Local Dementia Profile

Essex

December 2021

Alzheimer's Society
United Against Dementia

Contents

Introduction

What is dementia?

Dementia is a progressive neurological condition. It occurs when the brain is damaged by diseases (such as Alzheimer's disease) or by a series of strokes. The symptoms of dementia can include memory loss and difficulties with thinking, problem-solving, language and physical function.

The specific symptoms that someone experiences will depend on the parts of their brain that are damaged and the underlying cause of their dementia. The rate of progression will also vary from person to person.

This profile will give recommendations for local authorities to help improve the lives of people living with dementia in Essex.

What is a dementia pathway?

A dementia pathway will begin at the point that someone becomes aware of changes to their memory, or other symptoms associated with dementia, and will progress through diagnosis, post-diagnosis support, living well with dementia, and eventually end of life care.

Why are dementia pathways important?

There are currently 850,000 people living with dementia in the UK. This is set to rise to 1.6 million by 2040[1]. The scale and the need to prevent, diagnose, support, live and die well with dementia will only become greater.

Dementia causes complex cognitive and behavioural symptoms and is unpredictable. This means that the provision of appropriate care and support, across the entire dementia pathway, is also complex. This has led to significant variation in practice, with more focus on the early stages of the pathway, and less focus on the later stages, where people find it harder to access appropriate care and support.

This document will give more information about people living with dementia in the **Essex** area, and will provide good practice recommendations and case studies for each stage of a dementia pathway. These recommendations are only a few of the recommendations for each area, and form part of a larger body of work by the Alzheimer's Society.

Dementia and your local area

There are an estimated **20,402 people over 65 living with dementia** in Essex[2]

32,346 people will be living with dementia in Essex by 2030[3]

It is predicted that the cost of dementia care in Essex by 2030 **will be £1,514m**[6]

Currently, the annual cost of dementia care in Essex **is £932m**[5]

By 2030, it is estimated that there will be **20,964 of people living with severe dementia** in Essex[4]

Currently there are **15,006 people under the age of 65 living with dementia** in England[7]

What should be happening in your area?

Key recommendations to consider:

Each Clinical Commissioning Group (CCG) should have a dedicated dementia lead.

A CCG dementia lead should be responsible for ensuring the delivery of training to GPs on referral criteria, diagnosis and personalised care and support planning, as well as any other dementia priorities identified by the CCG. Having a dementia lead within a CCG area will help to remove variation in dementia services based on postcode.

Leads must have adequate, dedicated time to fulfil this role. Support from senior leadership at the CCG will be vital to making sure that the role of the dementia lead is understood at the GP level.

Involving people affected by dementia in the production and monitoring of local dementia strategies, and the planning of dementia services.

Where they don't currently exist, councils should work together with local Clinical Commissioning Groups (CCGs) to develop a local dementia strategy that maps current and future needs along the NHS England's well pathway.

People affected by dementia should be consulted during any refresh or development of a dementia strategy. To develop this even further the goal should be co-production. Co-production is a way to involve people who have dementia when producing or evaluating services or products for people with dementia.

Every health and social care professional directly involved in providing dementia care should be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework.

To ensure that people living with dementia receive the standard of care they need from health and care services, it is vital that all health and care staff who are directly providing care are adequately trained in providing specialist dementia care services. This must be accompanied by protected training time, targets for numbers of staff trained and training standards being a part of inspections by regulators. All staff indirectly working in health and social care should be trained to a Tier 1 standard.

Covid-19 and dementia at a glance[8]

We know that people affected by dementia have been disproportionately impacted by the Covid-19 pandemic.

45.8% of all care home resident deaths involving Covid-19 were people with dementia in England and Wales between March 2020 and 2 April 2021

Dementia and Alzheimer's disease was the most common pre-existing condition among COVID-19 deaths for care home residents. Between the two waves, there were **19,426 people with dementia who died of Covid-19 in care homes**

There were 42,341 care home resident deaths in care homes during the pandemic, including 21,677 deaths in the second wave. **This represents 24.3% of all deaths of care home residents**

For people who survived the crisis, the effects of social isolation were severe. **46% of people with dementia reported that the pandemic had a negative impact on their mental health**

92 million

During the pandemic, 92 million extra hours have been spent by family and friends caring for loved ones living with dementia. **95% of carers reported that this had had a negative impact on their mental or physical health**

What could the local authority be doing?

Key recommendations to consider:

Local authorities should have a recovery plan in place to help people living with dementia, and their carers, to recover from the adverse effects of Covid-19.

Local authorities, and local NHS partners, should have plans in place to help people affected by dementia, and their carers, rehabilitate and make sure their new needs are being addressed. This could be addressing physical or cognitive deterioration that someone living with dementia or their carers may have experienced due to the pandemic, or helping people living with dementia to re-start living the life they want once restrictions on movements and activities have been eased.

The needs of people living with dementia and their carers may well have changed, so support interventions should happen to ascertain whether any changed or additional support is needed to help the person to continue to live well and manage their condition.

Local authorities must guarantee that where care was stopped due to coronavirus precautions (particularly domiciliary care), it will be reinstated when deemed safe, without the need for unnecessary further formal assessment.

The care needs of people living with dementia did not stop during the Covid-19 pandemic, and in some cases, people's care needs will have intensified during a time when regular care may have stopped. It is therefore vital that care packages are re-instated as soon as possible, to at least the level being received before the pandemic, without having to wait for a formal assessment before care is resumed. We recognise that national government will have a part to play in this in supporting local authorities financially and with guidance.

Diagnosing well:

Data, recommendations and good practice

What is it?

Everyone with dementia should be delivered a diagnosis in a timely and compassionate way. The time between symptoms developing and receiving a formal diagnosis should be as short as possible.

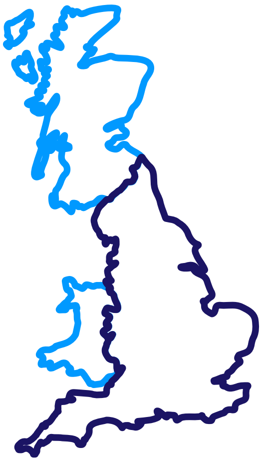
Why is it important?

Receiving a dementia diagnosis can be life-changing, and often leads to feelings of grief, loss, anger or helplessness. But a diagnosis is essential in supporting people to live well, even in the absence of a cure or drugs to slow the progression. It opens the door to emotional, practical, legal and financial advice and support.

Diagnosing well in your local area

The dementia diagnosis rate for Essex is 60.4%, the average for England is 61.7%[9]

12,321 people have received a dementia diagnosis in Essex[10]



The national target for **diagnosis rates in England is 66%**[11]

35 days

is the average wait time between a referral and an initial appointment at a memory clinic in England[12]

3 ⇨ 34 weeks

is the range of time **between referral and diagnosis of dementia** in England, meaning that many people wait over six months to receive a diagnosis[13]

58.5% of people are diagnosed in the mild/early stages of their condition in England[14]

Recommendations for diagnosing well

Key recommendations to consider:

Health and Wellbeing Boards should monitor the time it takes for a dementia diagnosis to be made.

As we recover from the impact of the Covid-19 pandemic, the initial aim should be a return to pre-pandemic timescales. Once achieved, the aim should be a maximum of six weeks between a referral being made and a diagnosis being received.

Memory services should consider accepting referrals from sources other than primary care, including social services and patients and carers themselves. This would support access to timely specialist input, especially in urgent or crisis situations.

Enabling direct access to specialist services from sources other than primary care, particularly in urgent or crisis situations, reduces the number of potential gatekeepers, therefore providing more timely access to a diagnosis. Speeding up the diagnostic process will allow people to better plan for their condition, as well as facilitate access to other support services sooner.

Memory services should have clear referral pathways to enable access to psychiatrists, psychologists, occupational therapists, social workers and dementia advisers, as well as linguists and interpreters, during the diagnostic process.

Navigating the health and social care sector can be complex and confusing for people with dementia. Yet identification of health and social care needs at point of diagnosis, with clear pathways to allied health professionals, clinicians, and support services, can enable people to access the right services, at the right time, for the right level of need.

Good practice for diagnosing well

Primary Care

As part of the Integrated Care Communities model in North Cumbria, a pilot is taking place in which a nurse-grade Memory Link worker is based in a GP surgery one day a week. The worker screens and reviews patients identified at the practice with existing or suspected dementia.

They can make fast-track referrals to the Memory and Later Life Service (MLLS), with the GP offering triage of more complex cases. This pilot is a partnership between MLLS and primary care, resulting from consultation with people living with dementia and their families. It aims to improve access to MLLS and free up GP time.

Supporting well:
Data, recommendations and good practice

What is it?

Everyone who has received a dementia diagnosis is entitled to immediate short-term support to help come to terms with their diagnosis, and plan for the future. A dementia diagnosis does not just affect the person with a diagnosis. Informal carers will also need support post diagnosis.

Why is it important?

Initial post-diagnostic support is vital to ensure that people can come to terms with their diagnosis and that they're better able to manage their condition. Given the variety of symptoms that people can experience; post-diagnostic support is essential to facilitate access to services.

Supporting well in your local area

The value of dementia support contributed by unpaid carers in **Essex is £598m**[15]

In Essex, 59.8% of carers spend 100 hours or more per week providing care[16]

55.9% of all carers reported caring for someone living with dementia in Essex[17]

Nationally, ADASS reported **4.2m more people became carers** in the first 3 months of the pandemic

The standardised figure for emergency admissions related to dementia is **3,517 nationally and 3,530 in Essex** per 100,000[18]

Recommendations for supporting well

Key recommendations to consider:

Everyone with a dementia diagnosis should have a named care coordinator. For example, this could be allocated during the initial post-diagnostic support meeting with the memory service but could be reviewed within primary care.

Under NICE guidance, everyone diagnosed with dementia should have access to a named health or social care professional. This person is responsible for coordinating their care from the point of diagnosis to the end of life. During the early stages of the condition, this may involve signposting to services. In later stages it may involve coordinating all aspects of the person's health and social care.

Memory services should all include dementia adviser services, with people automatically referred to the service unless they opt out. There must also be integration of dementia adviser services within primary care.

Receiving a diagnosis can be an overwhelming experience, often with too much or too little information given at the point of diagnosis. Diagnostic services are often only commissioned to provide diagnosis only, and will discharge once the diagnosis is given, allowing few opportunities for patients to follow up.

Therefore, ongoing dementia advice is a crucial part of supporting well, with people able to get advice as their dementia changes. This will help people to better plan for their care and be able to ask questions about their dementia progression.

Evidence-based, post-diagnostic support interventions should be provided for people with dementia and their carers. These must be appropriate and tailored, considering age, ethnicity, religion, gender and sexual orientation.

Post-diagnostic support interventions, when appropriate for that individual and tailored to their preferences, can be beneficial for cognitive function as well as general wellbeing, and provides a sense of personalised care.

Good practice for supporting well

In Bristol, the GP provides care coordination, but the Dementia Wellbeing Service ensures each GP and person living with dementia also benefits from the support of a named Dementia Navigator and named Dementia Practitioner – these are linked to each GP practice across the city.

The Dementia Navigator and Dementia Practitioner provide additional support to GPs to identify and support people with memory problems and possible dementia, as well as supporting the person with dementia. Every person with dementia has a named Dementia Navigator and knows how to contact them for consistent and proactive follow-up care and support.

Living well:

Data, recommendations and good practice

What is it?

We want to make sure that people affected by dementia live as well as possible for as long as possible.

Why is it important?

People can live well with dementia, given the right opportunities and support. This is helped by consistency of follow-up interventions, care coordination and care plan reviews. It can be achieved through support for carers, and further assessments of need as someone's dementia progresses.

Living well in your local area

In Essex, 73% of people reported having had a **dementia care plan re-assessment within the last 12 months**[19]

In Essex, **17.9% of carers reported feeling socially isolated**[20]

74.9% is the proportion of care home beds in Essex rated as ‘good’ or ‘outstanding’ by CQC[22]

74.1%

is proportion of care home beds in England rated as ‘good’ or ‘outstanding’.

In Essex, **63% of carers reported feeling stress or anxiety**[21]

50% of direct care staff report **having dementia-specific training** in the East of England[23]

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* This figure represents the proportion of care homes rates as either ‘good’ or ‘outstanding’ by the Care Quality Commission. The remaining homes may be yet to receive a rating, or have been rates as ‘requires improvement’ or ‘inadequate.

Recommendations for living well

Key recommendations to consider:

There should be ongoing opportunities for people with dementia and carers to access support interventions following diagnosis.

Dementia is a progressive disease, with symptoms worsening over time. This can lead to changes in care needs of the person living with dementia, and support needs for carers. Therefore, people affected by dementia should be able to easily access support interventions as soon as their needs or symptoms change. This can help people to live in the way that is important to them for longer.

Councils' carers' strategies should include a specific focus on carers of people with dementia, detailing the support to them, including access to psychological support and practical training for unpaid carers.

Carers of people with dementia are vital contributors to our health and social care system. Unpaid carers', or families and friends providing care to their loved ones, are providing care to a value of £13.9billion a year. Yet many of them are struggling in silence, often dealing with myriad challenges including practical, financial and emotional difficulties including stress, loneliness and depression.

Councils should work to ensure that their local authority area is dementia friendly and safe for those living with dementia.

Dementia-friendly communities are vital in helping people live well with dementia and remain a part of their community.

Too many people affected by dementia feel society fails to understand the condition they live with, its impact or how to interact with them. That's why people with dementia sometimes feel they need to withdraw from their community as the condition progresses.

Good practice in living well

Clinical input and quick access to advice and support from a multidisciplinary team working within care homes, to ensure people with dementia can access the right services at the right time and benefit from fast-track referrals.

For example, Care Homes Assessment Teams in Enfield is an integrated, multidisciplinary mental and physical health team. It includes community matrons, geriatricians, a consultant psychiatrist and mental health nurses, occupational therapy, a phlebotomist and pharmacists. It also works closely with primary care, frailty networks and a tissue viability service.

Dying well:

Data, recommendations and good practice

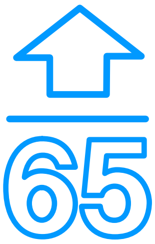
What is it?

Everyone deserves the chance to have the right support and setting at the end of life, and to be as comfortable as possible.

Why is it important?

Everyone diagnosed with dementia will have the condition at the end of their life. Dementia is a life-limiting condition and can be the primary cause of, or a significant factor contributing to, a person’s death.

Dying well in your local area

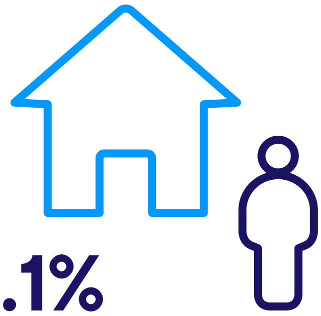


904.7*

is the standardised rate of mortality for people living with dementia over the age of 65 in Essex[24]

849.3

is the standardised national rate of mortality for people living with dementia over the age of 65



65.1%

was the percentage of people dying at their place of usual residence in Essex[25]

70%

was the national average of people dying at their place of usual residence

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* per 100,000

Recommendations for dying well

Key recommendations to consider:

Health and social care professionals should ensure that all people living with dementia have the opportunity to discuss advance care plans at each stage of a person's pathway.

When a person with dementia is approaching the end of their life, it can be a very difficult time for them and the people around them. Planning for the end of life is important for anyone who has a life-limiting condition. For a person with dementia, it is important to try and have these conversations as early and as often as possible, while they can make decisions for themselves. Discussions at each stage of the pathway will allow for revisions to be made to a care plan, should the person change their mind.

Health and social care staff should ensure that individuals' care plans are always up-to-date and include end-of-life plans.

CCGs and councils should ensure that where accreditation is available all directly delivered or commissioned services meet the National Gold Standards Framework end-of-life care.

The Gold Standards Framework (GSF) aims to optimise care for all people nearing the end of life by helping to improve the quality of care provided and how care is coordinated across boundaries, to enable more people to live well and die well at home.

The GSF provides quality improvement via training, quality assurance via the standards of care that it sets and quality recognition via its recognition scheme. This enables councils to track the standards of end-of-life care delivered by services in their area.

Clearly identify dementia as a terminal condition and conduct an area review of capacity and access to palliative care in care home settings. This must include an audit of training for care home staff, as well as access to out-of-hours support.

We know that people living with dementia often struggle to access palliative care services towards the end of life. This may be in part due to the fact that dementia is often not recognised as a terminal condition or incorrectly categorised as a mental health condition. Some health and social care professionals therefore do not see dementia as a condition that would require palliative care, and do not include end-of-life care in care plans.

Local authorities should conduct a review of their area to determine whether there is sufficient availability of palliative care services within care homes, and that staff are suitably trained to deliver end-of-life care.

Good practice in dying well

Developing partnerships between care homes and hospices, where there's extensive experience in palliative and end of life care. For example, Wigan & Leigh Hospice provide a service called 'Hospice In Your Care Home', which sees the hospice work with care homes in the borough. The service provides: support to care home staff to understand the principles of palliative and end of life care, a formal education programme and bespoke training, additional support at short notice if needed, support for the development of advance care plans, and additional support for those important to the person who is dying.

Further information and resources

- **Detailed look at the 'Well Dementia' Pathway**
- **Covid-19 and the impact on people affected by dementia**
- **'The Fog of Support': in-depth look at caring and dementia**
- **A future for personalised care**
- **Your Regional Public Affairs and Campaigns Team**
- **local@alzheimers.org.uk**

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    This figure represents the total of care homes rated as either 'good' or 'outstanding' by the Care Quality Commission. This does not mean that remaining care homes are 'requires improvement' or 'inadequate' as some care homes will not yet have received a rating.
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People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a regular donation please call us on **0330 333 0804**
or go to **alzheimers.org.uk/donate**

Alzheimer's Society operates in England, Wales, Isle of Man and Northern Ireland. Registered charity number 296645 and Isle of Man (1128)

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