

Suffolk Health and Wellbeing Board

A committee of Suffolk County Council

Report Title:	Creating a Dementia Friendly County: Building on the 2015 commitment
Meeting Date:	11 March, 2021
Chairman:	Cllr Tony Goldson
Board Member Lead(s):	<i>Georgia Chimbani (ACS Director, Suffolk County Council)</i>
Author:	<i>Dementia Forum represented by Sue Hughes (chair) and Lynden Jackson (Debenham Project)</i>

What is this report about and why is it coming to the Health and Wellbeing Board?

1. This report seeks to build on the Health and Wellbeing Board's 2015 commitment to create a dementia friendly county in Suffolk. It explains the progress that has been made over the past five years, but also considering the wider context including the expected continued increasing prevalence of people living with dementia. The resulting ask is for the Board to commit to act and support further activities to support people living with dementia and those who care for them.

The paper sets out the key actions necessary to improve support in Suffolk, starting with an agreed vision on what it means for Suffolk to be 'dementia friendly', and recommendations for the Board to support a real and sustainable change over the coming year.

Key questions for discussion:

2. The key questions for discussion are:
 - a) What does it mean for Suffolk to be dementia friendly?
 - b) How can the Board commit to make a measurable difference to improve the lives of people living with dementia and those who care for them?
 - c) How can the Board empower and encourage communities to be proactive in supporting vulnerable people and carers?

What actions or decisions is the Board being asked to take?

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| <ol style="list-style-type: none"> 3. To sign up to a shared vision of what it means for Suffolk to be a dementia friendly county. 4. To make a measurable commitment to improve the lives of people living with dementia and those who care for them over the next 12 months. |
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Why this action/decision is recommended.

5. In Suffolk's Joint Health and Wellbeing Strategy Refresh 2019-22, the Health and Wellbeing Board has committed to enable resilient communities, reduce health inequalities and to prioritise prevention. The Board has also agreed priorities to improve people's mental health and wellbeing (priority 4) and to provide a good quality of life for older people (priority 3). The COVID-19 pandemic has also disproportionately affected certain vulnerable communities, including people living with dementia and their carers' (as highlighted in recent Alzheimer's Society reports [Worst hit: Dementia during Coronavirus](#) and [The Fog of Support](#)). Working together to promote communities in Suffolk where people feel safe, included, and supported, will go some way to redressing this balance, and the resulting risk of health inequalities among these cohorts.

Evidence shows that the prevalence of dementia increasing (including particularly high rates in those 85 years and over), with an expected increase to the overall number of people aged over 65 in Suffolk, which is likely to further grow from 1 in 5, to 1 in 3 over the next 20 years. The Board is asked to act now to support all those people in Suffolk living with the impact of dementia on their lives (including those with the condition and equally their family carers), and to enable and empower our communities to provide direct support to them at every step of their journeys; from their first concerns, through diagnosis and learning to cope, to living 24/7 with the illness.

Who will be affected by this action/decision?

6. Suffolk communities and especially those living with dementia and the people who care for them.

How has co-production been involved in this work?

On 13 July 2017, the Health and Wellbeing Board approved its [principles of co-production](#).

7. This work has been conceived and developed by the Suffolk Dementia Forum, established by Healthwatch in April 2017. The Dementia Forum is open to people of all ages living with dementia and their carers', statutory and voluntary organisations, and community groups, who are connected to represent those of all ages affected by dementia.

In addition to sharing information, learning and effective practice, one of the main aims of the group is to actively give a voice and provide a safe platform to listen and gain understanding of the lived experience of people living with dementia and their carers'. Members of the Dementia Forum have been continuing to work directly with Healthwatch to truly embed the principles of co-production in all that we seek to deliver.

Sources of further information

The public have a right to inspect any documents included in this box – they are therefore in the public domain once the agenda is published. Background papers used in preparing the report must be kept by the report author for four years from the date of the meeting.

If there are no sources of further information, don't delete the box. Please insert the wording "No other documents have been relied on to a material extent in preparing this report".

- a) Dementia Friendly Communities: Guidance for Councils, Local Government Association, 2015

Main Body of Report

Context

8. It is estimated that around 13,000 Suffolk residents (including those with and without a formal diagnosis) were living with dementia in 2018, and that this number will increase to around 23,000 by 2040. Dementia is more common among older people, and the projected increase is in line with the number of people aged 65 or over in Suffolk which is set to grow from 1 in 5, to 1 in 3 of the population in 20 years' time.
9. In addition to the direct impact of dementia on the individual, the condition can have a profound wider impact on their family, friends, and the wider community. Whereas in the past, much of the focus has been on medical intervention to manage the condition, more recently there has been greater acknowledgement of the vital role local systems and communities play in enabling people living with dementia (pre- and post-diagnosis), to achieve significantly improved wellbeing. This includes the benefits of having proactive networks of support within their immediate communities, in helping people stay healthier for longer, and family carers to continue caring for their loved ones at home.
10. In 2012, the then Prime Minister set out a challenge to improve dementia care and research, including establishing dementia friendly communities and training people and professionals to become 'Dementia Friends' having a greater awareness of dementia and its' impact on individuals.
11. In January 2015, the Health and Wellbeing Board made a commitment to build on the Prime Minister's challenge to become a strategic dementia alliance, with a commitment to make Suffolk a dementia friendly county. This included promoting local dementia friendly communities, with individual member organisations agreeing to act to facilitate dementia friendly environments and work practices.
12. Suffolk Dementia Forum formed in 2017, bringing together statutory and voluntary organisations, providers', and individuals to provide a platform to hear the lived experience of people living with dementia and their carers', to share information and to act accordingly. More recently since April 2020, colleagues from North East Essex have joined the Dementia Forum to make it a wider Suffolk and North East Essex (SNEE) Dementia Forum
13. Establishing dementia friendly communities is a key role of Dementia Action Alliances (DAAs). Local DAAs are "groups of people and organisations,

representing different sectors within an area who come together to create a dementia friendly community alongside local people affected by dementia” ([Dementia Action](#)). In the past five years, several local DAA’s have formed in addition to other enabling communities (see point 14). However, there are still gaps in the development of DAA’s both geographically, and with specific communities requiring increasing support.

14. There are some significant independent initiatives e.g. The Debenham Project that offer pro-active local dementia support such as information and advice, lunch clubs, carers clubs, fitness, activities, social events, one-to-one, etc. However, the county-wide provision of such community-based services is limited.
15. The Alzheimer’s Society defines a dementia friendly community as: “A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia friendly community people, will be aware of, and understand, dementia and people with dementia will feel included and involved, and have choice and control over their day-to-day lives”. However, we would argue that Suffolk should recognise that to achieve this requires us to act proactively, further acknowledging that the cost to the family carer is also immense and treat their individual needs as a priority.
16. People living with dementia have described a dementia friendly community as one that enables them to:
 - find their way around and be safe.
 - access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas, and post offices)
 - maintain their social networks so they feel they continue to belong.
 - access the help and support that enables them to manage the impact of their condition as best as possible.

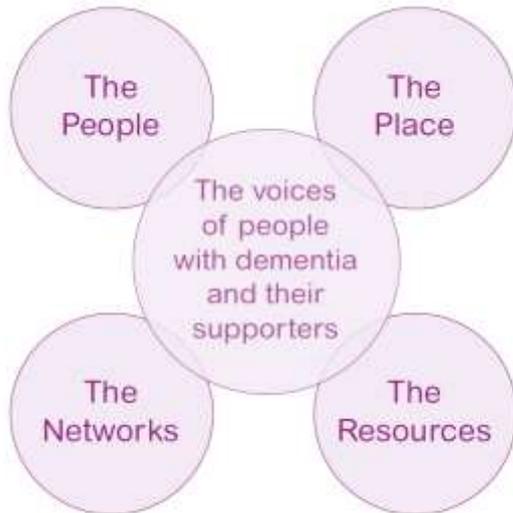
Dementia friendly communities are those in which both those with dementia and those who are caring for them, have the best possible opportunities to live beyond the diagnosis. This includes having opportunities to enjoy good times despite the difficulties they face and being supported to cope when times become tough.

17. From 2015-2017, the dementia friendly communities fund, with funding from Public Health, administered by Suffolk Community Foundation, has supported 24 local projects that have each contributed to support people with dementia and those who care for them.

Community framework

18. The [Local Government Association](#) created guidance in 2015 for health and wellbeing boards, setting out a dementia friendly community framework as a model to be considered when planning, developing, or assessing interventions to support dementia friendly communities. **The model provides five domains, each clearly describing suggested actions which councils and other organisations can take to make a positive difference to the lives of people living with dementia:**

The five domains



A. The voices of people with dementia and their supporters: Dementia friendly communities are responsive to what people want, but perhaps more importantly, people with dementia have the right to have a sense of ownership, investment, responsibility, and connectedness to their own communities.

B. The Place: The physical environment, from streetscape down to individual shops and facilities within it, as well as people's own homes, plays a key role in determining the extent to which people with dementia will find their communities dementia friendly.

C. The People: People make communities friendly – those people whom a person with dementia might interact within the course of everyday life.

D. The Resources: Consider how resources can be deployed in services that have the greatest potential to support people with dementia and their carers engage with their communities.

E. The Networks: It takes a lot of organisations and individuals to make a community, and it is therefore important that a range of organisations are involved in creating dementia friendly communities.

commitment to act.

20. The Health and Wellbeing Board is particularly well placed to act to address the many wider determinants that can influence the effectiveness of dementia friendly communities, including physical environment, transport, housing, planning, leisure and the quality of health and care services.

21. This new commitment would initially focus on people living with dementia and their carers first, before extending to a wider, supportive communities' approach to other vulnerable groups.

The Board is asked to agree to a shared vision of how dementia friendly communities will be supported and extended in Suffolk. The Dementia Forum has proposed the following:

“People living with dementia and their carers’ in Suffolk will have the best opportunities to be safe and well and continue to live an active life of their choosing, within an informed community that supports, includes and values them”.

22. The Dementia Forum is proposing a phased approach to make a lasting, meaningful impact on the quality of support for those living with dementia and their carers'. This will start with short, medium, and longer-term aspirations.

23. Based on the new vision for improving support for those living with dementia and their carers' in Suffolk, the Board is asked to agree to one or more of the following commitments over the first 12 months to the period March 2022:

- For each organisation represented on the Board to commit to one or more measurable actions to be completed over the next 12 months in line with the [LGA's dementia friendly community framework](#) (see above).

- For each organisation to consider and propose a project aimed at directly helping family carers and those they care for with dementia.
 - Considering whether the organisation will commit to sign up to become a dementia friendly organisation by March 2022, with respective measures in place to assess the positive impact on people living with dementia and their carers'. Criteria for becoming a dementia friendly organisation is available from the [Alzheimer's Society](#).
 - Consider opportunities to work alongside communities as supporters or sponsors of dementia friendly communities, joining an existing Dementia Action Alliance or supporting the development of a new Dementia Action Alliance. This will include reviewing what is already in place and working well, identifying gaps, considering what might be the priorities for action, taking an asset-based approach.
 - Consider how best to support communities to access sustainable funding (beyond one-off time limited grants) based upon demonstrated impact.
24. To achieve measurable, timely and realistic actions, the Board is asked to agree suitable governance arrangements to monitor this activity in coordination with the Health and Wellbeing Board Programme Office and the Dementia Forum.
25. The Board is also asked to agree to receive regular updates from the Dementia Forum to review overall progress in Suffolk, and to assess activity against this one-year commitment.

Appendices:

How can we work together to make this a reality?

Delivering a vision for a Dementia Friendly Suffolk

Proposed shared vision:

“People living with dementia and their carers’ in Suffolk will have the best opportunities to be safe and well and continue to live an active life of their choosing, within an informed community that supports, includes and values them”.

The Ask of The Suffolk Health and Wellbeing Board:

- Agree and sign up to the above shared vision.
- Each organisation represented, to sign up to one or more of the suggested commitments to be implemented over the next 12 months with a respective measurement of the impact of this for people living with dementia and their carers’.
- Consider the best governance arrangements to ensure progress against identified actions.

Suggested governance structure to progress the asks:

- Suffolk Health and Wellbeing Board to act as project sponsors in supporting Suffolk to become a “Dementia Friendly County”
- Consider the formulation of a Dementia Friendly Suffolk Board or DAA and provide appropriate senior representation.
- Support delivery and oversight of a county action plan (informed by organisational commitments and plans), to be developed, in line with [LGA’s dementia friendly community framework](#) with milestones and measurable objectives to be delivered over next 12 months.

Possible actions within the plan could include:

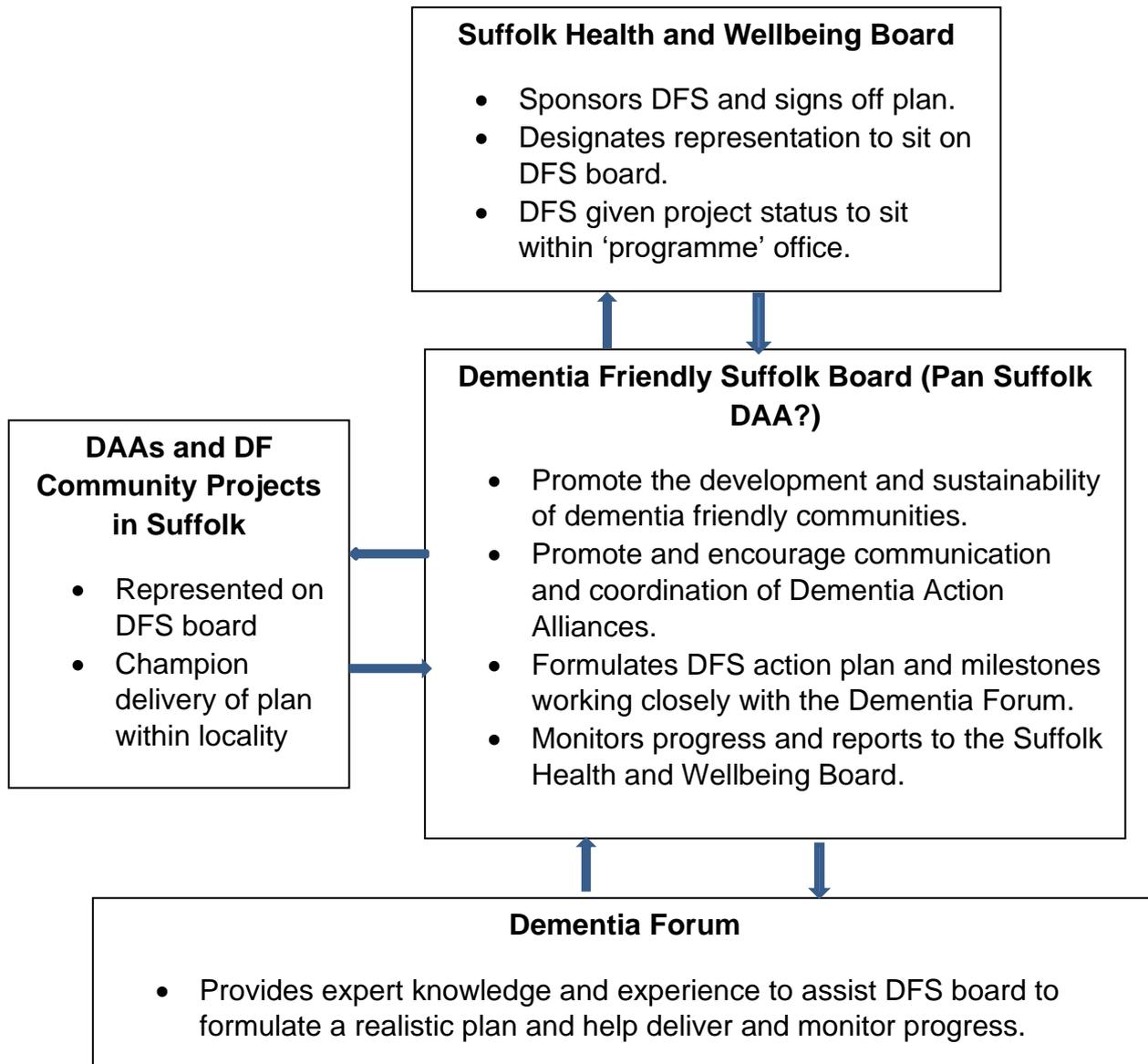
- Key organisations in Suffolk, beginning with those leading health and social care services, signing up to become a dementia friendly organisation by March 2022, with measures in place to assess the positive impact on people living with dementia and their carers’.
- Leaders in such organisations taking steps to consider opportunities to work alongside communities as supporters or sponsors of dementia friendly communities, joining an existing Dementia Action Alliance or supporting the development of a new Dementia Action Alliance.
- Run a public campaign to publicise the ambition of “Dementia Friendly Suffolk” and a call to action for potential local community leaders to step forward to help deliver the vision.
- Consider how best to support communities to access sustainable funding (beyond one-off time limited grants) based upon demonstrated impact.

Benefits to member organisations and to people living with dementia and their carers:

What are the benefits of being a dementia friendly community?		
Organisations	People	Community
Being better equipped to manage with current and future demand including the expected increasing demographic of people living with dementia	Being able to live with greater safety, independence, in their own homes. Carers feeling better able to cope for longer.	A community that supports prevention and early interventions, through community asset-based support
Potential to reduce financial impact upon statutory services and the community	Improved sense of wellbeing for people with dementia and their carers along the whole continuum from pre diagnosis to end of life	A better-connected and informed community whose members feel able to direct / signpost people to appropriate help and support
Reduced health inequalities	Reduced feeling of being stigmatised / forgotten	A vibrant active community with a range of activities accessible and appropriate for those living with dementia and their carers
Recognises, values, and supports volunteers and unpaid carers, for the contribution they bring (financial and practical) and the associated impact of this unpaid support on the budgets of statutory services	Reduced isolation for people living with dementia and their carers'.	A more understanding and compassionate community (for all), where people look-out for and support each other
Able to take an asset-based approach in working with communities to build on the support which is already there e.g., from the Voluntary and Community Sector	Social connectivity including opportunities for peer support	Availability of proactive, accessible, and timely support within the community, which meets the needs of those living within it.
	People living with dementia feel more able to move freely around the community where they live (due to environmental enhancements and approachability), and have improved access to local shops and facilities	Makes Suffolk a welcoming, supportive, and understanding place for people with dementia and their carers to live and visit

Dementia Friendly Suffolk (DFS)

Draft structure & governance for delivery



Suggestion of Membership of Suffolk Dementia Friendly Board – TBA

Appropriate HWBB rep/s, Local DAA's and Dementia Friendly Communities, Suffolk Dementia Forum Chair, key senior level stakeholders in ACS, Districts & Broughs and Health partners (CCG's), GP dementia lead, Local councillors, Fire, Police & Ambulance service, Alzheimer's society, Dementia Together (other to be considered).