Health & Adult Social Care Select Committee – The Dementia Journey: a rapid review of support for people living with dementia and their carers in Buckinghamshire

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Introduction

 Cllr Carol Heap ***Chairman of Review Group***	"Through the work of the Health & Adult Social Care Select Committee, the review group were aware of the council's Adult Social Care transformation programme which included work around improving services for people living with dementia and their carers. As a review group, we wanted to undertake this review within a short time frame so the findings and recommendations could be used to support ongoing discussions between health and social care colleagues. We had four weeks from agreeing the scope to the first evidence gathering meeting and we really appreciated people giving up their time to talk to us at such short notice. We held three full days of evidence gathering meetings, all of which were incredibly valuable in widening our understanding of the existing pathways and support provided for people living with dementia and their carers. I would like to take this opportunity to pay tribute to all those people who help support people living with dementia and their carers. Throughout the evidence gathering meetings, it became apparent just how much work is needed to provide the right level of support and how many people were directly affected by dementia in their own lives. We support the NHS, in recognising dementia as a key priority in its Long-Term Plan and hope the findings and recommendations in this report will help to raise awareness of dementia and lead to an integrated health and social care dementia support service to meet the individual needs of all those living with dementia and their carers on their dementia journey."

Cllr Shade Adoh (Day 1 only)

Cllr Phil Gomm

Cllr Robin Stuchbury

Cllr Nathan Thomas

Cllr Alan Turner

"There are currently around 900,000 people with dementia in the UK. This is projected to rise to 1.6 million people by 2040. There are over 42,000 people under 65 with dementia in the UK, known as young-onset dementia."

Alzheimer's Society website

Aim of the Rapid Review

As part of its remit, the Health & Adult Social Care Select Committee reviewed the refreshed Better Lives Strategy which is the council's strategy for providing support for adult social care clients. The strategy focusses on three levels of support – living independently, regaining independence and living with support. As part of the Better Lives Strategy and vision to ensure that people can remain as independent as possible, dementia support has been included as part of Adult Social Care's Transformation programme which includes a number of workstreams.

The Select Committee was keen to undertake a cross party rapid review to examine the existing dementia pathways, from diagnosis to end of life care, including a review of the prevention programme.

In addition, the Review Group wanted to identify examples of what is currently working well and discuss areas of improvement with key health partners and stakeholders leading to enhanced partnership working and a better integrated service.

Rapid Review scope

The review was set-up to achieve the following:

- A greater understanding of the prevalence of dementia, including the current diagnosis rates against the national target by Primary Care Network in Buckinghamshire;
- An understanding of current service provision and how these services are funded in Buckinghamshire. A comparison of funding with other authorities (ideally Oxfordshire and Berkshire West, part of our Integrated Care System);
- Clarity around who is responsible for delivering services in each pathway from diagnosis to accessing services, ongoing support to end of life care;
- Examine the quality of the signposting services and advice provided to dementia patients following diagnosis, including support and information for carers;
- Review the waiting times from referral to assessment for the memory clinic services;
- Review the current waiting times for carer assessments;
- Explore the involvement, co-production and engagement in developing dementia care journeys to help empower all people affected by dementia, including the partnership working with local communities and the voluntary sector;
- Overall aim – to identify potential gaps in the current pathways and develop a series of recommendations that could lead to improved working practices and provision of services.

Methodology

Evidence gathering sessions were held on Thursday 9th March, Tuesday 14th March and Thursday 16th March 2023 with the following groups of key stakeholders and individuals.

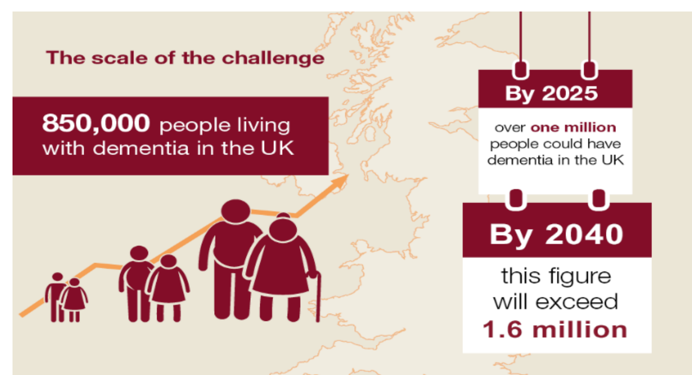
- Specialist Commissioning Manager (All Age Mental Health)
- Chair of the Dementia Strategy Group
- Lead GP for Dementia, Integrated Care Board
- Director of Public Health;
- Consultant in Public Health;
- Head of PCN Delivery and Development, Integrated Care Board;
- Consultant Psychiatrist and Associate Medical Director for Older People Mental Health (Oxford Health);

- Dementia Specialist Nurse (Oxford Health);
- Head of Service (Oxford Health);
- Head of Service, Localities, Adult Social Care;
- Dementia Connect Local Services Manager, Alzheimer's Society;
- Dementia Connect Adviser, Alzheimer's Society;
- Head of Service, Integrated Commissioning;
- Assistant Director, Adult Social Care;
- Communities Officer and Dementia Friends Ambassador, Aylesbury Town Council;
- Wendover Dementia Support;
- Princes Centre and Bourne End Centre;
- Dementia Action Marlow;
- Carers Bucks;
- Healthwatch Bucks;
- Primary Care Network Manager and Social Prescribers;
- Voices of people living with dementia and their carers;
- Care Home Managers;
- Nurse Consultant Older People, Buckinghamshire Healthcare NHS Trust;
- Clinical Lead – Mental Health & Learning Disability, South Central Ambulance Trust;
- Lead Nurse, Palliative and End of Life Care, Buckinghamshire Healthcare NHS Trust.

National Context

According to the Alzheimer's Society website, there are currently around 900,000 people living with dementia in the UK and there are projected to be over 1 million people with dementia in the UK by 2025. This is projected to rise to nearly 1.6 million in 2040. These numbers demonstrate the increasing scale and impact of dementia and the urgent need for action to be taken to meet current and future care needs. The NHS Long-Term Plan identifies dementia as a key priority and it is noted as one of the top causes of early deaths for people in England. There is a clear emphasis in the NHS Long-Term Plan on improving the care and support for people living with dementia, whether in hospital or at home and a commitment to continue working closely with voluntary organisations.

According to updated guidance published by the Office for Health Improvement and Disparities in February 2022, dementia costs society £34.77 billion a year in the UK and this cost is set to rise as the population ages. An estimated 540,000 people in England act as primary carers for people with dementia; half of these are employed, 112,540 have needed to leave employment to meet their caring roles and 66,000 carers have cut their working hours. The Alzheimer's Society shows that the contribution of unpaid carers of people with dementia in the UK totals £13.9 billion a year, costs which would otherwise have to be picked up by the government.



Source: Office for Health Improvement & Disparities website

Local Context

As of September 2022, 4,164 people were diagnosed with dementia (aged 65+) in Buckinghamshire. The current rate of diagnosis is 57.3% against a national target of 66.7%. The estimated prevalence is 7,266 meaning 3,102 people live with dementia but remain undiagnosed (as per NHS Digital report) which means they are not accessing appropriate support. It is estimated that there may be at least 240 people with young onset dementia in Buckinghamshire.

According to a recent needs analysis report produced by Buckinghamshire Council's Service Improvement team, which looked at Dementia in Buckinghamshire, it has been suggested that the gap is not within the current diagnostic pathways, but instead around increasing awareness, reducing stigma and encouraging people to come forward to be diagnosed. However, by employing proactive behaviour in identifying dementia signs and supporting access to a diagnosis, not only would the dementia diagnostic rate (DDR) increase but more people would access the appropriate dementia support sooner.

The Covid-19 pandemic impacted on national performance and the national diagnosis target rate is currently 62.2%. Buckinghamshire currently represents the 19th lowest diagnosis rate amongst 105 clinical commissioning groups (before they were abolished in 2022 and became part of an Integrated Care Board).

Dementia support is provided by a myriad of organisations across the health, social care and voluntary and community sector. Therefore, clear and coherent pathways are an essential part of ensuring the person living with dementia can readily access the right service at the right time. Supporting people to live independently for longer has a positive impact on the health and social care system, so ensuring the appropriate levels of care and support is a key part in achieving this.

Summary of Recommendations

The Health & Adult Social Care Select Committee Review group make the following recommendations, grouped together under the NHS England Dementia Well Pathway which has been adopted by Buckinghamshire.

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
The risk of people developing dementia is minimised.	Timely accurate diagnosis, care plan, and review within the first year.	Access to safe, high-quality health and social care for people with dementia and carers.	People with dementia can live in safe and accepting communities.	People living with dementia die with dignity and in the place of their choosing.

The NHS Dementia Well Pathway

Overview

Recommendation 1 – Develop a multi-agency Buckinghamshire Dementia strategy with specific action plans aligned to the Dementia Well pathway which brings together activities from across the health and social care system and local communities.

Recommendation 2 – Review the membership of the Dementia Strategy Group to include a broad representation within each pathway to ensure a strong, collaboration of key people responsible for delivering the dementia strategy.

Preventing Well

Recommendation 3 - Commitment by Public Health and Primary Care to provide a renewed focus on increasing the take-up of the NHS Health check for eligible 40-74 year olds. A memory question should be part of all health checks and a more consistent approach to the information provided to patients as part of the health check should be agreed.

Recommendation 4 – Public Health to include risks associated with dementia as part of all relevant public health campaigns, particularly on cardiovascular disease, so people make the connection that lifestyle choices affect both the heart and the brain.

Recommendation 5 - School Liaison Officers to explore whether a dementia awareness programme for all school age children could be developed and promoted to all schools in Buckinghamshire to help reduce stigma, address cultural differences and create a better understanding of dementia and what support is available.

Recommendation 6 – The BetterPoints initiative to be more widely promoted across Buckinghamshire to include all Members, council staff, BHT staff, South Central Ambulance Service staff, Oxford Health staff, Community Boards, voluntary and community groups and all PCNs.

Diagnosing Well

Recommendation 7 – Oxford Health to provide clarity about medication reviews to those people who are receiving dementia medication and to include contact details of who to speak to about dementia medication.

Recommendation 8 – Social care commissioners to review the memory service provided in Oxfordshire and consider introducing dementia support workers at the memory clinics to provide a joined-up service to those who have just been diagnosed.

Recommendation 9 – Primary care, social care commissioners and the Dementia Support Service to work together to develop a consistent approach to memory screening and reduce waiting times across the county. To clarify and promote the pre-diagnostic support available.

Recommendation 10 - Each Primary Care Network to introduce a named dementia specialist to co-ordinate the screening and pre-diagnostic support within primary care and to work closely with the Alzheimer's Society Local Dementia Advisers to deliver screening training to those nominated across the PCNs.

Supporting Well

Recommendation 11 – Adult Social Care (ASC) to ensure they refer people with memory concerns to the appropriate person – GP or social prescriber/named dementia specialist for a memory screening assessment and for those people with a dementia diagnosis, ASC need to refer to the Dementia Support Service.

Recommendation 12 – Agreement by the Integrated Care Board to additional investment in dementia support services for Buckinghamshire to address the current under investment in services. Additional investment to be used to provide a better integrated service across all pathways, with clear lines of responsibility.

Recommendation 13 - The recommendations in Healthwatch Bucks report on young onset dementia should be progressed alongside these recommendations in this report and therefore progress will be reported to the HASC Select Committee.

Recommendation 14 – Care homes to be part of the development of the Buckinghamshire Dementia Strategy and develop closer working between primary care network social prescribers, including the named dementia specialist, voluntary groups and local care homes to develop dementia specific activities to meet the needs of the local community.

Recommendation 15 – Care homes, primary care, hospital care and social care partners to encourage the use of "This is me" to help capture information on the person with dementia. Reassurance from BHT that the John's principles around the right to stay with people with dementia is part of the care offered during Hospital stays.

Living Well

Recommendation 16 – The Dementia Strategy Group to undertake an exercise to map current provision and highlight the gaps in support services with input from social prescribers, social care commissioners for day opportunities and community board managers with their local community groups. If the recommendation above to have a dementia specialist within each PCN is implemented, then we would encourage them to be part of this exercise.

<u>Recommendation 17</u> **– Consideration to be given to using existing space at the council-owned day centres at Buckingham, Aylesbury, Beaconsfield, Chesham, Wycombe and Burnham to accommodate dementia cafes, dementia support groups and other activities (both voluntary and commissioned) to increase access to these services across the county.**

Dying Well

<u>Recommendation 18</u> **– Buckinghamshire Healthcare NHS Trust educators work with the council's library services, voluntary groups and community board managers to re-introduce and develop a series of "Big Conversation" events across the county on a rolling basis.**

Please read on to understand more fully the reasoning and evidence behind the recommendations.

Key Findings & Recommendations

After carefully considering the evidence collected at meetings with key stakeholders and bringing together the background research, undertaken at the outset, the Review group wish to report on our key findings, observations and recommendations.

Buckinghamshire follows the NHS England Transformation Framework – the Dementia Well pathway so our findings and recommendations have been grouped under the headings of Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying Well.

Overview

We started our evidence gathering by talking to the council's adult social care commissioners to understand, in more detail, the work which is currently being undertaken as part of the Better Lives Strategy and the transformation workstreams which focus on dementia services. The workstreams are as follows:

- Pre and post diagnostic support;
- Intensive support (for those at risk of short-term crisis);
- Information advice and guidance (developing a single platform for dementia specific advice);
- Other broader workstreams relating to carers support and community opportunities.

We heard about the following activities which are supporting the workstreams.

- DiADeM pilot – a pilot focussing on increasing diagnosis of dementia within care homes;
- Dementia information resources focus group – launch of landing page on website;
- Dementia Connect Model – business case to expand the current support service to include named case workers;
- Dementia Diagnostic pathway – remodelling of the memory clinic service;
- Dementia intensive support – development of a business case for a multi-disciplinary support team.

As part of our background research, we read the "Dementia in Buckinghamshire needs analysis and recommendations" report which was produced in March 2022. The needs analysis report highlighted 6 key gap areas (listed below) which then led to 9 areas of recommendation to address these gaps.

- Named case worker;
- Specialist dementia nursing support;
- Timely diagnosis and assessment;
- Community opportunities/short breaks;
- Communications;
- Crisis support.

Whilst recognising that carers support and community opportunities both have a broader reach than just those people living with dementia and their carers, we would like to see these areas feature more prominently in the ongoing development of dementia support. Currently, the workstreams for carers support and community opportunities are led by different teams within adult social care and the deliverables from these workstreams are not clear.

The review group would like to see the areas of recommendation outlined in the gap analysis align more clearly with the existing workstreams and be used to develop a whole system, multi-agency action plan for delivering high quality dementia care throughout the entire pathway. We found it difficult to piece together how the council's work around dementia linked with the wider system work around dementia. Using consistent language and headings will provide some of the clarity needed to ensure a more joined-up, integrated approach as well as clear lines of responsibility for each area.

The needs analysis report states that Buckinghamshire follows the NHS England Transformation Framework – the Dementia Well Pathway so we feel that this pathway should be used to help develop the multi-agency action plan, with each pathway having a lead organisation(s) responsible for reporting progress to the Dementia Strategy Group.

Dementia Strategy Group (DSG)

Members noted that an All-Age Mental Health and Wellbeing Strategy Bucks 2020-23 has been developed. This strategy is supported by the Dementia Strategy Group (DSG) which brings together commissioners and local partners. The DSG meets bi-monthly and supports delivery of some of the actions that underpin the council's dementia transformation programme.

Throughout the evidence gathering meetings, we heard that some people regularly attend the DSG meetings whilst others did not always attend and some people did not know about the group. We received feedback that the meetings had a clinical focus and voluntary groups reported having to wait until the end of the meeting to be heard by which time some members had left.

We heard that dementia is not a mental health condition. It is primarily a set of progressive physical symptoms and whilst mental health issues may occur in some patients, for example, depression or delirium, this is not inevitable.

The review group heard that Buckinghamshire Healthcare NHS Trust has developed a dementia strategy and as mentioned above, the DSG supports specific actions, as part of the Adult Social Care's transformation work. However, we found no evidence of an overarching dementia strategy for Buckinghamshire involving all the key partners.

The review group feels that a multi-agency strategy, which is owned by the members of the DSG, would lead to a more joined-up, collaborative approach to supporting people living with dementia and their carers. Formulating a separate multi-agency dementia strategy, where specific action plans for each pathway are developed and owned by key partners, would separate it from the mental health strategy and give dementia its own platform. Progress on delivering the action plans should be monitored by the DSG and reported to the Health & Wellbeing Board.

As part of the background research, we reviewed examples of how other local authorities provided dementia support and we found some good examples of collaborative, multi-agency strategies. We particularly liked Birmingham and Solihull's dementia strategy and the joint health and social care dementia strategy for Surrey.

Examples of multi-agency dementia strategies

Birmingham and Solihull – Birmingham and Solihull Dementia Strategy 2022-2027 (icb.nhs.uk) (Draft strategy)

Surrey County Council – Joint Health and Social Care Dementia Strategy (surreycc.gov.uk)

Recommendation 1 – Develop a multi-agency Buckinghamshire Dementia strategy with specific action plans aligned to the Dementia Well pathway which brings together activities from across the health and social care system and local communities.

Recommendation 2 – Review the membership of the Dementia Strategy Group to include a broad representation within each pathway to ensure a strong, collaboration of key people responsible for delivering the dementia strategy.

Preventing Well

The NHS Dementia Well pathway describes "Preventing Well" as minimising the risk of people developing dementia.

- Although there are medicines available that can slow the progression of some of the early symptoms of dementia, these are not suitable for everyone. There is no cure for Alzheimer's disease or any other type of dementia. However, appropriate early diagnosis of dementia can extend independent living for up to 2 years and improve quality of life beyond that.
- We heard that 40 % of dementia is avoidable and lifestyle changes can significantly reduce the risk of developing dementia. Cardiovascular health is linked to dementia and promoting a healthy lifestyle is therefore crucial to help reduce the risk of developing dementia. ***"What's good for the heart is good for the brain."***

NHS Health Checks

- The NHS Health check is a preventative healthcare programme and invites adults aged between 40 and 74 for a health check-up every 5 years to spot early signs of stroke, kidney disease, diabetes or dementia. The check is for people who do not have a pre-existing condition as they will already be receiving regular check-ups. Local authorities are responsible for the commissioning of the programme which is normally provided by GP practices and carried out by healthcare professionals, pharmacists or the GP. The funding is provided through the Public Health budget.
- Data shows that less than 50% of eligible patients in Buckinghamshire between 2012 and 2018 had their health check – in Buckinghamshire, 73,855 NHS Health checks were recorded between April 2012 and March 2018 compared to 109,286 non-attendance (source: Microsoft Power BI).
- We understand that most of the GP practices in Buckinghamshire have signed up to carry out the health checks and practices are paid according to the number of checks carried out.
- We heard that patients are invited via letter and text to attend their health check. The Gov.uk website states that "health and care professionals should provide support and advice on dementia risk reduction as part of their daily contact with individuals. Every contact counts as a chance to educate and empower people to make positive choices about their own health". In Buckinghamshire, health and care professionals support the Making Every Contact Count approach.
- We heard one example of someone attending their regular diabetic check-up who mentioned to the healthcare professional that they had memory concerns. They then received a memory test but this was not a routine part of this check-up.
- We understand that there are programmes underway to promote the health checks within specific communities, as part of Opportunity Bucks, focussing on specific wards within Buckinghamshire. We heard that there are cultural differences surrounding dementia, with some cultures not recognising the condition within their own language.

- With the known pressures on GP practices, members are concerned about capacity within the surgeries to undertake the health checks and believe that there needs to be a renewed focus on promoting the benefits of the health check and for a memory question to be part of the discussion for all patient's receiving health checks.
- As health checks are carried out by different healthcare professionals in primary care, we are also concerned about potential inconsistencies in how the checks are carried out and would like to see a guidance note issued by Public Health to all GP surgeries.
- According to the NHS website and the detailed information about what to expect as part of the health check, it states that "if you're over 65, you'll also be told the signs and symptoms of dementia to look out for". The review group's view is that this should be part of every health check and not age specific as early onset dementia starts well before the age of 65.
- We would like to see a more concerted effort to encourage better take-up of these health checks by those patients who are eligible for them. We would also like to see a question around memory concerns as part of regular check-ups for people who have a pre-existing condition.

Recommendation 3 - Commitment by Public Health and Primary Care to provide a renewed focus on increasing the take-up of the NHS Health check for eligible 40-74 year olds. A memory question should be part of all health checks and a more consistent approach to the information provided to patients as part of the health check should be agreed.

Cardio-vascular disease and public health campaigns

- The Health & Adult Social Care Select Committee discussed the Director for Public Health Annual Report at its November meeting. The annual report focused on reducing the risks associated with cardio-vascular disease. We would like to see dementia risks included in all relevant public health campaigns which promote reducing cardio-vascular disease.
- We are aware that cardio-vascular disease is a strategic priority for the Integrated Care Board but there was little reference to dementia in the ICB strategy. As dementia is a key priority in the NHS Long-Term Plan, we feel that it should be more prominent in the ICB strategy and there should be joint activities to help reduce the risk of heart disease, stroke and dementia.

Recommendation 4 – Public Health to include risks associated with dementia as part of all relevant public health campaigns, particularly on cardiovascular disease, so people make the connection that lifestyle choices affect both the heart and the brain.

Raise awareness and reduce stigma within schools

- We heard about an initiative within schools to help increase the awareness of dementia, encourage more discussion and to help reduce the stigma. Young children recognised and related to dementia as seen in their own family or acquaintances and this could be built on to raise awareness in the community.
- This finding is slightly out of scope as we were not expecting to speak to colleagues from the Education service but speaking to school age children was acknowledged by health professionals as an important part of raising awareness and providing dementia information for different cultures would help to reduce the stigma and increase understanding. We appreciate that more work would be required before speaking to schools - we suggest that a piece of work be undertaken to see what has been done in other areas and whether there is a relatively easy way to get key messages about dementia to young people.

<u>Recommendation 5</u> - School Liaison Officers to explore whether a dementia awareness programme for all school age children could be developed and promoted to all schools in Buckinghamshire to help reduce stigma, address cultural differences and create a better understanding of dementia and what support is available.

"Bucks BetterPoints" initiative

- Public Health colleagues shared information on a new App, BetterPoints, which has just been launched (January 2023). People can earn points for undertaking healthy activities across Buckinghamshire which can then be redeemed as vouchers to spend at high street stores or donate to charities. This new initiative has been promoted on social media and the Bucks website and the target is to have 1,000 users this year and a further 1,000 the year after.

<u>Recommendation 6</u> – The BetterPoints initiative to be more widely promoted across Buckinghamshire to include all Members, council staff, BHT staff, South Central Ambulance Service staff, Oxford Health staff, Community Boards, voluntary and community groups and all PCNs.

Diagnosing Well

The NHS Dementia Well pathway describes "Diagnosing Well" as timely, accurate diagnosis, providing a care plan and review within the first year.

Memory Diagnosis Service (provided by Oxford Health Foundation Trust)

- We understand that most people with memory concerns contact their GP in the first instance. The GP will assess the patient and may decide to refer them to the memory clinic for a further assessment which could lead to a formal diagnosis. Following a formal diagnosis, a letter is sent back to the GP so the diagnosis can be recorded on the patient's record.
- The memory clinic is funded through the mental health block contract which is provided by Oxford Health Foundation Trust. The waiting times for the memory clinic are currently between 4-6 months. We understand the service is in the process of being redesigned to have a single point of access but it was not clear about how the proposed redesigned service would lead to reduced waiting times.
- There are currently 2 memory assessment clinics – Whiteleaf Centre and Saffron House. A number of GP practices used to offer consulting room space for memory clinics but due to challenges with surgery space, these have now been rescinded.
- We heard about the ambition to undertake memory assessments closer to home but this relies on appropriate space within communities, availability of staff to undertake assessments and the financial costs associated with this model.
- Recruitment remains one of the biggest challenges and we heard that it took 12 months to recruit a dementia specialist nurse. Recruiting in the south of the county continues to be a challenge as roles are competing with others nearby which offer London salary weighting.
- Oxfordshire has adopted a different model of delivery for people over 65 and those under 65 follow a neurology pathway rather than being mental health led.
- We heard that at the time of diagnosis, Oxford Health provide an information pack for the patient which contains details on the Dementia Support Service, provided by the Alzheimer's Society (Buckinghamshire Council is the lead contract holder and the service is funded by the Better Care Fund).
- Speaking to people who had been diagnosed with dementia and their carers as part of this Review, we heard that not everyone received an information pack and once diagnosed, there was no follow-up by Oxford Health. Oxford Health used to undertake this but they are no longer commissioned to provide the follow-up service to all those who attend the memory clinic. Oxford Health only provides follow-up to those who are prescribed medication for their dementia.
- We understand that the Dementia Connect Service is only available to those people who contacted them after being diagnosed – their details could not automatically be sent to the Dementia Connect Service due to data protection issues. People explained that they were often left to find their own information and support groups. We understand that in North Bucks, contact details from consenting patients are given to the Dementia Support Service to enable them to make contact to offer post-diagnostic support. However, there appears to be a gap in current service provision in South Bucks.
- The review group heard that in Oxfordshire, the memory clinics work closely with the Alzheimer's Society to ensure support can begin at the time of diagnosis by having a dementia support worker based in the memory clinic.
- We learned that the numbers of referrals to the memory clinic had increased markedly and that many of these cases could be dealt with in the GP/community setting, via screening and signposting to the appropriate support. This would serve to reduce waiting times and allow the clinic to concentrate on the more complex cases.
- We heard from a carer who had experienced problems with medication reviews and had been passed between the GP and Oxford Health. We understand that GPs cannot prescribe medication for dementia as this has to be done by the psychiatrist. To ensure this is clear, we would like to ensure that Oxford

Health provides this information when speaking to the person with the dementia and their carer and includes contact details for medication reviews.

Recommendation 7 – Oxford Health to provide clarity about medication reviews to those people who are receiving dementia medication and to include contact details of who to speak to about dementia medication.

Dementia Support Service (provided by the Alzheimer's Society)

- In 2022, the Dementia Support Service was recommissioned and was based upon delivery of a "dementia connect model" providing pre and post diagnostic support both on a face-to-face basis and virtually depending on the needs of the person. Tier 1 support is a national telephone service and is the first point of contact for someone with memory concerns. Tier 2 is the next level of support under the Dementia Connect model and includes support calls, home visits and follow-ups. The Dementia Adviser provides a named contact to the person with memory loss and their carer throughout their journey with dementia.
- In Buckinghamshire, the above service is delivered by 5 dementia advisers. Based on the estimated dementia prevalence and the capacity of the advisers, the current service reach is around 10%.
- The latest performance report on the Dementia Connect service shows that 110 referrals were made to Tier 1 between 1 October 2022 and 31 December 2022. 46 referrals were made to Tier 2 (33 were self-referrals and 4 were referrals from the memory clinic).
- Very few GPs are referring patients to the Dementia Support Service (11 referrals came via the GP during the same 3 month timeframe) which suggests GPs are not aware of the Dementia Support Service.
- Prior to the recommissioned service, we heard that the contract for dementia support services included a much broader range of services, including a memory screening test which was undertaken by a local dementia adviser, at the pre-referral stage to the memory clinic. The screenings took place in the community using the GP COG assessment tool.
- The Health & Adult Social Care Select Committee carried out an in-depth inquiry last year into the development of Primary Care Networks (PCNs). To support PCNs, the Additional Roles Reimbursement Scheme provides funding to recruit to additional posts to create bespoke multi-disciplinary teams, including mental health practitioners, social prescribers, health and wellbeing coaches and pharmacists.
- As part of the evidence gathering, we spoke to social prescribers from across the Primary Care Networks. Two of these social prescribers explained that they have undertaken training to use the GP COG assessment tool to screen people who have memory concerns. One social prescriber said that she took this responsibility on herself as she could see there was a gap in the screening process. She has screened over 90 people during the last few months.
- A gap in service provision seems to have occurred at the time of re-commissioning the service in 2022 which has meant that memory screening is no longer provided as part of the commissioned service.
- With waiting times at the memory clinic around 4-6 months, people do not seem to be receiving pre-diagnosis support in the same way that they did before the service was recommissioned. We are unclear about what pre-diagnosis support looks like in the current pathway. People told us that this long wait for a diagnosis was particularly stressful and that they and their carers felt unsupported during this time.
- We also feel that there should be named dementia specialists within each Primary Care Network who are responsible for co-ordinating the GP COG screening programme and training people within the PCN to undertake the screening. This will ensure a consistent approach and a forum for sharing learning and areas of improvement.

Recommendation 8 – Social care commissioners to review the memory service provided in Oxfordshire and consider introducing dementia support workers at the memory clinics to provide a joined-up service to those who have just been diagnosed.

Recommendation 9 – Primary care, social care commissioners and the Dementia Support Service to work together to develop a consistent approach to memory screening and reduce waiting times across the county. To clarify and promote the pre-diagnostic support available.

Recommendation 10 - Each Primary Care Network to introduce a named dementia specialist to co-ordinate the screening and pre-diagnostic support within primary care and to work closely with the Alzheimer's Society Local Dementia Advisers to deliver screening training to those nominated across the PCNs.

Supporting Well

The NHS Dementia Well pathway describes the "Supporting Well" pathway as providing access to safe, high-quality health and social care for people with dementia and carers. This pathway includes care at home, in care homes, hospital care and crisis support.

Social Care support and signposting services

- We heard from Adult Social Care (ASC) officers about their work in supporting approximately 307 people living with dementia who are eligible for council funding. With over 4,000 people living with a dementia diagnosis in Buckinghamshire, this represents a small number who are currently being supported by ASC.
- The role of Adult Social Care is to support people, who are identified as in need of statutory support for personal and social care, to live independently and well. Everyone is entitled to an assessment under the Care Act 2014 and we understand that the current waiting time is more than 30 days. If a person is eligible for council funding to help with their care needs, this funding can be used to provide support at home including sitting-in service or Day Centre opportunities (places are booked by the council at privately funded day centres). There are no council run day opportunities specifically arranged for people living with dementia.
- Adult Social Care also provide a Carer's assessment to support carers in their caring role. Support for carers is generally provided through the council's commissioned service with Carers Bucks.
- If a person is not eligible for council support, they are signposted to a number of different places, including Prevention Matters. We also heard about a paid for brokerage service which helps to match a person's needs to local services - this service costs around £300.
- In terms of dementia related support, we understand that the council commissions the Dementia Support Service (provided by the Alzheimer's Society) and Carers Bucks, as well as purchasing individual sessions at privately funded day centres based on assessed need.
- ASC also refer people to the NRS team to help maximise independence, security and support, for example, via the provision of pendant alarms, memo minders, GPS trackers and door sensors.

Prevention Matters (commissioned by Buckinghamshire Council)

- The review group understands that the council commissions another service called Prevention Matters. This service does not provide specific dementia support. Whilst reviewing this website, we found that some of the links do not work. For example, "finding activities and services near you" defaults to the Buckinghamshire Council landing page.
- We heard that ASC refer people to Prevention Matters which, according to their website, is a free and friendly advice service linking eligible adults in Buckinghamshire to social activities, voluntary and community services. In this instance, eligible means not eligible for funded social care services. It was not clear where people living with dementia (funded or otherwise) would be referred to by Adult Social Care for dementia support.
- From our limited discussions about this service during the review meetings, it appears that part of this service is very similar to that which is now provided by social prescribers through the 13 Primary Care Networks in Buckinghamshire.
- The Health & Adult Social Care Select Committee recently undertook an inquiry into the development of Primary Care Networks and one of the recommendations was to have a named social worker for each PCN. We feel that these links should help to ensure social workers refer people with memory concerns to the right place, ie. the GP or social prescribers/dementia specialist or the Dementia Connect Service if the person has received a dementia diagnosis.

Dementia Support Service (commissioned by Buckinghamshire Council)

- As mentioned in the earlier section, the council commissions the Alzheimer's Society to deliver the Dementia Support Service (DSS) in Buckinghamshire.
- The latest service specification (2022) states that the DSS should provide the Dementia Connect model, memory information sessions, post diagnosis information sessions, keeping in touch calls and memory screening assessment support.
- We heard that the Dementia Connect Service is currently delivered by 3.8 full-time equivalent advisers (1 full-time and 4 part-time) who look after between 12-20 cases, with 2-3 new referrals each week per adviser.
- We understand that some of the services described above are not currently being delivered due to the disruption caused by the Covid-19 pandemic. We saw evidence of very limited events taking place in the south of the county – Amersham Carer support group, run by a facilitator (face-to-face), Carers support group (held virtually and supported by a Dementia Adviser), Memory information sessions for members of the public in Amersham Lifestyle Centre and "Singing for the Brain" in Beaconsfield.
- The review group understand that the current reach of the Dementia Connect Service is only 10% of the prevalent population. We are aware of the business case to expand the Service to increase the reach to around 25% of the prevalent population of Buckinghamshire by providing named case workers for people living with dementia throughout their journey.
- We heard that Oxfordshire reaches around 39% of its prevalent population through greater investment in providing dementia support services. It appears that their offer includes a wider breadth of services, which includes the Dementia Connect model but also provides additional support via Admiral Nurses for the later stages of the dementia journey, when more intensive support is required. Dementia Advisers work closely with Oxford Health in the memory clinics.
- Through our evidence gathering meetings, we heard that access to the right information at the right time is not always happening. One carer mentioned that they were not given any information at the point of diagnosis and did not know where to go for support.
- We did hear from a carer who had accessed the Dementia Connect Service and spoke very highly about the support she had received from a Dementia Adviser. Some of the voluntary groups which we spoke to were not aware of the Dementia Connect service, but they were all aware of the support offered by Carers Bucks.
- We understand that the service specification for dementia support services prior to 2022 included the provision of community activities (including singing for the brain and community cafes to provide support for people with dementia and their carers) and advice and support for communities to help them become dementia friendly. Some of these activities continue to be provided by Alzheimer's Society but with reduced capacity.
- We support the business case to provide additional investment in the Dementia Connect Service. However, there are other gaps along the dementia journey which need to be reviewed and strengthened with additional investment in support services needed to ensure all needs are met.
- We would like to see a more blended approach to providing more dementia support services in local communities to ensure the needs, at all stages of the dementia journey, are met. The needs of people living with dementia change, but we did not feel that the current service is able to effectively meet the needs of the person throughout their dementia journey

Recommendation 11 – Adult Social Care (ASC) to ensure they refer people with memory concerns to the appropriate person – GP or social prescriber/named dementia specialist for a memory screening assessment and for those people with a dementia diagnosis, ASC need to refer to the Dementia Support Service.

Recommendation 12 – The Integrated Care Board to agree to additional investment in dementia support services for Buckinghamshire to address the current under investment in services. Additional investment to be used to provide a better integrated service across all pathways, with clear lines of responsibility.

Carers Bucks (commissioned by Buckinghamshire Council)

- In terms of support for carers who are caring for people with dementia, we understand that the council commissions Carers Bucks to provide information, advice, guidance and emotional support to unpaid carers in Buckinghamshire.
- They currently support 2,040 carers who are caring for someone with a type of dementia. Of those, 2,035 are adults aged 18 and above, with 3 being in the 18-24 age bracket, and 2,032 in the 25+ age bracket. They also support 5 young carers aged between 12-16 who are helping to care for someone with dementia.
  - Carers Bucks will make up to 6 home visits, where appropriate, to carers aged 75 and above who may struggle to access support through "usual" means – for example, if they cannot leave the person they care for, if they have their own mobility problems meaning it's hard to come to an in-person support group, if they have hearing problems rendering telephone support unsuitable
  - Their hospital support team cover the four Bucks hospitals – SMH/Wexham/Wycombe/Amersham – and are able to support carers on site, both practically and emotionally
  - They have limited funding pots which can be used to support carers with their own health and wellbeing, whether that's via access to talking therapies or complementary therapies.
- The feedback on the services provided by Carers Bucks, which we heard during the evidence gathering meetings, was very positive from both groups and individuals.

Young Onset Dementia

- Healthwatch Bucks recently carried out a project looking at young onset dementia. The aim was to find out about peoples' experiences of living with young onset dementia (where symptoms first occur before the age of 65). Their report detailed a number of recommendations including providing information in a timely, personal and age appropriate way, a named contact regularly reaching out to the person with young onset dementia and their carers and the creation of mini support networks. The full report can be found here Young Onset Dementia Report.docx (sharepoint.com).
- We heard through the evidence gathering meetings that there is no clear pathway for people diagnosed with young onset dementia. This type of dementia requires a different approach. For example, people affected are of working age so need different support and the disease can also progress rapidly. The estimated number of people with young onset dementia in Buckinghamshire is 240.
- Without wishing to duplicate the work of Healthwatch Bucks, we would like to use their report to highlight that there needs to be provision for young onset dementia as part of the overall dementia offer and to ask that their recommendations are considered alongside the Review Group's recommendations.

Recommendation 13 – The recommendations in Healthwatch Bucks report on young onset dementia should be progressed as part of the recommendations in this report and therefore progress will be reported to the HASC Select Committee.

Care Homes

We heard from care home managers that some of them were hosting dementia cafes/drop-in sessions before the Covid-19 pandemic and were now starting to re-introduce them as part of their programme of activities, as they were well received by those who attended. We felt that this idea could be developed further and we would encourage social prescribers from across the PCNs to link with the care homes in their areas to discuss how these activities could reach those within their PCN. It would also enable social prescribers to discuss local community activities with the care homes to ensure these are known to them and available to their clients. If the recommendation to have a nominated dementia specialist across the PCNs is implemented, that person should also be involved in these discussions.

From those we spoke to during the evidence gathering, care home managers are interested in the DiaDem pilot which aims to increase dementia diagnosis within care homes. We heard that there are currently significant numbers of people in care homes without a dementia diagnosis, including some who have been discharged to assess but are awaiting permanent placements.

We would like to see the inclusion of care homes in the development of a Buckinghamshire Dementia Strategy with specific actions around closer partnership working between PCNs, voluntary groups and care homes.

<u>Recommendation 14</u> – Care homes to be part of the development of the Buckinghamshire Dementia Strategy and develop closer working between primary care network social prescribers, including the named dementia specialist, voluntary groups and local care homes to develop dementia specific activities to meet the needs of the local community.

Hospital Care

- Through speaking to Buckinghamshire Healthcare NHS Trust colleagues (BHT) and South Central Ambulance Service colleagues (SCAS), we heard about the way both organisations currently support people living with dementia and their carers.
- We heard about the personalised care passport specifically used by people with dementia called "This is Me". The document contains individual information, for example, likes and dislikes of the person, their routines and cultural background. It is intended to go with the person to health settings and to enable person-centred care. Oxfordshire Health Trust have developed a similar passport and this document is called "Knowing Me". Care homes have their own paperwork on their clients. Whilst this is not a mandatory document, the usefulness in helping to meet the needs of the person with dementia was acknowledged. This is me | Alzheimer's Society (alzheimers.org.uk)
- Whilst recognising the difficulties associated with discharge summaries, we heard from key stakeholders about the poor quality of discharge summaries, with information missing or being inaccurate - in some instances this had resulted in a patient being re-admitted to hospital.
- We were made aware of a national campaign "John's Campaign" which is about the right of people who care for someone living with dementia to be able to stay with them – and the right of people with dementia to be able to have a family carer stay with them. Whilst acknowledging the difficulties with adhering to this during the pandemic, we seek reassurance from BHT that they adhere to these principles and have processes in place to ensure this happens. John's Campaign | Dementia Partnerships
- We heard that BHT have developed a Dementia Strategy and would ask that this is shared with all health care partners and the Health & Adult Social Care Select Committee.

<u>Recommendation 15</u> – Care homes, primary care and social care partners to encourage the use of "This is Me" to help capture information on the person with dementia. Reassurance from BHT that the John's principles around the right to stay with people with dementia is part of the care offered during Hospital stays.

South Central Ambulance Service (SCAS)

- Whilst SCAS remains on an improvement journey, following the latest Care Quality Commission (CQC) inspection, its plan to become a dementia-friendly organisation is not a key priority at the moment. Dementia awareness is included in induction training but due to operational pressures, dementia specific training ceased at the beginning of the year.
- The review group heard about a recent initiative to make their ambulances dementia friendly (and child friendly) by using reassuring stickers to help create a talking point and to reassure the patient. It was good to hear during the meeting that the BHT representative felt that it would be good to use the same

themed stickers on the Older People Hospital wards to create the same reassuring environment and continuity for the person with dementia.

Dementia Intensive Support Team

The review group heard about the plans for an intensive support team as part of the Dementia Transformation workstream. Plans are in place to develop a model based on a multi-disciplinary team, offering both clinical and social care support to people living with dementia (and their carers/supporters) who are at risk of short-term crisis leading to unplanned hospital admission or transfer into residential care.

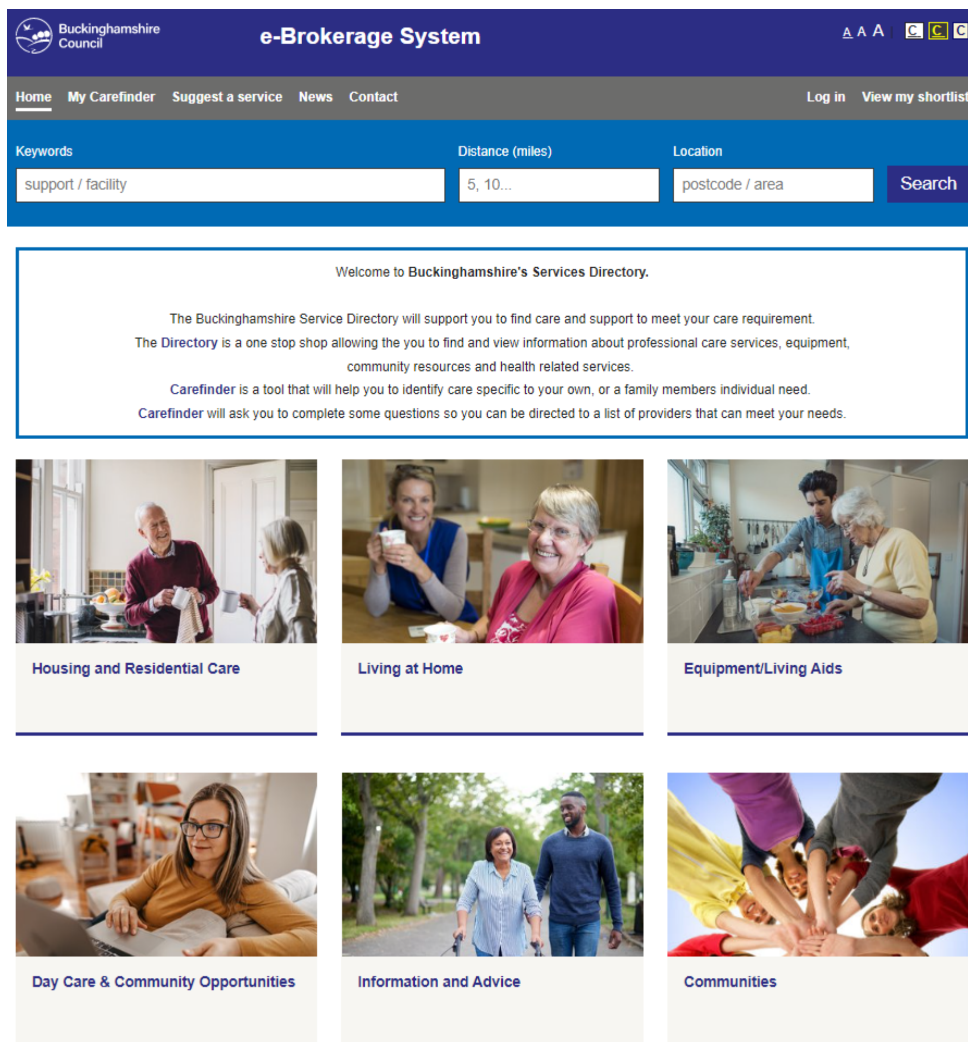
Whilst we appreciate the plans are in their early stages, we support the need for a crisis team who are able to support people living with dementia and their carers within their local community and look forward to hearing about the progress being made in delivering a crisis team in Buckinghamshire.

Living Well

According to the NHS Dementia Well pathway, "Living Well" represents people with dementia living in safe and accepting communities.

Access to information

- The review group is aware of the Bucks Online Directory and as part of the background research for this Review, we reviewed the website to see what dementia specific activities were available in certain parts of the county. Whilst we commend the website for bringing together community-run organisations, we felt there were gaps, some out of date entries and it did not represent all organisations, as it relies on self-registration. We found the search facility was not robust enough to ensure a meaningful result for someone who was looking for local dementia support groups.
- Throughout the evidence gathering meetings and as part of the background research, we reviewed various websites, including the council's website. There were a number of examples within the dementia support pages where the links did not work, for example to the carer assessment page.
- We heard about projects to improve the content of websites and we understand that the Dementia Strategy Group will be launching a "toolkit" for people to access information about dementia support through one front page on the website.



- The screenshot above is taken from the council's website and was found whilst researching the brokerage service which was mentioned during the evidence gathering meetings. This website has not been developed and we are not clear who is responsible for developing the content for it.
- We have not seen the new launch page, which the DSG are working on, but we hope it will include links to the information above as we felt this brought all the important aspects of support together in one place.
- Whilst we support the need for an updated, co-ordinated and user-friendly website, we also heard that people with dementia and their carers do not necessarily access online information and preferred written materials which they could refer to as and when required.

Planning for the future

- Advance Care Plans, Attendance allowance, Power of Attorney and other financial discussions are best had whilst the person still has capacity and should be encouraged at the time of diagnosis. We heard that people can feel overwhelmed at the time of diagnosis and giving lots of information can add to this so this needs to be handled in a way that ensures people have the information as and when they are ready. We would like to see future planning be a key part of the "Big conversation", more detail on this is in the next section.

Community activities

- Whilst the provision of meaningful and timely information is important, we heard that face-to-face meetings were crucial for people living with dementia and carers. The recent Covid-19 pandemic had created many challenges but we heard how some local community groups carried on throughout the pandemic, offering face to face meetings (adhering to social distancing), which were much appreciated.
- Having listened to local voluntary and community groups as part of the evidence gathering, we feel that there is not enough of this type of provision across the county to support people living with dementia and carers. That said, all those who we heard from are providing fantastic support, including regular cafés and singing activities but these rely heavily on the goodwill and availability of volunteers to successfully make these available in local communities.
- We understand that finding suitable local premises for dementia cafes and other support can be an issue but the need for regular, locally run activities which provide face-to-face contact for both the person with dementia and their carer is a crucial part of the dementia journey yet access to services across the county is not consistent. There is a current over-reliance on the voluntary sector to provide these services with minimal financial input. Some voluntary groups are having to restrict numbers due to capacity constraints.
- The council runs a number of Day Opportunity Centres across the county but these are primarily aimed at adults with learning disabilities and autism. Clients who have dementia are supported with some specific activities, according to their needs. We heard that the council books places at the Princes Centre and Bourne End for clients who are eligible for funded activities. These are excellent, volunteer-led Day

Centres set up to look after people living with dementia. Many more attendees are self-referred and pay for places at these centres. We heard that many of these do not have a formal dementia diagnosis or have not accessed other dementia support on their journey.

- Through the evidence gathering meetings, we did not receive clarity around the future plans for day opportunity centres and whether more provision could be provided for people with dementia at the existing centres. As mentioned earlier, we would like to see more evidence of a joined-up approach towards the provision of services within the community. At present, it feels as though there is a disconnect between council-run facilities and those run by voluntary and community groups. An exercise to bring the activities together and discuss the gaps in provision would help to plan the future services.

<u>Recommendation 16</u> – The Dementia Strategy Group to undertake an exercise to map current provision and highlight the gaps in support services with input from social prescribers, social care commissioners for day opportunities and community board managers with their local community groups. If the recommendation above to have a dementia specialist within each PCN is implemented, then we would encourage them to be part of this exercise.

<u>Recommendation 17</u> – Consideration to be given to using existing space at the council-owned day centres at Buckingham, Aylesbury, Beaconsfield, Chesham, Wycombe and Burnham to accommodate dementia cafes, dementia support groups and other activities (both voluntary and commissioned) to increase access to these services across the county.

Dementia Awareness events

- We were pleased to hear about a recent awareness event in Buckingham Library, where the Alzheimer's Society Local Service worked in partnership with the library to produce a new set of resources to support people living with dementia, including various games, activities and books from their era.

- There is an opportunity to replicate this initiative across other Libraries and we would encourage the Library service to work with the Alzheimer's Society to do this as part of the Big Conversation events which we refer to in the next section.
- We are aware of the Dementia Awareness Week (May 15-21, 2023) and would like to see more local engagement events following this national event.
- We heard that Aylesbury Waterside theatre offers dementia-friendly showings which were well received by those who we spoke to. There was a suggestion that it would be good to be able to offer the same at the Wycombe Swan, as Aylesbury is quite a distance for some people to travel to. Could theatres be used as a venue for the Big Conversation?

Dying Well

- Whilst this is the hardest and most emotionally charged pathway, we saw first-hand the compassion and enthusiasm from colleagues working within the Palliative Care and End of Life pathway.
- The over-riding key message which we heard through talking to colleagues was the importance of planning for this part of the journey as early as possible. Planning in the early stages is important whilst the person with dementia still has mental capacity to make decisions about their own care.
- We heard about the role of Buckinghamshire Healthcare NHS Trust (BHT) educators who help to promote the benefits of planning and what needs to be covered as part of the planning process. Examples might include, an Advance Healthcare Directive (Living Will), Power of Attorney, wishes for your funeral and having an up-to-date Will.
- Before the Covid pandemic, we heard that BHT educators ran a number of "Big Conversation" events across the county. There were very well received by those who attended and we heard that BHT educators would be willing to talk to dementia support groups.
- "Everyone's Business" – we heard that End of Life (EoL) talks had been delivered to BHT podiatrists as they have regular contact with people, some of whom may have memory concerns and would be in a position to discuss the benefits of planning within the context of wider health conversations. This is just one example of how every part of the health and care system has a role to play in reaching out to those living with dementia and their carers and can be part of the "Big Conversation".
- We would like to encourage more opportunities for planning conversations to take place to help support the Dying Well pathway. This pathway states that people living with dementia should die with dignity and in the place of their choosing and by working in partnership, this can be achieved.

Recommendation 18 – Buckinghamshire Healthcare NHS Trust educators to work with the council's library services, voluntary groups and community board managers to develop a series of "Big Conversation" events across the county on a rolling basis.

Conclusion

In bringing this report to its conclusion, the review group would like to reiterate the overriding take-home message which we heard throughout the evidence gathering meetings - people living with dementia and their carers need a joined-up, easy to navigate and easy to access, integrated dementia support service, which brings together all parts of the health, social care and voluntary sector. Face-to-face opportunities, whether that be 1:1 meetings with a dementia adviser or with a peer group at a dementia café or support group, were particularly valued by those we spoke to.

People living with dementia and their carers often struggle or do not have time to spend searching online resources (however good these may be) for information. There was a clear need for well written hard copies of information that could be kept and referred to at a later stage. The carers we spoke to as part of this review mentioned that having someone to contact when a crisis occurs was important.

The evidence shows that Buckinghamshire is currently under-funded in its dementia support service and there is significant unmet need across the existing dementia pathways which needs to be addressed.

There needs to be a renewed focus on raising awareness of dementia, reducing the stigma, increasing diagnosis rates in care homes and the community, as well as providing an integrated dementia support service.

The report highlights the importance of partnership working to support the person with dementia, their families and carers within local communities. There are many examples of outstanding services in Buckinghamshire but we need to do more, particularly in supporting the voluntary sector to deliver the necessary support services within local communities.

As outlined in the report, a Buckinghamshire Dementia Strategy needs to be developed for the entire dementia journey, clearly showing who the key partners are within each pathway and demonstrating an integrated and holistic approach with the person living with dementia at the centre. Regular reviews of how the strategy is progressing are needed with all key partners involved in those discussions.

Whilst acknowledging the pressures on budgets, the review group felt that there needs to be some creative solutions developed to maximise all available resources that are currently underutilised. Examples have been given in this report.

We would urge commissioners to review this report and its recommendations and to be ambitious in future commissioning. There are a number of different models for dementia support that could be considered but partnership working between the commissioned services should be a key component. We support the need for more dementia case workers but this is just one part of the dementia support needed and we would like to see more opportunities available within local communities to meet the needs of people living with dementia and their carers (including access to quality day opportunities for people living with dementia to allow their carers some respite).

We found that the uptake of the current Dementia Connect Service is low, so we feel that there needs to be a concerted effort to improve the communication of the Dementia Connect Service amongst GPs, Primary Care Network staff, hospitals, social care and other healthcare providers. There are examples from other authorities who provide support in different ways, such as specialist Dementia nurses. We would like to see more dementia support services being introduced in Buckinghamshire to ensure those living with dementia and their carers receive the support they need at the right time in their dementia journey.