Dementia Friendly

Aldeburgh, Leiston, Saxmundham, and Villages

Purpose of Report

The purpose of this report is to outline the need to develop a cohesive approach to supporting people living with dementia across the Community Partnership. It explores different models operating across Suffolk and seeks to make recommendation for a coordinator led approach across Aldeburgh, Saxmundham, Leiston and villages.

It should be noted that this report focuses on the voluntary support for people living with dementia at pre-diagnosis, and early post diagnosis, i.e., to support people to live well in their community. This has the outcomes of people living with dementia and their carers to be socially connected to their community to improve their resilience, mental health, and wellbeing.

1. Introduction

1.1 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 is not a natural part of ageing. It occurs when the brain is affected by a disease. There are more than 100 known types of dementia. The most common are Alzheimer's disease and vascular dementia.

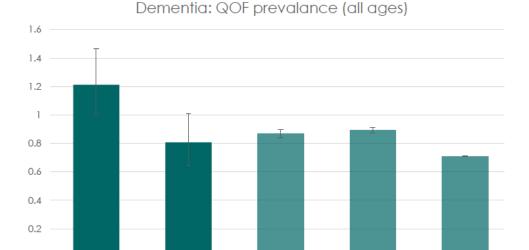
According to the Alzheimer's Organisationi

- ➤ There are currently around 900,000 people with dementia in the UK. This is projected to rise to 1.6 million by 2040.
- ➤ 209,600 will develop dementia this year, that is one every three minutes.
- > 70 per cent of people in care homes have dementia or severe memory problems.
- There are over 42,000 people under 65 with dementia in the UK.
- More than 25,000 people from black, Asian and minority ethnic groups in the UK are affected.

1.2 Estimated Numbers of People Living with Dementia

England	900,000
Suffolk	13,000

Predicted to rise by 2040 to 21,000



Prevalence of dementia is higher than the national average among patients Leiston Surgery. The estimated prevalence of dementia is also higher at Saxmundham Health Centre, but not statistically significantly so

NHS Ipswich And

East Suffolk CCG

Waveney CCG

England

Source: Quality and Outcomes Framework (QOF). Accessed via fingertips.phe.org.uk

Saxmundham

Health Centre

With >13,000 people living with dementia in Suffolk, and a high prevalence in Leiston and Saxmundham, it is essential to socially connect people living with dementia and their carers to improve their resilience, mental health, and wellbeing.

1.3 Social Isolation

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Leiston Surgery

People living with dementia report negative psychological and cognitive effects and are amongst the most isolated and vulnerable within our communities. Lack of social interaction increases feelings of isolation, loneliness, and reduced self-worth. Alzheimer's Society encourage communities to be dementia friendly so that people living with dementia (including their carers) can continue to live well and engage in social interaction in familiar surroundings (cafes, libraries, open spaces).

2. Existing Support

2.1 Suffolk – Dementia Connect, Alzheimer's Society

(Was Dementia Together run by Sue Ryder)

Dementia Connect is Alzheimer's Society's personalised support and advice service for anyone affected by dementia. It is a free, easy to access, and will put people in touch with Alzheimer's Society's dementia advisers. Through Dementia Connect expert dementia

advisers will listen, help with all dementia-related questions, and connect you to the support you need, from local help to phone and online advice.

Corinne Longland-Malam is the newly appointed Dementia Connect Local Services Manager for Suffolk alongside Wendy Hall and Angela Steggles as new Dementia Advisors covering East Suffolk.

Corrine.LonglandMalam@alzheimers.org.uk

Dementia Connect are currently recruiting for a Community Engagement post.

2.2 Across the Community Partnership

A recent mapping exercise of over 200 community groups across the Community Partnership shows a lack of dementia specific support from the voluntary sector.

2.3 Current initiatives

Suffolk Dementia Action Partnership <u>Dementia Action Partnership - Healthy Suffolk</u>

Over 30 different organisations have met over the past year and are working on a strategy to be completed in 2023. The strategy will be centred around 5 key themes:

- 1. Co-production redesigning pathways from diagnosis to end of life
- 2. Dementia training/skilled workforce
- 3. Dementia Friendly Initiatives
- 4. Collaboration stronger working relationships/sharing best practice
- 5. Proactive Support social opportunities, funding, support groups

The Partnership are currently recruiting a 2-year fixed term post to support the development of the strategy.

Suffolk and Northeast Essex Dementia Forum (SNEE)

A partnership that has 6 Task and Finish groups to work on various aspects of dementia at more grass roots level. SNEE Forum feeds into the Suffolk Dementia Action Partnership.

- 1. Memory Assessment & Diagnosis
- 2 Carers
- 3. Dementia Friendly Communities
- 4. Information & Advice
- 5. Prevention
- 6. Workforce

Also currently looking at intergenerational projects e.g., Archie the Scarecrow

The Archie Project is an exciting intergenerational dementia awareness project that links local primary schools, care homes, sheltered housing schemes, businesses, services, and community members to dispel the fear and stigma often associated with dementia and create more dementia friendly communities.

The Archie Project - Dementia Friendly Communities - Alzheimer's Society - YouTube



3. Models supporting people living with dementia across Suffolk

3.1 Dementia Action Alliances (DAAs)

The Dementia Action Alliance (DAA) was launched in 2012 as part of the Prime Minister's Challenge on Dementia. DAA's aims to improve the lives of people living with dementia and their carers through coordinated local action. A Local Dementia Action coordinates action and is recognised as dementia friendly community via the Alzheimer's 's Society's Recognition scheme.

DAA's are a voluntary collaboration and have been responsible for raising awareness of dementia:

- encouraging businesses and voluntary organisations to be more dementia friendly
- recruiting volunteer dementia champions to deliver information awareness sessions
- encouraging individuals to become dementia friends and committing to action/s to raise awareness of dementia in the community.

Most dementia initiatives across Suffolk have been developed through the DAAs including the services provided by the Good Neighbourhood Scheme in Leiston.

NB: Alzheimer's Society have recently changed their model to recruit volunteer Ambassadors to fundraise rather than champion greater awareness of dementia and promoting dementia friendly towns and communities who can no longer apply to be a Dementia Action Alliance.

The Suffolk Dementia Action Partnership is currently reviewing the old Dementia Friends and Dementia Friendly Community model and working toward a local model for dementia friendly Suffolk expected to be available in Autumn 2023.

There is no doubt that raising awareness of living with dementia and supporting communities to be more dementia friendly remains a key need. However, a more urgent and pressing need is to re-engage and kickstart the voluntary support groups who are key to providing social interaction and social connection.

Checking the DAA website there appears to be active DAAs in Newmarket, Ipswich and Needham market and Inactive Daas in Bury St Edmunds, Felixstowe, Haverhill, and Stowmarket.

3.2 Hour Community, Framlingham <u>Forget Me Not Club | Framlingham | Suffolk (hourcommunity.co.uk)</u>

Hour Community's Forget Me Not Club is a dementia friendly lunch club run by some fantastic volunteers who provide a whole host of activities and entertainment to over 30 people each month. The Forget Me Not Club is a place to come and meet new people, socialise, eat, and enjoy activities with others, in a safe and welcoming environment.

3.3 The Debenham Project <u>The Debenham Project – Welcome (the-debenham-project.org.uk)</u>

Dedicated to giving practical and emotional support to all in the Debenham area who care for those with dementia. The Debenham Project aims to help all those families in the area who are having to cope with the impact of dementia on their lives - to offer them the practical and emotional support which can make "living with dementia" a better place than when they were "on their own" - to show that that their community cares and wants to support them in their difficulties - and that there are those around them that have "been there" and understand the problems and emotions that they are going through.

3.5 Memory Lane, Felixstowe

The Felixstowe Dementia Action Alliance was set up in June 2015. It had 3 areas of focus to support people with dementia:

- 1. Ensure the sustainable future of a local support group
- 2. Clear signposting to support agencies
- 3. Raise awareness of dementia

By 2019 the FXDAA had established Memory Lane Support Group providing a weekly support group to approx. 30 people with an emphasis on providing stimulating and engaging activities. It had achieved 800+ Dementia Friends, 148 Digital Friends, 12 Dementia Champions, and 40 Alliance Business Members.

In 2019 the FXDAA revisited its terms of reference and developed a delivery plan, however due to Covid the plan has not been possible to action to date. The long pause in FXDAA delivery led to a loss in momentum and provided an opportunity to reflect on the purpose and future of FXDAA. As a result, going forward, the FXTDAA has been dissolved, moving away from a national umbrella and framework to a local model working for, and with, local people affected by dementia. Whilst the support group had acted on an entirely voluntary

basis it was felt that the clients – people living with dementia – would benefit from an experienced and trained dementia support worker, especially when families were moving into crisis, and a more structured approach to the activities. It has since entered a collaborative agreement with Home Instead, a home health care service, and has secured funding for a paid trained coordinator. Within this model it has opened a second Memory Lane in Trimley St Mary responding to increasing need across the Felixstowe Peninsula.

Leiston-cum-Sizewell Dementia Support Group and Good Neighbour Scheme

The Leiston Dementia Project started in 2017, again as a local DAA and recognition for being a 'Dementia Friendly Community' under the Alzheimer's Society scheme. The project also had an objective which was about improving support networks for people living with dementia and family carers. This led to setting up the Leiston Good Neighbour Scheme in 2018 with the help of volunteers. The scheme provides support to a wide range of people in the area including people living with dementia. It also provides a drop-in centre at Leiston Town Council.

It continues to work with other providers e.g., the sessions at the Waterloo Centre run by young musicians from Britten-Pears.

Community Partnership Recommendations:

To agree a coordinated approach to Dementia Services in the Community Partnership area.

¹ Facts for the media | Alzheimer's Society (alzheimers.org.uk)