CHESHIRE EAST PLACE DEMENTIA STRATEGY

Working for a brighter future together

Cheshire East Council

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This strategy has been developed by Cheshire East Council in partnership with Cheshire Clinical Commissioning Group (CCCG), local providers and service users. The strategy aims to consider local support needs in relation to dementia and review current service provision to identify and promote good practice and to address any gaps or areas for improvement. Our aim is to ensure we have the right services, in the right place, for the right people at the right time. The new strategy builds on the implementation of our first Joint Dementia Commissioning Work plan (2014-2017) and on the 5 themes of "The Well Pathway for Dementia" (NHS England, 2016).

This Dementia Strategy has been developed both pre and post the Covid 19 pandemic which has shone a light on the needs of people affected by Dementia. In addition, the Health and Social Care sector has been moving through a period of local and national transition as four local CCGs have merged in to one (Cheshire CCG) and as we prepare for the establishment of Integrated Care Systems and new ways of working.

Our strategy sets out the Cheshire East, ambition to support people to live well with dementia. One of Cheshire East's Corporate Plan objectives is to "*Reduce the reliance on long-term care by improving services closer to home and providing more extra care facilities, including dementia services".* It also reflects the national strategic direction outlined in the Prime Minister's Challenge on Dementia which details ambitious reforms to be achieved by 2020, including plans to improve Dementia Diagnosis Rates (DDR).

The strategy is informed by what people have told us about their experiences either as a person living with dementia or as a carer and is written for those people. We have also reviewed local and national good practice and aim to use this learning to improve services for those with memory concerns, those with a dementia diagnosis, their families and carers and the organisations supporting them. Other stakeholders who have also been involved in developing this strategy include, Dementia Friendly Community members, individuals living with dementia and their Carers, Body Positive, Care Community members, local health and social care providers, and voluntary organisations. We would like to thank everyone involved for taking the time to support this important work.

The main focus of our strategy is to move towards the delivery of more personalised and integrated care and support for those affected by Dementia. This involves; improving dementia awareness across all parts of society, early diagnosis, providing good information and advice when it is needed so that people can be involved in their care planning, and improving care pathways so that all services work together to ensure people access the services they need at the right time. We have used the NHS England Well Pathway for Dementia which provides a structure we can use to review our current performance and identify areas for improvement. The Framework puts the individual and their carer at the centre of service development and implementation across health and social care. Each element of the Framework is dealt with in a separate section within the strategy and will inform the development and implementation of a local Dementia Action Plan. The elements of the Framework are.

- Preventing Well
- Diagnosing well
- Supporting Well
- Living Well
- Dying Well

We are committed to minimising the impact of dementia whilst transforming dementia care and support within the community of Cheshire East, not only for the person with dementia but also for the individuals who care for someone with dementia. We want the wellbeing and quality of life for every person with dementia to be uppermost in the minds of our health and social care professionals

Our Vision

Our vision is to make a real and positive difference to the lives of people affected by dementia, living in and visiting Cheshire East. We want to ensure that people living with dementia and their carers, receive high quality, compassionate and timely care whether they are at home, in hospital or in a care home.

The impact of dementia on the individual and their family can be substantial and distressing. The Council, the CCCG and our partners intend to lead the way in engaging with and providing support to people with dementia and their families and carers as early as possible and will aim to develop and commission services that meet assessed needs in a timely manner. This will be done by working in partnership with all relevant stakeholders, including individuals living with dementia, their carers, and families.

We will continue to strive to make Cheshire East a truly dementia friendly place to live.

In supporting this vision, we have set out several long-term outcomes that we want to achieve as part of our commitment to people living with dementia and their carers, in Cheshire East.

1. People living with dementia and their carers and families will feel understood.
2. People living with dementia will be able to remain living within their own home and in their own community for as long as possible
3. People living with dementia and their carers will feel included and listened to and will be fully involved in decision making.
4. People living with dementia and their carers will know how and where to access support in their community
5. People living with dementia will receive a timely diagnosis and personalised and holistic support following diagnosis.

The strategy supports the work described in other key local documents including Cheshire East Council's Corporate Plan; Cheshire East Place Five Year Plan, the Joint Health and Wellbeing Strategy 2018 – 2021 and Cheshire East Falls Prevention Strategy 2019 – 2022 and Cheshire CCGs Commissioning Plans.

Delivering the Strategy

It is essential that a collaborative approach is taken across health, social care, community, voluntary and private providers, together with local people to achieve our objectives. Meeting the challenges faced needs a commitment and willingness towards innovation and learning, and there needs to be a focus on community led support, prevention, and a strengths-based approach to Adult Services i.e., for an individual to be enabled to see the value they bring and resources around them.

A Cheshire East Dementia Steering Group made up of people from a range of partner organisations and service users was established to develop the strategy for people who are living with dementia and their carers. The group's role has been to agree/propose strategic objectives, review current provision and develop best practice to ensure local people affected by dementia can get the care and support they need.

This work has been informed by the voices of people living with dementia, their carers, all cohorts of the community and any wider partnerships. There will be further regular opportunities for individuals, groups, and communities to feedback their own views and experiences when it comes to delivering this strategy and to ensure any response to the actions detailed within the plan are co-produced effectively.

Within the strategy there are ambitions and action plans for each element, these look at how we can work more collaboratively as partners to deliver the proposed outcomes within existing resources. However, there may also be more ambitious targets set out within the action plans which can be used for making the case for any additional funding should this become available in the future.

3. Background

Dementia is a progressive, non-curable disease that affects around 670,000 people in England alone. It costs society an estimated £26 billion each year . An estimated 25% of hospital beds are occupied by people with dementia and their hospital stays tend to be on average one week longer. Further, approximately 75% of people living in care homes have dementia. It is also the leading cause of death.

Cheshire East Dementia Health Needs and Priorities

In Cheshire East there are estimated to be 5,725 people over the age of 65 living with dementia *(NHS Digital).*

- 65% are likely to be women
- one in five people over 80 has a form of dementia
- one in 20 people over 65 has a form of dementia
- 67% of the estimated prevalence of people with Dementia in Cheshire East have a recorded diagnosis
- 3,840 people have received a dementia diagnosis in Cheshire East (*NHS Digital*)
- 18% of Cheshire East's population is over the age of 65.
- We have the highest percentage in England of over 65s compared to 16% nationally.

The Alzheimer's Society has published several statements which reflect the things people with dementia have said are essential to their quality of life. They are as follows:

- We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

- We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live-in isolation or loneliness.

- We have the right to an early and accurate diagnosis, and to receive evidence-based, appropriate, compassionate, and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

- We have the right to be respected, and recognized as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

- We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

As a borough, we are committed to adopting and promoting the Alzheimer's Society statements; we agree that anyone living in Cheshire East should be able to expect these as a right. We recognise that achieving all these consistently will require considerable work, but we would wish to test our performance against these standards.

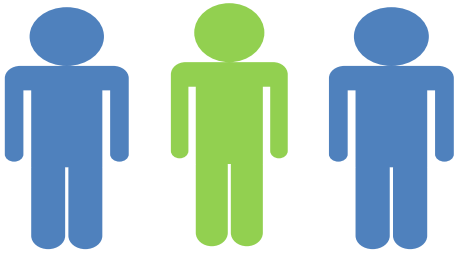
National Picture

There are currently 850,000 people living with dementia in the UK. 42,325 of these have young-onset dementia

The number of people with dementia is forecast to increase to 1,142,677 by 2025 – an increase of 40%

1 in every 14 of the population over 65 years has dementia

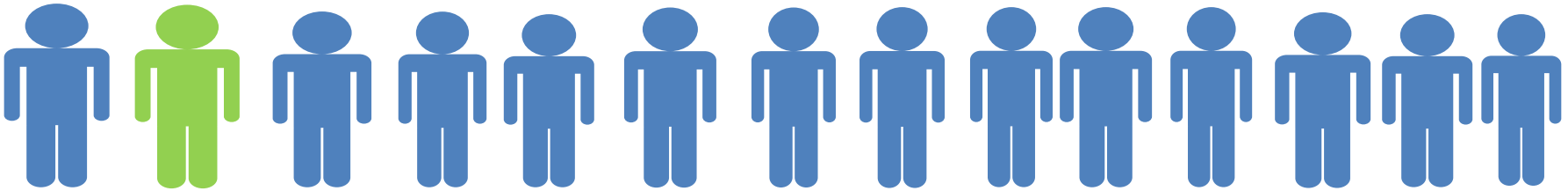
It is estimated that 1 in 3 people in the UK will care for someone with dementia in their lifetime



1 in 3 people who die over the age of 65 years have dementia. Dementia now accounts for 11.6% of all recorded deaths in the UK

In the UK 61% of people with dementia are female and 39% are male. There are a higher proportion of women with dementia as women tend to live longer, however, this does reverse when considering the data for people with young-onset dementia

It is estimated that there are 11,392 people from ethnic minority groups who have dementia in the UK. 6.1% of all those are early onset, compared with only 2.2% for the UK population, reflecting the younger age profile of ethnic minority communities



Local Provision - Celebrating Success

Cheshire Dance @ Leighton Hospital

In THIS Moment – dance and dementia

https://cheshiredance.org/Dance&Dementia/index.html

Museums (Nantwich, Congleton, and Silk)

An example of the work that the museums are involved in is Nantwich Museum hold a Dementia friendship group

Silk Ward (Macclesfield District Hospital)

The Silk Ward provides specialist inpatient treatment and assessment for people with dementia

Dementia Friendly Sandbach (DFS) (Dementia Wristbands)

For those who choose, they are simple and robust. DFS ordered about 300 initially and give them out free of charge. DFS are also looking to promote their use to local businesses and shops, to help them to support their customers living with dementia.

Bollington, Disley and Poynton – Time to Talk

These free, fortnightly drop-in sessions at Poynton, Disley and Bollington are aimed at people who are concerned about their memory, are living with dementia, carers or those concerned about a family member or friend

The Nantwich Thursday Club –Young Onset Dementia Group

This is a free dementia friendly social group for loved ones, carers and family. They meet evert fortnight at St Mary's Church Hall, Nantwich you can drop in between 10am and 12.30pm

SWAY Project (started in Alsager).

This is a project with the local high school where art students meet a couple, where one is living with dementia and creates an online memory box which can be adapted as their journey progresses

Holmes Chapel Tea Dance

This is an afternoon of Ballroom, Line, and 'exercise' dancing, along with tea and cakes. Held at the Community Centre on the fourth Friday of every month

Dementia Buddy Scheme (CW12 area) – Congleton Partnership, Congleton Lions and The Good Deeds Trust

The Dementia Buddy Guardian Angel devices help support families and carers looking after someone living with dementia

https://www.congleton-tc.gov.uk/dementia-buddy-scheme/

Dementia Strategy Survey

Between 17th July 2020 and August 14th, 2020 Cheshire East Council conducted a survey to gain information from those affected by Dementia to support the development of the Cheshire East Place Dementia Strategy. The aim was to learn how those living with dementia, their carers and families feel about current services and to get their views on how they might be improved. The survey asked respondents to give their views on several statements based on the five key NHSE dementia principles.

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

The findings from the survey have been incorporated into this strategy and informed the action plans where it is appropriate. More detail is provided in the relevant sections of the strategy, however, some of the key points raised in the survey are as follows:

Preventing Well

- Respondents felt more awareness of the 'One You Cheshire East' service was required along with a more accessible way to gain information for those who do not have access to the internet.

Diagnosing Well

- The majority of respondents agreed that 'seeking a diagnosis early, as problems become apparent is important to the individual concerned / their immediate family'. Within the comment's respondents expressed that there needs to be more support and information available after diagnosis. Some stated that they had received too much information to digest at the time of diagnosis with little / no follow ups whilst others felt they hadn't received enough information to begin with.

Supporting Well

- Respondents felt that there was insufficient information or support available with little advice given unless they searched for the information themselves. A more joined up approach would be beneficial.

Living Well

- Comments given were around the need for greater awareness of the support available or a request for more information / support. Those working full-time referenced difficulty in helping those living with dementia access services as they felt not many were available in the evenings / at weekends.

Dying Well (Planning and Caring Well)

- Most respondents agreed that there is a need to improve signposting to relevant services after the death of a loved one / cared for person e.g., bereavement service.

- Respondents also reported that there was very little emotional support or information on the help available for family / carers just before, during and after loss. There is a need to raise awareness of how the disease could progress and which services can be accessed at each stage with information on writing wills and power of attorney.

Work on the strategy began just before the start of the COVID pandemic and it was apparent from an early stage that this would have a significant effect on the vulnerable and the services they were able to access. The survey therefore also included questions about the impact of the Covid 19 pandemic, feedback included:

Impact of COVID 19

- Not being able to see family members or access support has been difficult and impacted negatively on the person living with dementia. Person living with dementia has deteriorated more quickly as a result of isolation and not having the stimulation. Person living with dementia didn't always understand the rules of social distancing / wearing masks and why people couldn't visit.
- Respondents referenced a negative impact on their mental health with feelings of stress, tiredness, anxiousness, isolation, and loneliness.
- Covid-19 restrictions have impacted on the usual services offered to those living with dementia and their family's / carers. Services have had to stop, are very limited or have had to move online which is not always appropriate / easy. It has made it harder to arrange care or access support meaning no respite for carers.

Face to Face Engagement Activity August 2021

What people said

It took me 3 years to get a diagnosis, and no one told me about any other services that could help. By chance I got referred to Alzheimer's Society from Salford Hospital I have so many many questions"

Younger Person with dementia

"I do think about it (planning) but he is now not in the right place to discuss it. It would have been a useful conversation early on. It's needed."

Carer

At present I feel I do have support and am much more aware of who and when to contact for advice and help. The carers section earlier on were helpful in getting some funding – i.e., Carers Allowance, Rate's reduction etc. Still wish there were easier ways to obtain respite and to be perhaps put with other people in a similar situation.

Carer

Very happy to have found Poynton Golden memories Group and I get information there – wish I had known about it earlier .

Carer

Getting information post-diagnosis-the most effective way was from meeting settings with peers going through the same process. The initial hurdle was getting up the courage to attend the first such meeting with potentially a bunch of strangers…….

Person living with dementia and their Carer

Alsager Partnership Organisation run a Memory Cafe at the Library once a month and also run an afternoon Tea and Games Session once a month for people living with Dementia. The information available at these venues is so important as well as the safe social atmosphere for people to enjoy. Representatives from various organisations drop in should people need that contact. For example: Cheshire East Carer's Hub; Alzheimer's Society; Cheshire East Social Work Dept. These Organisations with their support have helped us on our journey.

Person living with dementia and their Carer

At an annual health check some 9 months after diagnosis, a different GP asked would we like to be referred to the Memory Clinic at Crewe. This was a good action as the Memory Clinic Consultant runs a Clinic at our surgery. This was a very positive move for us, and we felt we were coming out of the dark. We got a lot of support - Reablement Support Worker called at our home over 3-week period to check our situation and provided information that could be of help to us. In particular she arranged for Age Concern person to call to help us with any benefits we were entitled to and helped us complete the form process. We would have benefitted from this referral immediately on diagnosis!

Person living with dementia and their Carer

I am constantly having to chase up things and am told different things by different people or that they do not know the answer and I have to ring someone else. Services need to be seamless and supportive. There should be a flow chart or information given to say what to do when something happens

Carer


Contact between GP surgeries and services available, needs to be better communicated and transparent. Not everyone is on IT…
Person living with dementia and their Carer
Carers gained their information from other carers and group activities (run by Alzheimer's Society and volunteer groups).
Carer
Complex diagnosis involving Parkinson's but had to persevere over a couple of years before getting a diagnosis. Saw different doctors who showed different sympathies, one felt it was stress and anxiety for a long time, only when wife had hallucinations and aggressive behaviour did, they change their mind. Over 2 years to get a diagnosis
Carer
Carer recognises that she hasn't reached out for support and likes to think she can deal with things, however, recognises this is changing.
Carer
I don't always want to attend groups that just have people with other health concerns .
Person living with dementia
I was given lots of information on what could help me to manage better at home that I just didn't know existed. They helped me to apply for benefits as I wouldn't want to do forms myself. I was taken and introduced to lots of different social activities which was great as I was stuck in the house as lost my confidence.to go out after the diagnosis.
Person living with dementia
When a new patient comes to the memory clinic and they are told of their diagnosis……When it's new information, we need just a little time to absorb what's being said and I wondered, even though I know how busy everyone is, would it be possible to slow down the delivery. If other patients are like us, they will need time to absorb and adjust their thinking to all this new information and what happens next
Person living with dementia and their carer

"By 2025, there will be an estimated 7,514 people over the age of 65 living with dementia in Cheshire East. However, dementia doesn't just affect older people. We estimate by 2025 there will also be approximately 1,991 people aged between 30 and 64 living with dementia in the North West". ***Taken from the Alzheimer's Society's Cheshire East Local Dementia Profile July 2019.***

With the incidence of Dementia growing and pressures on services increasing it is important that we adopt a more proactive approach to communicating the risks of developing Dementia and promoting healthier lifestyles. We should ensure that wherever possible the risk of Dementia is highlighted so that steps can be taken by individuals and organisations to reduce or delay the occurrence of dementia in Cheshire East. The first stage of the NHS Dementia Well Pathway focuses on the importance of prevention, reducing the risk of Dementia, the need to research and apply best practice and to consult with those affected by the illness so that we are continuously reviewing and developing good practice. This strategy will develop a range of actions to achieve this.

We want Cheshire East residents to lead healthy lives and be better able to manage their own wellbeing. To achieve this, people need to be supported and encouraged to engage in healthy lifestyle behaviours and be open to early prevention and interventions.

There is a need to raise awareness of the symptoms of dementia earlier and encourage people to make positive changes, this will in turn, support people and their carers / families, to plan for the dementia journey and promote early conversations with GPs to enable a timely diagnosis. An example of how we would do this is that we would work with GPs to provide information on dementia to people aged 50+ during their NHS Health Check. There is also an option for the Cheshire Clinical Commissioning Group (CCCG) to develop links within each care community to improve prevention / screening and healthy living.

We will work with relevant partners to ensure that more support is available in helping people with dementia including, early support, support in decision making and education for individuals, families and carers in all cohorts of the community. We will also ensure partners, carers and families work together to safeguard and support those people living with dementia who have care and support needs where best interest decisions need to be made ensuring the persons wishes, thoughts and feelings are listened to and considered. The need to have a joined-up approach which is adapted to individual circumstances and needs, is crucial to avoid a one size fits all approach.

What we already know

Healthy living is good for your physical and mental health

Reducing the risk of dementia or delaying its onset, can be influenced by a wide range of lifestyle factors. Establishing and maintaining a healthy lifestyle is important to help lower the risk of dementia, particularly vascular dementia. Encouraging people (particularly in their forties and fifties) to reduce their risk of dementia will support them in living longer, healthier lives.

There are several lifestyle factors that can increase the risk of dementia:

- A sedentary lifestyle (exercise in older people is associated with a slower rate of decline in memory and some thinking skills that occur with ageing)
- Excessive alcohol consumption (10% of the dementias are related to alcohol)
- Eating a poor diet high in saturated fat, sugar and salt and obesity in midlife.
- Smoking

Other risk factors that could contribute to the risks are - hearing loss, sight loss, hypertension, depression, and social isolation

To reduce the risk of dementia or delay its onset, the National Institute for Health and Care Excellence (NICE) suggest the following lifestyle changes:

- Stop smoking
- Be more active
- Reduce alcohol consumption (only drink within NHS recommended limits)
- Improve diet
- Lose weight if necessary and maintain a healthy weight.

Cheshire East Council already promotes healthier lifestyles through the 'One You Cheshire East' Service https://www.oneyoucheshireeast.org/

and has the "Live Well" website which supplies information and advice on a range of subjects https://www.cheshireeast.gov.uk/livewell/livewell.aspx.

In addition, Alzheimer's Research UK has also launched ***Think Brain Health***, which is a new awareness campaign to empower people to keep their brains healthy throughout life and ultimately, help reduce their risk of dementia. https://www.alzheimersresearchuk.org/brain-health/think-brain-health/

Information from the Alzheimer's Society's website advises that sight and hearing loss are both more common as you get older. For a person with dementia, this can cause extra problems, such as confusion about what's happening around them and problems with communication. Therefore, we feel there is a need to improve awareness around the fact that some of the issues that people may be experiencing could be linked to an undiagnosed form of sight or hearing loss, and not their dementia, also vice versa.

However, despite the abundance of information available on how to live a healthier lifestyle we know from our survey and the incidence of Dementia in Cheshire East that we need to do more to ensure the message is reaching the intended audience, especially under-represented groups. We should therefore continue to encourage more people to take responsibility for their own health and wellbeing and provide information, advice, and support for those who would like to adopt a healthier lifestyle and reduce their risk of getting Dementia or delay its onset.

Key Issues and Challenges

- The ‘One You Cheshire East’ site and its purpose did not appear to be well publicised, some people living with dementia and their carers / families are not aware of this service at all. Others reported that they are aware of the service but not in relation to dementia specifically.
- Some services are only available online; this causes a problem for those individuals who do not have access to the internet.
- The perceived stigma of dementia can prevent people from going to their GP about symptoms they may be worried about.
- It is important that there is good information available about the early signs and symptoms of dementia to enable a prompt diagnosis and referral to appropriate support.
- Many people manage to live well with Dementia, so it is important that we promote positive messages about the benefits of diagnosis and the available support to reduce the stigma associated with the disease.
- The diagnosis rate for people from ethnic minority communities has been historically low even though there is an increased risk of dementia for this group of people. There is a need therefore to raise awareness amongst this group and provide good information about the risk factors, information on the early signs of dementia and the benefits of diagnosis.
- For people with learning disabilities, particularly Down’s Syndrome, where there is also an increased risk of dementia, there is a need to ensure that they and their families and carers have access to information at an early stage about the risks of dementia and the early signs of dementia in an accessible format.
- Increased awareness is required with regards to those individuals living with Young Onset dementia, the risks, symptoms to look out for etc
- Education and early support are needed for those living with dementia and their carers, including those individuals identified as being ‘at risk’ from developing Dementia.
- Survey respondents reported a need for “professionals” to listen more to family members who often see the signs of Dementia first and need more information on supporting people at home.
- A one size fits all approach does not suit the differing needs of those living with dementia.
- Sight and hearing loss are both more common as you get older. For a person with dementia, this can cause extra problems, such as confusion about what's happening around them and problems with communication.

Ambitions for the Preventing Well pathway

Outcomes

To prevent or delay the onset of Dementia people living in Cheshire East should be encouraged to lead a healthier lifestyle, particularly those aged 40 and over. This would involve.

- Improved promotion of, and signposting to, existing services, E.G the 'One You Cheshire East' service.
- Provision of good information, using a range of media, about risk factors, early signs of dementia and the benefits of diagnosis across **all** ages, particularly those in high-risk groups, for instance people with learning disabilities or those from an ethnic minority background.
- Information should be provided in easy read/ accessible formats, for example, for those living with a learning disability or the visually impaired.
- Improved education and early support available for those living with dementia / partners and carers of those individuals more at risk from developing Dementia so that people who have concerns feel encouraged to seek a diagnosis.
- Working with partners to ensure information on how to access support is clear and consistent across Cheshire East.
- Individuals living with Dementia, carers, professionals and VCFS Sector will be advised about and decide if they want to be involved in research that looks at cause, cure and care for dementia and will be supported to take part.
- Service users will be involved in the review and development of local information and services to ensure they meet the needs of local people.
- People need to be encouraged to act when they think they may have hearing loss i.e., get their hearing checked and get hearing aids if appropriate.
- People need to be encouraged to act when they think they may have sight issues / loss i.e., get their eyesight checked and get glasses if appropriate

The Prime Minister's Challenge on Dementia 2020 sets out the UK Government's strategy for transforming dementia care within the UK. One of the key aims of this national strategy is to improve arrangements for timely diagnosis. The strategy includes recommendations for:

- Improving diagnosis, assessment and care for people living with dementia
- Ensuring that all people living with dementia have equal access to diagnosis
- Providing all NHS staff with training on dementia appropriate to their role
- Ensuring that every person diagnosed with dementia receives meaningful care.

Until recently Dementia Diagnosis Rates in Cheshire East were above the national target of 67%. However, the recent pandemic has meant that across the country health and social care services were unavoidably focused on the demands of COVID. Some memory assessment services were reduced, and people generally were reluctant to approach their GPs to discuss any concerns during this difficult period. This caused Cheshire East diagnosis rates to drop below the national target.

However, as services start to return to normal the number of people being diagnosed is increasing again. It is believed that of those estimated to be living with dementia in Cheshire East, approximately 65% have received a diagnosis (June 2021). Whilst it is good news that we are meeting the national target, there remains a significant number of people still to be diagnosed, people who are unlikely to be accessing the support they need. We are also aware that obtaining a diagnosis can be more difficult in some areas; waiting times for a diagnosis can vary and availability of post diagnostic support is inconsistent. . The table below shows the changing percentage of people diagnosed in East Cheshire since October 2019.

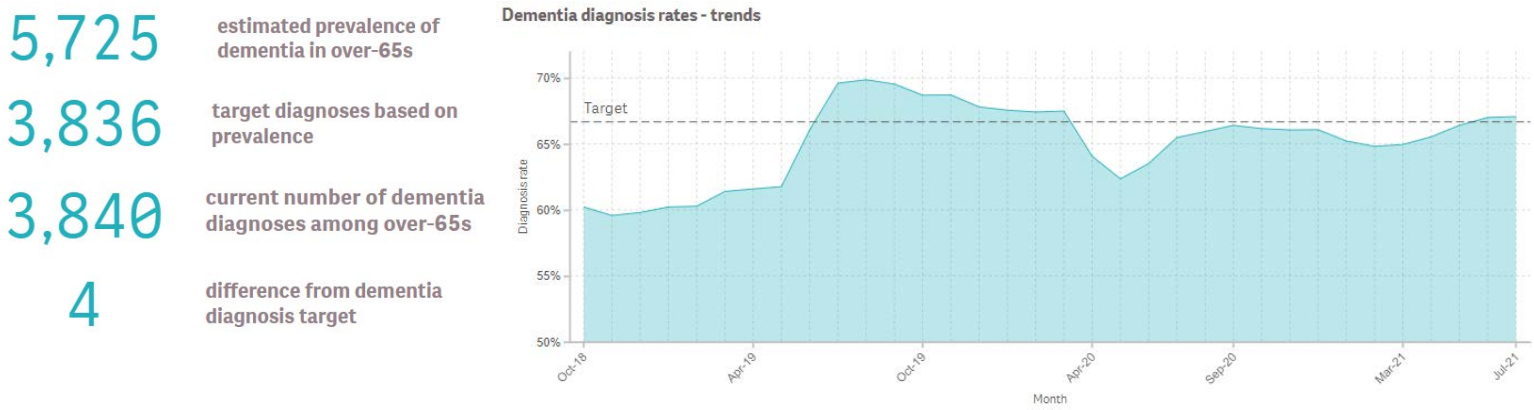


Table 1. East Cheshire Diagnosis Rates – Oct 2019 to June 2021 (Source NHS Digital)

The NHSE Well Pathway advocates, “Timely, accurate diagnosis” to enable personalised care planning and regular review. The patient and carer should be given information and advice on how they can manage the condition and how to get additional information, advice, and support when it is needed. Dementia is a life limiting condition and receiving a dementia diagnosis can be devastating for the individual and for those who care for them. However, it can also be a huge relief to get an explanation for changes in memory or behaviour.

Getting a timely diagnosis is crucial to the person affected by Dementia because s/he can:

- Access appropriate medical treatment and regular reviews
- Gain an understanding of the condition and take part in planning their care
- Get information, advice, support, and training on how to manage the condition and seek support when it is needed.
- Apply for any relevant benefits and allowances
- Plan ahead and make any necessary adjustments,
- Learn about other services, for example, safe and well checks from the Fire Service.

The Prime Ministers Challenge (2020) states that, “GPs should play a leading role in ensuring coordination and continuity of care for people with dementia”. It is therefore important that we work with and support our local GPs to assess and diagnose the simpler presentations of Dementia and to refer patients with more complex symptoms in a timely way to Memory Services for assessment and diagnosis. This will ensure that patients are offered timely treatment, guidance, signposting to appropriate support services and opportunities for regular review.

As noted earlier the current diagnosis rate across Cheshire East is increasing, however by working more closely with Primary Care and our local Memory Services there is scope to improve this further. There are two Memory Services in Cheshire provided by Cheshire and Wirral Partnership Trust (CWP). Historically these have developed slightly different service models; we will work with both services to ensure that a standard pathway and response is in place across the Cheshire East footprint.

There is a need to ensure all people receive training relevant to their role, so that there is a workforce across the Dementia care system that has the right skills, behaviours and values to support people living with Dementia and is equipped to do so. Therefore, training amongst all NHS and Social Care staff to increase early identification of the early signs of Dementia will be included as an action within the strategy action plan.

The drive to improve the diagnostic rate must not be an end in itself; improving the support available to people once they have been given the diagnosis is equally important. This also enables us to identify their Carers so that they can be registered on the GP systems, to ensure they are signposted to support and services at an early stage such as the Carers Wellbeing Programme (run by such organisations as the End-of-Life Partnership and East Cheshire Hospice). It is also important to recognise that contact with clinicians is not restricted to GPs; there are a range of other professionals, for example, opticians and pharmacists, who can be alerted to dementia related problems. The provision of support is addressed in more detail in the Supporting Well section of the

Among the UK's ethnic minority population, there can be lower levels of awareness around dementia, and it remains relatively rare for people to develop dementia, but the single largest risk factor is age. However, around 5% of people with Alzheimer's are under 65 and young onset dementia can affect people in their 40s, 50s, and 60s. People with learning disabilities or Down's Syndrome are particularly vulnerable to developing young onset of dementia. We need to ensure that these individuals are made aware of the risks of developing dementia and particularly vulnerable groups are made aware of the links and receive regular health checks so that early signs can be identified sooner.

For older LGBT+ people, living with dementia can be additionally stressful. Not only is this group of people less likely to have family members and children to provide support. They are also more likely to live on their own and be single. Many people fear that mainstream care services will not be willing or are not able to understand how to meet their needs.

The Prime Ministers Challenge (2020) recommends that "all clinical pathways should be tailored to people's personal circumstances, considering culturally specific beliefs, needs and values, as well as supporting carers and families of people with dementia." It is therefore important that we review our performance in this area and take steps to address any inequity or gaps within current care pathways.

Approximately 69 per cent of care home residents are currently estimated to have dementia. Evidence also suggests that people with dementia living in a care home are more likely to go into hospital with avoidable conditions (such as urinary infections, dehydration, and pressure sores) than similar people without dementia. The Enhanced Health in Care Homes Framework (https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf) recommends that there should be a systematic and proactive approach to identifying, diagnosing, and recording dementia and cognitive needs in a timely manner, following admission to the care home and upon first presentation of signs and symptoms.

Planning for the future

People with a diagnosis of dementia should be given the opportunity to plan for the future at an early stage, to ensure the person and their carer are fully involved in decisions on care at the end of life. These conversations will enable people living with dementia and their carers to plan ahead for their future care while they are still able to do so.

There are several tools which support staff and carers to have these conversations which can be difficult/sensitive. They include.

- NAMASTE principles
- People can also record their wishes if they can't write them down
- All About Me Booklet (need hyperlink)
- Reminiscence boxes – especially for people with learning disabilities

More detail about Planning and Caring Well can be found within the Dying Well (Planning and Caring Well) pathway.

Key Issues and Challenges

- There are long waits for a diagnosis in some areas of Cheshire East.
- Lower rates of diagnosis among people from ethnic minorities
- There is a need to review the Memory Clinic pathways across the Cheshire East footprint to ensure a standard response
- Early signs of dementia not being recognised in people with learning disabilities / young onset.
- At the point of diagnosis, some people receive a raft of information and advice (or not enough information), and it is not always easy for them to know where to access information and advice at a later stage. We also need to consider individuals changing circumstances and how they can be signposted / supported
- In some areas of Cheshire East, there are systems that are complicated and disjointed where people can get 'lost' along the way, particularly when their needs change. Follow ups are described as 'a bit hit and miss' with many looking for support and advice online or from other's living with dementia and their families / carers rather than from the health care system.
- There is a need to improve the diagnosis rates of those individuals living in Care Homes (Accommodation with Care)
- There is a need for more accessible information on who to go to, on the early signs of dementia and the benefits of getting a diagnosis.

Ambitions for the Diagnosing Well Pathway

Outcomes

- We will work with Primary Care and Memory Assessment Services to review current care pathways with a view to improving and standardising Dementia service provision in Cheshire East.
- We will review diagnosis rates and care pathways for those with Young Onset Dementia, people with Learning Disabilities, those from ethnic minority groups and the LGBT community to ensure equal access to services which meet their specific needs
- We will work with GPs to enable them to register all Carers on their systems, that are identified to enable them to be effectively signposted to relevant support at an early stage including a referral to the Local Authority for a carers assessment.
- Good quality support and information is available to people from the pre diagnosis stage and throughout the diagnosis journey and people know where to access this information, this will include such things as information on what can be accessed to alleviate financial pressures
- We will work on raising awareness with GPs and other health and social care professionals, around the repercussions faced by carers, mentally, physically, and emotionally when their loved one is diagnosed with dementia

Our ental and physical health are important whether we are living with a health condition or caring for someone with a health condition. It is recognised that carers, families, and friends support individuals with dementia living in their own homes. It also needs to be recognised that there are cases where isolation and depression are common amongst those living with dementia and those caring for someone with dementia, this was highlighted as one of the main issues facing these individuals during the Covid 10 pandemic. It is, therefore, vital to ensure we provide the right care and support at the right time, in the right manner, in the right place to those living with dementia and their carers.

Information taken from the Alzheimer's Society - Local Dementia Profile – Cheshire East July 2021 show that:

- The value of dementia support contributed by unpaid carers in Cheshire East is £169.7m
- 46.1% of all carers reported caring for someone living with dementia in Cheshire East
- In Cheshire East 51.2% of carers spend 100 hours or more per week providing care

The NHSE Well Pathway advocates, "access to safe, high quality health and social care for people with dementia and carers" to enable those living with dementia to stay in their own home for as long as possible. The person living with dementia and their carers will have access to joined up, holistic support from the Health and Social Care sector.

What we already know

People living with dementia and their families need to be confident that, when a need arises, they can readily access support without having to make multiple approaches to varying organisations / services. As part of this strategy, we are looking at how to improve the pathways and ensure that all services can work collaboratively.

We do, however, acknowledge that much of the support is designed for older people living with dementia and is often not suitable for those with young onset dementia. This means that people with young onset dementia can find themselves isolated within the community.

As the condition progresses, it may become necessary for the person living with dementia to require some extra care and support to enable them to live at home safely. People living with dementia / their carers and especially professionals and any staff involved in the delivery of their care, all need to consider the Mental Capacity Act (2005) processes when making care and support decisions. There is also a need to ensure a good understanding of dementia, including future decision making considerations, relevant to any role they perform or support they provide; therefore, good quality education and training are an essential part of the Supporting Well pathway.

There is a need to ensure that staff in all areas of Health and Social Care are aware of the wider issues in relation to the specific needs of those from the following cohorts:

- LGBT+
- Ethnic Minorities, religious minority communities and Gypsy, Roma and Traveler communities
- Sensory Impairment
- Learning Disabilities
- Young Onset

The overall vision is that people living with dementia stay and are cared for in their own home for longer. Where possible, people will be discharged to a home of their choice with the Mental Capacity Act and best interest decision making process followed where needed. We will work with Care at Home and Accommodation with Care providers, where required, to enable their staff to support those living with dementia to stay within their own home, should this type of service provision be needed.

Key Challenges and Issues

- People living with dementia and their carers / families feel that there is insufficient information and support available. Also, a lack of advice given unless they search for it / chase it up. This includes where people living with dementia have one or more other health conditions, as services often work independently of each other and there is little joined up working in some areas of Cheshire East.
- People with dementia from ethnic minorities, religious minority communities and Gypsy and Traveller communities, Learning Disability and LGBT+ community can feel that mainstream services are not able to understand how to meet their needs.
- Issues for people with more challenging needs and people with Young Onset Dementia.
- Gaps in training for care staff, health professionals etc as there is often a lack of confidence in supporting those from ethnic minorities, LGBT+, Learning Disability or Young Onset background
- There is a lack of age-appropriate activities, supported volunteering opportunities and groups for those living with Young Onset Dementia and those also living with a Learning Disability.
- Knowledge around advanced care planning / anticipatory care planning can be lacking in some areas including understanding of Lasting Power of Attorneys
- Delays in discharging people with dementia safely from hospital, there is a need to improve the Home First offer to residents

- Training for staff on equality and diversity ensuring that they are aware of the issues faced by specific cohorts of community. The care market should be able to respond to people living with dementia and support them to live well
- Lack of Mental Capacity Act (2005) and Best interest decision making process knowledge from professionals. People, families and carers need to understand this process if the persons cognition decreases and best interest decision making needs to be made.

Ambitions for the Supporting Well pathway

Outcomes

To ensure that those living with dementia and their carers have access to safe, high quality health and social care. We would ensure that:

- People are enabled to live at home for as long as possible and are discharged from Hospital to a home of their choice in a timely manner with minimal delay of best interest decision making to support discharge where required
- There will be sufficient information and support available to those living with dementia and their carers, this may include single information and advice sessions on dementia itself and how to support loved ones and deal with behaviours and how to access early information on how to apply for lasting power of attorney
- Where people living with dementia have one of more other health conditions, services supporting them will work collaboratively together
- People living with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing
- People living with dementia receive high quality care and support from staff appropriately trained in dementia care
- There will be increased knowledge around advanced care planning / anticipatory care planning across the Cheshire East footprint
- Staff training on equality and diversity will be investigated and taken forward. The care market can respond to people living with dementia and support them to live well

Since the launch of Cheshire East Council's Joint Commissioning Work plan and the former Prime Minister, David Cameron's, 'Challenges on Dementia' there have been significant improvements in terms of raising awareness about Dementia and creating tangible opportunities to improve the lives of people with dementia, their families, and carers. For example, there has been an increase in Dementia friendly communities within the Cheshire East footprint.

The NHSE Well Pathway advocates, "People with dementia can live normally in safe, and accepting communities" to enable those living with dementia and their carers to feel included and engaged in their community and are supported to live happy and fulfilled lives. They will also have access to clear and easily accessible information and advice.

What we already know

As stated in the Supporting Well section, we know that in some cases, people living with dementia and their carers can feel a sense of isolation, especially those living in rural areas, therefore, we will pay particular attention to this aspect when we look at addressing measures to prevent social isolation.

We need to ensure that our communities are committed to supporting our residents living with dementia and their carers, and that they are empowered to adapt to accommodate and meet their needs. There needs to be a focus on community led support, prevention, and a strengths-based approach to services, we will therefore work with community providers to maximise community provision as a tool to support people living with dementia and their carers. We will also look at how provision from other sources, such as the local hospices, can actively support those living with dementia and their carers.

Ensuring that people living with dementia and their carers have access to the right information and advice will play an important part in allowing them to engage and participate in community life and activities. We therefore need to make sure that information and advice is clear and easily accessible for people living with dementia and their carers so that they can access community services independently.

Access to information, advice and support is key to ensuring all people affected by dementia can continue to live well with the condition.

We will need to ensure that a range of different community-based options for people living with dementia and their carers are available, maintained and promoted so that they have more choice over the support they access. We will look at enhancing the role of prevention services such as Day Services, Community Respite and ensure these are considered as part of a pathway approach.

There has been a great deal of innovative work that has taken place within the local Dementia Friendly Communities, for example Schools being encouraged to include dementia awareness in their work programmes, and numerous dementia friend's awareness sessions taking place with the pupils of the schools, leading to the creation of dementia friendly generations.

The development of dementia friendly communities is also a key element of the work required to meet the challenge around dementia, and one which we have already seen great achievements being made within our current Dementia Friendly Communities. Simple changes to existing services, and awareness raising for those who come into day-to-day contact with people living with dementia, can help people with dementia. We understand, locally, the importance of listening to people living with dementia, their families, and carers, to inform and enable changes across all our services to:

- Raise awareness
- Challenge stigma
- Enable, inspire, and facilitate dementia inclusive communities.

It is important that we enable and empower residents living with dementia to have a voice and say in shaping their community and the support that they receive. We will ensure that we work in co-production with them as well as their carers / families, to help shape and design services and support so that they have choice and control over the decisions and services that affect them.

What it means to be dementia friendly?

Dementia-friendly communities are areas where people living with dementia are understood, respected, and supported, and confident they can contribute to community life. The aim of dementia-friendly communities is to improve the quality of life for people with dementia wherever they live. In a dementia-friendly community people are aware of and understand dementia, and people with dementia feel included and involved,

and have choice and control over their day-to-day lives. As the number and needs of those with dementia increases, we need to make sure that we create conditions for our local communities across the Borough that better support people with dementia.

Services that are being delivered and the support offered to our residents must be equitable and respectful to the specific issues which may be faced by the above cohort of the community.

Living Safely

How individuals can live safely, is an important part of enabling those living with dementia and their carers to continue to live independently, within their own homes.

People living with dementia and their carers, need to live in suitable housing that meets their changing needs (for example Extra Care Housing), this is supported by the work the Council have completed around the Vulnerable and Older People's Housing Strategy and the emerging Housing Supplementary Planning document. This is also a priority within Cheshire East Council's Corporate Plan where it states that we "reduce the reliance on long term care by providing services closer to home and providing more Extra Care Housing facilities, including dementia services" and that "we work with partners to develop appropriate accommodation and Extra Care Housing Models". There should also be a clear offer of equipment and assistive technology that optimises the individual's wellbeing and independence.

For those people whose needs have increased to the point they are unable to live at home, a residential or nursing care home (Accommodation with Care) setting may be more appropriate. Support should be easily accessible for the person and their families and carers to be able to make the right decision about their future care planning.

We will ensure where people's needs have increased and where they can no longer make an informed decision, that these decisions will be made through the legal framework of the Mental Capacity Act (2005) and Best Interest decision making process to support and safeguard individuals and make sure their voice is heard.

There is currently a proactive approach from services such as Fire, Police and Trading Standards that supports people living with dementia to live safely in their communities**.**

The support also provided by both Mid Cheshire Hospitals (Leighton Hospital) and East Cheshire NHS Trust (Macclesfield District Hospital) is very proactive in their support to those living with dementia, their carers and those suspected of needing a dementia diagnosis

Support for unpaid Carers

Unpaid carers, usually family members, provide enormous amounts of support to people living with dementia. Without this support, many people living with dementia would have many restrictions to their lives, or would have to use residential or nursing care, which is usually not what they want. Providing adequate and evidence-based support to carers is crucial if we are to achieve our vision of supporting people living with dementia to live independently as long as possible.

Cheshire East Carers Hub provides a single point of access for all Carers including both young and adult Carers. The hub will ensure that Carers of all ages

will have access to information, advice, and a wide range of support services. The Carers Hub have 2 support workers who are employed to specifically support those individuals who are caring for someone living with dementia.

There are Carers Wellbeing Programmes ran by the End-of-Life Partnership and East Cheshire Hospice, these are open to Carers of people living with dementia. Both services require a referral via a GP, therefore, it is vital that Carers are identified and registered at the point of an individual's diagnosis, to ensure the Carers can access such support at an early stage

There is also the Cheshire East Carers Forum which aims to be a voice to inform service providers of the needs of carers and their families. https://www.cheshireeast.gov.uk/livewell/looking-after-someone/cheshire-east-carers-forum.aspx

Dementia and Domestic Abuse

Cheshire East Council and such partners as My Cheshire without Abuse, Cheshire Clinical Commissioning Group, and the Carers Hub, have created a Project Team to investigate the current gaps with regards dementia and domestic abuse.

The team identified that there were three things that should be considered when looking at this area:

- Identification of changes in behaviour within the relationships of people affected by dementia, which could be regarded as challenging or abusive, (recognition that this is a situational issue, not an element of the disease and that this needs to be resolved or reduced whenever possible. We also acknowledge that communication difficulties are a common symptom of dementia and if a person living with dementia's ineffective attempts to communicate their needs are left unresolved or unaddressed this can result in aggressive behaviour)

- Assessment of risk

- Development of a risk management plan (ensuring that the plan is very specific to cover the issues that may be faced by carers and those living with dementia)

The team have developed such things as an awareness leaflet and an Adult Safeguarding – Domestic Abuse Guidance toolkit. This guidance aims to provide the framework of a consistent and effective response to tackling domestic abuse. There have also been awareness events to enable professionals, carers and those living with dementia to obtain a greater understanding of the subject.

Not one agency can address all the needs of people affected by, or perpetrating, domestic abuse. For intervention to be effective agencies and partner organisations need to work together and be prepared to take on the challenges that domestic violence and abuse creates. As a result of this the team will be continuing to research and develop areas of this subject within the Cheshire East footprint

Key Challenges and Issues

- People living with dementia and their carers will feel included and engaged in their community and are supported to live happy and fulfilled lives.
- There will be a focus on community led support, prevention, and a strengths-based approach to services. Our communities will be committed to supporting our residents living with dementia and their carers and will adapt to accommodate and meet the needs of those living with dementia / carers. Relevant community provision will be an option to support people living with dementia and their carers
- Those living with dementia and their Carers can become cut off from the community, leading to social isolation. They need easy access to peer support, carers groups and other such initiatives that help them to stay connected.
- Crises are common in people living with dementia and can lead to unplanned admissions to hospital and residential care.
- Falls and fractures are an issue for people with dementia and can lead to hospital admission and loss of independence.
- Lack of flexible breaks for carers, local respite / day services impacting on their ability to continue effectively in their caring role
- Low uptake of services from those from ethnic minority groups
- People with Learning Disabilities / Young Onset Dementia to have to have support to engage in age-appropriate activities / groups / volunteering opportunities
- Out of Hours support (out of working hours and at weekends) seem to be lacking.
- Barriers to sustainable Dementia Friendly Communities as they tend to rely on volunteers to steer them
- Some Transport providers do not feel equipped to support those living with dementia, and transport can be a particular challenge, particularly for someone living in more rural communities and/or where they can no longer drive.
- There is a need for greater availability of community housing options suitable for people with dementia.
- Practical and emotional support is available for family carers to support their health and wellbeing, including contingency planning and increased opportunities for peer support and respite care.
- Those living with dementia and their carers need to feel they have a voice at a strategic level.

Ambitions for the Living Well Pathway

Outcomes

To ensure that People with dementia can live normally in safe and accepting communities and have access to clear and easily accessible information and advice. We would ensure that:

- People will be enabled to access to peer support, carers groups and other such initiatives to help them stay connected and reduce social isolation
- Carers will have access to affordable local respite and day care options for a cross section of people living with dementia, as this will enable them to continue effectively in their caring role
- There will be different community-based options for people living with dementia and their carers
- Increase awareness and reduction in stigma required for those from ethnic minorities, religious minority communities and Gypsy and Traveller communities, and access to welcoming and inclusive provision which is relevant to the needs of ethnic minority groups
- People living with a Learning Disability / Young Onset dementia will have the opportunity to engage in age-appropriate activities and participate in services designed to support them to live well. They will also be supported to volunteer where such need is identified
- There will be equitable out of hours provision across the Cheshire East footprint
- Promotion of the benefits of communities becoming Dementia Friendly, working towards encouraging more volunteers to get involved in taking this forward, also promoting the fact that DFCs are intended to work alongside other established organisations and ease the load on professionals
- Organisations providing Transport will feel equipped to support those living with dementia and their carers.
- There will be greater availability of community housing options suitable for people with dementia
- Those living with dementia and their carers will have a voice at a strategic level and will be pivotal in addressing the actions detailed within this strategy

Dying Well is the final element of the national NHS Dementia Pathway and our own local strategy. Whilst we have stressed throughout this strategy that people with Dementia may, with an early diagnosis and appropriate care and support continue to live well with Dementia, it is important to understand that it is a life limiting illness. Dementia can be the primary cause of, or a key contributory factor in a person's death. The Dementia Pathway sets out an ambition that "People living with Dementia die with dignity in a place of their choosing". This can only be achieved if those with Dementia have an understanding of their care options and are encouraged to express their preferences whilst they are still able to do so. It is likely that many people will be involved in the care and support of the person with Dementia, so it's equally important to ensure that the patient's wishes are recorded in such a way that the information is easily accessible to those who need it.

Preparing for end of life can be a very difficult subject for many, for staff as well as patients and their families. Some respondents in our public survey suggested that we change the title of this part of our strategy in the interests of sensitivity. However, the End-of-Life Partnership circulated a survey on "Dying Matters" in 2021 and one of the overwhelming findings was that as a community we don't talk about end of life enough. One of the aims of this strategy is to encourage more open and honest discussions about death and dying, we want to avoid ambiguity and ensure that the importance of this part of the strategy is clearly understood. We have therefore retained the title used in the NHSE Dementia Pathway, though we have qualified this by adding the subtitle of Planning and Caring Well.

On average we can expect about 1% of the population to die each year. Whilst some deaths may be unexpected such as deaths caused by accidents, the number of unexpected deaths is far fewer than the number of people who we can predict with some certainty will be in their last year of life. This means that in most case there are opportunities to plan for end of life wishes and care preferences. Table 2 shows the number of deaths in Cheshire East since 2019 (as at September 2021) and the numbers dying with and without a dementia diagnosis. It is interesting to note that during this period 12,862 people died, 24% of whom had a Dementia diagnosis.

	Died with Dementia	**Died without Dementia**
2019	900	3010
2020	1034	3240
2021	1198	3480
Total	**3132**	**9730**

Table 2 – Deaths in Cheshire East since 2019 (with/without Dementia)

Advance Care Planning

Everyone should be involved in decisions about the care and support they would like to receive in the event of ill health, frailty, or disability. Like many long-term conditions, Dementia is a life limiting disease; however, the inevitable loss of capacity associated with Dementia makes it especially important to ensure discussions about care and support preferences take place early and as frequently as needed, to ensure the patient's choices are recorded and wherever possible respected. It should be recognised that these difficult conversations are part of an ongoing communication process and shouldn't be regarded as a single event. This reduces the likelihood that difficult and emotional decisions are made in crisis when the wishes of the person with dementia may not be known.

Sometimes described as Advance Care Planning these conversations might involve consideration of treatment options, where an individual wants to be cared for and who s/he would like to involve in decisions about their care. When asked about their care preferences at end of life, people report the most important priority is to have good pain management, the second is usually to be in a familiar environment with those most important to the patient. It is generally understood that most people would prefer to die at home or in their usual place of residence and care. This is especially important to those with Dementia as changes in routine and unfamiliar surroundings can be difficult for them to manage. There is also evidence to suggest that if a person's wishes are respected and a "good death" is achieved, those "left behind" are able to take some comfort in this. They are more able to cope with the bereavement and are less likely to suffer mental health problems in the longer term.

At the time of writing, 43% (1,717) of those aged over 65, currently living with Dementia have an Advance Care Plan. This compares favourably with the remaining over 65 population who do not have a Dementia diagnosis, of whom only 3% have an Advance Care Plan. However, this means that 57% of those with a diagnosis have not formally recorded any plans regarding their future care.

Recording Patients Wishes

In Cheshire East we know that approximately 3,766 people are likely to have Dementia, of whom 67% have a diagnosis. We record diagnosis data in GP records, we are also able to use the GP information system to record patients care preferences, like where a patient would like to be cared for in the event of a deterioration in their health, who should be involved in decisions about their care and where they would wish to die. We can also use this system to record and report on whether those wishes have been achieved. This data is collected in the Electronic Palliative Care Coordination System (EPaCCS) and is part of EMIS, the GP record system.

Although this information is held in the GP system it may also be accessed by other health care professionals who may be involved in the patients care at a later date. This can help to ensure that staff not directly involved in the advance care planning discussion are aware of the plan. For instance if paramedic calling on a patient with Dementia can see what the patients' wishes are this may prevent an unnecessary transfer to hospital when a patient has expressed a wish to die at home with their family. Whilst the information stored on EPaCCS supports care coordination for individuals, the information is also useful strategically for the purpose of planning and commissioning end of life services.

The Gold Standards Framework

The Gold Standards Framework (GSF) is a practical and systematic way of providing the best possible care to people nearing the end of their lives. The GSF provides for a planned system of care in consultation with the patient and those important to him/her. It sets out a series of care standards which support early identification of people at end of life, better coordination and collaboration between healthcare professionals through multi-disciplinary meetings and care coordination systems like EPaCCS and improved advance care planning discussions. The application of GSF can also optimise out-of-hours' care and prevent crises and inappropriate hospital admissions. The processes and standards in the Gold Standard Framework can be applied in primary and secondary care, in care homes and in the patients own home.

It is important to note that care and support can be provided to an excellent standard without applying the Gold Standard Framework. However, by applying the Framework consistently to all patients we are better able to monitor performance and patient experience in a more systematic, strategic way

Where possible a person with Dementia will have an Advance Care Plan, which is recorded on EPaCCs and as they approach end of life will be cared for using the Gold Standards Framework. Table 3 shows the extent to which this was achieved for those who have died since 2019 (with and without Dementia). This information shows that we are having more success planning and recording the wishes of people with Dementia than we are for those without a Dementia diagnosis. However the information also illustrates quite clearly that there is room for improvement.

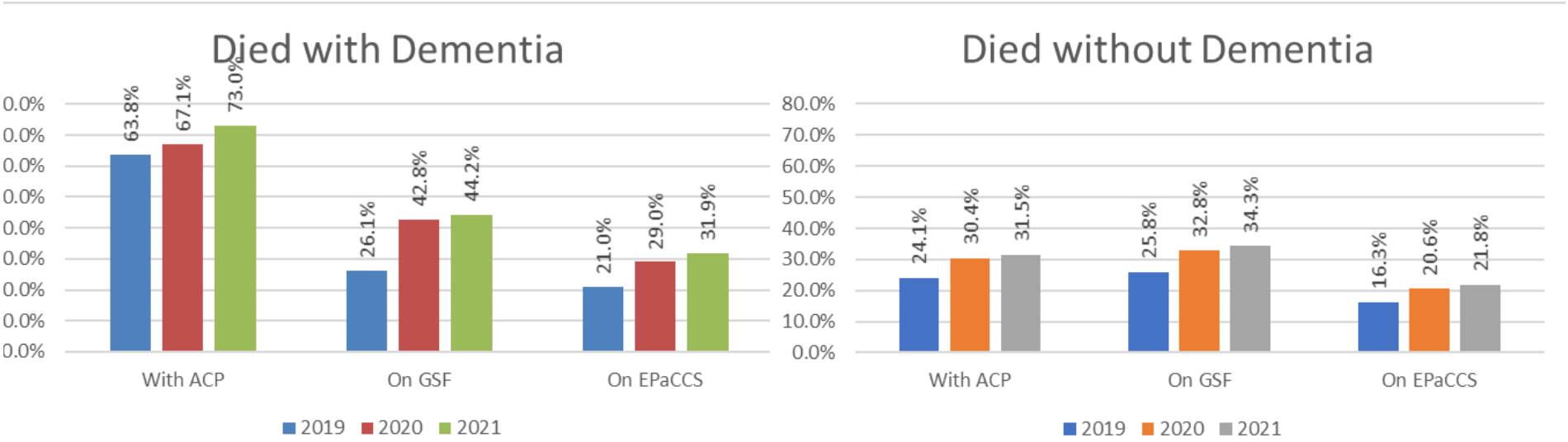


Table 3 - People who have died since 2019 (with and without Dementia) by year and by care element

Current Provision

General palliative and end of life care is currently provided by staff in primary care (GPs and community teams), secondary care (hospitals and hospices) care homes and by informal carers (family and friends). Where a patient's symptoms are complex there may be a need for specialist palliative care provided in hospital, hospices or by specialist palliative care staff in the community. The Palliative Care in Partnership is a new service commissioned by Cheshire Clinical Commissioning Group that aims to provide patients who are approaching the end of their life with care and support in a place of their choosing, usually at home or in their normal place of residence.

Planning with the 'whole family' and establishing that individuals have identified advocates to support them with health and welfare decision making is crucial, to ensure that the wishes of the individual living with dementia are reflected in the actions taken. This approach also assists the person's family as they will be directed to services that can support them once their loved one has passed away, such as bereavement services, as well as the formalities that will need to be carried out. There is a need for individuals to have a good death, which is dignified and comfortable as this can help those who are bereaved to deal with the circumstances better.

Information on caring for someone at end of life and bereavement can be accessed via the End-of-Life Partnership (EoLP), this support includes such things as:

- Making Plans for the Future (Wills, Care Plans)
- Understanding Palliative and End of Life Care
- Understanding Bereavement and Grief
- Looking after yourself or a loved one experiencing bereavement

Based within the End-of-Life Partnership there is the Advanced Dementia Support Team which is a small multidisciplinary team. The team works across health and social care settings and with families, to improve end of life care for people living with advanced dementia in East and Central Cheshire care homes.

Some groups provide ongoing peer support to carers whose loved ones living with dementia have either gone into Hospice Care, Care homes or passed away, whilst these exist, our engagement has identified that there is a need for more of such support to be available.

Both local hospices who support Cheshire East residents (St Luke's Hospice and East Cheshire Hospice), have numerous ways of supporting those individuals who are accessing a service or form of support from them, who are living with dementia and their carers. As well as the support they give to any individuals who are in patients at the Hospice they support in other ways including, Bereavement support, Advanced Care Planning and Counselling etc.

Key Issues and Challenges

- People feel that there is very little emotional support or information on the help available for family / carers just before, during and after loss (this includes those carers who's loved ones have been placed into a Care Home / Hospice etc)
- People diagnosed with dementia are not supported to plan for their future care soon enough after diagnosis. This includes such things as Advanced care planning to ensure that wishes are known before the patient loses capacity with frequent opportunities for people with dementia and their families / carers to make decisions about end-of-life care and review these decisions as the condition progresses
- There is a need to raise awareness around what support or information is currently available or on where to go, for example are there any groups for bereaved family members / carers to get support from one another.
- There is a need to raise awareness of how the disease could progress and on what services will be available at each stage with information on writing wills and power of attorney.
- There is a need for more support / information on end-of-life care with appropriate services in place so the person who is living with dementia is able to die where they want, and their wishes upheld.
- The need to ensure that families and carers receive the right level of bereavement support and counselling.
- The need to consider those individuals who are carers but are also living with dementia in anything we do
- Cultural considerations are needed when supporting those from ethnic minority groups

Ambitions for the Dying Well (Planning and Caring Well) Pathway

Outcomes

- People with Dementia will die with the care and support they need, in their preferred place, with the people important to them close by.
- People living with dementia, their families and carers will be aware of the importance of advanced care planning / end of life planning and will complete advance care plans that are recorded and held by the GP
- People are aware that they can appoint an advocate for their health and welfare at an early stage in the process, and these will be in place at a time that is right for the individual and family
- Carers and families receive bereavement support / signposting at a time that is right for the individual or family.
- Access to specialist palliative care where their symptoms are complex
- Discussion at Palliative Care Multi-Disciplinary Team's within Primary Care to support care coordination

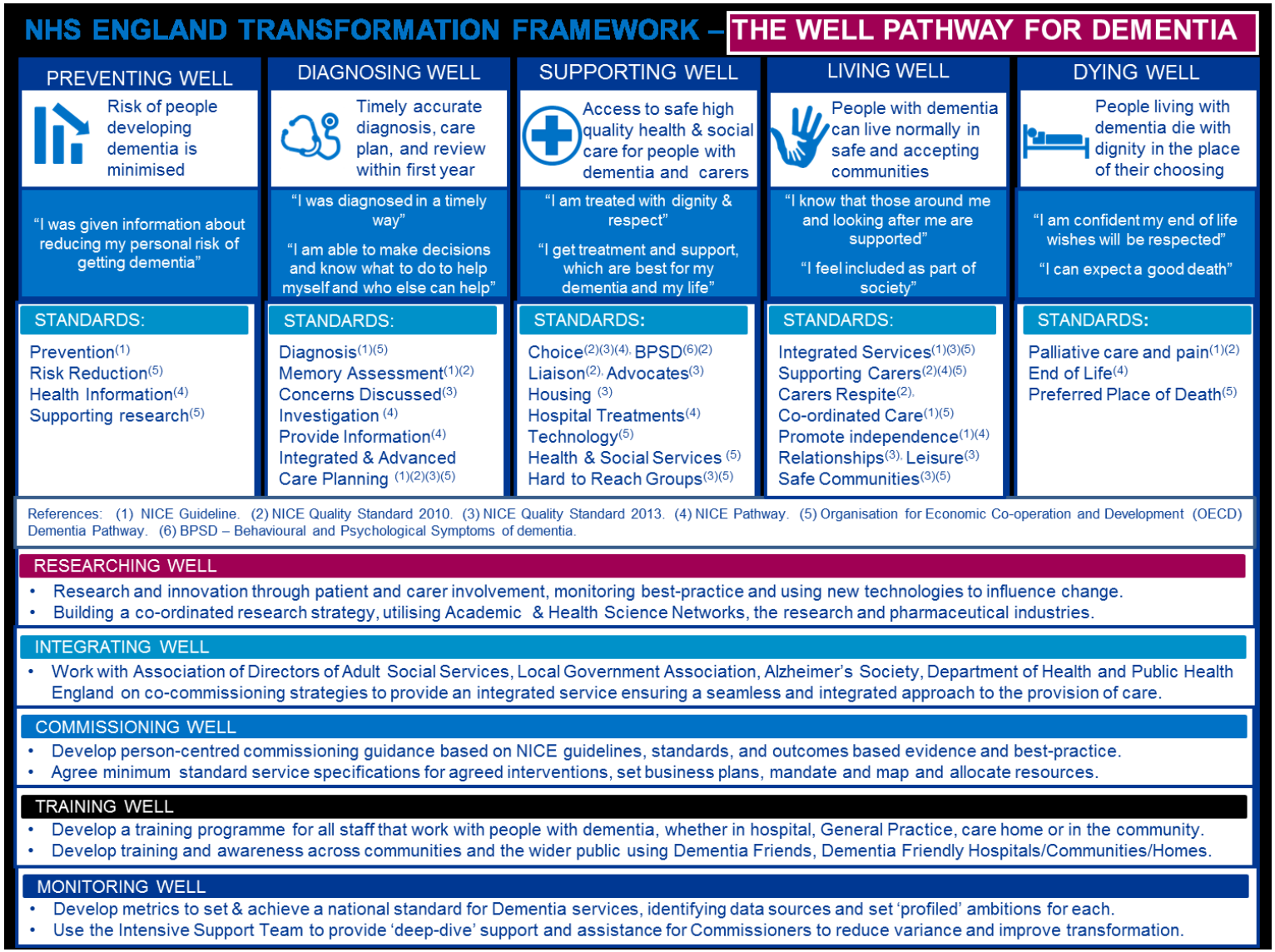
- Advance care planning discussions are also recorded and shared within Electronic Palliative Care Co-ordination System (EPaCCS)

The Cheshire East Dementia Strategic Group has developed a number of high-level ambitions which set out how we will improve the experience of local people affected by Dementia. These ambitions are referenced in each section of the strategy and summarised together in Appendix 2. They reflect the requirements of the NHSE Dementia Pathway, good practice and most importantly the information provided by those who have taken part in our survey and consultation exercises, ie people with Dementia, their carers and service providers. Each ambition is underpinned by a number of specific actions which will be carried out in the short, medium and longer terms.

The Group will continue to meet regularly to monitor and review progress and to ensure the proposed actions are implemented and our ambitions realised. Where necessary plans will be adapted to meet changing needs and to respond to any challenges or new opportunities as they arise. The Group will continue to engage with those affected by Dementia to ensure that we regularly assess and review whether this strategy is making a demonstrable difference to the experience of people living with dementia and their carers and families. We know that to really meet the needs of the individual; it is important to listen to them. We will therefore involve people living with dementia and their families in helping us achieve the ambitions set out in this strategy and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the strategy but helps to measure the impact of it.

The Steering group will produce an annual report on progress of how work around the action plans is going and what we have done and what we need to do, including identifying any issues we may have faced

The Well Pathway for Dementia is the treatment and care pathway that aims to ensure people have a better experience of health and social care support from diagnosis to end of life.



Ambition Action Plans

Overarching Ambitions of the Cheshire East Place Dementia Strategy

Throughout the development of this strategy and during our consultation with service users, common themes were identified which have been used to shape our overarching ambitions of this strategy. They are.

- **Preventing Well**
    - To make improvements in the way we communicate and work in partnership with others
    - To raise awareness of Dementia amongst staff and the local population to reduce the stigma associated with it
- **Diagnosing Well**
    - To make the changes needed to enable people to get their diagnosis as early as possible
- **Supporting Well**
    - To ensure good information / advice and support is accessible to all (in a format suited to their needs) throughout their dementia journey, for the person diagnosed and their carers
    - To ensure that Health and social Care work together to provide care and support to those affected by Dementia
- **Living Well**
    - To ensure that a range of different community-based options for people living with dementia and their carers are available, maintained and promoted so that they have more choice over the support they access
    - To enable and empower residents living with dementia to have a voice and say in shaping their community and the support that they receive
- **Dying Well (Planning and Caring Well)**
    - To work with partners to enable early conversations with people with dementia and their carers about advance planning and end of life care, so that people can plan ahead and ensure they are fully involved in decisions on care at end of life and that their wishes are known and acted upon
    - To ensure there are sufficient groups to provide ongoing appropriate peer support for those living with dementia and their carers.
    - To ensure that carers are supported pre and post bereavement.
    - to ensure the Mental Capacity Act and Best interest process is implemented, where necessary, to support in this decision making where early advanced care planning has not been considered/undertaken

Area	Action	Outcome
Improvements are required in relation to communication and partnership working	We will work on improving communication and partnership working across the Cheshire East footprint between Health and Social Care. The Demographics of each area will be considered, as a pathway in one area will not necessarily work in another.	Work will be undertaken to bring together NHS organisations, local government, and wider partners, to deliver more joined up approaches to improving health & care outcomes, looking at how local services and partners can better work together
Raising awareness to reduce stigma around dementia. Good information / advice and support is accessible to all (in a format suited to their needs) from presentation through to Dying Well for the person diagnosed as well as carers	• We will identify and share best practice for raising awareness and understanding of dementia in the community ensuring that we include **all** age groups and those from ethnic minorities (including religious minority communities and Gypsy and Traveller communities), LGBT+ and Learning Disabilities Communities • We will empower residents to recognise the signs of dementia, ensure they are supported and informed. • Encourage and promote champions for dementia within the community (including looking at local cultural champions within such groups as those from an ethnic minority and Learning Disability) and across the wider workforce. • We will ensure all information is available online, with hard copy (paper format) accessible at all libraries, dementia support venues, GP surgeries etc. We will ensure that information is accessible to all in a format suited to their needs, which will be accessible throughout the persons journey and as their needs change • An information pack will be available once diagnosis have been received and will include relevant contacts, support, and advice for various circumstances and what to expect long term. The information will be clear and concise We will also ensure that the Dementia aspect of the “Live Well” website is updated with relevant information to ensure that individuals have all of the information they need in one place.	Residents will have an increased awareness and understanding of dementia, across all age groups, this will include the benefits of receiving an early diagnosis. Residents across all areas of the community will be encouraged and supported to become Dementia Champions to enable them to create more Dementia friends within their communities Individuals diagnosed with dementia and their family or carers will have easy access to information upon diagnosis (the information supplied will be sufficient and individuals will be aware of who to contact for more information should it be required). Information and advice will be easily accessible throughout the person’s journey and as their needs change

To make the changes needed to enable people to get their diagnosis as early as possible	We will work to raise awareness of the benefits of obtaining an early diagnosis, and ensure there is a joined-up approach from all parties involved in the diagnosis pathways	People will be aware of the benefits of obtaining an early diagnosis, and have access to holistic support from the Health and Social Care sector
To ensure that a range of different community-based options for people living with dementia and their carers are available, maintained and promoted so that they have more choice over the support they access	We will look at enhancing the role of prevention services such as Day Services and Community Respite etc. We also look at what community support is needed, where and in what format	People will have access to a range of community-based options to support them
To enable and empower residents living with dementia to have a voice and say in shaping their community and the support that they receive	We will develop a Dementia Forum to ensure those living with dementia will have a voice at a strategic level. We will also ensure that, where appropriate, we will develop subgroups to assist us in addressing and delivering the actions within these action plans	People living with dementia will feel empowered to have a voice and say in shaping their community and the support they receive
To work with partners to enable early conversations with people with dementia and their carers about advance planning and end of life care, so that people can plan ahead and ensure they are fully involved in decisions on care at end of life and that their wishes are known and acted upon	We will work with partners (including those living with dementia and their carers) to identify where the gaps are and what the barriers are to enabling those living with dementia and their carers to make decisions on care at the end of life and individuals wishes at an early stage	People living with dementia and their carers will have access to information and support to enable them to make decisions at an early stage around individuals wishes and care at the end of life
To ensure there are sufficient groups to provide ongoing appropriate peer support for those living with dementia and their carers.	We will look at where there are currently peer support groups, and how they work, who they support. We will then work with and support partners to develop further groups appropriate to the needs of the local population, this would also include those living in rural areas, to ensure there is local / accessible support in their area.	People living with dementia and their carers will have access to appropriate peer support and groups.
To ensure that carers are supported pre and post bereavement	We will work with partners such as the local Hospices and End of Life Partnership (and those living with dementia and their carers) to identify what support is already out there for carers around Anticipatory Grief and Bereavement support. Where gaps or a need is identified we will work towards further developing the offer to carers.	People living with dementia and their carers will feel supported in relation to Anticipatory Grief and Bereavement.

To ensure the Mental Capacity Act and Best interest process is implemented, where necessary, to support in this decision making where early advanced care planning has not been considered/undertaken	We will ensure professionals across the partnership have access to training and education in Mental Capacity Act (2005) (MCA) to improve their confidence, knowledge and skills We will promote awareness campaigns about Lasting Power of Attorney (LPA) from the Office of The Public Guardian We will work to ensure that people living with dementia and their carers, have access to information and advice so that they understand the importance of early advanced planning and decision making When the cognition of people living with dementia deteriorates we will ensure the person, family and carers are supported through the MCA process	People living with dementia will be appropriately empowered and supported to make their own decisions related to healthcare needs. Any person with LPA for Health and Welfare are exercising their role appropriately under the MCA (2005) Professionals are able to apply the Mental Capacity Act(2005) process appropriately to support people living with dementia in applying the MCA.

Area	Action	Outcome
The NHS Health Check is aimed at adults in England aged 40-74 and people are eligible for health checks every 5 years. It's designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes, and dementia. CCG to establish links within each care community to improve prevention / screening and healthy living	We will work to raise awareness of symptoms of dementia earlier and encourage people to make positive changes. We will encourage and work with GPs to provide information on dementia to people aged 50+ during their NHS Health Check. Cheshire Clinical Commissioning Group (CCG) are looking to establish links within each care community to improve prevention / screening and healthy living	Harmful behaviours will be detected early which will enable people to be informed about their lifestyle choices, in order to improve people's physical and mental health at an early stage, when changes in behaviour can have a real impact on long term health and wellbeing.
All age healthy lifestyle promotion	We will support the promotion of digital tools, such as One You Cheshire East to raise awareness of healthy lifestyles and to support people to make changes to the way they manage their health and wellbeing. This service needs further awareness and promotion, health & social care professionals should signpost to this service, especially in relation to the risks linked to Dementia We will ensure local online and telephone directories, such as Live Well and Healthwatch Cheshire East https://healthwatchcheshireeast.org.uk/, are kept up to date with relevant contact details / links etc, with regards to healthy lifestyle services within Cheshire East for the public and health and social care professionals to support with signposting those identified as 'at-risk' to preventative activities. We will promote awareness campaigns within our communities from organisations such as the Alzheimer's Research UK and Think Brain Health etc	Residents will be encouraged to take more responsibility for their health and wellbeing and have increased awareness of ways of improving their health and reducing risk factors associated with dementia and other long-term conditions. There will be increased uptake of local healthy lifestyle services and improved There will be consistent signposting in the borough, so people know where to go to access support and what type of support is available. Also, that such information is kept up to date
There is greater awareness and understanding of the factors that increase the risk of dementia and how people can reduce their risk by living a healthier life	We will work to ensure that people living with dementia and their carers, have access to information and advice so that they understand the risk factors for dementia and how their risk could be reduced. Carers are supported to remain physically and mentally well.	Local GP practices, health and support services will offer guidance and signposting advice into appropriate support services.

Education and Early Support for those living with dementia / families and carers of those individuals identified as being 'at risk' from developing Dementia	We will work with relevant partners to ensure that more support will be available in helping people with dementia, including early support and education for families and carers of those who are identified as being 'at-risk' and will include **all** cohorts of the community. The approach will be joined up and adapted to individual circumstances / needs to prevent a one size fits all approach.	Education and Early Support for those living with dementia / partners and carers of those individuals more at risk from developing Dementia will be improved.
Early intervention and ongoing support for hearing loss / sight loss issues	People need to be encouraged to act when they think they may have hearing loss / sight loss (or problems) i.e., get their hearing / sight checked and get hearing aids / glasses if appropriate. To ensure that any hearing and sight loss / issues are picked up at an early stage	People will feel encouraged to act when they think they may have sight or hearing loss.
Research that looks at cause, cure, and care for dementia	We will advise individuals living with dementia, their carers, professionals and the VCFS sector when there is research available which they could take part in which looks at cause, cure, and care for dementia	Individuals living with dementia, their carers, professionals and the VCFS sector, will be informed and enabled to take part in any research at a local level, that we are advised of.
Accessible information on who to go to when you see possible signs of dementia, and the benefits of receiving an early diagnosis	We will work on developing more accessible information on who to go to, on the early signs of dementia and the benefits of getting a diagnosis. There will be an awareness campaign around early signs of dementia and the benefits of an early diagnosis	People will feel empowered to seek support and guidance, if they feel they have any possible signs of dementia. People will be aware of the benefits of an early diagnosis

Area	Action	Outcome

ALL residents receive a timely diagnosis	We will work with GP's, Primary Care and Memory Services to improve diagnosis rates across the Cheshire East footprint. Support is available for the person being assessed and their families throughout the diagnostic process. We will review the Memory Clinic pathways to ensure there is a standard response and support across the Cheshire East footprint We will work with GP practices, Memory Services and care homes to make it easier for care home residents to get a diagnosis of dementia as required, with a view to improving support for the residents and staff concerned.	CCCG are currently reviewing diagnosis pathways and are working with Primary Care to see where there are areas for improvement
Work with GP Surgery's to register any Carer's who are identified at the point of diagnosis (for clarity this will be for both anyone caring for an individual living with dementia, or the Carer themselves is living with dementia)	We will work with GPs Surgerys to ensure that any carers identified at point of diagnosis will be registered on their systems to ensure the Carers are effectively signposted to relevant support at an early stage	Carers will be identified and supported at an early stage, and registered with the GP surgery as a Carer at point of diagnosis
Improve diagnostic rates for Young Onset, ethnic minority groups and LD communities	We will work with younger members of society, ethnic minority groups, learning disability communities and local services to devise the most appropriate ways to increase awareness and reduce the stigma of dementia within their relevant cohorts. We will work collaboratively with differing cohorts of the community to promote the Dementia Champion scheme and how that can benefit their community, for example, Cultural Dementia Champion from those from an ethnic minority background We will also support staff from Cheshire East Council, Cheshire CCG, health, and social care providers, the VCFS sector etc to access dementia awareness sessions Cultural understanding of ethnic minority groups by GP's and their staff. We will work to developing translated resources	Residents will have the awareness that dementia can affect young people (not just the elderly) and encouraged to access health and social care services, support groups etc, for those thought to have Young Onset Dementia. Those from ethnic minorities and learning disability cohorts of community will have the awareness on how dementia can affect them, and be encouraged to access health and social care services, support groups etc. There will be more local Dementia Champions in all areas of the community, which in turn will create more dementia friends and increase awareness. Staff will feel empowered to discuss dementia with their service users to break down the barriers and stigma associated with dementia. Those from an ethnic minority background will feel supported by GPs who understand their cultural needs in relation to obtaining a dementia diagnosis and be able to access resources which are translated into the languages which best fit their needs

Appropriate access to information and advice at each point of the individual's journey	An information pack will be made available once diagnosis has been received to include relevant contacts (including local support groups), information around what can be accessed to alleviate financial pressures, support, and advice for various other circumstances and what to expect long term. Work will be undertaken to ensure there is sufficient and effective signposting at all stages in an individual's journey – for example GPs to signpost to relevant services etc	People diagnosed with dementia and their family or carers will have easy access to information upon diagnosis (ensuring that the information supplied is sufficient and ensuring that the individuals are aware of who to contact for more information should it be required). It will be easily accessible throughout the person's journey and as their needs change
Improved access to good quality joined up support following diagnosis	Post-diagnosis support will be tailored to include the needs of people under the age of 65, people with learning disabilities, ethnic minorities, religious minority communities and Gypsy and Traveller communities and people from the LGBT+ community	People from all cohorts of the community diagnosed with dementia will benefit from tailored post diagnosis support
Dementia Friendly GP Surgeries	Where there is a need, we will look at any increased training for GP's and their staff. (Look at Leaders in Dementia Care Programme recently developed by Mid Cheshire Hospital and EoLP for professionals) could this be rolled out to GP's Dementia Friends awareness to take place with staff at GP's surgeries Awareness needs to be raised with GP's and other professionals regarding the repercussions felt, mentally, physically, and emotionally by carers when their loved one is diagnosed with dementia	All GP surgeries will become Dementia Friendly, enabling those visiting the surgeries to feel supported and listened to. All GP surgery staff will be Dementia Friends GPs and other professionals will have awareness around the repercussions felt by carers, once their loved one is given a diagnosis of dementia.

Area	Action	Outcome
Partners / Professional Services are to work more collaboratively, including such provision as hospital and community support.	Pathways of support will be looked at to see where there is a need to improve collaborative working between partners / professional services, including hospital and community provision.	The need to 'search' for information and support will be reduced as partners will be working closely together and signposting to other services and support effectively
People living with dementia will be able to live at home for longer	We will prioritise Home First for patients discharged from hospital. Where possible patients will be discharged to a home of their choice There will be sufficient local provision of care and support at home where more support is required. We will work to ensure that people living with dementia stay in and are cared for in their own home for longer	The Home First service will be expanded and developed to support people to stay at home longer We will look at our current Care at Home provision to ensure there is sufficient capacity within the market to support those living at home for as long as possible Further work with Care Providers to see how they provide personalised care, where there are gaps or a requirement to increase knowledge, we will look at how to rectify this.

Education, training and development opportunities for people and organisations providing care and support for those living with dementia	We look at further developing the current offer in relation to education, training, and development opportunities for those people and organisations providing care and support for people living with dementia. at a level that fits with their individual responsibilities, this may include single information and advice sessions on dementia itself and how to support loved ones and deal with behaviours Care at Home and Accommodation with Care staff will have increased access to Tier 2 Dementia Care training	People and organisations who provide care and support to those living with dementia will have education, training, and development opportunities available to them at an appropriate level to ensure they can support an individual living with dementia in the most appropriate manner no matter their race, age, gender etc. We will look at training for Care Providers to increase their knowledge of how to support someone living with dementia and their carers in their home environment
Improve information sharing and signposting	Define what the current offer is around who shares information and signposts across the CE footprint, look at whether this needs to be streamlined. Identify the pathways and ensure all are made of such Develop a pathway of community support when individuals are exiting from Memory Clinics, to ensure they are aware of what is available to them in their local area after they have exited the memory clinic support – this is already being done by Dementia Friendly Community in Nantwich We will work with GPs to improve signposting to such support as Alzheimer's Society to prevent the need for individuals to have to look for where they can obtain support post diagnosis Work to ensure more use is made of community groups to share information and strengthen the messages	Information sharing and signposting pathway will be clear and streamlined, leading to those living with dementia and their carers being equipped with the information / support they require at the time they need it
Look at developing age-appropriate groups / supported volunteering opportunities and activities for those living with young on-set and or a Learning Disabilities	Those individuals living with young on-set dementia will have a choice of age-appropriate groups, supported volunteering opportunities and activities to attend We will work with partners / people living with dementia and their carers to understand what the offer of support currently looks like and what they would like it to look like, we will then work with such team as the Supported Employment Team to understand how they can assist, for instance those who wish to go back into a form of employment / volunteer etc	Those living with young onset dementia / Learning Disabilities will have a choice of age-appropriate groups, supported volunteering opportunities and activities which suit their needs

Improving knowledge around advanced care planning / anticipatory care planning	We will consult with such teams as the Advanced Dementia Support Team and local Hospices, to obtain on oversight of the current offer available to both those living with dementia and their carers. We will work collaboratively with such organisations as the local hospices when they are looking at how to deliver support to those living with dementia / their carers in a different way We will also use information from our engagement to inform what individuals living with dementia and their carers have advised they need.	People will have access to increased knowledge and support around advanced care planning / anticipatory care planning across the Cheshire East footprint
Improving knowledge of the Mental Capacity Act (2005) and Best Interest Decision making process for professionals. People living with dementia, their families and carers will also be aware of the process if the persons cognition decreases and best interest decision making needs to be made.	We will ensure professionals across the partnership have access to training and education in Mental Capacity Act (2005) to improve their confidence, knowledge and skills We will raise awareness with people living with dementia and their carers, so they understand the importance of early advanced planning, mental capacity and best interest processes We will promote awareness campaigns about Lasting Power of Attorney from the Office of The Public Guardian	Professionals, people living with dementia, their carers and families will have increased knowledge and / or awareness of the Mental Capacity Act (2005) and Best Interest Decision Making Process People living with dementia will be appropriately empowered and supported to make their own decisions related to healthcare needs. Any person with LPA for Health and Welfare are exercising their role appropriately under the MCA (2005) Professionals are able to apply the Mental Capacity Act(2005) process appropriately to support people living with dementia in applying the MCA.

Area	Action	Outcome
People living with dementia are enabled to live at home	• We will look increasing the use of technology to digitally enable people living with dementia and their carers to live at home safely • We will work with partners to develop appropriate accommodation and Extra Care Models. • We will work on further developing the offer around falls prevention to reduce the risk of falls. • There will be a co-ordinated offer of information, advice and guidance that enable people to have choice and control over their health and independence. • we will work with community providers to maximise community provision as a tool to support people living with dementia and their carers	Links will be developed with our partners around falls prevention, Housing, planning, Assistive Technology, sensory impairment etc and more people will be enabled to live at home supported by a digital offer More appropriate accommodation will be developed for those living with dementia and their carers Ensure those that signpost have access to the most up to date information (including the booklet we will look at developing)
Reduce Social Isolation: Including Peer Support Groups / Carers Groups, Transport etc Organisations providing Transport will feel equipped to support those living with dementia and their carers (including those living in rural areas)	Work will be undertaken to identify where the gaps in support are across the Cheshire East footprint, any areas of good practice that are already in place will be looked at and shared in areas where gaps exist (including rural areas) , and individuals / organisations will be encouraged to develop such good practice in those areas – for example Reflections Group in Poynton for those Carers who have been bereaved We will raise awareness around the current Transport offer available to residents living with dementia and their carers, and how they can use this service to access groups etc We will work with organisations providing Transport who require increase understanding of dementia, to identify any challenges they may experience in supporting those living with dementia and their carers We will also talk to residents living with dementia and their carers to understand the challenges they face when using Transport, and where there may be challenges around accessing relevant Transport in rural areas, Once both the above have been considered we will work towards creating an action plan to improve the services and reduce the barriers identified.	For people living with dementia to be enabled to maintain and develop social connections through peer support, carers groups. Current suitable transport provision will be promoted to ensure those living with dementia and their carers know who and what to access and when Organisations providing Transport will be equipped to support those living with dementia and their carers. Those living with dementia and their carers will feel the public transport they use is welcoming and inclusive.

Carers of those living with dementia can access support as needed and feel able to continue with their caring role Accessible Respite, Day Care and Community Based options of support for those living with dementia and their carers	We will work with community providers to maximise community provision as a tool to support those caring for someone living with dementia (this will also need to include those carers who are living with dementia themselves) We will work with partners to ensure that carers are identified at an early stage and are signposted to the Carers Hub in a timely manner We will look at enhancing the role of prevention services such as Day Services and Community Respite etc	People living with dementia and their carers / family to be put in the centre of their care and have access to flexible support that is responsive to their personal interests and needs
There will be greater availability of community housing options suitable for people with dementia	Cheshire East Council will ensure that future housing or community development plans (such as the planned re-generation of Crewe town centre) include consideration of dementia friendly housing options including Extra Care Housing and dementia friendly buildings Greater information and clarity to be provided to people with dementia and carers to support them access housing options that meet their care and lifestyle needs.	There will be adequate dementia friendly housing provision that will meet any increase in need for those individuals living with dementia, in order to support them to live well with dementia in their community. People with dementia and their carers will receive information about housing and care home options available to them to support them to make decisions about the future in advance.

Dementia Friendly Communities (including intergenerational work and simple changes to existing services)	We will: • Identify and share best practice for raising awareness and understanding of dementia in the community. • Empower residents to recognise the signs of dementia and ensure they are supported and informed. • Look at how Cheshire East Place can start to work becoming Dementia Friendly, including Dementia friends' sessions, awareness and working with employees, organisations, local groups etc • Ensure that young people are part of the community support for people living with dementia. • Work with education (from schools to colleges) to encourage them to include dementia awareness, for example the SWAY project and Dementia Awareness sessions to pupils, leading to the creation of dementia-friendly generations. • Work with public sector and public facing organisations to recognise and better support daily living for those living with dementia • Memory / Dementia Cafes will be linked in with GP surgeries, Carers Hub, Support Services, and providers. This is to provide neutral ground to have information clarified, share experiences, and obtain a better perspective of their situation.	There will be sustainable communities that are inclusive of people living with dementia.
Organisations providing Transport will feel equipped to support those living with dementia and their carers	Reduce Social Isolation – we will raise awareness around the current Transport offer available to residents living with dementia and their carers, and how they can use this service to access groups etc We will work with organisations providing Transport who require increase understanding of dementia, to identify any challenges they may experience in supporting those living with dementia and their carers We will also talk to residents living with dementia and their carers to understand the challenges they face when using Transport. Once both the above have been considered we will work towards creating an action plan to improve the services and reduce the barriers identified.	Current suitable transport provision will be promoted to ensure those living with dementia and their carers know who and what to access and when Organisations providing Transport will be equipped to support those living with dementia and their carers. Those living with dementia and their carers will feel the public transport they use is welcoming and inclusive.

Improve the knowledge and understanding of health and social care staff around: • those individuals who are LGBT+ living with Dementia and the specific issues that they may face. • The differences that exist within ethnic minorities, religious minority communities and Gypsy and Traveller communities – Cultural beliefs when it comes to Dementia etc. • The issues faced by those living with a Learning Disability and Dementia Care Market can respond to those living with dementia to enable them to live well	We need to ensure staff are aware of the wider issues and trained on equality and diversity. Services that are being delivered and the support offered to our residents must be equitable, respectful, and LGBT+ friendly. We need to ensure staff are aware of the wider issues and trained on equality and diversity. Services that are being delivered and the support offered to our residents must be equitable, respectful, and ethnic minority friendly. We need to ensure staff are aware of the wider issues and trained on equality and diversity. Services that are being delivered and the support offered to our residents must be equitable, respectful and Learning Disability friendly. Look at options for obtaining Training of Care Staff to tier 2 standard (should further funding be required we may possibly need a Business Case) Consult with the Advanced Dementia Support Team who currently provider Tier 2 training and look at how we can develop / increase the offer	Health and Social Care staff will understand the specific challenges that those individuals who are LGBT+ and living with dementia experience We need to ensure staff are aware of the wider issues and trained on equality and diversity. Services that are being delivered and the support offered to our residents must be equitable, respectful, and ethnic minority friendly. Health and Social Care staff will understand the specific challenges that those individuals living with dementia and have a learning disability experience Health and Social Care staff will have the opportunity to access various options of Tier 2 training, which will enable them to have an increased understanding of the condition and how they can support those living with dementia within their own home.
Equitable Out of Hours provision across the Cheshire East footprint	Awareness to be raised of the current Out of Hours provision available – including Cheshire and Wirral Partnership Crisis Line Gaps to be identified as to which areas such support is needed	People living with dementia and their carers will have equitable access to Out of Hours support across the Cheshire East footprint
Enable and empower residents living with dementia / carers to have a voice and say in shaping their community and the support they require. Also ensure they have a voice at a strategic level	A Dementia Forum will be created to ensure that the voice of those with lived experience have a voice at a strategic level. This will also feed into the established Carers Forum; this ensures that Carers also have a voice. We will work in co-production with people living with dementia and their carers to explore and identify best practice on engagement techniques.	People living with dementia and their carers will have a voice at a strategic level Identification of best practice and engagement techniques will be co-produced with those living with dementia and their carers

Area	Action	Outcome
People living with dementia and their carers will be aware of the importance of advance care planning and end of life planning, and will feel supported and confident to make these plans in good time	People living with dementia and their carers will be offered information by an appropriate health and social care professional regarding care planning and end of life planning and be supported/ signposted to put these plans in place. This information will be offered in a sensitive and timely manner following diagnosis to allow the individual to put their end of life wishes in place. Establish a baseline and monitor the number of end-of-life plans recorded in patient records	People living with dementia will have end of life plans and wishes in place while they have the capacity to make these decisions. Increase the number of end-of-life plans recorded in patient records
People living with dementia and their carers will be aware that they can appoint an advocate for their health and wellbeing and welfare at an early stage	People living with dementia and their carers will be offered information by an appropriate professional regarding how to appoint an advocate for their health and wellbeing and welfare	People living with dementia will have appointed advocates for their Health and wellbeing and welfare while they have the capacity to do so
People living with dementia will have their preferred place of death recorded in their patient record and upheld wherever possible	Ensure that any end-of-life plans and wishes are recorded in the individuals case notes by the health or social care professional involved with planning and, with consent, are shared with relevant professionals involved in their care e.g., specialist nurses and doctors. The number of end-of-life plans recorded in patient files will be monitored. Look at how to support as many people as possible to die at home wherever identified.	Health and social care professionals will be aware of an individual's end of life plan which will enable them to carry out care in line with the person's wishes. An increased amount of people with dementia who have recorded their home as their preferred place of death will be supported to do so when they are identified as being in their last days of life.
Education and Information for carers and professionals around best practice end of life care	As mentioned in the "living well" section, we look at the dementia training available for health and social care professionals, which will include reviewing current and potential training options regarding end-of-life care and end of life planning with people with dementia and carers. Health, social care, and Accommodation with Care staff to receive training to support them to identify when a person with dementia is at the end-of-life stage, and to provide appropriate and compassionate end of life care to individuals in line with NICE guidelines.	GP's and other health and social care staff will feel confident in raising and discussing end of life planning with people with dementia. Carers and Professionals will be aware of how to access education and information around best practice end of life care and how this can be of use to them, their loved ones Health and social care staff will be able to better identify when an individual with dementia is approaching their last days of life. This will lead to an improvement in end-of-life care, including assessment and management of symptoms and pain.

We will look at improving / increasing the support including bereavement support and signposting for Carers	Carers will have access to sufficient and timely support and signposting to local community organisations offering such things as bereavement support, peer support, this will also consider those carers whose loved ones have been admitted to a Hospice or Accommodation with Care placement. We will look at who would be best placed to discuss aspects of Dying Well (Planning and Caring Well) into their natural conversations, in an appropriate and timely way – for example the Dementia Reablement Service (possibly when they are discussing LPA & Wills etc).	Carers will have access to high quality bereavement support in a timely manner.
Emotional support or information on the help available for family / carers just before, during and after loss is required	We will build on the current offer available for carers / family just before or after loss – this includes Carers Wellbeing Programmes, Anticipatory Grief Awareness and Grief when caring ends (this needs to include those individuals who's loved one has moved onto a Care Home or Hospice environment and those carers who are living with dementia themselves)	Carers and Family will be equipped with information on what could support them just before, during and after loss
Specialist palliative care services	Review the availability of specialist palliative care for patients with Dementia so that complex symptoms are managed effectively. Make recommendations for any service redesign identified as part of the review.	Patients with Dementia, approaching end of life will have access to specialist palliative care when and where it is needed.
Advance care planning	Increase the number of discussions for people with Dementia, and ensure that they are recorded and shared within Electronic Palliative Care Co-ordination System (EPaCCS)	Patients and carers have opportunities to discuss care preferences which are recorded in a central place . All staff involved in the patient's care know what the patient's wishes are, what the care plan involves and understand what they are required to do to ensure the patient's wishes are respected.
Care coordination	Ensure patient's needs and wishes are discussed and reviewed at regular Palliative Care Multi-Disciplinary Team's Meetings.	All staff involved in the patient's care know what the patient's wishes are, what the care plan involves and understand what they are required to do to ensure the patient's wishes are respected.

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Cheshire East Council