

Dementia Strategy for Swindon 2022-2026



Bath and North East Somerset,
Swindon and Wiltshire
Integrated Care Board



Swindon Dementia
Action Alliance



Avon and Wiltshire Mental
Health Partnership
NHS Trust



SWINDON
BOROUGH COUNCIL

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Foreword

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

We are very happy to launch this Dementia Strategy for Swindon, which sets out our priorities for Dementia 2022-2026. A full action plan will accompany this Strategy with key deliverables to push forward this important agenda. We would like to thank everyone who has taken time to share their experience, thoughts and ideas to inform this Strategy. Having lived experience at the heart of this Strategy was really important to us and we will be involving people living with dementia and carers in the development of the action plans and monitoring progress.

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. We are proud to have been accredited by the Alzheimer’s Society as working towards a ‘Dementia Friendly Community’ in Swindon for the past five years in recognition of the work that has gone on within our community. It is important that we all play our part in making Swindon a place where people living with dementia are understood, respected and supported. This Strategy sets out our continued commitment to work together to make improvements along the whole dementia journey for people living with dementia and carers.

Councillor Brian Ford
Cabinet Member Adults & Health

Steve Maddern
Director of Public Health

Toby Kirk
Chair, Swindon Dementia
Action Alliance

Introduction and Purpose

Dementia affects at least 2,400 people in Swindon directly and many more as carers, friends and family of people living with the condition. This strategy outlines how, over the next 4 years we will work across Swindon to both reduce the risk of dementia and support people with dementia, carers and the community.

The purpose of the Swindon Dementia Strategy is to:

- Engage people affected by dementia in supporting and developing the Strategy
- Find out what people affected by dementia and working with people living with dementia think, and where the priorities should lie
- Acknowledge and highlight the excellent work that is already in place
- Set out the vision for what we want to achieve, working as a statutory and voluntary sector collective for Swindon

- Identify key priorities for what needs to improve
- Develop opportunities for working together
- Ensure there is a constant reminder that people are at the centre of everything we do

The strategy has been themed around the ‘Well Pathway for Dementia’¹ set out by NHS England and each section has been informed by the lived experience of people we have spoken to. Local priorities have been identified within each of these themes.

The themes are:

1. Preventing Well
2. Diagnosing Well
3. Supporting Well
4. Living Well
5. Dying Well

¹ NHS England » Dementia





What is Dementia

“I feel fine, I know I have issues with memory, and that’s annoying and I know it. I don’t necessarily feel ill, although I may be regarded as being ill”

Pennie who was diagnosed with dementia in 2020

“Sally has mid-stage dementia now, which has got worse over time... Mid-afternoon is her best time and she will make a cup of tea, but at other times it totally confuses her. Some days she knows where the tea bags are, sometimes she doesn’t know. The other day the water in the kettle was brown, as Sally had put a tea bag into the kettle. I’ve found the electric kettle on the cooker before where she’s forgotten it is electric. I play each day by ear. I’ve found people with dementia have all different symptoms and things they struggle with”.

Nicky, carer to her mother-in-law, Sally who has vascular dementia and Alzheimer’s

Dementia is a set of symptoms that over time can affect memory, problem solving, language and behaviour and get progressively worse. It is a physical illness, which affects the brain, rather than a mental illness. There are different types of dementia including Alzheimer’s disease, vascular dementia and dementia with Lewy bodies. A long-term condition has a high impact on a person’s health, social circumstances and family life. The implications can also be significant for family members and friends. The focus is on living well with dementia and recognising that whilst the diagnosis can be a huge shock, people can still retain independence in the early stages, and make the most of their lives with support and adjustments.

Development of this Strategy

Gathering and understanding lived experience is central to this Swindon Dementia Strategy. A number of people living with dementia and carers have shared their stories in interviews and focus groups, in order to help us develop a broader in-depth understanding of what is important to them, what works and where things can be improved. Professionals and other colleagues who work with people affected by dementia (such as Memory Café coordinators and support workers) have also been asked for their thoughts.

All this experience has been used to inform the Strategy and set the priorities for action, which will be developed in partnership with people living with dementia and carers.

Nationally, dementia remains a key public health issue as we emerge from the Covid-19 Pandemic. Studies show that people living with dementia have been disproportionately impacted by the Pandemic lockdown restrictions, many reporting increased difficulties in concentrating, memory loss and agitation. Carers of people living with dementia also reported strong negative impacts on their own mental health during the Pandemic².

The Secretary of State for Health and Social Care is due to publish a 10-year dementia plan later this year (2022). The focus of this will be on new medications and emerging science and technology to improve outcomes for people living with dementia. Maintaining a healthy lifestyle can reduce the risk of dementia and a balanced diet, regular exercise and stopping smoking is good for both the heart and brain.

Locally, dementia remains a key priority across different organisations. One in fourteen people in Swindon over 65 and one in six people aged over 80 are likely to develop dementia. There are currently approximately 2,400 people living with dementia in the Borough which is likely to

increase to just under 4,000 by 2040, with a doubling of those over 90 living with dementia due to the population changes in that age group³

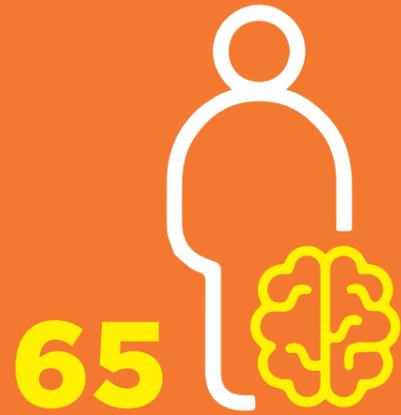
Although dementia is a medical diagnosis, planning for housing, care services, clinical and community support are key, whilst recognising that those most likely to be caring for people with dementia are likely to be older themselves and may well also have health conditions. We recognise that care and support needs to start with the individual and although someone is diagnosed with dementia, this illness is not just who they are.

As well as developing a strategy and plan for action, we have a number of collaborative cross-organisational groups in Swindon with representation from people affected by dementia. These include the Emerald Group (a local influencing group for people living with dementia), the multiagency Dementia Steering Group, the Swindon Dementia Action Alliance and Older People’s Mental Health Steering Group are all committed to working to improve the lives of people affected by dementia.

² https://www.alzheimers.org.uk/sites/default/files/2020-08/The_Impact_of_COVID-19_on_People_Affected_By_Dementia.pdf

³ Dementia (swindonjsna.co.uk)

Dementia in Swindon



There are an estimated **2,400 people over 65 living with dementia** in Swindon



3,908 people are likely to be living with dementia in Swindon by 2030



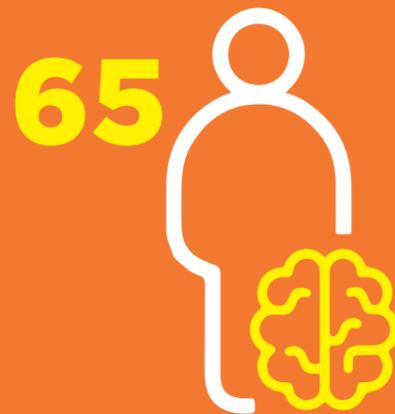
It is predicted that the cost of dementia care in Swindon by 2030 **will be £192m**



Currently, the annual cost of dementia care in Swindon is **£112m**



70% of care home residents and 60% of homecare recipients are living with dementia



1 in 14 people aged over 65 are likely to develop dementia

1. Preventing Well

Risk factors for dementia that cannot be changed include:

Age: people diagnosed with dementia tend to be over the age of 65. Above this age, a person's risk of developing Alzheimer's disease or vascular dementia doubles roughly every five years. One in fourteen people in Swindon over 65 and one in six people aged over 80 are likely to develop dementia.

Ethnicity: certain ethnic communities appear to be at higher risk of dementia than others. For example, people from a South Asian, African or African-Caribbean background seem to develop dementia more often than white Europeans⁴. Specific risk factors associated with these communities such as stroke, diabetes, hypertension and cardiovascular disease, as well as differences in diet, smoking, exercise and genes, are thought to explain this. Evidence shows that some minority communities tend to access services later-or not at all⁵. Swindon has diverse communities and therefore we need to raise awareness of dementia, what it is, why it is important to be diagnosed and what we all can do to help prevent it. We also need to look at ensuring that support services are culturally appropriate.

Gender: more women are affected by dementia than men. Worldwide, women with dementia outnumber men two to one. Twice as many women over the age of 65 are diagnosed with Alzheimer's than men whereas vascular dementia is diagnosed in slightly more men than women.

Genetics: in rare cases, Alzheimer's disease can be passed from one generation to another. This type of dementia usually affects people under the age of 65.

Getting older is undeniably the biggest risk factor for dementia, however, research suggests there are modifiable risk factors which include diabetes, high alcohol intake, high blood pressure, lack of exercise, obesity, poor physical health and smoking⁵. Latest research published by the Lancet also shows regular alcohol consumption of more than 21 units a week is also a risk factor (see infographic below)⁷.

Modifiable risk factors such as regular exercise, good hearing (including corrected hearing), mental stimulation and maintaining a healthy weight can all help to reduce the risk of dementia or slow its onset. Changes in mid-life can make the most impact on reducing risk. Smoking is also a risk factor for dementia, with research suggesting it can double the risk. Smoking rates tend to be higher in areas of greater deprivation and amongst routine and manual workers⁸. NICE recommend that Councils ensure that healthy living messages reference dementia, recognising what is good for the heart is good for the head⁹. NHS Health Checks provide an opportunity for healthy living messages and advice to be provided. NHS Health Checks are 20 minute assessments and all adults aged between 40-74 without a pre-existing condition are eligible to have one. Since 2018, risks around dementia and how to prevent it have been explicitly included in Health Checks.



Smoking and obesity are two of the key risk factors for dementia and there are a number of programmes in place to help people quit smoking and achieve a healthy weight. In addition, the Swindon Tobacco Control Strategy is being revised which will identify further priorities and actions to reduce the prevalence of smoking. A 'whole systems approach to obesity' has also been adopted to identify the wider factors that contribute to obesity levels in Swindon and actions to address these.



Priorities around preventing well in Swindon:

1. Better engagement with our diverse communities in Swindon, in order to raise awareness of dementia, the benefits of seeking diagnosis and support, and what we can all do to try and reduce risk. Linking in with existing groups and community leaders to raise awareness across Swindon.
2. Further promoting NHS Health Checks as an opportunity to talk about preventative steps around dementia.
3. Use the Tobacco Control Strategy and the Whole Systems Approach to Obesity work to reduce the prevalence of risk factors for dementia
4. Develop a communications strategy and plan for raising awareness of dementia and the benefits of a healthy lifestyle with our residents

⁴ www.dementiauk.org : Prevention and Risk Factors

⁵ Dementia across cultures and ethnicities, Dr Julia Botsford (for Dementia UK), 2017

⁶ Prevention and risk factors - Dementia UK

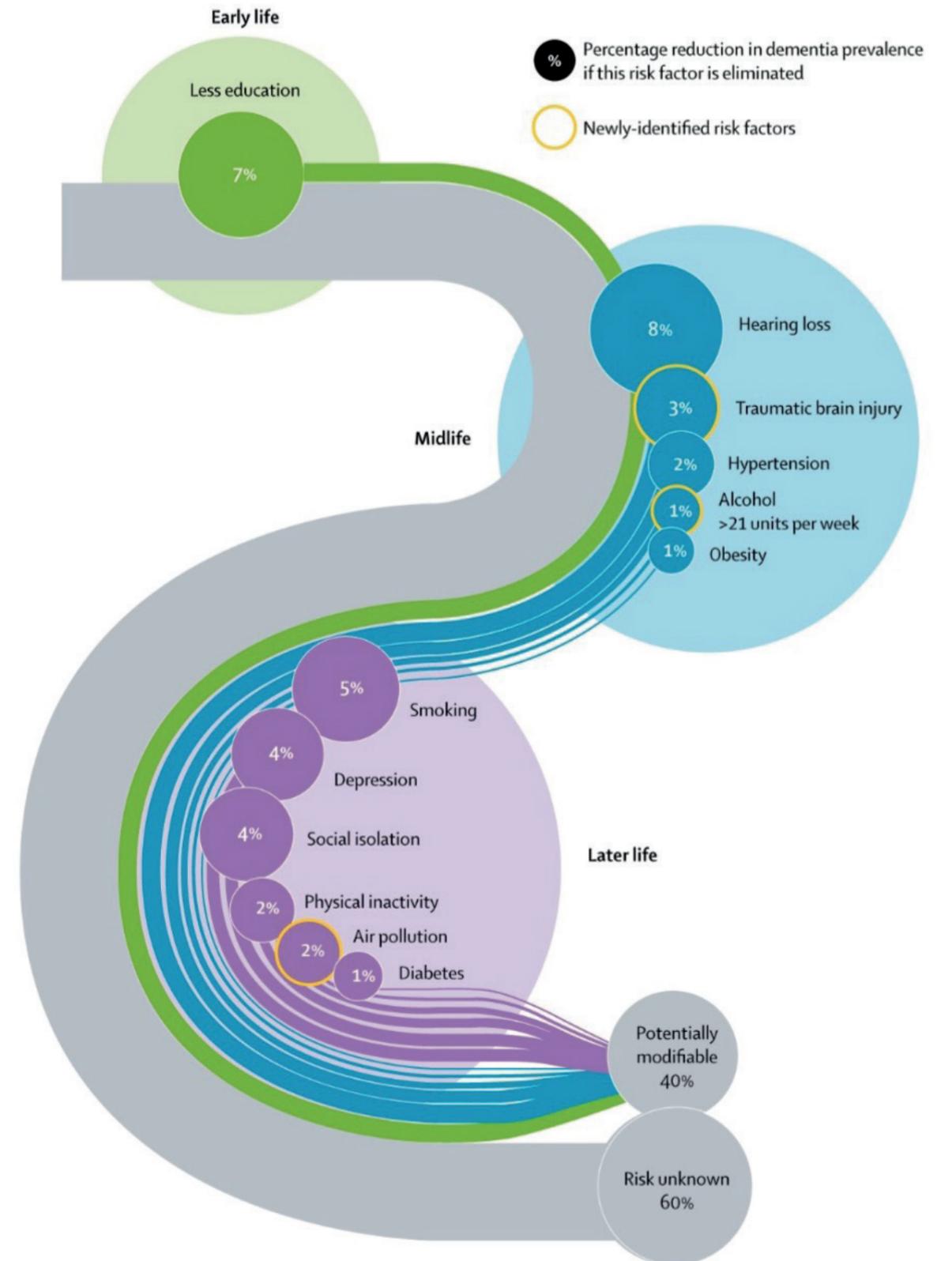
⁷ Dementia prevention, intervention, and care 2020 (thelancet.com)

⁸ UK Health Security Agency (2016). Health Matters: Health inequalities and dementia.

⁹ NICE. Quality standards for dementia. 2019
<https://www.nice.org.uk/guidance/qs184/chapter/Quality-statement-1-Raising-awareness-health-promotion-interventions>.

Risk factors for Dementia

An update to the *Lancet* Commission on Dementia prevention intervention, and care presents a life-course model showing that 12 potentially modifiable risk factors account for around 40% of worldwide dementias.





2. Diagnosing Well

In Swindon, most dementia diagnoses take place through the Avon and Wiltshire Mental Health Partnership at the Victoria Centre, following a referral from a GP or other health professional. Waiting times for diagnosis increased significantly during the Covid-19 pandemic, and currently stands at five months. The current Swindon rate (2022) of diagnosis is 53%, which remains lower than the national average of 61.7% and the national target of 66.7%¹⁰. Diagnosis rates are calculated by comparing recorded diagnoses to estimated dementia prevalence within the population of over 65s nationally. A review of the diagnostic pathway for Swindon is taking place with allocated funding to improving diagnosing dementia across Bath, Swindon and Wiltshire.

Having a timely and clear diagnosis is essential. The Alzheimer’s Society recommend a clinician should:

- Tell the details of the diagnosis sensitively and honestly
- Explain what options there are for support and treatment
- Talk about how dementia is likely to progress and what to expect for the future

People with learning disabilities, particularly those with Down’s syndrome, are at an increased risk of dementia. A person living with a learning disability may already have some differences in their thinking, reasoning, language or behaviour, and their ability to manage daily lives. This means carers, friends and family play an important part in helping to identify early signs of dementia, such as changes in behaviour or personality and loss of day-to-day abilities.

Diagnosis is essential in order to receive the right treatment, support and information and to plan for the future. Some people report feelings of shock, whereas others felt relief at being diagnosed.

¹⁰ <https://digital.nhs.uk/data-and-information/publications/statistical/recorded-dementia-diagnoses>

“At the time Steve refused to believe the diagnosis of dementia.” - Steve and Pam

“There was an element of relief, but surprise with the diagnosis. Colin often forgets things. Leaves conversations unfinished. He finds it hard to find words and say what he wants to say.” - Colin and Iris

People affected by dementia told us that they most commonly sought support from their GP after noticing memory issues. Often this was prompted by family members who had noticed changes, or an event that had occurred.

“Bob’s daughter first noticed change in Pennie - “Pennie’s not right”. Pennie has difficulty following conversations over a long period of time, which can be tiring and frustrating.” - Bob and Pennie

“Dad was beginning to forget how to get home when he was driving. He was only diagnosed as he blacked out in the car and had an accident- it went from there”. - Olive Tree Memory Café member

Some people reported feeling confused about their diagnosis - not knowing exactly what was going on, or a lack of clear information about what was happening next. Factors such as younger age and additional health issues can mean a longer period of monitoring prior to diagnosis. Research shows that people living with dementia are more likely to have multiple health conditions and more likely to have complex health needs.

“We went to the Memory Clinic twice. They asked lots of questions and did a scan. We don’t really know what is going on now. We have details of a nurse we can phone. If Michael’s condition deteriorates, we need to ring the nurse.” -Michael and Pearl, Haydon Wick Memory Café

“Nobody sat down with us and said this is this, that is that- then Covid hit and someone came to the house but all the PPE equipment they wore made it hard to communicate with them. It was pants really. Covid made things worse.” - Janet & Alan, Olive Tree Memory Café

“We had trouble getting Lorraine diagnosed due to her young age. It took three years of monitoring and doing test scores. The third time we went the consultant agreed it was early onset dementia. Ian wrote a diary of things going on at home to give a better picture of how Lorraine was over time.” - Lorraine & Ian, Wyvern Theatre Memory Cafe

“We went to the Memory Clinic 2 – 3 years before confirmed diagnosis in 2018. Steve also has multiple health issues... The process is quite frustrating and we feel “Missed for everything as due to various events we seem to have dropped off the waiting lists and have to start over again.” - Sue, carer to Steve, her husband who is living with dementia

Some people felt that clinicians spoke to the carer at appointments, rather than the person living with dementia. This again points to the importance of good quality, clear communication with both the person being diagnosed and any carers or family members present. Other people praised the positive support from staff at the Memory Clinic, where they were dealt with compassion and understanding.

“Last time at the Memory Clinic I felt really cross. Apart from asking him his name and date of birth, (staff member) just spoke to me all the time. I thought why are you talking to me? It made me feel really cross- I thought there’s two of us here in this room” - Janet & Alan, Olive Tree Memory Café

“I remember David saying everyone was talking to me, not him. Nothing was explained to him but he wanted to know what would happen and how it (his dementia) will progress” - Margaret who cares for her husband, David, who is living with dementia

“Jude was in tears as she couldn’t answer the questions asked, but (the nurse) held her hand, got tissues out and was really lovely to her” - Carer, Olive Tree Memory Café

Priorities around Diagnosing Well in Swindon:

1. Reduce waiting times for dementia diagnoses by looking at process/pathway of diagnosis. The Action Plan for this priority is being led by Avon, Wiltshire Mental Health Partnership Trust and the Integrated Care Board as part of a whole review of the dementia pathway.
2. Raise awareness of the signs of dementia so more people come forward for assessment. An Action Plan will be produced - which will include working with people affected by dementia to help produce a communications campaign and working with our diverse communities in Swindon to raise awareness.
3. Improve the role of primary care in dementia diagnosis and ongoing support, including medication so that those working in this field also have the necessary support and skills they need to help people living with dementia and their carers. The Action Plan for this priority is being led by Avon, Wiltshire Mental Health Partnership Trust and the Integrated Care Board as part of a whole review of the dementia pathway.
4. Ensure clear information is given regarding diagnoses, treatments available and next steps and support is available to help better understand and cope with their diagnosis and any treatments.
5. To talk directly to the person living with dementia at appointments, as well as any carers/family members who may also be present. To treat everyone with dignity and respect.
6. Ensure people with learning disabilities who have, or are at risk of development dementia are fully supported in long-term settings through linking dementia into annual health checks.

3. Supporting Well

Support for both the person living with dementia, and for unpaid carers who are helping to support people living with dementia are both equally important. Dementia UK advise that when someone is diagnosed with dementia, they should be supported to remain as independent as possible, and to continue to enjoy their usual activities and occupations. Support should be 'person centred' and focus on what the person still does have, not what they may have lost. NICE guidelines recommend offering a range of activities to promote wellbeing, cognitive stimulation and rehabilitation and group reminiscence to people living with mild to moderate dementia¹¹.

Carers often feel the profound effect the role can have on their own lifestyle- spending long hours providing care, juggling their own needs and those of the person they are caring for, and forfeiting their social time. As a result, carers of people with dementia are more likely to experience stress, depression and increased isolation¹². The Carers Strategy for Swindon sets out a vision for creating a community where carers are recognised, valued and supported¹³.

One local carer, Sue, talked about getting no respite from her caring role, other than occasionally with family for a couple of hours. Sue's husband won't accept any outside help and cannot be left on his own; if she does try and go out he makes excuses for her to return. This means Sue cannot do anything on her own unless someone comes and looks after him to give her a break. The pressure on carers to provide round the clock support to their loved ones and their role in supporting people living with dementia to live independently, cannot be underestimated.

Adjusting to living with dementia, or suddenly finding yourself caring for someone with dementia is a very individual process, as is the pathway for the disease. This Strategy proposes that everyone should have access to clinical advice and a range of support at every stage including peer support such as dementia related groups run by Swindon Carers centre, and other organisations.

¹¹ Recommendations | Dementia: assessment, management and support for people living with dementia and their carers | Guidance | NICE

¹² Alzheimer's Society, 2018

¹³ www.swindoncarers.org.uk/strategy-for-swindon



Experiences of support provided following diagnosis:

There were mixed experiences about how much support and information was provided following diagnosis in Swindon. Admiral Nurses (Dementia specialist nurses based at GWH) were highly praised for the support and advice provided when it was needed. Commissioned support organisations, such as the Alzheimer's Society and Swindon Carers were also praised. There were varying experiences of support from primary care, with some carers feeling there was a lack of expertise around dementia.

"I lost faith in our GP surgery - the lack of knowledge around dementia really shocked me. I rely on the Memory Clinic now, not the surgery. I just don't feel dementia is important to GPs. I found the Admiral Nurses were incredibly supportive and everything you'd hope for them to be in the situation." (Rob who cares for his mother with dementia).

"An Admiral Nurse came to see us at home. Tim was very nice and pointed me in all the right directions. He was great". - Olive Tree Memory Café members

"Swindon Carers Centre are a huge support "they look after me, as I look after her". You don't get asked to be a carer, you just do it". - Nicky and Sally

"The Memory Clinic in Swindon are absolutely fantastic." - Di, Carer

"We have six monthly appointments at the Memory Clinic which are good. They'll also take calls anytime – sometimes they may come back the next day. They are really good". - Olive Tree Memory Café members

"A carer was telling me yesterday that following diagnosis, she felt they were just left to get on with it and only through attending our Dementia Peer Support Group has she gained information and does not feel alone". - Group Coordinator, Swindon Carers Centre



Supporting people affected by Dementia as symptoms progress

Some people talked about the assumption that a care package for a person living with dementia was needed as their illness progresses, when what was more needed was a sitting service to support carers in their caring role. Some carers reported being offered a sitting service, which worked well - others were not offered it, and did not know who to approach about it. This highlights the need for clear and consistent information about what support services can be provided and how to access them.

Some carers we spoke to talked about behavioural issues with the person living with dementia becoming difficult to manage at home, which led families to have to deal with crises and look at care home options. A number of carers said they felt completely alone and didn't receive the support they needed from clinical services - this sometimes led to hospital admissions in order to get help. One carer reported moving into the area with her father, who was already diagnosed with dementia but unfortunately fell through the gaps between

primary and secondary care. Carers in crisis results in increased demand across the health and social care system and providing more support earlier for carers who are dealing with challenging behaviours from the person they care for and struggling to manage could benefit everyone. Carers reported a range of ongoing symptoms, which became more severe, or new more extreme behaviours that needed expert advice which they struggled to find. Support needs to be given before a crisis is reached together with clear information about who to contact in a crisis. We know from partnership work with Wiltshire Police that dementia related incidents requiring Police assistance have increased since the Pandemic, with care homes sometimes calling 999 because of the complexity of a person with dementia's behaviour. Some carers felt they were left to get on with their caring role with no real support from statutory services. Only when things reached a crisis point, was any real support provided.

"It was so frustrating as we were waiting for a Memory Clinic appointment which was a 10 month wait at the time, and our GP Surgery would not provide any support. Continence supplies were running out. We felt pushed out and not listened to. In the end the Alzheimer's Society got involved and provided phone numbers to help get things sorted out. I don't feel the GPs listened or heard what I said. The Memory Clinic were brilliant once we saw them". - Sue who cares for her father, Ralph who is living with dementia.

"People often listen to what you're saying, but don't hear what you need". - Carer attending the Olive Tree Memory Café

"I had to reach crisis point before things were put into place. You had to be at rock bottom before people will step up and do something". - Carer attending the Olive Tree Memory Café

"I needed help with the emotional/behavioural ups and downs. David began to talk to me in a threatening way (though I know he didn't mean it) and my family didn't want to leave us in the evenings just in case. Let me tell you, nobody was around in the evenings to give any help. Nobody from AWP, even the emergency line. In the end, David had a fall and was taken to hospital. They saw how advanced his dementia was and everything I had been dealing with. I wanted him to kick off, so they would help. They then told me David couldn't come home and so we looked for a care home. There was not a lot of help for us- Swindon Carers gave us more help than anyone else. It's been horrible". - Margaret, carer for her husband, David

It is clear from speaking to people affected by dementia; the significant role support organisations such as Alzheimers Support and Swindon Carers Centre have in supporting families where statutory outreach services may stop. The opportunity to speak to others who are in similar situations and have been through similar issues is extremely valuable. The range of peer support groups, Memory Cafes and activities available was highly praised. The Swindon Carers Centre has seen an increased number of carers coming to them for support since the Pandemic. The waiting time for Carers' Assessments is currently around 7 weeks in Swindon (2022).

“When you talk to people who’ve gone through it, they will give you more advice because they’ve had to go through it themselves. They are really helpful people” - re: Swindon Carers Centre. Rob who cares for his Mum

Swindon has a range of day services and respite options available, which can provide a range of activities for people living with dementia, a chance to socialise and hot meals, as well as giving carers a break from their caring role. Details are available via the Swindon Borough Council Local Offer website¹⁴, although some of the people affected by dementia we spoke to reported feeling reluctant to use these options, as they were unclear what was offered. Some had no idea these options were available, whereas others felt the person with dementia did not really want to go and felt guilty for booking them to go. One carer felt that respite should be offered in the own home (rather than a care setting).

“It’s not that easy to get respite cover at home. Now we sometimes feel “marooned” in our own home. I feel that if Terri went into a home, even for respite, it would completely “throw him” and he would decline. At home, generally he feels quite settled.”

- Peter who cares for his father-in-law Terri, who is living with dementia

“Nobody gives you information about how to get a respite break”.

- Olive Garden Memory Café member

“David went to Ridings a couple of mornings, but not since the Pandemic. He was doing it for me, for my sake, I said I really do need a break and he would go. I don’t send him now though”

- David & Margaret

“We approached Harry Garrett Court, but there was no availability. No other options were offered and I’m unsure if anything else available or if Thelma would like it.” - Thelma & John

We recognise that good quality, flexible home care services available can help people living with dementia maintain independence and reduce social isolation¹⁵. Assistive technology embedded into the care pathways across health and social care for people with dementia and the increased use of telecare / telemedicine can help people to live longer at home¹⁶. Telecare can include wearable alarms, monitored medication reminders, temperature, door and movement sensors. Assistive technology can support someone with memory problems by providing visual, verbal or audible reminders and prompts through apps for smartphones and tablet devices. Smart devices and virtual assistants (such as Amazon Alexa or Google Assistant) can allow voice commands or asking questions as well as controlling home systems (such as lighting, heating etc). Tracking and monitoring apps on mobile phones can help to easily locate a person.

Many people with dementia find that introducing and using technology as early as possible helps them to get used to it and means they can use it for longer¹⁷.

When designing outside spaces, it is important that there is appropriate, easy to follow guidance around dementia friendly design- including smooth, plain, non-slip, non-reflective paving and quiet, pedestrianised streets and welcoming open spaces with good lighting¹⁸.

¹⁴ Swindon Local Offer - Day centres

¹⁵ Evidence of what works to support and sustain care at home for people with dementia: a literature review with a systematic approach - PMC (nih.gov)

¹⁶ Dementia: Assistive Technology | SCIE

¹⁷ How technology can help | Alzheimer’s Society (alzheimers.org.uk)

¹⁸ http://www.housinglin.org.uk/_library/Resources/Housing/Support_materials/Other_reports_and_guidance/Neighbourhoods_for_Life_Findings_Leaflet.pdf

¹⁹ Risk Factors Associated with Falls in Older Adults with Dementia: A Systematic Review - PMC (nih.gov)

Supporting care providers and care homes:

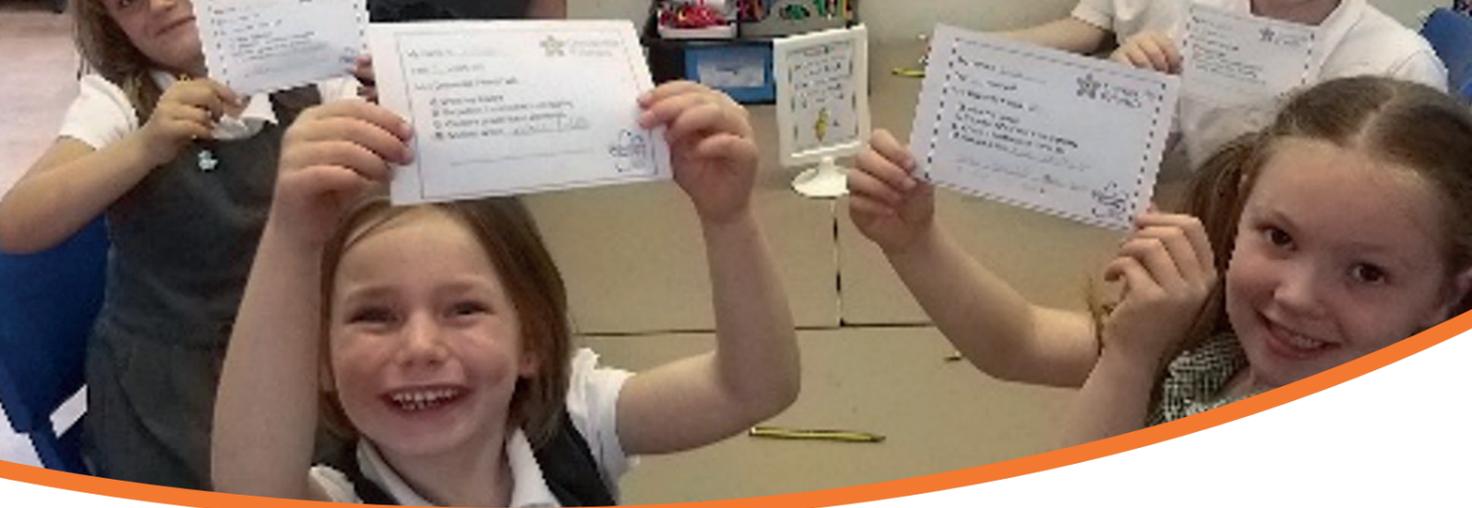
For people with dementia to receive the person centred care they need, people working with them need the right skills and training and understanding both the illness of dementia and the person centred approach that can make the difference between a good quality of life for someone and increasing the feelings of isolation and risk of challenging behaviour. Research from the Alzheimer’s Society in 2013 found that the main factor the public would look for in choosing a care home is training of staff. Training social care staff should also include the principles of the Mental Capacity Act 2005.

Part of maintaining independence for people with dementia is being part of a supportive and understanding community. This means that training should extend to all those who are public facing so staff in all aspects of day-to-day life (e.g. GP reception staff, housing officers, bus drivers etc.) are dementia aware. In Swindon we have over 10,000 dementia friends who have attended an information session and understand the basics of what dementia is, how it can affect someone and how we can all help. This programme is helping to make Swindon a Dementia Friendly Community, where

there is awareness and understanding of dementia. Police stations, schools, taxi forums, libraries, funeral parlours and shops across Swindon have all hosted Dementia Friends Information Sessions. During the Pandemic, online sessions were made available, and in person, sessions are not being organised.

People living with dementia have a greater risk of falls, and falls in care home residents are at least five times more frequent than in community dwelling adults¹⁹. The risk of falling can be reduced through multi factorial falls assessment, exercise that improves strength and balance, and evidence-based interventions, modifying intrinsic and extrinsic risk factors, and multi-disciplinary teams working in partnership across health and social care services. The Swindon Falls and Bone Heath Strategy outlines key priorities and actions to develop falls services accessible at the right time, in the right place and with the right workforce model. We are also working with Care Homes to share best practice and material around meaningful activities and offer positive effects on mental, social and physical health reducing risk of falls.





Priorities around supporting well in Swindon:

1. Ensure families and carers have access to dementia support services as soon as they need them- through the commissioning of high quality, responsive support services which meet local need.
2. Proactive, consistent and clear information on support services available for people living with dementia and carers be provided to all- including information on Day Services, Respite Local Offers and Sitting services. Exploring options of respite at home, for those people with dementia who would be too disorientated in a different setting.
3. Clear information and support about what to do in a crisis, including out of hours, so carers/care workers do not feel alone and to avoid unnecessary hospital admissions.
4. Improved liaison between secondary and primary care such as via a psychiatric consultant to link to primary care offering advice and guidance.
5. To ensure the availability of Admiral Nurses or equivalent in supporting people affected by dementia in Swindon.
6. Consider the feasibility of re-instating 'Living Well with Dementia' courses through Victoria Centre when capacity allows this.
7. Develop and implement a Swindon dementia training competency framework, incorporating local minimum standards for health and social care professionals directly supporting people with dementia (such as First City Nursing, SBC Care Home staff etc.) The Alzheimer's Society recommend these staff be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework.
8. Provide timely Carers Assessments to ensure that carers receive any support that they are entitled to as quickly as possible.
9. Work with Care Homes to share meaningful activity advice and best practice, relaunch of Senior Games in Care Homes for 2023 in order to reduce the risk of falls among people living with dementia
10. Work with Care Homes and Sheltered Accommodation to minimise chance of resident falls, and avoid unnecessary hospital transfers
11. Maintain accreditation of Swindon as working towards 'Dementia Friendly Community' status.
12. Plan of Dementia awareness sessions across Swindon as part of wider 'Dementia Friendly Swindon Work plan'. Ensure people living with dementia and carers are involved in designing this Work Plan.
13. Dementia-friendly design is considered for new housing development including 'homes for life' so people can remain at home for as long as possible

4. Living Well

“The illness left me with a speech issue, memory issues, and at times extreme tiredness. I personally find that I do what I need to do in the mornings. It is also very important to keep the mind active, and groups like this will play an enormous part in helping another cope with their day-to-day activities” - David, Living with Dementia

Living well with dementia means finding ways to promote wellbeing and quality of life for everyone affected by the dementia. It is recognised that with the right help and support when it is needed, many people live well with dementia for a number of years. Considerable collaborative work has taken place through the Dementia Action Alliance and Dementia Steering Group over the past five years to develop Swindon as a Dementia Friendly Community. Swindon has received official accreditation for this work each year from the Alzheimer's Society since 2017. A wide range of activities, groups and events take place to provide a wide choice of social opportunities.

These include Sporting Memory events at Swindon Town Football Club, Railway Reminiscence events at the Steam Museum, Silver Linings craft and walk sessions, TWIGS dementia friendly gardening sessions, Memory Cinema vintage film showings and we now have seven Memory Cafes across the Borough. Feedback from people affected by dementia, and those who work with them, is that these activities and events enrich and support them to live well with dementia. Dementia Action Week in May is a good opportunity each year to promote dementia awareness across Swindon. In 2022, this included an Information Expo with stands and colleagues to discuss dementia with, which was attended by over 70 people and included a free drop in Dementia Friends Information Session, and a Tea Dance with live music, which over 100 people living with dementia and carers attended.





“I love it here. It feels like home. I don’t know what’s going on in my head but I know my friends here and I love it here. It gives me confidence. And we have a laugh. People don’t realise what’s here. They don’t understand” - Jude, living with dementia who attends the TWIGS gardening group

“We get everything else we need from the groups we attend”
- Olive Garden Memory Café member

“We do so many things- walking for health groups, ramblers, memory cafes (at Wyvern, Haydon Wick, Highworth, Silver Linings and Christchurch community group). We also do Love to Move at Highworth, which mixes up music and movement. We really enjoy this, and it’s challenging for both our brains!” - Lorraine, who is living with younger onset dementia and her husband Ian

“We see patients diagnosed with dementia from all over the local area, and Swindon has by far the best range of Dementia Friendly activities available which provides invaluable support”
- Tim, Admiral Nurse at Great Western Hospital

“We weren’t ready to go to Memory cafes at first. Now we attend the Memory Cafes in Haydon Wick and Pinetrees, as well as Silver Linings art and walking group, TWIGS gardening and Singing for the Brain”. - Penny & Bob

Memory Cafes and other dementia friendly groups and activities also give carers the chance to meet other people in a similar situation, build friendships and to pursue their own interests whilst knowing the person they care for is looked after and supported. Dementia can be very unpredictable, so by keeping the groups as ‘drop in’ and flexible, people can just attend as, and when, they feel they want to. A ‘what’s on where’ guide is produced every month by Home Instead and the Swindon Dementia Action Alliance and distributed widely through voluntary sector colleagues as well as being made available online.

“I play each day by ear. I won’t know what activities she feels up to, until she’s up.”
Nicky talking about her mother-in-law with dementia, Sally.

There is a constantly updated Dementia Friendly work plan, written by Swindon Borough Council in consultation with people affected by dementia in Swindon. Current projects include establishing a Sporting Memory Café at Foundation Park, Swindon Town Football Club and a new Memory Café at the Prospect Hospice in Wroughton launching in November 2022. Physical exercise is also being included, with programmes like Love to Move from the British Gymnastics Foundation and dementia friendly walking groups providing opportunities for group exercise at people’s own pace. This links to preventing falls, and improving balance and core strength. Transport can sometimes be organised by group providers, although it is acknowledged this can sometimes be a barrier to people attending.



It is recognised that as symptoms worsen, someone living with dementia may become more dependent on others for transport and general help. The fear of becoming confused or wandering (getting lost) can also lead to some people going out less and restricting themselves to less demanding activities. This can result in greater isolation from the community and feelings of loneliness. The Public Health Team from Swindon Borough Council are working with Memory Cafes to look at how we can support those members of the community. This also links to being part of a Dementia Friendly Community, and us all seeing ourselves as ‘Dementia Friends’ who look out to support neighbours, friends or family in our neighbourhood. It may be appropriate for housing provision, such as extra care housing to be considered- as well as any special equipment, home adaptations and assistive technology as necessary with the aim of enabling the person living with dementia and their carer to live meaningful and independent lives.

Wiltshire & Swindon Police have relaunched the Herbert Protocol to support people who become confused and may go missing. The Protocol is a form that carers, family and friends of a vulnerable person, or the person themselves can fill in. It includes up-to-date contact numbers, medication required, memorable places the missing person may go to and a recent photograph. Keeping this form saves the worry of trying to recall the information during the stressful time of someone going missing, saving time for the police too. Herbert Protocol forms are available at www.wiltshire.police.uk website.

Priorities around Living Well in Swindon:

1. Working in partnership with people living with dementia, carers, Swindon Dementia Action Alliance (SDAA), Alzheimer's Society and other local partners to ensure Swindon continues to be recognised as working towards being dementia friendly
2. Taking every opportunity to improve public and professional awareness of dementia and reduce stigma
3. Ensure wide circulation of the monthly 'What's On Where' (WOW) produced through Home Instead and the SDAA
4. Comprehensive programme of Dementia Friends Information Sessions across the community
5. Work with businesses to raise awareness that staff training and understanding about dementia as central to good customer service and meeting customer need
6. All statutory organisations across Swindon who are partners of the Health & Wellbeing Board to provide opportunities to attend 'Dementia Friends Information Sessions'.
7. Ongoing engagement with people affected by dementia to ensure groups and activities provided are what they want and need. Explore expansion of voluntary transport provision to help ensure everyone who want to attend, can.
8. Ensure all eligible people living with dementia and their carers are offered a direct payment, with options to apply for the use of wider personal (health) budgets, on diagnosis/assessment where appropriate.
9. Publicising of Herbert Protocol and advocating use to carers/people living with dementia via support services.



5. Dying Well

The National Institute for Ageing highlights specific areas of consideration for end of life care for people with dementia²⁰. These include using advance care planning documents for people living with dementia, to help family know the person's wishes for when carers may need to make difficult decisions on behalf of their loved ones about care and treatment approaches. It is particularly important to try and record this at an early stage, as we know that as dementia progresses; a person with dementia at the end of their life may no longer be able to communicate choices about their health care. The Alzheimer's Society recommend having open discussions at different stages, to ensure plans and wishes are updated. There may also be difficult choices to be made around medication, and weighing up the benefits, risk and side effects of any treatments.

Being there for a person with dementia at the end of their life is another area highlighted. As dementia progresses, carers/family may find it hard to provide emotional or spiritual comfort to a person who has severe memory loss. However, even in advanced stages of dementia, a person may benefit from sensory connections (such as hearing, touch or sight) which may also bring comfort. Listening to music can help to relax some people and lessen agitation. Support for carers during this time, and bereavement support is important. In Swindon 73.8% of people die at their place of usual residence, which is slightly higher than the national average.

We know that every person diagnosed with dementia, will have the condition at the end of their life. There was a mixture of people we spoke to who had, or had not discussed end of life plans. For some it was still a taboo subject, which would not be discussed. For others, clear plans were made and recorded.

¹⁴ End-of-Life Care for People With Dementia | National Institute on Aging (nih.gov)



“We have talked about end of life plans, and sorted out a funeral plan when she moved in. We talked through whether she wanted to take dementia drugs. Sally doesn’t enjoy the way her dementia is affecting her and does not want to prolong this by taking any medications which may slow her dementia down.” - Nicky, Carer for her mother-in-law, Sally

“We sorted funeral plans and discussed wishes, David agreed we’d “let nature take its course.” The Care Home have asked and documented wishes too”. - Margaret, carer for her husband, David who is living with dementia

“Dad won’t talk about that. It’s not something we ever discuss” - Sue, Carer

“We haven’t discussed dying. I don’t want to upset him. I will do the best for him as long as I possibly can.” - Sue, Carer to her husband, Paul

It is essential that all services that are involved in a person’s dementia journey are aware of the importance of Advanced Care Planning (ACP) and ensure this is offered to people who are diagnosed with dementia as well as their carer. There should be opportunity to be involved in creating their own personalised Advance Care Plan, so that their wishes can be known and acted on. All people living with dementia and their carers should receive coordinated, compassionate and person-centred care towards the end of their life.

Prospect Hospice provides free support at the end of life to those living in Swindon and the surrounding area. This care is equally for the patient, the carer and the family and is provided by a range of highly skilled specialist hospice services before and after death. Preparing for death is an important part of the Prospect Hospice approach to individualised care provision.

This includes care at the hospice, inpatient beds (single rooms in a dementia friendly environment) a café and all meals are tailored to individual patient needs.



The hospice allows visiting family pets and all rooms have access to the gardens and safe paved walking areas. Additionally, personal care can be provided at home including overnight care and this can be in response to the need for carer respite.



Medical consultants are available on site and for home visiting with a team of specialist nurses to assess and advise with advanced care planning, spiritual care needs and symptom relief. Social workers who are specialist in palliative care, and understand dementia will be involved with supporting the patient, the carers and family as needed. Additionally, the multi-disciplinary team at Prospect Hospice provides support and advice on a case-by-

case basis to other healthcare professionals. They deliver education sessions to staff across primary care, care homes and the community as the specialists in end of life care. A bereavement service is also available for group and individual sessions.

Swindon Public Health Team have set up a monthly Memory Café in partnership with the Prospect Hospice so we can work together more closely in the future.

Priorities around dying well in Swindon

1. Planning for care at the end of life should be offered to all those diagnosed with dementia, to include a discussion of cardiopulmonary resuscitation (CPR). Advanced Care Plans should be recorded and kept by a person’s GP
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
3. Ensure all carers and families can receive bereavement support at a time that is right for them



Next Steps

The local dementia strategy in Swindon is intended to reflect local need whilst incorporating best practice and national guidance and imperatives. A detailed action plan will be produced to deliver against the priorities together with measures of success.

Progress will be monitored through the Dementia Steering Group, the Older Peoples Mental Health Forum and the Health & Wellbeing Board.

Thank you

We are immensely grateful to all those who contributed to this strategy and particularly local people living with dementia and their carers.



Photo Credits:

Many thanks for all the local groups and organisations who have allowed us to use photographs. These include: TWIGS, Swindon Town Community Foundation, Alzheimer's Society, Swindon Carers, Forget Me Not Café Highworth & Love to Move, Making Memories Wroughton, Swindon Theatres Memory Cinema & Memory Café, Haydon Wick Memory Café, Ferndale School and Central Library.



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