

A summary of responses to Cheshire East Council's

## **Dementia Strategy Consultation**

# Introduction

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## Purpose of the consultation

During March / June 2022 Cheshire East Council undertook a consultation to seek views on its draft dementia strategy.

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". This draft strategy sets out the Cheshire East ambition to support people to live well with dementia.

It has been developed by Cheshire East Council in partnership with Cheshire Clinical Commissioning Group (CCCG), and local stakeholders including those living with dementia and their carers. 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.

## Consultation promotion and responses

The consultation was promoted on the council's website and by partner organisations. A survey was held on-line with paper copies also available on request.

In total, 59 responses were received including:

- 40 main survey responses
- 17 easy ready survey responses
- 2 emails

## Respondent characteristics

Out of the 40 respondents who answered the main survey:

- 18 were carers, close family or a relative of a local resident living with dementia
- 11 were interested Cheshire East residents, and 1 was an elected Cheshire East Ward Councillor, or Town/Parish Councillor
- 4 were healthcare professionals, 3 were care home providers and 1 was an employee of Cheshire East
- 1 was answering on behalf of a group organisation or club and 1 was a volunteer.

The majority of respondents to the main survey were:

- female (28 out of the 39 who provided an answer)
- aged between 45 – 74 (29 out of 39 respondents)
- of White British / English / Welsh / Scottish / Northern Irish / Irish ethnicity (37 out of 40 respondents)
- considered their religion as Christian or had no religious beliefs (19 and 10 out of 39 respondents respectively)
- 10 stated that their day-to-day activities were limited because of a health problem or disability.

The majority of respondents to the easy read survey were:

- female (11 out of 17 who provided an answer)
- aged 65 or older (12 out of 17).

# Analysis of results

## The 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.

Respondents were first asked how they would rate the overall vision for dementia services in Cheshire East. Just over half of respondents (23 out of 40) rated it as good or very good as Figure 1 shows.

**Figure 1: How would you rate the overall vision for dementia services in Cheshire East? (Count)**



Respondents who rated the vision as 'poor' were asked how they thought the vision could be improved. 13 respondents left a comment, the comments received are summarised by theme below:

### 7 respondents provided a specific comment on the vision:

- Advance 'education' should be provided to properly plan for a loved one becoming affected by dementia
- The vision does not adequately acknowledge the absence of communication between some NHS providers - improved communication between relatives/hospitals and GPs is imperative for any plan to stand a chance

- Where is the support for new care home services? Living at home or in extra care is no longer appropriate for those whose needs are great. The majority do not fit with the expectation of modern standards of living this must be addressed as part of the strategy. More Extra Care housing is needed.
- Include reducing levels of dementia by promoting lifestyle changes across the population
- Add a sixth key outcome: People living with dementia will be supported to plan effectively for their future. Key outcome 1 suggest it reads 'understood and empowered', outcome 3 suggest it reads 'decision-making at both a personal and strategic level'.
- Vision is good but doesn't mean anything unless turned into outcomes that are delivered, in reality would be impossible to carry out.

**6 respondents provided a comment regarding current poor care or and service:**

- Have to fight for support for the individual living with dementia, the carers and families
- No financial support for carers
- Difficult to know how to access support, seems unavailable or hard to access
- There are geographical differences in provision provided, some services more effective than others
- Have to travel miles to see mother who is in a care home as she was not placed in a setting closer to where live
- Took too long to get a visit from the professional nursing services.

# The Overarching Ambitions

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 people 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.

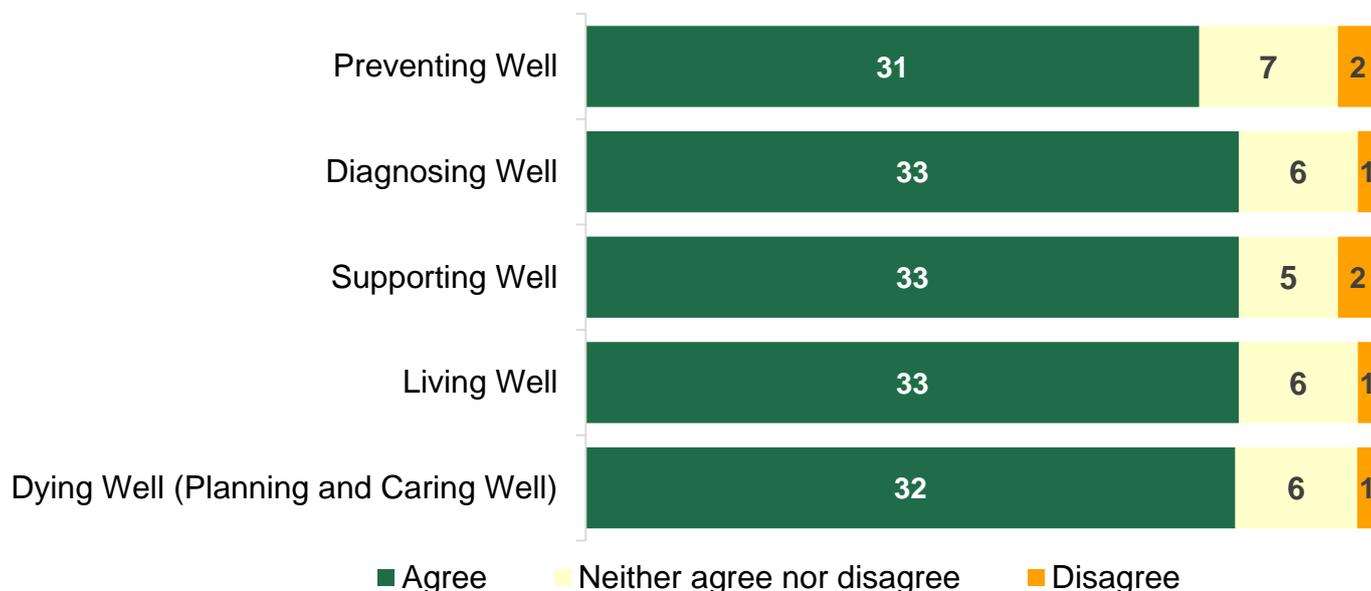
## Dying Well (Planning and Caring Well)

- 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 the end of their 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 decision making where early advanced care planning has not been considered / undertaken.

The majority of respondents agreed that the overarching ambitions are the right areas to focus on within the Cheshire East dementia strategy (31 or more respondents out of 40 agreed). See Figure 2.

**Figure 2: How strongly do you agree or disagree that the overarching ambitions are the right areas to focus on within the Cheshire East dementia strategy?**

(Count: total = 39 to 40)



Respondents were asked if they felt there was anything missing from the overarching ambitions. 15 respondents left a comment. The comments received are summarised by theme below:

**5 respondents felt there was a need for better support and facilities:**

- Need financial support and help claiming benefits
- Need more follow up support with consultant after diagnosis
- Those with younger onset dementia must have access to care that is age appropriate
- The gap of those living with dementia not engaging with support needs to be addressed
- Need to include a clearer recognition of the need to build communities of support so family & friends can carry on living with the person or can stay in daily contact by living in close proximity - people with dementia should be able to walk freely within secure areas - need to progress thinking beyond Extra Care into planning for retirement communities.

**4 respondents were concerned that it would be a struggle to implement the ambitions:**

- Will struggle to put those in practice - will need complete management change
- Ambitions are optimistic especially in the areas of supporting and living well – without real commitment and investment this will be a paper exercise of dreams

- The importance of GP's working together and any future strategy, will fail without adequate resource
- Sudden changes may have considerable effect on the plans and actions.

## **6 respondents offered specific suggestions:**

- The following in appendix 2 don't seem to align with the main document:
  - Diagnosing Well: 'residents feel encouraged to seek an early diagnosis, and are supported to manage the dementia diagnosis', 'residents with a diagnosis plan effectively for their future'
  - Supporting Well: 'to ensure good information/advice and sufficient quality support ...'
  - Living Well: 'any issues/outcomes for those living in care homes?'
- Suggestions concerning 'Diagnosing Well':
  - Not enough importance put on early diagnosis
  - Consistent with national policy, key factors to achieve success are: achieving national target for diagnosis, individuals with dementia have a care plan & a named support worker and effective joined-up support across Health and Social Care.
- Suggestions concerning 'Supporting Well':
  - Getting health professionals to work together is a key to success in this area.
- Those who don't access NHS services are not tracked or factored in the assessments on need for care home beds. A better alignment with the private sector is needed
- Cut the jargon.

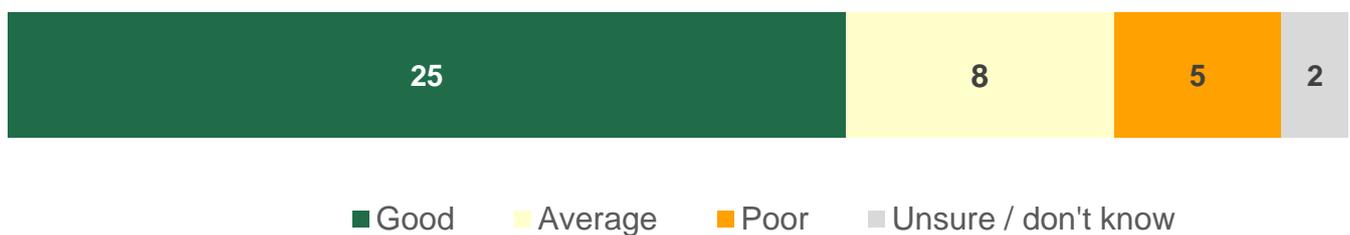
## The actions

A set of actions which will help deliver the overarching ambitions of the strategy were also proposed the details of these can be referred to within the [Draft Dementia Strategy pages 38 - 40 \(PDF 1.0 MB\)](#).

Just over one half of respondents (25 out of 40) thought the actions were good as Figure 3 shows.

**Figure 3: How would you rate the set of actions given which aim to achieve the overarching ambitions?**

(Count: total = 40)



Respondents were asked if they felt there was anything missing from the actions. 12 respondents left a comment. The comments received are summarised by theme below:

### **5 respondents felt that there was a need for more detail / actions:**

- Does not set out how Cheshire East intend to improve the offer for end-of-life care homes, for those that fail the means test for care home payments, or those who don't fit into the tenure model
- Issues that need more attention in the strategy: adapting one's home and considering rehousing rather than a care home, the opportunities of technology, living with poverty, issues of equality and the impact of workforce issues
- Nothing reflecting issue of capacity or affordability of support needs e.g., is staffing recruitment, retention and training at a sufficient level. Advance planning should be a theme in all legs of the strategy, not just about end of life
- Need a timeline for achieving outcomes.

### **3 respondents felt there was a need for more resource / connectivity:**

- All good if the staff can be found to fill the jobs in care
- External care market cannot always respond quickly – the charity providers play an important role and must be recognised in the strategy

- There needs to be more connectivity - felt abandoned after diagnosis, spent a long-time chasing thing up and finding out where we could get help.

**Other areas of improvement mentioned include:**

- Document isn't accessible or written in a way that makes it very clear (1 respondent).

## **Easy Read Survey - Plans**

17 respondents answered the easy read version of the survey. The survey provided respondents with a set of key plans and asked respondents if they felt they were good plans for those with dementia, their families and carers in Cheshire East. Almost all respondents to the easy read version of the survey agreed that the plans were good.

The plans listed and the full results are as follows:

- Improve the way we talk and work together with others, 16 agreed, 1 stated don't know
- Make more people aware of dementia to help stop any bad or unfair thoughts about it, 17 agreed
- Provide good information, advice and support to everybody, 17 agreed
- Make sure that there are different support options for people living with dementia and their carers that take place close to home, 16 agreed, 1 stated don't know
- Make sure that those living with dementia have a voice and say in shaping their community and the support that they receive, 16 agreed, 1 stated don't know
- Make sure those with dementia and their carers know the options for end-of-life care so that they can plan ahead and be fully involved in decisions when the time comes, 14 agreed, 2 disagreed, 1 stated don't know
- Make sure those near the end of their life have the care and support they need and are able to die in a place they value, with the people important to them close by, 16 agreed, 1 stated don't know
- Make sure there are enough groups to provide support for those living with dementia and their carers, 16 agreed, 1 stated don't know
- Make sure that carers are supported before and after the loss of the person they care for, 16 agreed, 1 stated don't know
- Make sure that the relevant English Law is used to support any end-of-life care decisions, 16 agreed, 1 stated don't know when the person living with dementia or their carers have not been able to make them, 13 agreed, 2 disagreed, 1 stated don't know.

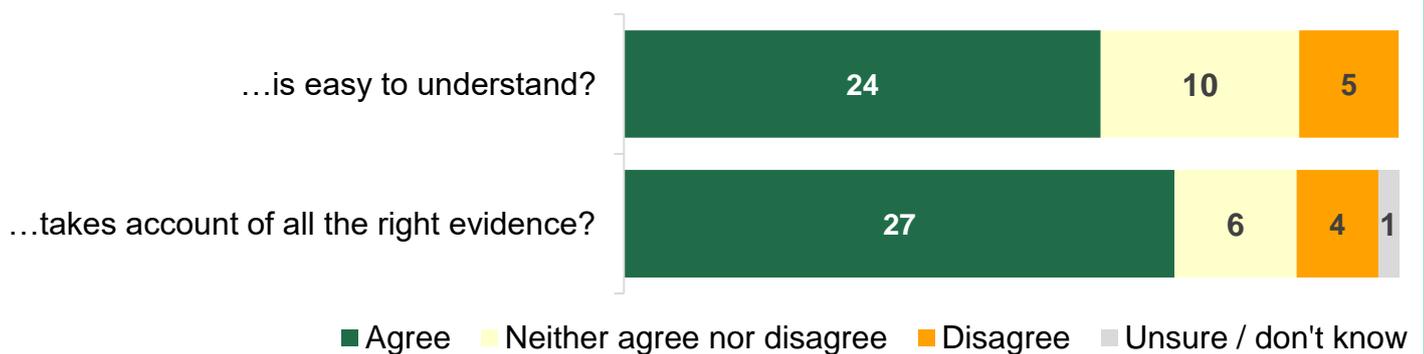
## Overall

Finally, respondents were asked some questions regarding the strategy overall – if they feel it is easy to understand, takes account of the right evidence and any other comments they may have.

24 out of 38 agreed the strategy was easy to understand and 27 out of 39 agreed it takes account of all the right evidence as Figure 4 shows.

**Figure 4: How strongly do you agree or disagree that the Dementia Strategy...**

(Count: total = 38 to 39)



23 respondents provided an overall comment regarding the dementia strategy. The comments received are summarised below:

### **7 respondents felt there was a need for more support / providers:**

- Lack of public transport means it is often difficult to access services. Many older people struggle to access GP services because of the expectation that patients access services on-line in the first instance. Make access to support easier – employ more nurses and home carers, more support in getting medical reviews at home and more support financially
- There is very little on increasing help, need to provide initial support and follow up. Some individuals manage to live on their own with their own personal network but if there is a sudden change in this support network the person can face a huge life change and it's to be hoped this can be addressed
- Need adequate provision for affordable extra care accommodation

### **7 respondents felt there needs to be more detail / awareness of those who don't fit the standard template:**

- Needs more attention to the person with dementia - once diagnosed I think you are forgotten
- Doesn't seem to have addressed the needs case for dementia beds and extra care or evaluated what the tenure model is, the correct locations, availability of land

- Encouraging people to register for dementia research is part of empowering those living with dementia - should be embedded in strategy, not just a line in action plan
- Very much focused on the over 60 age group need more of a focus on early onset and learning disability needs can be very different
- Need to recognise that some carers have jobs - they may need a different kind of support - working and juggling care means you can't always spend hours on the telephone chasing support.

#### **5 respondents felt the document was too long / not easy to read:**

- Document is difficult to read and comprehend, doesn't seem to have been written with the average person in mind
- For carers who have very limited time, 56 pages are very long to digest
- Is easy to understand but lengthy, very verbose.

#### **Other comments provided include:**

- Will struggle to implement – few people are attracted to health and social care roles
- Need a joined-up approach with interfacing strategies and better links with the physical planning of the development of Cheshire East's towns
- General negative comment.

Those who answered the easy read version of the survey were asked if they thought there is anything else we can do to support those living with dementia, their families or their carers. 9 respondents chose to leave a comment. The comments received are summarised below:

#### **5 respondents suggested improvements to support and care:**

- Ensure that those who live with dementia are properly diagnosed - there are many forms of dementia
- Make sure the doctors are more caring and listen more carefully to what we say
- Safe homes to stay as Independent as they can for as long as they can
- Introduce RESPECT documents so that end of life wishes/ ceiling of treatment plans are documented and can be shared with others
- Stop pushing the financial side of things to individuals, carers and their relatives.

#### **3 respondents suggested improvements to training and staffing:**

- Specially trained social workers who understand all dementia types and the symptoms
- Trained help for later stages of dementia
- Increase the wages for those who work in Care Homes

## **2 respondents felt there was a need for improved communication:**

- Improvements in communicating any help that is available
- Let carers know which care homes are available and the cost

**2 email comments were also received**, these have been sent to the relevant department for full review and consideration, however, in summary the key points were as follows:

- There doesn't seem to be any mention of the dementia reablement team & all that they can offer families/patients, or any mention of the dementia support workers
- Need to be careful not to induce guilt or shame on people who are diagnosed through no fault of their own. Will supporting those living with dementia to stay within their own home distance those who wish to take up placement in a care setting - does this consider the difficulties that can arise from caring at home. It is vital that Carers are identified & registered at the point of an individual's diagnosis, to ensure access to support at an early stage. Need to encourage more open and honest discussions about death & dying and acknowledge that different decisions are needed at different stages of disease - it is a live planning process that needs review

## **Summary and Recommendations**

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Respondents were overall generally happy with the vision, actions and ambitions within the draft strategy.

There were however a few suggestions provided within the comments for review and consideration. A lot of the comments were about the need to improve support, staffing and care options within dementia services whilst others were specific to the strategy document itself.

The research and consultation team recommend that all the comments are reviewed and considered as part of the finalisation of the dementia strategy document.