

# Literature Review: The role of volunteering in a society that lives well with dementia

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## 1. Introduction

Royal Voluntary Service (RVS) works to inspire and enable people to give the gift of voluntary service to meet the needs of the day in their communities. Across the United Kingdom, volunteers provide critical support to the National Health Service and other care services, enabling individuals who need support to live their best lives. Dementia prevalence is rising in the UK, and it is estimated that 1 in 2 people will experience dementia, either themselves or through caring for someone with dementia. This represents a considerable number of people who will rely on care services and is an area in which RVS is able to support individuals to better health outcomes. There is currently no cure for diseases classed under the umbrella term dementia, however, lifestyle activities can significantly improve health outcomes and the quality of life for people effected.

Built on a foundation of local volunteering, RVS provides people with more access to services in their communities such as Remember Me cafés, Living Well with Dementia groups and Memory Lane cognitive stimulation therapy groups. With over 60 dementia groups, RVS has supported over 1900 people since January 2021 and plans to grow this service to meet the increasing needs of UK health services. However, improving voluntary services is not just about increasing the number of community groups. RVS also wants to lead the way in the delivery of high-quality services, accessible to people living with dementia and their caregivers.

Through synthesising the literature this document will provide an overview of the research landscape to showcase current knowledge and progress in understanding dementia. By combining this with primary data collected from individuals' experiences of existing services, RVS will take stock and review how to expand service offerings. Through a Thought Leadership programme of work, RVS will help to propel volunteering services forward for the benefit of individuals, communities and society and assist in delivering charitable activities.

With a vision to influence relevant stakeholders and decision makers regarding the NHS, social care policy and volunteering, RVS is committed to help the UK population to live well with dementia.

## 2. Dementia in the United Kingdom

Dementia is an umbrella term describing a collection of symptoms that an individual may experience if they are living with one of many diseases affecting the brain. These symptoms are primarily linked to a progressive decline in cognitive abilities that are severe enough to impact a person's quality of life and physical functioning. Symptoms of dementia can also affect behaviours and emotions. Diseases under the group of dementias are linked to abnormal changes in the brain, and there are over 200 sub-types that have been characterised.

In the UK, it is estimated that 944,000 people are currently living with dementia (approx. 7.1% of over 65s) with this number expected to reach 1.6million by 2050. The economic cost of dementia across the UK is estimated to rise from £34.7billion spent in 2019 to £94.1billion in 2040, an increase of 172%. Health care costs accounts for 14% (£4.9 billion), with social care (publicly and privately funded) and unpaid care accounting for 45% (£15.7 billion) and 40% (£13.9 billion), respectively [1]. These alarming statistics highlight the need for increased funding for research and services that bring together the National Health Service, industry, academia, and charities to tackle dementia in the UK.

In addition to economic cost, dementia can have a significant impact on the lives of individuals with dementia and those who provide care for them. Current estimates put 700,000 people involved in the unpaid primary care of someone with dementia, with 1 in 3 of the UK population likely to have carer responsibilities in some capacity [2]. Providing care for someone with dementia can drive difficult emotions, such as feelings of guilt, confusion, and sadness, and unlike many other conditions, it can be difficult to communicate these feelings with the person.

On average people with AD have a life expectancy of around 5.8 years from diagnosis. This can be much shorter or longer on a case-by-case basis. A diagnosis of non-AD dementia is associated with 1-year shorter life expectancy than for AD [3]. This means there is a significant period whereby carer support is needed which is an often-overlooked aspect of dementia care. Difficulty in receiving information and support from the time of diagnosis to end-of-life care have been reported, with a need to understand how cultural differences may impact the service interaction experience [4]. Further to this, the COVID-19 pandemic placed extra strain on healthcare services and brought significant change to the lives of people impacted by dementia.

During the pandemic, dementia diagnosis and referrals to healthcare services were heavily reduced, restricting individuals from getting the support they needed [5]. Conflicting guidelines and a lack of access to support services, combined with the physical and emotional effect of the pandemic has significantly impacted perceptions of post-diagnosis care and support availability for people with dementia [6]. During the pandemic, people with dementia were at a high risk of worsening neuropsychiatric and behavioural symptoms and carers had to balance the risk of catching COVID-19 and worsening cognitive deterioration from increased social isolation [7, 8]. In fact, dementia was the most common pre-existing condition in deaths involving COVID-19 during the first wave of the pandemic (March – June 2020) [9].

Qualitative experiences of individuals impacted by dementia highlighted widening health inequality during the pandemic, possibly linked to differences in access to the shift of services to online settings [10]. In contrast, there were some positives reported regarding the

provision of online services. By offering a blended approach to dementia services, combining the opportunity to engage with both face to face and online support groups, access can be increased for both individuals living with dementia and caregivers. Deciding to offer such services in the community needs to consider the risk of marginalising certain groups and the preferences of individuals, however this can be mitigated in part through training in digital literacy and creating dementia-friendly approaches to technology [11].

As the UK emerges from the peaks of the pandemic, dementia referral rates are beginning to return to baseline levels as services are resumed. This is critical as it is estimated that 35.5% of people living with dementia currently don't have a diagnosis [12]. The formation of multidisciplinary teams to meet the demands placed on healthcare during the pandemic [13,14] highlight the potential for UK services to be improved substantially. For dementia related services this need is present more than ever. Now we have the opportunity to rebuild and integrate services offered in the UK to enable people affected to live well with dementia.

### **3. The most common types of dementia**

#### **Alzheimer's disease**

As previously mentioned, Alzheimer's disease (AD) is the most common type of dementia accounting for 60-70% of dementia diagnosis. Memory loss, confusion and changes in behaviour that impact daily living are common first signs of AD. These symptoms can progress to more severe deficits with accompanying neuropsychiatric symptoms often being experienced. Irritability, agitation and sleep disturbances are commonly seen in people with AD accompanied by depression, anxiety and apathy [15]. AD can be divided into two distinct types, familial AD, and late-onset AD, both displaying similar clinical features. Familial AD is an inherited form of dementia resulting in the development of symptoms earlier in life (before the age of 60). This means someone who carries one of the genetic mutations known to cause AD will experience symptoms in their lifetime.

Approximately 1% of total AD cases are because of familial AD, in which individuals will experience symptoms much earlier in their life. Familial AD is also associated with more severe clinical symptoms and neuropsychiatric symptoms [16]. Late-onset AD is much more common and occurs later in life, with age being the greatest risk factor. In addition to age, female sex and carrying certain genes can all increase the risk of AD. Unlike familial AD, you may carry the high-risk genes and not experience AD at any point. This emphasises the importance of managing risk factors that we can control such as engaging in a healthy lifestyle and management of existing health conditions.

#### **Vascular dementia**

Vascular dementia (VaD) is the second most common type of dementia, with 20 out of every 100 cases attributed to VaD. Symptoms a person with VaD may experience can be similar to AD and other types of dementia depending on the region of the brain impacted by vascular damage [17]. It is not uncommon for the individuals to experience problems with attention, information processing, difficulty completing complex activities and disorganised behaviours [17]. Memory loss is also common but may not be the first sign or symptom recognised. In around 80% of cases cognitive symptoms will be accompanied with neuropsychiatric symptoms. The severity and onset of symptoms can vary based on the type of VaD each of which are associated with restricted blood flow to areas of the brain. Post-stroke VaD can result in a more severe 'stepwise' onset of symptoms, although these can improve over time with recovery from the infarct.

#### **Dementia with Lewy bodies & Parkinson's dementia**

Dementia with Lewy bodies (DLB) accounts for approximately 10% of all dementia cases, meaning 100,000 people in the UK are living with DLB. DLB shares clinical and pathological features with Parkinson's disease and Parkinson's dementia which are distinguished based on the timing of symptoms experienced by an individual. Cognitive decline, effecting attention, executive functioning, and visuospatial abilities, are pronounced in DLB [18]. Recurring visual hallucinations and a history of rapid eye movement sleep disorder are also key symptoms preceding the onset of extrapyramidal symptoms effecting movement, characteristic of parkinsonism.

If the onset of Parkinson's precedes the symptoms of dementia, then a diagnosis of Parkinson's dementia is more common [19]. Although the exact mechanisms are not fully understood, the abnormal spreading of a protein called alpha-synuclein is linked to neurodegeneration. Age is the main risk factor, with advancing age increasing the likelihood of a person experiencing DLB. Men are more likely to get DLB than women and there is evidence that a family history of DLB can increase a person's risk. Individuals with a family history of DLB are 2.3 times more likely to develop DLB themselves although there is limited understanding of the genetic risk factors specific to DLB [18].

### **Frontotemporal dementia**

Frontotemporal dementia (FTD) is a rarer form of dementia, accounting for less than 5% of all dementia cases. The age that people first experience symptoms is typically younger than for other dementias, between the ages of 45-65 years old, although 25% of FTD cases still occur after the age of 65. The common symptoms of FTD are disinhibited behaviours, changes in personality, progressive non-fluent aphasia and/or impaired semantic memory. In addition, neuropsychiatric symptoms including apathy, a lack of empathy and impaired executive function with relatively spared episodic and visuospatial awareness are also commonly experienced. This can be accompanied by delusions, hallucinations, and periods of mania [20].

The pathology of FTD is characterised by degeneration of the frontal and temporal lobes of the brain [21]. This degeneration is accompanied by the accumulation of three proteins within the brain which can be used to further define the type of FTD a person is experiencing. There are genes which can increase the risk of a person having FTD and therefore there is a hereditary component to FTD. In many cases, there is no family history of FTD. Currently, there is a limited understanding of what risk factors can impact the likelihood of FTD in this instance, however, engaging in regular physical activity and managing existing health conditions may reduce the progression of clinical symptoms or help to prevent co-morbidities in all types of FTD [22].

### **Mixed pathology dementia**

Mixed pathology dementia is defined as the co-existence of multiple types of dementia, most often this is a combination of VaD and AD. As each type of dementia has a different pathological cause, a person can experience the onset and progression of more than one type of dementia. In fact, it has been suggested that mixed pathology is more common than the presentation of a single pathology of dementia.

A person living with mixed pathology may experience symptoms from different types of dementia although as many symptoms overlap it can be hard to diagnose the presentation of mixed pathology. Managing the risk factors associated with each dementia, for example, treating hypertension and hyperlipidaemia will help to reduce the progression of mixed dementia.

<b>Dementia subtype</b>	<b>Approximate percentage of total dementia</b>	<b>Clinical presentation</b>	<b>Typical Progression</b>
<b>Alzheimer's Disease</b>	60-80%	Memory decline, executive dysfunction, Language/ visuo-spatial impairment.	8-10 years, Insidious progression
<b>Vascular Dementia</b>	10-20%	Variable between cases. Stepwise changes in executive function and memory.	3-5 years, often stepwise progression
<b>Dementia with Lewy bodies and Parkinson's dementia</b>	5-10%	Parkinsonism (motor behaviour change), visual hallucination, fluctuating cognitive impairment, sleep disorders.	6-8 years, Insidious progression
<b>Frontotemporal dementia</b>	5-10%	Personality/ behaviour change. Speech and language impairment.	6-8 years, Insidious progression

#### **4. Current pharmacological treatment options for people with dementia**

Treatments for dementia are predominately limited to symptom management and have limited efficacy. There is currently no cure for dementia. Although memory impairments are most typically associated with dementia, there are a number of common behavioural and psychological symptoms including agitation, aggression, severe anxiety, delusions, depression, apathy, and sleep disturbances [23]. By managing the symptoms experienced by a person with dementia, interventions can help to sustain a better quality of life for a longer period of time and reduce the demands placed on caregivers.

When considering options for managing symptoms of dementia, non-pharmacological options are favoured as the primary interventions however medication may be beneficial for certain individuals. It is important to understand that these have limited efficacy and there are often side-effects associated with taking medication that also need to be considered.

#### **Uses and limitations of pharmacological treatment for cognitive symptoms in dementia**

Cholinesterase inhibitors are the first-line pharmacological treatment targeting cognition for individuals with dementia, most prescribed for mild to moderate AD. This is because there's less of a chemical called acetylcholine in the brain in people with AD. Acetylcholine helps brain cells send messages to each other and the cells that use acetylcholine decrease. This drop in acetylcholine and loss of cells are connected to making symptoms worse. Drugs like donepezil, rivastigmine, and galantamine work by stopping an enzyme called acetylcholinesterase from breaking down acetylcholine in the brain. This means there's more acetylcholine available, so brain cells can communicate better. This might help ease or keep symptoms stable.

Cholinesterase inhibitors are linked with modest benefits for cognition that persist with continued treatment and can reduce mortality risk for people with AD [24]. It has been estimated that approximately 68% of individuals respond to treatment that can stabilise declining cognitive function [25]. However, these benefits are only sustained with continued use and on withdrawal aspects of cognitive function can continue to decline [26]. There is also evidence of efficacy for slowing the progression of vascular dementia [27], with limited to no effect on other types of dementia. Memantine may be prescribed to individuals at more progressed stages of dementia and can be used in combination with Cholinesterase inhibitors [28].

### **Uses and limitations of pharmacological treatment for neuropsychiatric symptoms in dementia**

Neuropsychiatric symptoms of dementia encompass a group of non-cognitive symptoms that are experienced by over 90% of individuals afflicted with dementia. These symptoms are thought to appear due to the complex interaction between biological, psychosocial, and environmental factors, and include symptoms such as agitation, aggression, severe anxiety, delusions and hallucinations [23].

Neuropsychiatric symptoms are important to treat in people with dementia as they are notably linked to increased morbidity and mortality rates, heightened caregiver burden and susceptibility to burnout, augmented likelihood of nursing home placement, and amplified care-related expenditures for dementia patients [29]. However, pharmacological treatment should be avoided as first-line treatment as they are not risk-free and can induce unwanted side effects. Instead, on a case-by-case basis, treatments should be integrated into a comprehensive care plan that primarily encompasses non-pharmacological interventions and thorough medical evaluation for changes in symptoms. This is of particular importance as neuropsychiatric symptoms worsening can stem from undiagnosed medical conditions such as, urinary tract infections, pneumonia, or constipation [30,31].

Additionally, factors relating to environmental triggers can exacerbate symptoms, such as an under or over stimulating environment, or changes to a familiar environment. This has placed a growing interest in the development of dementia-friendly design which has been shown to reduce the severity of neuropsychiatric symptoms and increase social interactions [32, 33]. For individuals experiencing severe agitation, aggression and psychosis in dementia healthcare professionals may consider the use of antipsychotic medications. The use of antipsychotics is usually as a last resort to manage acute worsening of neuropsychiatric symptoms, this is due to the serious side-effects that can accompany their prescription [34].

The prevalence of neuropsychiatric symptoms in people with dementia highlight the need for proper management to increase patient well-being. Persistent symptoms can accelerate dementia progression, increasing morbidity and mortality rates and place additional pressure on caregivers. In some cases, pharmacological intervention can assist in the short-term symptom improvements, however, these treatments are not without significant adverse effects. Therefore, focusing on non-pharmacological interventions would likely lead to better outcomes for reducing neuropsychiatric symptoms in people with dementia [27, 35].

### **Success and challenges of disease-modifying treatment for Dementia**

Disease-modifying treatment options, for any type of dementia, are very limited in the UK. That is, treatments that are targeted towards preventing or reversing the underlying pathology of the disease process. This is partly because we still do not have a strong grasp of the causes of dementia or the precise timeline of changes that occur as the disease progresses.

Disease-modifying treatments for AD have been increasingly trialled for several years with the development of drugs targeting the removal of Amyloid-beta from the brain. This treatment is based on the 'Amyloid cascade hypothesis' which first describes the build-up of Amyloid-beta as the driving force behind the progressive neurodegeneration in the brain [36]. Such targeted treatments aim to prevent amyloid production, reduce aggregation, or aid clearance.

Recently, there has been significant progress in the treatment of AD with the development of passive immunotherapies targeting the clearance of Amyloid-beta from the brain which has been reviewed in detail [37]. Aducanumab, Lecanemab and Donanemab, are examples of these anti-amyloid beta immunotherapies that target the clearance of Amyloid-beta and can slow cognitive decline [38, 39]. Lecanemab under the trade name Leqembi, has gained significant attention for receiving approval for the treatment of early AD by the Medicines and Healthcare products Agency (MHRA) in the UK. However, the treatment has not been recommended by National Institute for Health and Care Excellence (NICE) to be available on the NHS due to cost and high risk of side effects [43].

The progress being made in the science of pharmacological treatments, brings hope that we are entering the 'beginning of the end' of Alzheimer's disease. However, there are still significant challenges that need to be overcome. The effectiveness of anti-amyloid therapies, and likely other treatments for dementia, appear most effective in the early stages of the disease process. Therefore, it is crucial that our ability to detect changes occurring prior to the onset of clinical symptoms is improved, as current methods rely on brain scans or the analysis of cerebral spinal fluid which are not routinely accessible for most people and are expensive to carry-out. This becomes a particular challenge when considering the number of people living with dementia who have yet to receive a formal diagnosis.

#### **Blood-based biomarkers to improve diagnosis**

Emerging blood-based biomarkers are a potential solution to this issue which could facilitate earlier diagnosis. Blood samples can be taken from an individual and separated into plasma (liquid that carries blood cells) which contains many proteins. Changes in amyloid-beta and Tau levels in blood plasma represent one promising set of biomarkers for early AD detection. In addition, markers associated with neurodegeneration can also be detected in blood plasma and are also being investigated using highly sensitive laboratory methods. If these blood-based biomarkers can be validated for clinical use, then we will be able to better monitor the effectiveness of pharmacological and non-pharmacological interventions in a cost-effective and accessible manner [40].

It is highly likely that a combination of pharmacological and non-pharmacological intervention is needed to maximise outcomes for individuals with dementia. At this time, and moving into the future, the delay and prevention of dementia should be the goal of UK health services, rather than relying on treatments as reaction to receiving a diagnosis or the onset of symptoms. In the UK, disease modifying therapy is not currently available. For individuals who progress to later stages of dementia, the management of symptoms and engagement in non-pharmacological interventions is still the best option for delaying the progression of symptoms and maintaining a high quality of life. Even if pharmacological treatments effective in reducing the underlying cause of dementias become available, lifestyle management and engagement in psychosocial activity will be key.

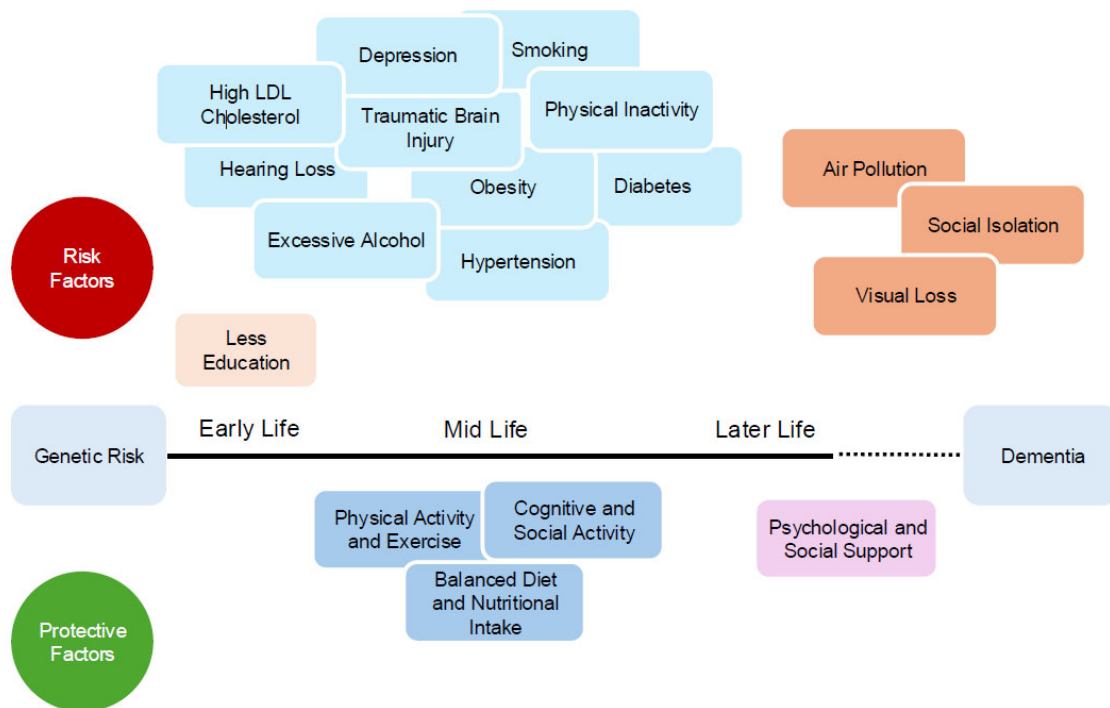
#### **5. Non-pharmacological interventions for people with dementia**

The number of people living in the UK over the age of 65 is increasing, with around 1 in 4 people expected to be in this age group by 2038 [41]. With increasing age being the most significant predictor for being diagnosed with dementia, there is increasing need to develop strategies to promote healthy ageing. Healthy ageing is not reliant on being free from all



disease or illness but is focused on enabling people to maintain functional abilities that can sustain or promote wellbeing as we age [42].

Many lifestyle choices and non-pharmacological interventions have been shown to reduce a person’s risk of developing dementia, whilst promoting healthy ageing. In addition, engagement in positive lifestyle choices can help to meet the psychosocial needs of individuals with dementia. As covered below, there is also huge benefit to be gained from the social interaction, cognitive stimulation, peer support and communication arising from group-based activities that can improve quality of life for both people with dementia and their caregivers.



### Lifestyle modification and dementia risk

The Lancet ‘Dementia prevention, intervention and care’ commission highlighted the importance of managing lifestyle factors that are evidenced to impact dementia risk [43]. Together the 14 (potentially) modifiable risk factors identified were proposed to account for around 45% of worldwide dementias, which consequently could theoretically be prevented or delayed. These include untreated vision loss, high LDL cholesterol, less education, hypertension, hearing impairment, smoking, obesity, depression, physical inactivity, diabetes, and low social contact, excessive alcohol consumption, traumatic brain injury, and air pollution. Prevention is particularly important for dementia as the pathology can begin to develop years before clinical symptoms are recognised and current treatments are not yet able to reverse the disease process. This emphasises the importance of engaging in a healthy lifestyle at all ages and it is never too late to act towards preventing or delaying the disease process.

### Physical activity

The world health organisation recommends that all adults should undertake 150–300 min of moderate-intensity, or 75–150 min of vigorous-intensity physical activity, or some combination of the two, every week. This includes regular muscle strengthening exercise and individuals should try to minimise sedentary behaviours [44]. Engagement in physical activity can come from leisure time or occupational activities forming part of an active lifestyle. Whilst barriers may limit some forms of exercise, engaging in some physical activity is better than none and should be included as part of a healthy-balanced lifestyle.



The health benefits of a physically active lifestyle or performing planned exercise bouts are well known. In older adults, regular physical activity is associated with improved cognition, independent functioning, and psychological health. Higher levels of physical activity are also linked with a lower risk of incident dementia independent of other lifestyle factors and comorbidities [43,44].

People living with dementia are typically less active than cognitively healthy individuals of the same age, which may stem from physiological and psychosocial factors [45]. Yet, engaging in physical activities can bring feelings of euphoria and bring a meaningful addition to weekly routines [46]. Thus, it is critical that attempts to mitigate barriers to physical activity in a personalised approach are made. For example, a lack of motivation, declining physical function and dependence on caregivers to aid activities have been described. These barriers may be relieved by people living with dementia to have the opportunity to join group-based activities the local community.

Physical activity, or a lack of, can create a negative feedback loop in which low physical activity reduces physical function, which can limit future activity. Therefore, it is important to promote activity throughout life and encourage a return to activities if periods of sedentary time occur. For example, if someone spends an extended period in hospital. This return to physical activity can prevent frailty which is linked to weight loss, tiredness, low grip strength and slow gait speed [47]. This is important as physical function and self-sufficiency can significantly impact quality of life for people living with dementia.

Physical activity and exercise are not just important for people living with dementia. Caregivers can also benefit significantly from maintaining an active lifestyle. Research into caregiver activity is limited, however, evidence from a randomised controlled trial showed that provision of a physical activity programme significantly reduced caregiving hours and reliance on formal services compared to caregiving skills training alone [48]. Furthermore, maintaining leisure time activity is associated with a reduced perception of caregiving burden and may help to maintain feelings of independence in caregivers [49].

### **Nutrition and diet**

Maintaining a healthy diet is crucial for healthy living and can reduce the likelihood of a person having health conditions linked to dementia, such as high blood pressure, heart disease and type 2 diabetes [50]. In addition, malnutrition tends to be more prevalent in older populations with malnutrition, weight loss and dehydration being common in people living with dementia [51].

Interestingly however, the research landscape suggests inconclusive evidence that nutrition is associated with cognitive health directly [52]. In concordance, diet was not included in the list of modifiable risk factors associated with dementia in the latest lancet commission [43]. This viewpoint often considers diet to be a single modifiable risk factor, however, dietary intake is a multidimensional factor including a range of healthy and unhealthy components, and significantly interacts with day-to-day life. For example, an individual may either smoke or not, yet a person adhering to a healthy balanced diet contains many more subjective and contextual factors that need to be considered. In particular, the needs of the individual must be considered, particularly when nutrient deficiencies are present.

Targeting specific nutrients through supplementation to improve cognitive health has been of interest in people living with dementia. These supplements target nutrient dependent factors linked with dementia such as high blood levels of homocysteine and antioxidant imbalances or by altering the neurological processes related to disease progression. B vitamins (Folate, B6, B12), Vitamin D, Vitamin C and E and intake of Omega-3 poly unsaturated fatty acids have been some of the most studied nutrients and are often marketed with claims of

improving brain function. However, these claims are often based on evidence from observational population data showing individuals with a lower nutrient intake have a greater risk of dementia or small-scale investigations.

Whilst it is likely that consuming adequate intake of these nutrients throughout life as part of a balanced diet is important, the efficacy of supplementing with individual nutrients over a relatively short period currently lack clear evidence for improving cognitive function. That does not mean that there is no benefit to addressing nutrient deficiencies for people with dementia, but it is unlikely that a single supplement will have a clinically meaningful effect.

Adopting a more Mediterranean diet has been of particular interest for improving brain health. Although there is not a set definition for the diet, it would include a higher intake of vegetables, fruits, whole grains, beans, nuts and seeds, and olive oil in comparison to a typical western diet. Greater adherence to a higher proportion of Mediterranean foods is associated with a lower risk of dementia [53]. There is also evidence that a Mediterranean diet is linked with greater volume in certain regions of the brain that shrink in dementia [54]. Currently, the Mediterranean-DASH intervention for dementia (MIND) is receiving significant research attention by combining elements of the Mediterranean diet with a nutritional advice for reducing high blood pressure and is being integrated into large multicentre trials [55].

Similarly, there is growing interest for low carbohydrate/ ketogenic dietary patterns to protect against neurodegeneration. Originally recommended for the treatment of certain cases of epilepsy, the ketogenic diet has been identified in small scale studies to show potential benefit for dementia. The high fat content and low sugar intake, inducing a state of ketosis, are linked with better blood sugar control, cognitive benefits and reduced inflammation [56]. However, before this dietary pattern can be recommended, large scale trials are needed to confirm its effectiveness [57].

Ultimately, consuming a healthy-balanced diet should be recommended for all individuals irrespective of age and whether they have certain medical issues. Avoiding nutrient deficiencies is perhaps the most critical factor when considering dietary intake for people living with dementia. As research progresses, we are learning more about how our dietary intake interacts with our genetic make-up and our microbiomes [58].

There is an increasing amount of data being collecting to understand how diet and out intestinal bacteria affect the brain, an example being the Alzheimer's gut microbiome project. Again, this does not suggest a supplement will be sufficient to reverse cognitive impairments, but emphasises the important of maintaining a varied diet [59]. These advancements will likely lead to a more precision medicine-like prescription on dietary advice at an individual level. Importantly, dietary changes need to integrate into a person's lifestyle where possible and be relatively easy to adhere to.

### **Cognitive stimulation**

Cognitive stimulation is an approach focused on the delivery of enjoyable activities that provide a general stimulation of cognitive functions, such as thinking, concentration and memory. Cognitive stimulation often takes place in group settings and can include discussions, word games, quizzes, physical activity and creative activities [60]. It is important to note that this is not the same as cognitive training for a specific domain of cognitive function, and instead focuses on a broad range of cognitively engaging activities, with a particular emphasis on improving quality of life and mood, in addition to cognition.

Individuals living with dementia often display a reduction in their participation of cognitive and social activities, which can begin long before a diagnosis is reached [61]. Thus, promoting interaction and engagement in cognitive stimulation activities is important for individuals with dementia, with very little to no drawbacks and can be successfully conducted in community and hospital-based settings [62].

In the UK, this forms a major component of the groups for people living with dementia which encourage a supportive environment for people effected by dementia. From the research literature, the implementation of cognitive stimulation has been shown to elicit favourable benefits, from reducing cognitive decline, improving memory, reducing symptoms of depression and preventing a decline in dementia severity ratings [63].

These benefits have been estimated to equate to a 6-month delay in cognitive decline typically seen in mild to moderate dementia [60]. Cognitive stimulation therapy is not just about maintaining cognitive function. There are widely reported benefits that are critical for promoting individuals with dementia to live well and maintain a fulfilling day to day life. Improvements in communication skills and social interactions have been reported from regular attendance to group cognitive stimulation sessions [60]. This can significantly benefit relationships between people with dementia and their caregivers resulting in a more positive outlook or optimism about the future [64,65].

Cognitive stimulation therapy can be performed at an individual level, which has also been shown to increase communication between caregiving dyads if performed regularly [66]. However, more significant benefits appear to arise from group interactions. An increased togetherness and shared identify, group support, group entertainment and the importance of companionship have been identified as key themes from group cognitive stimulation therapy [67].

Overall, increasing the provision of access to group cognitive stimulation therapy across the UK would represent a cost-effective way to improve the lives of individuals effected by dementia [68]. However, from the research literature it is clear that more evidence is needed to understand how to get the maximum benefits out of sessions. Wide-ranging implementation, duration, number of sessions and non-standardised delivery between sessions appear to explain the differences in benefits observed. Current best practice is suggested to provide access to twice weekly sessions, ideally in groups, to individuals as early as possible in the stage of dementia [60].

### **Multidomain Lifestyle interventions**

Research into the effectiveness of lifestyle modification has been increasing with a move towards more multidomain interventions [69]. Multidomain interventions bring together several aspects of behaviour change, for example, bringing cognitive training, nutritional advice and education, and a physical activity programme together, with the aim to slow the progression of, or prevent, dementia.

These combinations of lifestyle intervention are important as it is unlikely that changing a single domain of behaviour will have a significant impact on dementia risk over the duration of a study which can be relatively short in duration. This is highlighted by the multifactorial nature of dementia that progresses over a number of years. This may explain why there are differences in effectiveness from single domain interventions for improving cognitive function and quality of life.

A good example of can be found in the Dementia and Physical Activity (DAPA) trial, which found no effect of a 4-month intensive exercise program on cognitive function at 6 and 12 month follow ups [70]. However, physical fitness did increase, as measured by a 6-minute walk test. Physical fitness in older adults may be related to future cognitive decline and is linked to maintaining functional independence [71], thus, being more physically active is important for people with dementia and may impact caregiver burden. In contrast, the Promoting activity, independence and stability in early dementia and mild cognitive impairment (PrAISED) trial found no beneficial effects of a physical activity rehabilitation

programme on physical function compared to usual care. Whether there was any psychosocial benefits or changes in caregiver burden was not measured [72].

Multidomain interventions combining education with dietary changes, increased habitual physical activity and cognitive stimulation to varying degrees have shown more promise in favourable outcomes for people with dementia compared to single domain trials. These trials often have a significant behaviour change component to maintain participant engagement over longer periods of time [73,74]. Currently, the general recommendation is to remain cognitively, physically, and socially active in midlife and later life. Changing behaviours or habits can be difficult for many people, especially in mid-life, as we often do not think about how our current lifestyle could impact our brain health as we age. In addition, the implementation of lifestyle changes and engagement in psychosocial activities brings very little downside.

Keeping people with dementia physically healthy is important for their cognition. People with dementia have more physical health problems than others of the same age but often receive less community health care and find it particularly difficult to access and organise care. People with dementia have more hospital admissions than other older people, including for illnesses that are potentially manageable at home. Engaging in favourable lifestyle behaviours can significantly impact the burden of comorbidities and consequentially improve wellbeing and quality of life for people with dementia and thus, helps move towards healthy ageing.

### **Psycho-social and educational support in the management of dementia**

To increase the quality of life and wellbeing of people with dementia we must also consider the complex emotions and changing needs/demands that come with progression of the disease. As our ability to detect and diagnose dementia earlier improves, there will be a greater need for access to services to help develop support packages to ensure people can live well with dementia. It is therefore not surprising that a significant number of European countries prioritise the integration of structured support systems, aim to provide information and support at the earliest stages of dementia and create centres for meaningful and engaging activities for people with dementia and their caregivers [75].

The major focal point of these strategies is to facilitate people to live well with dementia. In the United Kingdom, the 'Major Conditions Strategy' has replaced any dementia specific policy and instead aims to develop a holistic approach to population level health. This makes sense from a risk factor viewpoint. As previously mentioned, 45% of dementia may be prevented by changing lifestyle factors, which are also likely to lower the risk of other comorbidities such as cancer or cardiovascular diseases. Therefore, any strategy that promotes preventative measures and support to reduce risk factors will likely improve the incidence rates of dementia in the UK. However, it is not known whether any specific targets will be included related to dementia, and it is critical that services are properly funded and developed to meet the needs of individuals currently living with dementia and their caregivers.

Support for individuals and their caregivers should include accurate and timely information and education about dementia, from what to expect following a diagnosis of dementia, how to manage risk factors, available treatment options and what access to services are open.

One ongoing approach currently being researched is the PRomoting Independence in DEmentia (PRIDE) program [76]. The PRIDE program worked on the development of a guide manual aimed at encouraging people with mild dementia, particularly those recently having recently received a diagnosis, to maintain activities of daily living and subsequently their independence. Some people with dementia may choose to live alone and for those individuals, retaining independence and routine can be very important. Living alone may also

be a result of certain circumstances rather than by choice and extra support is likely needed for these individuals. For others, family members, friends and neighbours may be significant caregivers, through significant time points including the onset of symptoms, receiving a diagnosis, reducing ability to perform activities of daily living and end-of-life care.

Psychosocial support can also greatly benefit caregivers of people living with dementia as well. If neuropsychiatric symptoms progress, or more intensive care is needed by a person with dementia to assist with daily activities, carers may experience declining mental health, increased stress and possibly a strained relationship with the person they provide care for [77]. Feelings of guilt and distress are not uncommon among caregivers [78].

As highlighted above, providing information and education can facilitate people to live well with dementia and support the needs of caregivers. Whilst providing information alone is not likely to change the outcomes of the disease, people with dementia and their caregivers, can significantly benefit from access to information when offered at the right time. In early stages of dementia, individuals can play an active role in future planning and voice their preferences for care options. This can also enable planning for potentially difficult conversations surrounding legal and financial situations. The Support, Health, Activities, Resources and Education (SHARE) care-planning intervention reinforced the importance of support in early planning for future care [79].

Building rapport and establishing effective communication is important for initiating care-related discussion in the early stages of dementia. Education about what can be expected from health professionals is also important to increase awareness of diverging attitudes surrounding care options. Building trust between people living with dementia, their caregivers and external supporting roles is important to maintain effective communication and the best outcomes for all involved [80].

One way to improve the provision of education is through support groups. Such groups can also act as a social network and meeting place for people with dementia and their caregivers with people going through similar life circumstances, or professionals with relevant experience. Social support groups have been shown to be helpful in reducing feelings of isolation. Group interactions can encourage the sharing of personal experiences, shared engagement in activities and the opportunity to learn from others which can significantly enrich relationships between people with dementia and care givers [81]. This can be particularly important if caregiving hours increase, as having the opportunity to engage in social networks can reduce perceptions of caregiving burden.

Social support doesn't have to be in the form of group meetings, there is evidence that one to one or small group counselling, psychotherapy, respite, and broader care coordinated programmes that integrate multidomain interventions can improve care for people with dementia. Similar to cognitive stimulation therapy, support groups have been implemented using both in person and online delivery methods and are effective for improving caregivers' psychological wellbeing, including depression, anxiety, burden and caregiving competence [82]. In particular, these support programmes can significantly improve caregivers outcomes by matching the changing demands of caregiving and enable tailoring support interventions that meet specific needs [83].

A major component of social support groups is information sharing enabling caregivers to increase their knowledge of the illness, develop problem-solving skills and integrate into social support structures [84]. Interestingly, evidence suggests technology-based Interventions significantly affect perceived caregiving burden while group-based Interventions affect anxiety, depression, insomnia and burden and quality of life and self-efficacy [85].

A review of the available scientific evidence for implementing multicomponent psychosocial interventions found that overall global physical activity, cognitive functions, and activities of daily living were improved, in particular those interventions with a social aspect. However, whether specific activities are more or less beneficial for different types of dementia, are impacted by the setting of the intervention or when implemented at different symptom severities is not known [86]. This is important to consider as there can be some unintended negative outcomes. One example of this, comes from the implementation of museum visits for people with dementia and their carers which mostly elicited positive outcomes for shared respite and reduced social isolation [87]. However, for some people, the increased intensity can heighten stress and caregiver perceived burden. This emphasises, that tackling dementia care is not suited to a one size fits all approach.

Another example can be seen because of the Covid-19 pandemic which greatly restricted access to group activity for people with dementia. In the UK, memory cafes form an integral component of available dementia support and can greatly enrich people's lives. As a result, efforts were made to set up virtual memory cafes, which could still bring social connectedness to people with dementia and caregivers. Importantly, this model of online memory cafe could also serve as a model for geographically marginalised and underserved areas. However, this requires access and the ability to use technology and may not be as appropriate for those at later stages of dementia [88]. In fact, whether caregivers engage with available services is highly personalised and dependent on multiple factors which may reflect the type of support offered.

Findings from a randomised control trial aiming to understand why caregivers may reject services offered from general practitioners showed that support for mental and physical health, and legal, financial support was widely accepted. However, social integration, specifically for caregivers, was rejected most and was dependent on the severity of symptoms experienced by the person living with dementia. Those with high physical function tended to reject support more often than those with lower activities of daily living, possibly due to a lower perceived care burden. This highlights the important of tailoring support services to meet the needs to caregivers and for an emphasis to be placed on the benefits of early integration into support services for the people living with dementia [89].

Since emerging from the pandemic there has been an opportunity to rethink dementia services in the UK, especially with the extra strain on the NHS services reducing the already limited access to post-diagnosis dementia support. Clearly, access to coordinated multicomponent physical and psychosocial interventions need to be enhanced with interdisciplinary teams of practitioners and carers. To achieve wide reaching and inclusive centres within communities there needs to be better connectedness between health care practitioners, carers, and volunteering groups.

## **6. Volunteering and the future of care for living well with dementia**

Volunteers form an essential part of the health and care community in the UK, giving their time and talents to support people beyond their close family [90]. Volunteering in the UK strengthens the link between the national health services (NHS) and local communities. This can ensure people in need of health and social care receive the best experience possible and reach marginalised communities who may otherwise not engage with available support.

Volunteer services facilitating recreational programmes have been found to promote feelings of social connectedness and improve mental wellbeing in both people living with dementia and carers [91]. In addition, volunteering can complement health services and increase the reach or services to people with dementia and other long term care requirements [92]. Ensuring that voluntary services are able to maximise their impact on communities and

increase resources available to family's effect by dementia is important, especially as novel therapeutic options become available and people are living longer with dementia [93].

The NHS taskforce for volunteering highlighted the need to improve the ease in which people can find voluntary roles and find ways to improve services user experiences [94]. With such an important role in enabling individuals to live well with dementia, it is important that we understand the motivations and needs of volunteers so that they can operate effectively, and available resources can be maximised. Whilst there is evidence that volunteering can be a highly rewarding endeavour with a significant impact on the lives of those effected by dementia there are several barriers that may limit a person's willingness to volunteer. Some of these have been identified as the lack of support and a lack of skills training [95].

From the 'Stepping Stones' programme, which looked at the perspective of older adults who volunteered in an activity based social programme for people with dementia, it was found that being part of a team and gaining satisfaction from social relationships was an important outcome. In addition, volunteering can help older adults deal emotionally with the prospect of experiencing dementia themselves or through a close relative [96]. In fact, the social relationships formed between volunteers, people affected by dementia and their families and paid care providers can be robust [97].

Another key motivator for people continuing to offer their time in voluntary services, is to have a clearly defined role within a team. This also includes setting expectations on the role from an early point [98]. This does not mean that training is unimportant, and volunteers can become part of wider dementia care teams. In fact, providing suitable training can improve psychosocial outcomes for both individuals with dementia and positively impact the experience of the volunteers [97, 99, 100].

Evidence from a volunteer training course that included theory and practical sessions over a 6-week period was highly valued by attendees, raising awareness about dementia and improving confidence in volunteers. This course involved training on providing person centred care, communication skills, health and safety, safeguarding for vulnerable adults and managing neuropsychiatric symptoms in people with dementia [101].

The provision of quality training has the power to shift attitudes towards what volunteering can do for people with dementia and improve knowledge about the disease. Although positive effects have been identified for the role of volunteers in enabling people to live well with dementia, there is a lack of research into the long-term effects of voluntary services on meaningful outcomes for people with dementia. This also extends to the lack of insight into the optimal form of training deemed to be most beneficial for volunteers to receive. This possibly undervalues the importance of voluntary services as a vital asset in dementia care. Moving forward, policy makers should increase efforts to facilitate the integration of volunteers and health professionals into communities to assist with improving the quality of life for people who have received a diagnosis of dementia and to support their caregivers [102].

A key intervention whereby volunteers play a fundamental role in helping others to live well with dementia is through community-based dementia support groups. These regular meeting points offer a safe and supportive environment for people with dementia and carers to engage in meaningful activities and discussions. In many cases this will combine psychosocial support, cognitive stimulation therapy and educational resources.

Several key components derived from the research literature highlight the need to build an opportunity to hold regular meetings, create an inclusive atmosphere, recruit trained/ experienced volunteers, host at a suitable and accessible location and a provide programme



of activities that reflects the interest and talents of those attending [103]. Additionally, the collaboration between medical professionals or research institutions and voluntary services can increase participation in meeting centres and create an effective hub connecting social care with medical care [104]. Bridging the gap between receiving a diagnosis of dementia and the delivery of community care and support is hugely important and should be considered in future guidelines for helping our communities to live well with dementia.

## 7. Summary

With the average age of the UK population ever increasing and the prevalence of dementia predicted to increase significantly, there is a growing pressure on health services to offer support for people living with dementia. Although developments in drug discovery continue to bring us closer to effective treatments, these are still far from being readily available and offer limited therapeutic benefit for a small number of individuals. However, as many as 45% of incident dementia cases are estimated to be preventable through lifelong engagement in healthy lifestyle habits. This means that emphasis is needed to highlight the impact of early and midlife health-related activities on later life risk of dementia and co-morbidity.

To meet the needs of individuals living with dementia, the UK needs to improve access to key services. Dementia support groups represent an existing community-based meeting point, that could be upscaled to provide access to psychosocial support, cognitive stimulation therapy and act as hubs of information for individuals needing additional support. In this sense, a multidomain lifestyle enrichment approach could be delivered directly into local communities which have been shown to be effective. There is good evidence that group-based support can improve the lives of people living with dementia and their caregivers. Importantly, by acting as hubs across the UK, dementia support groups can help to assist those currently without a dementia diagnosis to gain help if they are concerned over their health or the health of a loved one.

To maximise the effectiveness of group-based support, they need to run multiple times per week, offer education and opportunity for engagement in a range of cognitively stimulating activities. Within the groups, each individual will have specific needs and preferences that should be considered and accommodated into the running of sessions where possible. To mitigate against circumstances that would restrict access to support, or to increase the offering of support services, online groups could be integrated to create a blended approach. Further research is needed to fully understand how group-based meetings can be optimally delivered for maximum benefits.

It is important that people living with dementia are included in the development of ideas and are consulted in further research. Ultimately, these services should encourage citizenship and group belonging rather than creating an environment whereby people living with dementia feel like patients using a service. To achieve this, it is important to consider that dementia services in the UK rely heavily on the voluntary sector and unpaid caregiving, and demands on these services are going to increase significantly.

This means that increased funding for the provision of such services, opportunities for volunteer training and education and integration into multidisciplinary care teams across the UK is essential if we are to enable our society to live well with dementia.

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