

TASK GROUP REPORT
Dementia

Adult Social Care, Health and Housing Overview and Scrutiny
Committee

REPORT 2017 V4

Foreword

The Adult Social Care, Health and Housing Overview and Scrutiny Committee agreed in 2015/16 to undertake a review of Dementia. The first years report had a recommendation to continue into a second year, this was supported by the Scrutiny committee. This report contains the conclusion of two years of the Dementia task group work covering 2015/2016/2017. The report is not intended to repeat last year's interim in-depth details.

The second years work has explored the council's actions when considering Dementia and the wider work of the Community.

There have been two areas of focus for 2017:

1. How can Swindon Borough Council (SBC) contribute to Swindon becoming a Dementia Friendly Town?
2. What Lifestyle decisions or types of environments contribute to Dementia and what changes could be of benefit?

Dementia is a key priority for the Council in the context of an increasingly older population and likely demand on health and social care services. In the absence of a cure for Dementia the emphasis remains on prevention and support of people.

To enable someone to live successfully with Dementia there are a range of actions the council, together with other partners where appropriate, can undertake. These fall within the terms of diagnosis, lifestyle, environment, co-morbidities and palliative care, together with promoting the evidence which can help to prevent or delay dementia.

The Task Group wishes to thank all parties involved for their co-operation in preparing this report.

Members of the task group and those who have been members are:

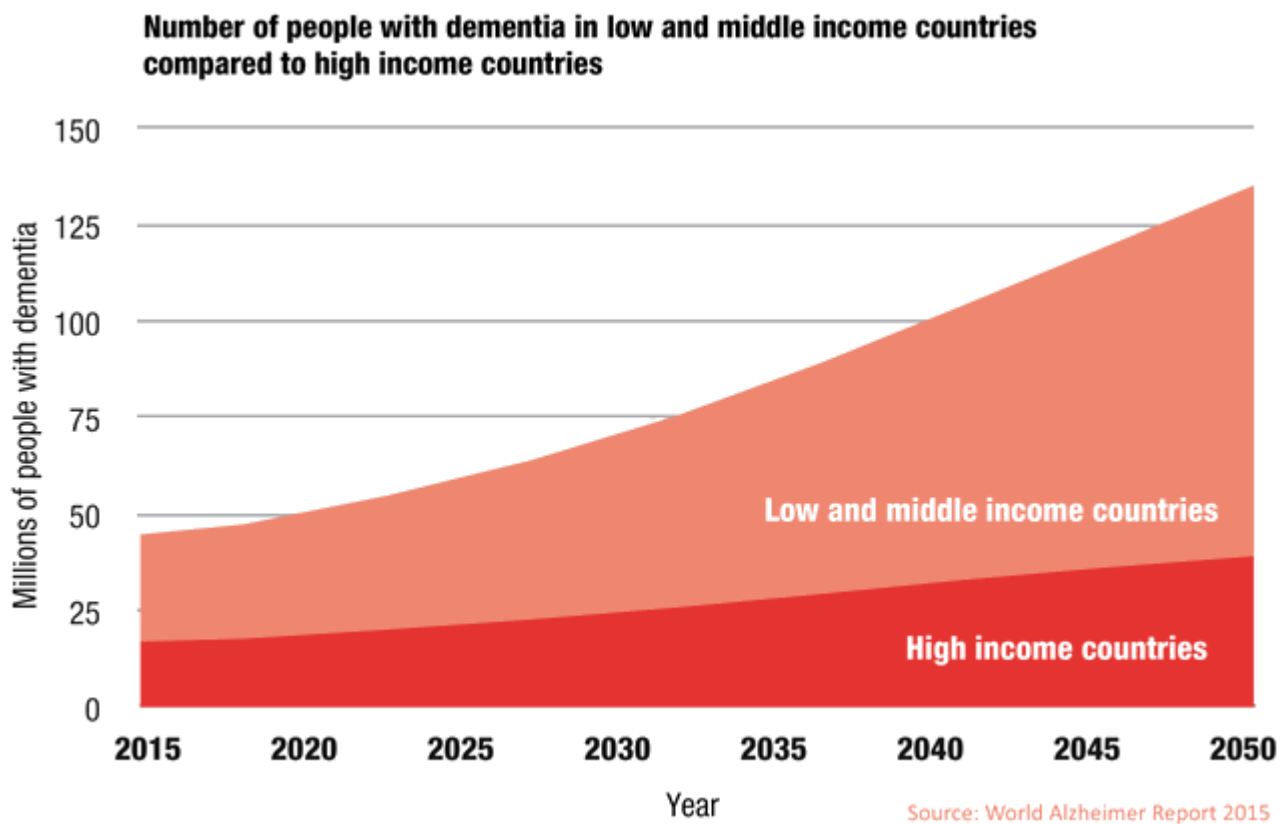
Councillor Bob Wright (Chair of the Task Group) Councillor Alan Bishop, Councillor Julie Wright, Councillor Steph Excell, Councillor Carol Sydney-Smith, Steve Henderson - Equalities (GWH), Mark Edwards (Healthwatch), Moira Pinson (Volunteer – Healthwatch) and other Healthwatch Representatives.

1. Introduction and Background Information

- 1.1 This report has been difficult to produce because of the frustrating differences in how Dementia is viewed and approached across the world and by Health professionals and other practitioners. There is inconsistency worldwide in the number of Dementia occurrences per members of population and there is inconsistency in the number of occurrences based on income, diet, environment and lifestyle. There are some countries with virtually no occurrences and other countries such as the UK with substantial increasing numbers of people affected.
- 1.2 The disparity in the number of deaths also relates to wealth which provides lifestyle differences. Whilst there are substantial difference between the low numbers in African/Arab States and high in Europe/USA there are localised difference for instance in Bulgaria which is a relatively poor European Country the Death rate caused by Dementia is 0.84 the UK is 24.35 per 100,000. (Published by WHO 2014). This may be at least partly due to differences in recording systems for dementia.
- 1.3 The cause of Dementia has led to conflicting postulations with at least 20 non-genetic risk factors. In spite of this there are no definitive causes or cures. This does not mean no difference cannot be made or progression be delayed. The controversy extends to some of the Medical profession challenging established views by suggesting alternative ways of assessing a person's health can lead to early intervention and reversal. This view is not prevalent in Western Establishment Medical Organisations but can be found in other societies and with alternative practitioners.

- 1.4 India is the home of Ayurvedic Medicine and the Death rate is 0.46 in comparison to the UK's 24.35. Ayurvedic Medicine has four pillars: 1) Diet/digestion, 2) Exercise, 3) Sleep/rest, 4) mental/emotional well-being. These are the specific strategies for prevention and health maintenance.
- 1.5 Elevated blood concentrations of total homocysteine and low-normal concentrations of B vitamins (folate, vitamin B₁₂, and vitamin B₆) are candidate risk factors for both Alzheimer's disease and vascular dementia. Seventy-seven cross-sectional studies on more than 34,000 subjects and 33 prospective studies on more than 12,000 subjects have shown associations between cognitive deficit or dementia and homocysteine and/or B vitamins. A definite causal pathway has yet to be shown. Raised plasma total homocysteine is a strong prognostic marker of future cognitive decline, and is common in world populations.
- 1.6 In the UK Medical professionals are led by guidelines such as those produced by NICE. These support healthy behaviour but are not compulsory and do not provide certainty in preventing Dementia. For the best Health Benefits the behaviour probably needs to start early in life. This is because it is possible to have a relatively early onset of Dementia.
- 1.7 There was an estimated 46.8 million people worldwide living with dementia in 2015. This number will almost double every 20 years unless something changes. As wealth increase in previously poor Nations and Western Lifestyles become established Dementia becomes the fastest growing cause of death in the elderly population. There are over 9.9

million new cases of dementia each year worldwide, implying one new case every 3.2 seconds.



1.8

The economic impact of Dementia is profound and is conditioning the response. In one direction large corporation and governments are looking for cures and in other directions it is limiting freedom and support for alternative treatments. If you do not confine yourself to the guidelines you will not get the funding from those who are charged with dispensing public money. This is particularly important when trying to influence changes for prevention. Public Health money in the UK has been decimated and makes it difficult for local councils and Health Organisations to provide early intervention services.

1.9

Direct medical costs are roughly 20% of global Dementia Costs. Direct social sector costs and informal care costs each account for roughly 40%. The relative contribution of informal care is greatest in the African regions and lowest in North America, Western Europe and some South American regions, while the reverse is true for social sector costs. The economic cost makes it the 18th largest economy in the world. Source [World Alzheimer Report 2015](#).

1.10

Many people live with Dementia without having a formal diagnosis; it was previously put down to senility. In countries with high income up to 50% of Dementia cases are recognised and documented in primary care. This 'treatment gap' is certainly much greater in low and middle income countries, with one study in India suggesting 90% remain undiagnosed. If these statistics are extrapolated to other countries worldwide, it suggests that approximately three quarters of people with dementia have not received a diagnosis, and therefore do not have access to treatment, care and organised support that getting a formal diagnosis can provide. The World Alzheimer Report 2011 shows that earlier diagnosis and early intervention are important mechanisms by which the treatment gap can be closed.

1.11

There is evidence that Alzheimer's is related to Lifestyle rather than genetics. Alzheimer's rates of Japanese-Americans living in the U.S. are closer to that of Americans than to Japanese. When people move from their homeland to the United States, Alzheimer's rates can increase dramatically. Therefore, when Africans or Asians live in the United States and adopt a Western diet, their increase in Alzheimer's risk suggests it's not genetics.

1.12

Dementia is the general umbrella name used to cover a range of disorders of the brain in which there is a progressive deterioration of brain function. Cognitive impairment is regarded as a natural part of ageing however Dementia can lead to memory loss, and major changes in thinking, language, mobility and personality. The average life expectancy for someone with progressive Dementia is 7 to 10 years. Alzheimer's is the most well-known form of Dementia covering two thirds of cases.

1.13

The notion of cognitive impairment being a natural part of aging is being challenged by the example of those who not suffer such age related impairment. Also whilst the average age of the population is increasing there still remains a natural lifespan with normal functioning associated with ageing.

1.14

There are plenty of elderly people with good cognition and it has to be questioned whether more people could benefit from good cognition if their lifestyle and environment change. Better diagnosis at a younger age provides a better chance to intervene and change. Earlier intervention could lower costly expenditure for an ageing population. There is hope a 25% reduction of Diabetes type 2 locally (nationally 24%) has been achieved through frontline Primary Care and Lifestyle changes. These could also lead to a reduction in Dementia referred to as Diabetes type 3 (still to be evidenced).

1.15

Dementia support services are very reliant on volunteers and volunteering has been impacted by Council decisions and cuts to budgets. Volunteers are at a premium and cuts to grants are having a direct impact on supply.

1.16

People with Dementia across the world have anecdotally identified improvements to their condition through the process of Ketosis. This process affects the glucose supply to the brain and is an alternative to insulin supply. Coconut oil which has other health benefits and has no known side effects is the main produce recommended by users.

1.17

Even in the short time the Task group has been looking at Dementia there has been a change in the way many Health Professionals are now viewing Dementia. There has been a move away from treating the symptoms of Dementia to understanding Dementia at source. This has helped Prevention by adopting more holistic approaches which are achieving encouraging results. Treatments are still being researched and tested however a more holistic view is being taken on potential alternative explanations and interventions.

1.18

Inflammation is associated with some causes of brain damage. Inflammation is a response to the cause of something doing harm to the body and brain. A similar response can be found throughout the body but because of its location the specific harm has sidelined clues to the potential problem found elsewhere in the body. It is what is causing the inflammation that requires understanding and changing.

1.19

The Brain is not a disembodied part of the body and it is wholly dependent on the food we eat and the environment we live in. Lack of exercise, Smoking and Stress can also contribute to associated health issues.

The form of Dementia being referred to as Diabetes type 3 has strong causal links to Obesity, Heart damage, Diabetes type 2 and some forms of Cancer (Non-Communicable Diseases).

If you treat the whole body right you will be treating the brain right. By adopting an approach that keeps the whole body healthy a person also helps the brain.

1.20

The Scrutiny Task group has sought to identify outcomes that could benefit Swindon residents through the existing Council roles. The Council is in a powerful position to aid and deliver changes. The prevention or delay of the early onset of dementia by 5 years will have a significant effect on Swindon resident's health, care and costs. This report seeks to aid the Council decisions by making a difference in service support, improving attitudes and assisting Cultural change.

3. Aims and Objectives

- The size of the subject matter means the task group feel further work is needed to do justice to the subject.
- The overall goal is for Swindon to become dementia friendly and somewhere that people can live well with dementia.
- The task group will review the 12 point Swindon Dementia Strategy document which is based on national strategy to see if working effectively.
- The task group will review the effects of a healthy diet on reducing Dementia risk, reflecting recent NICE guidelines.
- The task group will look at what practical outcomes could aid the council with its Public Health role with Dementia.
- The task group will deliver an output of a guideline for councillors.

4. Methodology

The Dementia Task Group has met on a number of occasions (year 2) with a number of people. These meetings are detailed below:

- 08.09.2016 Meeting of Dementia Task Group members to review the Terms of Reference for the group following Scrutiny Committee. Membership was extended to include Moya Pinson, a volunteer representative from Healthwatch. John Kirk attended the meeting as Chair of the Swindon Dementia Action Alliance (DAA) and discussed the work of the DAA and opportunities to make Swindon a dementia friendly community.
- 13.10.16 Meeting of Dementia Task Group included more detailed discussion on making Swindon Dementia Friendly and the initiatives and training available on dementia awareness. Links to loneliness and isolation were also discussed.
- 24.11.16 Meeting of Dementia Task Group attended by Patrick Weir, Head of Localities, Richard Bell, Head of Planning and Cindy-Ann Carter, lead planner for inclusive design. The group discussed the role of the community in supporting people with dementia and work of the Planning Department. Funding for a dementia friendly co-ordinator for Swindon had been agreed by the One Swindon Partnership.

- 19.01.17 Meeting of Dementia Task Group focused on delivery of a conference in March entitled 'Ageing Well in a Dementia Friendly Swindon' with Healthwatch. This followed on from the Dementia Summit organised by the Alzheimer's Society in November.
- 16.02.17 Meeting of Dementia Task Group with further discussion about the conference. Also attended by Karen McMahon, Head of Customer Services, who update group on customer service training and plans for future changes which should assist customers with a range of issues including dementia.
- 17.03.17 Dementia Conference held at Council Chamber. Attended by over 70 people including the Mayor, MPs, Dr Roger Bullock, John Kirk and many community representatives and local organisations. Feedback suggested everyone found it useful, people had time to spend with other organisations, everyone learnt something new and people found it interesting and inspiring.
- 05.04.17 Meeting of Dementia Task Group discussed the success and learning from the conference, the dementia strategy and update on the 12 priorities, and the draft report for Scrutiny Committee.

5. Context and Existing work

- There does not seem to be a day that goes by without a news headline stating a Dementia breakthrough has been made or reporting a failure of previously headlined breakthroughs. Whilst Dementia is not fully understood there has been progress in tackling possible contributing factors. These fall into two main categories – Food and Exercise which fall within the umbrella term of “Lifestyle” plus Environmental causes.
- Lifestyle changes are being advocated for a range of other health conditions. These are being promoted to reduce the risk of obesity, heart conditions and diabetes. Such Lifestyle approaches should, if the understanding is correct, help to prevent future numbers of cases of Dementia.
- The previous focus of medical professions on the symptoms of Dementia rather than the causes has led to conflicting studies and understanding. This conflicting information poses a problem for Councillors when trying to understand and advocate the best course of action in support of Council and Community services.
- The Council has a role through Public Health to promote prevention. The Council also provides Social Services ranging from Community Buildings to actual Health Care. The Council has in place a Management plan to address its role with Dementia which the Task Group has used as part of its work.

Healthy Eating

Healthy Food not only supplies the energy we need it also supplies essential minerals, vitamins and micro organisms which assist body health. Healthy Eating guidance is provided by NICE

Mental Exercise

This treats the brain as a muscle that needs to be exercised. This helps to reinforce brain connections or develop new connections

Physical Exercise

Physical Exercise can strengthen the body and develop the body including the Hippocampus which has a major memory role.

Gym work improves glucose regulation, improves blood flow to the brain, reduces stress levels and builds up resilience to stress, improves insulin sensitivity, lowers body fat and can help with sleep.

Stress Reduction

The Stress response which is not used as nature intended does harm. Brain Cells are killed off by some of the liquid responses generated. The Stress response also informs the brain to be better prepared for repeat experiences.

Stress is damaging no matter what the cause. There are different forms of stress which can be addressed through mental training such as yoga, learning from experience, removing your self from an environment, seeking assistance, changing environment and food intake.

Recuperation

The body needs rest and sleep. Sleep deprivation can lead to an elevated level of health risks such as obesity and diabetes type 2

Staying Independent

SBC uses its Health and locality Role to support Independent Living. Homeline assist independent living by responding to difficulties that do not have to escalate to Medical intervention.

Involvement

The council has attended Dementia Action Alliance meetings and contributes within its role remit. The council uses its 'One Swindon Role' to promote and assist Dementia Awareness via delivery of dementia friends sessions and partnership working. It has a Care and Health role as part of its statutory duties. It has recently appointed a Dementia Friendly Swindon Co-ordinator, funded by the One Swindon Partnership.

Being Active

The Council promotes physical activity and has a Get Swindon Active Strategy. Within Budget limits it provides assets directly or through Parish Councils to support Social and Community Activity.

Design

The Council has trained staff to assist customer services, planning and development of services suitable for Dementia users. It has some way to go however progress has been made as can be evidenced by the design of Havelock Square. It would be of benefit if the services could be reviewed by service users.

Information

Inform disseminated by SBC should be suitable for those with Dementia. The council has been updating its formats and it would be of benefit if the services could be reviewed by service users.

Safe Place

There is a Safe Places scheme in Swindon Town and Highworth. The Swindon scheme needs promoting further and could be used by Dementia sufferers.

Volunteers

Swindon has a volunteer centre and volunteers as well as family and friends are relied upon to provide help. Cuts to the Volunteer Centre is affecting their ability to help further. Further funding is needed to get things back on track. It is known the value realised by a small investment has real and tangible impact.

Working with others

There exists a Swindon Dementia Alliance comprising of a range of community, charities and volunteer organisations as well as Health and Council professionals. People with dementia should be at the heart of the Alliance work and the changes needed to move Swindon into a Dementia Friendly Place needs the widest involvement.

Healthwatch Conference on Ageing Well

Healthwatch provided a conference at the Council Offices on March 17th. This was very successful with three excellent speakers as well a range of local expertise. The will and momentum to deliver a network of organisations and services to help make Swindon Dementia Friendly was backed. The clear problem identified was threats to volunteers and there work.

The event helped to identify existing bodies and will help identify duplication of services and missing services. Through joint working and partnership the council can reduce resources by working with existing providers.

Swindon Borough Council (SBC) needs to be committed to advancing Swindon as a Dementia Friendly Place and can take a lead using its resources. SBC can contribute positively as part of an Alliance supporting the Dementia Friendly Place Goal. It has already demonstrated leadership by facilitating the conference.

RECOMMENDATIONS

- 1 Produce a simple do/don'ts list with useful contacts**
- 2 Produce a public health leaflet on non-communicable diseases**
- 3 Promote a holistic approach by addressing whole body health and non-communicable diseases together assisted by a 'healthy body healthy mind' campaign.**
- 4 Promote the clean Air acts and Healthy Environment enforcement**
- 5 Rollout non-communicable diseases training for all members and council staff.**
- 6 Review and Scrutinise the services and support which is available for people caring for those with dementia**
- 7 Raise awareness of Dementia for the young and youths.**
- 8 Extend the Homeline Services to cover public areas.**
- 9 Progress the outcomes of the 2017 Healthwatch conference.**

- 10 Produce a set of agreed goals with the Dementia Alliance to help develop a Dementia Friendly Swindon**
- 11 Produce a Dementia Friendly Swindon Dashboard and Scrutinise**
- 12 Request a report for Scrutiny of the benefits of early Lifestyle intervention.**
- 13 Use the Council Scrutiny role with Equalities/Dementia representatives to verify the course of actions taken by the council helps deliver a Dementia Friendly Place and what can be improved upon.**

(See Appendix 1 for more information about the recommendations)

14 Appendix 1

1. **Produce simple A4 list** do's and don'ts to help guide those with a low attention span. This should promote and encourage healthy lifestyle choices in line with NICE guidance promoting the use of diet and exercise (this can be existing lifestyle material). Including Walking clubs and Gyms, Meditation and Lowering stress technique opportunities, sleep advice clinics and professional support.
2. **Produce a public health leaflet** on non-communicable diseases which show the connection between lifestyle and the likelihood of developing Dementia. Illustrate how Healthy eating can help to reverse the early stages of Diabetes type 2 (25% reduction achieved locally). Insulin resistance can produce a 200% likelihood of getting a form of Dementia (source Dr Ewan McNay University of Albany). Slower eaters tend to eat less, are less hungry and are slimmer than fast eaters. Inflammation-creating infections are the key cause of Alzheimer's disease and dementia. The best control inflammation is healthy diet and regular exercise (Professor Goldacre).

3. **Promote a holistic approach** by addressing whole body health and non-communicable diseases together. Use the Health Ambassadors and Navigators and resources for addressing obesity, diabetes type 2 and other health issues such as low folic acid, malnutrition and some forms of cancer. Promote as **‘healthy body healthy mind’**. This will have wider benefits and reduce resources and costs.
4. **Promote the clean Air acts and Healthy Environment enforcement** to help address environmental causes of Dementia. Use Scrutiny to address this Recommendation.
5. **Rollout non-communicable diseases training for all members and council staff. Continue to support** the rollout of dementia friend’s awareness sessions to all frontline SBC staff. Provide the training for all new starters.
6. **Review and Scrutinise the services and support which is available for people caring for those with dementia** including supporting work at GWH to promote dignity in hospital. This includes assisting with the recruiting, development and support of volunteers.
7. **Raise awareness of Dementia for the young and youths.** Use the councils Public Health role and a specific guide suitable for children.
8. **Extend the Homeline Services** to cover public areas and the main population areas of the Borough (this technology is available and was ready for delivery by SEQOL)
9. **Progress the outcomes of the 2017 Healthwatch conference** including a further conference involving people with Dementia. Including the gap analysis of the existing organisational support and assisting the networking of support services. Set of agreed

goals with the Alliance to help develop a Dementia Friendly Swindon.

10. **Produce a set of agreed goals with the Alliance to help develop a Dementia Friendly Swindon.** Meet with Alliance members and also arrange two follow up meetings for those with Dementia and to review after a year.
11. **Produce a Dementia Friendly Swindon Dashboard** to help measure progress. Goals should be demonstrable through measurable Objectives that aid progress. Outcomes need to be agreed and identified against organisation or individual responsibility. SBC has existing responsibilities and needs to commit to supporting the Alliance agreed outcomes. Include the Scrutiny of the Dementia Friendly Swindon Dashboard as part of the Health Scrutiny work
12. **Request through Scrutiny a report on the benefits of early Lifestyle intervention** expenditure that aids prevention against the actual rising health costs. Consider if no changes are made what is the cost of further escalation.
13. **Use the Council Scrutiny role with Equalities/Dementia representatives to verify the course of actions taken by the council helps deliver a Dementia Friendly Place and what can be improved upon.**