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FOREWORD

My father in law died in 2008 and for the last three years of his life suffered from ever worsening dementia. It was one of the hardest things that our family have ever had to deal with. These days, very few families do not have first or second-hand experience of the devastation that dementia can bring: confusion, memory loss, change of personality and more.

Fortunately, a great deal has been learned about coping with dementia in the past decade and many people have done excellent work in preparing our communities to better help those whom dementia strikes, often coming like a thief in the night. Although research into this condition continues and millions of pounds are rightly being invested into it, there are some steps we can all take to support those who are struggling with this condition and their loved ones and carers which are simple and affordable.

That is why I am delighted to welcome this guide. It has been forged through practical hands-on experience as well as the compilation of data from different parts of the country. It builds upon the excellent work that parish and town councils carry out every day throughout the realm and looks to provide down to earth and current advice. I am thrilled that in my constituency of South West Devon we have several Dementia-Friendly Communities and I have seen and heard first-hand what a positive difference this can make.

As technology surges forward and life becomes ever more frenetic, it is vital that we do not leave behind the elderly and frail who have made their vital contribution to our nation's social and economic prosperity. Demonstrating how all of us can better care for them in a practical way is what this guide is all about.

I salute those who have invested so much time effort and expertise in putting it together and hope that it will be of enormous benefit to every community of the United Kingdom.

Sir Gary Streeter MP

INTRODUCTION

This guide has been produced in response to NALC's 2020 Dementia Survey undertaken by local (parish and town) councils. NALC has worked collaboratively with Plymouth University Faculty of Medicine, Dentistry and Allied Health in its production. It acknowledges the contributions of Ian Sherriff, B.E.M.MA. DMS. CQSW. DipCII Faculty of Health: Medicine, Dentistry & Human Sciences, Prime Ministers Rural Dementia Challenge Group and Cllr Liz Hitchins MA, chairman of Brixton Parish Council and chairman of Dementia Friendly Parishes around the Yealm.

Throughout 2020 the effects of COVID-19 have challenged all statutory and voluntary agencies to examine how they offer support and guidance to people living with dementia and their families. Local councils, as the most local form of government, have a major role to play in interpreting government and local COVID-19 plans to ensure that people living with dementia and their families continue to be included in all aspects of community life. This guide should be read, interpreted and implemented using current government guidance and local COVID-19 management plans.

NALC signed a strategic commitment on 31 October 2017 with the Alzheimer's Society to promote Dementia-Friendly Communities across England. The key aims of that commitment are:

- To ensure that people living with dementia, their carers, families have a voice and can maintain and, where necessary, increase their social contacts within their local community.
- To develop or contribute to the development of suitable inclusive social activities and services locally for people living with dementia and their carers.
- To work in collaboration with local groups and organisations and to, recognise that local councils and county associations can and do have a key role to play in achieving this.

The 2020 Dementia Survey was issued between February and July to England's 10,000 parish and town councils to discover how many local councils are Dementia Friendly, or working towards becoming Dementia Friendly.

Research identifies the prevalence of dementia in our society and the effects it can have on a person and their family; such as increasing isolation and loneliness. These effects are some of the largest problems that our rural

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communities face. Dementia-Friendly Communities, as supported by local councils, can ensure that people living with dementia can live well in their community.

NALC and the University of Plymouth designed this survey to identify the work that local councils are already doing to assist those most vulnerable in their communities. This research provides evidence to NALC to monitor the progress of implementation of Dementia-Friendly Communities across England.

Local councils, given the leadership that they can provide, should be acting as catalysts in their communities to support other organisations to work collaboratively. Although some councils have a limited resources, all councils are in a unique position to gather people together and inspire other organisations to take this agenda forward.

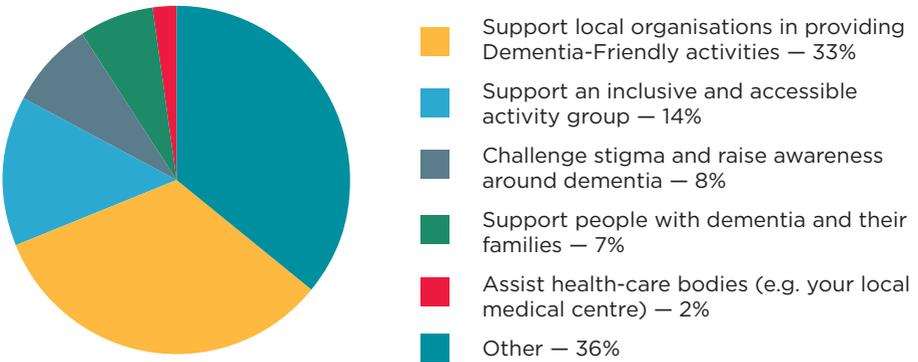
Is your local council Dementia-Friendly? A city, town or village where people with dementia are understood, respected and supported, and confident they can contribute to community life. In a dementia-friendly community, people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives.¹



¹ Alzheimer's Society, 2020

INTRODUCTION

What Dementia-Friendly activities or involvement does your local council have?



Do you work with any Dementia-Friendly organisations?



Would your local council benefit from a Dementia-Friendly Community guide?



DEMENTIA-FRIENDLY COMMUNITIES

The Alzheimer's Society stated "it became evident that the "lives of people living with dementia and their carers in rural communities would be enhanced if their everyday living tasks were made easier. People living with dementia and their family carers stated that the vast majority of businesses, organisations, agencies and communities, had no perception of what life is like for people living with dementia and their carers. The challenge to all of us is how do local councils become Dementia-Friendly and, promote Dementia-Friendly Communities and how can these be sustained?".¹

Given the prevalence of dementia and the associated issues of isolation and loneliness, which have increased as a result of COVID-19, the reduction of services and the development of social prescribing schemes, rural communities are ideally placed to respond and meet the challenges to improve the quality of life for people living with dementia and their families. Research indicates that a diagnosis of dementia can result in the person withdrawing from an active lifestyle in their community. Rural Dementia-Friendly Communities ensure that people living with dementia can live well in their community.

What is a rural Dementia-Friendly Community?

An inclusive rural Dementia-Friendly Community creates an enabling environment engaging with people living with dementia, their families and carers. This makes it possible for people living with dementia to continue to be involved in all aspects of local rural life. In a Dementia-Friendly Community people with dementia have a sense of belonging and a valued part of a family, community and civic life. (Source: National Dementia Declaration 2012).

An inclusive rural Dementia-Friendly Community works to sustain and improve the quality of life for all people, particularly people living with dementia in their communities and reduce the impact of stigma, isolation and loneliness.

Rural Dementia-Friendly Communities need to be flexible, adaptable and responsive to change. It is important to ensure that people living with dementia can continue with previous activities and groups, and their involvement with local organisations, businesses, GP practices, schools, and churches, voluntary and statutory agencies.

¹ Alzheimer's Society, 2020

DEMENTIA FRIENDLY COMMUNITIES

Dementia-Friendly Community initiatives should reflect the needs of each community taking into account accessibility, affordability and acceptability. One size does not fit all!

Why do we need rural Dementia-Friendly Communities?

Dementia, as a hidden disability, is a significant health and social care challenge faced by our society. This challenge cannot be ignored. It can only be tackled through new approaches that draw on all parts of our communities. In March 2012, the then Prime Minister, David Cameron, set a challenge to deliver major improvements in dementia care and research. One of the key aims of the challenge is to raise public awareness about dementia and build inclusive Dementia-Friendly Communities.²

Furthermore, this has been exacerbated by the COVID-19 pandemic which has seen disastrous effects for people living with dementia such as a reduction in memory, change in routine which has caused high stress, panic around the use of face masks due to not being able to see people's faces, reduction in confidence, further mental and physical deterioration and a significant increase in stress for carers.

COVID-19 has prevented the usual way of communicating with people living with dementia and their families. Whilst there is no substitute for human contact, innovation and flair has dominated the way organisations and communities have had to change how they engage with people living with dementia and their families. The Alzheimer's Society and other organisations have introduced singing for memory, carers' support line, online memory café's, using various forms of technology; support telephone calls have seen a major increase. Examples of technology use include ZOOM, Facetime, Microsoft Teams, WhatsApp, telephone calls, conference calls and, Messenger. These are just some of the examples of the use of new technology in maintaining Dementia-Friendly Communities.

² Prime Minister's challenge on dementia, 2020

BUILDING INCLUSIVE DEMENTIA FRIENDLY COMMUNITIES

Rural local councils can build strong, vibrant, and resilient communities, which deliver an ever-growing, more ambitious and innovative range of activities, as well as supporting the devolution agenda and taking over more services, assets and facilities from principal (county, district and unitary) councils.

Local councils have been responding positively to the social, economic and environmental needs of communities despite limited capacity, growing demands and increasing fiscal challenges including:

- Responding to the challenge of COVID-19; such as setting up emergency response volunteer groups, using the community emergency plan to look after their communities and residents.
- Promoting the use of new technology to increase connectivity with the community.
- Supporting adult social care and the NHS through social prescribing, building inclusive Dementia-Friendly Communities and reducing loneliness and isolation through social networks and other community projects.
- Working with principal councils to provide and support discretionary and other services under threat from spending reductions such as libraries, public toilets, parks and open spaces and youth services.
- Championing their local place to influence and work in partnership with other organisations and agencies.
- Using neighbourhood planning and other tools to promote housing and sustainable communities.

ACTION PLANNING CHECKLIST

For local councils to promote inclusive Dementia-Friendly Communities the following actions should be considered:

- At a council meeting formally adopt a proposal and plan to work towards becoming a Dementia-Friendly Council.
- Identify a councillor responsible for the promotion of the Dementia-Friendly Community approach.
- Identify and put in place technology and training to increase the flexibility and connectivity to your community.
- Have the development of a Dementia-Friendly Community as a regular item on the council agenda.
- Ensure all public buildings are Dementia-Friendly — see Alzheimer’s Society website or email communities@alzheimers.org.uk.
- Ensure that responses to planning applications demonstrate an awareness of dementia where appropriate.
- Engage with local organisations, businesses and schools to promote an inclusive Dementia-Friendly Community.
- As part of the council’s work plan, an audit of current Dementia-Friendly activities in the area would identify gaps to promote awareness. This should be reviewed annually.
- Working groups, which include people living with dementia and their families, can be set up by the local councils to establish networks with all stakeholders to develop a Dementia-Friendly Communities and work with existing community alliances, and other councils. This can include the use of virtual technology.
- Promoting the Alzheimer’s Dementia Friends programme — find out more at www.dementiafriends.org.uk.
- Ensure sustainability by considering all aspects of funding and support (in-kind) — for example, the use of council-owned buildings free of charge.
- Dementia-Friendly Community groups may vary and change over time responding to the needs and capacity of people with dementia and their families.
- It is important to consider succession planning; including where appropriate, how to build a pipeline of future volunteers.
- COVID-19 provides the opportunity for local councils to think differently in how they develop their Dementia-Friendly Communities in future by being innovative to respond to the needs of people living with dementia and their families in their community.

PROMOTING DEMENTIA FRIENDLY COMMUNITIES IN A COVID-19 ENVIRONMENT

Some issues you need to consider during your Dementia-Friendly Communities group meetings:

- What difficulties do people living with dementia and their carers face when wanting to participate and access services/activities in our local community?
- What changes can local councils and other community organisations make to resolve these difficulties to become dementia-friendly?
- What lessons can be learnt from Dementia-Friendly Communities already in place?
- How can my council develop the use of information technology to engage with its communities?
- Would a logo be helpful to identify your Dementia-Friendly Community? For example, the use of a logo in local community hotspots and on your website.
- No two communities are the same. Each Dementia-Friendly Community will be different reflecting the needs of their population.
- Small steps and changes make a big impact for people living with dementia and their families e.g. identifying someone to welcome people living with dementia and their carer to an established group.

This list will help you and your group grow to become a Dementia-Friendly Community.

CASE STUDIES

Holbeton Parish Council, Devon

Population: 600

Holbeton, is a picture-postcard South West Devon village, with 600 plus residents, many of them elderly. With two pubs, a church, local store, and primary school. It's one of five parish councils which are part of the ground-breaking community project, Dementia-Friendly Parishes around the Yealm (DFPY). This early group, now a charity, was amongst the first in the country to bring together five rural parish councils, Wembury Parish Council, Brixton Parish Council, Yealmpton Parish Council, Holbeton Parish Council and Newton & Noss Parish Council, to improve and change the lives of people with dementia, their carers and families.

Holbeton Parish Council has found it easy to become Dementia-Friendly. It didn't take a lot of money, or endless meetings, nor did they have to produce a new suite of policies, procedures and plans. All it took was a few small steps to make a big difference. Practical actions that would bring to life the DFPY mantra: "We can't change the person living with dementia but we can change the experience they have in their own community."

Most importantly, these practical steps were minuted by the parish council so that councillors could hold themselves to account.

Holbeton Parish Council's checklist:

- It already had a representative on the committee of Dementia-Friendly Parishes around the Yealm (DFPY).
- Feedback on dementia community initiatives was a regular topic at council meetings.
- Its website states a commitment to being Dementia-Friendly.
- Local businesses and organisations were already on board.
- An annual visit from DFPY to the parish council to support them moving forward

Plans for the coming year agreed and minuted by councillors (February 2020):

- To set up a dementia awareness session in the village.
- To sponsor the front page of "Holbeton News", the monthly magazine, to publicise the event.

CASE STUDIES

- DFPY Project Coordinator to attend the Holbeton Lunch & Social Club lunch in the village hall.
- To use DFPY guidance to audit the dementia friendliness of public buildings in the parish.
- To further promote Holbeton Parish as a Dementia Friendly Parish by encouraging local groups to be open, inclusive and dementia-aware

Find out more at www.dementiayealm.org.

East Peckham Parish Council, Kent

Population: 3,306

To mark the 125 anniversary, East Peckham Parish Council chose to become a Dementia-Friendly Community to support their residents and carers locally to celebrate. The parish council and our Kent County Council Community Warden investigated what we had in the village and what we needed to become dementia-friendly. We sought out people with the same thoughts and conducted some resident engagement to gain a better understanding of local needs.

To raise awareness of dementia, they have held Dementia-Friends awareness sessions and have over 190 Dementia-Friends, people of all ages and backgrounds, who can be identified by their special forget-me-not pin badges. The council-run these sessions on demand and is now looking to do these using ZOOM. Businesses too have become involved; all of the staff at the local garden centre is Dementia-Friends as is the staff at our local Village Stores, Chemist and Hair Salon.

The council has upcycled a redundant telephone kiosk by converting it into a Dementia-Friendly Information Hub and have upcycled a planter by turning into a Dementia-Friendly sensory garden with plans to install another shortly.

In October 2019, East Peckham was recognised by the Alzheimer's Society as a Dementia-Friendly Community and in November 2019, the council held an open day where the planter and information hub was officially opened by the Mayor of Tonbridge and Malling Borough Council. Representatives from the Alzheimer's Association and the chairman of the Kent Association of Local Councils also attended.

CASE STUDIES

Before COVID-19, East Peckham Parish Council was holding a monthly carers café. COVID-19 has been challenging but they have not stopped raising awareness. In June they held a socially distanced cake sale which raised £440 for the Alzheimer's Society. They also delivered 40 afternoon teas to people within their community who are carers or cared for, it was a way of the council saying that despite COVID-19 lockdown restrictions they were remembering and thinking of them. In August 2020, and to tie in with VE Day, the council held a Singing for Memories session with their local care home where the majority of residents are living with dementia. They also delivered specially made forget-me-not biscuits to their carers and cared for residents

The strategy for the near future is having more events to keep raising awareness so that more within East Peckham are Dementia Aware.

Find out more at www.eastpeckham-pc.gov.uk.

Harpenden Town Council, Hertfordshire

Population: 30,000

Harpenden is located just north of London, in Hertfordshire. The town has a population of just over 30,000 people, with approximately 17% of the population over age 65.

In summer 2019, the council established a Dementia-Friendly Harpenden Working Party with the goal of ensuring that Harpenden is a town where those living with dementia are understood, respected and included. The overall approach included increasing dementia awareness for the general public and establishing a local dementia café.

The council launched the initiative by organising a series of Dementia-Friends talks hosted by the local Alzheimer's Society Dementia Champion. These free sessions gave participants the opportunity to find out more about dementia and ways to make a difference locally, becoming Dementia-Friends at the end of the talk. The sessions are regularly booked to capacity and within the first five months of talks, the council facilitated Dementia-Friends training for 170 residents.

CASE STUDIES

The Dementia-Friends talks were also attended by council officers. The skills and information obtained in the talks have come in use by officers as they interact in person and over the phone with members of the public who live with dementia. Additionally, the council now provides dementia information and leaflets in the Town Hall Information Point and added a dementia resources page to its website, which provides updated information about dementia resources and activities.

Perhaps the most impactful aspect of the Dementia-Friendly Harpenden initiative was the creation of a dementia café in town. Harpenden Memory Lane Café was organised by the council to give those living with dementia a safe and friendly setting in which to gather. A local church kindly offered their coffee shop as a setting for the café, which takes place every other week, and the council provides complimentary cakes and hot drinks for guests. Special activities and information sessions – including talks with local organisations, nature walks, and music sessions – are planned alongside the café gatherings to give guests an option to chat casually or participate in more structured activities.

With the success of the Café and the Dementia-Friends talks, the Council is working on an action plan to continue making Harpenden a more welcoming place for people living with dementia.

Find out more at www.harpenden.gov.uk.

CONCLUSION

This guide provides an overarching framework of knowledge, ideas and recommendations to enable local councils to engage and support people living with dementia and their families.

Research shows that where local councils, rural communities and community organisation proactively engage in providing support, isolation, loneliness, stigma and despair experienced by people living with dementia and their locations reduces. This impacts positively on their health and wellbeing. COVID-19 has further exacerbated these issues, however, the use of technology and government guidance, such as social distancing, provides an opportunity to think differently about engaging with the local community.

Where local councils and their communities can act on the advice and guidance provided in this guide there is opportunity to make a major impact on the quality of life and lived experience for people living with dementia and their families in your rural communities.

This guide goes some way to identifying what local councils can do to develop a rural Dementia-Friendly Community. This will require all members of local communities to understand the needs, aspirations and the voice of people living with dementia and their families on what makes them feel a valued member of their rural community. We wish you all every success in your endeavours to become dementia friendly communities in these particularly challenging times.

FACTS AND FIGURES

Below is a list of facts and figures that demonstrates the severity of the illness and the need for a long term approach to support people with dementia and their families:

- The Alzheimer's Society COVID-19 study 2020 who surveyed, 2,000 people living with dementia and their carers during lockdown and isolation; it found that 82% of those respondents reported deterioration in their symptoms. Of those 82%, around half reported increase memory loss and difficulty concentrating, more than one in four (27%) said reading and writing had become more difficult and one in three said they had difficulty speaking and understanding speech. More than a quarter (28%) had seen a loss in the ability to do daily tasks, such as cooking and dressing.¹
- There are approximately 850,000 people in the UK living with a form of dementia. This figure is predicted to rise to 2 million by 2051.
- 1 in 3 people over the age of 65 will develop dementia.
- An increasing number of younger people between the ages of 30 to 64 are being diagnosed with a dementia.²
- About 225,000 people will develop a dementia every year (that's one every three minutes).
- A third of people living with dementia live on their own in the community.
- The total cost of dementia to the UK economy, including costs to the NHS, paid social care and unpaid care, has risen to £34.7bn and will rise further to £94.1bn by 2040.
- One in four beds in the NHS is taken by a person living with dementia.
- People with living dementia stay five to seven times longer in hospital than other patients.³
- People aged 65 and over comprise 23% of the rural population, well above the 16% of the urban population.⁴ However, in many rural areas the percentage of older people can be as high as 56% of the total population for that area.⁵
- 24% of older people in rural communities are themselves carers. Projections indicate that the number of older people in need of care will grow faster than the number of their children who might help provide it.⁶
- Current research suggests that 44,000 people, between the ages of 30-64, in the UK have an early onset dementia. This represents around 5% of

1 Alzheimer's Society, 2020

2 Alzheimer's Society, 2020

3 Alzheimer's Society, 2020

4 SORS, 2016

5 CFAS II, 2011

6 SORS, 2016

FACTS AND FIGURES

the 850,000 people who have a diagnosis.⁷

- Lonely socially isolated people have a 64% increased chance of developing clinical dementia.⁸
- Researchers have put a financial price on an “epidemic of loneliness” - estimating it costs £6,000 per person in health costs and pressure on local services.⁹
- In rural areas the lack of public transport to access services can often result in social isolation.¹⁰

7 Alzheimer's Society, 2020

8 Holwerda et al, 2012

9 Age UK, 2019

10 SORS, 2016

FREQUENTLY ASKED QUESTIONS

Our village is of modest size, with a small population size, how can we help residents with dementia?

Your council could consider working in collaboration with local organisations, such as WI, local radio stations, schools, Faith Groups, Rural Agricultural Benevolent Institute (R.A.B.I), Community Farming Network (C.F.N), and neighbouring parishes.

How can I receive Dementia-Friendly awareness?

Contact your local Alzheimer's Society or the national Dementia-Friends session webpage to set up a dementia awareness session or a Dementia-Friends session.

Our council does not have the structure to provide a lot of direct services. How can my council help?

No matter how small your council is, every action can help. As a council you might establish a network with local stakeholders to develop your own dementia friendly community or work with existing community alliances and other councils.

We are a small council with limited funding, what practises can be put in place for our residents?

Look to work with other local community groups to become dementia Look to work with neighbouring parish councils and other local community groups to become Dementia - friendly. This collaborative approach could open up other funding opportunities. This may be an opportunity for your council to consider raising its precept

My council is considering become Dementia Friendly, how could this be integrated with other council work?

Councils work can cover a depth and breadth of subjects. People living with dementia and their families are affected by the council's policies on health and wellbeing, neighbourhood planning, isolation, and transport. Within your project planning you should include Dementia Friendly practises to ensure that future project planning is inclusive.

FREQUENTLY ASKED QUESTIONS

My council does not have any local volunteers, what should I do?

Work in partnership with existing community groups to create a network of volunteers who then can receive dementia-awareness sessions by the Alzheimer's Society. This will enable your council to help people living with dementia and their families to take an active role in their community.

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