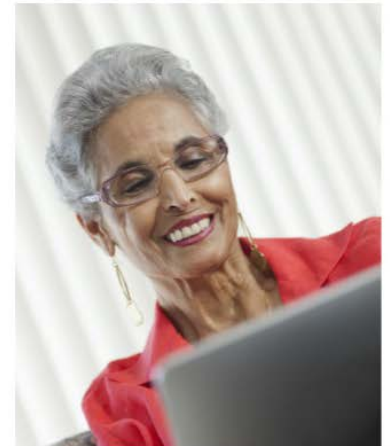


BETTER LIVES - DEMENTIA STRATEGY

**A REFRESHED STRATEGY FOR
SANDWELL 2019 - 2025**



“Those with dementia are still people and they still have stories and they still have character and they are all individuals and they are all unique. And they just need to be interacted with on a human level.”

Carey Mulligan, Actress (Alzheimers.net)



Contents

Foreword

Executive Summary

Introduction

Our Approach

Purpose

Promises for Action

Cross-Cutting Promises

1. A Knowledgeable and Skilled Workforce
2. Awareness

Preventing Well

3. Prevention

Diagnosing Well

4. Evidence, Assessment and Diagnosis

Living Well

5. Living Well with Dementia in the Community
6. Living Well in Long Term Care
7. Reducing the Risk of Crisis

Supporting Well

8. Supporting Carers

Dying Well

9. End of Life

Action Plan for delivering the Dementia Strategy (2019-25)

Next Steps

Appendix - Key Facts and Projections



Foreword

Dementia is one of our most significant health and social care priorities both nationally and in Sandwell. It has far reaching effects on people who live with the condition, their carers and the community.

We are very happy to launch our multi-agency dementia strategy for Sandwell. 'Better Lives' sets out our vision for Dementia 2019 - 2025 through nine key promises.

We were so pleased to see so many people come together to share their experiences and discuss such an important issue. Our thanks all those that attended for their contributions. We learned from our discussions that we are heading in the right direction. The plan sounds good, but people want to see us act. Working together with our partners, we are committed to making this strategy a reality. We will support people in Sandwell with dementia and their carers to live their best lives.

We know that dementia is a condition that still carries a great deal of stigma and fear. This can often prevent people from seeking the help and advice they need. It is a condition that is affecting more and more people each year. With access to the right support, treatment and care, people can live well with dementia. This is the message that we want to spread loud and clear throughout Sandwell. We want Sandwell to become a 'Dementia Friendly Community' and we must work together to achieve this.

We remain committed to the vision to support people along the whole dementia pathway, from prevention to end of life care and support their carers and wider family members with their needs.

The impact of dementia can be far-reaching. By increasing awareness and understanding amongst both the public and among professionals, we can make a real difference to improving lives.

Our commitment to the people of Sandwell is to do all we can to ensure access to care and support for those who need it.

Signed:



Councillor Yvonne Davies, Leader of Sandwell Council and Chair of Sandwell Health & Wellbeing Board



Dr Ian Sykes, Chair of Sandwell and West Birmingham Clinical Commissioning Group



Chris Christie and Deb Harrold
Co-Chairs, Sandwell Dementia Action Alliance

Executive Summary

The primary aims of the new Sandwell Strategy are to offer:

- Better and more consistent services and support;
- Better outcomes and clearer access and service pathways for people with dementia, their carers and key professionals, for example GPs;
- More effective general community awareness and prevention, and
- A better-trained and supported workforce.

The core of the Strategy consists of nine “Promises” to people with dementia and their carers, covering the following:

- Dementia awareness, information and advice
- A knowledgeable and skilled workforce
- Prevention
- Diagnosis and assessment
- Living well in the community
- Supporting carers
- Reducing the risk of crisis
- Living well in long-term care
- End of life

The Action Plan converts these nine Promises into over 50 measurable actions.

The Strategy and Action Plan 2019-25 has been the subject of extensive public and partner/stakeholder engagement between February and July 2019. Views and suggestions from this have been incorporated in the final Strategy and Plan. It is thought that key representatives of service users and carers will help us monitor and ensure delivery of the actions with regular updates on this to be provided to the Sandwell Health and Wellbeing Board.



Summary of the Sandwell Better Lives Dementia Strategy 2019 – 2025:

9 promises for people in Sandwell

1

A knowledgeable and skilled workforce

- Ensuring the workforce and leadership is right, with the right capacity and skill mix
- Agree local training standards across health, social care and community/ voluntary services
- Upskilling local people/ carers

Key outcome: All people working with those living with dementia and their carers should receive the support, awareness and training from knowledgeable and skilled professionals where needed. Annual refresher training should be available.

2

Awareness

- Raising general awareness about dementia
- Helping local organisations keep up to date to better support people
- Helping patients make informed choices

Key outcome: All people in Sandwell living with a confirmed diagnosis or suspected dementia, along with their carers and the wider community supporting these people, should have access to the right information, at the right time in the right place.

3

Prevention

- Giving wider health and wellbeing advice at the right time
- Supporting to remain independent
- Working with other services to prevent crisis
- Avoiding unnecessary admissions to hospital or long-term care

Key outcome: All people in Sandwell should have a right to good physical health and mental health and wellbeing to enable them to live fully and enjoy their independent lives for as long as they are able to do so.

4

Evidence, assessment and diagnosis

- Earlier identification of those at risk of or living with dementia
- Improving referral waiting times
- Assessing for meaningful care
- Emphasising the role of GP's in the coordination and continuity of care

Key outcome: All people living with dementia in Sandwell have a right to receive appropriate and timely diagnosis and co-ordinated support. This offer of support should be extended to their carers and it should be the voluntary and community sector that deliver this.

5

Living well with Dementia in the Community

- Supporting from diagnosis to end of life with advance care planning
- Tailored, person-centred support
- Working with others to offer wider support networks
- Option to apply for Personal Health Budget

Key outcome: All people living with and supporting someone with dementia should feel able to access and contribute to their community, carrying out their daily tasks in ways that support them to remain independent for as long as possible.

6

Living Well in Long Term Care

- Ensuring data on the quality of long term and residential care establishments, is up to date to help carers find appropriate care
- Ensuring continuity of support
- All local hospitals and care homes to meet Dementia Friendly criteria

Key outcome: All Sandwell residents living with dementia have a right to live well in long term care and able to access community support as appropriate.

7

Reducing the Risk of Crisis

- Ensuring the right support is at hand to limit the risk of crises occurring
- Ensuring that when a crisis occurs, high quality services are available to manage these situations
- Reducing avoidable hospital admissions

Key outcome: All people living with dementia and those providing support to them should receive support to reduce risk and help manage crisis

8

Supporting Carers

- Assessing carers for their needs
- Raising awareness on the support and resources available to them
- Helping them to support the person they care and cope with their responsibilities
- Improving carer health/wellbeing
- Prioritise respite opportunities

Key outcome: All local people who are caring for someone with dementia should feel informed and able to support their loved one, whilst able to maintain their own health and wellbeing.

9

End of Life care and support

- Having early conversations so the person with dementia and carers can be fully involved in Advance Care Planning and End of Life care decisions
- Providing compassionate palliative care with dignity
- Bereavement support for carers

Key outcome: All Sandwell residents living with dementia and their families should be provided the opportunity to plan, receive good end of life care and are able to die in accordance with their wishes.

Introduction

Dementia is a term used to describe a range of symptoms that affect the brain. This can include memory loss, problems with reasoning and communication, a change in personality and a reduction in a person's ability to carry out daily activities. Every individual's "dementia journey" is very different. It is a progressive condition. This means that the symptoms will gradually get worse with time. People may often have some of the same symptoms, but the effect on each person and the people that care for them will vary.

For many years, dementia has been a growing challenge. As people live for longer, it has become one of the most important health and social care issues, not just in the United Kingdom but around the world.

In this country, even before the publication of the *Living Well with Dementia Strategy* by the Department of Health over ten years ago, there has been a steady stream of national and local initiatives, promoting the importance of good dementia care. The most recent of these, the *NHS Ten-Year Long-Term Plan* (January 2019), reiterates the importance for a consistent standard of support for people living with dementia and those with responsibility for looking after them.



There has been a growing recognition of the huge emotional, social, psychological and practical impacts dementia has. Not just on the person who is living with this disease, but also more widely, particularly for those who have a direct role in supporting the person living with dementia and those services providing support. For some, the challenges they face and the financial pressures of the condition, mean the unexpected effects can have a

considerable impact on their own health and well-being as well as on the person who has dementia.

In England alone, it is reported that dementia affects around 850,000 people. It is reported to cost society an estimated £26 billion each year. In addition, the numbers of people who act as unpaid carers are reported to be around 540,000 people.



An estimated 25% of hospital beds are thought to be occupied by people with dementia and their hospital stays tend to be, on average, one week longer than other patients. Approximately 75% of people living in care homes have dementia, making it clear that dementia continues to have a far-reaching influence across the health and care sector and beyond.

In Sandwell (according to the latest Local Authority estimates) there are around 3,700 people who are living with dementia. The main support they receive is provided by a range of organisations, all of whom have an important contributory role in meeting their needs.



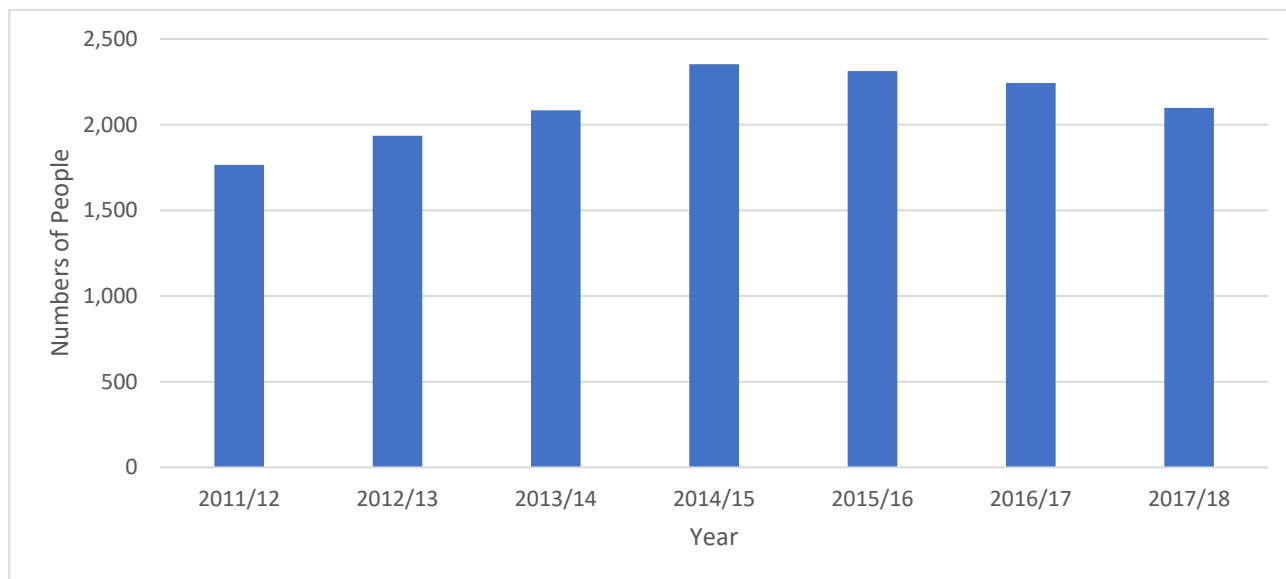
Of the estimated 3,705, 98.5% are aged 60 and over, 63.6% are identified as female and 36.4% male. See **Appendix** for more details, other facts and projections

There are an estimated 315 people living with dementia who are under the age of 65, with 32 who are under the age of 50 years (Midlands and Lancashire Commissioning Support Unit, The Strategy Unit, January 2019). Over the next twenty years, this total for both groups is projected to grow by 46% to 5,408 people. Approximately 62% are described as having Alzheimer's Disease (AD); 17% have vascular dementia; 10% have a mix of both Alzheimer's and vascular; 4% Lewy Bodies; 2% Parkinson's Disease; 2% front-temporal dementia with the other remaining 3% are undefined.

Not all of those anticipated to be living with dementia have been diagnosed. The national target is that 66.7% of the anticipated numbers of people thought to have dementia have a recorded dementia diagnosis by their GP. Sandwell and West Birmingham CCG had a recorded dementia diagnosis rate of 63.7% in June 2019, indicating that there is still a gap in diagnosing people and recording the diagnosis on the GP systems.

The past few years have seen an overall increase in the numbers of people diagnosed with dementia, however the recorded dementia numbers are variable. See **Graph 1** below.

Graph 1 – Numbers of people in Sandwell and West Birmingham who have a recorded dementia diagnosis



Since 2010, there have been many changes and developments in the way local health and care services have been commissioned and delivered to people living in this area.

The introduction of Clinical Commissioning Groups and the establishment of a Health and Wellbeing Board from 2013 have placed GPs at the heart of the decision making. They shape the commissioning priorities for the local area. At the same time, local authorities have taken responsibility for overseeing the Public Health commissioning agenda and other related tasks such as health promotion and health prevention.

The subsequent implementation by NHS England of the recommendations outlined in the *Five Year Forward View* have introduced new performance standards that local Clinical Commissioning Groups are now expected to achieve year on year. This has initiated a sense of priority that local services are expected to achieve.

There are increasing challenges that CCGs and Local Authorities have faced in meeting the rising health and care demands of their local community, whilst balancing these with the need to ensure the quality of services and expectations, all against a backdrop of austerity and financial constraints. Despite this, several new services and support opportunities have been commissioned and developed. These include support services for those living with dementia and their carers. These services are anticipated to increase in the future with a growth in the numbers of people being diagnosed.

In supporting many of these changes, all our partners in health and social care have recognised the importance and value of actively working together across our community.

Despite such welcome changes, there have been times when the services that have been commissioned and provided have not always been as good as they could have been. Together, on behalf of the health and social care services, we must acknowledge this and respond as best we can.



Our Approach

To find out what local people thought about current dementia services and how they could be improved, we held a co-design event in February 2019.

Through this we were able to interview service users and carers to start to build our strategy from their direct experiences and views. We focused on asking three key questions:

- *What does excellent dementia care look like?*
- *What isn't working so well now?*
- *How do we put it right?*

Through this event, local people told us:

- Improved awareness and education is required; in schools, hospitals and in general for all (i.e. the 'Dementia Friendly' approach), including regular campaigns.
- Improved information around earlier screening and earlier detection is needed.
- A helpline or support opportunity is required 24/7 following diagnosis.
- More information is required about the services available to help, such as a directory of services and better information on care homes.
- Post-diagnostic support services need strengthening to include befriending, respite, safety initiatives, follow-up visits or re-assessments, mediation/ counselling provision and assurance of service sustainability.
- Better post-diagnostic support for younger onset adults is needed.
- Families and carers need to be involved at every stage.
- An understanding that one size doesn't fit all.
- More work is required with faith groups and seldom-heard groups.

Between May 2019 and July 2019, professionals and voluntary and community sector organisations from Sandwell engaged with various people to get feedback on the draft dementia strategy. Engagement included:

- Surveys to residents and professionals who have an interest in dementia in Sandwell;
- One to one sessions with individuals living with dementia and their carers;
- Group sessions with residents affected by dementia; and
- Organised feedback events for local people to come and share feedback with the team.



Over 400 people attended events and discussions about the draft strategy over the 3-month period. 33 people completed the survey; 22 of these respondents were either living with dementia or had experience caring for a relative who had dementia. Thousands of people were reached on social media encouraging people to get in touch with feedback and comments across various local platforms.

A suite of documents was developed to support the engagement activity, including an infographic, a summary strategy, a questionnaire in paper and online formats, an invitation letter, a presentation and a press release.



Communications and digital activities were published on Sandwell and West Birmingham CCG website. There was a headline and introduction featured on the home page linking to the "News" section. A headline and introduction also featured on the "Get Involved" page under "Current Consultation and Engagement" with a link to the questionnaire.

Information was published on the Sandwell Council website and across Sandwell Council social media platforms. The survey was sent to all staff via a weekly staff newsletter.

A press release was also issued to local press and local organisations including the information about the survey in their communications to their stakeholders.

Letters were sent to various stakeholders who have been identified with an interest in dementia through a CCG database and via Healthwatch Sandwell.

The Dementia Strategy Group has tried to ensure that all the main feedback points and suggestions from this engagement have been reflected in the final Strategy and Implementation Plan. There was strong and consistent agreement to the core of the Strategy and its nine Promises.

The top three Promises or priorities from the survey responses were:

- better support for carers;
- living well in the community; and
- improved long-term care for people with dementia.

From the events and activities, the top three Promises were:

- better support for carers;
- raised awareness and promoting dementia-friendly communities; and
- better knowledge and skills in the workforce.

Full reports from these events are available upon request.



Purpose and Vision

Filling the Gap

There has been a lack of a local Strategy in recent years. The time is now right to remedy this with collaboration of Sandwell Metropolitan Borough Council (SMBC) and Sandwell and West Birmingham Clinical Commissioning Group (SWBCCG), particularly through the Better Care Fund (BCF). Collectively, we aim to make a real difference through looking at and supporting the whole dementia pathway from awareness and prevention through to end of life care.

Listening

Listening to people who have dementia, their carers and families has provided us with the core evidence and outcomes to inform the strategy. People told us that they felt current services wouldn't provide them with everything they needed and this was one of the reasons they didn't come forward as early as they should to get a diagnosis.

We have made a commitment locally to ensure that a diagnosis will give access to services that help people to live well with dementia.

We need to commission the delivery of the right services which ensure the person with lived experience and their carer are at the heart of the decision-making process to enable them to live in their own homes longer, preventing crises and avoiding unnecessary admissions to hospital.

Our underlying commitment is to the local population to support, inform and deliver high quality, outcomes-focussed responses that empower all local people and enable a better quality of life that is important for every person currently living with dementia and those that might develop this in the future.

The Future

We know that people are living longer which will result in more people developing dementia in the future as outlined above. Prevalence rates for dementia in the UK are well established so we can anticipate that one in six people over the age of 80 currently have, or will develop, dementia.

We need to build a model of sustainability through the services people living with dementia need and, moving forward, across the whole community.

Dementia Friendly Communities

The national vision established in 2013 was *“to create a society where every person with dementia...from all backgrounds, walks of life and all parts of the country...receive high quality, compassionate care from diagnosis through to end of life care. This applies to all care settings, whether home, hospital or care home.”*

Today, and for the next six years, our local ambition is about creating the right environment to build dementia friendly communities together with and for local people of all ages. The aim is for people to be better informed about dementia, to be helped and ready to act through lifestyle changes, reducing their personal risk of developing the condition.

This is our opportunity to increase awareness about dementia across the local population, to improve access to a timely diagnosis and to ensure support services can be provided for all that need them, especially for those seldom heard groups and from black, Asian and minority ethnic groups who we know currently do not access services.



Promises for Action

To help shape our main priorities for action for 2019 to 2025, we have been influenced by feedback from stakeholders and the National Dementia Strategy. We have therefore adopted the following themes:

- **Preventing Well**
- **Diagnosing Well**
- **Living Well**
- **Supporting Well**
- **Dying Well**

Each of the theme areas has a promise that underpins it. We have nine promises in total. Two of our promises are multi-agency approaches; they are important promises which are integral to enabling the delivery of all the others.

An Action Plan at the end of this Strategy outlines what we will do, how we will do it, who is responsible and in what timescale. As you will see, there are over 50 actions required across the nine promises. This aim is to show how the new Strategy will deliver the changes that are needed today to ensure a better tomorrow for all people living with dementia and for the rest of the community to be able to support them. We will ensure this action plan is monitored closely, with direct help from people close to the challenges of living with dementia, and with regular update reports to the Sandwell Health and Wellbeing Board.



Cross-Cutting

Promise 1: A Knowledgeable and Skilled Workforce

Key outcome: All people working with those living with dementia and their carers should receive the support, awareness and training from knowledgeable and skilled professionals where needed. Annual refresher training should be available from a wide range of accredited local providers.

To be able to deliver the vision of effective high-quality dementia care, ALL staff and, where appropriate, volunteers, regardless of sector, need to work together to assess and meet the needs of the local population. This will require the right workforce in place, with the right capacity and skill mix, in the right place at the right time, particularly including those from health and social care services and the voluntary and community sector.

Where appropriate, it is important there is a common and/ or minimum local standard that all organisations adopt and recognise. This should enable the essential skills and knowledge are in place for all staff involved in dementia care. Encompassed within this area are the standards needed in dementia education and training including dementia awareness raising opportunities in the local community, the knowledge and skills for those who have regular contact with people living with dementia and the knowledge and skills for those in leadership.



Promise 2: Awareness

Key outcome: All people in Sandwell living with a confirmed diagnosis or who have suspected dementia, along with their carers and the wider community supporting these people, should have access to the right information at the right time in the right place.

The issue of awareness of dementia across our local community is one of fundamental importance towards helping local people to take control of their care and support them to make well-informed decisions about the support they need.

It is essential that a key priority for the wider dementia care community is to help local people find and connect to the community-based resources and support that is available to help them access the information and advice they need.

This includes people who are currently living with dementia, those who are suspected of having it and carers, families or others supporting their loved ones' well-being at both a pre- or post- diagnosis stage of their journey.

To enable this, it is essential that information is widely available in a range of different formats and in a broad range of different media to take account of the needs of the whole community. In developing this, it is vital that this takes account of the wide diversity of needs across the local population and the different Asian, black and other minority ethnic groups as well as others identified as seldom heard in the local area.

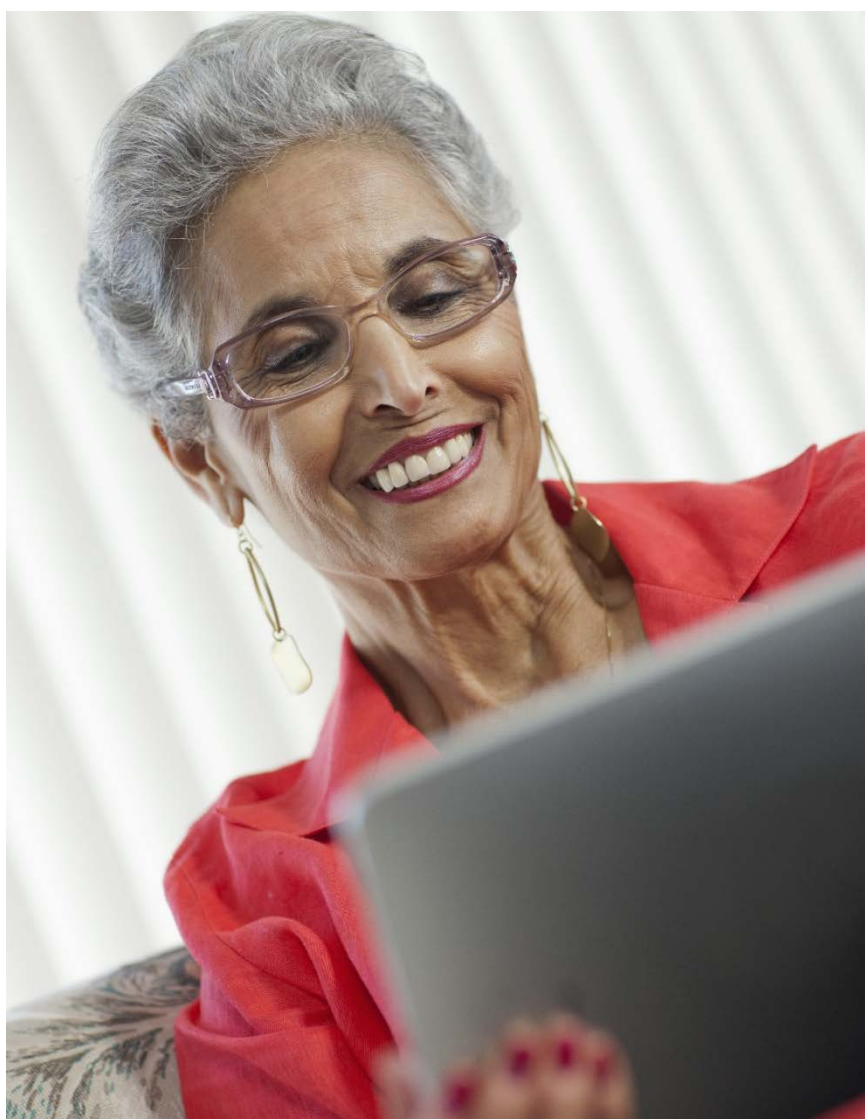


Active consideration needs to be given to the types of media used. For example, bill boards, web pages in different languages, paper leaflets, a dementia roadmap, patient information channels at GP practices or at other settings like hospitals, libraries, community resource settings etc. alongside more commercial and business forums (such as supermarkets or banks) where local people congregate and who may benefit from this kind of approach. This does not need to be overwhelming, particularly in those communities where in the past there has been a greater reluctance to access the specialist services such as the memory assessment services. It is important this is balanced with the offer of adequate support to those in need both pre- and post-diagnosis. This could be achieved through taking a 'dementia friendly community' approach.

It is important that the key messages are not directed just for the person living with dementia, but that it is also aimed at those providing support, such as those working in primary and secondary care, GPs or other clinical staff who can have a critical contribution to those in need. For those in primary care, as typically they are recognised as the first point of contact for a person, family member or carer who suspects dementia, it is important the strategy refers to some of the key roles within primary care that need to involve:

- The skills and knowledge for those carrying out an initial assessment and preliminary investigations in people with suspected dementia; and
- Referring on to memory assessment services for diagnosis, if more specialist help is needed, with the person's consent and the involvement of a representative from the voluntary and community sector where this is to the benefit of the person concerned and their carer.

It is essential that there is sufficient support and resources which are directed appropriately.



Preventing Well

Promise 3: Prevention

Key outcome: All people in Sandwell should have a right to good physical health and mental health and wellbeing to enable them to live fully and enjoy their independent lives for as long as they are able to do so.

There are currently estimated to be approximately 3,705 people over the age of 60 in Sandwell living with dementia. Of this total number, 1,318 (36%) are men and 2,334 (64%) are women.

Up to the age of 65, the incidence of those living with early onset dementia are mostly men but after the age of 75, there are markedly more women with the biggest area of difference being 80 and over when there is at least a 50% difference between female and male, with the former being in the majority.



According to the Alzheimer's Society (Dementia UK Update 2014) there are as many as 70% of people living with dementia who have other long term physical health conditions or disabilities, such as arthritis, heart disease, hearing loss or mobility problems. Many will have one or two of these, some will have more. This clearly emphasises the importance for people to receive the right advice and support when it is needed as well as consideration for their general health and well-being as an important preventative element of any new strategy. Increasing evidence from elsewhere (Blackfriars Consensus Statement 2014) has suggested the risk of some types of dementia can be reduced but it cannot be eliminated. Cardiovascular factors, physical fitness and diet have a major part to play in keeping the brain healthy and thus reduce the risk of

developing dementia in later life. Other lifestyle choices such as not smoking, limiting alcohol intake and keeping low cholesterol and blood sugar are also helpful.

Compared to our neighbours or comparative CCGs, Sandwell and West Birmingham CCG has a reported lower diagnosis rate. One of the contributory reasons other areas appear to be more successful is due to their approach to focus on awareness raising about dementia, specifically among the local black and minority ethnic (BAME) communities. This is achieved by holding community events that target the importance of addressing dementia as a long-term condition in the same way as diabetes and depression. This encourages a greater understanding about what it means to those living with the condition. The approach also makes it easier for local people to understand and become enabled to address the potential stigma or uncertainty sooner. As a result, they are in a better place to understand how health and care services can effectively support people with the condition.

At the start of this strategy, it was reported the cost to society of dementia was more than £26 billion. This would equate roughly £170m in Sandwell. The Alzheimer's Society has estimated the average annual cost per person with dementia is £30,000 for those living in the community against £37,000 to those in residential care. For people living in the community, approximately 75% of this cost is made up of indirect costs associated with the contribution of primary, unpaid carers who frequently provide a pivotal role in enabling a person to live well with dementia but in doing so may face a considerable emotional and financial burden of their own.

It should therefore be regarded a minimum for people living with dementia to live independently in their own homes for longer, for services to work together to prevent crises and avoid unnecessary admissions to secondary care services or long-term care.



Promise 4: Evidence, Assessment and Diagnosis

Key outcome: All people living with dementia in Sandwell have a right to receive appropriate and timely diagnosis and co-ordinated support. This offer of support should be extended to their carers and it should be the voluntary and community sector that deliver this service due to their experience and knowledge.

It is no coincidence that all policy publications share the view that dementia care and support should be led by primary care services with the support of secondary care, social care and the voluntary and community sector, thus enabling the delivery of coordinated and continuous care.

From prevention, early identification, diagnosis (in primary care and specialist settings) and referrals to post-diagnostic care and support, this strategy recognises a pivotal role for GPs in ensuring people with dementia can live in their own homes, crisis free, for as long as possible. Among the aspirations to achieve this vision, this strategy recognises the significant contribution that GPs and their primary care colleagues play:

- Equal access to diagnosis as for other conditions, with an expectation that the national average for a diagnosis of Dementia should be no longer than 6 weeks following referral from a GP (where clinically appropriate).
- GPs have a lead role in ensuring the coordination and continuity of care for people with dementia (as part of the existing commitment that from 1 April 2015 everyone will have access to a named GP with overall responsibility and oversight for their care).
- Every person diagnosed with dementia should have meaningful care following their diagnosis which supports them and those around them. Meaningful care will be in accordance with published National Institute for Health and Care Excellence (NICE) Quality Standards. This care may include:
 - receiving information on what post-diagnostic services are available locally and how these can be accessed;
 - access to relevant advice and support on what happens after a diagnosis and the support available through the journey; and
 - carers of people are made aware of and offered the opportunity for respite, education, training and emotional and psychological support so that they feel able to cope with their caring responsibilities.

The NHS Long Term Plan also commits CCGs and its partners to providing better support for people with dementia, by having a more active focus on supporting people in the community through enhanced community multidisciplinary teams and the application of the NHS Comprehensive Model of Personal Care. This specifically refers to the key role the voluntary and community sector can play in providing a range of advice and support services for people following a dementia diagnosis.

Promise 5: Living Well with Dementia in the Community

Key outcome: All people living with and supporting someone with dementia should feel able to access and contribute to their community, carrying out their daily tasks in ways that support them to remain independent for as long as possible.

Good dementia care ensures that the person living with dementia and their carer has good access to personalised care, coordination and support from diagnosis to end of life.

It is essential that all services that are involved in this journey are aware of the importance of Advance Care Planning (ACP) and those responsible for this ensure this is offered to all people who are diagnosed with dementia as well as their carer and that they are given the opportunity to be involved in creating their own personalised Advance Care Plan.

It is often said that many people with dementia would prefer to continue to live their life as normally as possible. This means staying in their own home, being part of their local community, having friends and sharing interests. As their symptoms worsen, they can become more dependent on others for transport and general help to be able to do this. The fear about becoming confused or wandering (getting lost) can also lead to some people going out less and restricting themselves to less demanding activities. This can then result in greater isolation from the community. It is recognised loneliness is an increasing problem and can lead to depression or anxiety.



Another recurrent theme of good dementia care is to enable the person living with dementia and their carer to live meaningful and independent lives. The provision of support should be regarded as person-centred and holistic. Depending on individual need, this level of support may be provided via health and social care, local authorities or voluntary organisations. For person-centred support, this may include:

- Appropriate housing provision such as extra care housing.
- Support to maintain relationships both at home and in the wider community.

- Support to maintain independence including the growth of dementia friendly communities, advocacy services, homecare services, campaign services and information provision.
- Support to engage in meaningful daily activities; this should be person-centred, available on an individual or group basis across a variety of settings, and particularly at evenings and weekends.
- Support, training and advice for carers, including respite care, peer support groups and training courses; support should also be provided in the work environment, and practical support including transport needs to be considered.
- Easier access to GPs and other NHS professionals for health-checks etc.
- Special equipment, home adaptations and assistive technology as necessary.

The traditional approaches to assessing people's needs are sometimes too focused on assessing for services. In fact, formal services are just part of a wider network of community support which encompasses other public services, voluntary and community services, local amenities and the informal support that Sandwell residents can give to each other.

With this updated strategy, our ambitions should be about offering an inclusive approach to help people live independently in their community, to help them to maintain their relationships and activities that matter to them. Enabling people, their families and communities to draw on existing strengths and resources should make better connections across the community.

For those who need more intensive support, health and social care agencies and the voluntary sector should work together to support individual needs and preferences. The option to apply for the use of Personal (Health) Budgets should be explored to support those with milder forms of dementia and their carers to plan for the help they may want in the future.

The ambition with the advent of this strategy proposes a shared commitment to Sandwell being recognised as a genuine Dementia Friendly Community where all local people are encouraged and empowered to have confidence in the local services the community has to offer, knowing they can contribute and participate in activities that are meaningful to them. The Dementia Action Alliance have a central role in making this happen.

Sandwell Council, the Clinical Commissioning Group and all other local health and care organisations, together with the wider community, need to actively consider establishing themselves as 'Dementia Friendly'. We hope this will encourage other similarly minded organisations across the local area to extend the number of people knowledgeable about dementia or learn who can help someone with the condition.

Examples of other key services that could and should be persuaded to demonstrate their commitment include emergency services such as the West Midlands Police Service, West Midlands Ambulance Service and the West Midlands Fire and Rescue Services. These approaches should also be extended to local businesses including other health and care services (GP surgeries, pharmacies etc.) as well as supermarkets, banks, schools, libraries etc.- some, but not all of whom, may be currently aware of the benefits of staff who recognise and support people with dementia.

Promise 6: Living Well in Long Term Care

Key outcome: All Sandwell residents living with dementia have a right to live well if in long term care and able to access community support as appropriate.

At the end of January 2019, there were calculated to be 147 people living with dementia in long-term nursing homes, with 269 people in residential care homes funded by Sandwell Council. This excludes people in care homes in the short term. This equates to an annual total expenditure of around £14m. We need to make sure we continue to provide current and accurate data about the quality of residential care to help carers and families to find appropriate care and ensure the continuity of support for the person they care for.

The Department of Health ambition is that all hospitals and care homes are required to meet agreed criteria to become dementia friendly by April 2020. This Strategy supports this ambition and we will ensure that Sandwell is able to achieve this goal.



Promise 7: Reducing the Risk of Crisis

Key outcome: All people living with dementia and those providing support to them should receive support to reduce risk and help manage crisis

It is important to remember dementia is a progressive, non-curable condition. It can result in a wide range of symptoms that are particularly challenging for carers and can often place unprecedented demand on services. Aggression, agitation, delusions, wandering (now known as 'walking with purpose'), night time waking, hoarding, loss of inhibition and shouting are all frequently cited examples of those living with the condition. People with dementia can also experience other physical or mental health problems which, if not identified and addressed, can lead to admission to acute hospital or mental health services.

Other crises can occur because of the carer themselves becoming injured, ill or unable to continue caring, leaving the person with dementia unsupported.

An estimated 25% of hospital beds are occupied by people with dementia (Fix Dementia Care; Hospitals Report 2016, Alzheimer's society) and their hospital stays tend to be, on average, one week longer.

This strategy makes clear that people with dementia and their carers need to know what required support is available to limit the risk of crises occurring in their lives or, where such crises occur, they can be assured there is a suitable range of accessible high-quality services and support available to help manage these situations. This support should be available throughout the time that the person living with the condition requires it, from the point of diagnosis onwards.



Supporting Well Theme

Promise 8: Supporting Carers

Key outcome: All local people who are caring for someone with dementia should feel informed and able to support their loved one, whilst able to maintain their own health and wellbeing.

It is important that this strategic priority is aligned to and actions progressed with reference to the Sandwell Joint Carers Strategy 2019-22.

The opportunity to access a person-centred service is aimed at improving the quality of life and the well-being of carers and the person with dementia. This can have a considerable beneficial impact.

With this refreshed strategy, carers should be recognised for the invaluable support and help they are able to offer and they themselves should be provided with support to not only cope with their own caring responsibilities, but to enable them to have an independent life alongside caring.

It is important to recognise and remind everyone of the support available to carers from a range of organisations dedicated to meet their own specific needs and that carers can get a formal assessment of their needs from Sandwell Council whereby one-off Direct Payments could be made available.

It is essential that health and care professionals listen to the carer and work with them to support the person with dementia. As well as giving the carer support, working together with the carer is known to lead to better outcomes for the person with dementia and ensure services have a fuller picture of the person's needs.



The provision and retention of respite services for carers should be regarded as a key priority in the roll-out of any updated strategy. If this is lacking, there would be concern that the services provided for the person who has dementia would not be as cost effective

either financially or in providing the level of support that is needed. It is understood there are many carers who reportedly take great personal satisfaction from their involvement and want to continue, however this can come at great personal cost. Around 40% of carers experience psychological distress or depression with those caring for people with behavioural problems having the highest levels of distress (Carers Trust: Triangle of Care: Best Practice for Dementia Care). Yet their ability to continue caring may be essential to the person being able to remain in the community.

It is also important that carers have access to other community resources. Too frequently there is only a narrow range of available day services and so the continued provision of dedicated Dementia Cafés or similar provides important alternative forms of support.

It is also important that such services and support is available to those in crisis as well as at times when services are usually provided during the working week.



Promise 9: End of Life Care and Support

Key outcome: All Sandwell residents living with dementia and their families should be provided the opportunity to plan for and receive good end of life care so they are able to die in accordance with their wishes

As indicated previously, it is important for local health and care services to recognise the need to have early conversations with people with dementia about Advance Care Planning and end of life care decisions, so that people can plan and ensure their wishes are known and acted upon.

It is understood that all people who are living with a diagnosis of dementia should be given the opportunity for Advance Care Planning as early as possible, to ensure the person and their carer are fully involved in decisions on care at end of life.

The local ambitions and goals need to maximise the person's quality of life and support their carers. All people living with dementia and their carers should receive coordinated, compassionate and person-centred care towards the end of their life and there needs to be consideration to help people dying with dementia to receive the appropriate levels of dignity they deserve. Some of this will be achieved through appropriate signposting and referral to Connected Palliative Care (Sandwell and West Birmingham's end of life and palliative care service).

This includes palliative care for the person with dementia and bereavement support for carers.



BETTER LIVES ACTION PLAN: DELIVERING THE DEMENTIA STRATEGY 2019-25

Local Promise	Purpose	Action number	Key Actions	Responsibility for Delivery	Timescale
Promise 1: A Skilled and Knowledgeable Workforce	<i>All local people with dementia receive support from knowledgeable and skilled professionals where needed</i>	1.1	Develop and implement a Sandwell dementia training competency framework, incorporating local minimum standards for each partner organisation (statutory, voluntary, community etc).	Joint Commissioning Manager	March 2020
		1.2	Provide sufficient, relevant and up to date, rolling dementia training across Sandwell in line with the relevant competency framework to ensure all people receive training appropriate to their role.	All Dementia Service Providers, Voluntary Organisations and Statutory Orgs	Ongoing with regular review
		1.3	All statutory organisations across Sandwell who are partners of the Health and Wellbeing Board to provide opportunities to attend 'Dementia Friends Information Sessions' and ensure attendance in line with the 'Dementia Friends Community' approach.	Joint Commissioning Manager	Ongoing with regular review
Promise 2: Awareness and Understanding	<i>All local people living with a confirmed diagnosis or who have suspected dementia, along with their carers and the wider community, have access to</i>	2.1	Develop and implement a local 'Publicity Campaign'; based on the Dementia Friends Information sessions approach, incorporating a range of materials/ formats/ media for different settings and situations, including schools and with extra efforts to reach "seldom heard" communities.	SMBC, SWBCCG, Joint Commissioning Manager and all Service Providers	March 2020/ refreshed every 2 years
		2.2	Develop and roll out a Sandwell Dementia "Road Map"— to help people at different stages of the dementia journey (with different needs and ages recognised), professionals and the public to better understand dementia, to navigate the system and access relevant information and support.	SMBC, SWBCCG, Joint Commissioning Manager and all Service Providers	March 2020

<i>the right information at the right time in the right place</i>	2.3	Develop and implement a data sharing agreement with all necessary organisations.	SMBC, SWBCCG, Joint Commissioning Manager and all Service Providers	March 2020
	2.4	Strengthen Sandwell Dementia Action Alliance (SDAA) to ensure full representation from each partner organisation.	SDAA Chairs, SWBCCG, SMBC	March 2020
	2.5	Develop and implement an overarching action plan for SDAA based on the Better Lives plan, with all areas of the Alzheimer's Society 'dementia friendly community' covered via partners (e.g. housing, transport etc).	SDAA Partners	March 2020
	2.6	Ensure the development of a 'Dementia Friendly Community' through the rollout of Dementia Friends Information Sessions and a dedicated SDAA Plan.	SDAA and Joint Commissioning Manager	Ongoing

Local Promise	Purpose		Key Actions	Responsibility for Delivery	Timescale
Promise 3: Prevention, Delaying Onset of Dementia, and Health Promotion	<i>All local people will have good physical and mental health and well-being enabling them to live full and independent lives for longer</i>	3.1	Ensure the 'Making Every Contact Count' approach is implemented to help promote health and well-being and reduce social isolation.	Sandwell Public Health and all Service Providers	December 2019/ Refreshed every 2 years
		3.2	Ensure up to date medical research is included in the Dementia Road-Map to outline what can and cannot be prevented (e.g. slowing down of onset of certain types of dementia).	SMBC and SWBCCG	March 2020
		3.3	Ensure increased awareness of dementia in higher risk/ seldom heard groups and provide information about the warning signs.	SMBC and SWBCCG	March 2020/ refreshed every 2 years
		3.4	Promote free NHS Health Checks for people aged 40-74 to spot early signs of conditions including dementia.	Healthy Sandwell Lifestyle Manager	Ongoing

Local Promise	Purpose	Action Number	Key Actions	Responsibility for Delivery	Timescale
Promise 4: Early Detection, Diagnosis and Assessment	<i>All local people will receive appropriate diagnosis and integrated support</i>	4.1	Improve on and consistently aim for the national 6 weeks waiting time for initial dementia diagnosis.	SWBCCG and GPs	March 2020/ Ongoing Monitoring
		4.2	Produce a simple flowchart of the dementia assessment/ diagnosis pathway and process to share with patients/ the public.	SMBC and SWBCCG	March 2020
		4.3	Set targets for increasing dementia diagnosis rates and enhanced quality standards from investment in primary care.	SWBCCG, GPs and Service Providers	March 2020
		4.4	Introduce simple dementia patient experience feedback forms to improve future practice (e.g. to avoid multiple visits from professionals).	SWBCCG	March 2020
		4.5	Provide more training and shared learning for GPs and other health and social care professionals on the recognition of dementia in higher risk groups; learning disabilities, substance abuse, people in custody etc.	SMBC and SWBCCG	March 2020/ Ongoing
		4.6	Explore how hospitals (with access to expert advice on dementia) can carry out cognitive screening of non-elective admissions and people with long-term conditions.	SWBCCG and local Hospitals	March 2020/ Ongoing
		4.7	Increase the CCG percentage of people with dementia receiving annual review with GP.	SWBCCG and GPs via the Primary Care Commissioning Framework (PCCF)	Ongoing via PCCF
		4.8	Ensure people newly diagnosed with dementia are offered support to better understand and cope with their diagnosis and treatment where clinically appropriate.	SWBCCG and GPs	March 2020

	4.9	Review current Memory Assessment pathways to identify approach, blockages, gaps and opportunities.	SWBCCG and Service Providers	March 2020
	4.10	Implement any new agreed MAS pathways and associated service specifications (to include monitoring of the MAS service).	SWBCCG	March 2020
	4.11	Ensure all newly diagnosed patients receive a care plan, with everyone given access to personalised care.	SMBC, SWBCCG, GPs and Social Workers	Targets set by March 2020 and monitored quarterly
	4.12	Ensure all eligible patients and their carers are offered a direct payment, with options to apply for the use of wider personal (health) budgets, upon diagnosis/assessment where appropriate.	SMBC, Social Workers and GPs	Targets set by March 2020 and monitored quarterly

Local Promise	Purpose		Key Actions	Responsibility for Delivery	Timescale
Promise 5: Living Well with Dementia in the Community	<i>All people living with dementia are encouraged to remain independent for as long as possible</i>	5.1	Ensure 80% of all GP practice staff (clinical and non-clinical) are identified as 'Dementia Friendly' by end of March 2020 through attending Dementia Friends Information Sessions.	SWBCCG and GPs	March 2020
		5.2	Ensure a shared aim of all health and care services in Sandwell being Dementia Friendly by end March 2022.	SMBC, SWBCCG and Service Providers	March 2022
		5.3	Conduct a post-diagnostic provision review to identify current provision versus demand and future provision requirements.	SWBCCG	October 2020
		5.4	Identify any gaps in future and current provision.	SWBCCG	October 2020
		5.5	Use the outcomes of the "capacity modelling" work to develop a fully costed plan to identify future requirements and resources.	SWBCCG	November 2020
		5.6	Develop, publicise and implement a 'Dementia Friendly Community Plan' to incorporate a wide range of stakeholders (e.g. transport, housing, emergency services, libraries, etc. with emphasis on the day-to-day and emergency needs of carers such as DWP/ benefits staff and NHS 999/111, understanding better that people with dementia cannot represent themselves).	Sandwell Dementia Action Alliance	March 2020
		5.7	Promote relevant available community development funding and support opportunities to help progress dementia-friendly communities.	SMBC and SWBCCG	March 2020 and every two years
		5.8	Involve people with dementia and their families/carers in commissioning decisions and ongoing review of	SMBC, SWBCCG and	Ongoing

			clinical and community support pathways (services need to cater for a wide range of options, cultures and beliefs).	Sandwell Dementia Strategy Monitoring Group	
	5.9		Ensure effective access for people with dementia to continuing healthcare.	SWBCCG	Ongoing
	5.10		Ensure (subject to assessment) that people with dementia and their carers have direct access to Disabled Facilities Grant payments to help adapt their homes to be more “dementia-friendly”.	Better Care Fund Team	Payments scheme up and running March 2020
	5.11		Ensure people with dementia have clear access to intermediate care, reablement and telecare services/ the very latest technology and extra care housing.	SMBC and SWBCCG	Ongoing
	5.12		Ensure relevant user-led academic research to inform the development of services and support (linked to the Dementia Road-Map).	Sandwell Dementia Strategy Monitoring Group	Ongoing
	Promise 6: Living Well in Long Term Care	<i>All local people with dementia live well when in long term care</i>	6.1	Ensure all care homes in Sandwell are committed to being dementia-friendly by March 2022.	Sandwell Care and Nursing Homes
6.2			Ensure all people living with dementia, their families and carers are made aware of what high quality care looks like, including care homes having a range of social and therapeutic activities and where to find it.	SMBC and SWBCCG	Ongoing
6.3			Ensure each care home has a dementia champion.	Sandwell Care and Nursing Homes	March 2021
6.4			Ensure people with learning disabilities who have, or are at risk of developing, dementia are fully supported	SWBCCG and GPs	Ongoing

			in long term care settings through linking dementia in to LD health checks.		
	6.5		Ensure people who are assessed as lacking capacity with no family or friends are referred to an Independent Mental Capacity Advocate where appropriate.	Social Workers	Ongoing
Promise 7: Reducing the Risk of Crisis	<i>All local people with dementia receive support to reduce the risk and manage crisis</i>	7.1	Scope the opportunity for an urgent response/ triage/ risk assessment 24/7 help-line	SMBC and SWBCCG	March 2020
		7.2	Ensure all people living with dementia, with complex morbidities, offered specialist information and support.	GPs and Service Providers	Ongoing
		7.3	Ensure specialist mental health inpatient beds for people with dementia are available for urgent assessment and treatment.	SWBCCG and NHS Providers	March 2020 and Ongoing
		7.4	Ensure specialist mental health/ dementia advice is available to GPs.	SWBCCG and NHS Providers	March 2020 and ongoing
		7.5	Ensure GPs and other practitioners are supported to follow the latest guidance on anti-psychotic medication and managing pain relief for people with dementia.	SWBCCG	Ongoing
		7.6	Ensure emergency planning including clinical emergency care planning is addressed as part of carers' assessments.	Social Workers	March 2020
		7.7	Ensure community and primary care able to respond to episodes of crisis in care homes appropriately.	SWBCCG and GPs	March 2021
		7.8	Ensure the specific needs of people with dementia and their carers are provided for in the Sandwell safeguarding Strategy and system.	Sandwell Safeguarding Adults Board	March 2020

Local Promise	Purpose		Key Actions	Responsibility for Delivery	Timescale
Promise 8: Supporting Families and Carers	<i>Carers are supported to enable people with dementia to remain as independent as possible</i>	8.1	Ensure carers of local people living with dementia are offered information, advice, training (e.g. in infection control, falls prevention) and support relevant to their needs and entitlements via the new Sandwell Dementia Road-Map. Carers are given help to access this where they do not have access to the internet.	SMBC and SWBCCG	March 2020
		8.2	Implement a 24/7 carers' help-line.	SMBC and SWBCCG	March 2021
		8.3	Ensure ex-carers are supported when the caring role ends and, where they wish, are trained to become mentors/ support for others.	SMBC and SWBCCG	Ongoing
		8.4	Ensure carers are offered assessments for themselves and that the process is clear and straightforward, recognising the different needs and pressures facing spouse carers, working carers and those still in the education system.	SMBC	Ongoing
		8.5	Ensure carers are able, via Direct Payments, to access a range of opportunities to take a break from their role as a carer.	SMBC/ Social Workers	December 2019
		8.6	Ensure carers are also able to access respite out-of-hours/ in an emergency.	SMBC and SWBCCG	March 2020
		8.7	Ensure carers and families have access to specialist mental health care advice on managing behavioural and psychological symptoms.	SWBCCG	Ongoing

Local Promise	Purpose		Key Actions	Responsibility for Delivery	Timescale
Promise 9: End of Life	<i>All local people with dementia and their families can plan, receive good end of life care and are able to die in accordance with their wishes</i>	9.1	Ensure people living with dementia, their families, carers etc can complete Advanced Care Plans that are recorded and kept by their GP.	SWBCCG, SMBC and GPs	March 2020
		9.2	Ensure people are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place of their choosing.	Service Providers, GPs and Social Workers	Ongoing
		9.3	Ensure all carers and families can receive bereavement support at a time that is right for the individual or family.	GPs and Connected Palliative Care Service	Ongoing
		9.4	Ensure people thought to be in the last 12 months of life are referred or signposted to the Connected Palliative Care Service for supportive end of life care.	GPs and Social Workers	Ongoing

Next Steps

The Action Plan aims to cover all the key comments and suggestions made from extensive public engagement.

Some of these actions will require extra funding, either temporary or ongoing. However, to ensure resourcing of the Strategy's actions properly, compare what is currently available with the gaps that are felt to exist in services and support across the whole of Sandwell, and meet those main gaps, a dementia "capacity modelling" piece of work has been commissioned. This will lead, shortly, to a costed plan for action plan funding.

Crucially, the largely officer-led Dementia Strategy Group that has led the public engagement and produced the Strategy and Action Plan will be replaced by a user-led group to properly oversee and challenge the various organisations to deliver the actions and ensure the Sandwell Health and Wellbeing Board receives periodic update reports on this. It is proposed that this new Group could be drawn mainly from the existing Sandwell Dementia Action Alliance – whose primary aim is to promote and champion dementia-friendly communities across the Borough.

APPENDIX

SANDWELL DEMENTIA STRATEGY 2019-22 – KEY FACTS AND PROJECTIONS

Sandwell residents with dementia

Dementia Projections over next 20 Years

Age Range	2019	2029	2039
Males -under 60	30	31	33
60-69	171	217	220
70-79	422	465	602
80-89	561	708	846
90+	165	235	376
Total Males	1319	1656	2077
Females – under 60	23	24	25
60-69	196	257	258
70-79	555	586	781
80-89	1016	1156	1307
90+	566	637	885
Total Females	2356	2660	3256
TOTALS	3675	4316	5333

Source: Alzheimer's Society 2014

Dementia: NHS Quality Outcomes Framework prevalence figures (all ages)

The recorded dementia prevalence is the number of people with dementia recorded on GP practice registers as a proportion of the people (all ages) registered at each GP practice.

Period		Sandwell Count
2011/12	●	1,765
2012/13	●	1,935
2013/14	●	2,084
2014/15	●	2,353
2015/16	●	2,313
2016/17	●	2,243
2017/18	●	2,098

Source: Quality Outcomes Framework (QOF), NHS Digital

This indicator is a measure of recorded prevalence and not actual prevalence and therefore under-reports groups who are less likely to be registered with a GP, such as ethnic minority populations, homeless people, migrants and travellers. QOF registers are constructed to underpin indicators on quality of care, and they do not necessarily equate to prevalence as may be defined by epidemiologists.

Latest NHS Digital/Public Health England Dementia Profile comparisons:-

Indicator	Year	Sandwell	England	West Midlands
% physically active adults	2016/17	32.3	22.2	25.0
Smoking prevalence in adults (18+)	2017	17.4	14.9	14.2
Estimated diagnosis rate (65+)	2018	61.9	67.5	65.1
Dementia care review documented in last 12 months	2017/18	79.3	77.5	75.7
Dementia: quality rating of residential care and nursing home beds (65+)	2018	79.4	68.6	61.8
Carer-reported quality of life score for people caring for someone with dementia	2016/17	6.00	7.50	7.50

Current Social Care and Health expenditure committed to Dementia services and support

Sandwell Council and Better Care Fund Dementia Budgeted Expenditure – 2018/19

	Council-only Spend £	BCF funding £	
Residential	6,918,302		Spot Placements
Nursing	4,917,647		Spot Placements
Day	308,892		Spot Placements
Domiciliary	751,309		Spot Placements
Supported Living	85,580		Spot Placements
Direct payments	511,544		
Total	13,493,274	-	
Fountain Court Residential	916,400		In-house service 20 year Block contract
SCCT Residential Block	1,034,700	1,195,200	
BUDS Grant	10,200		- Grant
Walker Grange day care	410,700		- In-house service
Dementia Navigators (2)		61,380	Contract
Dementia Beds		339,000	Annual Contract
	15,865,274	1,910,200	

PLEASE NOTE: Sandwell and West Birmingham Clinical Commissioning Group also funds annually significant expenditure on dementia care services and support, including the Memory Assessment Service and other key services provided by the Black Country Partnership Foundation Trust, but it is not possible to identify accurately expenditure specifically on dementia care from mental health spend more generally. It is also most important to note that the Sandwell voluntary and community sector makes a major contribution to the totality of dementia information, care and support services – the mapping and summarising of this will be picked up in the “capacity modelling” and other work referred to in the Action Plan for this Strategy.