Experiences of Frailty and Ageing Well in West Essex

April - September 2025

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Essex

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Produced by

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1.0 Introduction

1.1 Healthwatch Essex

Healthwatch Essex is an independent charity which gathers and represents views about health and social care services in Essex. Our aim is to influence decision makers so that services are fit for purpose, effective and accessible, ultimately improving service user experience.

One of the functions of a local Healthwatch under the Health and Social Care Act 2012 is the provision of an advice and information service to the public about accessing, understanding, and navigating health and social care services and their choices in relation to aspects of those services. This document was revised in July 2022 and the role of Healthwatch was further strengthened as a voice of the public with a role in ensuring lived experience was heard at the highest level.

1.2 Acknowledgements

Healthwatch Essex would like to thank all of the members of the public who took part in this project through discussions and engagement. Our thanks are also made to those individuals who took the time to speak with us and share their personal stories in more detail. We would also like to thank our many partners, contacts, and networks who worked with us to share the project throughout west Essex and help generate such a strong level of interest and feedback.

1.3 Disclaimer

Please note that this report relates to findings and observations carried out on specific dates and times, representing the views of those who contributed anonymously during this time. This report summarises themes from the responses collected and puts forward recommendations based on the experiences shared with Healthwatch Essex during this time.

1.4 Content Note

This report contains discussions of sensitive topics relating to frailty, health and ageing, including serious illness, disability, dementia, falls, hospitalisation, end-of-life care, carer stress and trauma, mental health, suicidal thoughts, bereavement, and experiences of neglect within health and social care settings. Some readers may find these themes distressing. We recommend that readers take care when engaging with the content and seek support if needed. Anyone can contact Healthwatch Essex's confidential Information & Guidance Service for help on how to access support. Email info@healthwatchessex.org.uk or call 0300 500 1895.

1.5 Topic Introduction

The term ‘frailty’ refers to an individual’s mental and physical resilience. It is a long-term condition which is often experienced by older people. However, anyone with multiple long-term conditions may experience frailty. The degree and severity of a frail condition can vary depending on the individual and can change over time. It is recommended that individuals are not labelled as ‘being frail’, but that they simply ‘have frailty’.

Frailty may cause an individual to take longer to recover from illnesses or be more seriously affected by an illness. Someone living with frailty might also take longer to complete some activities. However, evidence suggests a person-centred and goal-orientated approach can reduce poor health outcomes for individuals living with frailty. It is recommended that any interaction between an older person and a health or social care professional should include a frailty assessment. Therefore, it is important for all health and social care staff to be trained in frailty recognition.

Age UK provides information around some of the common signs, symptoms and conditions of frailty, which include:

Malnutrition and dehydration

According to Age UK, malnutrition affects around 1 in 10 older people. Those who are affected are more likely to visit their GP, be admitted to hospital and have longer recovery times from illness or surgery. Meanwhile, one of the most common reasons why an older person is admitted to hospital is dehydration. Dehydration in older people can lead to an increased risk of urinary tract infections, falls and pressure ulcers.

Falls

According to the NHS, every year more than one in three people over 65 suffer a fall, which can cause serious injury and even death. The costs to the NHS and social care from hip fractures alone are an estimated £6 million per day or £2.3 billion per year. Falls and fractures are a common health issue faced by older people. After a fall, many older people may lose their independence or need long-term care. Fear of falling can also lead to reduced activity, loss of strength, lack of confidence, and risk of further falls.

Bladder and bowel problems

In the UK, more than 14 million people experience urinary incontinence and 6.5 million people experience bowel incontinence. While incontinence can affect people of all ages, it is more often experienced by older people. People with continence needs are often too embarrassed or poorly informed about the possibility of improvement and even cures. Continence problems can be overlooked by providers in all settings. For this reason, NICE recommends case finding within all at-risk groups, including people aged 65 and over.

Dementia

Around 850,000 people are estimated to be living with dementia in the UK. The Alzheimer's Society predicts that 1 in 3 people born in the UK today will go on to develop dementia in their lifetime. Possible symptoms of dementia include issues with memory and mental agility, difficulties with daily living activities, mood and behaviour problems, hearing problems, and sight problems.

Delirium

Age UK defines delirium as an episode of 'acute confusion'. It can often be misrecognised as dementia, but it is preventable and treatable. According to the NHS, around 20 to 30% of older people on medical wards in hospitals will have delirium, and up to 50% of people with dementia will experience delirium. Older people with delirium may be at risk of longer hospital stays, falls, accidents or pressure ulcers, and admission into long-term care. It is estimated that between 10% and 50% of people who have surgery develop delirium, varying between surgeries and settings. In long-term care settings, its prevalence is under 20%.

Mental health problems

Mental health problems are common in later life, with conditions such as depression and anxiety affecting around 1 in 4 older people. However, mental health problems can often go undetected and be under-treated in older people. As of December 2024, Age UK estimates around 940,000 older people aged 65 and over in the UK experience loneliness.

Other signs of 'frailty'

In addition to these signs and symptoms, other experiences of frailty might include immobility, susceptibility to side effects of medication, unplanned weight loss, tiredness or exhaustion, slowing down, reduced strength, or more frequent hospital admissions. Common methods of assessing frailty include a timed 'up and go' test (standing up, walking and sitting back down), frailty scores (e.g. Rockwood Clinical Frailty Scale), PRISMA-7 (questionnaire assessment tool), gait speed (the time it takes to walk a certain distance) and grip strength (the measure of how tightly you can squeeze).

1.6 Topic Background

Healthwatch Essex were approached by the Hertfordshire and West Essex NHS Integrated Care Board (HWE ICB) to undertake a series of projects focussing on the lived experiences of people in the area in relation to their health, care and wellbeing. Two projects were selected per calendar year for in depth engagement, with the production of a report based on this engagement. One of the projects which was selected for in depth engagement was the healthcare experiences of residents living with frailty in west Essex.

In 2025, west Essex has a diverse population of approximately 330,000 residents across six Integrated Neighbourhood Teams (INTs), within the districts of Harlow, Epping Forest and Uttlesford. This includes:

- Harlow North (62,637 residents)
- Harlow South (40,767 residents)
- Epping North (65,619 residents)
- Loughton and Buckhurst Hill (62,095 residents)
- North Uttlesford (42,851 residents)
- South Uttlesford (55,696 residents).

The 2025 Overview of the Health and Wellbeing of the Hertfordshire and West Essex Population (Overview of the Population) identifies the following age trends.

- Among older age groups, the ICB has a higher proportion of the population aged 85+ (2.6% compared to 2.4%) but a lower proportion aged between 65 and 84 years old (14.7% vs 15.5%).
- Trends in registered population show that the fastest growth is in the 65+ and 85+ age groups (10% and 9% increase respectively). Rapid growth in these age groups is predicted, linked with the ageing population.
- The increase in the older population, particularly the population aged 85+, is lower than predicted, driven by the impact of the Covid-19 pandemic which disproportionately affected older age groups, resulting in higher mortality.

Deprivation and Health Inequalities

As stated in the overview, the most deprived areas in west Essex are Harlow and Epping, due to their significantly poorer health outcomes when compared within the HWE ICB, regionally and nationally. People in these areas are more likely to live with long-term conditions, require emergency care, and pass away before the age of 75 years old.

The West Essex Health and Care Partnership (WEHCP) shared the following figures, which indicate Harlow as having the poorest health outcomes.

- Harlow has a higher proportion of older adults living in poverty compared to the national average, with one in six older adults living in poverty.
- The under 75 mortality rate in Harlow is 392 per 100,000, higher than England, East of England, Essex and the HWE ICB.
- Harlow has the lowest age of those living with three or more long-term conditions.
- Life expectancy is lower than all comparators, with a 5.4-year gap between the most and least deprived communities.
- Mental health prevalence is notably high, with 19.1% of adults and 12.2% of over 65s estimated to have common mental disorders, both above national averages.
- Emergency hospital admissions are higher than expected, particularly for coronary heart disease and myocardial infarction, with high rates of emergency admissions for over 65s.

Other health indicators across west Essex in the HWE ICB's overview include:

- The prevalence of certain long-term conditions (including diabetes, heart failure, dementia and frailty), which are higher compared to the HWE ICB average, however this is likely to be due to improved diagnosis.
- Fewer people with a long-term condition are receiving core care as part of annual reviews, representing an opportunity for further proactive support and risk management.
- The rate of emergency admissions, admissions for falls, and the proportion of people with multiple admissions in their last days of life, has reduced among older people.

Frailty

The HWE ICB's overview states that approximately 110,000 people in Hertfordshire and west Essex are recorded as having frailty. The following figures were recorded:

- The majority of people at around 68% (76,000) have mild frailty, 22% of people have moderate frailty (24,000), and 10% have severe frailty (11,000).
- The prevalence of frailty in the area (6.6%) is higher than the national average, predictably due to improved disease detection and data quality.
- The variation of frailty rates between different areas is likely to result from differences in coding quality on patient records, with frailty prevalence at a Primary Care Network (PCN) level varying between 3.3% to 14.7%.

- Frailty prevalence increases with age and a high proportion of people with frailty are aged 80 years old and over (44%).
- A high proportion of people with frailty have at least two long-term conditions (61.6%), with cardiovascular disease (CVD) (69.1%) and diabetes (48.5%) being the most common conditions experienced.
- Locally, 4.45% of people aged 65 years old and over are prescribed 10 or more medications. However, this is likely to be a result of prescribing schemes, medication reviews, and effective care in the last year of life.

Dementia

According to the HWE ICB's overview, 12,701 people are recorded to have dementia in Hertfordshire and west Essex, compared to an estimated 19,490 people. This equates to a dementia diagnosis rate of 65.2% (data for December 2024) which is below the national target of two thirds of people with dementia receiving a diagnosis. The rate of emergency admission for people with dementia is the highest in west Essex. However, this could be associated with higher levels of dementia diagnosis.

Falls

West Essex is the only area to see a statistically significant change in the rate of emergency admissions following a fall in the community, with an 8.3% reduction. The following data on the rate of falls was shared in the HWE ICB's overview:

- The rate of falls increases with age, with the rate of falling nearly doubling for every additional five years of age. The rate of falls in the community is approximately 20 times higher in people aged 90 years old and over compared to people aged 65-69 years old.
- The rate of falls is statistically significantly higher in women than men even after adjusting for age (186.6 compared to 144.3).
- Following a fall, 82.9% of patients return to their usual place of residence. This has increased from 78.8% in the previous year.
- The chance of being discharged to a usual place of residence decreases with increasing age, with 10% fewer people aged 90 years old and over returning to their residence, compared to people aged 65-69 years old.

Emergency Admissions

The HWE ICB's overview explores the rate of emergency admissions for people aged 65 years old and over, identifying the following trends:

- The rate of emergency admission varies and is influenced by geographic and demographic factors. West Essex now has the lowest rate following a reduction of 3.9% compared to the year before.
- Rates of emergency admission among the older population increase with advancing age and with higher levels of deprivation. Every 5 additional years of age increases the rate of emergency admission by 30-50%.
- People living in higher levels of deprivation have a 50.2% higher rate of emergency admission compared to those in lower levels of deprivation.
- Men on average have a higher rate of emergency admission (after adjusting for age), with a 17% higher rate of emergency admission compared to women. This higher rate is observed across all age groups.

End-of-Life

The palliative care register has increased significantly between 2022/23 and 2023/24, from 0.4% to 0.9%, reflecting improvements in identification of people with end stage disease. According to the HWE ICB's overview, the register is more reflective of the number of people who are likely to be in their last year of life and therefore will benefit from advance care planning and palliative care support.

Current data on the proportion of people who have died that had three or more emergency admissions in the last 90 days of life shows that there is an increasing trend, from 5.8% (2022/23) to 6.7% (2024/25). The HWE ICB's overview states that "whilst this is not statistically significant, the pattern warrants further monitoring and actions to avoid poor experience and outcomes for people in their last days of life and potentially low value care for patients and the health care system". According to this data, males are significantly more likely to have multiple admissions in their last days of life compared to females (7.4% vs. 5.7%).

2.0 Purpose

The aim of this project was to explore experiences of frailty and ageing in the west Essex area. This included canvasing the views and experiences of the community aged 65 years old and over, and their families, friends and carers, to highlight some of the key changes that can be made to improve their health outcomes and experiences. Our engagement spanned across the three districts which form west Essex, including Harlow, Uttlesford and Epping Forrest.

2.1 Engagement methods

Participants were contacted via our extensive networks and the Healthwatch Essex website. Our partners, other organisations and working groups in west Essex, together with many individuals inside and outside of the NHS, supported our efforts to engage with as many people throughout the area as possible.

Participant Interviews

Individual interviews were conducted to collect personal stories from members of the public. To provide greater accessibility, conversations were carried out both in-person and via email, telephone and video calls during July and August 2025. All participants gave their consent to have their interviews recorded.

Expert Interviews

Professionals from public bodies with insights around local healthcare services were interviewed to gather further knowledge and understandings of experiences of frailty among the community. Interviews were carried out both in-person and via email, telephone and video calls during July and August 2025. All participants gave their consent to have their interviews recorded.

One-to-one interview questions varied for participants depending on whether they were a resident with experiences of frailty, ageing or an age-related condition, a carer, or a family member. Interviews were carried out in private and confidential settings, with interview times and locations organised at the convenience of participants, taking into account work and family responsibilities. Individuals were able to share their personal stories in their own time during these conversations, providing rich qualitative engagement, shaped into case studies.

Participants were willing for their experiences to be shared within this report, however, to ensure their anonymity and the confidentiality of the information they provided, all names used are pseudonyms to protect their identities.

2.2 Engagement Levels

Lived Experience

We spoke with 11 individuals who were willing to share their lived experiences and engaged with 7 further family members and friends. Another 11 individuals expressed interest in the project. This resulted in case studies with **9 lived experience participants**, including second-hand accounts of **3 further participants**.

Expert Insights

We spoke with 22 professionals from across the public sector, including health and social care, local government, and charity organisations. We also spoke with 4 professional networking and meeting groups (10-20 members each) as part of our engagement. Responses from **12 professionals** from various organisations across the public sector were used to inform our 'expert voices' chapter.

Community Outreach

We attended three public events where we engaged with local residents about the project, including an 'Age Well' fair where we spoke with **58 people**, a carer event where we spoke with **49 people**, and a local community event where we spoke with **61 people**. We also engaged with **5 community groups** involving residents from across west Essex, with between 12-35 members in attendance.

Social Media

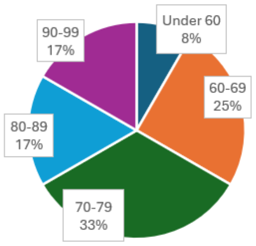
Promoted widely via our social media pages, the project was shared on Facebook, reaching **2,290 followers**, Instagram, with **1,514 followers**, and LinkedIn, with **1,509 followers**. (All figures taken from our social media statistics from September 2025.) We also shared information in **28 Facebook Groups** based in west Essex, with a total of **326,188 members**.

Other forms of engagement included email, telephone and online enquiries, organisation newsletters, word of mouth, networking events and via steering and action groups led by health and social care organisations and local government.

3.0 Demographics

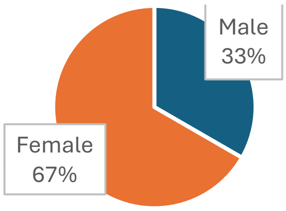
Demographic questions were asked to understand the key characteristics of participants, how this might impact their healthcare needs and experiences, and identify any trends in health inequalities for specific community groups. Questions focussed on age, gender, ethnicity, disability, long-term health conditions, location and carer status, and were answered on a voluntary basis.

Out of our **9 first-hand** and **3 second-hand** lived experience **participants**:



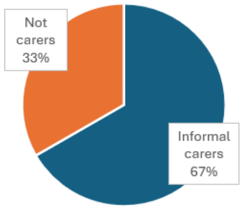
Age

- 8% (1 person) was under 60 years old.
- 25% (3 people) were 60-69 years old.
- 33% (4 people) were 70-79 years old.
- 17% (2 people) were 80-89 years old.
- 17% (2 people) were 90-99 years old.



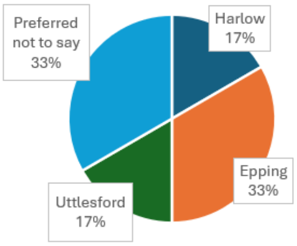
Gender

- 67% (8 people) identified as female.
- 33% (4 people) identified as male.



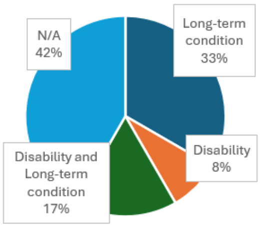
Informal Carers

- 67% (8 people) identified as informal carers or had previously provided informal care.
- 33% (4 people) were either the recipient of informal care or did not identify as carers.



Geographic Location

- 17% (2 people) lived in Harlow.
- 33% (4 people) lived in Epping.
- 17% (2 people) lived in Uttlesford.
- 33% (4 people) preferred not to say.
- Postcodes shared: CM5, CM6, CM16, CM20 and IG10.



Disabilities and Long-Term Conditions

- 33% (4 people) had a long-term condition.
- 8% (1 person) had a disability.
- 17% (2 people) had a disability and a long-term condition
- 42% (5 people) did not have either.

Ethnicity 100% (12 people) identified as ‘White British’. However, this is not representative of the ethnic population in west Essex. In the Census 2021, ‘White British’ accounted for 85.1% of Essex residents, with other ethnic groups accounting for 14.9% of the Essex population.

4.0 Expert Voices

As part of our discussions, we got in touch with professionals from across the public sector in Essex who provide support those aged 65 years and over. We spoke with a range of health and social care professionals, community workers and volunteers who were able to share their insights, knowledge, and lived experiences. We would like to thank everyone who took the time to talk to us to help us to produce this report.

Access to Primary Care

Social prescribers in GP practices are bridging gaps by linking people to community and wellbeing support. However, GP access barriers can push people into A&E unnecessarily, worsening hospital pressures.

- “Doctors have taken a step forward in regards to social prescription.”
- “Social prescribers seem so much easier to contact than a doctor.”
- “People now go to A&E for such small things […] because they can’t get through to their doctors.”
- “111 will say [to go to] A&E […] but half of them probably don’t need to be there.”

Loneliness, Isolation and Mental Health

Loneliness can contribute to severe mental health issues, including suicidal thoughts, especially among older people who have lost their partners or their sense of independence. Many clients are housebound and lack of transport or digital skills makes accessing groups and services difficult.

- “The majority of our caseload are people who are elderly and isolated. They're stuck at home, mostly due to mobility issues or mental health.”
- “Some people, they don’t speak to anybody at all. And when they see us, that’s the first conversation they’ve had all week.”
- “Some people are struggling with their mental health because they feel lonely and isolated and feel suicidal due to this.”
- “Some people don’t want to be here anymore. They don’t want help. They’ll tell you, ‘I don’t want it because it’s pointless.’”
- “Social isolation can definitely increase dementia symptoms […] it’s all about keeping [the] mind and body active.”

Community and Transport

Support availability varies widely by area, with rural and poorly connected places creating more challenges. Meanwhile, poor, costly, or inaccessible transport makes healthcare and community access much harder.

- "In Harlow, as much as it sits as a deprived area, there's a lot of funding, there's a lot of daily groups daily which people can walk to."
- "But if we're getting referrals from outside of Harlow, and they're isolated, getting to that [support] would be the problem."

Support and Awareness

Services are in place, but families and older adults often do not know that they exist or struggle to navigate them.

- "There's lots of support out there in Essex, the negative is lots of people don't know about it."
- "One lady's husband in his mid-80s […] got the attendance allowance form and said, 'I'm not even going to bother with it, I don't understand it.'"
- "Sometimes we encounter people that say, 'I don't want to bother my children, they're busy,' so they try to battle the system alone."

Referrals and Waiting Lists

Referrals often come indirectly, but long waiting lists mean people can remain without help for months. Older people are less likely to have advocates pushing for timely appointments and support, leaving them more vulnerable. Long waits for scans, assessments, and follow-up reviews can create anxiety, leave conditions unchecked, and make people feel like they are unsupported.

- "It could be six months or even more until you get that support in place."
- "At least 70% of our referrals are from community agents, often highlighted alongside another issue like needing a disability badge or home adjustments."
- "People are waiting a lot longer for diagnosis […] it just causes so much more stress on the families."
- "They're told you'll have reviews every six months. They just don't happen."

Communication and Information Sharing

Families face repeated failures in communication between hospitals, GPs, and specialists. Missed letters, delays, and inconsistent record sharing undermine trust and create health risks. Multiple disconnected systems leave families responsible for chasing, repeating histories, and navigating services alone. Integration is key.

- "I've got the NHS app, a separate app for doctors, a separate app for Princess Alexandra Hospital, and another for Queens Hospital […] it's crazy."
- "People get letters for appointments that were last week […] it's particularly confusing for those with multiple conditions."
- "You get all the way through one pathway and then told it's not that […] but no one refers you on. You have to start again via your GP."

Hospital Discharge and Rehabilitation Failures

Premature discharge and long delays in follow up support undermine recovery and increase risk of deterioration.

- "We hear constant complaints that patients were discharged before they were medically fit."
- "If it's not sorted before they leave hospital, it can take two months to triage once in the community."

Digital Exclusion

Reliance on digital systems can cut many older people off from services. Non-digital options are essential and printed information should be available via GP boards, pharmacies, parish councils, and supermarkets in the local community.

- "Older people just want to pick up the phone and speak to a human […] online systems put them off."
- "A lot of charities […] their promotion is all done on social media like Facebook, and a lot of the elderly […] they don't access those things."
- "My GP, specifically everything has to be done online, so you can't ring anymore […] for the elderly who can't get on online, I don't know how they're expected to get an appointment."
- "My dad, in his mid-80s, barely used his phone, let alone the internet."
- "The Alzheimer's Society's postcode search is brilliant […] but if you're not online, you won't find it."

Value of Befriending

Befriending services can create meaningful connections that reduce isolation.

- "Some of them are like best mates […] it's nice to see that about the support network. They wouldn't have that support in place otherwise."
- "Sometimes we sit for a bit longer than we should do and have a little [chat] they open up a bit more in their own surroundings."

Dementia Care Gaps

Dementia is still stigmatised, particularly among older adults who may avoid seeking help, leading to isolation. Support is inconsistent and there is a demand for dementia-specific services. Families need clearer information about dementia types, signs, and pathways. Professionals need training in dementia-friendly practice and communication. Hospitals are not always dementia-friendly, with lack of staff training and limited time leading to poor care, accelerating decline. GPs are well placed to support people with dementia, but lack of training and continuity of care leaves families feeling unsupported and misunderstood.

- "There needs to be more services that are specifically dementia-based rather than one size fits all."
- "GPs probably have the most contact with people with dementia […] but families often feel abandoned."
- "Even doctors only have a small part of their training on dementia […] frontline staff need awareness."
- "Hospitals need training on behaviours, triggers, and not challenging a person's reality."
- "Food and drink were left in front of [a patient] who couldn't feed herself."
- "Nurses were annoyed with a lady wandering at sundown, she just needed something to occupy her mind."
- "On children's wards you have play therapists and sensory rooms. Adults with dementia don't get the same."

System Challenges

Staff shortages, hospital closures, cuts, and demand overload mean people can't always access the care they need safely or quickly. Systemic strain on the NHS and social care can often lead to charities and volunteers having to fill the gaps. Risk-averse systems, slow processes, and absent feedback loops mean mistakes repeat, families lose confidence, and opportunities for learning are wasted.

- "The NHS is stretched […] then you're relying on charities to fulfil it, which is only going to be volunteer-led."
- "Families share their complaints with us, but they don't reach the hospital, so learning is lost."

Community Connection

Social changes like less community contact can make loneliness worse. However, local voluntary groups can provide trusted, accessible, and personalised support that reduces isolation and prevents decline, but they are under-recognised in formal care pathways.

- "People describe our groups as a lifeline."
- "Years ago you used to walk along the road and say good morning to people. That doesn't happen no more […] that good morning might be the first person they've spoken to all week."
- "No one really knows their neighbours. No one seems to keep an eye on anyone anymore."

Hidden Practical Barriers to Care

Everyday issues such as unsafe housing, hoarding, or equipment needs become critical barriers to safe care but are often overlooked until crisis.

- "We do lots of deep cleans, move furniture, fit key safes, arrange pendant alarms […] simple things that otherwise block discharge."
- "I was shocked at how many people are hoarders […] it delays discharge and creates safeguarding risks."

Pressure on Carers

Carers face long waits for support, high costs, and limited financial resources and can often neglect their own health and become unwell due to stress. However, structured support and peer connection can improve resilience and outcomes.

- "You can see how much more frail the partner becomes because of the stress and strain of caring."
- "Carers are working under complete stress."
- "People feel they're letting their loved ones down by putting them into care."
- "If they do want a sit-in service, they've got to pay for it. […] They don't have the money for that."

5.0 Case Studies

Many people offered to talk to us directly to tell us about their stories in depth. We would like to thank everyone who took the time to share their experiences to help us to produce this report. From those we have spoken to, we would like to highlight the following 9 case studies to reflect the lived experience of people in west Essex.

Case Study 1

‘Angela’

Angela is 87 years old. After her husband passed away eight years ago, she moved from Hertfordshire to west Essex to be closer to her family. She lives independently, but continues to drive. Family remains central to her life, with seven grandchildren and five great grandchildren nearby. She keeps active in the local community through volunteering at a hospice, organising church activities, and taking part in a gardening group. Most recently, she joined a local carers group to accompany her 92-year-old friend, who was reluctant to attend alone.

The interview began with an overview of Angela’s general health experiences, including any current or previous conditions and health concerns: “I take tablets for blood pressure and cholesterol, but I have done for years. I've got dry eyes. I had to have a double prolapse operation which was not successful so I've got an internal catheter which is changed every three months and a pessary which is changed at Broomfield Hospital every six months. And that is the one thing I have a problem with, not the pessary, but getting it changed and appointments and the rest of it. I've got a pinned left ankle and a new right knee, but I'm still going out and about.

I've had my operations and I've had my two cataracts done and you have to recover and exercise after those things, especially after the knee and the ankle operation. I had to have a thyroid operation as well. But I wouldn’t really call myself frail, not for my age. But I am very, very careful, because the doctor said if I do any more to the ankle, I had to have three operations on it, there’s not much more they can do for me.”

Discussing Angela’s experiences with GPs, she said: “The one thing with GPs is, you can’t really ring them up, or the hospital, because you're 20 or 15 in the queue. But if I ever need an appointment with the GP, I actually go into reception and stand there until she gives me one. My surgery is pretty good compared to some of the experiences my friends have had. I think that's the big thing with older people, is the fact that we can't get in contact with people when we've got concerns about our health. I never see the same GP, but they all seem very pleasant. I have to see the diabetic nurse and she's very good, and when I said to her 'I think I've got a prolapse', she went and got the doctor and said he would see me in half an hour."

Angela then shared her experiences receiving hospital treatment: "I would say my experience with my surgery is good, but I do have a lot of problems at the hospital. I have my pessary changed every six months, but they don't make appointments. They said they would ring me, but it was due in July and they didn't contact me, so I rang them up but couldn't get through. They didn't answer my daughter's emails, I went through to PALS because they're normally pretty good. I had a standard letter from them saying they were inundated with queries and it'll be some time before they can answer. I've still not heard anything.

I've got friends who are 92 or 94 and I've been taking them out recently and they will say 'Oh dear I can't get the doctor and I can't get the hospital, and you feel so sorry for them'." I don't know about other GPs in other surgeries because I do hear different tales from friends, but personally, even when I was in Bishop Stortford, they were really good. There's always loads of leaflets. There's quite a lot of good information that you can read. Now I've found this carers group, which I take my friend to, she's found them very helpful. But it's knowing where all of the services are. Or if the person you speak to can refer you to the right care."

The conversation then focussed around experiences of hospital stays. "I must admit the last operation I had was absolutely brilliant. We went in in the morning, we were in one ward, we took a step through the door and we were in the operating room. All the consultants stayed there who were operating. They brought us all sandwiches and coffee. You had likeminded people who had had the operation around you in other beds.

The only time I've had a bad experience was in a private hospital. I didn't find that that was very good, because you're in a room on your own and they don't answer the bell. When I sat up after the operation, I absolutely flooded everywhere because of the prolapse, and when the nurse finally came she said 'Oh I'm not changing you because it will disturb your sleep.' I was like that until the morning. I did tell the consultant and he wasn't very happy. But I thought considering it cost me £12,000, it wasn't very good."

On the topic of receiving care at home and in the community, Angela added: "Quite a few of my friends are sort of 90 plus and most of them seem to have carers. My granddaughter is a carer. They all seem very happy with that system. They seem to be quite efficient in the community. But I've got friends who have had to stay at hospital because they couldn't find any help in the community. We definitely need more care homes and also more carers. Because I think a lot of people are quite happy to have carers two or three times a day. Even one friend is monitored by the hospital with her heart problem and she's got some sort of pacemaker and she can connect to the hospital with that, so that's efficient. We just need more care in the community, more facilities and more people to do it."

Discussing whether Angela had ever made an advance care plan, she said: "I just don't really need one now. But being aware of this care group, and taking my friend to the meetings, I've heard all of the information. But the only problem is, this friend of mine, she knows what she should do but she doesn't want to do it. She lives with her son who's in his 60s, he's lived with her all his life. She's 92, she knows he can't cope with anything if she passes away and she has quite a bad heart condition. The carers group have told her that she should put in place a care plan for him. But he can be aggressive and I think she's frightened of him. She hasn't got anyone else to help her.

It's extremely frightening for people who don't have family. Most of my friends have very supportive families, but I do know a couple of people who haven't got anybody. But I mean the help is there and this care group has pointed out so many different avenues. But it's getting people to take advantage of them. I suppose that generation isn't used to that sort of thing.

My husband had a DNR, but because I didn't have any proof with me when he went into his coma, they wouldn't accept it, and they insisted on treating him. It was not a good end-of-life. So, I've got the information in my purse and registered it with my GP. I've done everything that I think I can do."

In relation to digital accessibility and finding information and advice about preventing frailty, Angela commented: "With my generation, it's very difficult for them. In my 30s, I went and did courses so I can use a computer quite basically. But the problem is, they will keep changing the system. I don't think our age group can take it in, we just can't learn it. But I think when our generation has gone in the next decade, they will be able to have much more things computerised that older people will understand. But even my son, who's in his 60s and runs his own business, he still asks his children for help. Because I said 'Oh I feel so helpless' and he said 'I feel helpless too'.

I think if they got information in the post in a leaflet, and then if they had someone to help them, because a lot of my generation can't do thing themselves and have had to give up driving. The written word is the easiest, because that's what we're used to. A lot of people who are in their own homes, even if they've managed to get some care, they probably haven't got anyone to take them on outings. I think care groups, if you can get people to them, is the best way to get elderly people back into the community. Churches are really helpful too in terms of their outreach, they do lots of good for the community. Especially with my age group."

She added: “I think we just need more carers. Some people my age don’t speak to people for days. Most of my friends have nice neighbours who pop in and get their shopping. But if you haven’t got anybody like that, it must be very soul-destroying. I think it adds to depression, and if you’re depressed you’re more likely to be vulnerable. Missed care in the community and people blocking hospital beds is a big problem.”

Case Study 2

‘Bill’

Bill is 72 years old. He wanted to share his story as a carer for his 96 year-old mother after taking care of her medical arrangements for the last few years.

Bill’s mother sadly passed away two weeks after our discussion.

“My mother is currently in an end-of-life situation. But her recent journey through hospital has been, in my view, quite appalling. With her general health, she's 96, she was living independent with carers. She had a whole range of different illnesses, atrial fibrillation, erythromelalgia, skin cancer, oedema, incontinence, high blood pressure, she was deaf and had arthritis. She also for the last few years has been suffering from various degrees of depression and anxiety.

She's on various medications, blood thinners, all sorts of things. She’s had a carer in the morning for an hour for the last three or four years to mobilise her. We [family members] would perform care increasingly over recent times. Before that she would do things herself, so she’s had a gradual decline in her health, mobility and motivation. She had a DNR signed in 2019 and ‘frailty’ was recorded as the reason for not resuscitating, and that followed a discussion with the GP. I don’t think there were any more follow up discussions about frailty and what to do about it. My father died in 2022 and had around three or four years of gradual decline. Through a couple of years he was diagnosed with lung cancer and COPD.

For the last two or three months, she's been feeling increasingly tired, there was a marked change in her capacity, but she was still living independently up until when she fell overnight and broke her right arm in two places. We suspect that she had laid there for three or four hours, she forgot that she had an alert button until 7am in the morning. Looking at the scene, I think she had multiple falls.”

After experiencing a major fall, Bill told us about his mother’s experience being admitted to hospital: “On the first day, the ambulance came and took her to hospital and got to A&E at around 9am in the morning. She could describe what had happened, she got up in the night, she wasn’t quite sure what room she was in, she had gone dizzy and had fallen over and then crawled around the bedroom until she remembered she had the button. We were there until about 5pm in the evening. By that time she had X-rays and a diagnosis. They said they were going to discharge my mother home with a care package. Bear in mind, she's incontinent, got all these various illnesses, nothing about her dizziness had been diagnosed or was attempted to be diagnosed."

Bill then talked us through some of the conversations he had with staff around his mother's hospital discharge. "The guy who attended was representing the orthopaedic section and he was saying 'there's no need for an admission, we're planning to discharge' He said to her, 'what do you think about it?' And she said, 'I don't think I can cope at all. I've broken my arm in two places. I won't be able to cope with carers.' So we started talking about making some arrangements, he then started talking about the possibility of a referral to Epping, and a step-down care reablement type of environment. And we felt that would be appropriate.

But he was very much trying to sell the solution of going home. It wasn't an objective discussion or an evaluation of her needs, it was more like a 'wouldn't you like to be at home, surrounded by your children, surrounded by the things you know and love?' Fortunately, my mother was able enough to say 'yes, I'd like to, but I won't be able to cope'. In preparation to discharge her he started doing a blood pressure test and her blood pressure collapsed from 145 over 75, which is normal for my mother, to 80 over 40 with a slow heartbeat. He seemed satisfied that it was now going to be a medical referral, rather than an orthopaedic case. He seemed rather pleased with himself that he managed to protect the orthopaedic bed from my mother occupying it. I saw evidence of it later in my mother's treatment, people were being inappropriately released home."

After her admission, Bill's mother remained at hospital for four weeks. After her blood pressure loss, he explained that she suffered from a dramatic reduction in her mental capacity. "Her nursing care throughout had been outstanding. After those weeks in the hospital, there was another attempt to discharge her home with a care package. Again, I thought this was inappropriate. I don't think she had the capacity to make the decision. When we talked to her she would say 'I'd like to go home, but I don't think I can. I don't see how I can cope'. But the discharge recommendation was to send her home into what they called a 'micro environment'. They wouldn't describe for how long or what duration. There was no plan. No one had been to her home to assess whether or not what they were proposing was a viable option. There was no falls assessment. No paperwork.

We were told this on Friday at 5pm. And they actually wanted to go and discuss her discharge with her immediately following the meeting. So I said 'no, we'll do it Monday' and then everyone kept coming up to my mother, talking to her about her discharge. She was absolutely petrified. In the end they made her extremely anxious, to the point where I formally wrote out a document expressing her wishes. I got a friend to witness the statement. I gave it to the administrators on the ward on Sunday, telling them they're not to ask my mother any questions about her discharge because it was creating such anxiety in her. It got to the point where she was waking up from her sleep, crying out 'I don't know, I don't know. Why are you asking me?' She was bursting into tears in front of my brother."

Bill explained how the hospital discharge team continued to insist that his mother would be going home with a care package. "She didn't have door keys, she didn't have clothes. I tried to take control of the situation, making it as difficult for them to discharge her as possible. Because during her previous admission, three or four years ago, they actually discharged her at 10pm at night with no medication, in her night clothes. […] I pointed out that I wanted all of the documentation, but we were given none. I wanted all of the assessments done. There was no medication. They were continuing to insist that they were going to discharge her home.

I went into the hospital to visit my mother and the ward manager came out and said, 'have you heard the news?' She said 'they've just told us that they're going to discharge her to Epping', and that she'd probably be discharged tomorrow. It was the day they wanted to discharge her on, but into immediate care. We could see that she was stable, so we accepted the discharge from the acute ward to free an acute bed. We just didn't want a discharge to home.

I went in and met with the ward manager and told my mother she was going to Epping. We came in the next day and that had changed, they hadn't secured a bed in Epping for whatever reason. So we had to tell my mother that actually she was going to Saffron Walden, which is about an hour drive away from where we all live. I heard reports that Saffron Walden was probably a better environment."

On the day of his mother's discharge, Bill told us about some of the challenges he faced with getting an ambulance to take his mother to Saffron Walden: "She was discharged at 5pm from the ward. As we were walking down, my brother-in-law and I were talking about what we were going to do with the cars. We planned to follow the ambulance up to Saffron Walden. The porters then said to us 'oh, if you've got a car, you won't need an ambulance'. They kept repeating it. Me and my brother-in-law had a brief discussion and we said 'no, how are we going to handle her in and out?', there were too many risks attached to it.

We walked into the discharge lounge, the lead porter said to the guy manning the desk 'Oh I think these people are going to take her in the car, they don't need the ambulance'. I said 'no, we're not. She needs to go in an ambulance and we'll follow on.' That was at about 5.10pm. We were sat waiting for the ambulance. At 6.30pm I went up to ask what was happening. The woman who was managing the computers said the ambulance was scheduled for 7pm, but she said she could see on the system that it would arrive at 6.45pm.

So we waited, but heard nothing. We got to 6.50pm and I saw the look on her face, I asked her what had happened. She said the ambulance has disappeared off of her system. The ambulance reported that it was overheating and would no longer be able to attend. I asked her, 'how often does this sort of thing happen?' They said 'at this time, we often get a problem with ambulances failing to attend'. It was hot, but I don't believe that the ambulance overheated.

I asked when the next ambulance was coming. They said 'Oh no, there won't be another one.' I asked, 'what are you expecting to happen to my mother?' They said that she would spend the night in the discharge lounge. It turns out they had four beds round the back. I realised that that's exactly where they were hoping to discharge my mother to from A&E four weeks earlier.

I asked if we should take her in the car. It was unacceptable, but under the circumstances, it was more acceptable than another overnight stay. I asked if someone could help us get her into the car. They said yes. I asked what would happen when we go to Saffron Walden. They said, 'we're not sure'. I said, 'if we're going to do this, we need to know that there's going to be people there who are able to get her out of the car safely and get her into the ward'. It turned out that at 8pm they have night staffing at Saffron Walden who they can't spare to come off of the ward and we would have arrived after 8pm. The Saffron Walden hospital also has a policy where they can't accept patients from cars. It astonished me that the discharge lounge didn't know that and was attempting to encourage us to take her in the car. So she stayed the night.

I asked what time they were organising the ambulance in the morning. They said they would request it at 7am. So we returned at 7am. At around 7.30am I asked what time the ambulance was due, I didn't get an answer. At 8.15am we had still heard nothing, so I asked again what time the ambulance was due, I was told that it was scheduled for 5pm that day. How can you order an ambulance for 7am and an acceptable response is to schedule it 10 hours later? I asked to speak with the person in charge of the ambulance. He wasn't in, and wouldn't be in until 10.30am.

The staff were brilliant, but it strikes me that the systems and the processes and the management of that place is absolutely appalling. It actually stops the staff from doing a good job. They were concerned, but they didn't feel that they had the authority to reschedule the ambulance."

Arriving at Saffron Walden, Bill described some of the differences in the quality of his mother received. "My mother went to Saffron Walden Community Hospital, and I've got nothing but praise for the whole organisation and environment and care that she's getting there. She's been there ever since. She's likely to pass away. However anybody who thought that discharging her home with three or four carers, at this stage in the process, was an appropriate course of action is beyond me. Saffron Walden hospital have said she's just not fit for discharge at any stage. So you've got massive contradictions in the quality of care.

It seems to me that the focus [at the previous hospital] was to protect beds, not protect and look after patients. No one tells you what the process is. All the events just emerge as a surprise, and with little time. All of it, I suspect, is aimed at achieving the outcome the hospital administrators desire, rather than what's best for the patient. The nursing and clinical staff are fighting an organisation that is out of control, and doesn't appear to help the frontline staff do their job, it just gets in the way of it or is imposing very significant pressures. The nursing care is excellent, outstanding in view of the managerial environment that's created. The systems don't work. And the frontline isn't really empowered.

Saffron Walden have processes all over the wall, documentation on various steps, assigned nurses. The level of care is probably the same as what we saw from the nursing staff before, it's just in a much more managerially-effective environment. People lead, processes are laid down, there's proper discussion about what we're going to do and how it's going to be done. And there's explanations when plans and approaches change. […] They've got a chart up about the seven stages of frailty and definitions against them. I've been reading about them and its very informative. It's there for the nurses and the patients. I've been looking at it and thinking about where my mother is on these stages. They have a whole board with information."

Bill then discussed some of the experiences that his mother had visiting her GP. "You get the sense that she's 'time-expired' because of her age, and her access to the GP has not been easy. We've had easy access to the nurses, and we've used that route to get access to the GP when we've needed it. […] I'm on various medications, I've got high blood pressure and atrial fibrillation. I get medications reviews every six months, I'm not aware whether my mother has had any.

Our GP surgery has changed over to an electronic system where they do an electronic triage. But my mother doesn't have internet. A landline is new technology for my mother. She has trouble with her TV remote. The way the system works, you have to have an email address. When they introduced the system, you could phone up and potentially the receptionist could fill out the form manually on your behalf. They've now withdrawn that service. So you can only access the GP through online input via this triage service."

In relation to whether Bill had considered his own care preferences, he said: "I've done my power of attorney, you need one to be able to fight against the hospital administration, it seems to me. People don't understand what should happen and are frightened to actually challenge [decisions]. I don't think the hospitals want to educate you to do that. Because then you can expose the fact that they're not adhering to processes. I don't know if I'd talk to the GP. I don't believe the GP would have time to talk through it. I've spoken to my wife about it."

Discussing what kind of information and resources would be helpful for someone trying to manage frailty or age well, Bill said: "You need some sort of handout that prompts the discussion. It needs to target carers. The carers are the ones that carry a lot of the information. But they're all under massive time pressure. We're doing part of the caring. In truth, we try not to admit that, because once you admit that you're a carer, you get more workload pushed onto you. There should be some guidelines around discharge and the stages they go through."

Case Study 3

'Calvin'

Calvin is 60 years old and lives with his wife and son, both of whom provide care for him. In 2019, he was diagnosed with Lewy body dementia. He decided to share his dementia diagnosis journey, and walked us through some of the difficulties he experienced navigating services. His case study raises several key issues that are important for understanding the lived experience of dementia, gaps in care, and opportunities for improving health and social care services.

The discussion began with Calvin reflecting on when he first expressed concerns around his health and decided to visit his GP. "In 2014, I went to the GP as I felt that my intellect had dropped a couple of notches. I was sent for some tests, only to be told, 'you scored quite highly, so there isn't a problem'. I didn't say anything, as at that stage, I didn't argue with doctors. In July of 2019, I went to the GP and said the same thing. This time, I was referred to the memory clinic. When I got home, I googled 'memory clinic', and was horrified to find that it was a dementia clinic. I was 54 years old and the GP suspected I had dementia.

Six months later, my wife and I attended the memory clinic. After taking the tests and talking with the consultant for an hour, she said, 'I am almost certain that you have Lewy body dementia [LBD], but the only way to confirm it is with a scan.' I wasn't about to believe it without a scan result. Then lockdown kicked in, the scan was postponed. When lockdown finished, I phoned the memory clinic to book my scan, only to be told, 'you have a diagnosis, you don't need a scan.' I disagreed, explaining what the consultant had said. I got my scan."

Calvin then shared his experience of receiving his diagnosis: "The second lockdown kicked in. I received a telephone appointment on a Friday morning. I didn't expect bad news. To paraphrase the 30 minute telephone call, they said, 'your diagnosis is confirmed after your scan. Make sure your will is up to date, put powers of attorney in place. Oh, and someone from the Alzheimer's Society will contact you in six weeks.' I thought, what do I want to talk to them for? I don't have Alzheimer's. I didn't say anything as I had a lot of other stuff rattling around inside my head. The consultant was sounding emotional during the call, she had that catch in her voice that people get when they are upset. I thought it can't be nice giving someone this type of news. Now I think, how I feel about my diagnosis is *my* decision. It took me two years to learn to want to live again.

It took the rest of the day to get my head around the idea. I wanted to talk to someone, but I couldn't, it was the end of the day and it was the weekend. My wife and I did the next best thing and asked Google. In hindsight, not a wise move. The majority of the pages we looked at were American sites. We ignored the Alzheimer's Society, because I didn't have Alzheimer's. These sites all give a timeline, the general consensus was 15 years from the date of onset. Based on the listed symptoms, I thought, I've had this for about 10 years. Sunday afternoon, I looked up at my wife and said, I want to go to Switzerland. I wasn't joking.

Monday morning, I phoned PALS and explained what had happened. The manager of the memory clinic phoned me that afternoon and said, 'six weeks is [the waiting period] patients told us they wanted'. I said, 'no one asked me, and why do I want to talk to the Alzheimer's Society anyway?' She said, 'they look after ongoing care for all types of dementia.' I said, 'but no one told me!' The Alzheimer's Society phoned the next day and have been brilliant ever since."

Calvin explained some of the challenges he experienced trying to explore what medications were available to him: "A few weeks later we joined an online support group. A short time later, a new lady joined who also has LBD, she raved about her Rivastigmine patches. Following this, I called the memory clinic to ask if I could try some medication. The reply was, 'we were just talking about discharging you, I suppose we can try you on some medication first.' It had been eight weeks after a terminal diagnosis and they were talking about discharging me. There are four medications for LBD; Rivastigmine, Memantine, Donepezil Hydrochloride and Galantamine. I have tried all four, and unfortunately had bad reactions to them all. The memory clinic had to be asked by me for each medication. The only one they told me about was Galantamine, and that was after I asked if there was anything else I could try."

After trying different medications, Calvin was eventually discharged from the memory clinic. "The memory clinic sent out the disclosure letter. When reading it, my wife and I agreed that they were talking about someone else. I contacted the memory clinic to ask them to write an accurate disclosure letter that represented the call we had with the consultant. I can only assume that no notes were taken during the call as their second effort also bore absolutely no resemblance to our recollection. They asked me to send them what I wanted in the disclosure letter. That is what they then sent me.

I asked about my prognosis and the details of my scan. I wanted to know my life expectancy. They were not very forthcoming about the scan and told me they couldn't give me a prognosis as 'no one knows'. It took me three months to accept about the prognosis. After nine months, I was still having to ask them about the scan results, all I wanted to know was what area of my brain was affected. I know people who have been given copies of their scans and they wouldn't talk to me about mine. During this time, I was getting very depressed and a psychiatrist was sent to the house. When we got the follow up letter, he had written my diagnosis down as Parkinsons. My wife and I had been talking about the Parkinsonism's side of LBD as my mobility was starting to play up. He didn't take any notes during the meeting and got just about everything wrong in the follow up letter, I don't know who he was talking about, but it wasn't me.

I then got a very abrupt and rude letter from one of the dementia nurses, paraphrasing, 'stop asking about a prognosis, there isn't one'. 'Stop asking about which area of your brain is affected, this information won't do you any good.' I phoned the memory clinic to complain. I was told the manager was in meetings all day. I phoned PALS who said they would talk to the memory clinic. The next morning the manager phoned me. A Zoom call was set up with the consultant, three other people from the memory clinic, my wife and myself. I was still upset over the psychiatrist's letter. I just wanted to know what area of my brain is affected. They said, the 'caudate nucleus'. I thought, how difficult was that?."

Exploring the impact of the support he received from the Alzheimer's Society, Calvin said: "The Alzheimer's Society has been life changing for me. They asked me to be the main speaker at Chelmsford Cathedral for dementia action week in 2021. The area manager for the Alzheimer's Society set up a strategy group with myself and two other people with dementia. She wanted our feedback on various topics. On one of these occasions, a local health commissioner joined us. All three of us told her our diagnosis stories. Theirs were not much better than mine. She made a lot of notes. She asked what would help us. I said, peer support would be nice, I have had it as part of the mental health service and it is invaluable. The next day our strategy group was given £80,000 in funding to deliver a service catered to this.

After a hectic year, we managed to deliver a bespoke peer support service for newly diagnosed young onset dementia. The three of us jointly won a 'Dementia Heroes Award' for Outstanding Achievement. We were the first within the society to do co-creation from start to finish. Because of this service, I know there are at least two people who are still with us, because I was there to pick up the phone. The service is the only one of its kind in the country."

Not long after his diagnosis, Calvin wrote the following statement: "We are told the NHS is from the cradle to the grave. When you get a dementia diagnosis, it feels like you are being told, 'we have got you this far, be a good chap and do this last bit on your own.'"

Case Study 4

'Donna'

Donna is 66 years old and runs a local carers support group. She is a full-time carer for her husband who is living with dementia, is partially sighted, and has a chronic heart condition. She is physically disabled, with multiple long-term conditions, including arthritis to the spine, hips, knees, hands and fibromyalgia. Due to these conditions, she regularly takes pain medication.

Alongside caring for her husband, she provides care for her 90 year-old mother who has arthritis to the spine, lives with chronic lymphocytic leukaemia, and is profoundly deaf. She also looks after three other family members, part-time and remotely, who live with a range of neurodiverse conditions, mental health issues and physical disabilities. Due to her caring responsibilities, she is in touch with local healthcare services several times a week.

Discussing how active and independent her family members are able to be in their daily life, Donna said: "My husband, really not at all. I've just taken him to a dementia group where he goes Friday mornings for two hours. But he couldn't survive on his own. My mum probably could just about survive. She still drives, she still cooks, all that kind of stuff. She still dresses herself, but she can't cope with any of the paperwork and administration of life. And the others? They would cope not so well. But they would cope. My mum lives next door, so we're very connected in that sense. I'm constantly in and out from one house to the next. I make sure that they are connected to the community. So with all the activities I organise for my husband, I make sure he has that cognitive stimulation in various parts of the brain. But I don't feel necessarily connected to the community. We go along to quite a few activity groups, but I'm supporting him at those groups and we're doing those groups for his benefit rather than for mine.

There's no one to be with him. There's no one to do my job for him. There's nobody going to step into my shoes. So I mean there are things out there, but it does involve me running around driving here, there and everywhere and to organise those things for him. My mum can't exercise with her arthritis. She struggles to walk. She was encouraged to go to an exercise class, but because she has hyper mobility, she damaged her back so much she was immobile for three months."

The conversation then moved on to understandings of what it means to live with frailty. "I don't think people would like to be called frail because I think they would feel very vulnerable. And it does imply getting old, and they don't necessarily want to acknowledge that. There are things they can no longer do, but I would classify my mother as frail. She hasn't fallen, but she could be prone to fall. She has very thin skin, she bruises easily. She can get a little bit confused. She can be a little bit disconnected from the world because she won't wear her hearing aids. So that does make her vulnerable and it takes her longer to absorb things. Now that the world is moving so fast, technology is moving on so fast, she's completely left behind, which makes her vulnerable as well."

Discussing her family's experiences visiting their local GP pratices, Donna said: "The relationship with the actual GP is probably good in terms of the quality of the service. In terms of the practice, I'd say it's atrocious. We rarely see a GP and when we do go to the GP surgery, we're fobbed off onto some sort of physician associate or practise nurse. I do everything online with them because you can't get a hold of them on the phone. It's pointless going into the reception, because the receptionist, all she does is take notes and pass it to somebody else so you never get an answer. So then you have to go back again or wait for a message. I have to be completely on top of the medication. For example, with the dispenser at the surgery, my mother's cardiologist stopped one medication and replaced it with another, but the dispensary then prescribed her both. Fortunately, she was on top of it and noticed that they'd given her the wrong stuff. If she'd taken both, she would have been killed."

Donna shared her frustrations navigating between services in different areas: "The disconnect between the computer systems is horrendous. My mother has to have monthly blood tests at the GP surgery, those are then sent to the hospital for analysis, and the results come back to the surgery. But the haematology consultant she was referred to is at a hospital in mid Essex. So I have to remind the surgery every month to e-mail them over. They seem incapable of putting a note on their system to do it automatically. She has a diagnosis of chronic lymphocytic leukaemia, and even though I have reminded the surgery every month that they need to e-mail the results to the hospital in mid Essex, the last time my mum had a phone appointment with the hospital they said they hadn't received anything for six months."

Donna explained how she frequently has to travel across the county to see different services for their different specialisms. "None of them talk to each other. The private sector doesn't keep the NHS informed. The NHS doesn't keep the private sector informed. Different areas don't talk to each other. It's all completely different computer systems, and I have to chase it all up individually. A couple of years ago, my husband's cardiologist said he needed to make an urgent change to my husband's medication. But he couldn't do that without consulting with another person at a different service because it would affect their medications. He couldn't get a reply. He chased and chased and chased. And in the end, it ended up with me physically taking letters between the services to get a reply. And it took six or eight weeks.

They never proactively follow anything up. They don't act on anything unless you chase them and the scope for error is real. If I wasn't there, for example, my mum wouldn't necessarily pipe up and say that she's allergic to a medication. If I wasn't with my husband for an appointment about his prostrate, who would be able to tell them that he's living with dementia, and they need to explain things in a different way? People just don't take accountability, they have no understanding of multiple needs, they're all disjointed and disconnected from each other. At an eye appointment for my husband, we were probably about 15 appointments in before they finally flagged on his notes that he's living with dementia, even though I'd said it every single time."

Donna shared another challenging experience navigating services as a full-time carer. "One time I had to take my mother to A&E, I obviously couldn't leave my husband at home, so I had to take them both with me. My mum couldn't walk. They had no wheelchairs available. I asked the reception, she said she would have to wait until one becomes free. So she's got to sit in the car and then I've got to try and nab a wheelchair from somebody that doesn't need it. I asked if I could check her in in the meantime. They said they couldn't check her in unless she's here. So they were expecting her to sit in the car, before I could even check her in, doubling the amount of time she would have to wait. It ended up with me standing in the A&E reception, shouting at the top of my voice to all of the patients, asking if anybody can possibly get out of their wheelchair so I can get my 90 year old mother in out of the car? Fortunately, one guy lifted his wife out of the wheelchair and gave me the wheelchair.

We started the process, but then they would only let one other person through to the treatment area. So I had to leave my husband with dementia sitting in the A&E waiting room on his own, with all the chaos and the noise that's going on there, while I took my mum through to the treatment area. And then I'm dashing back and forth between the two, trying to make sure he's okay, check what's happening with her, through a door which can only be opened by a member of staff.

It's atrocious. You've got somebody with dementia, sitting in an area he's completely unfamiliar with, absolute chaos, police coming and going, abandoned as far as he's concerned, abandoned on his own, not knowing where he is, with the potential for him to wander. Nobody listens to you. You try to explain to reception the situation. There's no process for them to actually recognise the needs of people who are caring for multiple people.

I filed a complaint in April to PALS about the issue at A&E. They came back to me on the phone in the September. They said it shouldn't have happened. I asked for a written reply to say what they were going to do about all these things. They said if you want a written reply, it needs to be raised as a complaint. I said, 'that's what I've done'. She said 'no, it's been raised as a concern. So if you want to make it a complaint, we need to start again from the beginning.' So we went all the way back through it again. And I've heard nothing since."

Exploring how service providers could better attend to patient's individual needs, Donna said: "With my mum, she's profoundly deaf, but she won't wear a hearing aid. At the hospital they will talk to me and ask me questions. 'Does she do this? Does she do that?' I'm thinking, she's sitting here, all you need to do is speak a bit louder and slower and she can understand. Don't talk to me like she's not there. At the pharmacy, there's a particular pill my husband takes which comes in two forms. Now he's partially sighted, but most of the time we get a tiny little white pill. Bearing in mind he takes 13 pills a day, so this tiny little white one is buried amongst all the others. He can't see it. But there is another version which is bright blue, about the size of my fingernail. And yet we can't get the pharmacist to give us the blue one. His partial sight is not taken into account with his medication.

The only medication reviews which have been done have taken place by a physician associate, sitting in front of a computer screen, filling in boxes and having absolutely no understanding whatsoever what the medications are for. I have to explain to her what they do. She asks my husband, how do you feel about your medications, but he's got no idea. I mean, I want him to speak for himself. She should ask him these questions. But then with taking his answers at face value, with him saying 'I do my meds every morning, I'm dealing with it okay', this is not true. Because in his head he's doing all these things, but that's not happening in reality. And I'm sort of sitting there behind him, sort of shaking my head, whether she's taking that on board or not, I don't know. It's called show timing, it can happen with dementia when you might try and impress someone in a situation when you think it's demanded. Someone with dementia, for a very brief time, can put on a very good show and appear completely unaffected. It's a recognised thing within dementia, but the physician takes it at face value."

Donna added: "My husband has been taking his heart medication since 2011 and I think apart within the GP surgery, he's had one review. That was this year. That's 14 years and he's had one review. He's been seen by the cardiologist annually, but the medication's never been reviewed. My mum has been taking medication for cramps for 20 odd years. As far as I'm aware, she's had one review, and that was this year. I've been taking my medication for 20 plus years, and I've had one review, that was this year."

The conversation then focussed on Donna's experiences trying to get a dementia diagnosis for her husband. "You're left to your own devices. Especially with dementia. Once you get diagnosed at the memory clinic, that is it. You have no follow up. You're discharged to the care of the GP who then does nothing. I spent more than two years when he was first diagnosed trying to find out what support we could possibly get and was pushed from pillar to post. The GP knew nothing. The NHS memory clinic couldn't care less. Initially, they diagnosed him with mild cognitive impairment. I was saying, 'no, it's worse than that'. After a year they said they would do a more complex analysis. And so they said, 'We've done these other tests, and you're right, he has got full blown dementia.'

I said to the GP that my husband needs a referral back to the memory clinic because I think there's been a decline and he needs to be reassessed. The GP assured me they contacted the memory clinic and sent a letter. And I've not heard a thing for several months. I'm fed up doing everybody else's job for them."

Discussing her family's experiences of hospital care, Donna explained: "One time my mum was taken into hospital with a suspected heart attack. She was monitored for a couple of days in a mixed ward. It was noisy, dirty, filthy. They said it was just a blood pressure issue and she could go. I got to the hospital. She had been kicked out of her bed and was sitting in the day room, surrounded by her belongings. So we got up to leave, just as we were about to get in the lift, a nurse came rushing out. She said 'we didn't check that you've had all the needles taken out of you. Can I just give you the once over to make sure you've got no needles left in you?' Fortunately, she hadn't, but they obviously hadn't ticked her discharge papers correctly.

Donna shared another experience at A&E, during which her mother was struggling to walk due to swelling in her legs: "It was the first indication she had of a heart problem. So I took her into the hospital. The consultant said it was probably something to do with her heart, he said to get the GP to refer her into the heart clinic. We went back to the GP and the GP said, 'why the hell couldn't he refer her into the heart clinic there? Why didn't he do it there and then at A&E?' So the GP did the referral. It was a three month wait. I said I'm not waiting three months, not if it's mum's heart. So we paid for my mum to go and see my husband's cardiologist privately. The consultant did his tests and had a copy of the X-ray which had been done previously. He said, 'I am at a loss to understand how anyone could have interpreted this chest X-ray as being clear.' Both the hospital and the GP had said that it was a clear X-ray, but the consultant said absolutely not. She had 35% congestive heart failure. She was put on emergency medication, three weeks after we'd been to A&E."

Donna considered whether receiving care close to home would be an option for her family: "I've been desperately trying to get somebody to come and talk to my carers group about hospital care at home and virtual wards. But I also feel that all they're doing is offloading the nursing care to amateurs in the community. They want to free up the bed, which is understandable, but they're offloading it to me to provide that nursing care at home. That's my interpretation of it. And yes, the person wants to be at home, which is fine. But what about the strain that puts on the rest of the family and the carer? What about rural isolation? It's all very well if the services are on your doorstep, but if I'm calling for help out where we are, it takes somebody 30 minutes to get to us."

On the topic of care preferences and whether Donna or her family members have ever made an advance care plan, she said: "My husband, when he was first diagnosed, we agreed that if I had to get into personal care with him then we would look at alternatives. The finances of it is the other issue, because there's probably nothing. Planning for what might happen in the future is an excellent idea. But it can't be for the one person in isolation, it needs to be for the whole family unit. It's not just the medical needs, but the care needs, the practicality of the house. If all my time is taken up supporting my husband and my mum, but the garden is ten foot tall, I can't get anything fixed. Housework is an issue because he used to do the heavy stuff that I can't do because of my disabilities and now nobody can do it. There's all these practical living issues that go beyond just the medical need."

Exploring some of the key issues that should be prioritised to improve services, Donna said: "It's got to be joined up. This whole thing of chasing from pillar to post between GPs and hospitals, hospitals in different locations, different health authorities, it's got to be joined up across the NHS. It's got to be multidimensional in that sense. They can't just look at the patient in isolation. They have to look at the whole social structure around that person, not just the carer, but other family members too.

And the other thing is the practicalities of life, whether that be rural isolation, maintaining the home environment, all those practicalities that impact on the health of people. My mum has me to advocate for her. If she didn't have me, she'd be dead behind a closed door. And we need to review our systems, I know there are probably thousands of elderly couples out there who are struggling on alone, isolated, and nobody knows. Because there's no proactive involvement in their lives. It's all reactive. You wait till something goes wrong.

I was delivering a local newsletter to someone in the local area because somebody else couldn't do it. I knocked on the door and this gentleman in his 80s opened the door and said, 'Oh my God, thank God you've come. My wife has been discharged from hospital. She broke her leg in three places. She's home, bed bound. She doesn't want me to leave and I can't get out of the house.' They had no food. They had nothing. He had no internet.

[…] So there is no proactive involvement. If you haven't got somebody to advocate for you, you are dead in the water or dead behind your closed door. That is one of my biggest fears. God forbid something happened to me. What would happen to my family? Because there is nobody checking up on them."

Donna added: "I'm not atypical. It's the same issues everywhere, the lack of joined up care, people having to repeat themselves over and over again, no support at home. There's no holistic approach to medical care and social needs. People are having to battle for everything, worried for their loved ones."

Case Study 5

'Edith'

Edith is 49 years old and is an unpaid carer for her mother and aunt. She is disabled, with multiple long-term health conditions. She is able to drive and uses crutches outdoors, but is often in pain and needs support for her health. She also experiences selective mutism and can struggle when stressed. Her mother is 84 years old and has arthritis and macular degeneration. Her aunt is 76 years old and has been diagnosed with slow progress early onset multiple sclerosis (MS).

"I try to stay as active as possible and take care of my health, but this can be difficult when caring. My mum and aunt are both as active and independent as possible. My aunt has needed help from falls and also from dislocating her hip in the bath. Mum has falls too and knocks herself resulting in injuries due to thin skin, I tend to care for most wounds if I can, we see a GP or nurse when needed. I feel my family would be considered frail due to age and health but I feel I may also be considered frail due to my health issues too. I feel there needs to be much more support available for those aging or those caring for them."

In regard to her family's experiences with their local GP practice, Edith said: "We have spoken to the GP in regard to mum's health issues, but I have also had conversations about my own health issues, however it is also perhaps a further conversation needed. The GP has a social prescriber who could be helpful, they are pretty good at keeping us informed on what support is available. I take constant medications, as does mum, we read up on them to make informed decisions and discuss our medication when needing advice. They are reviewed regularly by the GP and pharmacist and I am able to manage my medication for myself and mum.

There was a lot the previous GP surgery could have done differently but rather than ask and listen they made assumptions. They are not into caring, just money. They let mum down badly during the Covid-19 pandemic, having her wait an hour in the waiting area then making her sit out in the cold and be tested in full view of others, then they tried to force a mask on her when she is exempt. When I went for an appointment, they had a go at me for not wearing a mask, but I am also exempt. This was in front of an entire reception and the waiting room stated mum had covid. They also let me down very badly [on a previous occasion] leaving me traumatised and in a worse state. I feel they should have been way more aware of the difficulties we face, listened more, communicated better and cared more."

When discussing her family's care preferences and receiving care closer to home, Edith said: "I do worry about hospital stays as I cannot monitor what is happening and unfortunately the care is not always appropriate, I also worry that as mum is old they may decide not to keep her alive which should not be their decision. My preference would be to remain home as much as possible providing the care at home is appropriate. I am trying to plan [my care preferences and advance care] but it is difficult as others do not understand. I feel our GP surgery is very supportive, but because of experiences with previous GPs I am wary of what I share and who I trust."

Edith added: "I feel there should be some support for unpaid carers within the GP surgery, especially when caring for older people, the carer needs support for themselves and their changing circumstances as it can be a scary process."

Case Study 6

'Florence'

Florence is 79 years old and lives on her own on the outskirts of a village. A few years ago, her husband was diagnosed with dementia and experienced a major decline in his health. He is now being cared for in a dementia ward at a local care home. In her working life, Florence spent 26 years as a receptionist for her local GP practice. She was diagnosed with breast cancer at the age of 60 but underwent surgery and made a full recovery. Florence has arthritis in her spine and hips, and was recently admitted to hospital after experiencing a fall and being diagnosed with sepsis. She is currently being assessed for a hip replacement.

The discussion started with an overview of Florence' most recent healthcare experiences: "I had trouble last year with my breast. I had a new breast put in when I had breast cancer and I was getting pain in it, I had an X-ray and it was leaking. When I had sepsis, there was no warning, I was just shivering. And when I fell out the bed, I was on the floor for 9 hours. When I phoned my daughter she thought I'd had a stroke, which was good really, because the ambulance was there within 15 minutes. When I got to hospital, they put me straight on antibiotics. I was in there for about two weeks."

Florence then explained some of the difficulties she has been having with her hip: "I couldn't tell you what the pains like. It's excruciating. It's usually if I'm in bed it sometimes starts, and I can't get out the bed. The only thing to ease it is if you walk. I mean sometimes I get up in the middle of the night and go out in the yard and walk up and down to get rid of the pain, you never know when it's going to come on. The other week I was coming home with my shopping and I thought, 'how am I going to get home, I can't walk?' I got home eventually, but now I carry painkillers in my bag. A couple of my friends, they've been waiting two years to have a hip replacement. And for one of them, because of the long wait it's gonna be a more complicated operation, it's terrible in both her hips."

Florence explained: "I noticed it this year, it runs in the family. My mum had both her hips done. My elder sister had both her knees done and both her hips. I've got arthritis. When I went in for the sepsis, I had a body scan and they said I also had arthritis in my back. It seems to travel down. He said that the longer they leave it, the worse it will be. The recovery period is going to be longer. I went and made an appointment with a specialist. I had an appointment for two weeks after, and then had to wait another four weeks for a scan. I've got to have a replacement shoulder as well, but I can bear the pain. It's as if someone's stabbing me, sometimes putting a knife in me. But what am I going to do? My friend said you'd be about three to six weeks in a sling. So I'm persevering with that. I said to the consultant, just leave it and I'll let you know when I really need it."

Discussing how active and independent she is able to be in her daily life, Florence said: "That's what I'm worried about when [Florence's husband] eventually goes, I'm going to miss going up the care home every week, going out and chatting to them all up there. I don't stay in one day, I've got my friends and I've lived here 35 years. I met one friend up the road, she used to come round here about three days a week and have a coffee. But she got dementia, and I really miss her."

In regard to her experiences visiting the GP, Florence said: "You have to look at someone and see what's going on, haven't you? Rather than the phone. A lot of appointments you have to book online, my friends say they can't even do that. I had a computer when I worked, but then I didn't want to do it anymore. Unless they've got someone that can help them, you've gotta have someone who knows. I mean not many of my friends have got a computer. It's a silly idea. Everything's difficult now. The surgeries won't open on a Saturday anymore, and that used to be for people that went to work.

Now our local chemist, we've only got one chemist, he's not open on the Saturday. It's a long walk to where I have to go to the doctors. It takes me half an hour to get out there. When I go to put my prescription in, two days later I have to go up to the chemist, and twice they haven't done my prescription.

I mean, it's different altogether. Like I say, when I worked in a doctors, what I hear now is alien to me. Sometimes people used to come in and have a chat, and if someone phoned up with children, they'd give them an appointment straight away. Every month I used to have to sit and make a list of people over 70 and if they hadn't been in the surgery, one of the doctors would go and visit them. That's the worst thing now, you can't get a home visit. If you can get in the surgery, it always feels as if they're hurrying you. Because you haven't been in there for so long, you've got quite a lot of questions, haven't you? But they just send people to sit up in A&E and they send all their work up there more or less, don't they? Cause they've said it to me so many times. Well, go up if it's urgent. Go and sit in A&E. Well, I can't sit for three hours. I've got rheumatism. I can't do it.

You know, when I worked at the GP, we used to really cherish older people. Like I said, they used to have a visit, if they hadn't been in the surgery we'd make sure they're all well. Now nobody cares about anyone. Some people living on their own, a lot of older people, they don't see one person from one week to another. Some of my friends, they're in their 80s, they don't even bother phoning up their doctor anymore. They know what they're gonna say. You don't get an appointment. They'll go straight up the hospital. That's why the hospitals are so full up."

Florence considered whether she had ever planned or shared her care preferences: "Put it this way, I'd never be a burden on anyone. I wouldn't want anyone to take me in or anything. You know, I'd rather go in a home. And I mean, I didn't want my husband to go in a home, but he went to hospital and they phoned me up and said we're putting him in the home. I said no, you're not. I'd actually ordered a bed to come in and put in the lounge for him. And then she phoned me back 10 minutes later and said 'we're taking it out of your hands."

Discussing her experiences caring for her husband during his dementia diagnosis and health decline, Florence said: "He was very violent. He'd be devastated if he knew. And then he'd go wandering off. My sister's husband has just been diagnosed with dementia, she's getting a lot more help than I ever got. It was awful. I thought it was old age, that he was doing silly things. Every time he had a driving job he used to sit and map it out every night. And he was sitting down there for about 3 hours doing it. And then one day my friend came over, her three brothers had got dementia. She said to me, she thought he had dementia.

Straight away I phoned the doctor and said I need to come up with my husband. I told my husband that he was having an over 70's check and told the doctor he shouldn't mention the word dementia. She said he'd need a brain scan. We had to wait two months. I'd written 3 pages of all the things he was doing, forgetting things, and all that. The only person that helped me was a dementia lady. I got her phone number and if I had any problems with him, or if I was worried about him, I'd phone her up and she was so helpful. She'd tell me they don't like a lot of people around them, they can't digest what you're saying, they can't join in. But otherwise I had no help, it depends which area you live in.

One time a doctor did come over and I said he'd been a bit violent, but that I could cope with it at the moment. He said 'Oh, I'll put a stop to that'. I didn't sort of take no notice. He said 'here's the prescription, get it as soon as you can.' He told me to give him one tablet three times a day. Someone was coming round later, so I gave him his first tablet. Oh, my god, he was in a coma. My friend who came round said 'what have you done to him?' I said I'm putting these down the toilet these tablets. Can you imagine if I'd given him three? But that's what they do in the homes. You find half of them are in bed all day. I told the doctor, I don't want him having drugs like that. I don't want him like a zombie."

Florence explained how her husband was placed in several different care environments before being placed in his current care home: "The worst one was, he was in a mental health unit. It was disgusting. I'll never forget it. They wheeled him to the front door to wave to us and he was crying. And I said we gotta get him out of here. We had to. I used to go home from that mental home crying every night because I was just worried about him. I went in there one day and his face, you could have lit a cigarette on it. I said, 'what's wrong with him?' The staff didn't know what I meant. I said 'go and take his temperature and give him a Covid-19 test. That's what's wrong with him.' He had a sky high temperature. Another time he had bruises on his face. He was on 24-hour-care. That means he's got to be watched 24 hours. He fell over three times and the hospital reported the mental health unit. They said he's supposed to be on 24 hour care. How many times had he fallen over? It was really awful. How that place isn't shut down, I don't know. You'd look and there'd be wards of men just laid out on the bed, more or less unconscious, so they're not a nuisance to anyone."

Discussing what information and support was provided around how to care for a loved one with dementia, Florence commented: "The doctors are not very knowledgeable about dementia. The activities lady who works at the care home, she went on a three month course, there's all different types of dementia, so she had to find out what activity a certain one could do and what another one could do. She knew more than the doctor knew. You could ask her any question.

My husband is the only one in the care home that can't talk. It's been like that for years now. Sometimes he shouts out. But we don't know what he's saying. He doesn't know who I am. Sometimes he pulls on my clothes, sometimes he stares at me. I suppose he's trying to think if I'm someone familiar, 'who is she?'"

Case Study 7

'Gloria' and 'Henry'

Aged 87 years old, Henry lives with advanced dementia after having experienced a rapid health decline over the last few years. His daughter Gloria, who works full-time, and his wife Florence [see previous case study] shared care responsibilities for him during the early stages of his illness. The Covid-19 pandemic accelerated his decline after he was cut off from family contact.

He has experienced multiple moves between healthcare settings, including care homes, hospitals, and a mental health unit - often receiving inconsistent or poor levels of care. His daughter, Gloria, describes distressing experiences of overmedication, lack of personal care, and a lack of understanding of dementia care needs in some of these settings. Henry has recently settled down in the dementia ward of a local care home which has finally provided stability and reassurance for both him and his family.

The discussion with his daughter, Gloria, began with an overview of Henry's health experiences over recent years: "So his health history prior to him having dementia, it was pretty good. He was in good health. He had a heart attack when he was 70, that was caused by an incident which led to him experiencing hypothermic shock. Other than that, he's always had a healthy lifestyle. Very fit, very lean. He was working in construction, he wasn't one to sit down and watch telly.

Three years into him having dementia, he started to stumble as he walked. This was around 2017. He'd be driving and then one day he went missing and no one could get a hold of him. He started withdrawing from social settings, he started to get obsessive about things - obsessive, repetitive behaviour. And he was forgetful. It became a pattern of dementia behaviour. It was really bad, his deterioration. It was quick. He had a big mental health decline. A common thing to look for in people with dementia is moon lighting. Their personality changes. They can get aggressive, argumentative. He'd often try and run away all the time, not really knowing why. He became obsessed that someone was stealing his savings. So he kept going to the bank to check them."

Gloria then discussed Florence's experiences caring for Henry: "Florence's health [see previous case study] was sort of okay at the time. She did a lot for him, cooked for him. He used to have a few incontinence issues as well. She kept him safe because he kept trying to go out. He kept saying he had to go to work, he'd ask where his truck was. We didn't tell him that he had dementia, I don't think he ever took it on board. If he did know, he wouldn't acknowledge it. And then he just got that bad that he probably couldn't express that he knew something was wrong. If he did know, he would never tell us. I think he would feel embarrassed.

He didn't know what time it was, he'd forget the names of people, he needed prompting. He used to see things as well, he'd see his old dogs and children. I don't know whether he was thinking about years ago. His sight was really poor. They said he had a bleed at the back of his eye. He had good strength and balance, he was very physically fit. And so it was difficult for him to experience a mental health decline. It caused caring difficulties.

We used the helpline for dementia from the Alzheimer's Society. And then Florence got this lady to speak to some social care services. They could only send a carer for one hour a week. It's not much time to do anything. The worst thing about dementia is the health toll it takes on the person who's caring for them. Florence had breast cancer, it was a positive outcome, but the medication she took… the whole cancer treatment did some damage. I think it was causing her arthritis, and that runs in her family anyway. Right now it's really bad. But when she was looking after Henry it wasn't too bad. Few aches and pains, but that's age-related."

Discussing Henry's experience being placed in different care homes, Gloria said: "We knew he would probably end up going into a care home, Florence was very desperate because he would be abusive, violent. The care services we were in touch with were essentially making the decision. The first care home we went into was a temporary care home. They didn't know where he was going to go. They were assessing his care needs, because of the danger he posed to Florence. He didn't know why he wasn't able to come home.

With the second care home that he went into, he didn't know why he was there either. He had a male carer who looked after him who he had grown quite attached to. He was with my dad everyday, I think my dad felt more comfortable with him. But one day it was a woman who was sent to look after him. He didn't like any women doing his personal care, he found it upsetting. Maybe he was embarrassed. He wanted to leave, he kept trying to escape. He ended up outside and had pulled a tree out of the ground. Because the care home had private residents to consider, they tried to call social services to come out to him. But it was the weekend. They couldn't calm him down so they ended up calling the police, but they couldn't do much. They said he had to leave."

Gloria then explained Henry's experience of being taken to hospital after the incident: "The police didn't know what to do, so they took him to hospital. When he got to the hospital he started shouting. He didn't know where he was and there was no one with him. We asked the care home, 'why did you not call one of us?' We'd have come in, we'd have calmed him down, but they didn't. In the hospital, it's a medical environment, no one there knew him. He's screaming and shouting and probably pushing things around. They gave him what's known as the 'liquid cosh', it's basically an injection that knocks you out, calms you down. But they didn't put it into the muscle, they told me two days later. They rang me and said we have to inform you we've made a mistake, when they gave him the injection, they should have put it into his muscle so it's a slow release, but they just jabbed him in the arm so it went straight into his bloodstream. It could have killed him. And I said, why are you telling me now? They said they felt like I had to know. He was obviously drowsy for the next 36 hours.

They just put him in the old people's ward, because there's no dementia wards in hospitals, which I think would be a good thing to have. At the moment, they just put dementia people into normal wards with men and women. It's okay for some people, but I think they should have nurses that understand dementia in hospitals. There was a lady next to Florence when she was in hospital for sepsis, she kept climbing out of her bed. So they took the bed away and just put a mattress on the floor because she kept falling out and climbing out. And she laid there all day, just talking, which was fine for me and Florence because we knew straight away that she had dementia. But other patients in the ward thought she was crazy. They said they wanted her out of the ward, 'do something with her, we can't sleep'.

When you're in hospital with dementia, you don't get personal care. You get medical care. They're not going to get you up and make sure you're walking. If you don't eat your dinner, they think you're not hungry. But if someone has dementia, sometimes you have to encourage them to eat. […] So every time he went into hospital, our hearts would drop. We knew he was going to plummet again."

After his hospital stay, Henry was moved to a mental health unit. Gloria said: "They took him to a mental health hospital for men, a bit like a contained unit. There was no freedom to walk around. The men who worked there all wore white uniforms. The rooms were white. It was like a mental asylum. It wasn't fit for any of his needs. The patients were medically looked after. But there was no care. No kindness. No talking to them, listening to their interests or listening about their life, there was nothing like that. It was just like a medical unit. They would basically just assess them in the day and get them on whatever drugs they gave them to keep them all calm. They didn't know the first thing about my dad and he was in there for around five months. We tried so hard to get him out, but he was blacklisted from care homes, it was noted on his record of what had happened previously. No care home would accept him. There was nowhere for him to go.

I used to go up there, go through the drug list. And I'd say I don't want him taking this. I used to take notes, write everything down. Then I'd bring up the social worker. I kept tabs on it all the time, I think they were cautious of making sure they told me the right things and did the right things. And I kept saying it's not the right place for someone with dementia. You're just put in there, medicated, and that's it. They could only do the best they could do with what's available to them - but I felt they overmedicated people. Initially you had to make an appointment to be able to see him once a week. There was nothing to stimulate their minds, whereas in a care home there's pictures, there's music, there's things to touch and to feel. They have little cafes, music, events and games. The mental health unit did nothing.

He had a fall during his stay there. We think he was over medicated. He fell and hit his head. Then it happened again, and this time he went to hospital and stayed there for three days. The carer was supposed to be with him, he wouldn't have fell if a carer was there. The next time he went into hospital was for about six weeks because he had a chest infection and he tested positive for covid."

Gloria explained some of the challenges they experienced during the Covid-19 pandemic: "When Covid-19 first came, his whole care home was shut down. You couldn't go in, you couldn't visit. There was no communication. And the only communication he was mentally able to have was with his family who saw him all the time. And then to not see anyone for weeks, all you could do was ring up and talk to him over the phone. Well, he couldn't have a phone conversation because he didn't know who was at the end of the phone. We tried FaceTime. He struggled with that. So the whole Covid thing I think accelerated his decline with his dementia. Not seeing family, not having any interaction, physical touch, talking about things in his previous life. All that had gone instantly. And I think he struggled on his own, probably thinking in survival mode. All the care homes were locked down, people were wearing masks.

After a while they did introduce window visits. He didn't understand that concept at all. We couldn't hear him. He couldn't really hear us. And then he'd walk around the room, thinking 'why are they outside the window?' It's all very confusing for him. During lockdown, there was no one walking him around. So by the time he went to the mental health unit, he wasn't very good on his legs and because of the medication he was on, he had to be in a wheelchair a lot and then it was decided that he was too weak to walk. They said it would be best for him to be in a wheelchair because his legs were weak. He had to be hoisted in and out of bed because he couldn't stand for long."

After their experience with the mental health unit, Gloria wanted to explore alternative care options for her father: "We used to have a meeting with about eight different people. The people in the mental health unit, social services, doctors and nurses at the unit, people on zoom calls from other health trust divisions. And I just always wanted to get my point across that he wasn't going to stay in there long-term. It wasn't an environment for a dementia patient. He needed more attentive care, someone to talk to him, people to do things with him. It's not the sort of place where you should be long-term. You get a certain standard of care. They felt he'd been there long enough.

And then I had a call one day out of the blue, asking what homes I would consider. It would have to be somewhere Florence could get to if I wasn't around. There was one care home with a dementia ward that he used to live down the road from. Florence could get there easily on the bus, she'd be able to go every day. And then finally I spoke to someone who seemed like they were on my side. She said it sounded like a good idea and she was going to have a chat with them. She called me back and said there might be a space coming. We accepted it straight away."

Discussing the differences in care that Henry experienced in his new care home, Gloria said: "It was such a different environment to where he'd been. There was people who understood exactly what he needed. In one of the care homes that he'd been in previously, he didn't even have a pillow on his bed. At other care homes he had clothes go missing. They'd ask you what you want from the food menu, you never got what you chose. There's just no individual knowledge of the person you're caring for. They didn't know about his likes or dislikes. It wasn't very interpersonal. In his current care home they know a lot about him and his dementia. They know what challenges him. They care about him. He's been more stable, he doesn't have all the medication he had in the mental health unit.

They always send me emails notifying me about things, which other care homes never did. They have events and activity days, they include the family in it all. They want you to be a part of his world. It's more of a community approach to care."

Reflecting on what information or support she was given when Henry received his dementia diagnosis, Gloria said: "Social services gave us a book from the Alzheimer's Society. But every case is individual. You find information about different things as you go through it. I used to read a lot of forums about other families and what they did for certain things, how they dealt with situations, and that was really helpful. I think the support and advice was much better from people on forums, or the volunteer we spoke to from the Alzheimer's Society who had lived experience."

Gloria explained why she thinks there needs to be more understanding and awareness around dementia: "I don't think there's enough understanding at all. It really depends on the environment and the person you're encountering. […] There's not enough information about dementia out there. There's not enough help. You don't get any support or assistance, not until the final stages when you're caring for someone at home, by yourself, and you're really desperate. They keep brushing it under the carpet, but so many more people are getting dementia now. It needs to be recognised as an illness, like cancer is."

In relation to Henry's experiences visiting the GP and getting a dementia diagnosis, Gloria said: "It wasn't very good initially. If you ring up the GP and say you think you have dementia, they'll ask you why you think that. They'll test you and send you forward for more tests. But it's a very slow progress to get to a diagnosis. It could be a lot faster. It took about a year to get him diagnosed. And I would say I know more about dementia than the GP. They don't really understand. But I would say GPs just haven't got the time to deal with it. They know the basics, but like I say, they need to learn more about dementia. Before Florence took Henry to the GP to get diagnosed, she had a quite a few discussions with them. Firstly to explain that when they came in, the doctor shouldn't mention the word dementia to him. The doctor was quite helpful in that respect. But it's the processes. You have to go through all of it just to get help, it's all paperwork and tick boxes."

Gloria added: "I just think services need to be more connected and joint up. I think it's really confusing the amount of people you talk to. There's always someone different on the phone. Why can't I just have one person who follows the journey from start to finish? It's like a minefield. I can document stuff on my phone, send emails, but Florence doesn't know how to send an email. There's so many people involved. It's too much. Florence isn't digitally able, she's also quite rural. She's disconnected from the community, she hasn't got any local neighbours. She doesn't have broadband. So how can she deal with the situation without receiving emails? It's very difficult if you live somewhere isolated and you don't have a smart phone. People of an older generation become isolated."

Case Study 8

'Iris'

Iris is 90 years old and has been retired for 30 years. She lost one of her sons to a car accident many years ago, but speaks with her other son regularly. It's been 14 years since her husband also passed away. She lives alone in a bungalow, which due to being on a hill, makes mobility aids difficult to use. She has been housebound for a year after a severe fall impacted her mobility. Iris also has COPD and high blood pressure which runs in the family.

"The more recent difficulties which have made a big difference to my life is peripheral neuropathy with the legs, and the general loss of balance. I've had two falls, one of them was quite severe just over a year ago and has seriously affected my mobility. I suppose I'm quite frail. I've never thought of myself as frail because I was quite tall and quite physically strong. That was all gone really in the last year after I fractured my pelvis. The balance problem is getting slowly worse. I've been having private physiotherapy because NHS physiotherapy is hard to get and isn't always very good."

Discussing her experiences of receiving care after her first fall, Iris said: "I had very excellent care and follow up, I think by sheer chance. The ambulance was in the area. My son was with me that time. I tripped over a cable and fractured my pelvis in two places, so I was not very mobile. I had wonderful care at Whipps Cross Hospital. I really couldn't fault it. I was very pleasantly surprised. The consultant was very approachable, very thorough. And the aftercare, I couldn't believe how good it was because I had six weeks of physiotherapy once a week and that was excellent. I went from being afraid to take a couple of steps to being able to move around the garden and even on the pavement outside. I also had personal carers for six weeks, four times a day. But after that, it's not been quite so wonderful.

The second fall was bad. That was 15 months ago. At the beginning of lockdown, I developed shingles in my legs up to the side. At that stage the GPs had just gone into telephone-only appointments. I phoned my general practice, I think I got a relatively inexperienced doctor, and I got brushed off. I know that it left me with some nerve damage in my legs because I've had persistent itching. But also I think more serious damage to the nerves, but that hasn't been confirmed.

I had my first fall towards the end of 2020. I was able to get around, but I was in pain. And I was worried as to whether I'd fractured anything. But the doctor couldn't do very much. He just said to keep taking paracetamol and go to A&E. Well, A&E at the time was dreadful. And so I put it off, but in the end I did call an ambulance. They came and gave me a thorough hands on examination, which was the first time anybody had checked me physically because of lockdown. The paramedic said she could feel no sign of fracture. Knowing what the delays were at the hospital, she didn't think that it was a good idea to take me in. So I accepted that, but the pain continued.

I was fed up with the GP by this stage because I always seemed to get a recent recruit who wasn't very confident. In the end I paid for an X-ray at a private hospital in Buckhurst Hill. I sent it to my friend who is a healthcare consultant, there were two fractures of the vertebrae which had healed. But not perfectly. So there was pressure on the spinal cord. Possibly all of this could have been avoided, but people were grappling with a very difficult situation during the Covid-19 pandemic. I did feel a bit unsupported, but I managed to sort of get back to normal after that fall. It was 2024 when I had my second fall, which was much more serious and has made a much bigger difference to my life."

Reflecting on her experiences with her GP further, Iris added: "When I originally rang up about the shingles, the GP told me to send a photograph. I asked if they could give me an e-mail address because I can attach my camera file to an e-mail. They said 'we don't give patients emails, use your smartphone'. I said, 'well, I've only just got a smartphone a couple of weeks ago and I still can't take photographs with it. It's very difficult to photograph the back of your legs, to get it in focus. I already had a bit of a tremor. I couldn't send him a photograph and I didn't really get any advice on how to cope with the shingles.

I don't know if the practice has a policy with dealing with falls. I mean, falls are so common with old people. We now have a falls unit in our area, which will call on people who fall to check how badly they're affected and take the appropriate action. That's what I needed. I didn't really get anything, except being told to go to A&E and take paracetamol. There may not have been much more they could have done, but I did feel shaken up and unsupported."

Iris then reflected on how her GP practice has changed since the Covid-19 pandemic: "I think the problem for old people, which is a big generalisation, but the way the NHS is going, it's becoming more like a supermarket. You can get your quick appointment with the GP. Everything is geared to quick turnover. It sounds alright on paper, but I think it is very difficult for old people because you have to be energetic about getting the health care you want. I'm supposed to be annually monitored for high blood pressure and COPD. Well, because of the Covid-19 pandemic, that was done by telephone. I've not had a proper test since 2020.

A lot of GP work has been delegated to a hub, which wasn't explained to patients. I've been housebound since I fell the last time. I don't get a home visit from the GP. I can understand, they simply couldn't do all the home visits patients might want. I've had visits from physician associates, but on two occasions, communication between the hub and the practice has not been timely. On one occasion, a visit that was promised didn't happen at all. Luckily, I was able to get telephone advice from a doctor who actually rang to apologise a few days later. On another occasion, the physician associate didn't bother to feed her report back to the GP.

On a couple of occasions, I've called 111. In my experience, 111 is fantastic. I'm sure it's not so for everyone. They have long delays. I did get a call back at two am once, but I was glad to have it. The 111 triage is normally very efficient. [...] The only way a housebound person in my area can get a visit from a GP is to call 111. It's a much better system than the system we've got in place.

My GP practice used to have a patient experience group and suggestions and complaints on their website. But both of those have disappeared. Now you have to take up a complaint directly with the practice. Sometimes people don't feel comfortable doing that."

The conversation then focussed on Iris' connections to the local community. "I used to be well connected to the community. You get to the age of 90 and the friends who are at your age or a bit older have died or become very dependent themselves. A couple of friends locally, who are much younger than me, would certainly come to my aid if I needed it. I have a lovely neighbour who was a district nurse. But I do try to be as independent as possible while I can. People have busy lives, I'm hesitant to ask for help on a regular basis."

On the topic of managing medications, Iris said: "I have three inhalers for COPD. Two medications for blood pressure, something for reflux. Either patches or paracetamol for continuing pain in the pelvic region and my lower back. I did go to see a neurologist about my condition, the GP said it wasn't Parkinson's but it was peripheral. The risks when you read a leaflet are so appalling that you'd never take anything. I sort of understand the risks. I've been on both the blood pressure and the COPD medication for quite a long time. I'm sure there are long-term side effects, but they have kept the conditions under control. And at my age, I'm not worrying too much about long-term side effects. I have annual telephone conversations with the practice nurse. But I sometimes feel that the review, which is primarily for those two conditions, is a bit more superficial than it could be."

Discussing her experiences of hospital care and her feelings around receiving care closer to home, Iris said: "I'm one of those people who quite likes going to hospital. But at the end of her life, my sister-in-law was very well looked after at home. She had three children within reach who provided support and care. She had daily visits from district nurses, the doctor visited twice a week. I think it depends on your situation. I would accept home care if it was offered. But what I quite like about hospital care is, all aspects are looked after."

Iris then reflected on where she goes to find information and support for any health concerns. “I use the internet, mainly the NHS website. A well-designed information leaflet, no longer than A4 would be useful for different health conditions. I think the GP practice does have some leaflets in the waiting room, but it is a bit random. The GP should be aware of what information is available to recommend. For myself, I've now got to the point where I do rely on the internet, but I’m very well aware of the risks. Leaflets are occasionally useful for me. But it is concerning that my generation, going down to people in their 70s, are not all comfortable with smartphones, computers or the internet.”

Iris added: “With the digital problem, it’s very difficult to teach an older person to use the computer. I've tried with a couple of friends. They’re afraid of the computer. You just can't persuade them to try. People in my age group, on the whole, are not enthusiastic about learning unfamiliar things.

I set my heart on health visitors for the elderly. Better service for the elderly will relieve GPs of a lot of work. It needs to be more responsive, geared to home visits. A wide range of knowledge so that something which might worry the old person, but which actually doesn't need the GP, can be treated or advised by a health visitor. Old people do become some ways, like infants.”

Case Study 9

‘June’

June is 70 years old and lives with her 79 year old partner. She was diagnosed with breast cancer in 2022, and has now recovered, but still suffers from the side effects of chemotherapy, including peripheral neuropathy and vertigo. In 2010, her partner had a heart bypass and has since been diagnosed with two different types of lung disease, including bronchiectasis. At the same time June received her cancer diagnosis, her partner experienced a deterioration in his health and was diagnosed with Parkinson’s.

Discussing this experience, June said: “I was dealing with my breast cancer and my partner had Parkinson's and deteriorated at the same time. I feel that I haven't really recovered because I've had to care for him. Just before I had my operation, he deteriorated. I couldn't cope because I was really exhausted from the chemotherapy.”

June then described some of her partner’s experiences being treated at hospital: “One of the problems that I felt happened was when he went into hospital to rehabilitate after he had a kidney stone. They didn't deal with his urinary incontinence. They were across the road from the urology department and they didn't even seem to know it existed. They didn't properly rehabilitate him, and I've always had to fight to get physiotherapy for him. He's got naturally low blood pressure, but Parkinson's causes low blood pressure, and the medicines he takes cause low blood pressure. That's another thing they didn't sort out.

I should have complained about the surgeon that did his kidney stone operation because I believe he botched it. My partner came home, clearly incontinent, he was bleeding. I told them and they said, 'it's quite normal.' But he clearly had a problem, I phoned up again and the consultant said, 'I'm on holiday so I can't see you for another month.' I will never go to private care anymore, because there was no backup. There was nobody to deal with it. If he'd been in an NHS hospital, there would have been another consultant while he was away. I had to put my partner in a care home for two weeks because I could no longer cope with him.

When he was in the care home, I went back to the hospital and said, look, he's still bleeding. And they said to bring him in. I said 'I can't bring him, and we're not capable of bringing him in.' And they said, 'well, we can't come to you.' So I agreed to bring in a urine sample and they said the consultant was going to be there. I then rang his secretary and she said he was still on holiday. So the hospital itself didn't even know he wasn't there. I wrote to PALS, but I never got a response and I was too exhausted to follow it up."

Reflecting back on when her partner was first diagnosed with Parkinson's, June said: "It's difficult because one of the things I have is chemo brain. I'm significantly worse with remembering things. I've forgotten how traumatic the first year was. I had my breast cancer treatment at the same time and was trying to sort out my partner. When it came to his diagnosis, we had a great consultant, she was really helpful but overloaded with work. I can't remember whether it was a whole year before we got to see her. But we had this really weird situation where we were meant to go and see her and they cancelled the appointment and put him with a different consultant. When I contacted the secretary, she said 'you've never seen this consultant' and she accused us of lying.

Eventually they referred him to the care of the elderly, but they kept altering his medicines and it would make his blood pressure far worse. Fortunately, we had an appointment with a new neurologist who was very thorough and really good. The only trouble is she upped his medicine and it made him so weak he was collapsing, so we had to take him back off."

June then began to share her experiences as a carer in more depth: "I'd forgotten how traumatic the first part of it was. There were so many different people, you know? You'd get an occupational therapist, there's one person from Essex County Council, another one from the hospital, but I couldn't get much help. Apart from, I had a carers assessment and the woman there was helpful because she said what I needed was the community matron. We've had the community matron help out, because I just got lost with who all the different people were.

The big problem was every time you dealt with a medical person, they hadn't had time to read all the notes. So you'd have to start explaining to them the different problems. Fortunately, two years ago, one of the GPs phoned up and I said 'the problem is, each time I talk to a different GP, I'm having to go through the background again'. And he decided to take on my partner, which has made an enormous difference. I was suffering from depression at the time, so he's took me on as well. And he was very good, he was giving me a call every couple of weeks.

I think there's this problem of having too many people to deal with. Not knowing what support is out there. I still don't think I have a direct number for a falls team. And early on, I was quite resistant to joining any carers group, but when I finally did, it's been good having a carers group to go to."

Regarding their experiences with paid care providers, June said: "It was quite difficult finding paid carers because we're in a rural area. I've had terrible experience with them. When he came out of hospital the first time, we put a key safe outside because I'm not good in the morning, and I was being woken up at night. They kept coming and they didn't bother to use the key safe. They said they couldn't find the information, so they'd bang on the door.

I've had rows with carers being rude to me, they treated me like I was some sort of servant. One manager turned up, it was Covid-19 times. He wasn't wearing PPE, so I reported him. We finally found our own care company, they're generally good, but it's a bit of a battle constantly to make sure that we get the right carers because it's expensive. My partner has savings, he's not particularly well off, but his savings are just ticking down and down. It might be that at some point he will run out of money for carers. But it was the only way we could get decent ones.

Another time the hospital put on some carers, they turned up at lunchtime and they only had 15 minutes. They couldn't make anything, so it was pointless. I said, look, there's no point in coming. They said they'd come in the evening. One carer turned up in the evening, I had to show them where the food was and all they could do was make a ready made meal. They had 15 minutes so they didn't have time to wait to give him his pudding, they didn't have time to make a drink. And I told them it was taking up more of my time than them being helpful.

At the moment he has a carer who comes in for an hour in the morning. They get him up and get him ready, they come halfway through the afternoon if I need to go out. Some of them are great, the one coming this afternoon is wonderful. But even when you pay for care and it's meant to be a good care company, it's hit and miss. Once you've got carers that you trust, it's really difficult to change."

The conversation then focussed on communication around support and accessing services: "It's a bit muddled, to be honest, it's a bit unclear. I should have had another carers assessment by now. I probably have to chase it. It's been a year and six months since I've had a carers assessment. The GP recently ordered some more of the ointment my partner needed. I phoned the GP up, they said they'd issued it. The pharmacy said 'no, we haven't had it.' Eventually the GP gave me a QR code. I went down to the pharmacy - it's six miles each way - they said 'Oh, they didn't put our name on it', so they ordered it again. It was needed two weeks ago. Turns out they sent it to the wrong people.

It's just these constant things I have to do each week. The care rota comes through. I have to check that they've got the right carers, that they haven't sent somebody my husband doesn't know in the morning, that they've put in the right times for things. I have to negotiate with them if I need extra care at times. I have to plan whether I have to be back home. I suppose very early on you could do with somebody who can navigate the whole system."

June described how delays in receiving support have impacted her partner's health: "I think the biggest problem I've had is this lack of support for rehabilitation for my partner. Lately he's got a lovely physiotherapist, but at one point we had a physiotherapist who came out and obviously didn't like coming to a rural area. Anyway, we finally got this other one and he was great. He got my partner walking again, he was getting him going to the toilet. That physiotherapy was the most important thing. And then when my partner collapsed due to low blood pressure, that shook his confidence. At that point, I said he needs physiotherapy again. Well, it was a year and a half before we got back the physiotherapist. He said 'I can see there was a referral and it got left for a whole year'. So because of that, my partner is now stuck in a chair all day. He can't get up. And his whole health deteriorated. Adequate care, particularly for Parkinson's physio is incredibly important to keep them moving. But yeah, too little, too late."

She described another situation in which her friend received inadequate support: "I've got this friend, she's gone blind. She broke her thigh, but they didn't give her physiotherapy when she got home. She's had a lack of support, she's on her own completely. I recently have to phone up her GP because she was clearly unwell. They sent a paramedic around. She's got lymphoma. It was another two or three weeks before the GP saw her. When the GP got there, he put her in hospital. But each time they send her home with medicines she can't read. She was taking twice the dose of morphine that she should have been until her friend got there. I've learned that unless you phone people up and say 'this isn't okay', you don't get anywhere. I worry about people like her even more so."

6.0 Ageing Well and Frailty Public Communications Toolkit

NHS
Hertfordshire and
West Essex
Integrated Care Board

Ageing well and frailty
Public Communications Toolkit

As part of this project, we engaged with the community across west Essex to gather their feedback on the ‘Ageing Well and Frailty Public Communications Toolkit’ designed by the NHS Hertfordshire & West Essex Integrated Care Board.

This communications toolkit aims to support organisations in sharing clear, consistent, and accessible messages about ageing well and frailty. It brings together key information, ready-to-use materials and suggested messages to help you communicate with confidence and impact.

Toolkit Engagement

Our feedback included views from residents aged 65+, families and unpaid carers, healthcare and social care professionals, public health professionals and voluntary organisations. Engagement methods included focus group discussions, conversations with local community groups, interviews and online discussions.

Members of the public were provided with a selection of resources from the toolkit which were identified as most relevant to them, while working professionals were provided with the full toolkit. Toolkit resources used for public feedback included:

Information Handouts:

- Factsheet: ‘Right care, right place, right time’
- Factsheet: ‘Making medicines work for you’
- Q&A: ‘Helping Older Family to Stay Well’
- Leaflet: ‘Integrated Neighbourhood Teams’

Social Media Materials:

- Digital Screen and Poster: 'Help and Advice to Age Well'
- Social media graphic: ‘Make Time to Talk’
- Social Media Graphic: ‘Care Close to Home’

Selected Toolkit Resources

Right care, right place, right time

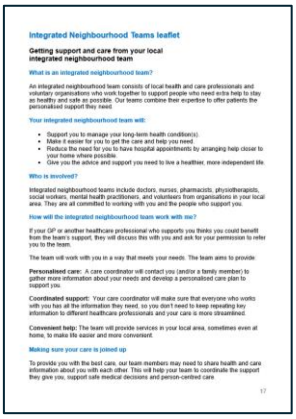
How to get the care you need, and avoid a hospital visit if it's not needed.

Making medicines work for you

More isn't always better with older people's medicines. More than 1 in 10 people aged over 65 take at least eight different prescribed medications each week. If you take lots of medicines, it's important to check they are working for you.

HEALTH ADVICE FOR YOUR FAMILY

Helping older family to stay well



Integrated Neighbourhood Teams leaflet

Getting support and care from your local integrated neighbourhood team

A mix of print and digital versions of the resources were presented to participants depending on and in accordance with accessibility requirements and personal preferences. The following questions were used to prompt responses.

Feedback Questions

- Is this a resource you would use?
- What do you think about the information that was provided?
- How useful was the information provided?
- How engaging was this resource?
- What do you think about the structure and layout of this resource?
- Was the information and text clear and easy to read?
- Was this resource easily accessible for you?
- How did you feel about the language that was used?
- Do you feel better informed after reading this resource?
- Do you think there is any key information missing?
- Are there any other topics that you think should be discussed?
- Where would you want this resource to be provided and in what format?
- How would you improve this resource?
- What changes would you make?

Engagement Feeback

During our engagement period, we received a range of different responses from participants around the readability, useability, and accessibility of the resources.

Positive Engagement:

General positivity about toolkit and certain materials:

“I really enjoyed reading all the resources.”

"The toolkit looks well rounded and visually appealing. I like the different formats used, good choice of graphics images and messaging is clear.”

“I think it's informative and I think it pinpoints things you might not think of.”

Integrated Neighbourhood Teams (INTs) leaflet:

“I like the integrated neighbourhood teams leaflet. I think it sets out the information better. I can read it with bullet points. It breaks it down more into main questions. That all sounds like a good idea, if they could come round to visit you instead of you going out to see them. I think I would not worry as much about my health if I had other people checking in on me.”

“The integrated neighbourhood teams was the most helpful information. I've never heard about this. There needs to be more information out there about this.”

Provision and Distribution:

Preferred places for access:

“All these leaflets could be printed and displayed on surgery and pharmacy notice boards with local phone numbers printed clearly and in large print.”

“Patients have plenty of time whilst waiting for appointments to read them and the leaflets should be displayed below for patients to take home.”

Professional signposting:

“Doctors and nurses at the surgery should be told to ask the patient if they have any problems and direct them to the appropriate leaflet. The neighbourhood team contact for that area should be prominently displayed.”

Lived-Experience Feedback:

Accessing GP appointments:

“Ringing the GP is great advice, if you have a great deal of time to spare and wish to be waiting on the phone line for up to 40 mins, then to be told all appointments have gone for that day and it is not possible to make one in advance, you have to ring up on the day, where you would merely be facing the same problem.”

Medication reviews:

“Yearly medicine checks sounds great but they seem to have been discontinued at our surgery, although possibly they could be made over the phone.”

“They used to tell you that you've got to come in for a medicine review. I haven’t been asked for a review for I don’t know how long, about five or six years. But yeah, it's good to review them because they might stop working. You might need to decrease them, increase them. There's some people that don't know what they're taking. And there are people who get prescriptions they don't need.”

“Every time I go online to order my medication, it says ‘this needs to be reviewed’. So I ring up the pharmacy and I say I can't get my medication. They sort it out, and then the next day I look, it's been prescribed. So how was it reviewed?”

Hospital and home care:

“I have never heard of any friend who has been offered treatment by the hospital, at their home. This seems to me to be something patients should be told about when they feel bad, blocking a hospital bed, through no fault of their own and the home seems to be recognised as the best place for their ongoing care.”

“I would prefer to go to the hospital than receive care at home. There's all different doctors in there, depending on what they find, they can get advice from other doctors. I think if there was good provision for being cared for at home, after perhaps you've had a short illness in the hospital, I think it could be a good thing. But everyone's different. It depends how serious your condition is. If something goes wrong, you have to be rushed back to hospital. You've got to be monitored.”

Advance care planning:

“I don’t think you can plan ahead if you don't know what's wrong. But maybe when you have got something, you can write a bit of a list of how you want it to go? Nobody wants to think about when they're not going to be their own self. Some people just don't like talking about it. You can have an advance care plan, but what you put down on paper isn't always going to happen in the event.”

“I've never known anyone to make plans. I just take life as it comes.”

Accessibility Issues:

Format and readability:

“I wonder if the layout is accessible by all – those with poor eyesight or cognitive impairment would benefit from less text heavy literature – a version with larger text and simplified layout will be useful.”

“I would leave the online part to later as many would stop reading, it should be large print as most older people have eye issues. […] Also break info up rather than a long fact sheet as it is less daunting and easier to read.”

“I think the print is too small. It's far too small for me.”

“It could be a two or three page foldable thing, if the sections were broken down I think people will read it more. I’d just pick out the most important parts.”

“With the leaflets you get in the doctors, you just want to pick them up and go. I couldn’t read the whole thing at once. I'd lose interest halfway.”

“At the moment it looks like it's in the early stages of being formed. It needs to be broken down more into chapters.”

Digital exclusion

“The people you're trying to help, half of them aren’t online, I’d say nearly 90% of them. They're on their mobiles, but not computers.”

“Having someone to talk us through the toolkit has helped. But I wouldn't pick it up unless I needed to. I’d only read parts of it. If you're 80, you're not going to pick that up and sit and read it all, are you?”

Social Media Materials:

Readability and design:

“I don't like this white on blue, it's very hard to read. I’d lose interest. With the title ‘Make time to talk’, most people who live busy lives, they haven’t got time to talk, have they?”

Relevance of imagery:

“I don't really like the pictures. I guess the pictures are helpful in showing who it's targeting. But I feel like it looks like a business card.”

“I think with care closer to home, they could show someone going through someone’s door to their house, like they're calling round to check on them, because at the moment it’s very formal.”

Exclusion through digital tools:

“I don’t know what a QR code is. I wouldn’t know how to use one. So if you're not computer literate, it doesn't apply to you.”

Tone and authenticity:

“They're trying to be too positive about it. It feels very corporate, like they're selling you something, but they're not.”

Suggested Improvements:

Simplification and design:

“It needs to be scaled down.”

“I think it would be better if it was more colourful.”

"A leaflet format, more resources to go to. I think they’re overdoing everything. There’s too much writing.”

“Sometimes you just want to pick something up and you want those key points in bold bullet points.”

Content and relevance:

“Including lived experience stories and quotes from the local community will make the information more relatable to readers.”

“The basic requirement of more carers does not seem to be addressed.”

“I feel this does not really cover the most important elements as it is only health based, it should also be around care in terms of support available (e.g. Essex carers support, social prescriber at GP).”

“I feel this was repetitive info of what is always presented rather than the info that is really needed. I feel these sorts of things are so often overlooked and anyone needing support or care is left not knowing which way to turn.”

“I don't really like the title ‘right care, right place, right time’, it doesn't really explain what it's about. People might get fed up of reading that.”

Signposting for further information

“When you get to the end of it, there should be some resources to contact, different departments you can go to with further questions. It's not telling you where to find the help that you might need.”

“I think they're telling you what you should know, but they're not following through with where you need to find further information. It would be good if they directed you to services near you.”

“The toolkit may be more impactful to communities if a list of local assets is provided as a standalone sheet – so details of community group sessions can be updated easily. Albeit there is a link to Frontline but this still requires a person to have digital access and there’s still a lot of navigating to do on Frontline to identify details of memory café timetables or falls prevention referrals to strength and balance classes etc.”

Other Comments:

"I think the doctors should have more information about dementia."

"I feel like this is something that you would get handed once you're in the system of some sort of help. Like a carer coming round. Someone would give you this at a later stage."

"Age UK is an excellent organisation and our local U3a has set one up in this area as we did not have one. Their talks are helpful and informative and if carers can take patients there, they can access someone to speak to who will deal with their problems."

Toolkit Recommendations

Below is a list of recommendations based on engagement feedback and observational findings which explore how the toolkit could be further developed.

Language and Clarity

- Use larger fonts and plain, accessible language, avoiding jargon, acronyms, and overly clinical terms.
- Ensure all terminology (e.g. "care closer to home," "integrated neighbourhood teams") is clearly explained from a patient's perspective.
- Provide guidance on who each resource is aimed at, so readers can easily identify relevant information.
- Use the same phrasing when describing services, conditions, or pathways to avoid confusion.

Structure and Formatting

- Begin each chapter on a new page, with clearer section breaks and subheadings to make the content easier to follow.
- Add clear contact information for further guidance or support.
- Break content into shorter, more digestible sections for easier reading.
- Present contact details and website links clearly and fully written out.

Usability

- Enhance the contents page by including page numbers and short summaries of each chapter.
- Include a more detailed introduction outlining the purpose of the toolkit, its intended audience, and how it should be used.
- Include a glossary at the back for common healthcare terms.
- Consider including a quick reference guide or summary sections.

Content and Information

- Expand information on practical topics such as:
    - Accessing GP appointments
    - Hospital care at home (what it involves, how to access it)
    - Organising medication reviews (via GP or pharmacist)
    - Guidance for volunteers on handling common questions
- Provide clear signposting at the end of the toolkit, including where to find further information, access services, or seek help.

Engagement and Design

- Make the toolkit more visually engaging by incorporating images, illustrations, graphics, and colour.
- Use step-by-step visuals to explain processes and improve navigation of resources.
- Include lived experiences, quotes, and case studies to make information more relatable and practical.

Distribution

- Reduce reliance on digital-only formats to avoid digital exclusion.
- Ensure printed versions are widely available in community spaces such as GP surgeries, pharmacies, hospitals, and community centres.

Additional Points to Consider

Tone and Framing

- Avoid framing frailty or ageing in terms of decline, use strength-based, positive language to emphasise independence, resilience, and ageing well.
- Ensure the toolkit doesn’t inadvertently stigmatise or label people, make it empowering rather than medicalised.
- Using an authentic tone builds trust and relatability by showing people that their real experiences and challenges are understood. This makes the information more engaging, reduces resistance, and increases the likelihood that people will act on the information being provided.

Practical Use

- Consider creating an easy-read version for better accessibility.
- Signpost local resources and contacts as well as national support for people want to know what is available in their area.
- Ensure the toolkit is able to be reviewed and updated regularly so that information stays current.

7.0 Key Findings

The case studies in this report provide a rich, first-hand account of the realities of navigating health and social care for older people, their families, and carers. While each case study is individual, key findings and common themes emerge, helping us to recognise some of the shared realities and lived experiences of the older community, including those living with frailty or age-related conditions.

Case Study 1

'Angela'

Angela's story highlights the tension between independence and vulnerability in later life. Despite multiple health conditions and past surgeries, she remains active and engaged in her community. Yet her experiences expose systemic barriers in accessing care, particularly difficulties with hospital bureaucracy, GP appointments, and age-based exclusions from preventive services. She points to shortages in carers and care homes, and the risk of isolation and depression for those without strong family or community support. Angela's proactive approach to advance care planning contrasts with the fear and reluctance she sees among peers, underscoring the need for sensitive conversations and accessible information. Her case emphasises the importance of reliable communication, timely community care, and recognition of older people's desire to remain independent while feeling supported.

Case Study 2

'Bill'

Bill's case study explores the challenges of caring for frail, elderly patients in complex healthcare systems. Key issues include inconsistent quality of care, where nurses often provide excellent care despite poor hospital management and inefficient systems, which can lead to unsafe or inappropriate discharges. There were problems assessing the patient's capacity, frailty, and fall risks, as well as poor communication with patients and families, causing anxiety and confusion. Systemic pressures often prioritised freeing beds over patient needs, and older patients faced barriers accessing primary care due to digital systems. Family carers played a crucial role in managing care but were often unsupported. The case also shows the importance of clear processes, documentation, and advance care planning to guide decisions and reduce stress.

Case Study 3

'Calvin'

Calvin's case study showcases the significant challenges faced by people navigating a dementia diagnosis and the gaps in health and social care support. Key themes include delayed and inconsistent diagnosis, unclear communication from healthcare professionals, and a lack of tailored information about Lewy body dementia, leaving him and his family to rely on incomplete online resources. Miscommunication and poor documentation from memory clinics and associated services caused confusion, anxiety, and delays in accessing medication or support. The case also illustrates the critical importance of peer support, advocacy, and co-created services, as demonstrated by the transformative role of the Alzheimer's Society in providing guidance, community, and opportunities for involvement. Overall, the case underscores the need for clear, compassionate communication, person-centred care, timely access to information and treatments, and structured support networks to help patients and families navigate the emotional, practical, and medical challenges of a dementia diagnosis.

Case Study 4

'Donna'

Donna's case study illustrates the immense challenges faced by family carers managing complex, multi-person care needs, and highlights systemic gaps in health and social care. Key themes include the fragmentation of services, poor communication between primary, secondary, and private care providers, and the lack of joined-up systems, which leave carers repeatedly chasing results, appointments, and medication management. The case underscores the burdens on carers, including navigating inaccessible GP practices, coordinating multiple hospital visits, advocating for appropriate care, and managing practical household needs, often while coping with their own health conditions. Issues around accessibility such as sensory impairments, rural isolation, digital exclusion, and insufficient consideration of individual patient needs further complicate care. Donna's experiences reveal a reliance on informal advocacy, the lack of proactive support for vulnerable adults, and minimal follow-up after diagnoses, particularly for dementia. Overall, the case highlights the urgent need for integrated, person and family centred care, better coordination across services, proactive support systems, and recognition of carers.

Case Study 5

'Edith'

Edith's case study highlights the challenges of being an unpaid carer while also living with long-term health conditions and disabilities. She provides daily support to her mother and aunt, both older and experiencing health issues, while managing her own pain and mobility difficulties. Her experiences show the physical and emotional strain carers face, the importance of accessible and compassionate primary care, and the risks when services fail to listen or adapt to individual needs. While her current GP surgery is supportive, with regular medication reviews and good communication, past experiences with another practice left her and her mother feeling dismissed, exposed, and traumatised. Edith worries about hospital care, fearing age-related discrimination in treatment decisions. Her main concern is the lack of formal support for unpaid carers within GP surgeries, especially as caring roles evolve and intensify, leaving carers vulnerable and often unsupported in managing both their relatives' and their own health needs.

Case Study 6

'Florence'

Florence's story highlights the pressures and risks facing older people who live alone and care for a partner with dementia. It exposes gaps in primary care access, such as through online booking systems, missed prescriptions, and reduced home visits, alongside the practical hardship of travelling to appointments and collecting medication. The case also shows how hospital and care placements can be unsafe or unsuitable, with inconsistent standards between units and poor communication about care decisions. Throughout her case study, there is a strong theme of system fragmentation, reduced proactive outreach to older people, and inconsistent dementia knowledge among clinicians. This contrasted with the positive impact of a single helpful dementia worker, underscoring the need for more compassionate, coordinated, and person-centred care.

Case Study 7

'Gloria' and 'Henry'

Gloria and Henry's case study illustrates the deep challenges of navigating advanced dementia within a fragmented and often unprepared health and care system. Key themes include inconsistent and sometimes unsafe care across multiple settings, from care homes to hospitals and a mental health unit, with repeated experiences of overmedication, lack of personal care, and limited dementia understanding among staff. The Covid-19 pandemic further accelerated his decline by cutting off vital family contact and social interaction. Gloria's account highlights the emotional toll on families, who must advocate persistently to secure safe, compassionate, and appropriate care. While his eventual placement in a dementia-specialist care home provided stability, personalised support, and reassurance, the case underscores wider systemic issues such as slow and confusing diagnostic processes, limited GP knowledge, poor communication and coordination between services, digital exclusion for older carers, and the absence of consistent, joined-up support. Overall, this experience reflects the urgent need for dementia-aware healthcare environments, continuity of care, family inclusion, and stronger recognition of dementia as a serious health condition requiring the same priority and resourcing as other major illnesses.

Case Study 8

'Iris'

Iris's case highlights the challenges faced by housebound residents living with multiple long-term conditions. While she experienced excellent hospital care and short term rehabilitation after her first fall, later experiences exposed gaps in GP access and follow-up care. This was exacerbated by Covid-19 changes and reliance on digital systems that exclude many older people. She describes inconsistent GP support, poor communication between services, and an over-reliance on telephone and online systems that do not meet her needs. Although she values NHS 111 and some home care support, Iris feels socially isolated and misses the more personal, proactive approach of the past, such as health visitors for the elderly. She stresses the need for responsive, home-based care, better communication, and more accessible information. Especially for those who cannot or will not engage with digital technology. Her case illustrates the need for services to adapt more effectively to the realities of ageing.

Case Study 9

'June'

June's case illustrates the strain of managing complex, overlapping health needs within a fragmented and inconsistent system. Having recovered from breast cancer while simultaneously caring for her partner with Parkinson's, lung disease, and heart problems, she continues to face exhaustion and long-term side effects while navigating a maze of services. One key issue included poor hospital care and follow-up, which led to missed rehabilitation, unmanaged incontinence, potentially unsafe surgery, and lack of continuity of care. Other difficulties involved accessing timely physiotherapy and lack of coordination between professionals. While her GP's continuity of care has been a lifeline, she has experienced delays, conflicting advice, and a lack of reliable information about available support. Carer support is inconsistent, with long gaps between assessments, little proactive help in navigating services, and highly variable quality of paid carers. Financial pressures have added further stress, while rural living and fragmented record systems across services have created further challenges. In summary, June's story highlights the urgent need for joined-up care, timely rehabilitation, reliable carer support, and stronger recognition of the impact that caring has on individual's own health and wellbeing.

Summary of Key Findings

The key findings set out below distil these themes into areas where local health and social care services can focus improvement efforts.

Access to Primary Care

- Digital-first systems exclude and isolate the older community, with many patients and carers experiencing difficulties accessing timely GP appointments, particularly face-to-face appointments.
- Lack of continuity with the same GP means many patients have to repeat their health histories and receive inconsistent advice and care.
- A positive impact was seen when a GP took responsibility for ongoing care.

Hospital Care and Discharge

- Unsafe and poorly planned discharges were often felt to be driven by hospital bed pressures and did not focus on patient needs.
- A lack of inadequate falls assessments, frailty assessments, or home planning before hospital discharge was commonly experienced.
- Poor continuity of care and communication between hospital teams was experienced, with patients and carers having to liaise between services.
- Failures in rehabilitation support led to further health deterioration.
- Poor handling of frailty conditions and care needs was experienced.
- Communication failures were common, with poor follow-up coordination.

Dementia and Frailty Care

- Inconsistent recognition and management of frail conditions was common.
- Dementia care needs were poorly understood in some healthcare settings.
- Overmedication and lack of personalised dementia care was reported.

- Pandemic restrictions caused rapid deterioration by cutting family contact.
- A lack of clear communication around advance care planning was evident.

Carer Experiences

- Family carers often received minimal support from healthcare services.
- Case studies highlighted the emotional and physical toll of caring.
- Poor communication and lack of recognition of carers' expertise occurred.
- Carers were forced to advocate to secure safe care for their loved ones.
- More formal support for carers needs to be embedded in GP practices.

Paid Care and Community Support

- Shortages of formal carers and care home vacancies were experienced, with variable quality in domiciliary care for the elderly.
- Some paid carers were undertrained, rushed, or poorly managed.
- Financial pressures caused stress and led to insecurity about future care.

Communication and Information

- Patients and carers were often left without clear information about diagnoses, support services, or future care options.
- Many patients and carers experienced poor handovers between services.
- There was often reliance on carers to chase up results and appointments.
- Lack of transparency and poor communication often fuelled mistrust.
- Simple and accessible information about living with frailty, dementia, age-related conditions and available support services was strongly desired.

Psychosocial and Emotional Impacts

- Many individuals experienced mistrust due to unclear care decisions.
- Isolation and loneliness were experienced, worsened by digital exclusion.
- Depression and exhaustion was experienced among carers.
- Stress was amplified by financial strain, rural isolation, and service gaps.

Examples of Good Practice

- Compassionate, skilled frontline staff were recognised and praised.
- Single points of contact from health and social care staff provided stability.
- Peer support groups within the local community were highly valued.
- Positive impact was noticed when a consistent care coordinator, social prescriber or community matron was involved to support patients.

8.0 Recommendations

Below is a list of recommendations based on the lived experiences shared in our case studies and the key findings identified during our engagement. Together, they highlight key priorities for local health and social care services and explore how we can improve the healthcare experiences of residents aged 65 years and over, including those living with frailty and age-related conditions in west Essex.

Improve Access to Primary Care

Accessibility and Inclusivity

1. Maintain **non-digital booking options** (in-person, telephone) alongside online systems to avoid digital exclusion. Consider reducing telephone waiting times with call-back systems and lines dedicated to older patients.
2. Increase **home visits and in-person GP reviews** for patients who might be frail or housebound and are in need of a face-to-face appointment.

Continuity of Care

3. **Enable patients to see the same GP or clinician** for an ongoing health issue. This would improve healthcare coordination, prevent delays in receiving care, and avoid patients having to repeat their health histories.
4. Provide **proactive medication reviews** and routine monitoring of long-term conditions to ensure patients are receiving appropriate healthcare.

Strengthen Hospital Care and Discharge

Hospital Discharge Processes

5. Guarantee safe, **patient-centred discharge planning** with home assessments, frailty assessments, falls checks, and clear documentation.
6. Establish **clear discharge protocols**, ensure the patient and their support network is informed about discharge plans, and arrange reliable transport.
7. If the patient is being discharged to another care provider, ensure clear **communication around discharge plans**, safe and reliable transportation, and effective digital and analogue handover is being carried out.

Communication and Follow-Up

8. Improve **communication, joint-working and record sharing** between services, including acute hospitals, community hospitals, and primary care. Ensure timely **follow-up after hospital appointments**, with advance booking options for routine procedures and regular health check-ups.

Expand Care Close to Home

Care Options

9. Provide **further information and resources on 'care close to home'** and alternative care options to hospital admission.
10. **Support community-based care**, including 'hospital at home' and virtual ward models, and implementing Integrated Neighbourhood Teams.

Quality of Care

11. **Commission high-quality domiciliary care** with adequate visit lengths and trained caregivers to ensure individuals maintain quality of life while receiving support. Increase respite, live-in care, and day service options to support independence and reduce isolation.
12. Ensure **timely access to home-based services** such as physiotherapy, rehabilitation, community nursing, rapid response, and falls prevention to avoid deterioration in health and mobility and avoid hospital admissions.

Improve Communication and Awareness

Age-Friendly Language

13. Train NHS staff on trauma-informed communication in relation to frailty, dementia and age-related care. Encourage a **culture change around perceptions of frailty and ageing** and tackle misconceptions. Use person-first, strength-based and respectful language when discussing frailty, ageing and age-related conditions.

Health and Care Discussions

14. Ensure conversations about health and care decisions are handled with **privacy, confidentiality and compassion**, and ensure communication and information given is clear, consistent and transparent.

Recognise and Support Carers

Inclusion and Involvement

15. **Ensure carers are involved and supported** in health and care settings, especially during health discussions regarding their loved ones. Recognise the importance for patients to have carers nearby to support their needs and make amendments to enable accessibility for carers.

16. **Embed carer support within GP practices**, with proactive check-ins and named carer leads. Involve carers in hospital and discharge decision-making by treating them as core members of the care team.
17. **Recognise carers' health needs** and provide information on support, respite, benefits, equipment provision, training and local support groups.

Embed Patient-Centred Inclusive Care

Patient-Focussed Care

18. Ensure healthcare providers use **patient-focussed decision making**, taking into account patient's priorities, care preferences and advance care plans. Ensure care is **adapted to individual's needs** and is provided with compassion, awareness and understanding.
19. Healthcare staff should **involve patients in care discussions unless advised by their carer**. Many patients express frustration when a healthcare professional speaks directly to their carer and does not make them feel included in conversations around their healthcare.

Enhance Dementia and Mental Health Support

Education and Training

20. Ensure health and care services receive **dementia-friendly training** to strengthen awareness and understanding of dementia symptoms, signs, behaviours, and care needs, reduce stigma, and promote respectful care.

Dementia-Friendly Environments

21. Ensure all healthcare settings are **dementia-friendly accredited**, with staff champions, healthcare leads, and specialist units for dementia care needs.
22. Healthcare environments should also be designed to be dementia-friendly to **ensure all spaces are safe and accessible for dementia patients**.
23. Strengthen staff **training on behaviour management** for patients with complex needs to ensure patient and staff safety, and encourage non-drug interventions and safe medication use.

Diagnosis and Support

24. **Improve diagnosis pathways** and provide **post-diagnostic follow-up** support and monitoring to ensure continuous care.
25. **Provide families with information**, **advice, guidance and resources**, especially around respite opportunities and safeguarding practices.

Build Age-Friendly Communities

Social Isolation and Loneliness

26. Invest in **social prescribers and promote community hubs**, social spaces, local support groups, peer networks and befriending services to reduce isolation and loneliness. Provide community hubs with updated information and support and use the hubs to set up pop-up clinics and health checks.

Transport and Rural Isolation

27. Improve access to **affordable community transport schemes** through volunteer drivers, subsidised taxi schemes, or on-demand minibuses.
28. Encourage **mobile clinics and outreach teams** to arrange regular visits by nurses, GPs, or allied health professionals to rural villages and hamlets.
29. Recruit and retain **healthcare staff in rural and underserved areas** and upskill other healthcare workers and providers, such as paramedics, pharmacists, and healthcare assistants, to provide broader care.

Integrated Neighbourhood Teams

30. Provide further **information and resources** on Integrated Neighbourhood Teams and work in partnership with community hubs to provide local support, identify residents living with frailty or age-related conditions, those who are socially isolated or housebound, and those needing extra support.

Managing Falls

31. Continue to share information and guidance on **how to safely manage and prevent falls**, with contacts for local rapid response and support services. Individuals who are living with frailty, including those who live alone or are alone for long periods, should be provided or advised to **create a falls plan**.

Address Digital Exclusion

Remove Digital Barriers

32. Maintain **non-digital options** for accessing care and information and ensure healthcare systems accommodate those without digital skills or confidence (e.g. providing alternatives to QR codes and online systems).
33. Promote **digital training initiatives** to reduce digital exclusion among older communities, without removing face-to-face access to healthcare.

Support Advance Care Planning

Support Conversations

34. Encourage conversations and provide further information and guidance on **how to communicate care preferences** and advance care plans.
35. **Involve families in decisions** about hospital care, discharges, procedures and treatments, and provide advice and guidance or access to an advocate for those without family support.

Further Recommendations

Preventative Care

36. Encourage early identification and assessment of frailty and age-related conditions through preventative care approaches.

Public Health Coordination

37. Improve communication and coordination between healthcare services and systems to join up the patient journey for those using multiple services.

Lived Experiences

38. Sharing lived experiences, case studies and patient testimonies, can help to humanise healthcare issues, and tackle stigma and misconceptions.

Co-Production

39. Involve the local community in shaping and co-producing services so they are realistic and meet the needs and priorities of people living in the area.

Public Awareness

40. Inclusive, wide-spread messaging can increase public understanding and awareness of experiences of frailty, ageing, and age-related conditions.

9.0 Conclusion

This report highlights critical findings in relation to experiences of frailty, ageing, and age-related conditions in the west Essex area, providing further insights and understandings of some of the challenges faced by the community and potential opportunities for improving healthcare for residents aged 65 years old and over.

The experiences shared throughout this report reveal both the strengths and the shortcomings of current health and care services for older residents in west Essex. While many individuals value the dedication and compassion of frontline staff, they too often face fragmented systems, barriers to access, poor communication, and a lack of joined-up support. For those living with frailty, long-term conditions, or dementia, these gaps can have profound consequences, leading to avoidable deterioration, unnecessary admissions, social isolation, and strain on carers.

The recommendations outlined in this chapter provide a clear, practical roadmap for change. They emphasise the importance of accessible, patient-centred primary care, safe and well coordinated hospital services, high-quality care closer to home, stronger support for carers, dementia and age-aware healthcare environments, and building age-friendly communities that reduce isolation and promote wellbeing. Above all, they highlight the need to place older people and their families at the centre of decision-making, respecting their voices, preferences, and dignity.

By acting on these recommendations, local health and care services in west Essex have the opportunity to build a more compassionate, inclusive, and sustainable system. A system that not only meets medical needs, but also supports independence, connection, and quality of life. In doing so, services can ensure that residents with experiences of frailty and ageing in west Essex are not just cared for, but are supported to live well, with confidence and respect, at every stage of later life.

10.0 Information and Resources

Below is a list of useful information and resources which have been gathered during the writing of this report.

Living with Frailty

NHS England - Practical Guide to Healthy Ageing
https://www.england.nhs.uk/publication/practical-guide-to-healthy-ageing/

NHS England – Live Well
https://www.nhs.uk/live-well/

HWE ICS – Ageing Well
https://www.hertsandwestessex.ics.nhs.uk/your-health-and-care/stay-well/ageing-well/

Essex County Council - Adult Social Care and Health
https://www.essex.gov.uk/adult-social-care-and-health

Essex County Council – Essex Support Directory
https://www.essexsupportdirectory.org/

British Geriatrics Society - NHS Ten Year Health Plan: How it affects you
https://www.bgs.org.uk/nhs-ten-year-health-plan-how-it-affects-you

Age UK – Advice on Keeping Active and Ageing Well
https://www.ageuk.org.uk/information-advice/health-wellbeing/

Age UK - Frailty in Older People
https://www.ageuk.org.uk/our-impact/policy-research/frailty-in-older-people/

Centre for Ageing Better – Health and Wellbeing
https://ageing-better.org.uk/health-and-wellbeing-state-ageing-2025

NICE - Supporting Guidance on Healthy Ageing
https://www.nice.org.uk/search?q=Healthy+ageing

Public Health England – Productive Healthy Ageing and Musculoskeletal Health
https://www.gov.uk/government/publications/productive-healthy-ageing-and-musculoskeletal-health/productive-healthy-ageing-and-musculoskeletal-msk-health

Caring for Frailty

NHS England

NHS England - Practical Guide to Healthy Caring
https://www.england.nhs.uk/publication/a-practical-guide-to-healthy-caring/

NHS England – General Practice in Supporting Older People Living with Frailty
https://www.england.nhs.uk/publication/toolkit-for-general-practice-in-supporting-older-people-living-with-frailty/

NHS England - General Practice on Dealing with Mental Health in Older People
https://www.england.nhs.uk/wp-content/uploads/2017/09/practice-primer.pdf

NHS England - General Practice on Dementia Diagnosis and Management
https://www.england.nhs.uk/wp-content/uploads/2015/01/dementia-diag-mng-ab-pt.pdf

GOV.UK

Office for Health Improvement & Disparities - Healthy Ageing
https://www.gov.uk/government/publications/healthy-ageing/healthy-ageing-applying-all-our-health

NIHR

NIHR – Frailty: Research Shows How to Improve Care
https://evidence.nihr.ac.uk/collection/frailty-research-shows-how-to-improve-care/

NIHR - Comprehensive Care: Older people with frailty in hospital
https://evidence.nihr.ac.uk/themedreview/comprehensive-care-older-people-with-frailty-in-hospital/

NIHR - Multiple Long-Term Conditions (Multimorbidity) and Inequality
https://evidence.nihr.ac.uk/collection/multiple-long-term-conditions-multimorbidity-and-inequality-addressing-the-challenge-insights-from-research/

NIHR - Continence, Dementia, and Care that Preserves Dignity
https://evidence.nihr.ac.uk/collection/continence-dementia-and-care-that-preserves-dignity/

NICE

NICE - Falls: Assessment and Prevention in Older People
https://www.nice.org.uk/guidance/ng249

NICE - Older People: Independence and Mental Wellbeing
https://www.nice.org.uk/guidance/ng32/resources/older-people-independence-and-mental-wellbeing-1837389003973

NICE - Safeguarding Adults in Care Homes
https://www.nice.org.uk/guidance/ng189

NICE - Mental Wellbeing of Older People in Care Homes
https://www.nice.org.uk/guidance/qs50

British Geriatrics Society

British Geriatrics Society - Comprehensive Geriatric Assessment
https://www.bgs.org.uk/CGA

British Geriatrics Society - Hospital at Home for Frailty
https://www.bgs.org.uk/HospitalAtHomeFrailty

British Geriatrics Society - Preparing for Winter: Checklist
https://www.bgs.org.uk/WinterChecklist

British Geriatrics Society - Be Proactive: Delivering Proactive Care
https://www.bgs.org.uk/be-proactive-delivering-proactive-care-overview

British Geriatrics Society - Preferred Language When Referring to Older People
https://www.bgs.org.uk/preferred-language-when-referring-to-older-people-in-a-health-context

Centre for Ageing Better

Centre for Ageing Better – The State of Ageing 2025
https://ageing-better.org.uk/state-ageing-2025

Centre for Ageing Better – Ageism: What's the harm?
https://ageing-better.org.uk/sites/default/files/2023-02/Ageism-harms.pdf

Centre for Ageing Better – Better homes, Better lives
https://ageing-better.org.uk/sites/default/files/2025-02/Better-homes-better-lives.pdf

11.0 Glossary

Terminology

Advance Care Planning This is the process of making decisions about the care you would like to receive in the future. Planning ahead can help make sure wishes are followed if you are unable to make decisions in the future.

Atrial Fibrillation A heart rhythm problem that can cause an irregular and fast heartbeat, palpitations, chest pain and other symptoms.

Bronchiectasis This is a long-term condition where the airways of the lungs become abnormally widened. It leads to a build-up of mucus that can increase risk of infection.

Chronic Lymphocytic Leukaemia A slow-growing type of cancer that affects the blood and bone marrow. In people with CLL, the bone marrow makes too many abnormal white blood cells, called lymphocytes.

Comprehensive Geriatric Assessment This is an assessment which provides a holistic overview of an individual’s needs and concerns.

DAT Scan A nuclear imaging test that looks at the function of dopamine transporters in your brain. It is often used to help distinguish Parkinson’s disease from other causes of tremor or difficulties with movement.

Emergency Admission Admission to an inpatient hospital setting where the admission was unplanned and non-elective.

Frailty A health state related to the ageing process where multiple body systems gradually lose their reserves, leading to increased risks of adverse events and reduced functional capacity and capability.

Fibromyalgia This is long-term adverse health condition which can involve widespread chronic pain.

Haematology A branch of medicine concerned with the study of the cause, prognosis, treatment, and prevention of diseases related to blood.

Inequalities The unfair and avoidable differences in health access, experience and outcomes between different groups within society.

Integrated Care Board Integrated care boards (ICBs) are NHS organisations that plan and manage health services within each ICS area.

Integrated Care System Integrated care systems (ICSs) are local partnerships of health and care organisations and other sectors that aim to improve outcomes and reduce inequalities.

Integrated Neighbourhood Teams Bringing together healthcare, social care and voluntary organisations who support communities in different settings, integrated neighbourhood teams focus on providing preventative and holistic care to people in the community and closer to home.

Lewy body dementia This is an umbrella term for two different types of dementia: dementia with Lewy bodies (LBD) and Parkinson's disease dementia. It is a progressive, challenging condition, which is thought to account for 15-20% of cases of dementia. It particularly affects the person's movement, and can cause hallucinations, delusions, changes in alertness and sleep disturbances.

Lymphoma This is a cancer of the lymphatic system. It develops when blood cells called lymphocytes become abnormal.

Macular Degeneration This is a common condition, also known as 'Age-related macular degeneration' that affects the middle part of your vision.

Multiple Sclerosis This is a condition that affects the brain and spinal cord.

Oedema A condition which involves swelling in the ankles, feet and legs often caused by a build-up of fluid in these areas.

Palliative Care Palliative care offers physical, emotional and practical support to people with a terminal illness. It is offered at any point after a terminal diagnosis.

Patient Advice and Liaison Service A service which offers confidential advice, support and information on health-related matters, also known as 'PALS'.

Peripheral Neuropathy This is a condition which develops when nerves in the body's extremities, such as the hands, feet and arms, are damaged.

Peripheral Nervous System The is the network of nerves that lie outside the central nervous system (the brain and spinal cord).

Premature mortality/Under 75 mortality Terms used interchangeably to describe deaths in people under the age of 75 years.

Power of Attorney This is a way of giving someone you trust the legal authority to make decisions on your behalf if you're no longer able to make them yourself

Selective Mutism Selective mutism is an anxiety disorder where a person is unable to speak in certain social situations

Tinnitus A condition characterised by the perception of noise, such as ringing or buzzing, in one or both ears without an external sound source

Urinary Catheter This is a flexible tube used to empty the bladder and collect urine in a drainage bag.

Urology A field of medicine focussed on the urinary tract and male genital organs.

Acronyms

ADRT	Advance decisions to refuse treatment
AI	Artificial intelligence
ACP	Advance care plan
CGA	Comprehensive geriatric assessment
CLL	Chronic lymphocytic leukaemia
COPD	Chronic obstructive pulmonary disease
CVD	Cardiovascular disease
DAT	Dopamine active transporter
DNR/ DNACPR	Do not resuscitate/attempt cardiopulmonary resuscitation
ECC	Essex County Council
HWE ICB	NHS Hertfordshire and West Essex Integrated Care Board
INTs	Integrated neighbourhood teams
LBD	Lewy body dementia
MS	Multiple sclerosis
NHSE	NHS England
NICE	National Institute for Health and Care Excellence
NIHR	National Institute for Health and Care Research
OHID	Office for Health Improvement and Disparities
ONS	Office for National Statistics
PAH	Princess Alexandra Hospital
PALS	Patient advice and liaison service
PCN	Primary care network
SWCH	Saffron Walden Community Hospital
WECAN	West Essex Community Action Network
WEHCP	West Essex Health and Care Partnership

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