healthwatch
Thurrock

Delving into Dementia

Contents

About Healthwatch Thurrock

Healthwatch Thurrock is the independent champion for health and social care services in Thurrock. As part of a national network, we gather and represent the views of local residents, highlighting what is working well and where improvements are needed.

Healthwatch was established in 2013 as part of the Health and Social Care Act 2012 to ensure that people's voices are heard in shaping health and social care services. Healthwatch England oversees and supports local Healthwatch organisations, ensuring that public concerns influence national policy and service improvements.

Alongside consultation work and gathering residents' voices, Healthwatch Thurrock provides information, guidance, and signposting services to help individuals navigate health and social care systems. Residents are encouraged to "speak out" through an online forum, targeted surveys, conversations, and face-to-face engagement within the community.

By amplifying lived experiences, Healthwatch Thurrock presents the voices of local people to identify areas for change, support best practices, and ensure informed decision-making before new services are commissioned. Our recommendations to providers are based on real experiences, ensuring that services truly meet the needs of Thurrock residents.

We believe that services improve when people actively participate in their development. By learning from real experiences and feedback, health and social care providers can adapt and deliver better, more effective services for the community.

Our vision

To bring closer the day when everyone gets the care they need.

Our mission

To make sure that people's experiences help make health and care better.

Our values

- **Listening** to people and making sure their voices are heard.
- **Including** everyone in the conversation especially those who don't always have their voice heard.
- **Analysing** different people's experiences to learn how to improve care.
- **Acting** on feedback and driving change.
- **Partnering** with care providers, Government, and the voluntary sector – serving as the public's independent voice.

Delving into Dementia: Informing the Report

In 2022, the new Dementia SET strategy was finalised. This strategy brings together key organisations from health, social care, and the voluntary sector, all working towards a shared goal: to make Southend, Essex, and Thurrock places where people can live well with dementia.

Over the past year, Healthwatch Thurrock has been actively engaging with residents of Thurrock to gather insights into dementia support and the lived experiences of individuals within the borough. Through this engagement, Healthwatch Thurrock aims to ensure that the voices of service users and people living with dementia are central to the ongoing development of high-quality dementia care in Thurrock.

Our goal is to make sure that the needs and experiences of those affected by dementia are consistently reflected in the delivery of best practice care and services across the borough.

Methodology

To begin this project, we developed a detailed engagement plan aligned with the priorities outlined in the SET Dementia Strategy 2022, which we were assigned to review. Healthwatch Thurrock's engagement officers used this plan to carry out extensive and meaningful engagement throughout the year.

For gathering feedback, we determined that a survey would be the most suitable tool. As a team, we created three distinct surveys: one for patients with dementia, one for family members and carers, and one for professionals. Each survey was tailored to suit the specific group; for instance, professionals were not asked about personal experiences, but instead about their daily work in the field. The three surveys were combined into one platform, where participants could select the appropriate survey based on their role.

The surveys were made accessible online through social media, the Healthwatch Thurrock website, and the CVS newsletter. Additionally, paper copies were distributed at various engagement events by our team.

While the survey did attract some responses, we quickly recognised that it was not the most effective tool for engaging the community on such a sensitive issue. Feedback revealed that the survey's length and the inclusion of difficult topics—such as end-of-life care—were significant barriers to participation. Many respondents felt uncomfortable completing these sections, resulting in lower response rates.

Furthermore, we noticed a potential issue with the survey link. Our analytics indicated that the geographic distribution of responses did not align with our expectations, raising concerns that the link may have been compromised.

In response to these challenges, we decided to revise our engagement strategy. Instead of continuing with the lengthy survey, we simplified the process by focusing on two key questions, **which are further discussed in this report**.

Below, we have outlined the priorities from the SET Dementia Strategy that we were tasked with exploring in greater detail.

Priority 2: Supporting unpaid carers: Unpaid carers are supported to enable people with dementia to remain as independent as possible

"An estimated 540,000 people in England act as primary carers for people with dementia. Roughly 21% of unpaid carers have needed to leave employment to meet their caring roles, 66,000 of these have cut their working hours" (source: Dementia SET Strategy 2022)

Action 2.1 - Improve pathways to formal assessment where needed (see pg.6)

Action 2.2 - Support and training for unpaid carers of people with dementia (see pg. 6, 7, 8 and 9. We did not receive comment on training specifically)

Priority 6: Diagnosis and Support: All people with dementia will receive appropriate and timely diagnosis and integrated support

"Dementia diagnosis rates in Essex remain below the national average at 62%. Support in the key weeks after diagnosis is also recognised as a critical window for early support and intervention that promotes a positive view of diagnosis, facilitating access to timely care and support, thus enabling people to live with dementia in their preferred place of residence" "(source: Dementia SET Strategy 2022)

Action 6.1 - Design, promote and support activities that enable people to understand how to seek a diagnosis (We designed and promoted the survey to accompany this work to open a dialogue around understanding how people currently seek diagnosis, and to provide positive recommendations moving forward)

Action 6.2 Good quality support and information available from pre diagnosis journey and people know where to access this. This also includes engagement around living with dignity (see pg.11)

Priority 7: Living well with dementia in the community: All people with dementia are supported by their communities to remain independent for as long as possible

Action 7.1 - Development and delivery of a co-produced dementia awareness programme to improve awareness, challenge stigma, enable, inspire and facilitate dementia inclusive communities (see pg. 8)

Action 7.2 - People with young onset dementia, from ethnic minority and LGBTQ+ communities receive support appropriate to their specific needs (incorporated into section two of this report)

Priority 9: End of life: people with dementia and their families plan ahead and receive good end of life care and are able to die in accordance with their wishes

Action 9.1 - Work with health partners to enhance choice, aid delivery of person centred end of life care, help to guide care when mental capacity is lost and provide support for families and carers (see pg. 12)

Action 9.2 - People are given opportunities and supported to have early conversations about advanced care and treatment options, including but not limited to faith and culture, to allow for informed decision making, and providing a person centred approach to allow for individuals to remain cared for in their preferred care setting (see pg. 12)

Dementia Survey

Healthwatch Thurrock want to engage with local residents to ensure the voices of those living with dementia are being full captured. We are also interested in hearing from carers, family members and professionals so we can paint an in-depth picture of the current support for dementia in Thurrock to review what is working well and what could be improved.

We would love to hear from you to ensure Thurrock is truly a dementia friendly community.

Win a £50 voucher

Complete your questionnaire and you'll be entered into a draw

Please complete the survey here

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Findings from the Survey

We received 19 responses to our 'Delving into Dementia' survey

1 response was from a person living with dementia

6 responses were from a family member or unpaid carer

12 professionals responded

Carers assessments

What is a carers assessment?

"It's a chance to let your local council or trust know how your caring responsibilities affect you physically and emotionally. They will use the assessment to find out what support you need, whether you're willing or able to carry on caring, what you want to achieve in your daily life and whether you qualify for help"

(Source: Carers UK website)

We asked survey responders, if they could change one thing about the current pathway to a carer's assessment what would it be and why?

The most frequently mentioned concerns that people would like to see changes to are waiting times, access to clear information and an easier referral process. There is a desire in the responses for a more streamlined and understandable system, with a focus on early identification of carers. It was noted that changes have already started to happen with Thurrock Carers Service now being able to deliver carers assessments.

"Ensuring it is easily accessible, delivered in a timely manner and that carers know what to ask"

"More organisations that can signpost to carers assessments"

"Reduce waiting times for carers assessments"

"More day centres/respite centres are needed to provide respite for carers as well"

"A lot of changes in Thurrock are already happening around the delivery of carers assessments. Thurrock Carers Service will be able to start to delivery carers assessments"

Integrated support and Impact on day-to-day life

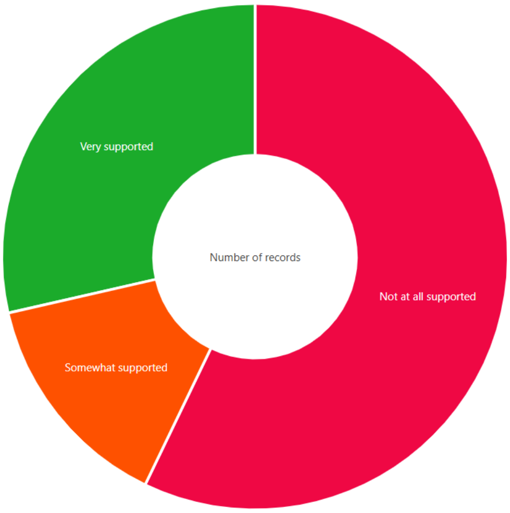
We gathered feedback from individuals about their experiences with dementia diagnosis and its impact on their daily lives. Respondents were asked about the level of support they felt following the diagnosis.

In terms of support…

4 selected ‘not at all’

2 selected ‘very supported’

1 selected ‘somewhat supported’



Professionals were not asked this question so the responses are only from those with dementia and their loved ones. Out of 7 responses, over half reported feeling a lack of support.

Some of the feedback highlighted both positive and negative experiences. One respondent shared, ***“After my husband’s diagnosis, I received a call from both Alzheimer’s Society and the memory clinic, who took the time to answer further questions we had. We have been supplied with contact and support group information.”*** In contrast, another respondent noted, ***“My husband is sadly no longer alive, but at the time of diagnosis, I wasn’t aware of any support.”*** One individual described their experience of receiving the diagnosis over the phone with no follow-up care, mentioning, ***“We were just given the number for Thurrock dementia services, and there was no care for the mental process that follows the diagnosis.”*** Others spoke positively about support, such as one respondent who stated, ***“I have received support from my family and friends,”*** and another who mentioned, ***“My mum is really well supported in the care home she is in. All the staff are well trained and very good with her.”***

We also asked respondents how the dementia diagnosis has impacted their day-to-day lives. Many respondents described the profound effects the diagnosis has had, particularly related to the loss of identity and grief associated with dementia.

In fact, when asked if they had experienced this, 63% of respondents agreed. One respondent shared, ***“Carers report not enough support after diagnosis,”*** while another stated, ***“As professionals, we deal with families of dementia patients, and it is very apparent that family members and carers aren’t educated and supported enough to deal with the grief, the loss of identity, and the issues that living with this disease brings.***” Another stating, “Because of no support, I had to cope on my own for 7 years.” Respondents also noted that accessing therapy for dementia can be difficult, and the sense of grief and loss of identity often goes unspoken.
These findings highlight the significant emotional and psychological challenges that both individuals with dementia and their carers face. The lack of consistent and sufficient support following a dementia diagnosis remains a critical issue that needs further attention and improvement.

Place based support

We asked respondents if they were aware of the different dementia cafes and spaces within Thurrock

11 out of 19 respondents said yes

It is encouraging to see that so many respondents were aware of the different dementia cafes and spaces within Thurrock. This demonstrates that they are both accessible and broadly advertised. We then asked respondents **what extra support in the community would they like to see?**

The most common themes that emerged from this question were

- **Financial help**
- **Community based support**
- **Café groups and singing groups (more social groups)**
- **More support for loneliness**
- **More bereavement support**

"More respite for families not coping"

"More carers and cared for sessions"

"A dedicated space in the community for dementia support such as a dementia hub"

"Support with befriending and loneliness. Also support with transport, those with dementia can't drive"

"More support for loneliness"

"More practical and logical support, how to deal with everyday things and how to cope with behavioural changes"

"Early bereavement support for carers of loved ones with dementia as they have already lost their loved one"

"I think people like me with a family member with dementia have to fight for information. How do people find out about support? There should be a higher profile considering the number of people with the illness. Advertising eg in supermarkets, a clear route to support available at GP surgeries, with staff being briefed to be able to answer questions on the phone."

Diagnosis

Another priority that Healthwatch Thurrock focused on was about respondent's experiences in seeking a dementia diagnosis and their suggestions on how the process could be improved.

When asked where they went to seek a diagnosis, four individuals indicated they went through their GP, while others mentioned turning to online resources or a community hub for information.

The survey also asked respondents what could make the process of receiving a diagnosis easier. Many pointed to the barriers created by long waiting times. One respondent highlighted the complexity of the process, stating, ***"Waiting time and the steps you have to take – barrier number one is getting a GP appointment, then the wait time for a memory assessment, then the wait for a diagnosis."*** Another respondent echoed this concern, saying, "*Shorter waiting times*" would be a significant improvement. A third respondent was more specific, stating, ***"Bring waiting lists down, the time between the initial GP appointment and diagnosis is unacceptable."*** These responses underscore the frustration caused by prolonged delays in accessing timely care and diagnosis.

The issue of waiting times and accessibility to healthcare professionals was further emphasised in another suggestion: ***"GP surgeries to get an appointment. If there was an allocated dementia person in Thurrock that you could call to get an appointment, it would avoid having to go through a busy GP."*** This indicates a need for more targeted and accessible dementia care within the local healthcare system, potentially reducing the barriers to diagnosis.

Another respondent pointed out the importance of involving those who live with the individual on a daily basis, stating,

> ***"I think that the person who lives day to day with the patient should be listened to more as they see things that the memory clinic doesn't see during the assessments. My husband was not diagnosed on the first visit, so we had to return 9 months later for reassessment and were then given a definitive diagnosis."***

This highlights the importance of taking into account the insights of family members or carers who may have a more nuanced understanding of the person's condition than the clinicians conducting the assessments.

The lengthy diagnostic process was also highlighted by one individual, who noted that ***"A shorter and more accurate way to get diagnosed. People go through so many tests and assessments before getting a diagnosis – it can take up to two years currently."*** This points to a desire for a more efficient and streamlined diagnostic process, which could reduce the stress and uncertainty for individuals and families navigating the journey to a diagnosis.

While some respondents reported that their diagnosis journey was straightforward through the GP, with one stating, *"Our diagnosis was fairly straight forward via the GP,"* the overall consensus was that the real challenge emerged post-diagnosis due to a lack of support. As one individual noted, ***"It is post diagnosis that is not easy and not enough support."*** This suggests that while the diagnostic process itself may vary, there is a clear gap in the support available once a diagnosis has been made.

Respondents were also asked about the role of denial in receiving a diagnosis. Several individuals shared their experiences of how denial or reluctance to acknowledge the condition can delay seeking help. One respondent shared, ***"My mum has clear signs of dementia but refuses to get a diagnosis or help – I believe it's a generational and cultural thing personally."*** Another respondent remarked, *"It would be depressing to be told you have a life-limiting illness."* This reflects the emotional difficulty that a dementia diagnosis presents, and the hesitation some people may feel in accepting the reality of the situation.

Others mentioned how individuals with dementia might downplay their symptoms, with one person stating, ***"It's not something a patient wants to hear so in our case my husband played everything down."*** There was also recognition of the stigma that still surrounds dementia, with one respondent noting, *"There is still a stigma attached to the word dementia."* This stigma can contribute to the challenges of seeking a diagnosis, as individuals may fear the implications of such a diagnosis.

Denial and fear were recurring themes in the responses, with one participant observing, ***"Denial can play a huge part as asking for help is difficult,"*** and another adding, *"Not wanting to admit it or feel vulnerable."* Many respondents also acknowledged the fear and uncertainty that comes with a dementia diagnosis, with one individual saying, ***"People are scared about the future,"*** and another commenting, *"If someone does not seek support they do not have to face it."*

These findings highlight the significant barriers individuals and families face when seeking a dementia diagnosis, including long waiting times, lack of support, and the emotional challenges of accepting the diagnosis. Additionally, the stigma and denial that surrounds dementia only further complicates the process, delaying diagnosis and potentially prolonging the suffering of both individuals with dementia and their families. There is a clear need for improvements in the diagnostic process, greater support post-diagnosis, and a shift in cultural attitudes towards dementia in order to help individuals and families navigate this difficult journey with more ease and dignity.

Dignity

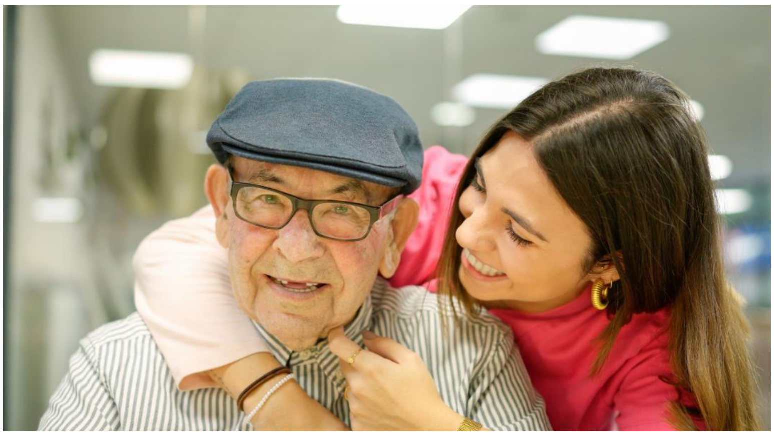
One of the priorities we were asked to look at in more depth focused on dignity and care of individuals with dementia, gathering responses from both carers and those directly affected. When asked whether their dignity was maintained following a dementia diagnosis, all respondents affirmed that they felt respected and supported.

One carer shared, ***"The care home mum is in don't refer to dementia in front of residents and they mix together rather than isolate the dementia residents from others."*** Another carer added, ***"Only because we as a family ensure it has."***

One respondent praised the kindness and professionalism of the dementia service caring for their husband, stating, ***"Yes, the dementia service has been very kind to my husband whilst maintaining professionalism."***

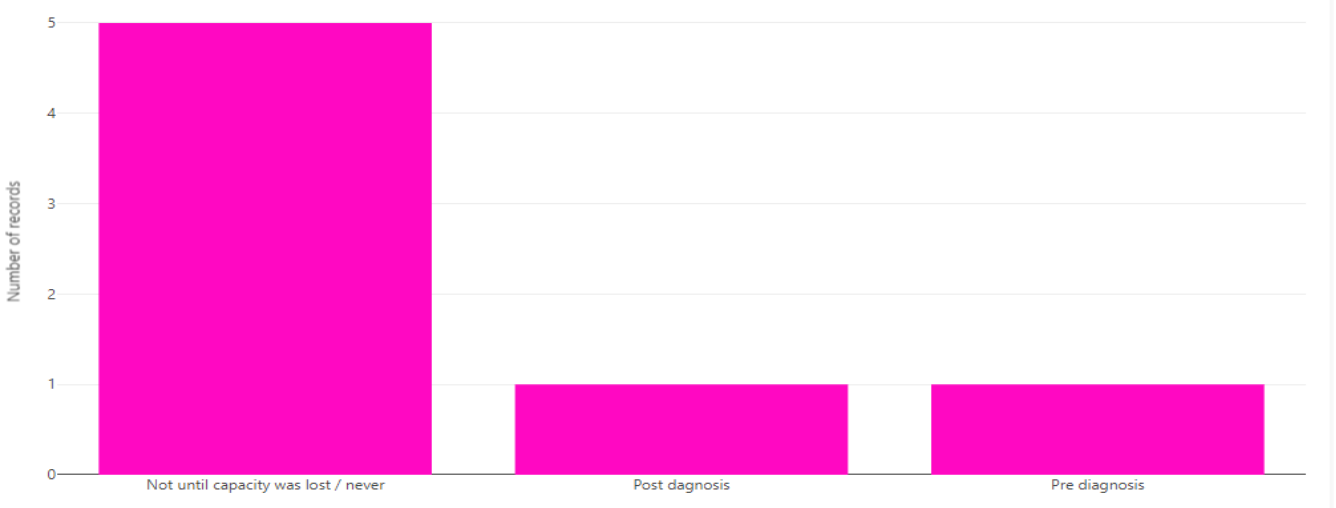
Healthcare professionals and carers shared insights on how they maintain dignity in dementia care. A key focus was ensuring that the voices of individuals with dementia are always heard. One professional mentioned, ***"Ensure their voice is always heard, that they have control over their own life and can live to the best of their ability."*** One practice's approach to longer appointments and early consent was also highlighted, with one practice manager stating, ***"The practice offers longer appointments and holds a carer register. We advocate for early consent to share to be given whilst there is still capacity."*** A holistic and individualised approach was emphasised, with one professional sharing, ***"Treat each person as an individual, listen to their needs and support holistically."*** Another professional added, ***"See the person underneath the diagnosis, get to know the person, and build a good working relationship. Never assume that people can't do anything."***

Further reflecting the importance of personalisation, one response noted, ***"Find out what is important to the person with dementia. Everyone has different needs and personalised care is the key."*** Other responses spoke to the emotional support involved, such as, ***"Nonstop love."*** Lastly, maintaining privacy and confidentiality was also stressed, with one carer stating, ***"Encourage and promote confidentiality, privacy, right to choice and encourage input with family members."***



End of Life care

Healthwatch Thurrock's engagement also explored the experiences of individuals and their families regarding discussions around end-of-life care during the dementia diagnosis journey. One of the key questions asked was: ***At what point in your loved one's diagnosis journey were conversations around end of life introduced?***



Out of the seven respondents who answered this question, the majority, five individuals, indicated **that end-of-life discussions were not initiated until the individual had lost capacity or, in some cases, never occurred.** This reflects a significant delay in engaging in these crucial conversations. The remaining two responses were split, with one respondent stating that these discussions occurred *"pre-diagnosis,"* while another indicated that the conversations took place *"post-diagnosis."*

Delaying or avoiding end-of-life care conversations can have serious consequences for both individuals with dementia and their families. Without these discussions, individuals lose the opportunity to express their preferences regarding care, dignity, and end-of-life decisions once they lose cognitive ability. This can lead to feelings of powerlessness. For families, the absence of early conversations creates confusion and stress, potentially leading to conflicts and difficulties in decision-making during an already emotionally challenging time.

Rushed or poorly planned decisions often occur when capacity is lost, leaving limited options for ensuring the person's wishes are met. In contrast, addressing these conversations early—either before or shortly after diagnosis—helps ensure the person's preferences are known and respected. It also reduces confusion and emotional burden for families, giving them guidance and allowing individuals with dementia to retain control over their care decisions for as long as possible.

The importance of having a Lasting Power of Attorney (LPA) in place cannot be overstated. It provides legal clarity and peace of mind, ensuring that individuals' wishes are honoured even when they can no longer communicate them. Early planning through LPA can alleviate the stress of making critical decisions later and ensure a more compassionate and dignified care journey.

Findings from the Questions

As discussed at the start of the report, we decided to revise our engagement strategy around half way through the project. Instead of continuing with the survey, we simplified the process by focusing on two key questions.

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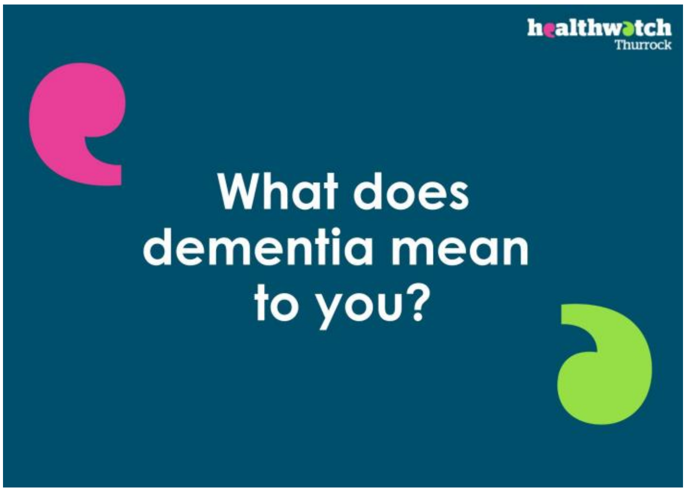
Where would you go if you suspected a loved one had dementia?



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What does dementia mean to you?

As a team, we reviewed the priorities outlined in our strategy and identified that two specific questions provided valuable insight into key themes such as access, support, stigma, and diagnosis.

To gather responses, we displayed these questions on a board in our office breakroom, shared them through our social media channels and newsletters, placed them in the building's reception area, and included them at all engagement events. Additionally, we reached out to our partner organisations, encouraging them to contribute their responses via email.

After changing our engagement strategy, we received 132 pieces of feedback to these two questions. This is a 594% increase in engagement for this project

Responses to questions one: Where would you go if you suspected a loved one had dementia?

After reviewing the responses to this question, we found that the most common responses were...

GP and Medical Professionals

A significant number of respondents mentioned that they would go to the GP or doctor as the first step in seeking advice and diagnosis. Some also refer to memory clinics or specialists for a referral.

Examples: "I would speak to my GP," ***"I'd book a GP appointment,"*** "Discuss with their GP," "The person's GP/memory clinic." "Talk to the community teams and the GP,"

Online Resources and Information

Many respondents turn to online platforms for guidance, including websites of dementia organisations. Some specific sites mentioned are Alzheimer's Society, NHS Direct, and Dementia UK.

Examples: ***"Look online for information and support organisations,"*** "Alzheimer's Society website," ***"Google local support services,"*** "Online assessments."

Family and Friends
Seeking advice from family, friends, or other loved ones is a common theme. Respondents often mention discussing concerns with those closest to them for emotional support or practical advice.

Examples: ***"Speak to family or others for advice,"*** "Family and friends."

> ***"I went to the GP, who then referred my mum on to a specialist. She was closely monitored by Adult Social Services and also received help from Thurrock MIND"***

Responses to questions two: What does dementia mean to you?

After reviewing the responses to this question, we found that the most common responses were...

Dementia is a deeply personal and often painful journey, affecting not only those diagnosed but also their loved ones. The below highlights the main themes that emerged from discussions on what dementia means to people.

1. Loss of Memory, Identity, and Independence

One of the most commonly mentioned aspects of dementia is memory loss and its impact on identity. Many described it as ***"a person gradually losing themselves, their memory of the people in their lives and their past."*** Others spoke of ***"being trapped in the past, living as the person you were, not the person you are."*** One response referred to ***"Someone's brain viewing their life from a different time"***

The fear of losing independence was also a major concern. As one person put it, dementia means ***"a gradual decline in mental awareness and ability to do and think for yourself and others."*** Another described it as ***"losing control, choice, personality, and dignity."***

2. Emotional and Social Impact on Families and Friends

Dementia is not just an individual struggle—it affects entire families and communities. Many respondents described the heartbreak of ***"watching someone you love drift away from you"*** and ***"mourning the loss of someone you love through disease."*** One person shared, ***"My mum had the start of this awful disease, and I slowly watched her suffer from memory loss. She was lonely and frightened."***

3. Fear, Stigma, and Uncertainty

Fear and worry were prominent themes, with people expressing concern about their own future: ***"I worry about having it myself at some point."*** Others pointed to the stigma surrounding dementia, with one respondent stating, ***"There is still a stigma, and people worry about the label, so they may avoid being tested."***

The unpredictable nature of dementia was also mentioned. One respondent described it as ***"fear of the unknown,"*** while another called it ***"a cruel disease"*** that leads to ***"anger and frustration."***

Another reflected on the importance of patience: ***"It's a profound challenge, not just for the person living with it, but for their loved ones, as it is a journey of patience."***

Responses from seldom heard groups

As part of our efforts to engage with seldom heard communities, we reached out to various faith groups through Thurrock CVS Faith members and local faith leaders. This led to an invitation to an interfaith conference at the Stanford-le-Hope Mosque. Additionally, we engaged with the local LGBTQ+ community organisation and attended one of their social events to gather insights into their understanding of dementia and where they would seek help.

Misconceptions and the Need for Awareness

Many respondents highlighted a lack of awareness and common misconceptions surrounding dementia. One individual expressed the belief that dementia was not a disease but rather a condition affecting older people that could be managed with care and attention:
"It is not a disease; mostly old people have it. If we care for them, see them, and give them time, then we can get rid of it."

Others acknowledged their limited knowledge, with one respondent admitting, ***"Not as much as it should because I have never had first-hand experience of it. I would really like to know more."*** This highlights the need for better access to information and education on dementia within these communities.

Emotional and Practical Challenges

Several individuals described the emotional impact of dementia on both the person affected and their loved ones. One participant reflected on the painful experience of witnessing cognitive decline, saying, ***"Watching someone you love drift away from you."*** Another emphasised the wider effect on families, stating, ***“The decrease of quality of life not only for the sufferer but also for the family that cares for that person."***

Seeking Help and Access to Support

When asked where they would go for help, responses varied. One individual mentioned they would seek support from a mental health hospital to obtain a diagnosis: ***"I would go to a mental health hospital."*** However, others pointed out difficulties in accessing information, particularly within community organisations:
"The information is not readily available to me for my charity organisation. It would be really good if it was."

In terms of care, a common sentiment was the preference for supporting loved ones at home for as long as possible before seeking external help. As one respondent shared, ***"Support them at home for as long as possible, before seeking external help."***

These insights underscore the need for increased dementia awareness, improved access to information, and culturally appropriate support services within seldom heard communities. Addressing these gaps can help ensure that those affected by dementia, along with their families, receive the guidance and support they need.

Case Studies

3. Susie's story

"The attached photo is of me with my beautiful grandmother, who I used to call Barbar. She had vascular dementia and I cared for her at home for 2 years before she had to move into residential care. I went away on holiday and when I came back, after only 2 weeks away she didn't know who I was anymore, she kept asking me if I knew when Susie was going to come and visit her.

I asked her "Barbar don't you recognise me?"
She replied "No but I feel your closeness to me." and after she said that, ***it didn't matter that she didn't know who I was, because I knew she felt our connection, and that meant more than anything***.
I took this photo after we had this conversation."

"My mother, who died in 1997, had dementia in latter years and gradually became unable to recognise me, which I think hurt me more than her as I came to realise that when I did visit she was always pleased to see me and recognised me as someone she loved despite not knowing what our relationship was and this gave me comfort"

3. Tracey's story

"My mother in law was diagnosed with Alzheimer's in 2018 although she had started to show signs of this at least 6 years prior. The rest of the family struggled to acknowledge the diagnosis, and I realised she was on a similar pathway to my mother. Although the spark of who she was remained, and was always pleased to see us when visiting despite not knowing our relationship to her.

It was sometimes hard to find the positives, but there are things that I will always remember from her later years such as suddenly singing along to a song using the correct words; she used to be a great fan of quiz shows and it was always astonishing that we may be watching the TV when visiting her in the care home and she would suddenly and unexpectedly give the right answer to the question, which was lovely"

"My father in law on the other hand, a usually jolly person, with a keen interest in anything and everything, developed mixed dementia, not long after her and his personality changed drastically to become an angry, rude and violent person which was extremely sad. It was very hard to witness his struggles as sometimes he had flashes of insight and realised what was happening to him which left him even more frustrated. That was a very cruel experience"

Conclusion

Dementia is an increasing concern for individuals, families, and healthcare services in Thurrock, affecting not just those diagnosed but also their carers and wider support networks. This report captures the lived experiences of Thurrock residents, highlighting the challenges they face in accessing diagnosis, ongoing support, and appropriate care, as well as the improvements needed to ensure a more dementia-friendly community.

One of the most pressing concerns raised was **the difficulty in securing a dementia diagnosis locally.** Many families reported long waiting times and inconsistent information, making it harder to access early intervention and plan for the future. Some individuals felt unsupported following their diagnosis, **with a lack of clear pathways to local services**, leaving them uncertain about where to turn for help. The complexity of navigating health and social care systems in Thurrock was another key frustration, with some feeling that available support was fragmented or poorly communicated.

Carers play a vital role in supporting loved ones with dementia, yet many reported feeling isolated and undervalued. The emotional and physical toll of caring for someone with dementia can be overwhelming, and in Thurrock, access to respite care and tailored carer support remains limited. **Many carers expressed the need for better recognition of their role**, with more opportunities for training, peer support, and access to mental health services to help them cope with the demands of caregiving.

Despite these challenges, there is a strong community-driven desire to improve dementia care in Thurrock. Residents emphasised **the need for more dementia-friendly initiatives**, including accessible social groups, local memory cafés, and public spaces designed with inclusivity in mind. **Training for frontline staff**—such as those in GP practices, transport services, and retail environments—was highlighted as a key improvement to ensure that individuals with dementia are treated with understanding and respect. Additionally, families stressed the importance of **raising awareness to combat stigma**, enabling those with dementia to live with dignity and continue participating in their communities for as long as possible.

In conclusion, there is a call for Thurrock to continue to develop a more person-centred approach to dementia care—one that empowers individuals and their families rather than leaving them to struggle through a system that often feels disconnected. As one participant powerfully stated, ***“Rather than writing people off, we need to enable and encourage them to keep as much control over their lives and choices as possible.”*** This sentiment reflects a broader call for change: ensuring that dementia care in Thurrock is not only accessible and well-coordinated but also compassionate, proactive, and centred on the needs of those living with the condition.

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