

# Cheshire East Dementia Strategy

## Engagement Questionnaire for people living with dementia and their carers

Cheshire East Council and NHS Cheshire CCG are committed to improving the care, support and experience of people with dementia and their family and carers.

To make this happen, it is essential to work with people living with dementia, their families and carers and partner organisations to capitalise on the work we and our partners have already done.

Part of the work being done includes asking you, people living in Cheshire East, about your experiences of your dementia journey so that we can understand what currently works well and what we need to improve and in what ways.

There are no right, or wrong answers so please feel free to tell us as much or as little as you want to.

### Preventing Well

Reducing the risk of dementia or delaying its onset, is 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.

#### **Q: Were you aware that lifestyle changes could reduce your risk of dementia?**

- Had your GP ever discussed risk factors and the benefits of a healthy lifestyle?
- Have you heard of the “One You” Cheshire East service?
- Has anyone spoken to you about how you can get involved in Dementia Research?
- Where did you go to for information about dementia prior to your diagnosis?

### Diagnosing Well

Working with local GPs is essential to ensure that people are referred in a timely way for assessment and diagnosis and that those worried about their symptoms, or their family/ carers, are provided with relevant information and advice

Improving the support available to people once they have been given the diagnosis is important. It is also important to recognise that contact with clinicians is not restricted to GPs; there are a range of other professionals, for example, opticians and pharmacists, who can be alerted to dementia related problems

#### **Q: What was your experience of receiving your diagnosis?**

- How was your experience with your GP?
- How was your experience with Memory Clinic?

- Did you get the opportunity to ask questions and did you feel your voice was heard and your questions answered?
- What other organisations did they signpost you to for information and support after your diagnosis?
- When did your GP add you (carer) to their Carer register?
- Were you invited for a review with your GP?
- Do you feel you have been given adequate support throughout your diagnosis?
- What suggestions do you have that would improve the diagnosis process?

## **Living Well**

Once a diagnosis of dementia has been made it is important that people with dementia and their carers and family have easy access to information and support to enable them to live independently. People with dementia should live in a supportive community, with access to appropriate housing and a transport system that will allow them to stay connected to their community.

Carers should have access to flexible breaks, respite and day services to allow them to continue in their caring role.

### **Q: What support were you offered post diagnosis and what support do you feel would have been most helpful?**

- What information was provided at point of diagnosis? Was it too much or not enough?
- Where were you signposted to for further information about your diagnosis?
- What further support would you like to receive to improve the quality of your life?
- Do feel confident and supported enough within your community to allow you to continue with activities and hobbies?
- Do you fully understand your diagnosis and do you have any unanswered questions about living with dementia?

## **Dying Well (Planning and Caring Well)**

Planning for end of life is important for anyone with a life limiting condition. For a person with dementia, it is important to have these conversations early and as often as possible, so they can make their own decisions for themselves.

### **Q: What support, information and options have been discussed with you regarding your future care and wishes?**

- Have you heard of and discussed making an Advanced Decision?
- When you do feel the right time to discuss this would be?
- How comfortable would you be to have this discussion with your family? Do you think this discussion would be easier if led by a professional?
- what bereavement support would you expect to receive, or would you find a bereavement service useful?

**Please tell us any additional information that you would like us know, that you feel would make life easier for you, either as a person living with dementia or a carer of someone living with dementia.**