



Dementia & Complexity... Listening to the Workforce

Key Insight Report

February 2024



Caring for People with Dementia

With a particular focus on
complexity around
distressed behaviours...



Essex County Council





Essex County Council
Adult Social Care

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Acknowledgements

This research was commissioned by Essex County Council on behalf of the people of Essex. It was designed by Adult Social Care (ASC) and Health Integrated Care Systems and delivered in collaboration with the Research and Citizen Insight team at Essex County Council, with endorsement from the Essex Care Association (ECA) and the support of North, Mid, South and West Essex Provider Forums.

Capturing the insight would not have been possible without the openness of our care market, who provide care and support for people living with dementia in our communities, and we would like to thank them for sharing their time to be involved in this research.

Who is this report for?

This report is of interest to stakeholders across the care and support marketplace. It comprises a suite of research findings that provides further intelligence in key areas of focus that have emerged through engagement with the care market providing services for people living with diagnosed and undiagnosed dementia in an Essex care-setting. These workforce findings further develop our evidence base to be drawn upon to inform wider insight, learning and opportunities.

Preface - Introduction to Report

The background to this work was led in North-East Essex where approximately 70% of care home residents are living with diagnosed and undiagnosed dementia. To date, there are ongoing difficulties in Adult Social Care in the Older Adult Mental Health team, and across the county in sourcing domiciliary, residential, and nursing providers for adults with dementia and functional mental health being discharged from hospital being declined due to their past presentation. In turn, this creates delays in discharge from Mental Health/Acute hospital settings, with an increase in placement breakdowns in care homes, including hand backs, and notice served to existing adults. This is leading to hospital re-admission and higher fees being paid, with providers appearing to be less willing to accept adults with dementia with distressed-challenging behaviours.

As part of the challenge and opportunity, shared discussions across social care, health, and wider partners took place to explore maximising support for this particular cohort around unmet needs and recognised the need to understand this more from a provider perspective. To further understand, Essex County Council launched a survey on dementia in care homes. To engage with the workforce to better understand the journey and experiences of accepting applications and caring for adults with diagnosed and undiagnosed dementia in a care setting, especially with residents with more complex presentations including distressed-challenging behaviours.

We know from our ASC Business plan, there is increasing demand for support and services, with increasing evidence of high complexity of needs. In taking an approach that uses opportunities to capture wider insight and support the evidence-base that is fed back into the system can maximise opportunities to prevent, reduce or delay the need for care. This focusses on ensuring the right type of care for people in receipt of support, including those with conditions that might escalate into crisis, recognising people living with dementia. We know people living with dementia often have other impairments and comorbidities, and often their primary support reason may not be their dementia. Or, the reverse,

in that the cumulative impact of their co-morbidities may be overlooked, i.e. the person may only be seen in terms of their dementia, and recognised factors that can increase the risk of crisis.

The aim of the survey was to identify opportunities for improvement to benefit both care setting staff and residents, with work adopting a systemic approach, taking a listening approach to give providers a voice in the issue and solution. Our vision for Adult Social Care is for people to be able to live their lives to the fullest, supported by a community-based model of social care that is preventative and localised. We were keen to hear about what barriers may be to accepting applications to care for adults with dementia, and also hearing about solutions that have been sought to remove barriers on where it is working well. The survey questions took an integrated care and health design approach launching across Essex in February 2023, for a period of eight weeks.

This report creates a place to hold insight from the workforce on caring for someone with dementia with a focus on complex needs and enables wider opportunities to utilise the findings and the learning of what we have heard in support of live-well outcomes and wider system benefits.

Dementia Survey Overview

Essex County Council (ECC) sought to understand experiences of care providers within a care setting looking after adults with Dementia and explore:

- How current services could be improved.
- How care providers in the residential care sector could be better supported in their role.
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The methodological status of the survey was self-completion and notes some return segments of low number, in total a sample return of fifty respondents was received, and whilst not statistically representative of all Essex care homes. The survey covered a range of views across locations and positions, to increase confidence with the insight as a starting point to better understand workforce experiences of care providers, with the survey being received positively.

“We are really pleased to hear that this survey is out there, as we can see the value in this” (Care Home Manager)

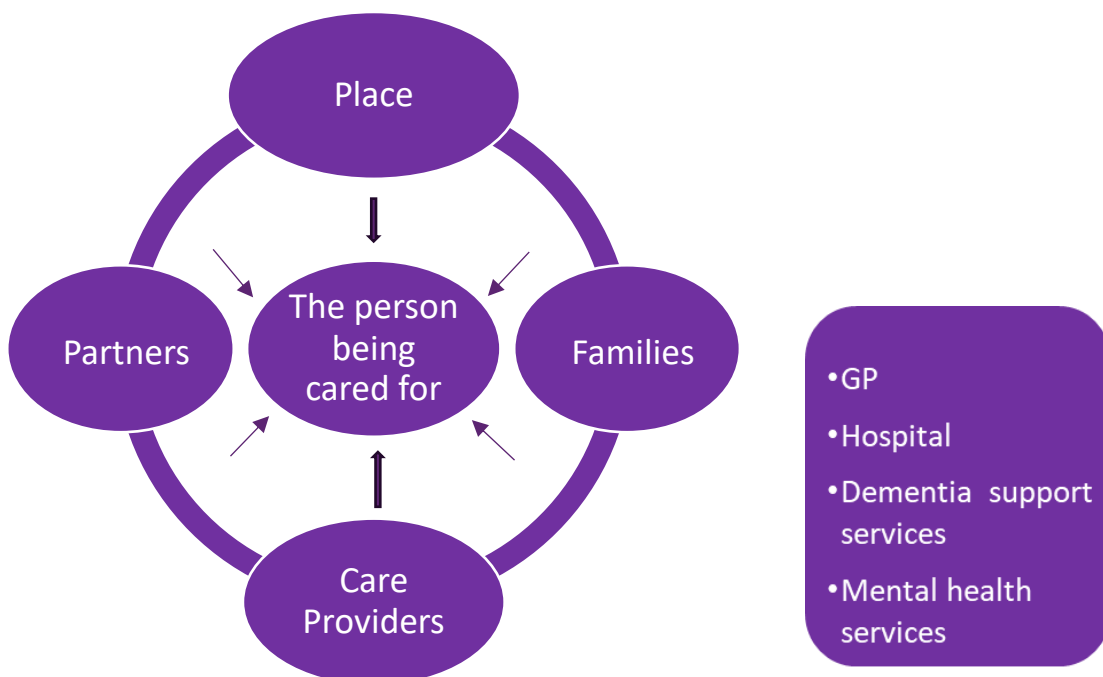
Following on from the survey which closed in April 2023, further work took place until December 2023 to share the survey findings across the system in various care and health forums, this also included care provider engagement sessions, and reference groups. This activity supported wider discussions and using the findings to check back have we heard you right and the key areas to focus on. This approach took a look-forward view and has created opportunities to align survey themes to future work activity, also supporting a ‘you-said, we-did, and doing’ approach to the findings.

Survey Key Findings

Through text-analysis of what we heard from providers; we were able to theme findings which identify a common thread around four emerging areas of focus:

- 1. Support** – to reduce the number of calls to emergency services.
- 2. Information** about the adult, to allow care providers to have the right resources in place to reduce number of notices served.
- 3. Training** on how to manage distressed behaviours and better understand the different types of dementia to reduce placement breakdown.
- 4. Environment** that is more dementia friendly to reduce distressed behaviours.

The feedback also identified elements around continuing focus on the integration of health and care pathways.



As shown, we heard if one of these four elements becomes disconnected, then challenges can arise. For example, distressed behaviours from residents, the need to contact emergency services, impact on staff capacity and other residents' safety and wellbeing could be affected. This tells us the importance and benefits of place-based care networks through multi-disciplinary teams (MDTs) to be drawn on at the earliest opportunity, through open and integrated pathways of care and support, especially in response to escalation of need.

Respondents told us that they are less likely to accept people living with dementia who have a history of distressed/challenging behaviours and told us there are gaps in current service provision.

We heard...

- There is a need to receive an accurate assessment and clear information about residents from professionals and families.
- The biggest challenge for care homes is understanding how to manage distressed behaviours.
- More dementia-friendly homes would reduce distressed behaviour.
- There is a need to improve support from external partners, such as Mental Health services, GP's, wider NHS including Dementia Intensive Support Teams.
- There is a need to improve support internally within the care setting; appropriate funding, and training to support staff recruitment and retention.
- A need for increasingly join up care to meet needs, increased benefits for residents and decreased frustrations for staff.

Some respondents told us that they have given a notice to residents in the past 12 months, and whilst we were not able to identify a particular

adult's journey as survey anonymised, wider insight in situations when notice given tells us:

- A review of the adult's needs is made, and may result in an exceptional need payment, for additional 1:1 support, in which notices maybe withdrawn, or ongoing request to source an alternative placement.
- The adult may be returned to hospital as a failed discharge, social admission to Accident & Emergency and/or detention in accordance with the Mental Health Act 1983.
- In addition this may also factor other finance provisions considered such as Continuing Healthcare (CHC) and 117 ICB funding to source alternative placements.



To provide further context around strategy relating to dementia and care in the Market, the current Essex Market Position Statement (MPS) for Dementia provides further detail on the Essex Provider Hub, which can be found here: [Link](#)

Forward Focus

Through the survey this has increased visibility through a workforce lens of caring for someone with diagnosed and undiagnosed Dementia with complex presentations in a residential, nursing, and wider community care setting, and highlighting aspects of the wider pathway around the care setting. Findings support an ongoing focus to activity that promote effective transitions, and the integration of pathways across multiple disciplines at a local system level, and key to supporting delivery of positive place-based outcomes. In turn, increasing the likelihood of stable and secure lives for people living with dementia, and where those needs change to be able to continue to live-well.

Activity for market focus currently and in the shorter-term 2023-25:

- A new Needs Assessment Tool (NAT) system to deliver exceptional needs payments has been created which is simpler, more straight forward and joined up to enable a more open and transparent process to receiving payments more quickly.
- Allocation of the Market Sustainability Improvement Fund (MSIF) grant to support fee increases and launch of additional funds for ASC providers to promote access to free training, with payment to attend, and a retention bonus fund.
- Future commissioning of care, including residential, nursing, and domiciliary, and emerging thinking on models responding to increasing complexity in the marketplace.
- Focus on gaps in service-support to look at what could work differently, been available sooner, including discharge through transfer of care arrangements to support improved outcomes and experiences of people living with dementia, in transition between health and care settings.

- Cross commissioning opportunities to use contractual influence across the wider sector and within localised systems to influence a wider wraparound of dementia care and support in communities at place-level.
- Build on discharge schemes and learning from pilot activity to understand what works best to support people post-discharge from acute settings to have a good transition into a care setting and decrease in placement breakdowns and/or readmission to hospital for people living with dementia.
- Focus on transitions and pathways across local systems that impact on the delivery of effective place-based outcomes in community through ongoing progress with integrated and locality working.
- Ability to use the survey findings with increased confidence and areas of workforce focus in relation to training, information, support, and environment. This is shaping a new training offer, and the development of a new Dementia page on the Essex Provider Hub.
- Explore solutions in the challenges and opportunities, to inform the evidence base for interventions, including Pilot activity, such as discharge schemes and Technology Enabled Care (TEC).
- Insight supported wider workstream activity around quantifying dementia complexity through wider interface, and multiple themes cross referenced to other internal data and analytical products.
- Using the Essex Dementia Friendly Communities work to support uptick in dementia-friendly accreditations in our Essex care-based settings, and further opportunities to promote TEC.
- At a place-based level promoting a wider social model that moves beyond connecting people with wider services but connecting people in care settings within the centre of community life, with people of all ages and interests.

- Key dependencies to progressing work around Integrated Care Systems (ICS) Market Shaping, Care Market Workforce and overarching strategies linked to the support offer for people living with Dementia in Essex.

Following the survey, time was built in to triangulate data from wider sources from our ASC data to develop an interface with other analytical products linked to dementia complexity. Further information on this wider data and insight can be found in Appendix 1.

What we heard good looks like

The survey also captured learning when caring for people with dementia works well, which has been captured below in eight statements, and can be seen as co-produced principles to consider and reflect, alongside other tools to review progress within activity.

A safe and dementia friendly environment for residents to get about independently.	Staff have received training and have better understanding and patience.
Receiving external support, from the GP, Dementia services, Mental Health services and families.	Sufficiency of staff to provide one-to-one support. Staff retention; and consistent staff working with the person.
Experience working with the person, so the care provider understands the persons needs and can provide a person-centred approach.	Having multidisciplinary team meetings to enable a multidisciplinary approach.
Good communication between care providers and receiving accurate information about the person being cared for.	Early intervention and planning for transition before adults go into care.

Aspects of Insight and Policy

Aspects of insight captured in this report links to wider areas of national policy, some of these key links provided below for further reference:

1. [The Integration White Paper.](#)
2. [Integrating care: next steps to building strong and effective integrated care systems across England.](#)
3. [Major Conditions Strategy: Case for change and our strategic framework](#)
4. [People at the Heart of Care.](#)
5. [Next steps to put People at the Heart of Care.](#)
6. [Care workforce pathway for adult social care: overview.](#)
7. [Health-and-Social-Care-integration-joining-up-care-for-people-places-and-populations.](#)

Of Note

Whilst this survey was focussed on the paid care workforce, these findings recognise the potential impact on the unpaid workforce, such as Carers and wider family members of people living with dementia through shared experiences of health and care. We have seen similar themes emerging in the areas of support, information, and training in unpaid carers surveys. The findings from the survey have been shared widely with colleagues to support work activity in both the paid and unpaid carer spaces.

We also remained cognizant of Covid-19 and impact on people living with dementia and cognitive impairment, the care and health system, paid and unpaid carers, and wider communities during the peak of the pandemic during 2020-22, and impact on recovery in the shorter and longer-term.



Appendix 1 – Wider Survey Slide Packs



FULL - Caring for
Adults with Dementia



Dementia Insight -
Survey + Additional C



Summary Version -
Caring for Adults with

This information is issued by:
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can be translated, and/or made available in
alternative formats, on request.

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