

SOUTH TEES

JSNA

Joint Strategic Needs Assessment

JUNE 2024

MISSION

We will promote independence for older people.

GOAL

We want to ensure our communities are dementia friendly.

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1. Introduction

1.1 Mission led approach.

The South Tees Health & Wellbeing Boards have agreed to a “mission-led” approach, structured across the life course. Each mission is a response to a significant local challenge, one where innovation, working together and aligning resources has a big part to play in driving large-scale change. The Missions each have a set of ambitious goals that further articulate and explain the Mission.

The JSNA will provide the intelligence behind the Mission(s) – it will develop our collective understanding of the Mission(s); the issues behind and the broad contributing factors to the current outcomes experienced. We are working across the Tees Valley authorities to develop a process on that footprint that facilitates deeper engagement from the ICB.

The vision and aspirations under the life course framework already exist following previous development sessions of the LiveWell Board. The life course framework consists of three strategic aims – start well, live well and age well.

Vision	Empower the citizens of South Tees to live longer and healthier lives		
Aims	Start Well	Live Well	Age Well
Aspiration	Children and Young People have the Best Start in Life We want children and young people to grow up in a community that promotes safety, aspiration, resilience, and healthy lifestyles	People live healthier and longer lives. We want to improve the quality of life by providing opportunities and support so more people can choose and sustain a healthier lifestyle.	More people lead safe, independent lives. We want more people leading independent lives through integrated and sustainable support.

1.2 Age well strategic aim.

There are two missions within the age well strategic aim. **The first mission relates to promoting independence for older people and the second mission relates to ensuring everyone has the right to a dignified death.** The third goal within the first mission, and the focus on this needs assessment focuses on ensuring our communities are dementia friendly.

Aims	Mission	Goal
Age Well	We will promote independence for older people	We want to reduce the levels of loneliness and isolation in our communities and ensure our places promote healthy ageing
		We want to reduce the level of frailty to improve healthy ageing
		We want to ensure our communities are dementia friendly
	We will ensure everyone has the right to a dignified death	We want to improve the identification of people who are approaching end of life and enable choice - relating to personalised and coordinated care

2. What is our mission and why do we need to achieve it?

2.1 We will promote independence for older people.

To understand the level of independent living within our older people population, we must first define what independent living refers to. Independence has multiple meanings for older people, but certain meanings are common - accepting help, doing things alone, having family, friends, and money as resources and preserving physical and mental capacities¹. At its most basic level, independence means having full autonomy over one's own life.

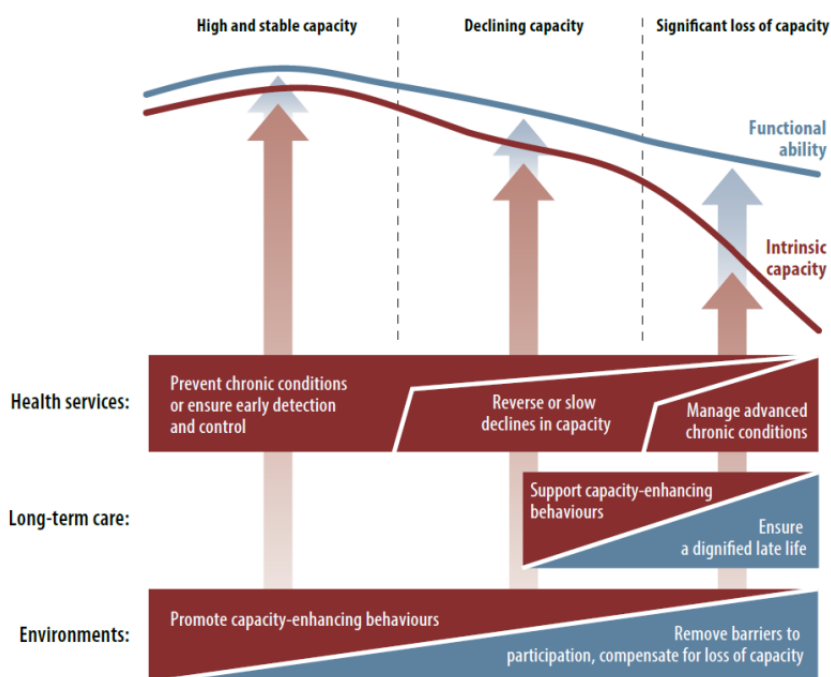
Independent living means disabled people living in the community with the same choices, control, and freedom as any other person, including having choice and control over things like who they live with and where. This requires the removal of barriers to equality of opportunity and for any practical assistance to be based on disabled residents' choices and aspirations.

Disabled people refer to people with different barriers:

- Physical, this affects the way a person can move or get around.
- Cognitive, this affects the way a person can communicate, make decisions, and remember things.
- Sensory, this affects the way a person touches, smells, sees or hears.
- Residents who use services who face barriers for a range of reasons and require support.

The term of healthy ageing and independence for older people are intertwined. The World Health Organisation (WHO) define healthy ageing as the process of developing and maintaining the functional ability that enables well-being in older age². This report focuses on 'functional capacity,' a combination of their intrinsic or internal resources such as mental and physical abilities and assets, combined with how they interact with their environment. Figure 1 demonstrates the levels of capacity and how these can be raised based on different interventions.

Figure 1 - Public health framework for ageing



Source – WHO report on health and ageing.

The Office for Health Improvement and Disparities (OHID) has built on the WHO framework to create four domains that best align with the levels of functional capacity change. These four domains are;

- **Optimise health and reduce risks early.**
- **Improve wellbeing and wider determinants of health.**
- **Reverse or live well with a long-term condition.**
- **Enhance care and support.**

These domains allow for the collation of datasets and indicators to help local areas understand how their population is ageing well and living independently.

2.2 Level of independence in South Tees

The level of older people living independently in South Tees is significantly worse than the England average. Figure 2 below is a selection of indicators from the four domains described above that are key drivers in older people living independently and as a collective help to demonstrate the level of independence. In South Tees, Middlesbrough performs significantly worse compared to England for all indicators and Redcar & Cleveland performs significantly worse for all bar two indicators, suggesting our older population is not living independently.

People living in South Tees are dying at a younger age and are living with poor health from a much younger age, compared to the England average. Local rates are some of the lowest in England.

Middlesbrough males on average are living 4 years less than the England average, whilst Redcar & Cleveland males are living 1.9 years less. Middlesbrough females on average are living 3.3 years less than the England average, whilst Redcar & Cleveland females are living 1.6 years less. Middlesbrough males have the 2nd lowest life expectancy in England and females the 4th lowest.

Healthy life expectancy shows the years a person can expect to live in good health (rather than with a disability or poor health). That figure is 4.3 years less for males and 3.3 years less for females in Middlesbrough compared to England and 6.2 years less for males and 5.4 years less for females in Redcar & Cleveland. Redcar & Cleveland has the 8th lowest healthy life expectancy for males in England.

Alongside the local population having significantly lower life expectancy and healthy life expectancy, a large amount of older people are living in poverty, with 23% in Middlesbrough and 17% in Redcar & Cleveland.

Significantly higher proportions of Middlesbrough and Redcar & Cleveland residents are self-reporting poor health as well as long term mental and physical health problems including Musculoskeletal (MSK). There is higher prevalence of Dementia locally and higher number of older people suffering from hip fractures, with Middlesbrough the 3rd highest nationally. We know hip fractures are a debilitating condition – only one in three sufferers return to their former levels of independence and one in three ends up leaving their own home and moving to long-term care.

Both Middlesbrough and Redcar & Cleveland have significantly lower rates of reablement services offered after hospital discharges and significantly higher rates of delayed transfers of care in hospital, permanent admissions to care homes and clients accessing long term social care, all of which drastically alter our older populations level of independence.

Figure 2- key indicators for older people living independently in South Tees

Indicator	Period	Middlesbrough		Redcar & Cleveland		England
		Rate	Rank	Rate	Rank	Rate
Life expectancy at birth (Male)	2018-20	75.4	2nd <i>Lowest</i>	77.5	29th <i>Lowest</i>	79.4
Life expectancy at birth (Female)	2018-20	79.8	4th <i>Lowest</i>	81.5	26th <i>Lowest</i>	83.1
Healthy life expectancy at birth (Male)	2018-20	58.8	27th <i>Lowest</i>	56.9	8th <i>Lowest</i>	63.1
Healthy life expectancy at birth (Female)	2018-20	60.6	42nd <i>Lowest</i>	58.5	21st <i>Lowest</i>	63.9
Older people living in poverty %	2019	23.3%	22nd <i>Highest</i>	16.8%	64th <i>Highest</i>	14.2%
Health related quality of life for older people - mean score	2016/17	0.70	28th <i>Lowest</i>	0.71	36th <i>Lowest</i>	0.74
Long-term physical or mental health condition % *	2022	60.2%	12th* <i>Highest</i>	60.2%	12th* <i>Highest</i>	53.5%
Reporting long term MSK problem %	2021	21.3%	22nd <i>Highest</i>	24.3%	4th <i>Highest</i>	17.0%
Dementia Prevalence % (65+)	2020	4.6%	16th <i>Highest</i>	4.1%	55th <i>Highest</i>	4.0%
Hip fracturs per 100,000 (65+)	2020/21	687	3rd <i>Highest</i>	542	65th <i>Highest</i>	529
Offered reablement services following hospital discharge % (65+)	2020/21	0.6%	11th <i>Lowest</i>	1.4%	23rd <i>Lowest</i>	3.1%
Delayed Transfers of Care (%)**	Mar 18 - Feb 20	6.0%	-	6.0%	-	4.2%
Permanent admissions to residential & nursing care homes per 100,000 (65+)	2020/21	844	11th <i>Highest</i>	700	25th <i>Highest</i>	498
Clients accessing long term social care support per 100,000 (65+)	2021/22	8,600	10th <i>Highest</i>	6,400	64th <i>Highest</i>	5,055

* Rate and rank is for Tees Valley CCG

** Data if for South Tees NHS Trust

Compared to England

Significantly worse	Similar	Significantly better
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Source – OHID Fingertips, NHS Digital and NHS England

We know from these high-level indicators that our local population does not appear to be living independently, and their loss of independence is happening at an earlier age compared to other areas nationally.

3. What is our goal and why do we need to achieve it?

3.1 We want to ensure our communities are dementia friendly.

A dementia friendly community is a city, town, or village where people with dementia are understood, respected, and supported. Dementia friendly communities are vital in helping people live well with dementia and feel a part of their community. It is where people with dementia are empowered to have high aspirations and feel confident, knowing that they can contribute and participate in activities that are meaningful to them and can continue to live the way they want to in a community that they choose. (Alzheimer's Society)

Dementia friendly communities are those in which people with dementia have the best possible opportunities to live well or as well as possible.

Too many people affected by dementia feel like society fails to understand the condition they live with, its impact, or how to interact with them and people with dementia sometimes feel they need to withdraw from their community as the condition progresses.³This is why many councils are working in partnership with their local communities to develop innovative ways to enable people with dementia take part in everyday activities and retain their independence for as long as they are able to.

Examples include developing dementia friendly Businesses and Organisations, where as a result of simple adaptations and awareness raising among staff working in shops, shopping becomes easier for people with dementia. Simple changes to existing services, and awareness raising for those who come into day-to-day contact with people with dementia, such as staff working in libraries or in leisure centres, also help people with dementia to feel more confident and welcome in using council services.

Councils that look at dementia strategically and positively, working with key partners and communities locally, help mitigate the pressures on their services, particularly health and social care, from growing demand, while also unlocking enormous potential from people living with dementia, their carers, and the wider community. Health and social care services alone cannot meet the challenge of dementia. Dementia requires a community response, and all communities need to be set up as well as they could be to support people with dementia to live well.⁴

The Alzheimer's Society defines a dementia friendly community as:

"A city, town, or village where people with dementia are understood, respected, and supported, and confident they can contribute to community life. In a dementia friendly community people will be aware of and understand dementia, and people with dementia will feel included and involved, and have choice and control over their day-to-day lives."

People with dementia have described a dementia friendly community as one that enables them to:

- find their way around and be safe.
- access the local facilities that they are used to and where they are known (such as banks, shops, cafes, cinemas, and post offices)
- maintain their social networks so they feel they continue to belong.

Dementia Friendly Communities (DFCs) is a standardised national recognition process by the Alzheimer's Society and enables communities to be publicly recognised and celebrates their work.

Middlesbrough Council continues to be committed to making sure that people living with dementia were able to remain active and included members of their communities, maintain their independence for as long as possible, be treated with understanding and respect and receive support when necessary

and in 2016, Middlesbrough Council received national recognition from the Alzheimer's Society for working towards being a dementia friendly town.

Middlesbrough Council also worked with Redcar and Cleveland Council (RCBC) Colleagues to share best practice and secure funding and resources to enable RCBC to start their journey of being a Dementia Friendly Town and in May 2018, Redcar & Cleveland also achieved a key milestone for working towards being a dementia friendly town.

(See 5.2 for information on the South Tees Commissioned Service for developing Dementia Friendly Communities)

3.2 What is dementia?

Dementia is a complex, life changing and progressive condition that poses significant challenges to the individual, their families, and carers. It affects memory, thinking, orientation, language, judgement, calculation and learning capacity. Whilst most common in older people, dementia can be diagnosed in people under the age of 65, known as early onset dementia.

Dementia is caused by many different diseases or injuries that directly and indirectly damage the brain. As an umbrella term, dementia describes the symptoms that occur when the brain is affected by certain diseases or conditions. There are over 200 subtypes of dementia including Alzheimer disease, which was first described in 1906 - over 100 years ago by the German psychiatrist and neuropathologist, Alois Alzheimer. The disease named after him is the most common form of dementia and contributes to around 60–70% of cases of dementia today. Its prevalence continues to increase with an ageing population.

Other common forms of dementia include vascular dementia, dementia with Lewy bodies (abnormal deposits of protein inside nerve cells), and a group of diseases that contribute to frontotemporal dementia (degeneration of the frontal lobe of the brain).

Dementia can also develop after a stroke or in the context of certain infections such as HIV, because of harmful use of alcohol, repetitive physical injuries to the brain (known as chronic traumatic encephalopathy) or nutritional deficiencies. The boundaries between different forms of dementia are indistinct and mixed forms often co-exist.⁵

Most symptoms of dementia become worse over time, while others might disappear or only occur in the later stages of dementia. As the disease progresses, the need for help with personal care increases. People with dementia may not be able to recognize family members or friends, develop difficulties moving around, lose control over their bladder and bowels, have trouble eating and drinking and experience behaviour changes such as aggression that are distressing to the person with dementia as well as those around them.

Early signs and symptoms are:

- forgetting things or recent events
- losing or misplacing things
- getting lost when walking or driving
- being confused, even in familiar places
- losing track of time
- difficulties solving problems or making decisions.
- problems following conversations or trouble finding words.
- difficulties performing familiar tasks.
- misjudging distances to objects visually.

Common changes in mood and behaviour include:

- feeling anxious, sad, or angry about memory loss
- personality changes
- inappropriate behaviour
- withdrawal from work or social activities
- being less interested in other people's emotions.

Dementia affects each person in a different way, depending upon the underlying causes, other health conditions and the person's cognitive functioning before becoming ill.

The estimated prevalence figure for young onset dementia, where diagnosis was between age 30—64, is 92 per 100,000 of the general population. Young onset dementia is a preferable term to 'early onset' dementia to avoid confusion with the early stages of dementia generally.

Prevalence rates for young onset dementia in ethnic minority communities are higher than for the population as a whole and people from these backgrounds are also less likely to receive a diagnosis or support.

People with a learning disability are also at greater risk of developing dementia at a younger age. Studies have shown that one in ten develop young onset Alzheimer's disease between the age of 50 to 65. The number of people with Down's syndrome who develop Alzheimer's disease is even greater. (World Health Organisation)

Figures taken from Dementia UK show that for a diagnosis of young onset dementia: -

- On average, a person may see between two and five different consultants before a diagnosis is made.
- The average time to diagnosis is 4.4 years in younger people compared to 2.2 years for people aged over 65.
- In England in August 2018, the estimated dementia diagnosis rate for under 65s was 41%, compared to 68% for people aged over 65.
- Awareness amongst GPs is still relatively low and when people are younger, symptoms are often attributed to stress, anxiety, depression or menopause
- People who are under 65 are more likely to be diagnosed with a genetically inherited form of dementia or a rarer dementia that can be difficult to recognise

There are differences in the types of dementia commonly diagnosed in younger people with dementia compared to those of an older age: -

- Alzheimer's disease is the most common form of dementia in younger people, accounting for around a third of younger people with dementia, in comparison to about 60% in the older age group.
- Vascular dementia is the second most common form of dementia in young people. Around 20% of younger people with dementia have vascular dementia.
- Around 12% of younger people with dementia have frontotemporal dementia, compared with just 2% in older people. It most commonly occurs between the ages of 45-65. In about 40% of cases there is a family history of the condition
- Korsakoff's syndrome – around 10% of dementias in younger people are caused by a lack of vitamin B1 (thiamine), most commonly associated with alcohol abuse.
- Around 10% of younger people with dementia have dementia with Lewy bodies

- Around 20% of young people with dementia have a 'rarer' form of the condition. Examples include conditions that can lead to dementia including Parkinson's, Huntington's disease and Creutzfeldt Jakob disease
- Younger people are more likely to have rarer familial forms of dementia caused by genetic mutations including: familial Alzheimer's disease, familial frontotemporal dementia and familial vascular dementia.

(Source Dementia UK)

WHO recognises dementia as a public health priority and published a global action plan in May 2017. The plan includes creating dementia inclusive societies and increasing research and innovation to tackle the disease⁶

Although there is no cure for dementia, a lot can be done to support both people living with the dementia and those who care for them. People with dementia can take steps that help them to maintain their quality of life and promote well-being by:

- being physically active
- taking part in activities and social interactions that stimulate the brain and maintain daily function.

In addition, some medications can help manage dementia symptoms:

- Cholinesterase inhibitors like donepezil are used to treat Alzheimer disease.
- NMDA (N-methyl-D-aspartate) receptor antagonists like memantine are used for severe Alzheimer disease and vascular dementia.
- Medicines to control blood pressure and cholesterol can prevent additional damage to the brain due to vascular dementia.
- Selective serotonin reuptake inhibitors (SSRIs) can help with severe symptoms of depression in people living with dementia if lifestyle and social changes do not work, but these should not be the first option.

If people living with dementia are at risk of hurting themselves or others, medicines like haloperidol and risperidone can help, but these should never be used as the first treatment (World Health Organisation 2023)

Dementia Disease Trajectory

Despite the variations in the type and severity of symptoms and their respective patterns of development, most dementias are typically a gradual onset, progressive in nature and are irreversible.

The course of dementia is often characterised as occurring in three stages:

Mild or early-stage dementia

Deficits are evident in a number of areas such as memory and personal care, but the person can still function with minimal assistance.

Moderate or middle-stage dementia

Deficits become more obvious and severe, and increasing levels of assistance are required to help the person maintain their functioning in the home and community.

Severe or late-stage dementia

Characterised by almost total dependence on care and supervision by others⁷

3.3 Dementia Carers

Caring for a person with dementia is unlike caring for someone with any other condition or disability, due to the complex, unpredictable and progressive nature of dementia.

It is thought that there are over 700,000 people in the UK acting as informal carers for people with dementia. The financial value of this care is estimated to be £13.9 billion each year (Alzheimer's Society, 2019)

The 'Prime Minister's 2020 Challenge on Dementia' reports that carers of people with dementia should be made aware of and offered the opportunity for respite, education, training, emotional and psychological support so that they feel able to cope with their caring responsibilities and to have a life alongside caring.

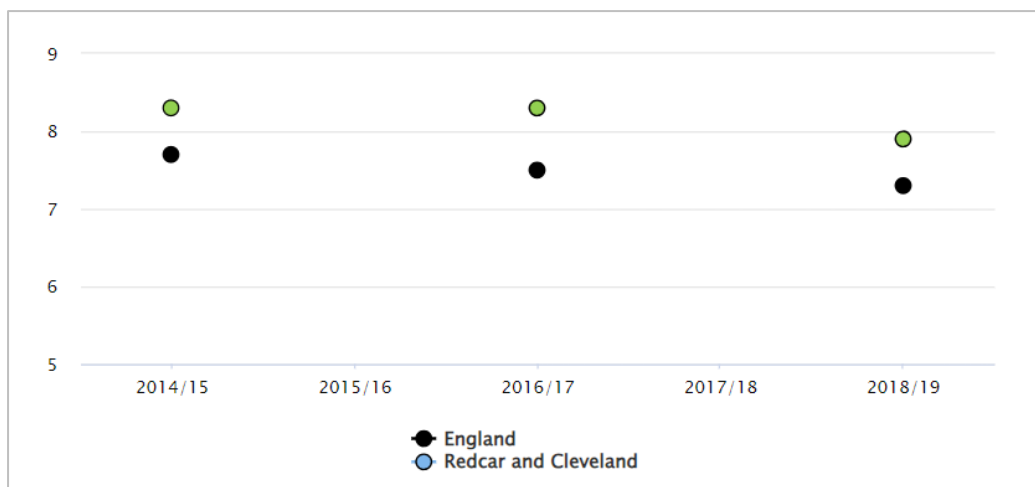
Local Authorities have a statutory duty to offer carers assessments as well as provide information and advice to carers in relation to their Caring role and their own needs and work closely with Carers Services and other agencies to promote information, advice, and signposting.

Caring for a person with dementia can have a big impact on Carers own mental and physical health and wellbeing and often have reduced quality of life with many carers neglecting their own needs due to the impact of their caring role.

There is considerable evidence demonstrating that family carers of people with dementia have a lower quality of life (QoL) than non-dementia carers and non-carers. Studies show that existing carer interventions, such as psychoeducation interventions and cognitive behaviour therapy are effective for reducing carer burden and depression in family carers of people with dementia.⁸

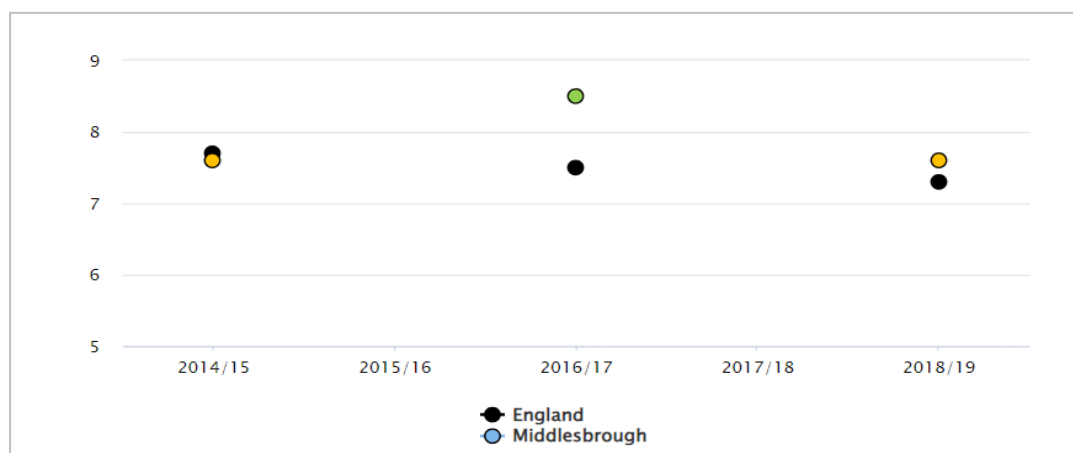
Figures 3&4 below are taken from the adult social care outcomes framework results and shows self-reported quality of life for carers in Middlesbrough and Redcar and Cleveland up to 2018/19. The orange dots show that satisfaction is similar with England and green dots show that it is significantly better.

Figure 3- Carer-reported quality of life score for people caring for someone with dementia.



Source- NHS Digital, Adult social care outcomes framework

Figure 4-Carer-reported quality of life score for people caring for someone with dementia Middlesbrough.



Source- NHS Digital, Adult social care outcomes framework

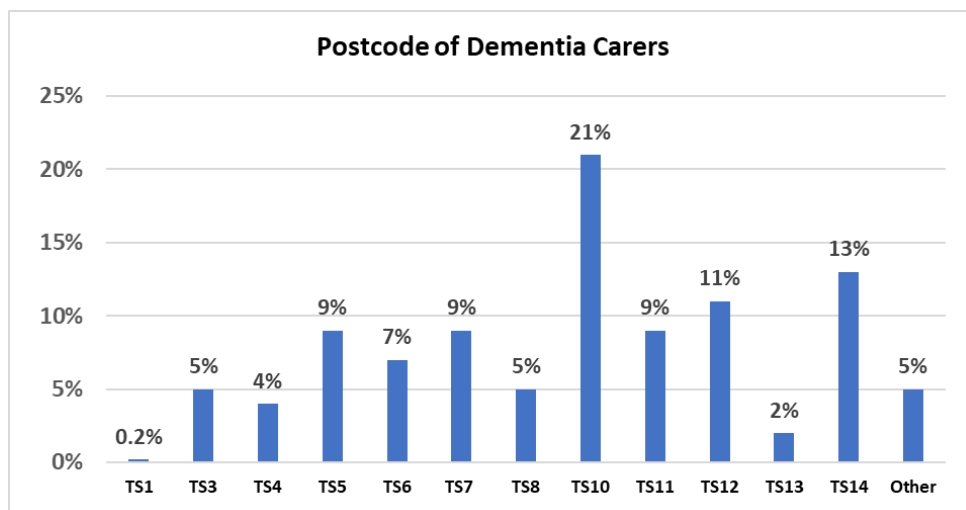
Alzheimer's Society research finds that carers often struggle to open up about how this can make them feel – almost 60% of carers surveyed experience feelings of guilt when seeking support and say they feel like they are putting their needs before the person they are caring for.⁹

Carers of people with dementia have told Alzheimer's Society of how they have struggled with exhaustion due to countless sleepless nights, stopped socialising, and neglected their own health.

There are over 2000 Dementia Carers currently known to Carers Together in Redcar & Cleveland and over 450 in Middlesbrough. Between 1st April 2022 and 31st March 2023, nearly 450 different Dementia Carers accessed Carers Together services.

- 78% (343) of carers who accessed services during the 12-month period were female and 22% (99) were male.
- The highest percentage of Dementia Carers (75%) who accessed the service during the 12-month period were aged between 55 and 84.
 - 55-66 (116)
 - 65-74 (99)
 - 75-84 (117)
- Almost twice as many Dementia Carers came from TS10 (central Redcar) as other areas in Redcar & Cleveland.

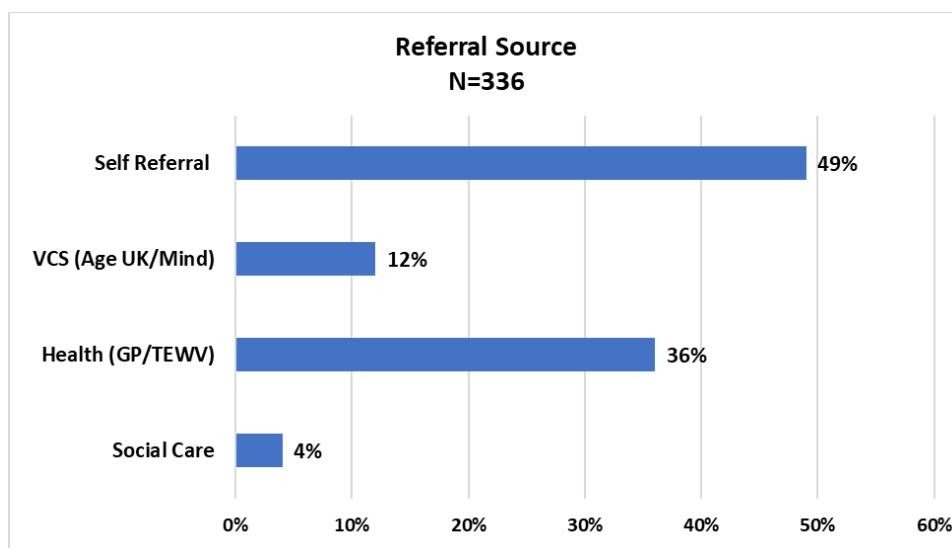
Figure 5 - Population of Dementia Carers by postcode



Source - Carers Together

The referral sources have been grouped into four categories, as there was a wide range of referrers. 49% of all referrals were self-referrals (carers contacted the service directly). Health services made 36% of referrals, VCS made 12% of referrals and Adult Social Care made 4% of referrals (see figure 6 below).

Figure 6- Referral sources for dementia carers



Source- Carers Together

Informal carers are a huge resource that most services have but do not support and utilise enough. Building on community activity and support, identifying carers at an earlier stage, and developing staff to inform and signpost carers provides service users with the opportunity to remain supported in their own homes for longer and support the health and wellbeing of the carers to do this.

Continued support for carers can enhance carers' wellbeing as well as maintain independence for the person with dementia.

3.3 Risk factors for dementia

There are many risk factors for dementia. The risk of developing the condition depends on a mixture of these and varies from person to person. Some of these are factors you cannot change, such as age, genes, sex, and ethnic origin. Although age is the strongest known risk factor for dementia, it is not an inevitable consequence of biological ageing.

Dementia does not exclusively affect older people. Young onset dementia (defined as the onset of symptoms before the age of 65 years) accounts for up to 9% of cases. Studies show that people can reduce their risk of cognitive decline and dementia by being physically active, not smoking, avoiding harmful use of alcohol, controlling their weight, eating a healthy diet, and maintaining healthy blood pressure, cholesterol and blood sugar levels. Additional risk factors include depression, social isolation, low educational attainment, cognitive inactivity and air pollution.

Risk factors for dementia are complex, and generally fall into those which are and are not, generally modifiable to mitigate these individual risks. 'Non-modifiable' risk factors include:

Age is the strongest risk factor for dementia. Over the age of 65, a person's risk of developing Alzheimer's disease or vascular dementia doubles roughly every five years. It is estimated that dementia affects one in 14 people over 65 and one in six people over 80.

Genes determine how characteristics are passed down through families. There are more than 20 genes known to increase a person's risk of developing dementia. There are also a few genes that directly cause dementia, but these are very rare. Some people worry about their family history but there is no genetic test for Alzheimer's disease in people over 65 that you can take through the NHS. Some risk factors for dementia cannot be changed.

Sex - Women are more likely to develop Alzheimer's disease than men (even allowing for the fact that women on average live longer). Men are at slightly higher risk of vascular dementia. For most other forms of dementia, women and men have much the same risk.

Ethnic origin. There is some evidence that people from certain ethnic communities are at higher risk of dementia than others. For example, South Asian people (from countries such as India and Pakistan) seem to develop dementia – particularly vascular dementia – more often than white Europeans.

There are many factors that can be changed, which include ways of keeping the body and mind healthy. ***As a general rule, what is good for the heart is good for the brain.***

'Modifiable' risk factors for dementia include:

- **Hypertension/Vascular risk:** Midlife clustering of vascular risk factors has been associated with late-life dementia, but causal effects of individual biological and lifestyle factors remain largely unknown
- **Socioeconomic inequality:** is a large contributor to the development of dementia and issues such as leaving education early, have been implicated in cognitive decline
- **Smoking:** Smokers show an increased risk of dementia, and smoking cessation decreases the risk to that of never smokers. The increased risk from smoking is more pronounced in apolipoprotein E ϵ 4 noncarriers. Survival bias and competing risk reduce the risk of dementia from smoking at extreme age
- **Diabetes:** Higher or unstable HbA_{1c} levels and the presence of diabetic complications in patients with type 2 diabetes are associated with increased dementia risk. Effective

management of glycemia might have a significant role in maintaining cognitive health among older adults with diabetes

- **Physical Activity:** Exercise has emerged as a key intervention for influencing cognition positively, including reducing the risk of age-related cognitive decline and dementia
- **Alcohol consumption:** The risk of dementia was increased in people who abstained from alcohol in midlife or consumed >14 units/week. In several countries, guidelines define thresholds for harmful alcohol consumption much higher than 14 units/week. The present findings encourage the downward revision of such guidelines to promote cognitive health at older ages
- **Social isolation:** Feeling lonely is associated with a nearly 60% increased risk of all-cause dementia
- **Depression:** evidence suggests that depressive episodes may also be a cause of dementia
- **Traumatic brain injury:** Despite much previous research stating that traumatic brain injury (TBI) has been confirmed as a risk factor for dementia and Alzheimer disease (AD), findings from observational studies are mixed and are of low methodological quality
- **Hearing loss:** Speech in Noise (SiN) hearing impairment is independently associated with incident dementia, providing further evidence for hearing impairment as a potential modifiable dementia risk factor
- **Air pollution:** studies have found evidence of a positive association between residential levels of air pollution and being diagnosed with dementia, which is unexplained by known confounding factors.¹⁰

(World Health Organisation)

3.4 Dementia in the UK

In the UK there is an estimated 944,000 people living with dementia and 7.5% or 70,800 are living with young onset dementia where symptoms occurred under the age of 65. As well as the huge personal cost, the overall economic impact of Dementia in the UK is estimated to be £26 billion per year. Rates of diagnosis are improving but many people with dementia are still thought to be undiagnosed. In the absence of a treatment or cure, it is important that action be taken to reduce the numbers of people getting Dementia, postpone the onset of Dementia and/or mitigate its impact.¹¹

According to projections, the population share of later-life age groups is set to increase further in future years. By 2041, the 1960s baby boomers will have progressed into their 70s and 80s, and by 2068 there could be an additional 8.2 million people aged 65 years and over in the UK – a population roughly the size of present-day London. This would take the UK's 65 years and over age group to 20.4 million people, accounting for 26.4% of the projected population.

In 1998, around one in six people were 65 years and over (15.9%), this increased to one in every five people in 2018 (18.3%) and is projected to reach around one in every four people (24.2%) by 2038. (ONS, 2018)

Worldwide, Women are disproportionately affected by dementia, both directly and indirectly. Women experience higher disability-adjusted life years and mortality due to dementia, but also provide 70% of care hours for people living with dementia.

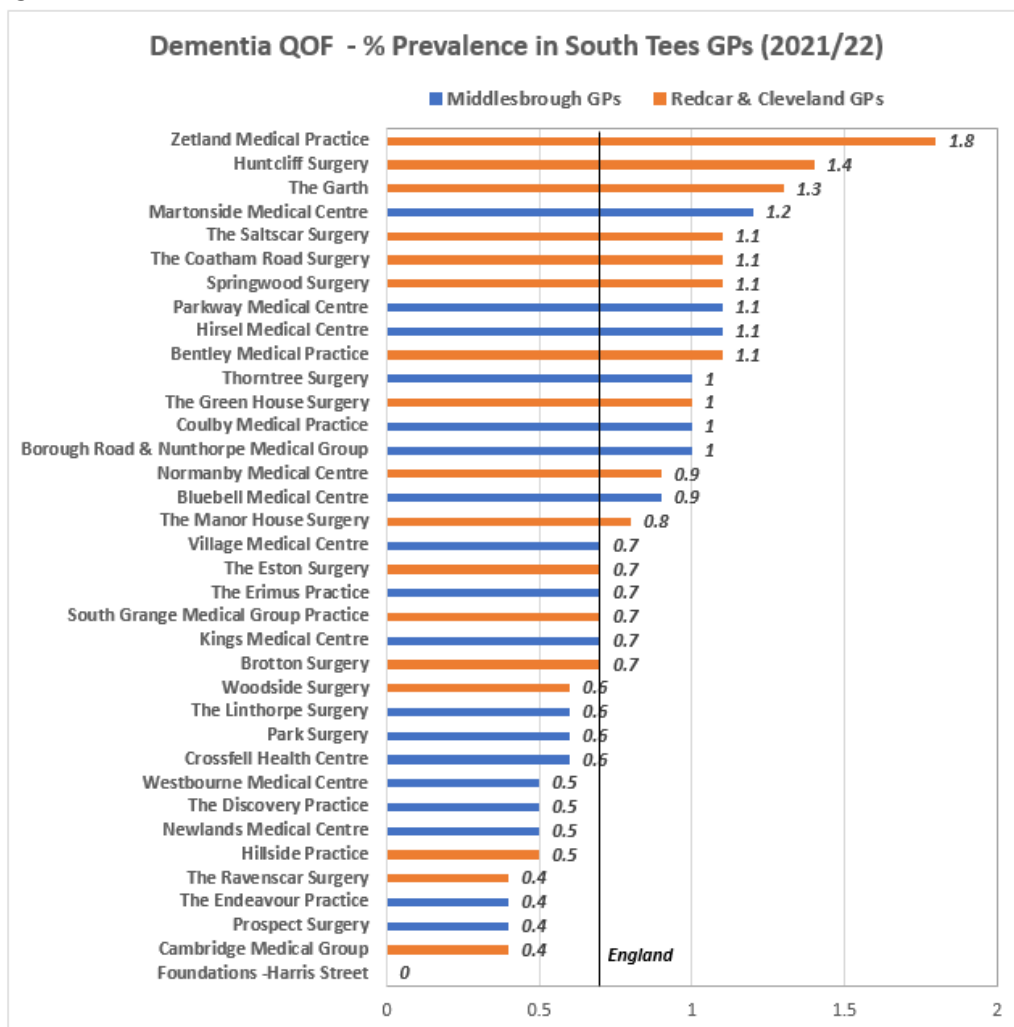
Dementia is a costly condition in its social, economic, and health dimensions and nearly 60% of the burden is concentrated in low and middle-income families, which is likely to increase in coming years. The cost of care drives millions of households below the poverty line and the overwhelming number of people whose lives are altered by dementia, combined with the staggering economic burden on families, makes dementia a public health priority.

4. Key data and drivers for change?

4.1 Dementia Prevalence

In 2021/22, there were 2,521 patients recorded as having dementia on GP systems in South Tees. This equates to 0.8% of the practice populations. This is similar to the England rate of 0.7%. There is variation across South Tees GP practices as shown below in figure 7. Zetland Medical Practice in Redcar & Cleveland had the highest prevalence rate of 1.8%.

Figure 7 - Dementia QOF Prevalence in South Tees



Source - NECS business intelligence team

Data provided by North of England Commissioning Support Unit (NECS) business intelligence team shows the recorded prevalence of dementia as a rate per 1,000 patients as per GP registered populations as of September 2023. The home addresses of patients have been used to show the local authority and ward of residence.

Figure 8 below shows that Redcar & Cleveland has a higher dementia rate at 10 per 1,000 compared to Middlesbrough at 7.7 per 1,000 and the Tees Valley average of 8.9 per 1,000. The table shows the wards in South Tees with the highest rates, with Saltburn ward in Redcar & Cleveland highest at 23.8 per 1,000, followed by Stainton & Thornton ward in Middlesbrough with 23.1 per 1,000. The highest

rates for wards and in Redcar & Cleveland will partly reflect the higher proportions of older patients in those areas.

Figure 8 - Dementia prevalence highest wards

LA: Ward Name	Prevalence per 1,000 population
RC: Saltburn	23.8
M: Stainton & Thornton	23.1
RC: Kirkleatham	19.1
RC: Coatham	17.4
RC: Guisborough	15.8
M: Coulby Newham	14.7
RC: Eston	13.1
RC: Hutton	12.8
M: Longlands & Beechwood	12.3
M: Linthorpe	11.6
Redcar & Cleveland	10.0
Middlesbrough	7.7
Tees Valley	8.9

Source – NECS business intelligence team

There is a strong correlation within age bands between deprivation and recorded dementia prevalence per 1,000 population, particularly in the older age groups as shown below in Figure 9. Although dementia rates rise significantly for older populations (especially for those aged 85 years and over), areas that are very deprived have significantly lower life expectancy and so the proportion in those age groups is lower compared to all age population.

Figure 9 - Dementia prevalence highest wards

IMD decile of residence	Recorded dementia prevalence per 1,000 population		
	65 to 74	75 to 84	85 and above
1 - most deprived	17	78	204
2	13	62	182
3	18	84	190
4	10	54	169
5	12	50	170
6	7	42	117
7	10	43	130
8	7	38	122
9	8	38	122
10 - least deprived	7	37	116

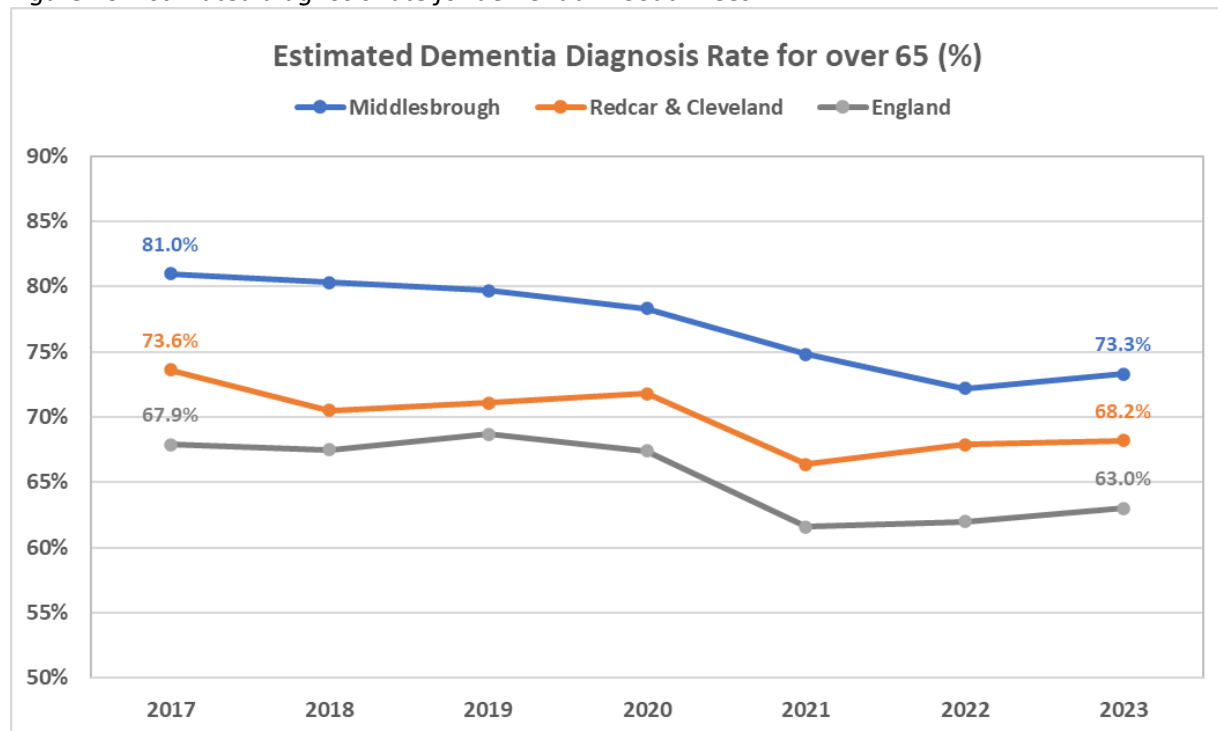
Source – NECS business intelligence team

There is a national commitment to increase the number of people living with dementia who have a formal diagnosis to two-thirds. The estimated diagnosis rate shows the proportion of the population aged 65 and over who have a diagnosis of dementia per person estimated to have dementia given the characteristics of the local population. Figure 10 below shows that South Tees has a higher diagnosis rate with Middlesbrough at 73.3% and Redcar & Cleveland at 68.2% compared to 63% in England.

The figure 10 below shows that the rate for both local authorities reduced in 2020 and the Covid-19 pandemic has contributed towards this. Analysis by Alzheimer’s Society found that people with dementia were struggling to access GPs and memory clinics during the pandemic – with GP

assessments down 38%, new memory assessment service (MAS) referrals down 22% and MAS assessments down 50% in the 12 months between June 2020 – May 2021 compared to June 2019 to May 2020. Despite the COVID-19 pandemic and the drop-in memory assessment services, both areas were still above the National Average.

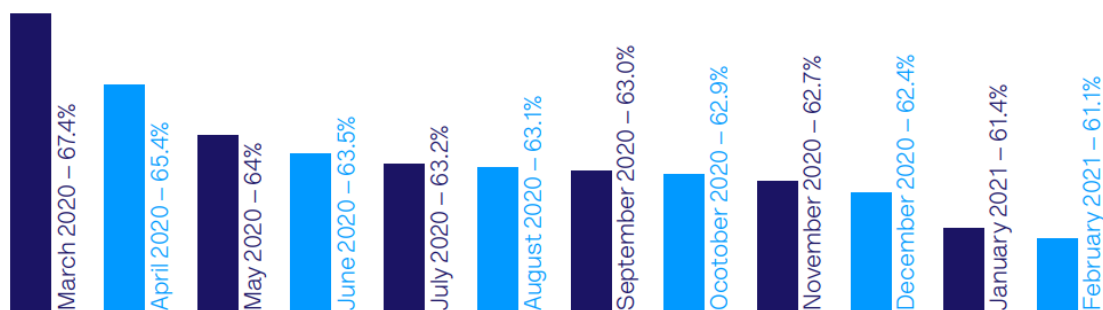
Figure 10: Estimated diagnosis rate for dementia in South Tees



Source – Fingertips, OHID

Nationally, the impact of the pandemic on diagnosis rates is stark. In just one year, the national diagnosis rate for people aged 65 and over dropped by 6.3 percentage points, from 67.4% in March 2020 to just 61.1% in February 2021.8 from May 2021. The Alzheimer’s Society estimate that over 33,500 diagnoses are needed nationally to get back to pre-pandemic diagnosis levels.

Figure 11 impact on diagnosis rates during the covid-19 pandemic



Source: Alzheimer’s Society report on regional variation (Nov 2023)

NHS Health Checks are health check-ups for adults in England aged 40 to 74 to spot early signs of conditions and since 2018 the check has had a specific dementia component. Adding the dementia element to the NHS Health Check programme enables healthcare professionals to talk to their

patients about how they can reduce their dementia risk, such as by maintaining their social life, keeping mentally and physically active and stopping smoking.

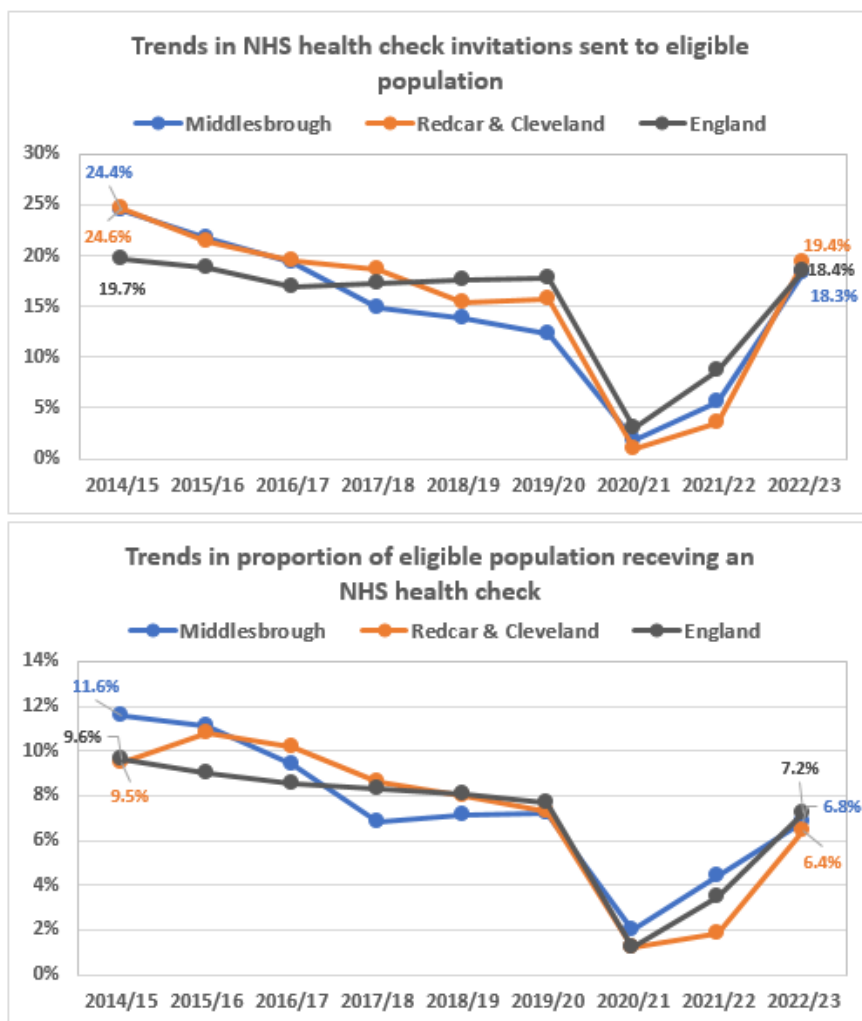
In 2018 the Alzheimer’s Society reported that: -

- 52% of adults name dementia as one of their top three health worries.
- 28% have no awareness of any of the risks factors and only 2% are aware of all the things they can do to reduce the risk.
- As many as one third of dementia cases may be prevented by improved lifestyle choices

Research by the Alzheimer’s Society suggested that new dementia diagnoses were significantly more likely to be identified in those who attended NHS Health Checks than those who did not. Take up of these checks has been low since is low – 83.1% of people eligible for a health check between 2013 and 2017 did not attend.

The figure 12 below shows that trends for eligible people receiving invitations to NHS health checks and the proportion of eligible patients receiving an NHS check dropped significantly during the pandemic but are nearly back to pre-pandemic levels for both Middlesbrough and Redcar and Cleveland, however both areas are still lower than the National average for patients receiving an NHS check.

Figure 12 - Trends in NHS health check invites and take up.



Source – OHID Fingertips

An early diagnosis of dementia can provide the individual, their carers and families time for planning care, financial and legal issues and putting arrangements in place to deal with the progression of symptoms. It enables the individual and their carers and family to have access to treatments that are available at the earliest opportunity as well as ensuring they receive holistic and coordinated care. Many people with dementia live well for years after their diagnosis, so information, advice and support are essential to achieve this.

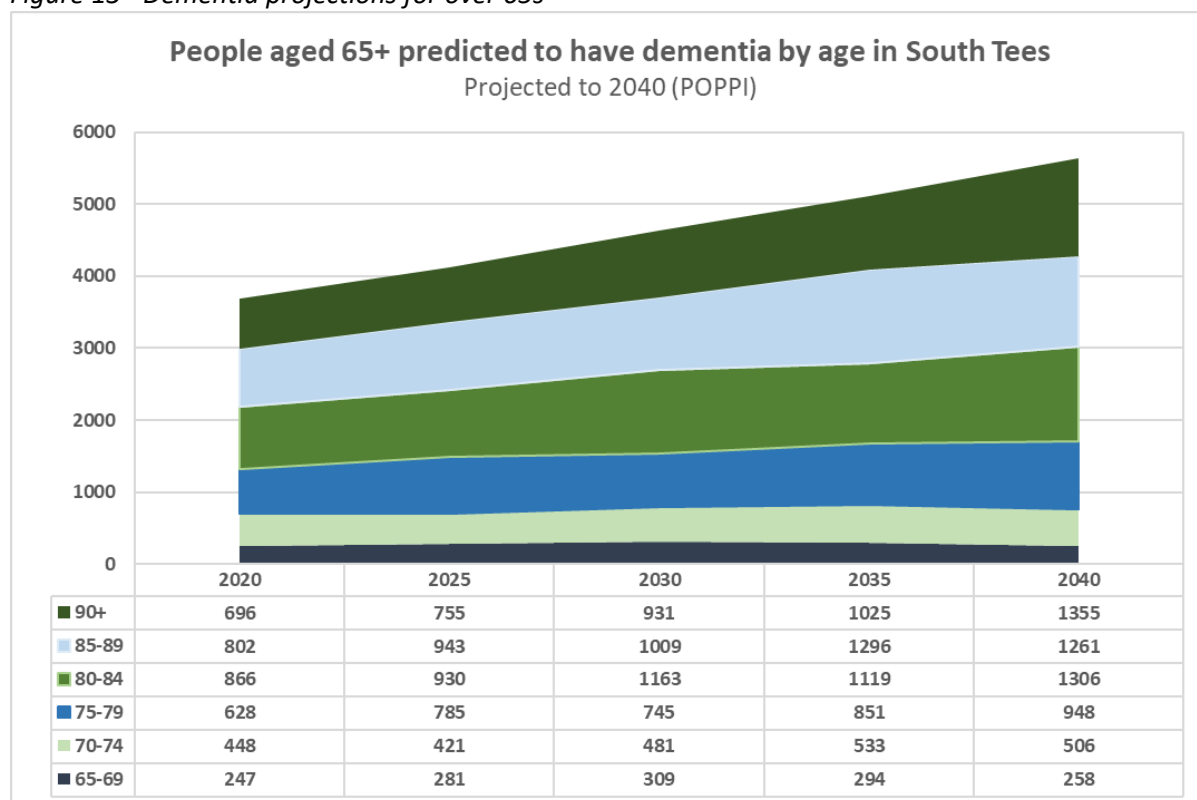
Both areas need to monitor and support the ongoing implementation of NHS Health checks which could help to improve an earlier diagnosis of dementia or motivate people to adopt a healthy lifestyle, to reduce their risk of developing dementia.

Screening processes for clinics serving long-term conditions that are risk factors for dementia may be beneficial. This does not have to be time-intensive – it could involve simply asking people about concerns with their memory or cognition or using a short cognitive test.

4.2 Dementia Projections

Estimated dementia prevalence projections show that in South Tees there will be a 53% increase in prevalence from 3,685 in 2020 to 5,634 by 2040. This prevalence rate projection increases with age with only a 4% increase in the 65-69 age cohort compared to a 95% increase in the 90+ age cohort.

Figure 13 - Dementia projections for over 65s



Source – POPPI

4.3 Dementia Care Plan Reviews

The time after diagnosis can be a very difficult and emotional time for people newly diagnosed with dementia and responses vary across the spectrum from denial to a desire to know and understand everything about dementia. Therefore, people working in services need to understand that people respond to diagnosis in varied ways and post diagnostic support must be person centred to each individual as opposed to a standard pathway. This means accessing post-diagnosis support in a timely way, which fits the individual needs of the person with dementia and their carer.

Post-diagnosis reviews should also be undertaken at intervals and in ways which reflect the individual needs of the patient. To ensure the maximisation of benefits for the person with dementia and their carer, the review should be meaningful, holistic in approach with actions and outcomes being clearly recorded in the care and support plan.

Personalised care and support planning (PCSP) should take place as soon as possible after diagnosis (irrespective of where that happens) and the frequency of reviews should be responsive to the needs of all individuals diagnosed with dementia. It is important that a review date is set when the initial care plan is agreed. As a minimum, the plan should be reviewed annually, and any reviews should always be with the person living with dementia and their family and carers to reflect changes in needs and wishes.

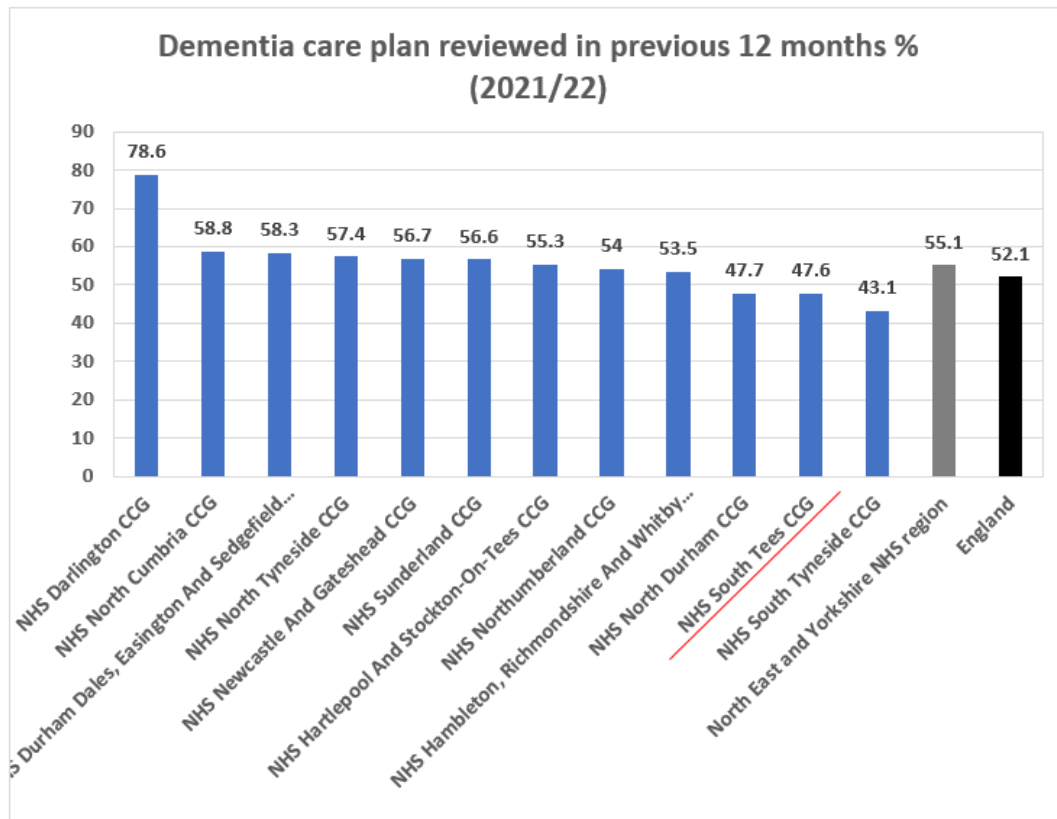
Face-to-face reviews are recommended as this allows primary care practitioners to fully assess the changing needs of people with dementia and their carers and ensure that coordination between health and social services is achieved.¹³

The NICE quality outcomes framework indicator (NM107) measures the percentage of people with dementia who have an annual face-to-face review of their care plan with an aim to encourage the coordinated delivery of health and social care services for people with dementia. Care plans should be agreed with health and social services for people who have dementia and there should be formal reviews at agreed frequencies. Regular reviews are important because the needs of a person with dementia and their carers may change over time. A 12-month timeframe has been selected for this indicator in line with the frequency for review of social care plans recommended by the Department of Health in the report – Prioritising need in the context of Putting People First (2010)

Any member of primary care staff with the necessary competencies should complete a PCSP with the person living with dementia, and their carer if the person gives consent or if they lack capacity, in accordance with the Mental Capacity Act Code of Practice. Dementia Advisors are ideally placed to establish the initial development of a personalised care plan, which could then be augmented by GPs. Also, if appropriate training can be provided, other members of the practice team could progress the initial formulation.

Data from 2021/22 shows that in South Tees CCG area, only 47.6% of dementia patients had their care plan reviewed in the previous 12 months. This is lower than the national average of 52.1% and significantly lower than the regional average of 55.1%.

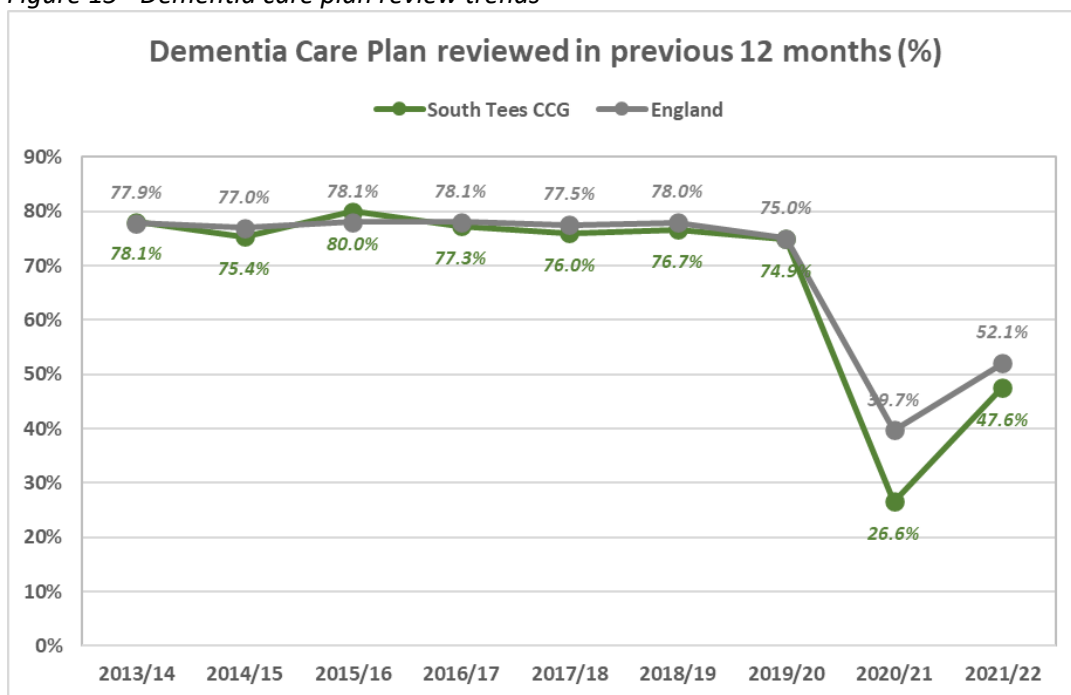
Figure 14 - Dementia care plan reviews



Source – Fingertips, OHID

Trends shown in figure 15 below highlight that review rates locally were in line with England before a significant reduction due to the Covid-19 pandemic, which affected local rates more than England reductions. Rates increased the following year but are far short of pre pandemic levels.

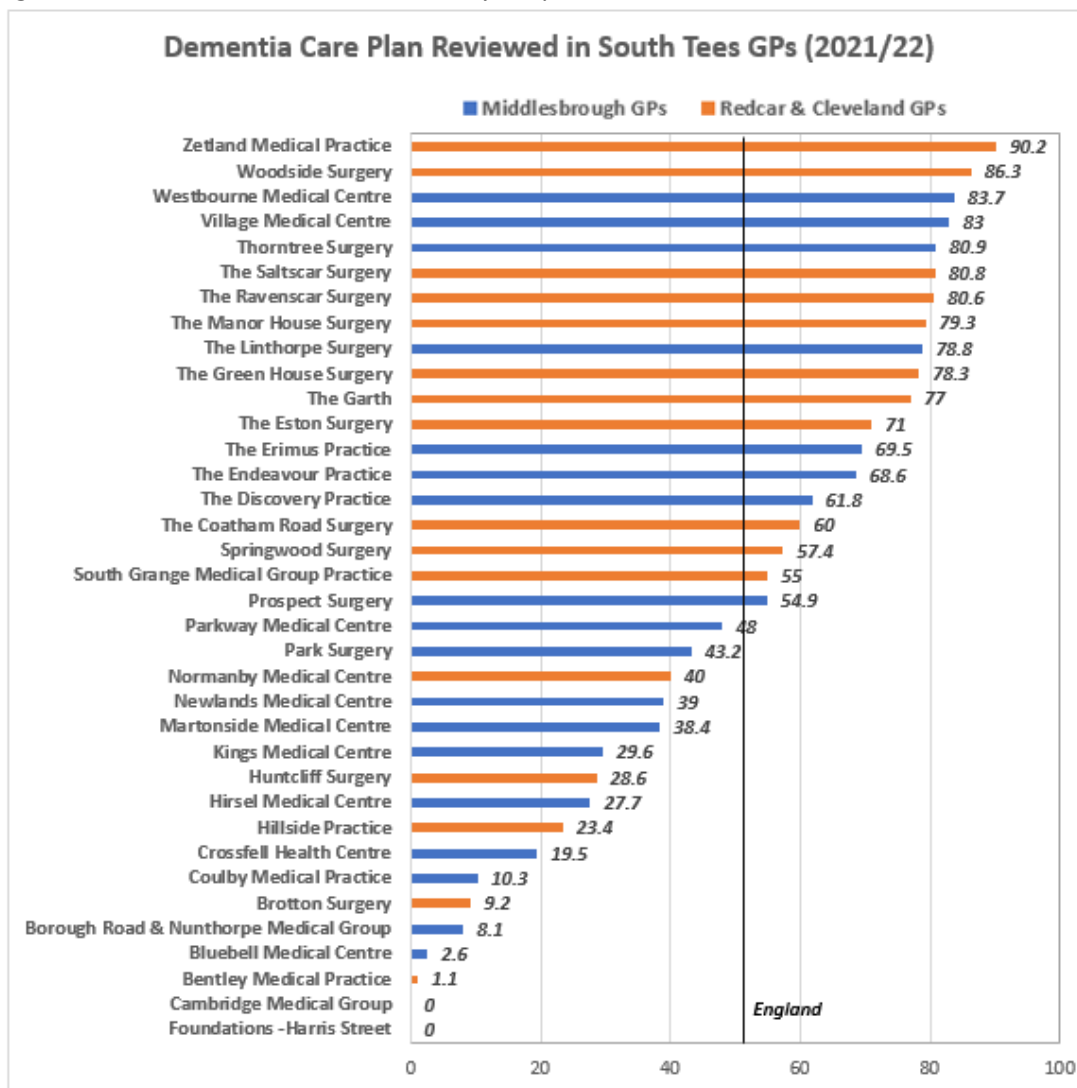
Figure 15 - Dementia care plan review trends



Source – Fingertips, OHID

Data by GP practice across South Tees shows significant variation in dementia patients having their care plan reviewed in the previous 12 months. Two practices in the area are above 85% whilst there are 12 practices with rates below the minimum QOF threshold of 35%. There is no significant link between deprivation levels and proportion of patients with dementia who have received reviews within Tees Valley. Women with dementia are more likely to have received a review (58.2%) than men (55.7%). Patients in care homes were more likely to have received a review (66.1%) than those in their own homes (51%). Also, there was no significant difference between practices operating EMIS and SystemOne IT systems.

Figure 16 - Dementia Care Plan reviews by GP practice



Source – Fingertips, OHID

Personalised Care and Support planning is a priority for NHS England and plays a vital role in improving the quality of mental health and dementia services. PCSP is a crucial element in delivering improved care for all people living with dementia and supporting their families and carers. This includes a series of facilitated conversations in which the person, or those who know them well, actively participates to explore the management of their health and well-being within the context of their whole life and family situation.

The process recognises the person's skills and strengths, as well as their experiences and the things that matter to them most. It addresses the things that are not working in the person's life and identifies outcomes and actions to resolve these.

PSCP has been brought into sharp focus through the CCG Improvement and Assessment Framework which includes indicators for dementia diagnosis and post diagnostic support.¹⁴

Improved personalised care and support planning in dementia services will be achieved by:

- supporting a standardised approach reducing unwarranted local variation in process or outcomes.
- promoting equality and tackling health inequalities.
- ensuring alignment with relevant cross condition care plans such as diabetes; and
- drawing on examples of good practice around the country.

Services need to work with individuals to discuss and record information in a way that is accessible to the patient, using a language that is recognised. This could involve the use of advocacy services, interpretation and translation services, peer support, or the provision of information in alternative formats, such as easy-read, pictorial, or audio. Where individuals have a disability, impairment or sensory loss, NHS organisations are legally required to follow the accessible information standard and provide information that can be easily read or understood, and to support individuals in communicating with services.

Advance care planning means people thinking about, discussing and recording their wishes and decisions for future care. It is about people planning for a time when they may not be able to make some decisions themselves, such as what happens if or when capacity is impaired, wishes regarding care and treatment in the later stages of dementia, including preferred place of death, and whether the patient wishes to discuss an advance care plan for end-of-life issues.¹⁵

It is important that there is a person who is responsible for co-ordinating all aspects of health and social care. Whilst this person is not necessarily responsible for the delivery of all aspects of the care and support plan, someone needs an overview to ensure that services and care are delivered in a co-ordinated and timely manner, without duplication. This ensures that the person living with dementia or the person's family have the security of knowing who to contact and stops people having to constantly repeat their history and care needs.

See Item 6 for Healthwatch report 'have your say' on Care Plan reviews.

4.4 Person Centred Care for Dementia

Person-centred care is a philosophy of care built around the needs of the individual and contingent upon knowing the person through an interpersonal relationship. It challenges the traditional medical model of care that tends to focus on processes, schedules, and staff and organisational needs. It requires commitment from everyone within the organisation, especially leadership. Whether referred to as "person-directed," "resident-focused" or something similar, the core principles are essentially the same.¹⁶

Person-centered care is essential to good dementia care and the underlying philosophy of the 2018 Alzheimer's Association Dementia Care Practice Recommendations.

Figure 17 - illustrates the goals of quality dementia care.



Source: - Alzheimer's Association Dementia Care Practice Recommendations

The Dementia Care Practice Recommendations were developed based on a comprehensive review of current evidence, best practice, and expert opinion, to better define quality care across all care settings and throughout the disease course. They are intended for professional care providers who work with individuals living with dementia and their families in long-term and community-based care settings. Person-centred focus is the core of quality care.

Evidence from studies shared by Kitwood and Bredin (1992) suggested that dementia does not universally progress in a linear fashion, and most importantly, it varies from person to person. The person with dementia is in a state of relative well-being or ill-being, and indicators can be observed through detailed observation. The studies found a need for high-quality interpersonal care that affirms personhood, recognition, respect, and trust.

Kitwood founded the Bradford Dementia Group, University of Bradford, in 1992. He firmly believed that viewing people with dementia in purely medical terms, leads them to be seen as objects and as having no subjectivity or personhood. His specific ideas relating to person-centred care developed positive approaches to people with dementia.

Kitwood identified a number of fundamental psychological and social human needs. He argued that these human needs have to be met for us all, in order to maintain a good sense of well-being. He developed the idea of person-centred care.

Figure 18 - Flower of emotional needs



Source: Reflections (voluntary service, set up by husband and wife, Peter and Janet Ley in July 2016)

In his work, Kitwood emphasized six psychological needs that are essential to all people:

- **Love:** unconditional acceptance and empathy.
- **Comfort:** the person needs security, warmth, and proximity.
- **Identity:** is connected to know who one is and has a connection with the past.
- **Affiliation:** linking ties, relationships with others. To experience confidence and trust in the relationship, so that you have someone to go to in difficult situations.
- **Meaningful employment:** to participate in your own life in such a way that you use your abilities, strength, and experience. That you are needed and that you have something to do.
- **Inclusion:** Being part of a social community and feeling accepted.

Kitwood argues that all people with dementia need support to meet these universal needs.¹⁷

Brooker et al outlined four key components suggesting that these are integral to a person-centered care approach for people with dementia, which can result in a shift in practice and culture. These components are:

- valuing and respecting persons with dementia and those who care for them.
- treating people with dementia as individuals with unique needs.
- seeing the world from the perspective of the person with dementia, so as to understand the person's behaviour and what is being communicated, and validating the subjective experience that is being perceived as the reality of the individual; and
- creating a positive social environment in which the person with dementia can experience relative well-being through care that promotes the building of relationships.¹⁸

Early

Julie has always been an independent woman. Although she was diagnosed with Alzheimer’s disease, she wants to remain as independent as possible. She goes through her day as she always did, although her husband Alan is always there for support if needed. Alan sometimes needs to assist Julie with a task, help with finding the right word, or give a friendly reminder. Alan always includes Julie in decisions, including treatments, future care, and finances.

Middle

Frank was a professional musician and played at all of the local and regional clubs. Since he played late night gigs, he was used to staying up late each night as well as sleeping late each morning. When Frank’s care needs became too much for his wife, she looked for a memory care center that would support his lifelong schedule. In his new home, Frank stays up late in his room, listening to old records. Staff let him wake on his own each morning and include that information in his care plan. Since there is a piano in the reception area, Frank often plays for other residents and visitors.

Late

Emily was an avid gardener. Her garden was perfectly kept with many varieties of plants, which she grew from seed. She loved fragrant bushes, especially lavender. One side of her yard was filled with beautiful bushes. Throughout the progression, she stayed involved in gardening. In the later stage of the Alzheimer’s disease, care providers looked through seed catalogues with her, and talked about different varieties. They kept fragrant cut flowers and plants in her room, especially lavender when available. They kept a small satchel of dried lavender under her pillow, and also used a nice lavender lotion to moisturize her hands and feet.

The person with dementia should always be treated as an individual, regardless of the stage of the disease, and care should be individually tailored to their unique needs, interests, or habits.

The Alzheimer Society developed a framework around person-centred care for Care homes. The hope is that the framework will influence the culture of care homes to encourage care home staff to recognise the individuality of people with dementia in the following ways:

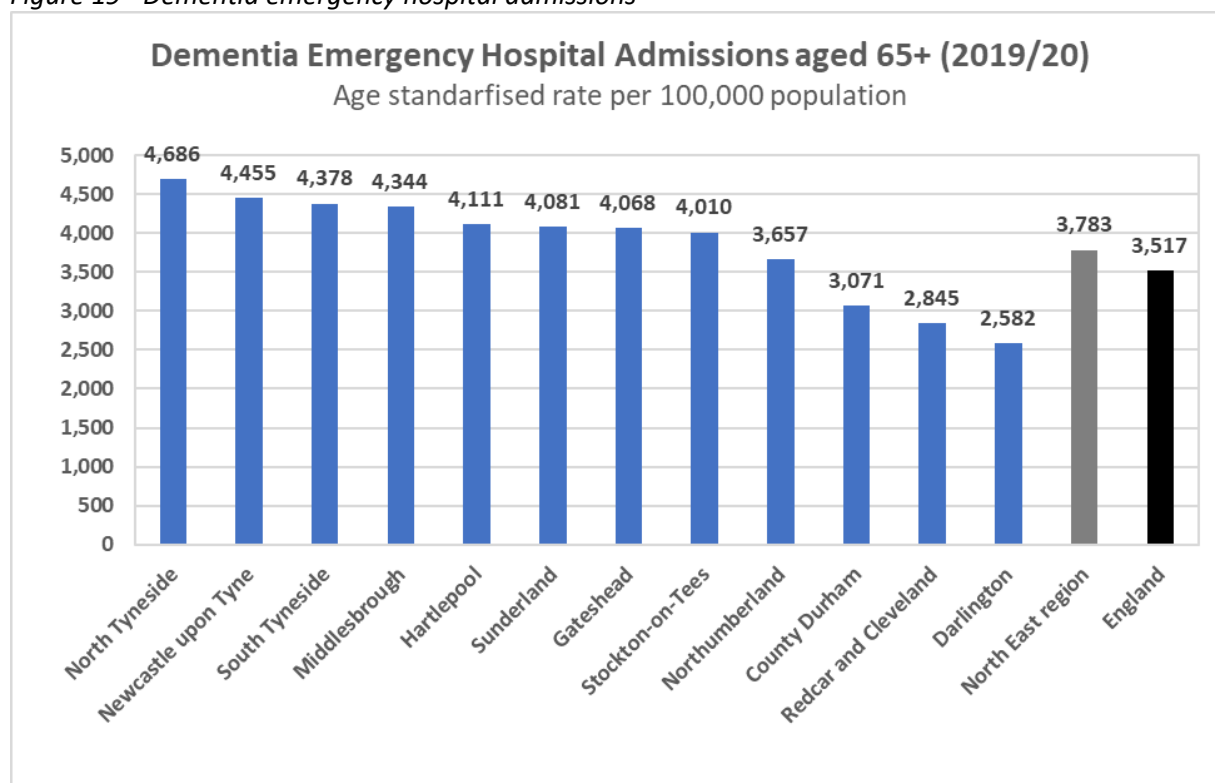
- Ensure that people who work in care homes understand what a person-centred philosophy of care means and are able to practice it.
- Make sure that relationships and interactions with people with dementia are respectful.
- Focus on maintaining, supporting, and/or restoring the independence of the person living with dementia.
- Develop strong bonds with family members of people with dementia and engage them in activities whenever possible.
- Provide quality care to all residents with dementia regardless of their cultural background, age, or mental ability.
- Anticipate the needs and reactions of people with dementia and adjust individual, social, and environmental factors to reduce negative behaviours.
- Encourage and support persons with dementia to make choices in keeping with the person’s lifelong values, preferences, and interests.

<https://alzheimer.ca/en/help-support/im-healthcare-provider/providing-person-centred-care>

4.5 Dementia Admissions

People living with dementia often experience longer hospital stays thus resulting in increased time in leaving hospital. Figure 19 below shows the rate of emergency admissions for dementia in over 65s for local authorities in the Northeast. There was a total of 1,865 admissions in South Tees during 2019/20. As a rate Middlesbrough had higher admissions in 2019/20 compared to England with 4,344 per 100,000 compared to 3,783 in England. Redcar & Cleveland admission rate was significantly lower at 2,845 per 100,000. National research estimates that two thirds of emergency admissions for people living with dementia are avoidable with appropriate care and support, for example admissions due to infections, falls and dehydration¹⁹.

Figure 19 - Dementia emergency hospital admissions



Source – Fingertips, OHID

Data provided by South Tees NHS Foundation Trust business intelligence team shows the number and rate of dementia emergency admissions for a period between April 2022 and September 2023. Figure 20 below shows these admissions by Middlesbrough and Redcar & Cleveland wards, with the tables ordered by the wards with the largest proportion of the population who are aged 65 years and over. Some wards have higher rates against total admissions and against population such as Stainton & Thornton that has 20% of the population aged 65+ and in Redcar & Cleveland Saltburn ward has a high rate of emergency admissions for dementia however this has an older population at 31% over 65 years old.

Figure 20 - Dementia emergency hospital admissions

Middlesbrough Wards	Emergency Admissions with Dementia					Redcar & Cleveland Wards	Emergency Admissions with Dementia				
	Total Pop	Pop 65+	No.	Rate/1,000 all admissions	Rate/ 1,000 population		Total Pop	Pop 65+	No.	Rate/1,000 all admission	Rate/ 1,000 populatio
Kader	4,807	31%	33	37.8	6.9	St Germain's	6,597	32%	69	60.6	10.5
Nunthorpe	5,331	26%	75	96.2	14.1	Saltburn	6,437	31%	185	162.7	28.7
Marton West	5,350	26%	32	45.8	6.0	Hutton	6,706	30%	75	73.2	11.2
Coulby Newham	8,338	22%	152	105.0	18.2	Longbeck	3,979	30%	22	39.4	5.5
Trimdon	6,300	22%	25	30.5	4.0	Teesville	5,995	27%	49	42.3	8.2
Marton East	6,063	21%	18	24.7	3.0	Belmont	4,528	27%	38	68.6	8.4
Hemlington	6,572	20%	30	26.1	4.6	Guisborough	7,638	26%	138	89.8	18.1
Stainton & Thornton	3,652	20%	146	202.2	40.0	Lockwood	2,329	26%	10	24.9	4.3
Acklam	5,899	20%	17	22.4	2.9	Ormesby	6,463	26%	34	33.3	5.3
Ladgate	5,508	19%	47	44.9	8.5	West Dyke	5,952	25%	34	35.5	5.7
Park End & Beckfield	8,334	18%	70	39.5	8.4	Normanby	6,613	25%	31	29.1	4.7
Linthorpe	6,703	17%	71	68.0	10.6	Zetland	4,369	24%	58	81.2	13.3
Park	9,589	15%	50	29.4	5.2	Loftus	6,356	24%	53	55.2	8.3
Longlands & Beechwood	11,226	14%	182	74.9	16.2	Kirkleatham	7,571	23%	159	97.7	21.0
Ayresome	6,301	14%	20	19.9	3.2	Brotton	6,847	23%	34	32.0	5.0
North Ormesby	3,264	14%	38	60.4	11.6	Coatham	4,836	22%	140	122.2	28.9
Berwick Hills & Pallister	9,057	12%	132	69.9	14.6	Skelton West	4,453	21%	11	19.3	2.5
Brambles & Thorntree	9,315	12%	76	40.5	8.2	Eston	7,419	20%	120	71.1	16.2
Newport	10,771	9%	76	44.0	7.1	Skelton East	4,387	20%	22	33.3	5.0
Central	11,490	8%	79	42.4	6.9	Dormanstown	4,643	19%	16	18.4	3.4
						Newcomen	5,137	18%	35	40.3	6.8
						South Bank	5,431	14%	25	28.0	4.6
						Grangetown	6,388	12%	16	15.8	2.5
						Wheatlands	5,440	11%	19	36.5	3.5

Source – South Tees NHS Foundation Trust business intelligence team

Hospital admission can trigger distress, confusion, and delirium for someone with dementia and can contribute to a decline in functioning and a reduced ability to return home to independent living. Over recent years there have been a range of initiatives on improving the experience and outcomes of hospital care for people with dementia, such as the National Dementia Action Alliance and Dementia Friendly Hospitals Charter. [Dementia Action Alliance Hospital Charter](#)

NICE guideline [NG27] covers the transition between inpatient hospital settings and community or care homes for adults with social care needs. It aims to improve people's experience of admission to, and discharge from, hospital by better coordination of health and social care services.

The guideline includes recommendations on:

- person-centred care and communication and information sharing
- before admission to hospital including developing a care plan and explaining what type of care the person might receive
- admission to hospital including the establishment of a hospital-based multi-disciplinary team.
- during hospital stay including recording medicines and assessments and regularly reviewing and updating the person's progress towards discharge
- discharge from hospital including the role of the discharge coordinator.
- supporting infrastructure/
- training and development for people involved in the hospital discharge process.

5. What are we doing already in relation to this goal?

A consultation workshop held in July 2023 at Inspire to Learn in Redcar and Cleveland, included over 40 professionals including ICB leads, NHS Clinical Leads and other representatives from Statutory and Voluntary Community Organisations, to share their expertise, knowledge, and experience in relation to the JSNA goals including the goal – we want to ensure our communities are Dementia Friendly, with a focus on the below questions.

A summary of the table discussions and further reflections are included below.

- What partnerships, programmes and projects are in place in relation to this goal and what is the focus of their work?
- What services (including commissioned services) are in place to address local needs in relation to this goal?
- What are older people's experiences in relation to this goal?
- What are the key recommendations in relation to this goal?

5.1 What partnerships, programmes and projects are in place in relation to this goal and what is the focus of their work?

Tees Esk and Wear Valley Trust (TEWVT) collaborated with local Primary Care Networks (PCN's) to trial new ways of working to improve dementia referrals. TEWV staff were given access to system one by the GP practice to allow them to complete the dementia assessment and diagnosis on the GP system allowing for a smooth flow of information between the two services. The benefits to the patient will be that they can be seen in a familiar environment, at their GP surgery, the GP would not have to complete a referral form, instead they would be able to note the patient consultation on system one recommending a memory clinic assessment. This would then go to the TEWV practitioner to pick up and arrange an assessment.

This work was a pilot in 2019 working alongside Redcar and Cleveland GP practices. The aim was to prevent referral into memory clinic by seeking out those patients who may be diagnosed within primary care, for example those who may already have a diagnosis of a mild cognitive impairment and had noticed decline since this diagnosis, or those in care homes with a clear history of decline in cognition and function.

This pilot identified that this did not significantly reduce the referrals to memory services, so this pilot was not rolled out in Middlesbrough. However, the PCN nurses remain in GP practices, and they have been working alongside this service to reduce inappropriate referrals with the aim of reducing waiting times. For example, patients presenting at GP practices with an active delirium where 'confusion' symptoms which may mimic dementia are present but where appropriate treatment of cause of delirium may be the best course of action. Furthermore, they are working alongside PCNs to consider functional mental health causes of memory difficulty for example depression, anxiety, or trauma and to improve awareness of the impact that this may have on cognition and promote signposting to appropriate services.

Middlesbrough Dementia Network

The Middlesbrough Dementia Network was established in 2016 to bring together a Partnership of Agencies and Organisations all working together to improve outcomes for people living with Dementia and Carers in Middlesbrough including: -

- Providing a multi-agency forum, which works collaboratively to achieve a shared vision for supporting people living with Dementia in Middlesbrough, to live as well as possible.
- Develop and mobilise a highly accessible, relevant, and valued wellbeing offer for people living with dementia and Carers in Middlesbrough.
- Deliver high quality and sustainable outcomes for people living with dementia across the NHS well pathway for dementia (as outlined below).
- Continuously seek improvement and pioneer innovation across all Agencies and Stakeholders.

NHS Pathway for dementia

- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well

The network consistently and meaningfully seeks the voice of people living with dementia and Carers. This in practice means that ensuring that people living with Dementia and carers play an active role in the development, implementation, and review of the schemes of work initiated as part of the Networks remit.

Dementia Awareness Week

The Dementia Network coordinates a programme of activity in line with the Alzheimer's Society, 1-week National annual Campaign, which aims to promote local action to raise awareness of dementia and reduce the stigma, which in turn will help increase diagnosis rates.

Local action included information stalls with Services that support people with dementia committing to having a presence in local shopping centres and at an Older People Event at Middlesbrough Town Hall. This year 2023, the Alzheimer's Society as well as the Woodside Dementia Hub and Carers Together reported a rise in referrals, as a direct result of people accessing the information stands and being made aware of what services are available to them.

In Redcar and Cleveland, a wide range of social activities and information, advice and guidance community sessions took place throughout the week, in partnership with Dementia Action Teesside, Dementia Advisory Service and our local Admiral Nurse. Activities included, Redcar College students producing a large Wooden Forget Me Not, the symbol of dementia, to start conversations and awareness raising about the disease and what support is available (See appendix _for photos) A Dementia Dance, a Dementia Friendly cinema screening of Matilda, a Dementia Friendly walk and much more.

Many partners collaborated to raise awareness of support systems and services available in Redcar and Cleveland for people living with dementia and their carers so they can continue to access this beyond Dementia Awareness week. In addition, the week aimed to encourage individuals and their families to recognise symptoms and access support for an early diagnosis. The team spoke directly to 500 residents throughout the week and 11 referrals were made to the Admiral Nurse for further support.

Redcar and Cleveland Dementia Steering Group

The Redcar and Cleveland Steering group consists of members from the Alzheimer's Society, Age UK Teesside, local councillors, staff in public health, Local Authority Dementia Services Commissioners, social workers, MIND support workers, Healthwatch, domiciliary care services and social prescribers.

The aim of the group is to share good practice, join up resources for the best outcomes, and support each other to link with GPs, district nursing and community psychiatric services. Objectives include

identifying gaps in services and developing new ways of working to ensure the resources available in the area are used for the best outcomes and are inclusive for clients, carers, and families. The group has been working on a health and wellbeing passport for clients in the South Tees area to support clients and their loved ones on their health and social care journey.

Initiatives so far have seen links being forged with local care homes to form singing groups that are available for the community to attend. A local rugby club promotes indoor and outdoor sports and activities other than rugby. Services have been developed to support clients and their carers to visit different local pubs for tea on a Saturday. The groups and services are very much client driven, offering what people need to live well.

Director of Public Health Annual report (Dementia Friendly Middlesbrough)

Public Health continues to play a key role in Developing Dementia Friendly Services. The director of Public Health 2015/16 annual report on Dementia Friendly Middlesbrough which was positively received by people with dementia and carers and acknowledged by the Council Executive in September 2016. The report set out the scale of the problem locally, discussed preventable causes of dementia, early diagnosis and effective management and support of the condition, and explored what it means to create dementia friendly environments and how to support people with dementia to achieve a good death.

A recommendation of the report, was that a detailed dementia health needs assessment be undertaken to inform the development of a dementia strategy and action plan and Public Health appointed NWA Social Market and Research to assist in developing the needs assessment which would consider how Middlesbrough Council can:

- Ensure the patient and carer voice is at the heart of service planning.
- Ensure the needs of vulnerable groups are understood.
- Ensure better knowledge and awareness of dementia (to help tackle stigma and improve understanding)
- Strengthen working arrangements for the Dementia Collaborative AND
- Review future service planning, to take account of population projections and the impact dementia will have on the demand for health, social care, and other related services.

One of the key themes that emerged from the Needs Assessment was that a named place be set up, where people with Dementia and their carers could access advice and information in one place and in familiar surroundings.

Woodside Dementia and Wellbeing hub

In 2021 a Dementia and Wellbeing Hub in Middlesbrough was established through a collaboration with Public Health, Middlesbrough Council and TEWVT which acts as a first point of access for Dementia. The Hub is based at Woodside and the core function is to offer a 'one session' model whereby those people who are being referred for memory clinic assessment, can, where appropriate, be seen for relevant assessments and appointments in one day, allowing them to be assessed, diagnosed, and start treatment. However, the person can access the Hub as often as required and if the person is eligible for pharmacological support, then follow up appointments will be arranged. The Hub is occupied by a range of services including Staff from Tees Esk and Wear Valleys NHS Foundation Trust, Adult Social Care Staff, and voluntary sector organisations.

It is estimated that approximately 600 people in Middlesbrough with dementia are not yet known to health and social care services and through good marketing and promotion of the Dementia hub, it is hoped that this encourages people who are worried about their memory to seek advice and support

so they can get an early diagnosis. This enables the individual and their carers and family to have access to treatments that are available at the earliest opportunity as well as ensuring they receive holistic and coordinated care.

As well as providing information and advice, the hub provides a venue for a number of different organisations to work from including Carers Together Adult Social Care, Age UK Teesside Dementia Advisor Service, Alzheimer's Society, and other VCS Organisations. This model allows people living with dementia and their carers to access additional relevant services within the same venue or during the same visit and referrals or signposting to other services such as Carers Together for a carers assessment allows carers to get the help and support that they need to fulfil their caring role. The Hub also provides a full timetable of activities, assessments and one to one appointments.

A co-located services model meant that we would be looking to pull people into the hub for additional support, so it wouldn't just be the initial appointment and diagnostic, but also follow up sessions and Cognitive Stimulation Therapy sessions as well as regular support and social activities, including singing for the brain, games for the brain, dementia support groups, arts and crafts and intergenerational activities as well as training for Carers. These activities aim to reduce the isolation that is being experienced by carers and people living with dementia.

As the Hub is based alongside the memory clinic it helps to improve early diagnosis rates and effective management of dementia, increasing awareness of early diagnosis services and providing simpler and more consistent referral pathways, building strong relationships with GP practices and social prescribing leads, and building community resilience.

Woodside Memory Clinic

The Memory Clinic at Woodside Middlesbrough have been completing approximately 18 memory assessments per month and there is a wait list for initial assessment of 6 weeks. This is just over the target of 28 day for initial assessment and they are working on staffing establishments with the aim of bringing this wait down.

The Memory Clinic at Redcar and Cleveland (Reed March House) have had an average of 100 referrals per month and are carrying out approximately 18 memory assessments per week. There is currently a 10 week wait for an assessment.

Healthwatch South Tees Star Awards

On 19th April 2023, Staff from the Dementia Hub and Dementia Advisor Service were nominated and attended a Health Watch South Tees Star Award Event at Middlesbrough Football club and won the award for "Leading the Way to Change". This accolade demonstrated a collaboration of partners working together successfully to provide person-centered care for people living with dementia and their carers and supports a whole system approach to integrating care around the person as well as highlighting the passion and enthusiasm of the staff and the value of their work.

Dementia Friendly Care Home Guide

A Dementia Friendly Care Home Guide has been designed by Stockton Borough Council's Dementia Service Development Leads and with their endorsement Public Health has copied the guide and localised it for Middlesbrough and Redcar and Cleveland Care Homes.

The self-assessment tool in the guide is designed to help Care Homes improve their dementia offer through providing good quality accessible activities, examine and improve the physical environment to better meet the needs of their residents, improve leadership and management and identify any

workforce development and training needs. It is designed to help care homes to support, enable and empower residents to live well with dementia by undertaking actions to achieve positive outcomes, which can contribute to CQC regulations and registrations.

Dementia Community Services Guide

Public Health have produced an A3 interactive resource guide which includes services and support for people living with dementia and carers in Middlesbrough. This is to help professionals and the public to navigate where people can get help and support throughout the dementia journey, from awareness and risk reduction, diagnosis, future planning, and welfare advice as well as support for carers. Services guide can be access via. [www.middlesbrough.gov.uk/health and wellbeing /dementia](http://www.middlesbrough.gov.uk/health%20and%20wellbeing/dementia)

Carers Passport

The Middlesbrough Council Carers Staff network introduced a Carers Passport in 2022 to help employees achieve better work life balance but contributes to the Council being a flexible working employer, by meeting the expectations of a modern workplace.

The aim is to help create a supportive working culture where MBC employees feel that they can talk about their circumstances in a safe environment. The passport is a digital tool and is designed to enable a carer (paid or unpaid) and their manager to hold supportive conversations and open discussions. The passport can be completed by any employee who has caring responsibilities which they believe could have an impact on their ability to work currently or at some point in the future.

[Carers Passport Preparation Guide and the Carers Passport \(Form\)](#)

Carer Friendly GP Practices

Sue Lee from Teesside Mind, a primary care link worker, has worked tirelessly to promote the role of carers who care for a loved one with dementia. The aim is to help carers have better support in primary care as well as be able to identify themselves as an unpaid carer and utilise a range of services. Her work has also involved implementing the NHS Quality Mark for carers. This includes offering carer awareness sessions to all staff in GP surgeries and supporting staff who choose to become carer ambassadors.

We Care You Care

We Care You Care is designed to collate information, advice, and self-signposting for carers in Middlesbrough and Redcar and Cleveland and has included a dedicated page for information for dementia carers to access. [We Care You Care](#)

Carers Together

Carers together support all carers whatever their caring role, their situation, or their circumstances. This includes people who care for someone with memory problems and dementia.

Carers together can also provide carers assessment. This assessment gives carers an opportunity to talk about what they do to support the person they care for and how caring affects their lives, their health, work, finances, and relationships. It also helps identify further support needs and referrals to the local council or other support organisations.

Carers together also facilitate a wide range of activities for carers including Virtual Coffee Mornings, Quizzes, Singalongs and History Talks

[Carers Together](#)

South Tees Carers Forum

A South Tees Carers Forum has been established to work in Partnership to shape services offered to carers across the area to develop a South Tees Carers Strategy. Members include representatives from Middlesbrough Council, Redcar & Cleveland Borough Council and Carers and those representing Carers; voluntary and community sector organisations and infrastructure organisations (MVDA and RCVDA); public health; primary and acute care; education; business; and housing.

The Forum acts as an advisory body and the vision is to improve services, support, recognition, and outcomes for unpaid Carers of all ages and backgrounds in South Tees by working collaboratively and sharing expertise, learning and resources.

[South Tees Carers Forum](#)

Tees Esk and Wear Valley START Programme

TEWV work with a number of different VCS organisations across the Redcar & Cleveland to ensure that the people they see are linked into meaningful activities suitable for their needs. Support is offered to carers using the START programme and is managed by a psychologist and community nurses. The START programme has been created to support carers and family members in their role in caring for someone living with a dementia. The START programme helps carers and family members to improve their own well-being when caring is stressful.

Age UK Teesside

Age UK Teesside is an organisation working with and for older people developing and delivering services and activities in consultation with or response to the needs of people aged 50+ living in Hartlepool, Stockton, Middlesbrough, and Redcar & Cleveland. The aim is to promote well-being and independence, ensuring later life is a fulfilling and enjoyable experience for older people. Age UK Teesside's support, advice and care enables hundreds of older people across the area to live better, healthier, and happier lives.

Age UK Teesside is also leading the Dementia Advisory Services for both Middlesbrough and Redcar and Cleveland

[Age UK Teesside](#)

Middlesbrough Admiral Nurse Clinic Service

See Chapter 6 – 'what are the key issues?'

Herbert Protocol

The Herbert Protocol is a national scheme introduced by the police in partnership with other agencies to encourage carers to compile useful information which could be used to help locate a vulnerable person if they go missing.

The initiative is named after George Herbert, a war veteran of the Normandy landings, who lived with dementia. George Herbert died whilst 'missing', trying to find his childhood home.

John's Campaign

John Campaign Is a campaign for extended visiting rights for family carers of patients with dementia in hospitals in the United Kingdom, founded on 30 November 2014 by the writers Nicci Gerrard and Julia Jones. Behind its simple statement of purpose lies the belief that carers should not just be allowed but should be welcomed, and that a collaboration between the patients and all connected with them is crucial to their health and their well-being.

Dementia Health Passport

The Dementia Health Passport has been developed in collaboration with the Redcar and Cleveland Steering Group and is intended to provide professionals with information about the person with dementia as an individual. This will enhance the care and support given while the person is in an unfamiliar environment.

5.2 What service including commissioned services, are in place to address local needs in relation to this goal?

Dementia Diagnosis and Assessment Pathway

Tees Esk & Wear Valley (TEWV) work within the remits of the NICE Guidance clinical care pathway. Each patient is required to have some pre assessment checks with their designated GP prior to referral. This helps the memory clinic staff to rule out any other physical or psychological causes of the cognitive decline prior to the assessment taking place. Once the pre referral checks have been completed, each person is then seen for an assessment.

Once a working diagnosis has been made the person is then offered pharmacological interventions of non-pharmacological interventions as per their diagnosis. Non-pharmacological interventions are delivered in a group setting or as 1:1 session in the person's own home.

If the person commences on a shared care medication, then they will be issued three prescriptions and follow up appointments by TEWV before being discharged back to their GP. The non-pharmacological route is similar but more flexible due to the nature of the 1:1 sessions and the person's needs at the time of the visit. Any person with an assessed risk or high level of need or complexity will be taken on to the community nurse caseload for support and intervention as required.

Middlesbrough Dementia Advisor Service

Middlesbrough Council commissions a Dementia Advisor Service which is led by Age UK Teesside. The Staff and Services are based at the Dementia and Wellbeing Hub and support the smooth running of activities delivered there as well its own service offer including.

- Support groups for people living with Dementia.
- Support groups for Carers
- Welfare benefits advice
- Lasting Power of Attorney/Deputyship
- Maintenance Cognitive Stimulation Therapy

The service also offers drop-in advice sessions to those who have a diagnosis of Dementia and their Carers. The sessions are designed to offer as much practical advice and support as needed through Dementia Advisors. The also refer and signpost to other organisations or those within Age UK Teesside where required.

The service actively engages with initiatives such as the Dementia Steering Group and Age Friendly Steering Group, to ensure the needs of people living with dementia and their Carers, are represented, and heard.

Since April 2023, the DAS has been receiving around 25 referrals per quarter and are working with an average caseload of 100 people who either have a dementia diagnosis or are awaiting a memory assessment or other clinical intervention. Staff have undertaken around 12-25 home visits per quarter and have delivered between 40 – 70 community-based support sessions per quarter. An average of 400 clients and carers have been accessing inclusive group and peer support activities at the hub, these are either delivered directly by the DAS or external VCS organisations, who are timetabled into delivering activities at the Hub.

Redcar and Cleveland Dementia Advisor Service

Redcar and Cleveland Borough Council also commissions a Dementia Advisor Service which is led by Age UK Teesside

The overarching aim of the Dementia Advisory Outreach Service (DAOS) is to provide quality dementia support for Adults and their Carers and families through the life-course of living with dementia. It delivers practical support for adults living day to day with dementia, who are newly diagnosed or awaiting diagnosis.

The service operates an outreach service across the Borough and delivers support from various venues in the community, including residents' homes, community venues and Reed Marsh House, which is the memory clinic.

The service collaborates with other health and care professionals, initiating, developing, and maintaining effective working relationships with other local professionals working in the field of dementia. The service collaborates with the voluntary, statutory, and private sectors, to maximise the outcome for the adult living with dementia and their Carers, at the earliest opportunity, through signposting and joint working agreements.

The service actively engages with initiatives such as the Dementia Steering Group, South Tees Carers Forum and Redcar and Cleveland Borough Wellbeing Network, to ensure the needs of people living with dementia and their Carers, are represented, and heard.

The current Dementia Advisory Service had over 142 referrals in the first 9 months of its operation and over 50% were contacted within 2 days. The current service carried an ongoing active case load of 70 adults per month.

Dementia Friendly South Tees Programme

Given the high profile that Middlesbrough has for being a dementia friendly town, key to its success is the Dementia Friendly South Tees Programme. This Project has been commissioned by Middlesbrough Council (Public Health South Tees) since 2016 and now have a joint contract with Redcar and Cleveland Council Adult Social Care and Dementia Action Teesside, who successfully deliver the Dementia Friendly South Tees Programme.

Dementia Action Teesside have worked with over 400 Businesses across Middlesbrough and Redcar Cleveland since 2016 and have supported them to become dementia Friendly as well as create thousands of Dementia Friends which includes Staff in all the registered Businesses and Organisations as well as hundreds of Health Social Care Students at Middlesbrough and Redcar and Cleveland College. Figure 21 below shows the number of Dementia friendly Businesses that were signed up in quarter 3 in 2023.

Figure 21 - Dementia friendly Businesses

	BUSINESS	DFC
1	Amala Wellness CIC	Redcar
2	Amala Wellness CIC	Middlesbrough
3	ARCH Teesside	Middlesbrough
4	ARCH Teesside	Redcar
5	Cleveland Housing Advice Centre CHAC	Middlesbrough
6	Daisy Mae's Tea Room	Redcar
7	Eva Women's Aid	Redcar
8	Flatts Lane Woodland Country Park	Redcar
9	Lockforce Locksmiths	Middlesbrough
10	Lockforce Locksmiths	Redcar
11	Middlesbrough College	Middlesbrough
12	PC Tech Repairs Normanby	Middlesbrough

Source Dementia Action Teesside

Dementia Action Teesside also offers reminiscences through music sessions as well as regular dementia friendly dances in a number of locations across the Middlesbrough and Redcar and Cleveland areas as well as a range of other dementia friendly activities.

Pubtastics and Weekenders

Pubtastics and Weekenders are peer and social support groups for carers and their loved ones living with dementia and were set up in collaboration with the Specialist Admiral Nurse and Dementia Action Teesside project lead, due to lack of services and support on an evening and weekend.

The figure 22 below shows the number of attendances at the various activities facilitated by Dementia Action Teesside and wider partners.

From July – September 2023 (Quarter 2) this year there were 718 attendances.

Figure 22 - Quarter 2 figures for attendees at dementia activities

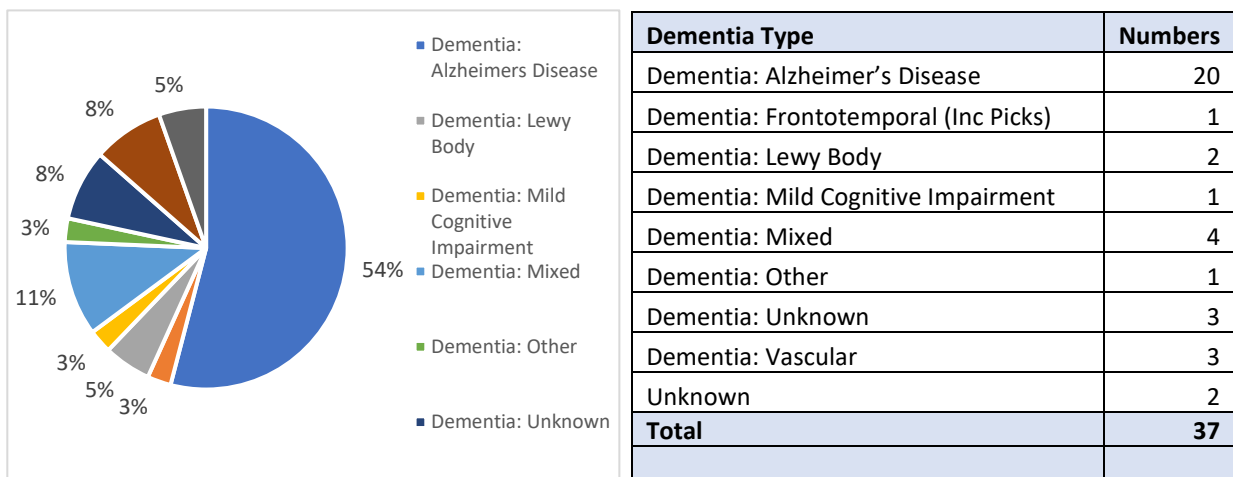
Event	No of people registered	Activities/ Dances	Attendances
Acklam Green	58	10	372
Kirkleatham Museum	0	0	0
Memorial Hall	39	10	232
Redcar College	25	1	25
MFC Legends Lounge	50	2	75
Pubtastics	17	3	29
Weekenders	30	3	36
TOTALS	219	29	718

Source: Dementia Action Teesside

- There has been a **23% increase** in people living with dementia attending activities compared to the same quarter in Year 1.
- There were **37 individuals living with dementia** attending dances and other activities under the programme this quarter.

- 35% of those living with dementia resided in Middlesbrough and 46% reside in Redcar & Cleveland.
The remaining 16% are from Stockton on Tees or outside Teesside – 3% (N Yorks).
- **13.5% of participants are living with Young Onset Dementia** (i.e., under the age of 65).
- Alzheimers Disease is the most prevalent type of dementia amongst the participants (54%)
- **70% of participants live at home with their partner.**
- **8% are veterans.**

Figure 23 - types of dementia recorded for activity participants.



Source: Dementia Action Teesside

The below case study demonstrates that services and staff are willing to flex and adapt to the needs of the participants, so the activities are accessible regardless of condition or circumstances.

Case example of a participant of a Dementia Friendly Activity

David (62) lives in the Marske area and is supported by paid carers who accompany him to the dementia friendly dances and the Weekenders and is a keen ukelele player, often accompanied by his house mate.

We knew David would love the Music for the Mind sessions at Middlesbrough Cathedral but despite best efforts had been unable to go, usually because of a clash with essential health appointments. We advised his carer that the sessions are live streamed and this has opened up the opportunity to watch live or watch previously recorded sessions and join in with his Ukelele.

Both David and his house mate are regular attendees of Music for the Mind ...online !!

Source: Dementia Action Teesside

[Dementia Friendly South Tees Programme](#)

Everyone is Friendly

Dementia Action Teesside joined forces with Everyone is Active in Redcar to provide a selection of weekly activities to those who are living with Dementia with a view to keeping everyone physically fit and active, reduce social isolation and loneliness and promote wellbeing. Those that attend can try various activities including badminton and skittles, take part in a weekly quiz and look at memorabilia.

The Alzheimer's Society announced that the Middlesbrough and Redcar and Cleveland were the best performing Dementia Friendly Communities in England and Wales and had supported the highest level

of businesses and organisations. From June to December 2022, 58 businesses and organisations had registered their pledges with the Alzheimer’s Society out of 269 across England and Wales (22%).

GENS Support Group (Grangetown, Eston Normanby and Southbank)

The GENS group was set up by the Local Admiral Nurse in the PCN area due to lack of services and support. This was based on the meeting centre model of community dementia care (University of Worcester) and Hosted by Grangetown Generations

The Group is Supported by TEWV Dementia Hub Co-Ordinator and other local voluntary and charitable organisations. Offering general advice, support and information to the local people who live within the PCN and local area. It is for Carers and those living with a memory problem or dementia.

Dementia Friends

Middlesbrough and Redcar and Cleveland currently have 9 active dementia friendly trained ambassadors who collectively have delivered 1,296 dementia friends awareness sessions since 2016, creating over 21,000 dementia friends across both areas. Figure 24 below shows the number of dementia friends created and sessions delivered by dementia friendly ambassadors from 2016 up to November 2023

Figure 24 number of dementia friends created, and sessions delivered.

Middlesbrough		Redcar and Cleveland	
Type	Total	Type	Total
Dementia Friends Ambassadors	5	Dementia Friends Ambassadors	4
Completed F2F Sessions	782	Completed F2F Sessions	497
Private Virtual Sessions (DF Ambassador's postcode)	14	Private Virtual Sessions (DF Ambassador's postcode)	3
Total Sessions	796	Total Sessions	500
Friends Reported at F2F Sessions	12,262	Friends Reported at F2F Sessions	6,203
Friends Reported at Public Virtual Sessions	29	Friends Reported at Public Virtual Sessions	11
Friends Reported at Private Virtual Sessions	211	Friends Reported at Private Virtual Sessions	13
Digital Friends	1,108	Digital Friends	1,217
Total Friends	13,610	Total Friends	7,444

Source: Alzheimer’s Society

Over 20 Middlesbrough Council elected members have also become dementia friends, by attending a 1-hour information and awareness session to help to raise the profile of Middlesbrough Council being a Dementia Friendly Town, raise awareness of the condition in the wards they represent to reduce stigma and get more people to seek advice if they are worried about their memory.

South Tees NHS Trust Dementia Lead

The South Tees NHS Trust appointed a Dementia lead nurse in March 2022 to scope out dementia care and models of service regionally and nationally, identify key areas of focus within South Tees Trust, as well as reviewing dementia training and education for internal staff.

North Ormesby Day Service

The North Ormesby Resource Centre provides a safe and secure environment where older people with differing needs can experience social, physical & psychological interactions. The day service provides a high-quality service that enables service users and their carers to live as independently and active as

possible. Dedicated staff treat everyone as individuals, meeting their individual needs through person centred care planning.

Lavan Dementia Day Care Services

Lavan Dementia Day care services has been established in Redcar and Cleveland to offer Weekend Gold standard specialist day care service for people living with dementia. The service also offers: -

- Independent clinical specialist advice,
- bespoke tailored training and education for care homes, health professionals and businesses
- Consultancy to care homes on CQC regulations and inspections.

Public Health Dementia Grants

In 2021 and 2022 Public Health and Middlesbrough Council launched a Dementia Friendly and Age Friendly small grant scheme to support activity aimed at ensuring Middlesbrough residents, including those living with dementia living in Middlesbrough have access to activities aimed at helping to improve their quality of life. Figure 25 below is the list of awarded Dementia Grants in 2022.

Figure 25 - 2022 Awarded Grants for Dementia Friendly Community Activity

Men's Shed Hero project	This project supported men's mental and physical health; the 'shedders' work on an allotment; gardening and building a part of a team. The project looks to work with 30 people in the borough who are currently living with a diagnosis of dementia, or memory loss and seeking a diagnosis; alongside 30 carers being offered the option to either attend the session with their loved one or use this time to have some well needed respite.
Friends of Marton Library	The friends are a group of volunteers who are very active in their local area, as well as volunteering in the library in order to keep it open. The aim of this funding was to provide multiple community activities aimed at all age groups including those with dementia and the elderly.
Dementia Action Teesside	Music for the mind session. To improve the quality of the life for the person with dementia, allowing the person to express their feelings through art, music, singing and dance.
Nuvo Wellbeing	The project included two dance and fitness (Seated Yoga) sessions over a twenty-week period, for members aged 50+ in Middlesbrough including those with dementia.
Grass Roots Music CIC	To continue the weekly dementia café at My Place Community Hub and Care homes.
Terry Doyle (sole trader)	Empowering Carer's of adults living with Dementia to have greater resilience and wellbeing.
Middlesbrough Football Club	This project is to create memory room experiences for people in Middlesbrough who are living with dementia. It uses the unique power of football and Middlesbrough Football Club to engage people with dementia through memorabilia and stories, to trigger the participants own memories of the games and the town.
TVCA	The project supported older people (Over 60's), and people living with Dementia, offering weekly social sessions every Thursday at Hemlington Lake Recreation Centre. Sessions include a reduced-price hot meal, followed by bingo and occasionally, live music

Source – Public Health/ MBC Small Grants Fund

6. What are the key issues?

There is currently no Dementia Collaborative in place to provide strategic direction on specific priorities in respect of dementia. The South Tees Collaborative disbanded in 2016 and a proposal was submitted via the CCG to the better care fund to re-establish the collaborative, which was declined and to date no other strategic forum for dementia across South Tees has been set up.

Figure 26 below shows the aims of the collaborative, which was to improve the quality of care and outcomes for people living with dementia and their families and carers. Some of the underpinning principles of the work of the collaborative were to: -

- Reduce emergency admissions
- Reduce emergency re-admissions
- Reduce delayed discharges from hospitals
- Reduce admissions to permanent residential care.

Figure 26 - South Tees Dementia Collaborative Strategy

SOUTH TEES DEMENTIA COLLABORATIVE STRATEGY					
VISION	Improving the quality of care and outcomes for people living with dementia, their carers and their families				
AIMS	Preventing Well Minimise risk of people developing dementia. There will be good access to information about dementia and memory loss and where to seek help when needed	Diagnosing Well There will be prompt diagnosis/referral to specialist services where necessary and provision of appropriate information and advice	Living Well People with dementia and their families will be listened to and <u>person centred</u> integrated care will be delivered	Supported Well Services will be provided to people with dementia to enable them to stay at home and be independent for as long as possible. A range of services will be available as more intensive support is required	Dying Well Support will be available to ensure that the requirements and wishes of individuals are respected and services address personal needs
PRIORITIES	<ul style="list-style-type: none"> • Review local dementia information and advice that is available to the general public/people with dementia/carers/families/primary and secondary healthcare/social care and independent sector (including areas such as maintaining healthy lifestyles / risk reduction) • Ensure appropriate, updated information is available for the above groups in different <u>formats</u> • Continue to support general initiatives that aim to promote awareness of dementia across health, social care, the independent sector and other appropriate <u>organisations</u> • Support ongoing development of Dementia Friendly Communities and Dementia Friends Training 	<ul style="list-style-type: none"> • Increase dementia diagnosis rates and continue primary care led identification of dementia by General Practice and timely referral to secondary care assessments / memory clinic as <u>appropriate</u> • More open referral pathways • Ensure people newly diagnosed with dementia and/or their families/carers receive specific, user friendly, written and verbal information about their condition, treatment and the support options in their local <u>area</u> 	<ul style="list-style-type: none"> • Fully understand local requirements/demand in relation to capacity of services to meet the needs of the local population, to inform future commissioning <u>decisions</u> • Ensure effective delivery of dementia advisor <u>services</u> • Provision of relevant information and advice • Ensure people living with dementia have a comprehensive assessment and ongoing personalised integrated care plan, agreed across health and social care that identifies a named <u>co-ordinator</u> and addresses individual <u>needs</u> 	<ul style="list-style-type: none"> • Work with partners and stakeholders to identify gaps in support and develop evidence-based post diagnosis support packages for people living with dementia <u>including</u>: review provision of ICLS /coordination of care role, better treatment of physical health needs, home care support, housing options, day care, advocacy • Better training and awareness across all services/sectors (including carers and family) • Ensure a coordinated approach between primary care and service user and carer support (RPIW) • Improve treatment for physical and psychological health in care homes to prevent admission: scope to include Behavioural and Psychological Symptoms of Dementia pathway (RPIW) • Ensure effective information and advice is provided around supported housing and extra care <u>housing</u> • Coordinate and arrange access to assistive technology services to support independent <u>living</u> 	<ul style="list-style-type: none"> • Develop end of life care pathway across all agencies • Improve support in care homes re <u>end of life</u> care (RPIW) • Achieve Gold Standard Framework accreditation for <u>dementia</u> • Ensure any <u>end of life</u> care strategies and procedures takes the needs of people with dementia into consideration • Increasing the number of people with dementia who have died in their preferred place of care
Working Better in Partnership – Leadership and Advocacy – Whole System Approach – Community Engagement					

Healthwatch – Have Your Say – ‘Why it is important to review the care of someone with dementia.’

In July 2019 Healthwatch Launched a summary of their research to find out if people with dementia where getting the support they need. The research found that: -

Fewer than half of all people with dementia who use social care are getting the regular care review they are entitle to. As well as-

- People do not always have a clear understanding of the support available to them and how to access care.
- On average, people wait over two months between requesting support for dementia from the council to that support being put in place. However, by the time that people ask, they are at crisis point.

- Once people have a care plan, over 45% are reviewed annually.
- People with dementia are more likely to receive unplanned reviews triggered by an emergency or sudden event than general social care users.
- 65% of people with dementia who had a review were referred a full reassessment. However, half of these reassessments led to no change in the level of care and support.
- One third of people with dementia, using long-term care services did not receive any review, whether planned or unplanned.

Whilst this is common across the social care sector, as dementia affects memory and cognition, there are additional barriers to getting the right information. Many people are also unaware that they may be eligible to access further support through a review if there is a change in their circumstances over time.

Report recommendation included that: -

- Councils should ensure that everyone with a diagnosis of dementia, with eligible care and support needs in accordance with Care Act guidance, has a personalised care plan in place. This should be subject to at least one planned review per year.
- In accordance with guidance from the National Institute for Health and Care Excellence (NICE), local authorities and social care providers must provide information and advice during the care planning and assessment process in a manner that is clear, transparent, and accessible.
- Local government needs to get better at capturing and using data to know whether they are compliant with the Care Act. They need to make sure that people know their rights and where they can go to get support.
- The Department of Health Social Care should review national eligibility thresholds and how consistently they are being used, to ensure that all reviews and reassessments have fair, proportionate and accurate outcomes.
- If a review finds that someone's needs have deteriorated or improved significantly, it should lead to a full reassessment of need as they may have become eligible for many greater levels of support. For example, a person using a home care service may require more intensive nursing for which they were not previously eligible.

Middlesbrough Admiral Nurse Clinic

Admiral nurses are employed by Dementia UK and are continually trained, developed and supported. The specifics of their role vary according to where they are hosted but they all focus on case management, dealing with complexity, partnership working and offering support at critical points in a family's experience of dementia.

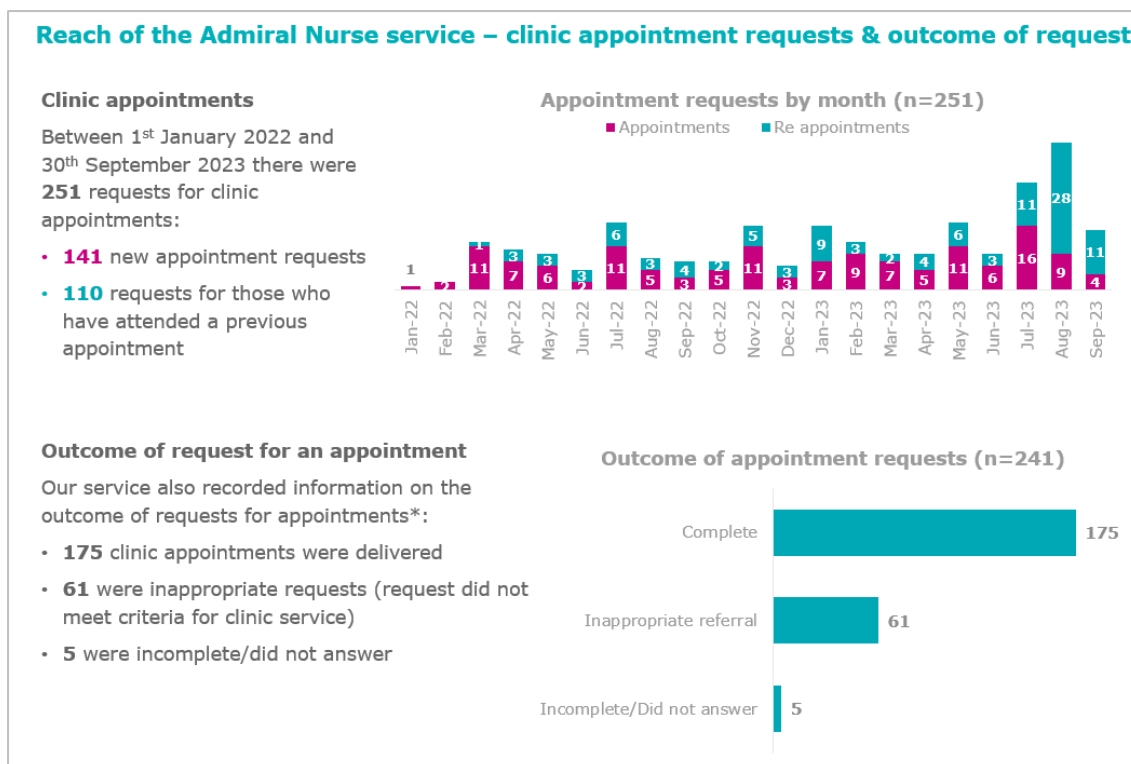
A local Admiral Nurse aligned to the Eston Primary Care Network (PCN) has been providing 1:1 clinic appointment as well as support in the community, offering one to one support, expert guidance, and practical solutions to people living with dementia and their carers. Figure 27 shows the reach of the admiral nurse clinic.

From January 2022 – September 2023. 251 requests for clinic appointments were received and 175 clinic appointments were delivered. Some unfortunately did not meet the criteria but were signposted for other support.

Figure 27 shows the reason for appointment and type of intervention. Between 1st January 2022 and 30th September 2023, 1,641 clinical interventions were delivered during appointments. The most common interventions recorded were:

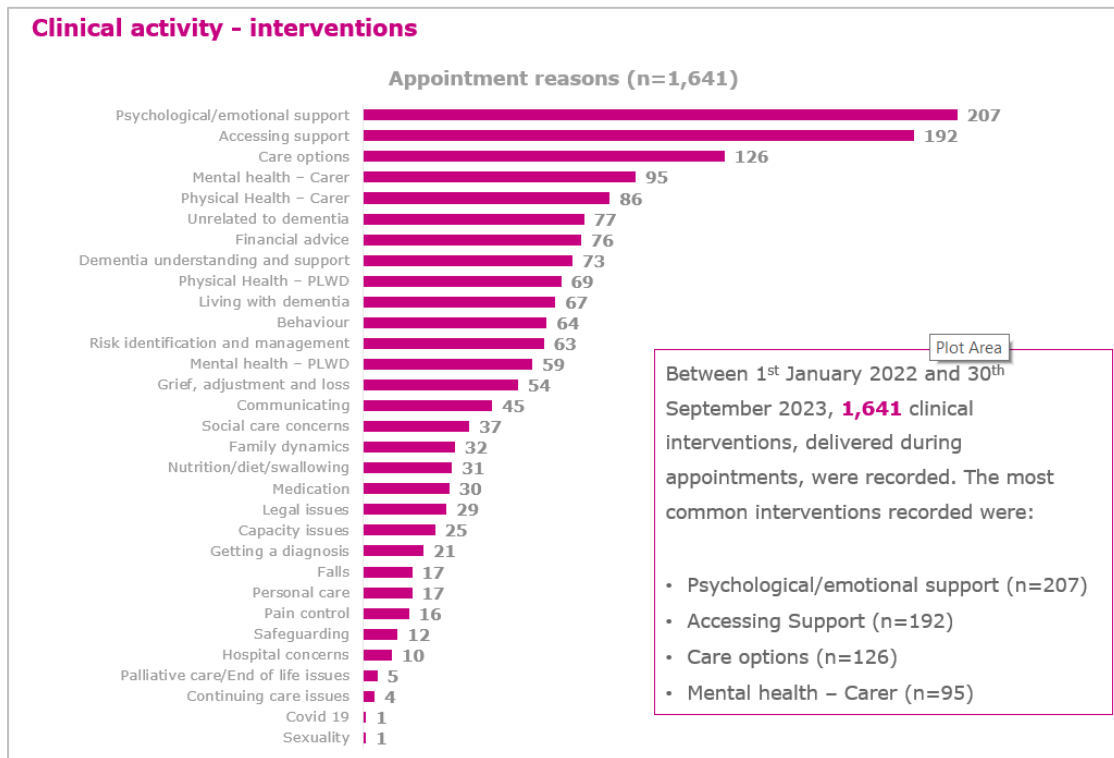
- Psychological/emotional support (n=207)
- Accessing Support (n=192)
- Care options (n=126)
- Mental health – Carer (n=95)

Figure 27 - clinic appointments and outcomes of requests for an appointment



Source: Admiral Nurse Steering Group – clinic updates

Figure 28 - appointment reasons and type of clinical interventions



Source: Admiral Nurse Steering Group – clinic updates

Sadly, the Admiral Nurse clinic will be decommissioned on 6th Jan 2024 due to lack of funding. This has been a successful service and has been fundamental to meeting the needs of families living with the complexities of dementia.

7. What is the current evidence base?



M Din & A Divers – Summary of evidence and issues regarding dementia

- Issues surrounding the design of outdoor environments that are dementia-friendly (Blackman, Van Schaik, and Martyr (2007). Gan, D.R., *et al.* (2022) Chaudhury, H., Mann, J., and Wister, A.V. (2022)). Dementia-friendly neighbourhoods and the built environment
- Transport for those with dementia and how to design and run appropriate services Jarvis, A., Mountain, A., Crow, R. and Moroney, M. (2019)
- Projections of older people with dementia and costs of dementia care in the United Kingdom, Wittenberg, R., Hu, B., Barraza-Araiza, L. and Rehill, A. (2019)
- The changing prevalence and incidence of dementia over time (Wu *et al* 2017)

The main recommendations put forward by the above papers include:

- Post-diagnostic support programmes can provide people with dementia and their carers the opportunity to think about what ‘home’ means and plan for their future housing needs, alongside financial planning, making a will and Lasting Powers of Attorney.
- Registered social landlords should review the information they produce about the types of housing that they offer so they are clear to people with dementia.
- Local authorities to endeavour to include older people, people with dementia and carers in strategic development and service design.
- By informing staff, building robust community services, and working together across services to identify early help needs, individuals can remain at home for longer.
- Informal carers are a huge resource that all services have but do not support and utilise enough. Building on community activity and support, identifying carers at an earlier stage, and developing staff to inform and signpost family/carers provide service users with the opportunity to remain supported in their own homes for longer and support the health and wellbeing of the carers to do this.
- Informal settings are important for delivering information to people who might not naturally identify dementia in themselves or a loved one.

8. What do local people say?

Dementia Action Teesside 2023 Satisfaction Survey below captured the following views from residents accessing dementia friendly social activities.



Redcar & Cleveland Dementia Carers Report (March 2020 – February 2021) – Carers Together

Over a 12-month period, three emerging themes were found in relation to Dementia Carers and the impact of Covid-19.

1. Practical Support

Carers have declined practical support, especially respite provisions i.e., care homes, day centers and domiciliary care, over fear of the cared for person getting ill with Covid-19 or not being able to visit them in care homes.

2. Condition progressing

Carers have reported that the person with Dementia have declined both physically and mentally as symptoms have progressed rapidly since the start of the pandemic, resulting in an increase in care needs. Cared for people have experienced confusion and have become agitated due to a lack of stimuli, which has led to challenging behaviors. Due to staying at home, people with Dementia have become less mobile, meaning the carer has needed to complete more practical tasks. Carers have felt a loss of their own identity, being seen as a carer and not as a wife or son etc.

3. Isolation

Dementia Carers have stated they feel disconnected from the community, as their caring role has taken over. Carers report having a lack of social support, particularly due to them not being able to see family and friends. Carers have experienced an increase in stress, and for some this has resulted in depression and anxiety.

Quotes from Carers Accessing the Woodside Dementia and Wellbeing Hub

"My Husband's favourite quote is 'I love the hub' and no matter what day of the week it is, his first words are always, are we going to The Hub today? He lights up instantly if it is a day we are able to go, and the opposite is true if a day we either can't or don't go".
"We are lucky to have the resource at Woodside. It is the key to supporting our loved ones and family and carers in the community safely. It is a warm welcoming environment, and the staff are always passionate and caring and treat us as individuals knowing when we need that extra bit of care".
"Our loved ones are always pleased to spend time with each other. They are like a community and are all supportive and caring of each other."
"The different activities are always a lot of fun, and I am in no doubt that the work that is happening at the Woodside Hub is allowing us to live well and stay well for as long as is possible."
"If you could be a fly on the wall, you would be very proud of the hard work that the staff, put in to making our journey with a Diagnosis of Dementia fun and making us all feel special."
"They are always thinking of ways to provide a varied program."
"From my point of view as my husband's Wife and Carer The opportunity to meet other Caregivers and talk about how our weeks have been and to realise that the things, we find difficult and sometimes feel guilty about are the same things we all struggle with. It gives us an opportunity to talk about things you would not share with just anybody."
"Sometimes we just talk and have a laugh with each other about things that aren't related to the lives we walk on our carers journey other times we hold each other's hands or put an arm around the shoulder of the person who's having a particularly bad week"
"We asked for some training to understand why the things we struggle with happen. The Hub Staff listened to us and provided a course with different speakers."
"We have learned strategies to help cope but above all have felt supported and cared about."
"We always know we can ask for advice on anything we need help with"
"I know without a doubt my husband would not have been able to live at home for as long as he has without The Hub and the dedicated workers there."
"So not only is it my Husband's favourite place but mine also they make a difference to many lives that need that extra something in their journey with a diagnosis."

Despite dementia being a very complex and life changing condition, it is possible to live well with dementia. The Department of Health National Dementia Strategy – Living Well with Dementia (2009) has four broad themes:

- Raising awareness and understanding
- Early diagnosis and support, and
- Living Well with Dementia
- Create dementia friendly communities to support people living with dementia remain active and independent within the community.

We want Middlesbrough and Redcar and Cleveland to be the best places to live with a diagnosis of dementia and for people to be able to say:

- I have personal choice and control or influence over decisions about me.
- I know that services are designed around me and my needs.
- I have support that helps me have my life.
- I live in an enabling environment where I feel valued and understood.
- I know there is research going on which delivers a better life for me now and hope for the future.

- A 'no wrong door' approach between primary and secondary care whereby the two areas grants work closely together to have a seamless service for residents of Redcar & Cleveland.

9. What are the recommendations?

1.	<p>Reduce the variation between diagnosis and reviews by GP practice so everyone has the same experience by: -</p> <ul style="list-style-type: none"> • improving early diagnosis and effective management of dementia • ensuring that diagnostic capacity and effective support is in place for patients, families, and carers. • Including culturally sensitive diagnostic tools • Improved diagnostic tests for people at risk of dementia such as stroke patients. • Explore the role of specialised dementia GPs and or social prescribers to provide more localised support with dementia diagnosis. • Targeted support to GP practices through dedicated support from TEWV to facilitate education sessions as well as assess, and review GP care records with pilot practices.
2.	<p>Ensure information and advice is widely available so that people understand the risk factors for dementia and how their risk could be reduced. Include improved interventions around modifiable risk factors such as smoking and exercise (intervention having more focus on dementia risk reduction)</p>
3.	<p>Develop a Tees Valley or Regional Dementia Strategy, which includes direct input from people living with dementia and their carers, setting out how the Councils, wider Health and Social Care Partners and the Tees Valley Integrated Care System, will work with other organisations to support people with dementia, their families, and carers to obtain a diagnosis, maintain their independence and enjoy a good quality of life. Need to include comprehensive training and education offer for health care professionals</p>
4.	<p>Dementia Friendly Transport to increase access to support and improve connectivity. Increase dementia awareness training for bus operatives and taxi drivers. (Teeswide Dementia Network group leads are researching local transport issues and meeting with Stagecoach and Arriva directors)</p>
5.	<p>Increasing the role of the housing sector in promoting independent living through joint planning and service delivery, for availability of appropriate housing, equipment, and adaptations – Increased Dementia Training for Beyond Housing and Thirteen Housing staff. (Include elements of Dementia Care Home Guide)</p>
6.	<p>Improve the dementia services offer in all Care Homes, to include the Introduction of a Dementia Friendly Care Home guide/self-assessment tool, which can contribute towards CQC registration and regulation. Actions can be reflected in CQC reports and can go towards achieving higher ratings.</p>
7.	<p>Improved support and outcomes for families, enabling people to stay longer in their own homes with the right support. Includes Improved communication between Primary Care, Adult Social Care, and the Voluntary Community Sector Organisations to identify people in the community. Need to include embracing telecare and assistive technology to support independent living</p>
8.	<p>Patients living with dementia identified on hospital admission and bedside/personal identification applied from point of admission or contact. Carer's details to also be entered in healthcare records. (Include Launch and Promotion of Dementia Health Passport)</p>
9.	<p>Ensure that the needs of carers for people with dementia are a priority to enhance both the carers wellbeing and maintain independence for the person with dementia. Improved Identification through carer friendly GP Practices. Social Prescribers signposting Carers to support services and community activities.</p>

10. References

- ¹ [The meaning of "independence" for older people in different residential settings - PubMed \(nih.gov\)](#)
- ² https://apps.who.int/iris/bitstream/handle/10665/186468/WHO_FWC_ALC_15.01_eng.pdf;jsessionid=C2FEB62A55B9434B5C2958DFE14B7562?sequence=1
- ³ [What is a dementia-friendly community? | Alzheimer's Society \(alzheimers.org.uk\)](#)
- ⁴ [Dementia friendly communities: guidance for councils \(local.gov.uk\)](#)
- ⁵ [Dementia \(who.int\)](#)
- ⁶ [9789241513487-eng.pdf \(who.int\)](#)
- ⁷ [The disease trajectory | Dementia Australia](#)
- ⁸ [Factors predicting quality of life in family carers of people with dementia: The role of psychological inflexibility - ScienceDirect](#)
- ⁹ [Carers for people with dementia struggling in silence | Alzheimer's Society \(alzheimers.org.uk\)](#)
- ¹⁰ [Dementia \(who.int\)](#)
- ¹¹ [Young onset dementia: facts and figures - Dementia UK](#)
- ¹² [Dementia diagnosis rates drop during pandemic. Alzheimers Society June 2021.](#)
- ¹³ [Prioritising need in the context of Putting People First: A whole system approach to eligibility for social care Guidance on Eligibility Criteria for Adult Social Care, England 2010](#)
- ¹⁴ [NHS England Dementia: Good Personalised Care and Support Planning Information for primary care providers and commissioners](#)
- ¹⁵ [Advance care planning in dementia - SCIE](#)
[NHS England policy template 3 - no photo](#)
- ¹⁷ [1.2 Approach to care according to Tom Kitwood - Respect & Respite \(dcare.training\)](#)
- ¹⁸ [Understanding Interactions Between Caregivers and Care Recipients in Person-Centered Dementia Care: A Rapid Review - PMC \(nih.gov\)](#)
- ¹⁹ <https://www.alzheimers.org.uk/news/2021-05-17/emergency-admissions-dementia-care-failures-soaring-and-worse-come-warns-charity>