

The economic impact of dementia

Module 4: Impact of early diagnosis and treatment
September 2024

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Introduction to the study

CF partnered with Alzheimer's Society to produce a report in four modules, to understand the current and future economic and healthcare impact of dementia

MODULE 1

Overall annual cost of dementia now and projected to 2040, broken down by:

- Cost type (health care, social care, unpaid care, quality of life and economic costs)
- Dementia severity
- Regions of England and devolved nations

MODULE 2

Healthcare utilisation now and projected to 2040 of people with dementia, including:

- A&E attendances
- Inpatient admissions
- Outpatient appointments
- Primary care, community and mental health contacts
- Prescriptions

MODULE 3

Cost and outcome comparisons with other conditions (e.g. cancer, CVD)

Cost and outcome comparisons with similar countries

Presented here

MODULE 4

Potential cost savings due to early and accurate diagnosis and effective treatment

The aim of the study was to quantify the economic impact of dementia, using detailed healthcare data to bring new insight into the costs of dementia

- The **projected rise in dementia prevalence** poses a significant **healthcare, social care and economic challenge**, and highlights the urgent **need to prioritise it as a health and care concern**
- Carnall Farrar (CF) was commissioned to **develop a body of evidence** that can **illustrate the economic impact of dementia** in the UK
- This research estimates the **present and future costs of dementia to 2040** across a broad spectrum of cost categories and conducts a deep dive into the healthcare utilisation of people with dementia
- The research identifies **valuable insights into current dementia management** and highlights key findings and strategies for future management

1

This is one of the largest UK studies of healthcare utilisation by people with dementia, using a study cohort of **26,097 people with dementia** across North West London. This data **enabled identification of people with mild, moderate and severe dementia using MMSE results recorded for 2,757 patients.**

2

This study undertook a unique data-led, real-world evidence approach, leveraging **linked record-level patient data** across primary and secondary care, mental health, community and prescribing used to **identify real per person healthcare costs.**

3

This study considered the **costs associated with dementia beyond just health and social care** including **quality of life** (additional heating costs, legal costs, transport costs, police call-outs and scams) and **loss of economic consumption. The costs were separated by payer, to provide an understanding of costs for individuals and their families.**

4

This study included an estimation of the **healthcare costs of people with undiagnosed dementia compared to** people with dementia with a diagnosis, by analysing two years' worth of healthcare costs pre-diagnosis.

5

The data leverages key national datasets for population forecasts and trends in real-term prices over time to **project costs up to 2040.** The study also uses health and social care statistics to **extrapolate the activity and cost projections to other regions of England, and Scotland, Northern Ireland and Wales.**

The study builds on previous work to estimate costs of dementia, which supported key assumptions around dementia prevalence and use of care services

Prince, M. et. al. (2014). *Dementia UK: update*. Alzheimer's Society.

- This study aimed to provide an accurate understanding of dementia prevalence and cost in the UK to assist in policy development, influencing, commissioning and service design, through use of an expert Delphi consensus approach based on a systematic literature review of currently available research data

Wittenberg, R. et. al. (2019a). *The costs of dementia in England*. *International journal of geriatric psychiatry*, 34(7), 1095-1103.

- This study estimated the societal costs of dementia in England for 2015, encompassing costs of health, social, and unpaid care.
- Estimates were derived from multiple sources, including ONS population projections, the Population Ageing and Care Simulation (PACSim) model¹, the Cognitive Function and Ageing Study (CFASII)² and the MODEM project³

Wittenberg, R. et.al. (2020). *Projections of care for older people with dementia in England: 2015 to 2040*. *Age and Ageing*, 49(2), 264-269.

- This study built on Wittenberg, R, et. al. (2019a) to project the cost and prevalence estimates to 2040 in England
- People aged under 65 are not included

Wittenberg, R. et. al. (2019b). *Projections of older people living with dementia and costs of dementia care in the United Kingdom, 2019–2040*. London: CPEC, LSE, 79

- This study built on Wittenberg, R, et. al. (2019a) and Wittenberg, R, et. al. (2020) to develop prevalence and cost estimates to 2040 for the rest of the UK



Executive summary

Earlier diagnosis and treatment could delay need for more expensive care for some people with Alzheimer's disease, creating lifetime savings between £8,800 and £44,900

- Currently, NHS England reports that 64.8% of people aged 65 and over in England with dementia are formally diagnosed, slightly below the 66.7% target¹. In Scotland, Wales, and Northern Ireland, estimated diagnosis rates are 64%², 53.9%³, and 62%³, respectively.
- Dementia diagnosis can happen for people while they are in care homes, likely at a more advanced stage of dementia. While still valuable, at this stage there is less opportunity for intervention and improving the course of the disease after diagnosis.
- For older adults, prevention and treatment should aim to delay the onset of severe symptoms, compressing their period of ill health to later in life. This approach would reduce the time during which they require intensive care, improving their quality of life.
- For some people with dementia, available treatments can delay the progression of symptoms and the need for nursing home care. These treatments not only enhance quality of life and independence but also offer potential cost savings by delaying the expensive, intensive care required for the more severe stages of dementia.
- To achieve these benefits, early and accurate diagnosis is crucial. Modelling suggests savings of £8,800 to £44,900 per person where nursing home admissions can be delayed through effective management and treatment of Alzheimer's disease.
- There may be other benefits including decreased need for unpaid care and healthcare services which are difficult to quantify with the current level of evidence. The modelling also does not include the effect of other effective interventions such as memantine and cognitive stimulation therapy. Potential savings could therefore be higher than those modelled.
- This modelling relies on the critical assumption that treatment does not impact the survival time. Although there are other benefits, the cost savings do not occur if people live longer and therefore require an overall longer period of care.
- More long-term studies and real-world evidence are needed to fully understand the impact of available treatments. This research is essential to improve outcomes for those affected by dementia and realise the potential benefits of early diagnosis and intervention.



Supporting literature, methodology, assumptions and limitations

The main aims of early diagnosis and treatment are to reduce the impact of the disease on people's lives, as well as the costs of care

- In the Chief Medical Officer's 2023 annual report¹, Chris Whitty discussed how the focus of prevention and treatment for older people should be on compressing their period of illness into later life
- For people with dementia, there are currently several treatments in varying stages of development and approval that aim to alter the course of disease and delay its progression, known as disease modifying treatments
- There are also currently available treatments, including acetylcholinesterase (AChE) inhibitors, which can help treat the symptoms of the disease, but do not delay progression
- Studies have shown that early initiation of treatment is associated with long-term benefit², meaning it is crucial that people with dementia receive a timely and accurate diagnosis in order to commence treatment

Estimated per person costs of dementia by severity and setting

2024 UK average

	Mild	Moderate	Severe
All costs	£28,676	£42,793	£80,892
Social care	£16,464	£8,759	£47,629
Unpaid care	£9,688	£33,369	£32,265
Healthcare	£7,734	£7,437	£7,976
Economic costs	-£2,500	-£5,000	-£7,500
Quality of life costs	£910	£1,709	£522

- As well as improving quality of life, treatments can offer an opportunity to reduce the costs associated with dementia
- The costs of dementia increase with increasing disease severity, especially the social and unpaid care components
- This module investigates the potential cost savings if the amount of time during which people need the higher levels of care associated with more severe symptoms is reduced
- The study is restricted to the use of AChE inhibitors, which can be offered as treatment for people with Alzheimer's disease. Memantine and cognitive stimulation therapy also offer benefits but are not considered in this analysis.

Research has shown that acetylcholinesterase (AChE) treatments¹ can delay nursing home placement if taken early enough

Cohort studies have shown that inhibitor drugs can delay Alzheimer's disease symptom progression

- Several studies have shown that people with dementia who receive more persistent exposure to inhibitor drugs over the course of their illness have a significantly slower rate of decline on key measures of cognition, global functioning, and basic activities of daily living and that these effects are cumulative over time
- Studies have also shown that inhibitors can delay dementia-related nursing home placement
- Some studies have shown associations between AChE inhibitor usage and decreased risk of myocardial infarction, stroke, and death in patients with dementia

Evidence on the length of symptom delay is limited as most randomised controlled trials are short

- Few randomised controlled trials examine the effectiveness of AChE inhibitors in Alzheimer's disease beyond one year of treatment or follow up beyond this point
- Studies looking at long-term cognitive decline are difficult due to high attrition and loss to follow-up
- The ethical dilemma of prolonged exposure to placebo generally limits longer-duration randomised trials
- Where data does exist, the findings are mixed, as the treatment is not effective for everyone

Evidence suggests that earlier treatment is more impactful

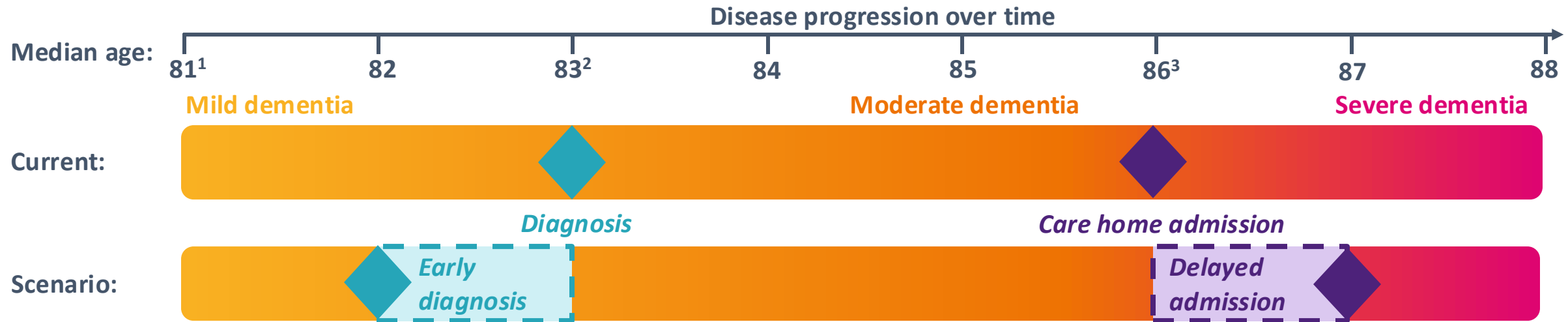
- Studies have shown that early initiation of treatment is associated with long-term benefit, while withdrawal and re-initiation of treatment is detrimental²
- This analysis focuses on AChE inhibitors but does not consider memantine or cognitive stimulation therapy
- It does not consider disease modifying treatments as none are currently approved for use in the NHS

Overall evidence is mixed

- Overall, the evidence of the impact of AChE inhibitors is mixed – while some studies indicate a potential benefit, others do not find significant effects
- More robust, longer-term studies are necessary to determine the true impact of these medications

Note: 1) Acetylcholinesterase inhibitors including galantamine, rivastigmine and donepezil
Source: 2) Rountree, S. E. et. al. (2009) and Loy, C. T. et. al. (2019)

This analysis presents scenario modelling to show the potential cost savings if someone is able to receive treatment that delays their need for more costly types of care



Earlier diagnosis means that people can **take earlier intervention** i.e. lifestyle modifications as well as available treatments including AChE inhibitors.

There is evidence to show that treatment can **delay nursing home admissions** for people with Alzheimer's disease. This is modelled as a reduction in costs of nursing care over a person's lifetime.

A note on methodology: This analysis presents the cost savings in a possible scenario where AChE inhibitors are effective in delaying care need progression. Evidence around the effectiveness of AChE inhibitors has informed this scenario, but it does not include an exhaustive analysis of publications on the evidence of these treatments. The median ages are evidence-based but taken from a variety of sources.

The costs and time periods associated with the modelled scenario are based on literature review and analyses performed in previous work

Parameters	Value	Justification	
Costs	Cost of diagnosis	£897	<ul style="list-style-type: none"> From Module 1, the estimated cost of diagnosis in a memory clinic Diagnosis costs are included in the modelling to ensure the costs of providing a timely and accurate diagnosis are included
	Cost of treatment with AChE inhibitors	£112	<ul style="list-style-type: none"> Annual cost of AChE inhibitor prescription Based on analysis of prescribing data from DiscoverNOW
	Cost of healthcare activity after diagnosis	£1,000	<ul style="list-style-type: none"> Annual difference in cost between someone with dementia with and without a diagnosis Costs vary with disease progression, therefore the median cost is used Based on analysis of healthcare use from DiscoverNOW data
	Cost of domiciliary care	£15,561 ¹	<ul style="list-style-type: none"> Annual cost of domiciliary care Costs vary with disease progression, therefore the median cost is used
	Cost of nursing home care	£63,689 ²	<ul style="list-style-type: none"> Based on weekly cost information from PSSRU and Care Information Scotland
Time periods	Increased time spent as diagnosed patient	12 months	<ul style="list-style-type: none"> See following pages for details Based on amount of time required on treatment in order to see benefits
	Delay in admission to nursing care	12 months (3-6 months also modelled)	<ul style="list-style-type: none"> See following pages for details Sensitivity analysis is performed in Appendix 1
	Overall survival time	No change	<ul style="list-style-type: none"> Studies are inconclusive on the impact of treatment on survival time Further discussion of the impact of survival time given in Appendix 1

Evidence on the length of delay in symptom progression is limited, given that most randomised controlled trials last less than 18 months

Study	Study type and cohort size	Delay in symptom progression	Findings
Arvanitakis, Z. et. al. (2009)	Literature review based on 22 observational studies and 5 randomized clinical trials	6 months	<ul style="list-style-type: none"> • Six months treatment with AChE inhibitors associated with 2.4 points slower decline in a 70-point cognition measure. This corresponds to a six-month delay in symptom progression, relative to natural history studies of Alzheimer’s disease • The size of clinical benefits is uncertain • Small improvements were also found in activities of daily living and behaviors
Knight, R. et. al. (2018)	Systematic review and meta-analysis	3 months	<ul style="list-style-type: none"> • Results suggest a treatment effect of a total of 1 MMSE point measured at 3, 6, and 12 months after treatment initiation. Since studies suggest the annual rate of decline in MMSE score amongst people with dementia is 4–5 MMSE points, this is equivalent to approximately 3-months delay in cognitive decline. • While the effect sizes are small, they could have a significant impact in costs and hospital or nursing home admissions, which have both been shown to be linked to the level of cognitive function
Lopez, O. et. al. (2002)	270 patients (50% with probable Alzheimer’s and 50% control group)	1 year	<ul style="list-style-type: none"> • Measured change in cognitive and functional performance over a 1 year period • Use of AChE inhibitors decreased the risk of nursing home admission. • No association, however, between use of AChE inhibitors and time to cognitive and functional end points, or to death.
Doody, R. S. et. al. (2001)	205 AChE inhibitor-treated and 218 untreated AD patients	Not specified	<ul style="list-style-type: none"> • MMSE scores declined significantly more slowly after 1 year of AChE inhibitor treatment compared to people not receiving treatment. Duration of these benefits is unknown because the longest double-blind placebo-controlled studies reported were only approximately 6 months long.

A note on methodology: These are studies used to determine the parameters for the scenario modelling. Other studies have shown limited impact, such as:

Birks, J. S. et. al. (2018)	Meta analysis of 28 studies	--	<ul style="list-style-type: none"> • 26 weeks of treatment with donepezil was associated with small improvement in cognitive tests, but not behavioural symptoms measured by the Neuropsychiatric Inventory, Quality of Life or total patient healthcare resource utilisation
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There is stronger evidence to show that treatment can delay nursing home admission, and studies estimate this delay could be as long as 21 months

Study	Study type and cohort size	Delay in symptom progression	Findings
Wattmo, C. et. al. (2016)	881 outpatients with Alzheimer's disease diagnosis	3 – 8 months	<ul style="list-style-type: none"> • People who exhibit a positive short-term response to AChE inhibitors can expect to stay in their own home for 3-8 months longer after 6 months of AChE inhibitor treatment
Geldmacher, D. S. et. al. (2003)	671 Alzheimer's disease patients	18 - 21 months	<ul style="list-style-type: none"> • A delay in first dementia-related nursing home placement of 21.4 months was associated with donepezil use of at least 5 mg daily for at least 36 to 48 weeks. • A delay of 17.5 months to permanent nursing home placement was associated with donepezil use of the same dosage and duration
Salib, E. et. al. (2011)	339 probable Alzheimer's disease patients	12 months	<ul style="list-style-type: none"> • During the first 30 months of follow-up there was a delay in care home placement by a median of 12 months in those who took AChE inhibitors compared with those who did not
Lopez, O. et. al. (2009)	943 probable Alzheimer's disease patients	Not specified	<ul style="list-style-type: none"> • People who used AChE inhibitors had a significant delay in nursing home admissions, while people also using memantine were more than seven times less likely to go to a nursing home
Feldman, H. H. et. al. (2009)	584 Alzheimer's disease patients	Not specified	<ul style="list-style-type: none"> • For each year of treatment with galantamine or other AChE inhibitor, the risk of being admitted to a nursing home within a given period was reduced by 31% (galantamine) and 29% (other AChE inhibitor)
Halminen, O. et. al. (2021)	7,454 Alzheimer's disease patients	Not specified	<ul style="list-style-type: none"> • Early anti-dementia medication reduces the risk of admission to 24-hour care both in people living unassisted at home and those receiving professional home care

A note on methodology: These are studies used to determine the parameters for the scenario modelling. Other studies have shown limited impact, such as:

Courtney, C. et. al. (2004)	565 Alzheimer's disease patients	--	<ul style="list-style-type: none"> • Small improvements in MMSE score and functionality 1.0 BADLS with donepezil over the first 2 years. No significant benefits were seen with donepezil compared with placebo in institutionalisation or progression of disability
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Study Limitations

Limitation

- 1 There is no evidence that AChE inhibitors can halt or reverse disease progression of dementia. There is evidence that AChE inhibitors can reduce the severity of symptoms; it is assumed that this reduction in symptoms leads to a reduction in personal care and healthcare costs. Other treatments including memantine and cognitive stimulation therapy have not been modelled.
- 2 AChE inhibitors have only been shown to have an impact in Alzheimer's disease and Lewy body dementia. This study models Alzheimer's disease and therefore only applies to Alzheimer's disease and cannot be extrapolated for other forms of dementia.
- 3 It is assumed that earlier treatment leads to a 12-month delay in nursing care costs (admission to a nursing home). Note that this does not impact any other cost estimates. Healthcare savings have not been modelled.
- 4 It is assumed that the hypothesised person with Alzheimer's disease is able to take these drugs and receive benefits from doing so. In reality, it is estimated around half of people with Alzheimer's disease benefit from AChE inhibitor treatment. The person must receive treatment early enough in the course of their disease to see benefits.
- 5 There are limited studies analysing the impact of earlier diagnosis and many of these are more than 15 years old.
- 6 There are other important benefits of early diagnosis, including allowing patients more opportunities to plan for their future care, and giving their families a better understanding of how to support them. The financial impacts of these benefits are not easily quantified, so have not been included in this study.
- 7 There is regional variation in the costs associated with dementia and the distribution across payers. Local figures can be substituted into the calculation to give an estimate of potential savings in different geographical areas.

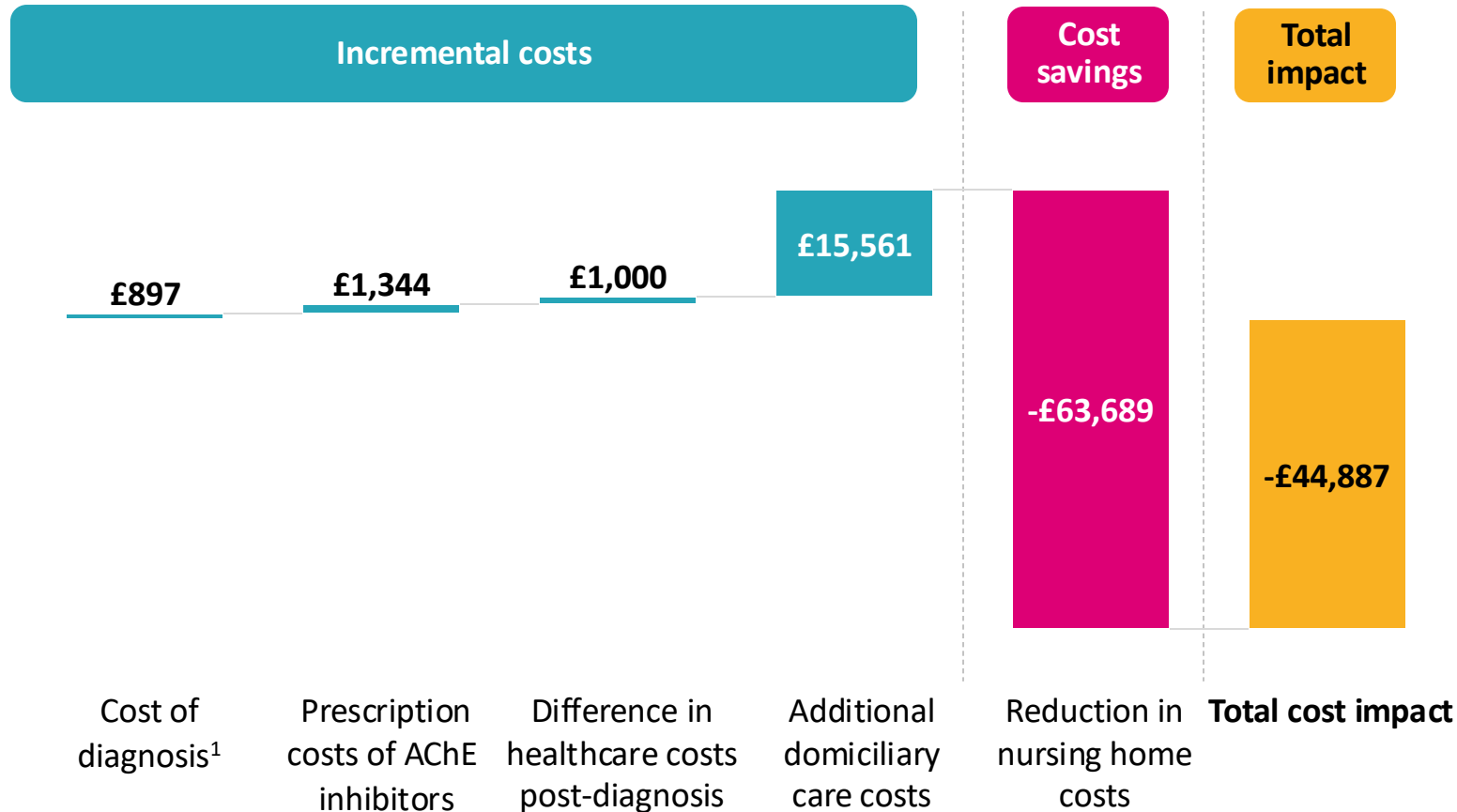


Potential savings due to earlier diagnosis and treatment

The cost saving for a person with Alzheimer’s disease diagnosed early enough to take treatments that delay symptom progression is estimated to be up to £44,887

Effect of earlier diagnosis and treatment on lifetime costs for a person with Alzheimer’s disease

2024 prices



- There is an **increase in costs associated with earlier diagnosis and treatment**, including the costs of diagnosis and treatment and an incremental increase in healthcare costs
- There are also assumed **additional domiciliary care costs** for the period of time that is no longer spent in a nursing home
- These **costs are offset by a cost saving due to the assumed delay in admission to nursing home care**
- This **modelling assumes no increase in survival** – see Appendix 1 for a discussion of the impacts of this assumption
- **There may be other savings associated with delayed symptom progression**, for instance lower use of healthcare services, but due to lack of evidence these are difficult to quantify

Cost savings from earlier diagnosis and treatment are expected to be distributed across both people with dementia and the state, with people with dementia and their families saving up to £10,000

Impact of intervention for Alzheimer’s disease by payer

2024 prices

	Cost savings		Incremental cost	Total impact
	Local authority	Self-pay	NHS	
Net Impact	-£38,000	-£10,100	+£3,300	-£44,900
<i>Nursing care</i>	-£38,000	-£25,700		-£63,700
<i>Domiciliary care</i>		£15,600		£15,600
<i>Healthcare costs</i>			+£1,000	£1,000
<i>Diagnosis cost</i>			+£900	£900
<i>AChE inhibitors</i>			+£1,300	£200

- **Local authorities could save an estimated £38,000 per year** for every person for whom they can successfully delay nursing home admission
- **People with dementia can expect to save £10,100 in their lifetime** if they are diagnosed early enough to take treatment at a point where it can have the maximum impact
- The NHS is expected to **pay a small cost of £3,300** for early diagnosis and additional treatment, **but this may be offset by healthcare savings in later years** – these savings have not been included in this analysis given the lack of evidence in this space
- While savings have been modelled for a single representative person, if **symptom transitions can be delayed for large numbers of people there is potential for a significant aggregate cost saving for local authorities and people with dementia**

A note on methodology: Distribution of costs based on average distribution across the UK.

Sensitivity analysis

Delay in nursing care admission

- Given the variability in the delay in the literature, the analysis was repeated with different assumed lengths of delay in the nursing home admission
- If the delay is assumed to be three or six months (instead of 12), the total potential cost saving are £8,791 and £20,823 respectively

Length of delay in nursing home admission	Reduction in cost of nursing care	Overall potential saving
12 months	£63,689	£44,687
6 months	£31,845	£20,823
3 months	£15,922	£8,791

Survival time

- The scenarios presented assume there are no changes to the person's overall survival time
- Changes in survival time are difficult to model, evidence of the impact of AChE inhibitors on survival time is mixed. It is unclear how the additional time will be distributed across the various stages of disease severity and care need and difficult to predict the natural mortality for older people.
- From Module 1, the annual per person costs of dementia for mild, moderate and severe cohorts are £28,700, £42,900 and £80,500 respectively. The estimated £44,687 saving due to early diagnosis and treatment initiation would be eroded with the following extensions in life expectancy:
 - Two years if in the mild stage
 - One year if in the moderate stage
 - Six months if in the severe stage

Further research that makes use of real-world evidence is required to better understand the economic impact of diagnosis and treatment

Additional research into Alzheimer's disease symptom progression, diagnosis and the impact of treatment

- While several studies have investigated the impact of treatment on Alzheimer's disease progression, there is a lack of consensus around the length of delay in disease and symptom progression
- Additionally, progression through stages of dementia (including Alzheimer's disease) from mild cognitive impairment to severe dementia, is poorly documented
- Social care is the largest component of cost, but these savings are also typically outside the scope of the existing literature
- Longer follow-up studies and more real-world evidence is required to more accurately track the healthcare impact and cost impact of treatments, ensuring that the health and care space is ready for new disease modifying therapies (DMTs)
- There is also more evidence required around the use of behavioural management and non-pharmacological treatments like cognitive simulation therapy

Further deliberation from NICE on the impact of Alzheimer's disease treatment on quality of life and system-wide savings

- There is some evidence that Alzheimer's disease treatment has the potential to improve quality of life for people with dementia and drive a significant cost benefit for both local authorities and for people with dementia if taken sufficiently early
- While healthcare costs are likely to increase marginally per person, there are potentially significant overall savings and benefits to people and society



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