CHESHIRE EAST PLACE DEMENTIA PLAN 2023 to 2027

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2. Introduction

This plan has been developed by Cheshire East Council in partnership with Cheshire and Merseyside Integrated Care Board (ICB), local providers and service users. The plan 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 plan 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 Plan 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 our previous Cheshire Clinical Commissioning Group has now changed to the Cheshire and Merseyside ICB as part of the establishment of an Integrated Care System and new ways of working.

Our plan 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, including plans to improve Dementia Diagnosis Rates (DDR). In August 2022 the Prime Minister announced that he would be launching a "national dementia mission", to tackle dementia, the mission includes an additional £95 million in research and clinical trial funding. This will create opportunities for people to take part in research and we can support and encourage residents to take part in this where appropriate.

The focus of our plan 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 and communication so that all services work together to ensure people access the services they need at the right time.

We have based the plan on 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 plan and will inform the development and implementation of a local dementia ambition 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 Cheshire and Merseyside ICB 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 a range of 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 and empowered

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 both at a personal and strategic level

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.

6. People living with dementia will be supported to plan effectively for their own future

Delivering the Plan

The plan 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 plan 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.

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. There needs to be a focus on community led support and prevention.

A Cheshire East Dementia Steering Group made up of people from a range of partner organisations and dementia friendly community leads was established to develop the plan 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 plan and to ensure any response to the actions detailed within the plan are co-produced effectively.

There are action plans which support implementation of 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. Dementia is a term used to describe a set of symptoms linked with progressive neurological (brain) disorders and may include memory loss, difficulties with thinking, problem-solving or language. The specific symptoms the person with dementia experiences will depend on the part of the brain which is damaged and the type of disease which has caused the dementia. Alzheimer's disease is the most common cause of dementia. Other types include Vascular Dementia, Mixed Dementia and Dementia with Lewy Bodies. There are also other forms of dementia associated with excessive alcohol consumption such as Wernicke- Korsakoff Syndrome. They are all life limiting diseases

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.

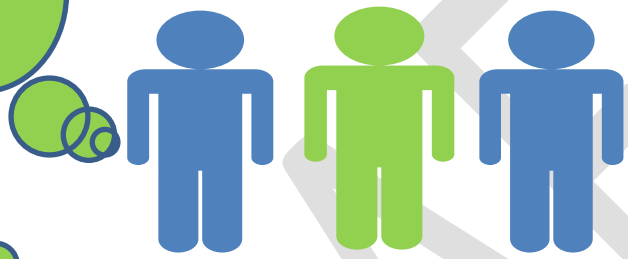
National Picture

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%

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

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

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

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

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).*

- 18% of Cheshire East's population is over the age of 65.
- In Cheshire East we have 23% of our population who are over 65 compared to 16% nationally.
- one in 20 people in Cheshire East over 65, has a form of dementia
- one in five people over 80 has a form of dementia
- 65% of people living with dementia are likely to be women
- 65% of the estimated prevalence of people with Dementia in Cheshire East have a recorded diagnosis
- There were 113 adults aged between 30 and 64, predicted to have Early Onset Dementia within Cheshire East in 2020 (Projecting Adult Needs and Service information (PANSI)
- 3,840 people have received a dementia diagnosis in Cheshire East (*NHS Digital*)

Local Community Led 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

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 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 every fortnight at St Mary's Church Hall, Nantwich you can drop in between 10am and 12.30pm

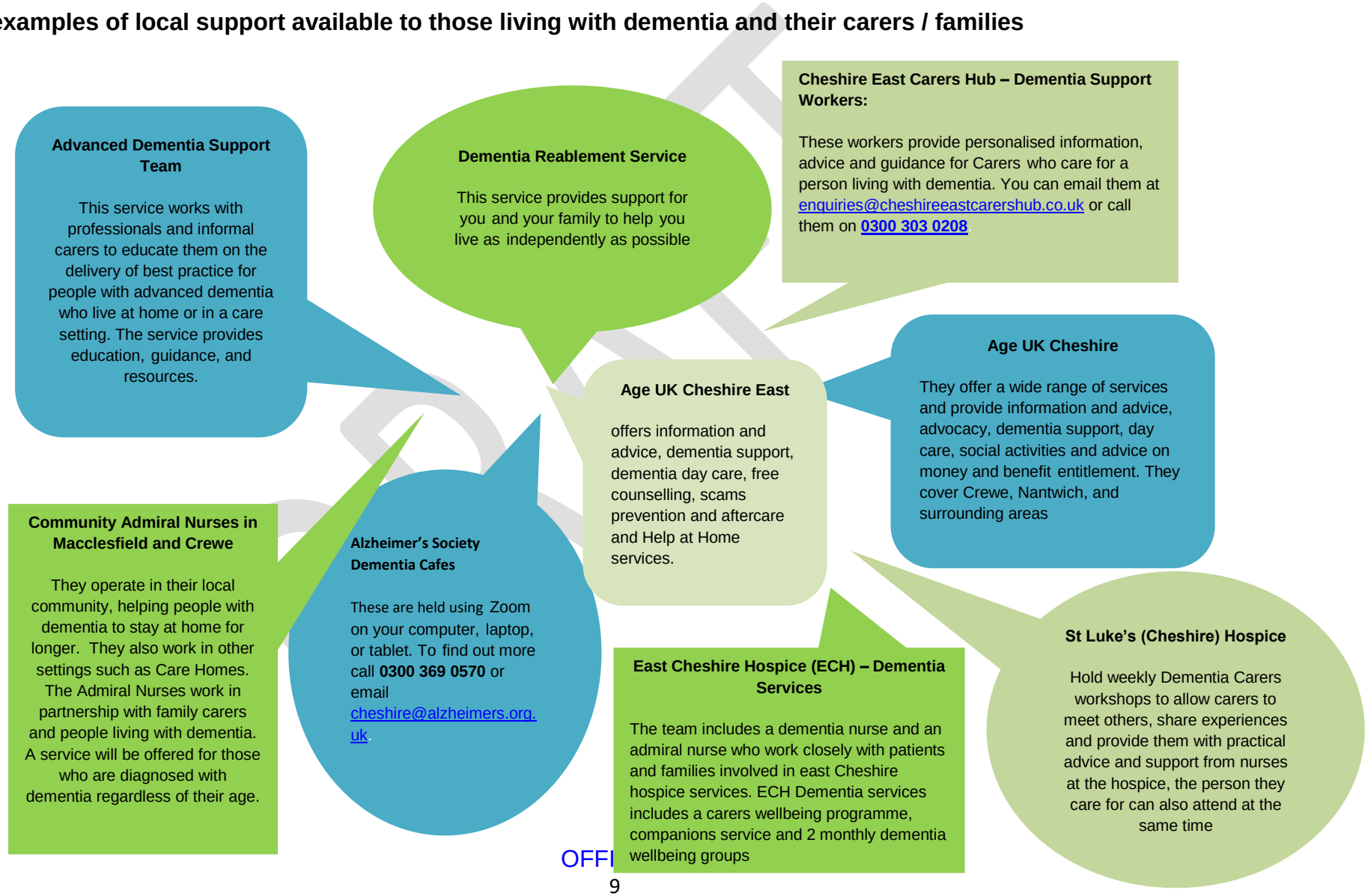
SWAY Project (started in Alsager).

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

Some examples of local support available to those living with dementia and their carers / families



Dementia Plan 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 Plan. 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 plan and informed the action plans where it is appropriate. More detail is provided in the relevant sections of the plan. The link to the full survey can be found here: https://www.cheshireeast.gov.uk/pdf/Council-and-democracy/Consultations/Dementia-results/Dementia-Survey-Report-Final-PDF-290KB.pdf

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 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.

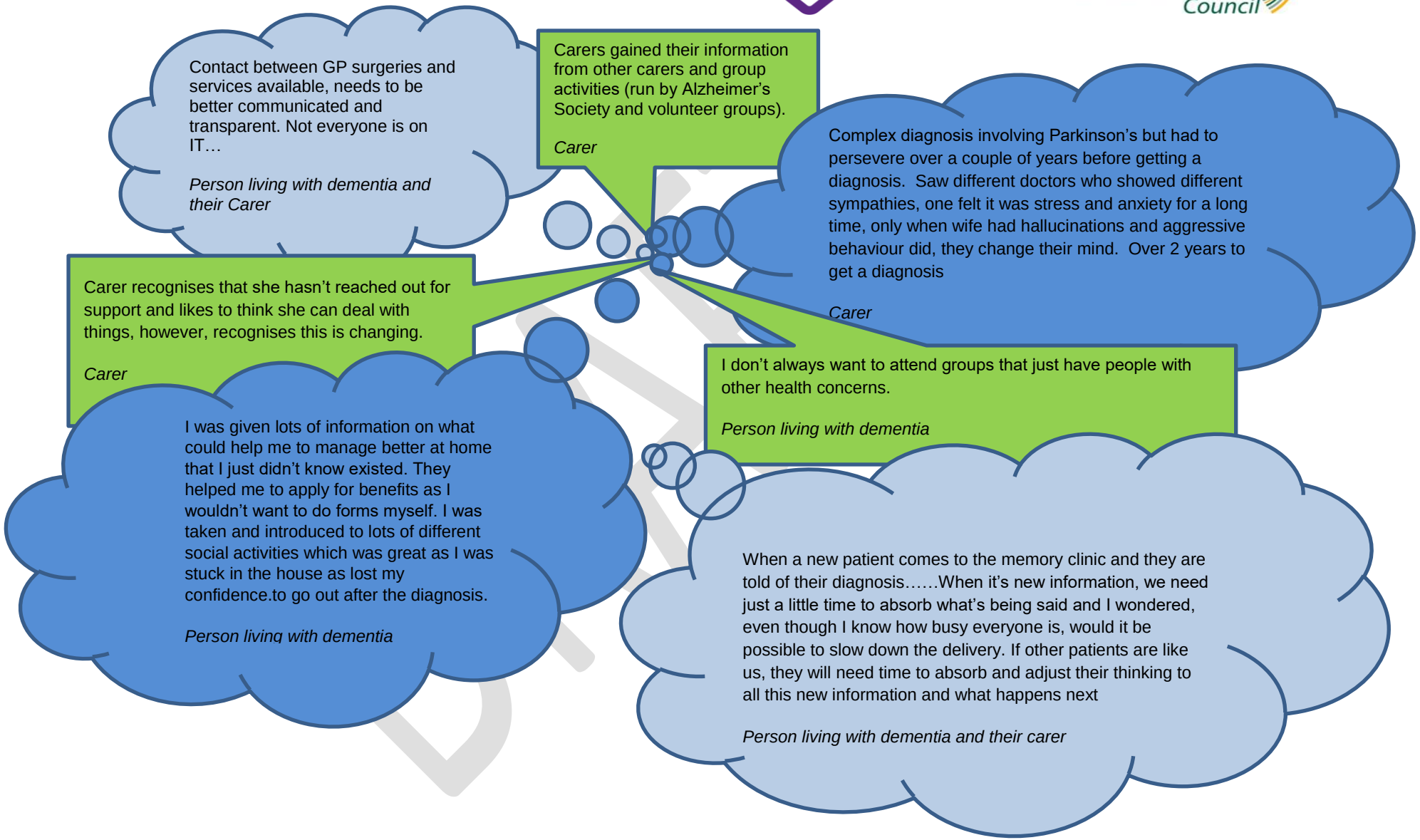
Person living with dementia and their Carer

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

4. PREVENTING WELL

"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, the negative impact on individuals and their families and increasing pressures on services it is important that we adopt a more proactive approach to communicating the risks of developing dementia and promoting healthier lifestyles. The first stage of the NHS Dementia Well Pathway focuses on the importance of prevention, reducing the risk of dementia. It considers the need to research and apply best practice and to consult with those affected by the illness so that we are continuously reviewing and improving provision. This plan will develop a range of actions to achieve this.

Prevention

In most cases dementia has several causes, known as risk factors. Some of these risk factors, like age and genetics are beyond our control and cannot be changed. But adopting a healthier lifestyle can help to ensure our brains stay healthier for longer, and so reduce our risk, or delay the onset of dementia. A key focus for this plan is therefore finding ways we can engage and encourage people at risk of dementia to make changes that may reduce the likelihood of developing the disease.

Learning from people affected by dementia and developing good practice

As noted earlier, this plan has been produced in partnership with people affected by dementia and a range of other stakeholders, including commissioners, and providers from the statutory and voluntary sectors. It is intended that this collaborative approach will continue as we develop and implement our local action plan. We wish to build on our learning about the needs of local people who are affected by dementia and will consult with them on a regular basis to ensure that the services we provide meet local need. We will also regularly seek out and review best practice developed in other areas, or by local providers, and amend our action plan on a regular basis to reflect any agreed changes in direction and our ongoing learning.

Research

Current treatments for dementia are limited. It is therefore important that we support efforts to reduce the impact of dementia and the ongoing challenge to find a cure. The Prime Minister has recently announced plans to invest £95 million into dementia research. We will promote the

benefits of supporting this research and encourage individuals to take part in any local or national initiatives which may lead to improvements in the care and treatments available to people affected by dementia. Information on dementia research, can be found at, Join Dementia Research (Join dementia research - register your interest in dementia research: Home (nihr.ac.uk)

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 that you make some lifestyle changes to address the factors detailed above.

Cheshire East Council already promotes healthier lifestyles through the 'One You Cheshire East' Service https://www.oneyoucheshireeast.org/ This is a free health and lifestyle service which enables local residents who require support to; eat well, drink less, move more, lose weight and become smoke free through dedicated classes. There is also 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 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. This

indicates a need to improve awareness that some of the issues people may be experiencing could be linked to an undiagnosed form of sight or hearing loss, and not their dementia.

Our consultation identified a number of difficulties associated with the lack of knowledge around how dementia can be prevented or delayed, a summary of which is provided below.

Key Issues and Challenges

- Some of those consulted reported being unaware of the available information on healthy lifestyles or the advice regarding ways to delay the onset dementia.
- Some services, information and advice are only available online; this causes a problem for those individuals who do not have access to the internet or for those who find technology difficult to manage.
- The fear of a dementia diagnosis and the associated stigma can prevent people from going to their GP about symptoms they may be worried about.
- Many people manage to live well with Dementia, but there are very few positive messages about the benefits of diagnosis and the available support.
- A one size fits all approach does not suit the differing needs of those at risk of developing dementia.
- There is limited awareness of 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.
- People with dementia who also have sight or hearing loss may have difficulty with communication and are at greater risk of feeling isolated.

Ambitions (Outcomes) for the Preventing Well pathway

To address the issues identified and achieve the ambitions set down in the NHSE Preventing Well guidance we have agreed several key actions and outcomes. Our overarching aim is to work with our partners to encourage and support local residents to lead a healthier lifestyle, (particularly those aged 40 and over) to prevent or delay the onset of dementia wherever possible. It is also our intention to support any research initiatives which may contribute to a reduction in the incidence or impact of dementia. Our action plan will reflect the work needed to achieve this.

5. DIAGNOSING WELL

The Prime Minister's Challenge on Dementia 2020 sets out the UK Government's strategy for transforming dementia care. One of the key aims of this national strategy is to improve arrangements for timely assessments and diagnoses. The plan 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.

Most patients concerned about memory loss will first approach their GP, who may then refer the patient on to the local Memory Service for assessment and diagnosis. Until recently the Dementia Diagnosis Rate (DDR) in Cheshire East was above the national target of 67%. However, the recent pandemic has meant that across the country health and social care services were 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 the Cheshire East diagnosis rate 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 improving, there remains a significant number of people still to be diagnosed. This may be due to several factors; perhaps a lack of awareness about the illness, fear of the diagnosis and its implications or it may be due to delays or other problems within the care system. We are 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. Whatever the reason, those who have undiagnosed dementia are unlikely to be accessing the support they need.

The table below shows the changing percentage of people diagnosed in East Cheshire since October 2019.

5,725	estimated prevalence of dementia in over-65s
3,836	target diagnoses based on prevalence
3,840	current number of dementia diagnoses among over-65s
4	difference from dementia diagnosis target

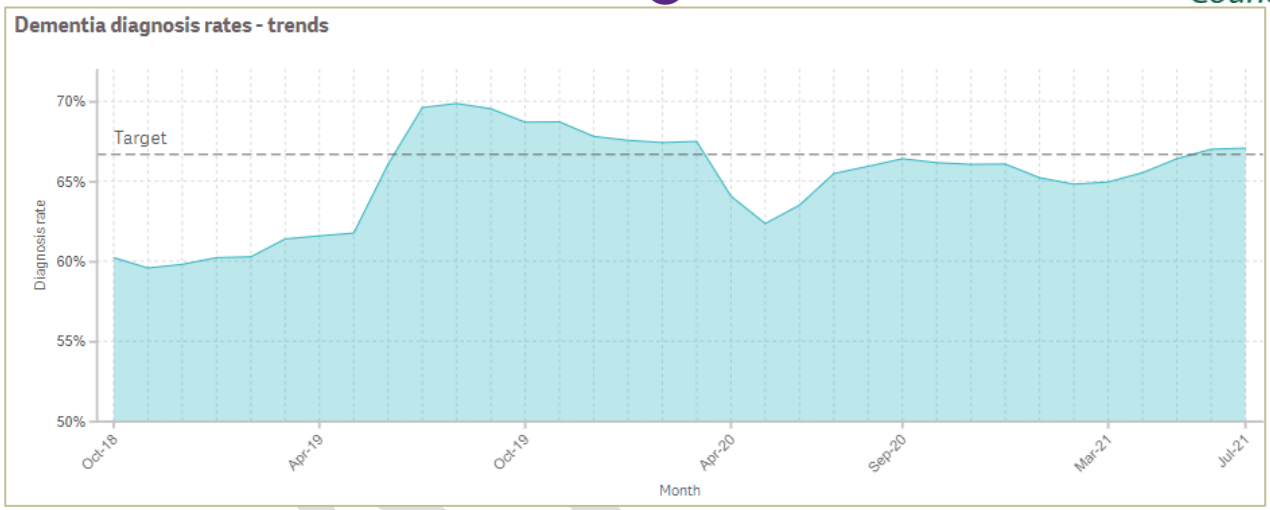


Table 1. East Cheshire Diagnosis Rates – Oct 2019 to June 2021 (Source NHS Digital)

The Benefits of a Timely Diagnosis.

The NHSE Well Pathway advocates, “Timely, accurate diagnosis” to enable personalised care planning and regular review. 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 relief to get an explanation for changes in memory or behaviour. On diagnosis the patient and carer should therefore be treated with compassion and understanding.

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 and make any necessary legal and environmental 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 prompt 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.

Raising Awareness of Dementia to Improve Diagnosis Rates

Ensuring people get a diagnosis is not the sole responsibility of GPs or Memory Services. As noted in the section Preventing Well, there is a need to raise the profile of dementia within our communities so that people live healthier lifestyles. However, increasing awareness of dementia and showing that people can live well with the illness might also improve patient confidence and may encourage more people to seek a diagnosis when they have concerns. This might be achieved by improving information, advice and support services and making our communities more dementia friendly.

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.

For instance, we know that certain groups in society have a greater risk of developing dementia or may be less aware of the illness or less inclined to seek a diagnosis. They may also have particular needs or concerns which should be catered for in the information and services we provide.

Whilst age is the highest risk factor for developing dementia there is evidence to suggest that people from black African and Caribbean communities may be at a higher risk of developing dementia. Dementia can also affect people in their 40s, 50s, and 60s and because of their age they find it more difficult to get a diagnosis and/or age appropriate support; approximately 5% of people with Alzheimer's are under 65. People with Downs Syndrome are particularly vulnerable to developing young onset dementia.

For older Lesbian, Gay Bi and Transexual+ (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 be single and live on their own. Many from the LGBT+ community fear that mainstream care services will not be willing or are not able to understand how to meet their needs.

We therefore need to make provision for these groups in our communication and engagement plans to ensure they are aware of the risks of developing dementia and to encourage them to seek a diagnosis. Through regular consultation we must also ensure that the services we provide take account of their specific needs.

Raising Awareness Amongst Staff to Improve Diagnosis Rates

There is also a need to ensure that all health and social care staff are aware of dementia, can identify the signs of dementia and are able to encourage patients to seek a diagnosis or access appropriate information, advice, and support. All staff should therefore receive training relevant to their role, so that the Cheshire East workforce across the dementia care system has the right skills, behaviours, and values to support people living with dementia and is equipped to do so.

Identification of Carers

As already noted, the drive to improve the diagnosis rate is not an end in itself; improving the support available to people once diagnosed is equally important. Improving diagnosis rates also enables us to identify Carers so that they can be registered as such on the GP record system. This will enable GPs to signpost carers to information, advice, and support services at an early stage such as local Carers Wellbeing Programmes.

Planning for the future

One of the advantages of getting an early diagnosis is that it provides an opportunity for those affected to start planning at an early stage, before capacity is lost. It enables the person and their carer(s) to understand how the illness will progress and to be fully involved in decisions about their care and support, including their preferences at end of life. These conversations may be difficult but shouldn't be regarded as a "one off" event, as circumstances change so may the care preferences. Staff providing support should therefore be equipped to manage these conversations whenever the need arises, with confidence and compassion. (More detail about Planning and Caring Well can be found within the Dying Well (Planning and Caring Well) pathway).

Our consultation exercise highlighted a number of issues associated with getting a diagnosis, a summary of which is provided below.

Key Issues and Challenges

- Long waits for an assessment and diagnosis in some areas of Cheshire East.
- Low rates of diagnosis among people from BAME communities
- Younger people report difficulties getting a diagnosis (under 65s)
- There is a need to improve the diagnosis rates of those individuals living in Care Homes (Accommodation with Care)
- Care pathways vary depending on where you live meaning different arrangements for those seeking a diagnosis.
- Early signs of dementia not recognised in people with learning disabilities.
- Inconsistencies in the way information is provided at the point of diagnosis - some people receive more information than they can cope with, others not enough.
- Information on the early signs of dementia and the benefits of getting a diagnosis should be more accessible and actively promoted.

Ambitions (Outcomes) for the Diagnosing Well pathway

To address the issues identified and achieve the ambitions set down in the NHSE Diagnosing Well guidance we have agreed several key actions and outcomes. The key aim for this part of the plan is to ensure residents of Cheshire East who are concerned they may have dementia are able to get a prompt assessment and diagnosis so they can access the support they need and plan for the future. Our action plans will reflect the work needed to achieve this.

6. SUPPORTING WELL

Our mental 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 19 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.

Integrated Pathway of Support

Dementia needs to be seen as a long-term condition that requires on-going management over a period of years. Inevitably it is very common for people with dementia (including their carers) to also have other long-term conditions. Therefore, it is essential that people with dementia, their families and carers know how to access support as their dementia or other health conditions progress. This requires an integrated pathway of support, including between community and hospital provision. The person with dementia and those around them need to be put at the centre of their care

Examples of Dementia Support Services and equity of support

In Cheshire East we have the Dementia Reablement Team which offers help and support for individuals in the early stages of dementia following a formal diagnosis, and their families and carers. The service places a strong emphasis on empowering people with early dementia to have the confidence to manage independently, and for families and carers to take positive risks to ensure they continue to lead a good quality of life.

We also have Dementia Support Workers in some parts of Cheshire East, these workers listen to people's stories and help to develop an individual plan coordinating support and services around the needs of the patient and carer. The aim is to help those living with dementia and those caring for them to live well and as independently as possible.

This service is not available throughout the Cheshire East footprint and indicates the need for equal access to services across the Borough.

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 plan, we are looking at how to improve the pathways and ensure that all services and support can work collaboratively.

We also acknowledge that not everyone who lives with dementia engages when they have support needs, therefore, improved awareness, seamless pathways and effective signposting is required to enable this to take place more effectively.

Young Onset

We 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, therefore we will work towards ensuring that the support given to those with young onset dementia is age appropriate.

There is also a need to ensure that those individuals who are working at the time of diagnosis (including carers) maintain their employment for as long as possible and encourage our communities and workplaces to work together to help make adjustments for people with a dementia diagnosis or caring responsibilities.

Support at Home

As the condition progresses and /or there are other health conditions to be considered, it may become necessary for the person living with dementia to access 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, and work in an appropriate manner to ensure they are fully supported:

- LGBT+
- Ethnic Minorities, religious minority communities and Gypsy, Roma, and Traveller 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.

Our consultation identified a number of difficulties associated with the current support available, a summary of which is provided below.

Key Challenges and Issues

- People living with dementia and their carers / families feel that there is insufficient information, advice and support available, especially when the dementia has reached an advanced stage.
- People living with dementia who have additional health conditions have difficulty finding out what is available because services often work independently of each other.
- 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.
- Delays in discharging people with dementia safely from hospital, there is a need to improve the Home First offer to residents.
- Equity of services across the Borough is required.
- We also need to consider individuals changing circumstances and how they can be supported.
- The care market should be able to respond to the changing needs of people living with dementia and support them to live well.
- Follow up support is described as "a bit hit and miss" with many looking for support and advice online or from others living with dementia and their families / carers rather than from the health care system.
- Increased awareness of carers who have their own health issues (which may include dementia) is also required.
- People with dementia from minority, religious minority communities and Gypsy and Traveller communities, Learning Disability and LGBT+ community can feel that mainstream services don't know how to meet their needs.
- Training for staff on equality and diversity is required to ensure that they are aware of the issues faced by specific cohorts of community, and they have the knowledge, skills, and confidence to provide appropriate support.
- Support for those living with young onset dementia is limited.
- There is a lack of age-appropriate activities, supported volunteering opportunities, groups and support to stay in employment for those living with Young Onset Dementia and those also living with a Learning Disability.
- Knowledge and application of advance care planning, anticipatory care and Lasting Power of Attorney is limited in some areas.

- Some staff have limited knowledge of the Mental Capacity Act (2005) and Best Interest decision making processes. These are applied when an individual with reduced capacity needs support to make decisions about their care or when a decision has to be made on their behalf, for example when an individual's dementia is advanced.

Ambitions (Outcomes) for the Supporting Well pathway

To address the issues identified and achieve the ambitions set down in the NHSE Supporting Well guidance we have agreed a number of key actions and outcomes. The key aim for this part of the plan is to ensure residents of Cheshire East who are living with dementia and their carers, are supported effectively and have access to safe, high quality health and social care. Our action plans will reflect the work needed to achieve this

7. LIVING 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, but there is still more to be done around this.

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

There is potential for people with dementia to live meaningful and satisfying lives, but this requires support from all those people and services surrounding the person including their own community.
Breaking down the stigma of dementia is key and initiatives such as Dementia Friendly Communities can help people to access their local communities and reduce the risk of social isolation and loneliness.

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 will therefore engage with those living and working in such areas to investigate the issues and problems experienced by those affected by dementia. For example, we will link into the work identified in the Cheshire East Rural Action Plan 2022 – 2026 as it looks at what is needed to address social isolation in our rural areas.

We also know that individuals who are working at the time of diagnosis (including carers) may need to maintain their employment for as long as possible, therefore we will encourage our communities and workplaces to work together to help make adjustments for people with a dementia diagnosis or caring responsibilities.

Community and Voluntary sector

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, where individuals are enabled to see the value they bring to the community, we will therefore work with community / voluntary 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.

Information and advice

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. There is a need to ensure that people living with dementia can physically access support, groups and services via public and local charity transport which is dementia friendly.

Those living with dementia, their carers, and families, also need to access Out of Hours support, especially as some work and need to source support out of working hours.

Benefits

As people's circumstances change, they may need to maximise their income, therefore, may need support in accessing appropriate benefits (see reference on page 17)

Dementia Friendly Communities

There has been a great deal of innovative work that has taken place within the local Dementia Friendly Communities (see examples on page 8), for example Schools being encouraged to include dementia awareness in their work programmes, and numerous dementia friends 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.

Co-production

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, this also includes encouraging individuals to get involved in dementia research.

Accommodation

Having good quality, safe and familiar accommodation is a key feature to "Living Well" for everyone, but it is particularly important for people affected by dementia. As the population ages and needs evolve and increase, there will be a requirement to adapt care and support services and to develop more innovative housing and care options which support people to remain as independent as possible for as long as possible. The Council recognises this in the Corporate Plan where there is a commitment to reducing "reliance on long term care by providing services closer to home and providing more extra care housing facilities, including dementia services." The Council has also been working with the Housing Options Team to ensure provision is made for those living with dementia. This is supported by the Councils', Vulnerable and Older People's Housing Strategy which can be found here Vulnerable and older persons housing strategy (cheshireeast.gov.uk) and the Housing Supplementary Planning Document which can be found at Housing Supplementary Planning Document (cheshireeast.gov.uk).

For those people who are unable to live at home, a residential or nursing home 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 accommodation and care planning.

Care Homes

There are almost 100 care homes in Cheshire East, supporting over 4,000 older people, 70 to 80% of whom are likely to have dementia. They are also likely to have other mental and physical health problems and the evidence 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 residents without dementia. The length of stay in hospital is also likely to be longer. Despite the increasing prevalence of dementia in care home residents there is a concern that diagnosis rates are still low.

The recent pandemic significantly increased the challenges care homes were already facing, like rising management costs, recruiting and retaining staff, and accessing community services for residents with increasingly complex needs. However, the pandemic also raised the profile of care homes and highlighted the need for health and social care sectors to work more closely with care homes.

As our population ages and the number of people developing dementia increases so will the need for more care home beds and different models of supported living. This is currently being addressed in other local plans and strategies as noted earlier. However, because of the high prevalence of people affected by dementia already living in care homes, we think it important to discuss current provision and plans to build on this.

The Enhanced Health in Care Homes Model

The important role of care homes is recognised in the NHS Long Term Plan and in a national and local ambition to strengthen the support for those who live and work in and support care homes**.**

The details of how this might be achieved are set down in the Enhanced Health in Care Homes (EHCH) Model, which is currently being implemented across England. This approach moves away from traditional reactive models of care and support, towards proactive care that is centred on the needs of individual residents, their families, and staff.

The EHCH Framework identifies several areas commissioners and providers should focus on to achieve these aims, one of those priority areas is dementia. The Framework recommends those steps which may be taken to enhance the identification and management of dementia in care homes and have been used to inform the proposed care home outcomes, which are detailed in our action plan. The EHCH Framework can be found here; https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf.

A Strategic Approach to Supporting Care Homes

Cheshire and Merseyside Integrated Care Board (formerly Cheshire Clinical Commissioning Group) established a strategic group to support and oversee the implementation of the recommendations in the EHCH Framework. The group meets monthly, and membership is made up of colleagues from health' social care and voluntary sector organisations to ensure an integrated approach to improving support for care home staff and residents.

Primary Care and Care Homes

In addition to the framework, the application of the EHCH Model outlines the way GPs and community teams should provide services to care homes. These changes are aimed at every care home and include:

- Alignment to a named Primary Care Network
- A named clinical lead
- A weekly 'home round' or 'check in' with those residents prioritised for review
- Person-centred holistic health assessments of residents' needs (to include physical, psychological, functional, social, and environmental needs and personal goals)
- Personalised care and support plan(s), based upon their holistic assessment
- Structured medication reviews

These requirements are captured in local and national GP contracts and have been implemented across Cheshire.

Current Support for Cheshire East Care Homes

Local commissioners and providers from health and social care have worked together to develop several initiatives which provide information, advice, and support to care home staff. They include a recently developed Care Home Support Service aimed at working with care home managers to identify specific staff training needs and to develop bespoke solutions. Examples include support to improve end of life care, signposting to other care and support services, leadership skills training for managers and dementia training for care staff.

In addition to the above, an Advanced Dementia Support Service is available on a consultancy basis for formal and informal carers, including care home staff. This service is aimed at people in the latter stages of their dementia journey, maybe approaching end of life and/or

experiencing complex symptoms or behaviour. The service supports carers to develop strategies to manage this complexity and to enable people with dementia to die at home if they wish.

In addition to the services established to support care homes, the Council also holds a regular forum with care home managers to discuss any issues of concern, to provide support and to share any good practice.

Technology in Care Homes

The recent pandemic challenged services to change their way of working to limit the spread of infection. To support this, care homes were provided with i-pads to facilitate virtual consultations with GPs and other health professionals. The i-pads also enabled care home residents to stay in touch with family and friends when visiting was restricted.

Funding has been made available to trial RITA (Reminiscence/Rehabilitation Interactive Therapy Activities), in Cheshire care homes. Using an interactive tablet residents can access a range of digital activities which assist residents with memory impairment to recall and share events from their past. The activities include familiar films, news stories, music and games which can aid communication and improve wellbeing.

To improve secure communication between care home and NHS staff, care homes have been supported to set up NHSmail accounts. An NHSmail account also gives care home staff other benefits like access to free NHS online training.

Identifying, monitoring, and responding to changes in resident's health

The recent pandemic highlighted the importance of quickly identifying any deterioration in the physical and mental health of residents, allowing staff to arrange the most appropriate clinical response to limit or prevent further decline. Free training on RESTORE2 and RESTORE2 Mini (an evidence based deterioration tool) has been offered to all Cheshire care homes. Digital options are currently being considered.

Equipment

There is a need to promote and enhance the use of assistive technology, including new technologies that will help keep people safe and independent for longer.

To ensure people living with dementia can live at home for longer, they need to have access to and be aware of what equipment and assistive technology is available to them, that could that optimise their wellbeing and independence.

Mental Capacity Act and Best Interest Decision

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.

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 for as long as possible.

Examples of some support available to unpaid Carers are:

Cheshire East Carers Hub provides a single point of access for all Carers including both young and adult Carers.

Both of our local Hospices provide support programmes for carers of people living with dementia, and carers can self-refer via the hospice website.

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

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

Dementia and Domestic Abuse

Cheshire East Council and relevant partners have created a Project Team to investigate the current gaps with regards dementia and domestic abuse.

The team found 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 specific to cover the issues that may be faced by carers and those living with dementia)

No single 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.

Our consultation identified several difficulties associated with how individuals are currently enabled to live well with dementia, a summary of which is provided below.

Key Challenges and Issues

- People living with dementia and their carers can feel excluded and unable to engage with their local community leading to social isolation.
- Easy and equitable access to peer support, carers groups and community led initiatives is needed to help people to stay connected.
- People with dementia are at greater risk of falling, which can lead to injury, admission to hospital and loss of independence.
- The lack of flexible breaks for carers, local respite / day services impacts on their ability to continue effectively in their caring role.
- Low uptake of services from those from ethnic minority groups.
- Out of hours support (out of working hours and at weekends) is limited.
- Sustaining Dementia Friendly Communities is a challenge in some areas as they tend to rely on the support of volunteers.
- Affordable and regular transport is especially important for those living in rural communities and those unable to drive. However, some transport providers are not currently able to meet the travel needs of people affected by dementia.
- There is a need for greater availability of community housing options suitable for people with dementia.

- Practical and emotional support needs to be 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 do not feel they have a voice at a strategic level.

Ambitions (Outcomes) for the Living Well Pathway

To address the issues identified and achieve the ambitions set down in the NHSE Living Well guidance we have agreed several key actions and outcomes. The key aim for this part of the plan is to ensure that people with dementia can live safely in their own home / care home and within compassionate and accepting communities for as long as possible. Carers (formal and informal) will be supported in their caring role, and all affected by dementia will have equitable and easy access to a range of clear information and advice and local support. Our action plans will reflect the work needed to achieve this.

8. DYING WELL (PLANNING AND CARING WELL)

Dying Well is the final element of the national NHS Dementia Pathway and our own local plan. Whilst we have stressed throughout this plan that people with dementia may, with an early diagnosis and appropriate care and support continue to live well, it is important to understand that the conditions associated with dementia are life limiting. 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 understand 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 plan in the interests of sensitivity. However, the End of Life Partnership (EoLP) 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 plan 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 plan 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 cases 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 (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 (ACP)

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 illness; 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 should not 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.

Advance care planning (ACP) is the term we use to describe a range of ways we consider future wishes or care preferences. 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" can 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 ACP. This compares favourably with the remaining over 65 population who do not have a dementia diagnosis, of whom only 3% have an ACP. However, this means that 57% of those with a diagnosis have not formally recorded any plans regarding their future care.

Whilst advance care planning is to be strongly encouraged to ensure the needs and wishes of those affected by dementia are considered, it should be noted that facing a future with dementia and/or planning for end of life may be too difficult for some and offers to discuss plans for the future are sometimes declined or postponed, and this must be respected. However, it should be made clear that the option to plan for end of life is always available whilst the individual has capacity. Once capacity is limited plans may be made with the support of the carer and/ or an advocate.

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.

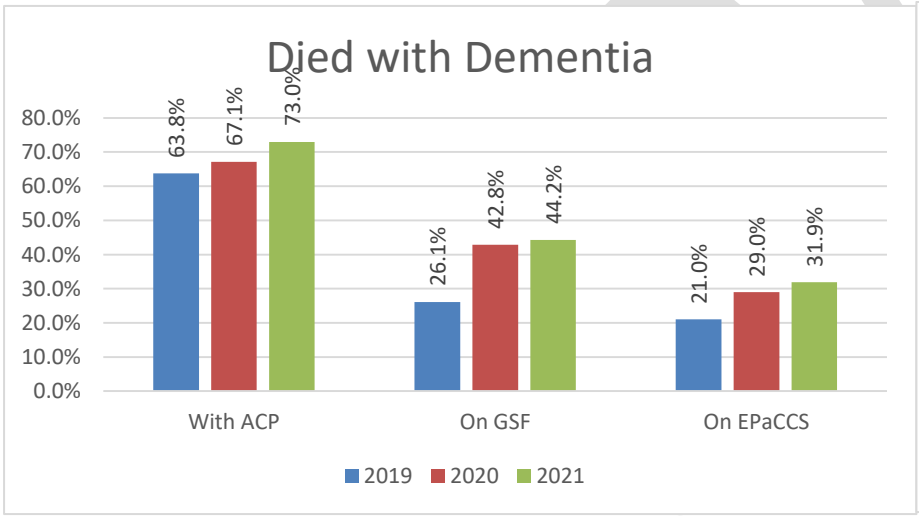
Although this information is held in the GP system it may also be accessed by other health care professionals who may be involved in the patients care at a later date. This can help to ensure that staff not directly involved in the advance care planning discussion are aware of the plan. For instance, if a paramedic calling on a patient with dementia can see the patients' recorded wishes 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 patient's 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 ACP, 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.



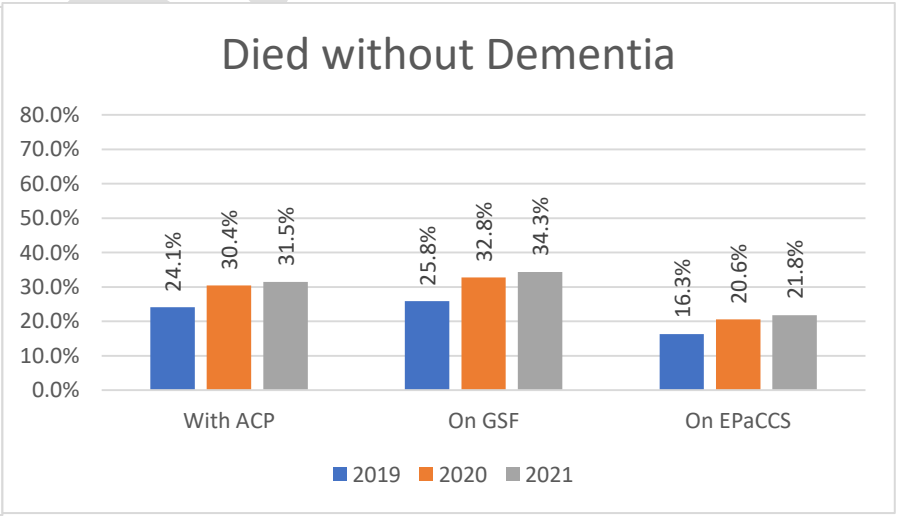


Table 3 - People who have died since 2019 (with and without Dementia) by year and by care element

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 initiative is a new service commissioned by the Integrated Care Board, 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 is available on the End of Life Partnership's (EoLP) e-page. The website Knowledge Base | The End of Life Partnership (eolp.co.uk) provides the following information and advice:

- 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

The End-of-Life Partnership's Advanced Dementia Support Team works across health and social care settings and with families in their own homes, to improve end of life care for people living with advanced dementia. This service can provide support to formal and informal carers, services range from education and training for staff to complex consultancy when an individual's behaviour or symptoms have become difficult to manage.

A variety of important local community initiatives have developed over time to provide ongoing peer support to carers of people affected by dementia. This includes support for those coping with the loss of a loved one who may have moved into a Hospice or a Care home because of their changing needs. Bereavement support is also available for carers in some areas. Carers across Cheshire East should be able to access this type of peer support in their communities.

There are two local hospices providing care and support in Cheshire East, St Luke's Hospice and East Cheshire Hospice. Each have numerous ways of supporting individuals and their carers living with dementia who are also using hospice services. In addition to providing traditional end of life and specialist palliative care, hospices can assist in other ways through the provision of bereavement support, assistance with Advanced Care Planning, alternative therapies, and counselling etc.

We are aware of lots of good practice in Cheshire East regarding this element of the Well Pathway, however respondents to our consultation reported several issues associated with planning for the future, support for carers and the care and support currently available for people with dementia at the end of life. A summary of the feedback received is provided below.

Key Issues and Challenges

- Those affected by dementia (including their carers) need access to clear, consistent, sensitive, and timely information about how their illness may develop so that they understand the implications, for example likely loss of capacity, and are able to prepare for any changes ahead.
- Appropriate care and support should be available for individuals approaching end of life so that where possible they can be cared for and die in their preferred place.
- People diagnosed with dementia should be supported to plan for their changing needs and future care (see advance care planning) at a time that is right for them.
- ACP should include frequent opportunities for review as the condition progresses and end of life approaches.
- Practical information on writing wills and organising power of attorney is needed to support advance care planning.
- Facing a future with dementia and/or planning for end of life may be too difficult for some, offers to support advance care planning may therefore be declined and this should be respected.
- People report a lack of information 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).
- There is a need to raise awareness of what support and information is currently available for carers.
- Families and carers may need bereavement support and counselling.
- The need to consider those individuals who are carers but are also living with dementia themselves in anything we do.
- Some services are only available in parts of Cheshire East – there is a need to ensure provision is equitable across the area.
- Cultural considerations are needed when supporting those from ethnic minority groups.

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

To address the issues identified and achieve the ambitions set down in the NHSE Dying Well guidance we have agreed a number of key actions and outcomes. The key aim for this part of the plan is to ensure that people living with dementia and their carers / families are enabled to have early conversations about advanced care planning and end of life decisions. This will ensure that those who need to be, are fully involved in decision making and that their wishes are known and acted upon. Our action plans will reflect the work needed to achieve this.

8. General Conclusions

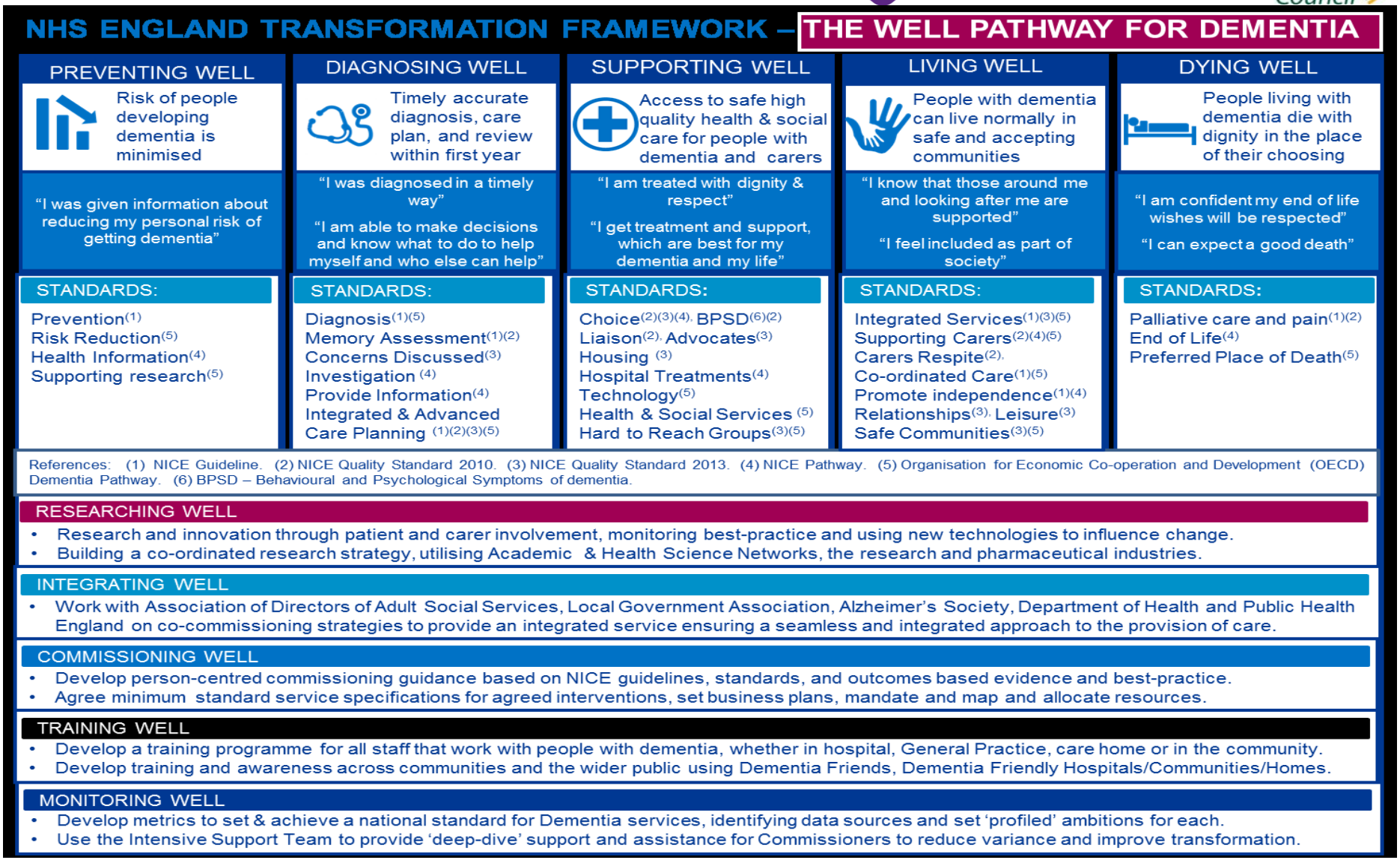
The Cheshire East Dementia Steering Group has developed several high-level ambitions which set out how we will improve the experience of local people affected by Dementia. These ambitions are referenced in each section of the separate Ambitions Action Plans and our overarching ambitions are summarised 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, e.g., people living with Dementia, their carers and service providers. Each ambition is underpinned by several 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 plan 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 plan and will continue to re-visit our vision to ensure the voice of lived experience not only remains central to the plan but helps to measure the impact of it.

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

Appendix 1 - NHSE - The Well Pathway for Dementia

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.


NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA
PREVENTING WELL
Risk of people developing dementia is minimised
"I was given information about reducing my personal risk of getting dementia"
STANDARDS:
Prevention(1)
Risk Reduction(5)
Health Information(4)
Supporting research(5)
DIAGNOSING WELL
Timely accurate diagnosis, care plan, and review within first year
"I was diagnosed in a timely way"
"I am able to make decisions and know what to do to help myself and who else can help"
STANDARDS:
Diagnosis(1)(5)
Memory Assessment(1)(2)
Concerns Discussed(3)
Investigation (4)
Provide Information(4)
Integrated & Advanced Care Planning (1)(2)(3)(5)
SUPPORTING WELL
Access to safe high quality health & social care for people with dementia and carers
"I am treated with dignity & respect"
"I get treatment and support, which are best for my dementia and my life"
STANDARDS:
Choice(2)(3)(4), BPSD(6)(2)
Liaison(2), Advocates(3)
Housing (3)
Hospital Treatments(4)
Technology(5)
Health & Social Services (5)
Hard to Reach Groups(3)(5)
LIVING WELL
People with dementia can live normally in safe and accepting communities
"I know that those around me and looking after me are supported"
"I feel included as part of society"
STANDARDS:
Integrated Services(1)(3)(5)
Supporting Carers(2)(4)(5)
Carers Respite(2),
Co-ordinated Care(1)(5)
Promote independence(1)(4)
Relationships(3), Leisure(3)
Safe Communities(3)(5)
DYING WELL
People living with dementia die with dignity in the place of their choosing
"I am confident my end of life wishes will be respected"
"I can expect a good death"
STANDARDS:
Palliative care and pain(1)(2)
End of Life(4)
Preferred Place of Death(5)
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.
RESEARCHING WELL
• Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
• Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.
INTEGRATING WELL
• Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.
COMMISSIONING WELL
• Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
• Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.
TRAINING WELL
• Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
• Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.
MONITORING WELL
• Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
• Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.

Appendix 2
Overarching Ambitions of the Cheshire East Place Dementia Plan

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

- **Preventing Well**
  - To improve the way we all communicate and work in partnership with others.
  - To raise awareness of Dementia across the Cheshire East footprint to reduce the stigma associated with it and encourage individuals to live a healthy lifestyle which can delay the onset of dementia.
  - To continue our learning about the needs of our local population who are affected by dementia. This would include learning from best practice, reviewing the Ambition Action Plans regularly and promoting and encouraging involvement in research.
- **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 individual needs) throughout their dementia journey, for the person diagnosed and their carers.
  - To ensure that Health, Social Care, and the voluntary sector 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 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.

Appendix 3

Key Partners in developing this plan:

Cheshire East Council
Cheshire and Merseyside Integrated Care Board
Alzheimer's Society
Age UK Cheshire East
The End of Life Partnership
Cheshire East Carers Hub
East Cheshire Hospice
St Luke's Cheshire Hospice
Mid Cheshire Hospitals NHS Foundation Trust
East Cheshire NHS Trust
Cheshire and Wirral Partnership
Dementia Friendly Community leads and representatives in Cheshire East
GP Clinical Lead
Cheshire Fire and Rescue Service
Healthwatch (Cheshire East)
East Cheshire Mental Health Forum

Links to other Key Documents

The plan supports the work described in other key local documents including:

Cheshire East Council's Corporate Plan Corporate Plan (cheshireeast.gov.uk)
Cheshire East Partnership Five Year Plan 2019 – 2024 Layout 1 (cheshireeast.gov.uk)
The Joint Health and Wellbeing Strategy 2018 – 2021 Layout 1 (cheshireeast.gov.uk)
Cheshire East Falls Prevention Strategy 2019 – 2022 Falls Prevention Strategy.pdf (cheshireeast.gov.uk)
Cheshire East Council Day Opportunities Strategy 2022 – 2027 3c. Day Opportunities - Appendix 2 Day Opportunities Strategy.pdf (cheshireeast.gov.uk)
All Age Carers Strategy 2021 – 2025 All Age Carers Appendix 2 Draft All Age Carers Strategy.pdf (cheshireeast.gov.uk)
Live Well for Longer Plan
Rural Action Plan Rural Action Plan 2022.pdf (cheshireeast.gov.uk)
Connected Communities Strategy 2012 – 2025 Layout 1 (smartsurvey.io)
Cheshire and Merseyside Integrated Care Board (ICB) Commissioning Plans.