningful music and activities.**

Living with dementia can be one of the biggest challenges any of us can face. For many people spiritual support becomes an anchor of stability to help during the happiest and darkest days of dementia. We value spirituality because of our roots in the Methodist Church which has helped inform our knowledge, experience and commitment to spiritual care. We will enhance this further by:

- Promoting innovative forms of worship including **Biblical Yoga**. This relates to our belief that worship needs to be made meaningful and inclusive for everyone in our communities, including people living with dementia and their families.
- Creating new guidance relating to dementia and pastoral care.

Furthermore, we will make music more accessible to people living with dementia by:

- Increasing the use of music therapy.

- Collaborating with Playlist for Life to train Music Detectives. Their role will be to create **Personalised Music Plans** for people living with dementia.
- Working in partnership with the Alzheimer's Society to facilitate pilot sites for **Singing for the Brain**.

Finally we will increase the range of activities available by:

- Introducing the use of **activity based technology** including 'magic tables' and digital based life story work.
- Promoting the use of **reminiscence, attachment items and life story work**.
- Creating an **e-resource** of activity ideas, products and recording for activity coordinators.
- Promoting the use of attachment based objects.
- Working with the British Gymnastics Foundation to promote the exercise based programme 'Love to Move'.

"It's about engaging with the residents with dementia, finding out what gives them peace and contentment."

MHA chaplain.

"He joins in the singing and even danced with me, making life seem almost normal again."

Relative of MHA resident, talking about a group music therapy session at an MHA care home.

"The art sessions are very beneficial; they have provided a stimulus for my mum to become engaged with the world again."

Relative of MHA resident, talking about an art session at an MHA care home.

"Just because they walk through our doors doesn't mean they can no longer do what they used to."

MHA care home manager.

What does the research say?

The use of spirituality or faith in daily life enables people living with dementia and their families to develop strategies to cope with the dementia (24), maintain positive relationships with others from their faith group (25) and improves the quality of life both for the person living with dementia and their family carer (26).

There is now a vast amount of evidence that supports the benefits of music for people living with dementia (27,28 & 29).

Meaningful activity for people living with dementia decreases the risk of social isolation (30), behaviour (31), cognitive and physical decline (32).

References

1. Prince, M et al (2014). Dementia UK: Update Second Edition report produced by King's College London and the London School of Economics for the Alzheimer's Society.
2. Alzheimer's Society. (2019). Facts for the media | Alzheimer's Society. Retrieved February 7, 2019, from <https://www.alzheimers.org.uk/about-us/news-and-media/facts-media>
3. Alzheimer's Society (2017). Turning Up the Volume: unheard voices of people with dementia. Alzheimer's Society, London.
4. Alzheimer's Society (2015). Creating a dementia-friendly workplace: A practical guide for employers. Alzheimer's Society, London.
5. Greenwood et al. (2017). A qualitative study of carers' experiences of dementia cafés: a place to feel supported and be yourself. *BMC Geriatrics*, 17 (164) 2 – 9.
6. Smith, R, et al (2018). The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Archives of Gerontology and Geriatrics*. 76, 188-195.
7. Stockwell-Smith G, Jones C & Moyle W (2011). 'You've got to keep account of heads all the time': staff perceptions of caring for people with dementia. *Journal of Research in Nursing* 16(5): 400-412.
8. Kokkonen, T.M., Cheston, R.I., Dallos, R. and Smart, C.A. (2014). Attachment and coping of dementia care staff: The role of staff attachment style, geriatric nursing self-efficacy, and approaches to dementia in burnout. *Dementia*, 13, 544-568.
9. Leung, J.L.M., Sezto, N.W., Chan, W.C., Cheng, S.P., Tang, S.H. and Lam, L.C.W. (2013). Attitudes and perceived competence of residential care homes staff about dementia care. *Asian Journal of Gerontology and Geriatrics*, 8, 21-29.
10. Davies, S. and Nolan, M. R. (2004). 'Making the move': relatives' experiences of the transition to a care home. *Health and Social Care in the Community*, 12(6): 517–526.
11. Bauer, M. (2012). Attitudes towards family–staff relationships in Australian residential aged care settings: Development and psychometric evaluation of the 'Family and Staff Relationship Attitude Tool' (FASRAT). *Australasian Journal on Ageing*, 33(3): 170–173.
12. Ryan, A. A. and Scullion, H. F. (2000). Nursing home placement: an exploration of the experiences of family carers. *Journal of Advanced Nursing*, 32(5): 1187–1195.
13. Kellett, U. M. (2000). Bound within the limits: facing constraints to family caring in nursing homes. *International Journal of Nursing Practice*, 6(6): 317–323.
14. Gilley DW, Bienias JL, Wilson RS, Bennett DA, Beck TL, Evans DA. (2004). Influence of behavioral symptoms on rates of institutionalization for persons with Alzheimer's disease. *Psychological Medicine*; 34:1129–35.
15. Balestreri L, Grossberg A, Grossberg G. (2000). Behavioral and psychological symptoms of dementia as a risk factor for nursing home placement. *International Psychogeriatrics* ;12:59–62.
16. Fossey, J., Ballard, C., Juszczak, E., James, I., Alder, N., Jacoby, R., and Howard, R. (2006). Effect of enhanced psychosocial care on antipsychotic use in nursing home residents with severe dementia: cluster randomized trial. *British Medical Journal*, 332, 756-761.
17. Ballard, C., Gauthier, S., Cummings, J., Brodaty, H., Grossberg, G., Robert, P. (2009). Management of agitation and aggression associated with Alzheimer's disease. *National Review of Neurology* 5: 245–255.
18. Tampi, R. Tampi, D. Balachandran, S. and Srinivasan, S. (2015). Antipsychotic use in dementia: a systematic review of benefits and risks from metaanalyses. *Therapeutic Advances in Chronic Disease*. 7 (5), 229 – 245.
19. Department of Health (2009). The use of antipsychotic medication for people with dementia: time for action. Department of Health, London.

20. Marquardt, G., et al. (2009). Dementia-friendly architecture: environments that facilitate wayfinding in nursing homes. *The American Journal of Alzheimer's Disease and Other Dementias*. 2009;24(4):333-340.
21. Davis, S., Byers, S., Nay, R., Koch, S. (2009). Guiding design of dementia friendly environments in residential care settings: Considering the living experiences. *Dementia*. 8(2):185-203.
22. Fleming, R., Kelly, F., and Stillfired, G. (2015). 'I want to feel at home': establishing what aspects of environmental design are important to people with dementia. *BMC Palliative Care*, 14: 26.
23. Kok, S., J., Nielen, M.A., and Scherder, E., J., A. (2018). Quality of life in small-scaled homelike nursing homes: an 8-month controlled trial. *Health Quality & Life Outcomes*. 16:38.
24. Daly, L., Fahey-McCarthy, E., & Timmins, F. (2016). The experience of spirituality from the perspective of people living with dementia: A systematic review and meta-synthesis. *Dementia*, 1 (1). 1 – 23.
25. Carr, T. J., Hicks-Moore, S., & Montgomery, P. (2011). What's so big about the little things? A phenomenological inquiry into the meaning of spiritual care. *Dementia*, 10, 399-414.
26. McGee, J. S., Myers, D. R., Carlson, H., Funai, A. P., & Barclay, P. A. (2013). Spirituality, faith, and mild Alzheimer's disease. *Research in the Social Scientific Study of Religion*, 24, 221-257.
27. Fusar-Poli, L et al (2017). The effect of music therapy on cognitive functions in patients with dementia: a systematic review and meta-analysis, *Aging & Mental Health*, 1- 10.
28. Ming, H, H et al (2015). Individual music therapy for managing neuropsychiatric symptoms for people with dementia and their carers: a cluster randomised controlled feasibility study. *BMC Geriatrics*. 15:84, 1 – 19.
29. Van der Steen JT, Smaling HJA, van der Wouden JC, Bruinsma MS, Scholten RJPM, Vink AC. (2018). Music-based therapeutic interventions for people with dementia. *Cochrane Database of Systematic Reviews*, Issue 7.
30. Phinney, A, Chaudhury, H., & O'connor, D.L. (2007). Doing as much as I can do: The meaning of activity for people with dementia. *Aging & Mental Health*, 11, 384 – 393.
31. Vollicer, L., Simard, J., Heartquist Pupa, J., Medrek, R., & Riordan, M.E. (2006). Effects of continuous activity programming on behavioral symptoms of dementia. *Journal of the American Medical Directors Association*, 7, 426 – 31.
32. Brooker, D.J., Wooley, R.J., & Lee, D. (2007). Enriching opportunities for people living with dementia in nursing homes: An evaluation of a multi-level activity based model of care. *Aging & Mental Health*, 11, 361 – 370.

Notes

[illegible]





Epworth House, Stuart Street, DE1 2EQ
01332 296200 | mha.org.uk

MHA Dementia Strategy 2019-2022