OXFORD BROOKES UNIVERSITY

ipc institute of public care

Supporting People Living with Dementia:
Evidence from Research

April 2023

Briefing Paper

Contents

Supporting People Living with Dementia: Evidence from Research

1. Introduction

More than a decade ago – in March 2012 – the then Prime Minister David Cameron, set out his "challenge on dementia," and the ambition "to make a real difference to the lives of people with dementia." Three key areas for action were identified:

- Driving improvements in health and social care.
- Creating dementia friendly communities that understand how to help.
- Better research.

An update on the policy in 2015 raised the bar and set its sights on the twin goals that by 2020 England would be:

- The best country in the world for dementia care and support, and for people with dementia, their carers and families to live; and
- The best place in the world to undertake research into dementia and other neurodegenerative diseases.

It is difficult to judge what the 'balance sheet' currently looks like, but the impact of Covid-19 since 2020, combined with the downturn in the economy and the rise in inflation have combined to create enormous pressures on public services, notably including health and social care. The consequences for many people living with dementia will have been negative, with people struggling to get access to care and support.

1 in 5 of people aged 90 and older have dementia.

In the United Kingdom it is estimated that 850,000 people have dementia, and that this is true for one in 14 people aged over 65. The likelihood of developing dementia increases exponentially with age and the ageing of the population and the growth of the very elderly cohorts are significant for the projected increase in the population living with dementia. While 1 in 71 people aged 70-74 have dementia, this is true of 1 in 13 people aged 80-84, and almost 1 in 5 people aged at least 90 (Parkin & Baker, 2021). Because of the growth in life expectancy and the survival of many more people into their 80s and 90s, the numbers of people living with dementia in the UK are expected to double by 2040.

There have been some hopeful developments in clinical research, including the announcement in November 2022 concerning the impact of Lecanemab on the early stages of Alzheimer's, and slowing the rate of progression. However, for people already living with dementia, particularly at advanced stages, such developments offer no immediate help or hope.

Rather than being a counsel of despair, this raises vital questions about how best to address the quality of life of people living with dementia (and their carers and family members). This is about more than 'dementia awareness', and brings a wider focus to dementia care services, and raises the vital question of what good looks like and how this should inform commissioning approaches.

This was the subject of a recent literature review that IPC undertook for Cardiff Council, but the findings are of wider relevance, and the key reflections are highlighted in this briefing paper.

2. Scoping the Evidence

It is important at the outset to understand the limitations and caveats to this exercise. We have not undertaken a conventional systematic review or meta-analysis that reviews and synthesises a vast academic literature. Such an exercise would require months of research and analysis and would result in a lengthy thesis that would probably be of considerable academic interest, but of limited value to the immediate policy and practice agenda of service commissioners and providers. We have therefore adopted a more pragmatic and limited exercise as described below.

There is a vast – and growing – research literature around dementia and we needed to establish some clear inclusion/exclusion criteria to refine our focus. We were therefore concerned with identifying:

- Peer reviewed national and international literature published between 2010-2022.
- Materials published in the English language.

This still represented a potentially enormous number and range of resources. We used the on-line library search facility of Oxford Brookes University and searched the WorldCat database which captures content from multiple publishers and suppliers.

We undertook several linked searches using different keyword combinations including:

- Dementia + timely diagnosis
- Dementia + social care
- Dementia + reducing long term care
- Dementia + innovative support
- Dementia + technology
- Dementia + BAME communities
- Dementia + LGBTQ
- Dementia + carers

We identified 23,236 references across these different searches. As we noted above, it would be impossible to review all of these for this piece of work. We organised the materials into the 'Best Match' against our search criteria and for each of the above searches we manually reviewed the top 150 items in each category and selected those which seemed to be most relevant and saved these citations to EndNote.

After removing duplicates from the various searches, we have a library of 530 citations. This is still a very large dataset, and we do not claim to have been able to interrogate all the items, as this would be a major undertaking and would require months of investigation.

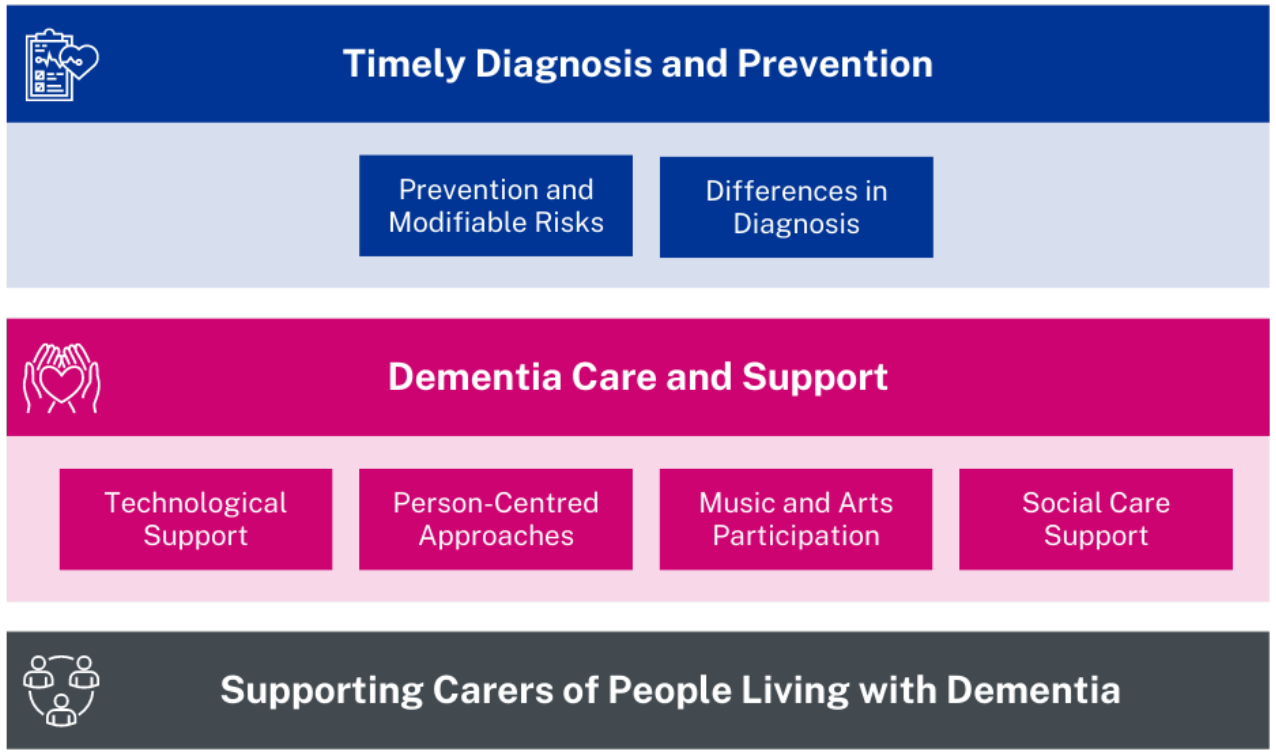
This is a rich and diverse set of contemporary research reports and evaluations and provides a valuable resource to inform understanding of 'what good looks like' in supporting people living with dementia, and their carers. We have used this library to explore the key themes and to highlight the messages that are especially important in understanding and developing high quality and evidence-based support for people with dementia and their carers.

The literature on dementia research is extensive, but much of it comes from a biomedical perspective where the prime focus is on diagnostic models, pharmaceutical treatments and the quest for a cure. We have not included this literature in our review, rather our interest is in exploring what makes a difference, or has the most potential to make a difference, to people living with dementia and the quality of life that they and their carers experience.

This review also draws on other relevant research we have previously undertaken, including analysis for NHS England of support for older carers and carers of people with dementia (Henwood, Larkin, & Milne, 2018), and a scoping review of carer-related research evidence (Henwood, Larkin, & Milne, 2017).

The purpose of our analysis is not to provide an academic or purely theoretical discussion of the literature, but rather it is to identify the *evidence base for best practice* across a number of dimensions. In presenting this analysis we are mindful that many of the conclusions and implications go beyond the remit of the responsibilities of adult social care, but this underlines the central importance of adopting a partnership approach both with the NHS, and with wider council functions and services involved in creating a dementia-friendly city and culture.

In this briefing we highlight the key reflections across the following inter-related themes:



3. Timely Diagnosis and Prevention

The issue of ‘timely diagnosis’ is important in ensuring that people get the right support as early as possible, and it is especially relevant because dementia is often undiagnosed -an estimated two-thirds of cases in the community never have a diagnosis or contact with specialist services (Stokes, Combes, & Stokes, 2015). In addition to a lack of clear pathways for diagnosis, there are also behavioural factors that lead to delays in people seeking a diagnosis.

Research indicates an average delay of more than a year (57 weeks) between people thinking that something is ‘not quite right’ with their memory to discussing this with a family member or friend. There is a further delay of around 1.3 years between this conversation and making first contact with a healthcare professional for advice and investigation (Chrisp, Thomas, Goddard, & Owens, 2011). A delay of more than two years can be critical in losing opportunities for appropriate support (including medication) and opening a gateway to services.

Why people delay so long before seeking a professional opinion is likely to be due to a complex mix of factors including fear of likely diagnosis, and a sense of despair in the absence of a cure and a belief that ‘*nothing can be done.*’

However, timely diagnosis is vital in enabling people to live their lives and maintain independence for as long as possible. Opportunities for diagnosis in primary care are often missed, meaning that people do not get the information they need; access to interventions (pharmacological and other) that may improve their quality of life, and crucially do not get the chance to have discussions with family members and others where they can express their wishes and preferences for the future (Low, McGrath, Swaffer, & Brodaty, 2019).

“Research indicates an average delay of more than a year (57 weeks) between people thinking that something is ‘not quite right’ with their memory to discussing this with a family member or friend.”

3.1 Prevention and Modifiable Risks

Interventions that can delay the onset of dementia could have great potential. Enabling people to maintain their activities and social networks, and reduce the chances of becoming socially isolated (something that has been a particular feature since the Covid-19 pandemic), are recognised to be significant in reducing the risk factors associated with depression and dementia. There is evidence that the level of social engagement is protective against the onset of dementia; while a decline in social engagement is associated with a range of changes linked to cognitive decline.

Analysis of the English Longitudinal Study of Ageing (ELSA) on levels of social engagement of people with dementia prior to and in the two years following diagnosis led the authors to conclude:

> *“This research suggests that when an individual is diagnosed with dementia, there could be value to exploring the range of social activities they are involved in and offering social prescriptions to encourage their engagement. Further, there could be a need to ensure adequate provision of dementia-friendly social activities in communities to facilitate supportive social engagement.”*
>
> (Hackett, Steptoe, Cadar, & Fancourt, 2019, p. 9)

Some recent research has identified the role of hearing aid use in delaying the onset of dementia because of the associations between hearing loss among older people and adverse conditions including depression, social isolation, cognitive decline, falls, and reduced quality of life (Mahmoudi, Basu, Langa, McKee et al., 2019).

The reasons why hearing aids can be effective is unclear and complex, but the evidence indicates:

> *“Hearing aids may facilitate greater social engagement, decrease levels of effort required to recognise sounds and speech, decrease levels of depression or anxiety, increase levels of physical balance, and promote greater feelings of independence and self-efficacy. Believing in one’s physical and cognitive ability to engage socially and accomplish a task or participate in social events has been shown to advance cognitive functioning.”*
>
> (Mahmoudi, 2020, p. 671)

A Commission on dementia prevention, intervention and care established by the Lancet in 2017 identified 9 potentially modifiable risk factors (Livingston, Sommerlad, Orgeta, Costafreda et al., 2017). Further reviews and meta-analyses in 2020 added a further three risk factors (the last three on the list below) (Livingston, Huntley, Sommerlad, Ames et al., 2020). These are:

- Less education
- Hypertension
- Hearing impairment
- Smoking
- Obesity
- Depression
- Physical inactivity
- Diabetes
- Low social contact
- Alcohol consumption
- Traumatic brain injury
- Air pollution

The implications of the analysis are significant, as the authors remark:

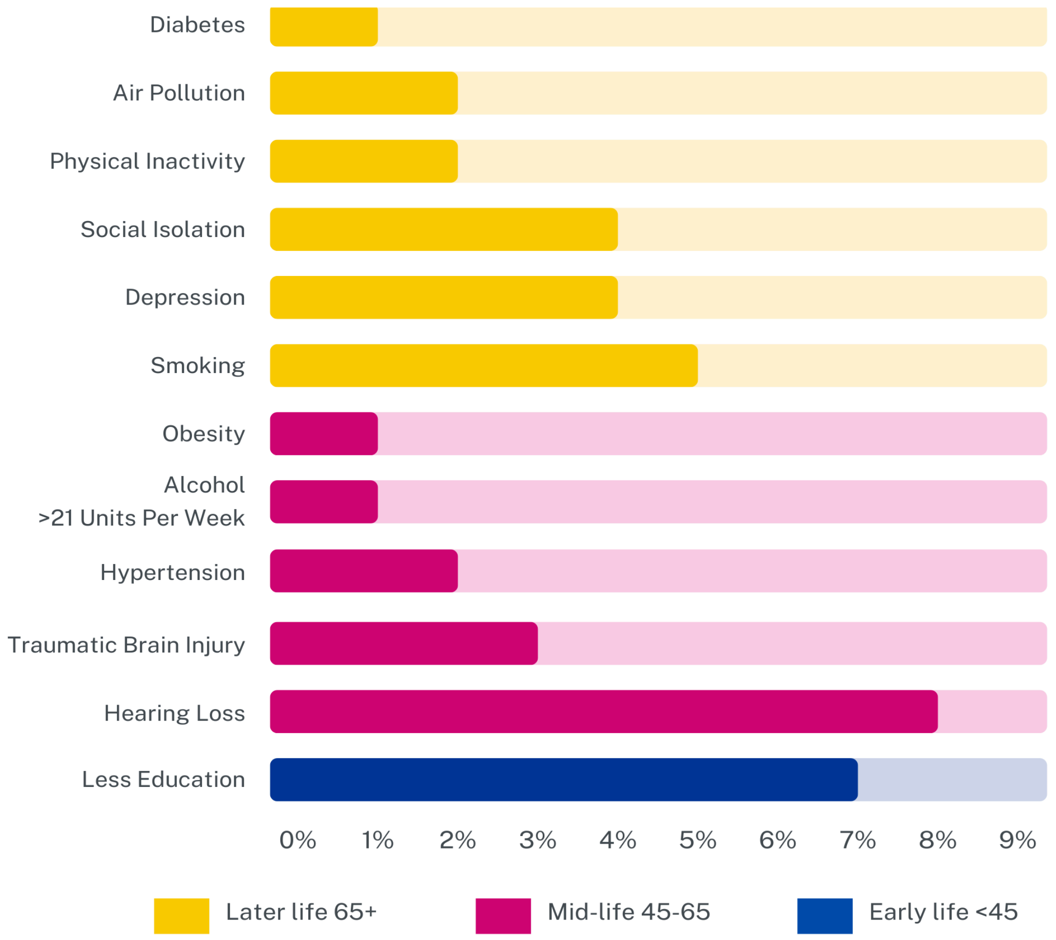
> *"Our new life-course model and evidence synthesis has paramount worldwide policy implications. It is never too early and never too late in the life course for dementia prevention. Early life (younger than 45 years) risks, such as les education, affect cognitive reserve; midlife (45-65 years), and later life (older than 65 years) risk factors influence reserve and triggering of neuropathological developments. Culture, poverty and inequality are key drivers of the need for change. Individuals who are most deprived need these changes the most and will derive the highest benefit."*
>
> (Livingston et al., 2020, p. 413)

Acknowledging that behaviour change is difficult and some associations might not be causal, nonetheless **"individuals have a huge potential to reduce their dementia risk."** Doing so requires both public health, and individually tailored interventions.

Figure 1 summarises the estimated Population Attributable Fraction (PAF) of dementia worldwide that could be reduced by eliminating risk factors, and the relative contribution of each factor.

Figure 1:

Population attributable fraction of potentially modifiable risk factors for dementia



Source: Livingston et al (2020), Dementia prevention, intervention and care: 2020 report of the Lancet Commission, Figure 7, P.428

As the figure indicates, the potentially modifiable risk factors account overall for 40% of dementias, while 60% are likely to result from unknown (and therefore currently unmodifiable) risks. The significance of less education in early life having an impact on the risk of developing dementia later in life is clear, and the single greatest risk factor of hearing loss is important to highlight, particularly if the use of hearing aids can reduce this excess risk.

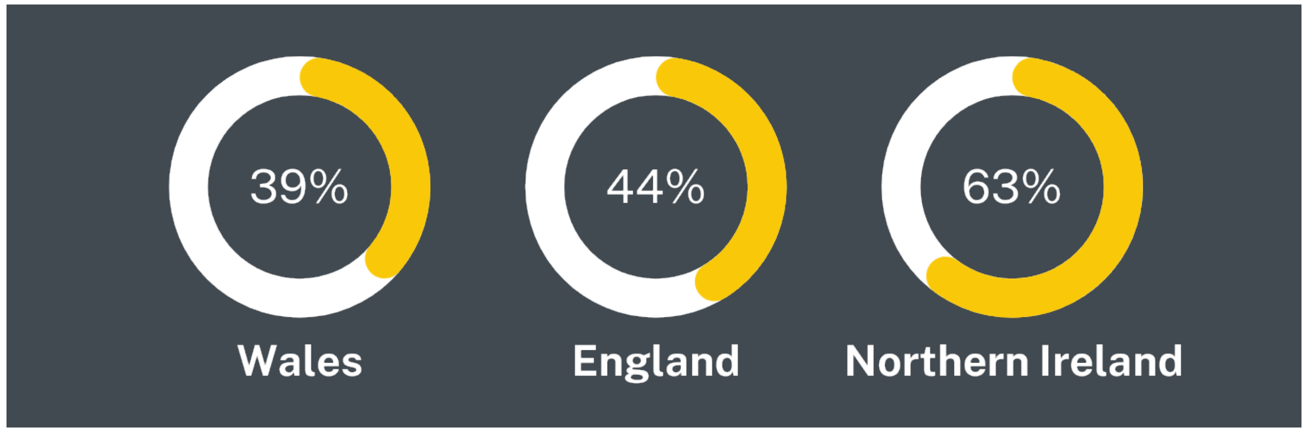
The evidence suggests that hearing loss is only associated with worse cognition among people not using hearing aids, and that "hearing loss might result in cognitive decline through reduced cognitive stimulation" (Livingston et al., 2020, p. 418).

The Lancet Commission is clear that there is a strong case for addressing prevention around dementia:

> *"Although a need for more evidence is apparent, recommendations should not wait, as clear indications of ways to reduce the chances of developing dementia without causing harm will also lead to other health and wellbeing benefits (...) Although we have more to learn about effectiveness, avoiding or delaying even a proportion of potentially modifiable dementias should be a national priority for all."*
>
> (Livingston et al., 2020, p. 429

3.2 Differences in Diagnosis

There are some significant differences in the percentages of people with dementia who receive a diagnosis within the UK. In 2012 it was estimated that this was much lower in Wales (39%), than in England (44%) or Northern Ireland (63%). Such disparities in diagnosis and disclosure are also evident between other countries across the world (Mitchell, McCollum, & Monaghan, 2013; Ng & Ward, 2019).



The reasons for under-diagnosis are, however, complex, and reasons include:

> *"personal preference not to receive a diagnosis, families' failure to recognise symptoms, the potential of causing people with dementia distress and primary care teams' reduced level of confidence in delivering a diagnosis."*
>
> (Mitchell et al., 2013, p. 21)

There is evidence that the level of social engagement is protective against the onset of dementia; while a decline in social engagement is associated with a range of changes linked to cognitive decline. Analysis of the English Longitudinal Study of Ageing (ELSA) on levels of social engagement of people with dementia prior to and in the two years following diagnosis led the authors to conclude:

> *"This research suggests that when an individual is diagnosed with dementia, there could be value to exploring the range of social activities they are involved in and offering social prescriptions to encourage their engagement. Further, there could be a need to ensure adequate provision of dementia-friendly social activities in communities to facilitate supportive social engagement."*
>
> (Hackett et al., 2019, p. 9)

It is, of course, important not to discuss dementia as a single condition, or to imply that all people with a dementia diagnosis have the same needs. This also has implications for diagnosis. Killen et al explored the support and information needs of people with Dementia with Lewy Bodies (DLB), and the general lack of condition-specific information provided around the time of diagnosis:

> *"Respondents identified the importance of tangible support and information around diagnosis, yet 50% stated that they were not offered this. The current lack of DLB specific support groups excludes access to the benefits of emotional and instrumental social support from peers."*
>
> (Killen, Flynn, De Brún, O'Brien et al., 2016, p. 499)

Diagnosis of other groups of people with other forms of dementia is a further consideration, and this is a particular issue with regard to people with learning disabilities. With the longer life expectancy of people with learning disabilities, such as Down's Syndrome, many are now experiencing additional age-related cognitive impairment including dementia (Krinsky-McHale & Silverman, 2013).

A study using a large nationally representative sample examined incidence of dementia diagnosis by White, Black and Asian ethnic groups in the UK and found people from a black ethnic group had a higher incidence of dementia diagnosis, and people from Asian backgrounds had a lower incidence, compared with the white population (Pham, Petersen, Walters, Raine et al., 2018). However, the higher incidence of dementia among Black men only partly reflected the actual incidence:

> *“We estimated that Black men with dementia were around 10% less likely to be diagnosed than white men. The lower incidence of dementia diagnosis in Asian populations may reflect underdiagnosis or lower incidence of dementia.”*
>
> (Pham et al., 2018, p. 957)

The incidence of dementia among Asian populations particularly reflects vascular dementia; (the second most common type of dementia after Alzheimer’s Disease) older age, male gender and Asian ethnicity are all identified as non-modifiable risk factors for vascular dementia (Reichelt, Lewis, Burgess, & Allan, 2018). However, as the Lancet Commission also emphasised, there are higher risks for socially disadvantaged groups that include disproportionate numbers of Black, Asian, and minority ethnic groups, and there are modifiable risk factors to address both through health promotion and in wider strategies to reduce inequalities and promote safer, healthier environments (Livingston et al., 2020).

There is a lack of effective treatments for vascular dementia (with no recommended pharmacological treatments), and intervention is generally focused on the modifiable risk factors that include hypertension, diabetes, obesity, smoking and exercise to reduce the incidence and progression of vascular cognitive impairment (Reichelt et al., 2018).

The need for assessment is nonetheless important:

> *“Assessment can aid understanding about the presence of any significant cognitive concerns, and enables access to other support and services which can greatly improve quality of life, and promote independence.”*
>
> (Reichelt et al., 2018, p. 14)

Receiving a diagnosis of dementia can have a profound impact on people, and the fear of what it might mean can lead to feelings of loss, anger and depression. There is some evidence that the risk of suicide in the first year after diagnosis increases, and underlines the importance of support at the time of diagnosis (Schmutte, Olfson, Maust, Xie, & Marcus, 2021).

There is controversy around increasing diagnosis rates, with some arguing that it leads to increased anxiety and misdiagnosis, and warning against early diagnosis being seen as an end in itself (Trueland, 2013). Partly as a reflection of this debate, there has been a shift away from focusing on ‘early diagnosis’ and greater emphasis placed on ‘timely diagnosis’ (Trueland, 2013; Watson, Bryant, Sanson-Fisher, Mansfield, & Evans, 2018). However, determination of what is ‘timely’ needs to be person-centred and it will vary between people, with some preferring to know as soon as clinical tools indicate a probable diagnosis, and others preferring not to be told until later, or indeed at all. Watson et al observe:

> *“People with cognitive impairment are capable of expressing their preferences in relation to their health care and desire for involvement in decision making. All consumers should be given the opportunity to indicate if and when they would like to be told about a diagnosis of dementia. Enabling people with dementia to exercise such control may be the first important step in ensuring enduring person-centred care and respect for autonomy from pre-diagnosis to later life.”*
>
> (Watson et al., 2018, p. 7)

A review of family carers’ experience in 5 European countries, involving more than 1,400 participants found almost half (47%) of carers would have preferred an earlier diagnosis (Woods, Arosio, Diaz, Gove et al., 2019). The most common factor associated with delayed assessment concerned the reluctance of the person with dementia to have an assessment.

The study also found that the manner in which a diagnosis was shared could have a considerable impact on adjustment:

> *“There was a clear association between quality indicators of the diagnostic-disclosure process and immediate and later adjustment, in relation to acceptance and feelings of sadness and depression.”*
>
> (Woods et al., 2019, p. 120)

4. Dementia Care and Support

As the above discussion of dementia diagnosis has indicated, a diagnosis should be a critical point in the journey of people living with dementia, and of their carers, in accessing appropriate care and support. We are not concerned here with reviewing the effectiveness of pharmacological treatments, but with other interventions which enable people to maintain quality of life and independence for as long as possible.

It is important to acknowledge that all carers are different and that they will have different needs depending on where they are in the 'dementia journey.' Research by Newbronner et al is helpful in understanding the journey and identifying the key stress points when support or advice is most needed (Newbronner, Chamberlain, Borthwick, Baxter, & Glendinning, 2013). It is also clear from other research that carers typically experience the health and care system as confusing and at times impenetrable (Peel & Harding, 2014).

Below we explore some of the key messages and evidence emerging from the literature. We need to be mindful of the context in which this discussion takes place, and particularly of the impact of the Covid-19 pandemic on people. The lock-down measures and enforced social isolation which were introduced in most countries to a lesser or greater degree, and often for extended and repeated durations, had a significant impact on people's health and wellbeing (Liu, Howard, Banerjee, Comas-Herrera et al., 2021).

Page et al explored the impact of mask wearing and social distancing on people with dementia on mental health wards in hospitals in Wales, and found that mental health nurses were able to adapt their care, particularly around the restrictions on visiting by families (Page, Davies-Abbott, & Jones, 2021). This cohort of people were those with moderate to severe dementia whose mental health needs were such that they could only be cared for in an NHS mental health unit. Despite expecting highly negative impacts on people, the research found patients experiencing higher levels of mood and engagement:

> *"We suggest that these outcomes were directly attributable to sensitive and adaptable mental health nursing care with practitioners deliberately shifting their focus, to aspects of care they believed would provide the greatest patient benefit."*
>
> (Page et al., 2021, p. 966)

Nursing care staff were able to increase their non-verbal communication techniques to adapt to the difficulties of mask wearing and other PPE limitations. This does not mean that short-term strategies and adaptations would be maintained throughout the different waves of Covid-19, and nor does it mean that the behaviour of nursing staff in this case study was typical, but it does indicate that mitigation is possible.

However, there are some significant risks and threats to the nature and quality of dementia care because of Covid, as the authors comment:

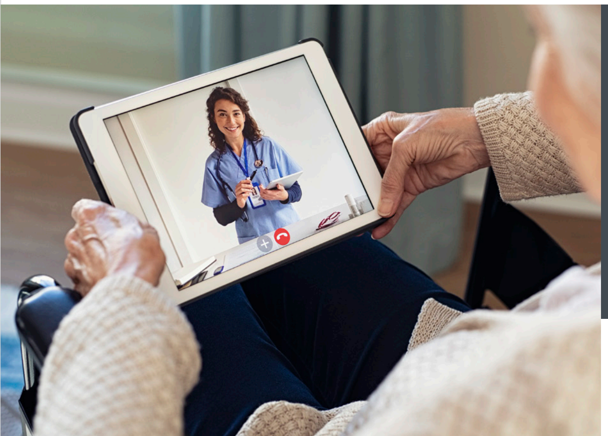
> *"It may be that dementia care services are at risk of stalling the progress made regarding person-centred approaches as the physical barriers, potentially symbolized by PPE, may result in care givers feeling less able to provide psychosocially supportive care and may lead to a focus on the physical tasks of meeting the need for comfort at the loss of the psychological comfort."*
>
> (Page et al., 2021, p. 968)

For some people with dementia, and for their carers, the impact of Covid was further magnified because of the closure of services (such as day care) and the shutting down of visiting opportunities for residents in care homes. Commentators suggest that:

> *"Such a drastic shift in their lives and enforced physical inactivity are expected to lead to a significant worsening of their cognitive and functional status, exacerbation of pre-existing neuropsychiatric symptoms, and onset of new disruptive behaviours. As a consequence, this snowball effect adds more strain to already high levels of burden and exhaustion of their familiar relatives, especially those who have become full-time carers and/or are in remote working."*
>
> (Barros, Borges-Machado, Ribeiro, & Carvalho, 2020, p. 1)

This has been supported by findings from an online survey of carers in Spain which found people with dementia experienced deterioration of symptoms during lockdowns including increased agitation, apathy and sadness. At the same time, their carers reported increased anxiety and depression (Carcavilla, Pozo, González, Moral-Cuesta et al., 2021). Many people coping with the restrictions brought by Covid-19 would have reported similar negative emotions and deteriorating mental wellbeing, but the impact is likely to have been intensified for people living with dementia, and for their carers supporting them with little or no help during this difficult time.

However, while the pandemic has had major and multiple negative impacts, it has also seen the emergence of new models of support as a pragmatic response to circumstances. Weens et al describe how some in-person support models have 'pivoted' during covid to offer virtual care (Weems, Rhodes, & Powers, 2021).



"While the pandemic has had major and multiple negative impacts, it has also seen the emergence of new models of support as a pragmatic response to circumstances."

Despite being developed as an alternative model because of extraordinary barriers to traditional forms of support, there is likely to be value in maintaining a range of approaches in future, although virtual models of delivery are largely unevaluated as yet:

> *"Virtual support can extend outreach, addressing access and providing safe care during a pandemic; however, implementation differs among organizations. Some elements of virtual support may be long-lasting beyond the pandemic as they represent efficient ways to increase access, facilitate engagement, and address isolation."*
>
> (Weems et al., 2021, p. 11)

4.1 Technological Support

There is growing interest in the scope for using technology to support people with dementia, and since 2017 the Social Care Institute for Excellence (SCIE) has been supporting a web resource 'Using technology to support people with dementia', based on a belief that technology can enhance, rather than replace, human relationships. Technology is seen "as just a useful tool", rather than as something that can or should replace vital human contact (Holmes, 2017).

Technology-based tools and support for people with dementia refer to a wide range of models and approaches. Lorenz et al have identified 7 different types of assistive technology (Lorenz, Freddolino, Comas-Herrera, Knapp, & Damant, 2019):

- The largest group of technologies were concerned with safety and security (from smoke detectors to pendant alarms).
- The second largest group of interventions were concerned with enhancing people's memory (usually people in early stages of dementia).
- A third group was concerned with treatment and care delivery – such as technology-aided reminiscence.

Their review identified the range of technologies that are available for people with dementia and their carers, but:

> *"There is very little evidence of widespread practical application. Instead it appears that stakeholders frequently rely on everyday technologies re-purposed to meet their needs."*
>
> (Lorenz et al., 2019, p. 726)

The authors comment that in order for technologies to be effective for people with dementia and their families, they need to be accessible at the right time, able to adapt to changing needs, easy to use and low cost. People do not have the time or resources to invest in technologies that may not be of lasting value and are more likely to use existing technology (such as mobile phones and baby monitors) to meet their needs.

The use of assistive technology (AT) and telecare to support independent living among people with dementia is widely promoted, but there has been little evaluation or evidence of effectiveness.

Assistive Technology or Smart Assistive Technology (SAT) refers to mechanical or electronic devices intended to support independence and quality of life by assisting with daily living activities, reducing risks and improving communication. This includes, for example, reminder and prompting devices, monitors and detectors. Telecare refers to monitored alarms and sensors also intended to support people living independently.

A useful summary of some of the key issues that arise in the use of technology supporting people with dementia has been produced by Alzheimer's Queensland:

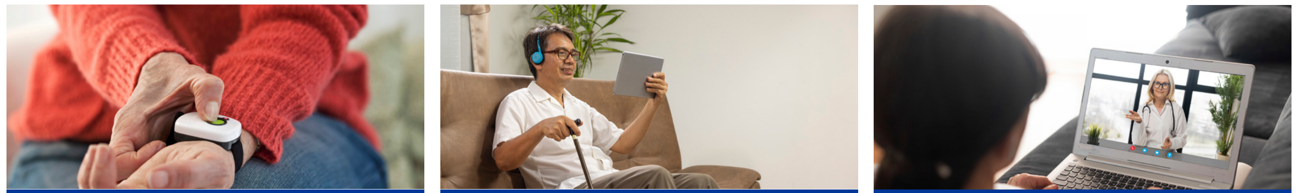
- Identifying what the actual need is.
- Establishing whose needs are being met by use of the SAT.
- As needs change there should be regular follow-up to ensure ongoing suitability of any SAT.
- SAT use does not resolve all caring needs and is not a substitute for human contact.
- One size does not fit all.
- A SAT requiring active participation and learning by the person with dementia who has declining capacity can be impractical.
- There are interface issues between multiple systems on the market.
- Questions of privacy and autonomy arise when the person with dementia is not the person making decisions about use of SATs. (Mackrani, 2015)

Much of the research literature on technology in supporting people with dementia is descriptive, or concerned with 'mapping' what exists, while much less attention has been directed to evaluation of impact. There is a gap in high-level evidence, and studies often have small sample sizes, lack a control group and are concerned with short-term interventions without follow-up. Hoel et al comment that this "generates weak evidence that is not always generalizable" (Hoel, Feunou, & Wolf-Ostermann, 2021).

A scoping review of assistive technology products in the UK identified 171 ‘products’ and 331 services, which they suggested could be organised into 11 categories based on purpose and function, as summarised below (Gibson, Newton, Pritchard, Finch et al., 2016).

Figure 2

Types and Sub-Types of AT in Dementia



Used "by" people with dementia

- Time/place orientation
- Prompts and reminders
- Communication aids
- Tools and aids
- Alerts and alarms

Used "with" people with dementia

- Prompts and reminders
- Play and enjoyment
- Reminiscence

Used "on" people with dementia

- Telecare systems
- GPS and location alarms
- Safety and security

Devices used *by* people with dementia are those that can be used independently and are focused on helping people with daily activities, by providing prompts and reminder alarms. Devices used ‘with’ people with dementia refers to those technologies that encourage communication and interaction, such as through reminiscence aids, games and activities. The third class of technologies (used ‘on’ people with dementia) are operated without the involvement or direct participation of the person with dementia, and includes remote monitoring and alerts to formal and/or informal carers.

As the authors remark, the AT market in dementia care is highly fragmented and characterised by:

> *“Wide variation in the range and scope of products available, in access to AT services, service charges, in the range and scope of information available about AT, and in where and how AT products could be accessed."*
>
> (Gibson et al., 2016, p. 694)

The predominant focus of AT development emphasises safety and risk minimisation, leaving arguably “little room for a broader, more person-centred use of technology in dementia care.”

The use of human-interactive robots for social enrichment, particularly in supporting people with dementia, has been discussed for several years, and the baby harp seal robot ‘Paro’ is the best known of these, and mostly used in Japan (Shibata & Wada, 2011). The value of such robots in providing companionship and opportunities for interaction with people with dementia has attracted increasing attention, and generally appears to be associated with positive outcomes such as facilitating communication (Bennett, 2019; Gibson et al., 2016; Hoel et al., 2021).

Howard et al conducted a Randomised Controlled Trial of 495 people to examine the clinical and cost effectiveness of ATT in supporting people with dementia to continue living safely in their homes (Howard, Gathercole, Bradley, Harper et al., 2021). Their results did not find ATT to be cost-effective:

> *“We found provision of home-based technology, installed following an individual needs assessment within current practice in England, had no significant effect on the time that people with dementia were able to continue to live independently in their own homes. There was no evidence of cost-effectiveness in terms of days lived in the community, impact on health-related quality of life.”*
>
> (Howard et al., 2021, p. 887)

This does not mean that ATT is irrelevant, but certainly its use and appropriateness needs to be considered critically. Howard et al suggest that it would be wrong to assume that more extensive ATT systems are cost-effective compared to more basic applications including carbon monoxide detectors and pendant alarms. Basic systems may be effective in preventing harm, while:

> *“more extensive ATT systems are inadequately supported by providers, or inadequately tailored to the needs of people with dementia and their caregivers.”*
>
> (Howard et al., 2021, p. 889)

Bächle et al have also drawn attention to the uncritical adoption of ATT in the absence of evidence of economic and social impact (Bächle, Daurer, Judt, & Mettler, 2018). There is also an increasing critical voice from commentators who question the ethical and human rights implications of ATT use, and how it impacts on people’s privacy and dignity (Bennett, 2019).

In addition to monitors and alarm systems, assistive technology includes a wide range of electronic devices to help people and their carers with daily living activities. This can include reminders to take medication (and automated pill boxes), with ‘tracking devices’ at the other end of a continuum of devices. With the continued development of technology in everyday life, many of these devices may be mainstream rather than specialist technologies. The advancement of ‘smart’ devices that can activate household appliances and respond to voice controls is an area of potential application.

A review of assisted technology for memory support in people with dementia found:

> *“there is no high-quality evidence to determine whether AT is an effective means of supporting people with dementia manage their memory problems.”*
>
> (Van der Roest, Wenborn, Pastink, Dröes, & Orrell, 2017)

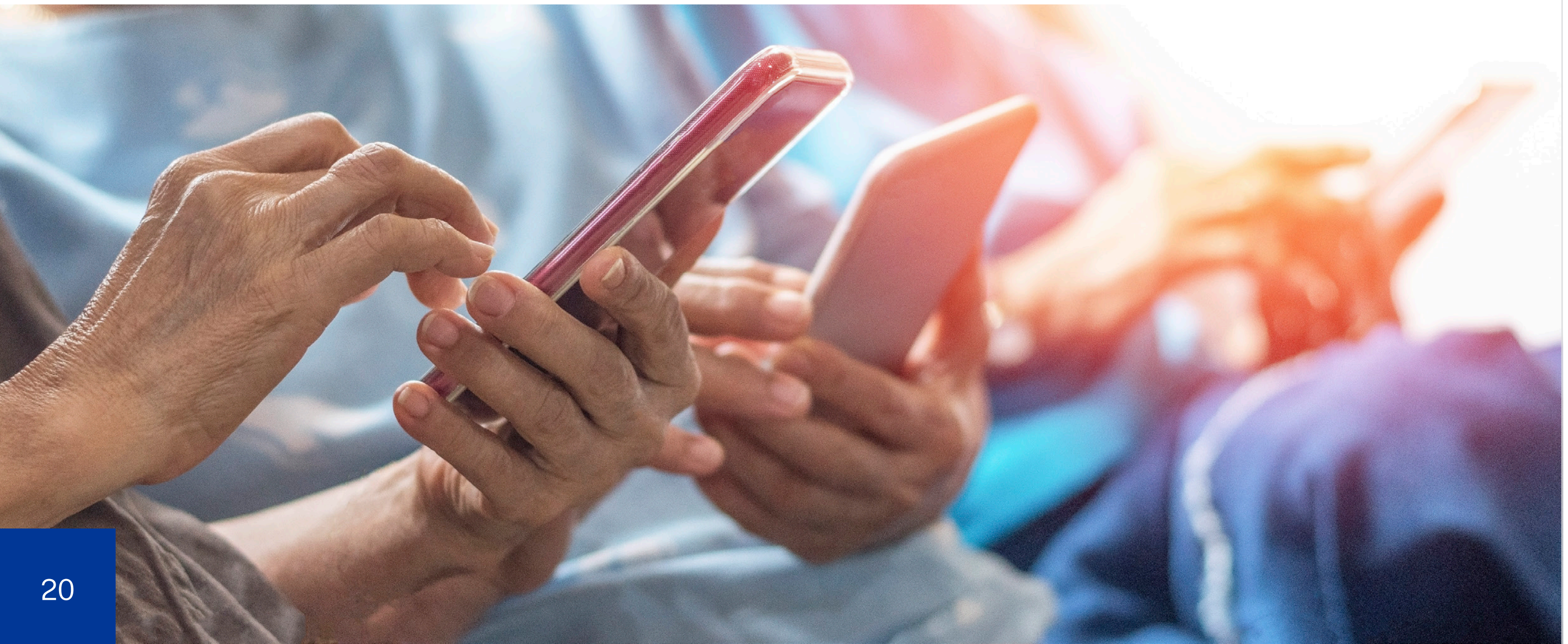
As others have pointed out, the development and application of technologies to support independent living for people with dementia needs careful introduction and support, and devices cannot simply be switched on and left. Evans et al, for example, underline the role and contribution of Occupational Therapists (OTs) can be key (Evans, Carey-Smith, & Orpwood, 2011)

It is not only people with dementia who are the focus of ATT, and consideration also needs to be given to any benefit derived by informal carers. An evaluation of the use of preventive sensors in the Netherlands observed that the system “appeared to reduce the burden of care on the informal caregiver” (Nijhof, van Gemert-Pijnen, Woolrych, & Sixsmith, 2013). In particular, carers highlighted the reassurance that the system gave them when they weren’t able to make visits or calls, as they knew there was active monitoring underway.

A Canadian study found that while carers make limited use of technology, they believe in its potential value and indicate a willingness to use it. Lack of access to technologies (smart phones, computers etc) appears to be a significant barrier to technology use in dementia care (Mo, Biss, Poole, Stern et al., 2021).

Several studies draw attention to the importance of working with people with dementia, and with their carers, both in designing appropriate technology and in adequately training and supporting them in its use. This also demands the development of training manuals and programmes for people who may have limited technological experience or knowledge (Megges, Freiesleben, Jankowski, Haas, & Peters, 2017).

As we commented earlier, the impact of Covid-19 has increased the pressures on carers (Curelaru, Marzolf, Provost, & Zeon, 2021), but also increased the awareness of the potential of technology both in supporting carers with the care of a person with dementia, but also in facilitating contact with support networks. Wojcik et al have highlighted the importance of understanding carers’ technology use and acceptance.



A survey in Poland with 102 carers of people living with dementia conducted between February 2020 and January 2021 found high current use of smartphones among carers (91%), with 81% using a computer or tablet:

> *“The main purposes of smartphone use in daily living were contact with relatives/ support, seeking information and contact with health professionals. These may also have been influenced by the Covid-19 pandemic, social distancing restrictions, and limited face to face contact. On the other hand, caregivers use the computer mainly for information seeking and hobbies/entertainment purposes. These differences in smartphone and computer use could help create new apps and programs for dementia caregivers.”*
>
> (Wójcik, Szczechowiak, Konopka, Owczarek et al., 2021, p. 10)

Such findings are consistent with other research identified above underlining the importance of person-centred approaches in developing the use of technology, and adapting existing familiar technologies rather than necessarily seeking new ones in supporting people living with dementia, and their carers.

4.2 Person-Centred Approaches

The importance of person-centred care (PCC) has already been mentioned; the personalisation agenda in social care recognises that each person has unique needs, and should be treated as an individual. This requires the focus of care to be on the whole person, their life story and their personality and preferences, and to adopt a strengths-based approach rather than focusing on the limitations caused by dementia. In addition to this approach increasingly being accepted as a principle of good practice, there is evidence that the wellbeing of people with dementia can be improved by person-centred approaches (Chenoweth, Jeon, Stein-Parbury, Forbes et al., 2015; Vernooij-Dassen & Moniz-Cook, 2016).

Person centred support has been evaluated more fully in residential care settings, but it is likely that it is equally applicable to other forms of support. Appropriate leadership in services is essential in supporting person centred approaches and supporting staff in developing appropriate skills and values:

> *“Long-term care homes, whose managers show leadership in supporting PCC, tend to produce care services that focus on meeting the unique needs of people with dementia."*
>
> (Chenoweth et al., 2015, p. 2056)

Befriending and ‘buddying’ projects are further examples of person-centred approaches which recognise people’s individuality and need for interaction and engagement. Preston and Burch point out that although such schemes are often assumed to be of value, there is a lack of evaluation (Preston & Burch, 2018).

They describe the evaluation of a volunteer dementia buddies pilot operating on two hospital wards providing mental health services for older people (one was an assessment ward for older people with dementia, and the other provided continuing healthcare for people with specialist mental health needs relating to dementia).

A different culture was evident between the wards, with staff on the assessment ward less person-centred, and this proved to have a significant impact on the performance of the dementia buddy pilot:

> *"As such, when it was piloted, its performance was found to depend on the compatibility between the caring culture of the scheme and the caring culture of the ward where it was introduced. Where these two aligned, the scheme acted as a catalyst for positive change, was welcomed by staff and carers, and led to satisfaction among the buddies. Where the two did not align, the scheme led to a cycle of disbenefits among these groups."*
>
> (Preston & Burch, 2018, p. 146)

While the comment relates to the particular example and context of the pilot scheme, the findings about the impact of culture are of wider relevance and again underline the importance of a person-centred culture being established and reinforced throughout services as a precondition for other person-centred initiatives to flourish and make positive changes.

4.3 Music and Arts Participation

Participation in the arts, including music and singing, are often identified as beneficial for older people generally, including people with dementia, but 'hard' evidence is often lacking (Chapwell, 2014; Monroe, Halaki, Kumfor, & Ballard, 2020). An evidence review commissioned by the Baring Foundation found limitations in the evidence base but identified a range of positive impacts at the level of individuals, communities and society (Mental Health Foundation, 2011). There is increasing evidence of the self-reported value of engaging in singing and community choirs for older people (as for other groups) (Clements-Cortes, 2013), and of the benefits of music for health and wellbeing (Music for Dementia UK, 2022).

A meta-analysis published in 2017 explored the effects of music on agitation in dementia and provided:

> *"The first systematic and quantitative overview supporting clinically and statistically robust effects of music intervention on agitation in dementia. The analysis provides further arguments for this non-pharmacological approach and highlights needs for future systematic research reviews for the investigation of intervention types."*
>
> (Pedersen, Andersen, Lugo, Andreassen, & Sütterlin, 2017)

Dementia friendly choirs and other singing groups are also reported to have positive impacts (Harris & Caporella, 2014; Harris & Caporella, 2019), although the measurable impact on communication skills is weak (Monroe et al., 2020).

The organisation Playlist For Life was founded by broadcaster Sally Magnusson following the death of her mother from dementia, and based on the principle that "we all have a soundtrack to our lives.": (Ranscombe, 2020)

> *"Our vision is simple: we want everyone with dementia to have a unique, personalised playlist and everyone who loves or cares for them to know how to use it."*

The website provides the resources for people to build their own individual playlist, and has links to training for care professionals.

A systematic overview of reviews of non-pharmacological interventions to treat behavioural disturbances in older patients with dementia found that overall music therapy and behavioural management techniques were effective (Abraha, Rimland, Trotta, Dell'Aquila et al., 2017. However, evidence is limited owing to methodological quality of studies and to variations in approach and definition of interventions and outcomes.

A Cochrane Review of music-based therapeutic interventions for people with dementia found 22 trials, all of which involved people living in nursing homes or hospitals. The review explored evidence of music-based interventions improving the emotional wellbeing and quality of life of people with dementia (Van der Steen, Smaling, Van der Wouden, Bruinsman et al., 2018).

> *"We found moderate-quality evidence that at the end of treatment music-based therapeutic interventions improved depressive symptoms and overall behavioural problems but did not improve behavioural problems or aggression. There was low-quality evidence that it improved emotional well-being including quality of life and anxiety, and did not improve cognition. There was very low quality evidence of benefit on social behaviour."*
>
> (Van der Steen et al., 2018, p. 25)

The authors commented that music-based therapeutic interventions may be used for people with dementia in institutional settings in order to improve depressive symptoms. Given that depression is very common among people with dementia, regardless of the stage of illness, and that it is related to low quality of life, this would seem worthwhile. However:

> *"It is not clear whether effects will persist beyond the intervention period and music-based interventions may need to be continued for prolonged periods for a sustained effect."*
>
> (Van der Steen et al., 2018, p. 27)

The interventions "probably also improve overall behaviour," but with larger effects on depression than on agitated or aggressive behaviour. There may also be improvement on emotional wellbeing, but effects are less certain than effects on depression.

4.4 Social Care Support

A systematic review of evidence on the cost-effectiveness of prevention, care and treatment strategies in relation to dementia identified the evidence on both pharmacological and non-pharmacological interventions (Knapp, Iemmi, & Romeo, 2013). As noted earlier, our focus here is not on pharmacological interventions, although there is more evidence on the cost-effectiveness of these than on other treatments.

However, cognitive stimulation therapy, tailored activity programmes and occupational therapy were found to be more cost-effective than usual care; moreover:

> *"There was some evidence to suggest that respite care in day settings and psychosocial interventions for carers could be cost-effective. Coordinated care management and personal budgets held by carers have also demonstrated cost-effectiveness in some studies."*
>
> (Knapp et al., 2013, p. 551)

Evidence on cost-effectiveness and achieving better value for money in dementia care is problematic, not least because of:

> *"the scarcity and low methodological quality of the available studies, making it difficult to draw conclusions with confidence."*
>
> (Knapp et al., 2013, p. 557)

What does quality in support for people living with dementia look like? Breen et al suggest that there is no consensus on this and defining quality involves the views of multiple stakeholders. However, dimensions that are often identified include:

- Timely, flexible and individualised support.
- Management of co-morbidities.
- Delay of admission to residential care, (Breen, Savundranayagam, Orange, & Kothari, 2021)

It is also well-documented that there are multiple challenges to care providers in delivering high quality care, including inadequate resources, poor training resulting in lack of knowledge of dementia care. Breen et al worked in Canada with care workers supporting people with dementia to identify their perspectives on quality home care, and highlighted three dimensions:

- Person-centred.
- Delivered by support workers with dementia-specific training.
- Facilitated by support worker characteristics and experiences.

However, there were differences between definitions of quality and the experience of support workers when delivering care:

> *"Participants insisted they had insufficient time to deliver quality care, their education did not prepare them fully to provide quality care for persons with dementia and they felt excluded from the interprofessional care team."*
>
> (Breen et al., 2021, p. 6)

How is social care commissioned for people with dementia living at home? A study by Davies et al used a national survey of English local authorities to explore approaches (Davies, Hughes, Ahmed, Clarkson et al., 2020). They found that joint commissioning approaches between health and social care were less likely to be used for services for people with dementia than for generic services for older people.

The authors comment:

> *"Nevertheless, as the population with dementia ages and physical health needs increase, joint commissioning of services for people with dementia and their carers will become increasingly important, informed by the experience of existing service users and their support planners. This will be important in the provision of tertiary prevention, ameliorating difficulties and enhancing wellbeing for people with dementia in achieving the goal of living well."*
>
> (Davies et al., 2020, p. 58)

If joint working is important in delivering high quality care to people living with dementia, there are questions about the different understandings and attitudes of health and social care professionals towards person-centred care in general, and support for people with dementia in particular. Dingwall et al explored whether a drama-based educational intervention with third year social work and nursing students made a difference to attitudes (Dingwall, Fenton, Kelly, & Lee, 2017). The existence of different 'models' of working between health and social care is well known, and typically referred to in terms of the clash of medical and social models of disability (Haegele & Hodge, 2016). Unsurprisingly perhaps, Dingwall et al found this was reflected in differences between social work and nursing students in 'person-centredness.'

However, it was revealing that:

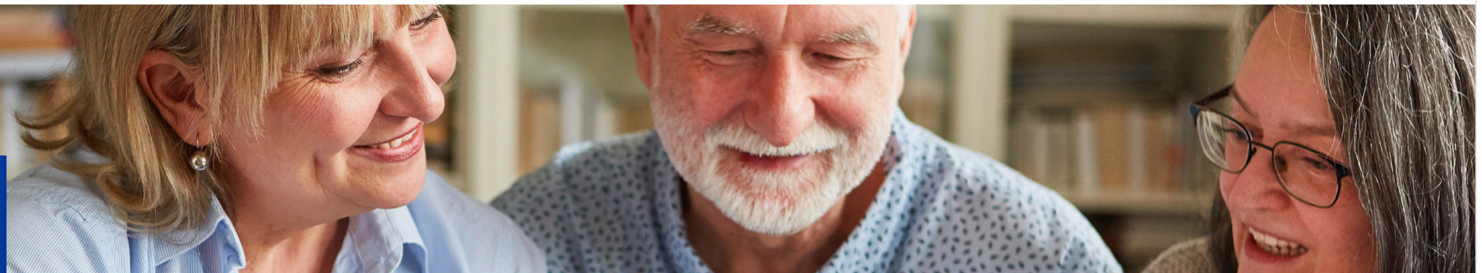
> *"Risk aversion and feeling of a lack of appreciation of the nursing role by others emerged as a fundamental barrier to true person-centred nursing practice. Overall there is a need to encourage nursing students to widen their focus from secondary care and increase their understanding of community health and social care delivery and associated decision-making processes."*
>
> (Dingwall et al., 2017, p. 6)

For both professions, the authors conclude, it is vital to understand the context of each other's practice context. They argue that a fundamental barrier to developing this understanding is that:

> *"Social work education is concerned with risk acceptance as a priority, whereas nursing education prioritises safety first."*
>
> (Dingwall et al., 2017, p. 6)

Foster et al have made similar observations about the training of Health Care Assistants (HCAs) providing most of the hands-on care to care home residents, and the tensions between person-centred approaches and the task-based demands of their work:

> *"The challenge for the aged care industry is to recognise the cognitive dissonance for HCAs when the focus of HCAs' training and development is on task-based care, and yet they are asked to embrace the philosophy of person-centred care (...) If HCAs are to be involved in the cognitive and emotional lives of residents through the shift to a person-centred care approach, the training has to be tailored to this direction."*
>
> (Foster, Balmer, Gott, Frey et al., 2019, p. 923)



Harding et al have developed a long-list 'Core Outcome Set' (COS) for use in evaluating non-pharmacological community-based health and social care interventions for people living with dementia (Harding, Morbey, Ahmed, Opdebeeck et al., 2019); it is worth exploring what it reveals, particularly because the study included the lived experience of people living with dementia as co-researchers. After refinement through stakeholder workshops, 121 outcome items were reduced to 54 outcome measures that are used in existing trials of non-pharmacological interventions or found in other key literature. These were grouped into four domains:

- Self-managing dementia symptoms
- Independence
- Friendly neighbourhood and home
- Quality of life

Further work to distil these items was planned, with identification of core outcomes alongside reviewing existing outcomes measurement instruments to determine how – if at all – such measures reflect the core outcomes identified. This is important in answering questions about the impact and outcomes of interventions – what is measured, and how it is measured, are not neutral or necessarily objective; ensuring that measures reflect the issues that matter most to people living with dementia will be of increasing importance.

The emphasis on neighbourhood is particularly relevant to the concept and aspirations surrounding '**dementia-friendly communities**.' People living with dementia are largely living 'in the community' rather than in residential or nursing homes, but at the same time people with dementia are at high risk of social exclusion and frequently report feeling lonely and rarely leaving the house.

Laird et al explored the experiences and perspectives of community psychiatric nurses, day centre managers and social workers about supporting clients with and without dementia and attending a generic day centre in Northern Ireland (Laird, McGurk, Reid, & Ryan, 2017). One of the key themes identified concerned easing the transition from home to attending day care:

> *"An emphasis was placed on fostering relationships, and ascertaining life stories to inform plans for meaningful activities and social groupings at the day centre. Life story work is a hallmark of quality in the dementia trajectory as it has potential to affirm personhood and promote positive cultures of care."*
>
> (Laird et al., 2017, p. 6)

It was interesting that perceptions indicated the local community's view of ageing and dementia was more positive when the day care was operating from buildings that were used for a variety of community activities, rather than just for care services. This approach is also consistent with promoting social integration and participation, as was support for clients with and without dementia in the same service. The opportunity to engage in meaningful social interaction at the day centre is a further benefit and other research indicates this is highly valued by clients and can enhance a sense of purpose and belonging.

The authors concluded:

> *"Our overall finding is that a generic day care service that provides a blend of care, treatment, social support and recreation and attended by older adults living with and without dementia is feasible and realistic."*

We have already highlighted the inequalities in diagnosis of dementia among different population groups, and whether the service experience of people with dementia, and of their family carers, is different within Black and Minority Ethnic (BAME) communities is an important question, and one which is relatively under-researched. Dodd et al (Dodd, Pracownik, Popel, Collings et al., 2020) explored disparities in service provision between BAME and White British communities within a primary care led dementia service and found that while many areas of service provision showed no evidence of inequality,

> *"important differences remain including the time at which people present for assessment and the range of post-diagnostic services which are discussed."*
>
> (Dodd et al., 2020, p. 622)

Furthermore, people from the BAME community were less likely to be assessed cognitively, and when they were, they had lower average scores. Changes made to the service included improving assessment processes for people whose first language is not English, and employing community development coordinators to work with the BAME community to improve awareness of dementia and promote equality of access.

Research by Subramaniam et al has similarly highlighted the apparent underrepresentation of BAME communities in dementia memory services and the authors have commented on the possible causes which may include:

> *"Traditional cultural practices and reluctance in seeking help from Western services, the role of the extended family system, and the perception of the inevitability of dementia and it being seen as a part of normal aging decay. The barriers these pose should be explored in further studies."*
>
> (Subramaniam, Mukaetova-Ladinska, Wilson, & Bankart, 2020, p. 151)

5. Supporting Carers of People Living with Dementia

Support for people living with dementia must also take account of support for their carers, particularly because of the impact of caring on people's own health and wellbeing (Henwood et al., 2017; Henwood et al., 2018). The research literature typically refers to support which reduces 'carer burden,' in terms of building resilience and improving quality of life, and there is some emerging evidence around what works.

As Cherry et al point out, carers' resilience is contingent on a range of variables including social and cultural factors; the nature of the caring relationship, and carers' psychological characteristics (Cherry, Salmon, Dickson, Powell et al., 2013). Identifying carers who are particularly vulnerable, and developing tailored interventions to support them, requires an understanding and awareness of individual circumstances and caring situations.

Support for all groups of carers is important but it is generally recognised that the carers of people living with dementia typically experience greater 'carer burden' because of the combination of demands from behavioural changes and physical care needs, the progression of the condition and the difficulties of navigating and coordinating care. (Francke, Verkaik, Peeters, Spreeuwenberg et al., 2016). Moreover, the carers of people with dementia are often their partners who are typically also older people and facing their own health and support needs.

What works in supporting carers is a question about which there is relatively little evidence. Henwood et al reviewed the evidence and highlighted, for example that the evidence on cost-effectiveness of respite care is limited, despite qualitative evidence from carers themselves often pointing to the perceived benefits of respite and short breaks (Henwood et al., 2017). A meta-review by Parker et al of international evidence on interventions to support carers (Parker, Arksey, & Harden, 2010) found the strongest evidence of effectiveness was in relation to education, training and information for carers, which increased their knowledge and abilities:

> *"Beyond this there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is not the same as saying that these interventions have no positive impact. Rather, what we see here is poor quality research, often based on small numbers, testing interventions that have no theoretical 'backbone,' with outcome measures that may have little relevance to the recipients of their interventions."*
>
> (Parker et al., 2010, p. 67)

An updated version of the meta-review in 2017 reached similar conclusions (Thomas, Dalton, Harden, Eastwood, & Parker, 2017):

> *"However, what seems clear is that contact with others outside the carers' normal networks (whether professional or other carers) may be beneficial, regardless of how delivered (...) there is potential for effective support in specific groups of carers. This includes shared learning, cognitive reframing, meditation, and computer-delivered psychosocial interventions for carers of people with dementia; psychosocial interventions, art therapy, and counselling for carers of people with cancer. Counselling may also help carers of people with stroke. The effectiveness of respite care remains a paradox, given the apparent conflict between the empirical evidence and views of carers."*
>
> (Thomas et al., 2017, p. xxiv)

Evidence for interventions that may have a positive effect for carers of people with dementia included:

- Opportunities to share with and learn from others (carers or professionals) may have a positive impact on depression and anxiety, and on subjective 'burden.'
- Reframing the way carers think about dementia may have a positive impact on mental health, subjective burden and stress.
- Meditation techniques may have a positive impact on depression.
- Psychosocial interventions delivered virtually may have a positive impact on depression and anxiety, and on subjective burden and stress. (Thomas et al., 2017, p. 97)

The types of interventions reviewed by Thomas et al include: carers support groups; telephone counselling; educational programmes; art therapy; meditation-based interventions; computer-based interventions; cognitive reframing; couple-based interventions and psychosocial interventions.

A meta-review by Chien et al of professionally led support groups for carers of people with dementia found them to be 'significantly effective':

> *"This result might suggest that educational groups can immediately provide useful information, such as caregiving skills, ways of self-adjustment, knowledge for handling legal issues, role play and discussion, and thus facilitate caregivers finding available resources that can reduce their burden in patient care quickly. Psychoeducational groups not only provide practical information on patient care but also focus on caregivers' psychological and emotional status as well as establishing a social supportive network, and are more effective at improving caregivers' psychological wellbeing and depression."*
>
> (Chien, Chu, Guo, Liao et al., 2011, p. 1096)

Hurley et al also report positive outcomes from meditation-based interventions for carers of people with dementia, which also appeared to relieve perceptions of burden:

> *"Consequently, it appears that meditation-based interventions offer a feasible and effective intervention for dementia caregivers experiencing burden or depression."*
>
> (Hurley, Patterson, & Cooley, 2014, p. 286)

McKechnie et al examined the use of psychosocial information and communication technologies (using DVDs, CD-ROMs, or the internet) to provide carers of people with dementia with information while also improving their wellbeing and coping skills (McKechnie, Barker, & Stott, 2014). Evidence was mixed but generally positive although it was difficult to disentangle the components of complex interventions and some studies were poorly designed with vague outcomes or a lack of control groups. McKechnie et al concluded this was an area of development worth expanding to reach more carers, and in the last couple of years the increasing familiarity with using technology and virtual communication in response to Covid-19 has probably accelerated such models of support for carers. However, more research is needed:

> *"..to ensure that interventions are maximally effective. Research needs to consider the effects of interventions on people of different ethnicities and carer-care recipient relationships, as there is evidence that differential effects exist between groups."*
>
> (McKechnie et al., 2014, p. 1634)

Lack of access to computers, and lack of skills and confidence in using such resources can be a significant barrier for some carers, particularly older groups. A randomised controlled trial exploring the effectiveness of a coping strategy programme for carers of people with dementia has been evaluated and followed up over a six-year period (Livingston, Barber, Rapaport, Knapp et al., 2014; Livingston, Manela, O'Keeffe, Rapaport et al., 2019). The START (STrAtegies for RelaTives) intervention is a psychosocial programme delivered by supervised psychology graduates that has been shown to reduce carer anxiety and depression. The authors conclude:

> *"The START intervention is clinically effective, improving carer mood over 6 years. It does not increase patient or carer service-related costs and thus should be made available. The numbers of people with dementia and the diversity of culture, geographic location and available NHS resources mean that further research is necessary to widen access and optimise implementation. For example, to consider whether the intervention can be delivered remotely (through a Skype or similar application), through the existing voluntary sector carer support infrastructure (as some carers do not see themselves as patients), and be adapted for ethnic groups with different cultures."*
>
> (Livingston et al., 2019, p. 41)

McEvoy et al have analysed another psychodynamic model of support based around a communication skills training course called Empowered Conversations, targeted at carers providing intensive support for people living with dementia (developed by Age UK Salford's Dementia Support Service) (McEvoy, Morris, Yates-Bolton, & Charlesworth, 2019). The model is being evaluated by the University of Manchester, and they are exploring running a national trial of the Empowered Conversations approach.

Other evidence of the value of psychosocial interventions has also been identified; Johannessen et al, for example, reported on a Norwegian intervention for people living with dementia at home, and their carers (Johannessen, Bruvik, & Hauge, 2015). This programme featured a combination of education, counselling and group meetings, and learning cognitive techniques. The small-scale qualitative evaluation found carers reporting positive effects and highlighting the need for flexible and earlier interventions. There is evidence that carer resilience is an important factor in wellbeing; Jones et al highlight that:

- Carers with high resilient coping skills report less depression, anxiety, stress, and burden than those with low resilient coping.
- Resilient coping can act as a partial mediator between carer wellbeing and carer distress.
- Interventions that enable carers to develop or maintain resilient coping skills may help reduce the impact on carer wellbeing associated with caring for someone with dementia. (Jones, Killett, & Mioshi, 2019)

Other research on resilience also points to the association of social support with high resilience. Jones et al explored resilience through a questionnaire to 108 carers of people with dementia. ‘Social support’ can include a range of dimensions including emotional/informational support; tangible support; affection, and positive social interaction (Jones, Woodward, & Mioshi, 2019). Carers with high resilient coping perceived themselves to have greater access to all forms of social support compared to carers with low resilient coping, but no one domain of social support proved to be predictive of high resilient coping. The authors conclude:

> *“Nurses and social care providers should enable carers to maintain existing, and develop new social support networks, to ensure they have access to the multi-dimensional social support required to support their resilience.”*
>
> (Jones, Woodward, et al., 2019, p. 588)

Social support, and particularly peer support, also emerges in the literature as a feature that is valued by carers. Larkin et al, for example reported on a qualitative study exploring support for carers of older people and people with dementia and found interviewees identifying such features:

> *“What I would say works effectively are your social situations (...) for instance we have a group where it’s people that are living with young onset dementia, but their families as well –usually a spouse or a partner –will come along and once a month we’ll go out for a meal (,,.) go to different venues; we have a meal, and we have a chat and we have a laugh.”*
>
> (Larkin, Henwood, & Milne, 2020, p. 248)

What was also apparent was that people preferred to see such support without a service label:

> *“Like not calling something a ‘dementia group,’ or whatever; that’s unfortunately what tends to happen, or ‘dementia café.’ People don’t want to live by labels.”*
>
> (Larkin et al., 2020, p. 248)

Larkin et al also highlighted the style and approach of support for carers was at least as important as the support itself:

> *“It is not always the specific intervention that makes a difference to carers, but the style of the service and/or the combination of types of support that are most effective in bolstering resilience. It is not simply the ‘what’ of a service, but also ‘how’ it is offered and delivered that is valued by carers.”*
>
> (Larkin et al., 2020, p. 250)

6. Key Messages and Conclusions

This briefing paper is not a systematic review of ‘what works’ in supporting people living with dementia and their carers; this would require a much larger and more extensive exercise and a hefty report. However, we have reviewed key recent literature and research with the aim of identifying some underlying messages and offering reflections on what could inform the commissioning of support for people living with dementia.

It is important to recognise that developing and supporting dementia friendly communities is a challenging and long-term commitment, with implications for a wide policy agenda. Henwood et al reflected on the experience of the Dementia Challenge in the South of England and observed that the cultural change required to deliver genuinely inclusive dementia friendly communities is profound (Henwood, Butler, & Pollard, 2015).

> *“This has implications not only for the health and social care economy, but for a breadth and depth of vision that embraces all aspects of society. This can include, for example, the built environment; public transport; high street shops and services, and schools and colleges. The experience of the projects has underlined both the challenges that this entails but also the potential for transformation when the agenda is embraced across agencies and organisations. Successful innovation typically requires partnership across many different agencies.”*
>
> (Henwood et al., 2015, p. 51)

Reducing the risk of developing dementia is often discussed and much researched and there is a distinction between factors that can be modified and those that can’t. The evidence is by no means unequivocal and the familiar lifestyle messages about healthy diets, exercise and public health measures are relevant, but beyond this it appears that the most important variable likely to impact on people’s risks of developing dementia, and their rate of decline and quality of life, is social engagement. In the wake of Covid-19, this is especially important given the disruption which people have experienced in their normal social interaction, and the consequences especially for people living with dementia who were already at risk of isolation.

We have seen that there is a shift in much of the narrative away from discussion of 'early' diagnosis and towards 'timely' diagnosis of dementia. With few treatments available for dementia, the purpose of diagnosis is primarily to support people living with dementia to maintain their independence and wellbeing as long as possible.

Person-centred support and care is a defining feature of what good should look like across health and care; the approach focuses on the whole person, understands their life story and their preferences and experiences. This is a central principle underpinning personalisation in social care. However, the needs of some groups of people are not always addressed with the same level of inclusivity. In addition to the needs of people with dementia from BAME communities, there are also the particular requirements and needs of people for example from the LGBTQ communities. The heteronormative assumptions made by services risk marginalising older members of these communities, including people living with dementia, and there is a need to ensure cultural competence in services and professional practice.

Support for the carers of people living with dementia is also of vital importance, particularly given that most people with dementia live in the community and do so with the help of family carers (particularly a partner or an adult child). The research literature identifies that carers of people with dementia are more likely to experience high levels of 'carer burden' impacting on their own health and wellbeing. Evidence on what works in supporting carers is relatively thin, but lack of evidence is not the same as evidence of ineffectiveness. Rather it points to the methodological shortcomings and limitations of many evaluations. However, there is growing evidence for the value of some psychosocial interventions with carers, as well as the importance of education and information about caring and different conditions, support groups (including peer support) and counselling. Strengthening carer resilience is also positively associated with carers being able to maintain their support for people with dementia, and social interaction appears to support resilience. Enabling carers to maintain and expand their social support networks is therefore of particular value.

It has also been a recurring theme that support requires the involvement of both health and social care partners, but also of the wider community and of other mainstream services including the built environment and transport (Röhr, Rodriguez, Siemensmeyer, Müller et al., 2022). Enabling people living with dementia to engage in inclusive communities as fully as possible, for as long as possible, is probably the most important contribution to maintaining independence and wellbeing, and supporting people living with dementia to have a quality of life on their own terms, and grounded on what matters to them, and to their carers and family members.

> "Enabling people living with dementia to engage in inclusive communities as fully as possible, for as long as possible, is probably the most important contribution to maintaining independence and wellbeing."

7. References

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