

A Future for Personalised Care

A discussion paper on reform
and the quality of social care

March 2021



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Foreword

The Governments of England, Wales and Northern Ireland are all starting to address the long standing issues in the provision of social care. Commitments to implement reform are a hugely positive step forward in terms of a better future for people affected by dementia but the lack of a clear timetable and detailed plans are deeply worrying.

We know the time to act on social care reform is now. Whilst any reform is subject to the examination of complex funding options, Alzheimer's Society firmly believes that long term reform must first be rooted in the recognition of what good quality care looks like, how it becomes truly personalised for people with dementia and their carers in real terms, and how it can be provided consistently for people using it within a sustainable system integrated with healthcare. When organised well, we know social care can help each of us live in the places we call home, doing what matters to us, with an ecosystem of support and relationships that we can draw on to live our lives the way we choose to, with meaning, purpose, and connection.

Our recent report, 'From diagnosis to end of life', looks at the NHS Well pathway for people with dementia in England, examining what the National Institute for Clinical Excellence (NICE) and the Government say people with dementia should be receiving at each stage in terms of health services, and comparing this with peoples' experiences. Across all three nations, while people living with many conditions can get their support from the NHS, free at the point of use, people living with dementia, as their condition progresses, draw on support from social care. But guidance is far less clear on what they should actually be able to access or where people can turn to in order to hold services to account. Their experience of care is often one that focuses on help with tasks such as eating or bathing, often known as personal care, rather than delivering care that is personalised to an individual's needs, focuses on what is important to them and enables them to live how they want to. This isn't a case just of care not delivering what is needed; the system itself fundamentally isn't designed to be centred on people's needs and to deliver personalised support.

We have long highlighted the issues of an unsustainable social care system that has been in need of an urgent overhaul for many years, calling for people affected by dementia to be able to draw on the care they deserve, when they need it, and without unfair cost. These calls long pre-date the Covid-19 pandemic, however this crisis has shown us that the need for reform has never been more pressing. People affected by dementia have been the 'Worst Hit', as we demonstrated in our recent report focusing on dementia during coronavirus. A quarter of all those dying of Covid-19 have been people living with dementia. Care home residents have been cut off from their loved ones for a year, without face-to-face contact, stripping them of their most important connection to the world, and those living in the community have been unable to access a whole range of services. Family carers spent an additional 92 million hours providing care during the first lockdown, with 95% of carers we surveyed reporting these extra caring hours negatively impacted their own physical or mental health. Since the pandemic, thousands of people with dementia have seen a devastating deterioration in symptoms – due to lockdown causing social isolation, and health or social care service interruptions – reported by 83% of the family carers we spoke to. From widespread reporting on the experiences of people in care homes during the pandemic, the public now have a greater understanding of the social care system, its issues, and the need for more to be done to protect some of the most vulnerable people in society.

The Covid-19 pandemic has also highlighted the divide and lack of integration between the NHS and social care, and the discrimination that people who require support from social care face, helping to build public appetite for social care reform. The health sector is increasingly making calls for urgent reform for social care, not just for social care itself, but for the future sustainability of the NHS, with the recognition that social care and the NHS are two sides of the same coin, and where failure of social care is putting the aims of the NHS Long Term Plan in jeopardy. Reform and the effective integration of health and social care is pivotal to ensuring that people receive the support they need to stay well at home, reducing avoidable emergency admissions and demands on other NHS services.

Now is the opportunity for reform to set a new vision for social care and to design a new system to deliver on this. In this paper we re-examine what people with dementia have previously stated they want and need from good quality social care and we start to consider how this can be delivered. Over the coming months we will be speaking with people living with dementia to learn more about what social care means to them, to ensure their voices are heard in the debate on reform, and to build on this work by bringing the latest research evidence into the policy debate and practice.

As we begin to emerge from the pandemic, we are determined to make sure that governments across the three nations of England, Wales and Northern Ireland:



recognise the unmet needs of people with dementia



understand what quality, personalised care entails



start to make the necessary changes without any further delay

Fiona Carragher

Director of Research and Influencing, Alzheimer's Society



The Dementia Statements

Our calls for social care reform and what is particularly important for people affected by dementia are based upon lived experience and what people with dementia consistently tell us they want as real outcomes.

The Dementia Statements, originally developed in 2010 and revised in 2018 by people with dementia and their carers, set out the things people with dementia have said are essential to their quality of life, and are enshrined in the Equality Act, Mental Capacity legislation, Health and Care legislation and International Human Rights law¹.

For people with dementia using social care, either through visits from a care worker in their own home or through living in residential care, this care will have a key role in determining their quality of life. The Dementia Statements should be the starting point in understanding what matters most to people with dementia in social care, as well as across all settings.

We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part.

We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live.

We have the right to continue with day to day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness.

We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it.

We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future.

Recommendations

Alzheimer's Society's longstanding view is that people with dementia must be able to access the care they require when they need it, that they must not face unfair costs, and that care must be of good quality and meet their needs.

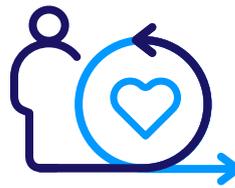
As we outlined in our report 'Worst Hit: Dementia during coronavirus', any proposal for long term reform needs to address these basic principles:



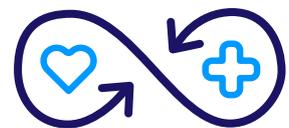
There must be a minimum set of national standards



Care should be person-centred and include an element of choice



Informal carers should be recognised as an integral part of the care ecosystem



This must be underpinned by effective integration between health and social care².

Currently, social care sadly doesn't always focus on what matters to people – it can be too transactional, driven by time and task and not enough by connection, purpose or genuine outcomes. Social care should not only focus on the basic personal care that merely allows for daily functioning – while it is essential, this basic personal care alone will not necessarily give people a good quality of life, which everyone should have the right to.

The central principle of social care must be that it focuses on what matters to people, including as core principles the importance of care that:

- Offers people choice and control, responds to changing needs, actively seeks feedback, and encourages and supports people to maintain their independence.
- Supports the individual with choosing and setting their own goals and working with qualified care workers to plan how social care will support them in meeting that goal.
- Recognises the importance of relationships to health and wellbeing – as all care plans should – including building or strengthening relationships with loved ones, family members or people in their community as a focus.
- Improves people's experience of 'living well', grounded in research. Research suggests that for people with dementia this should include measures of psychological factors including optimism, self-esteem, loneliness and depression.

England national recommendations

We call on the Westminster Government to set out and consult on a new vision for social care to re-examine the purpose of social care and start meaningful reform in 2021.

The Wellbeing Principle of the Care Act (2014) sets out the need for personalised care, but all too often this isn't people's reality when drawing on support. Personalised care is crucial, but while many stakeholders* across the sector are supportive of personalised care and a vision based on these principles, we need a fresh commitment to the principle from the Government as part of their core vision for social care. A formal consultation, with meaningful involvement of people who use social care including people with dementia and people who work in social care, would help build consensus on the purpose of and vision for a new sustainable social care system.

Over 200,000 people with dementia with care needs currently receive no professional support – this can result in their condition deteriorating to the point of crisis, increasing care needs that could have been avoided, and increasing the burden on unpaid carers. We need a collaborative social care system able to provide proactive, preventative care that everyone is able to access.

To deliver this new standard of care on the ground, national Government should:

- Set out a robust vision for delivering personalised care for people with dementia with appropriate accountability in order to uphold the ideals of the Wellbeing Principle held in the Care Act.
- Ensure social care partners have parity in Integrated Care System structures, where their contribution to place-based population health and wellbeing is valued, supported and enhanced.
- Recognise that staff themselves need to be valued and respected for the work they do. Staff are a key part of the support network for people with dementia. Current working conditions can undermine the ability of staff to provide good quality care. Government needs to work with staff and other stakeholders across the sector to develop and publish a People Plan for social care, including:
 - Mandating minimum levels of evidence-based skills development and training in personalised dementia care for every care worker, and providing the funding for this training to providers to deliver through investing in the sector. For example, 'NIDUS' training for home care staff and 'WHELD' training for care home staff, as described in this paper, should be considered for rolling out to all social care staff.
 - Introducing a defined framework of career progression for care staff, tied to increasing training and development, and increasing pay levels, appropriate for the skilled and valued work that staff do and designed to properly support staff and reduce turnover.
 - Including in this framework appropriate training and support for roles in leadership.
 - Ensure plans enshrine parity of the social care workforce with the NHS workforce. This framework should support staff moving between social care and the NHS.
- Commit to expanding and enhancing the evidence base for what works best in social care practice. Currently very little social care is based on evidence of delivering improved outcomes. The Government should increase the support and funding for research and innovation and its translation into evidence informed practice.
- Deliver their manifesto commitment to double dementia research funding, including increasing support and funding of research into how quality is defined, evaluated and improved in social care, to generate more evidence-based practice.
- Create a dedicated fund to support local innovation and improvement projects on the frontline within social care that pilot new ways of delivering quality care, with effective evaluation and rolling out learnings more widely from existing networks such as the Department of Health and Social Care funded Social Care Institute for Excellence (SCIE), Think Local Act Personal (TLAP) and Shared Lives Plus' Social Care Innovation Network.

*Such as members and supporters of the Dementia Choices Action Network (dcan.org.uk/who-we-are/), SCIE, Think Local Act Personal, Coalition for Personalised Care, National Voices, the Health for Care coalition, Local Government Association, Association of Directors of Adult Social Services and more

- Ensure that interventions which have a growing body of evidence of their effectiveness in improving outcomes in social care for people with dementia are able to be rolled out widely, including using evidence of:
 - the impact of psychological factors on living well, and relationships are essential to health and wellbeing and social care’s valuable role in strengthening relationships to enhance health and wellbeing, not solely physical support with personal care.
 - evidence-based training initiatives that deliver improved outcomes in care, such as WHELD and potentially NIDUS.
 - the role and benefit of cognitive rehabilitation, such as the GREAT into Practice rehabilitation approach.
- Be accountable for social care. Further accountability needs to be introduced to raise standards and ensure standards are maintained to avoid the current care crisis persisting. We welcome proposals in the new white paper ‘Integration and innovation: working together to improve health and social care for all’ for further assurance in social care and look forward to understanding what new duties for Change to Care and Quality Commission (CQC) and new powers for the Secretary of State to intervene will mean in practice.
- Mandate a minimum set of data relating to quality of care that all services are required to report on, and that should be published and made accessible to the public. This should include data on outcomes for people using the services and training levels of staff working in care. New data needs to be meaningful and needs to ensure it doesn’t create unnecessary administration for local authorities and providers. The current lack of evidence makes it difficult to assess quality of care as a whole and makes it difficult for families choosing services. We welcome proposals in the new white paper ‘Integration and innovation: working together to improve health and social care for all’ for further data collection and look forward to understanding what will be included.

England local recommendations

- Local authorities and providers should continue to build and strengthen connections with partners in the NHS and the community sector, including through:
 - greater use of multidisciplinary teams such as with the Enhanced Health in Care Homes programme to support people with dementia and sharing single care plans. People with dementia often require support across sectors, and care can be disjointed when these sectors don’t work together and share information.
 - collaborating in sharing knowledge and skills. Dementia leads and other dementia specialists in the health sector should make links with social care where this may bring benefits, and social care representatives should have parity within shared bodies such as Integrated Care Systems as part of the new duty to collaborate proposed in the new white paper ‘Integration and innovation: working together to improve health and social care for all’.
 - joint commissioning of services which support the welfare of people affected by dementia, in particular post-Covid-19, such as cognitive rehabilitation services, and make these available to people with dementia, including those supported by social care, to help address the impact of cognitive impairment on what they are able to do or engage with in an area important to their daily life. This could take place in a community setting for people supported by homecare, and should also be considered in a care home setting where this may be of benefit.
 - supporting people with dementia who use social care to have their voices heard during consultations on reform. This could include setting up advisory panels. People affected by dementia should also be part of determining local service delivery through appropriate consultation.
- Local authorities and providers demonstrating best practice should actively seek to share learnings and insights with other local authorities or providers to help spread best practice, as well as sharing with government and regulators such as CQC for consideration in the development of their plans and for disseminating more widely.

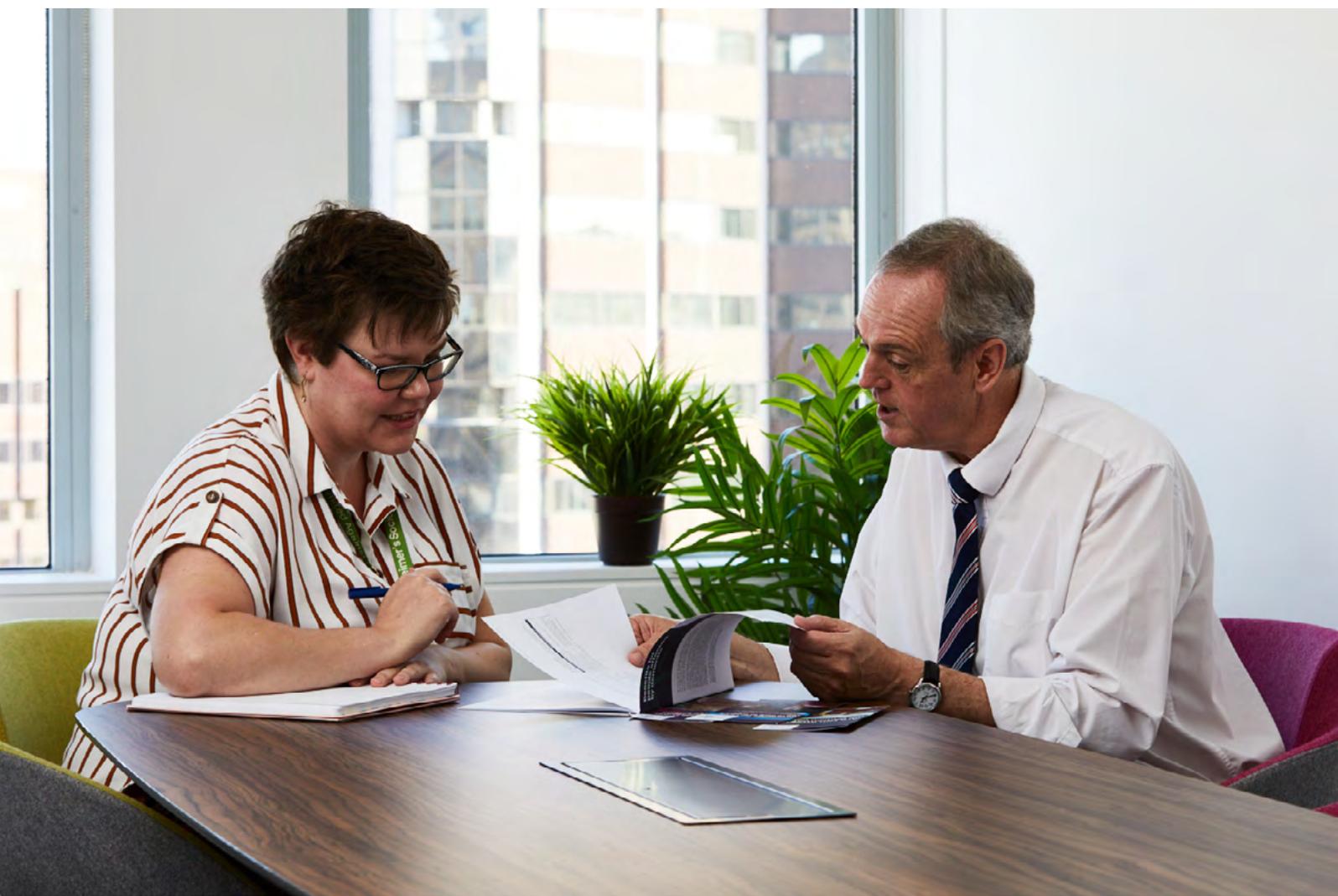
Wales national and local recommendations

- The next Welsh Government to implement the recommendations of the Holtham Report on paying for social care. Widely accepted, this report sets out the options for paying for social care in Wales. Despite its publication in 2018, no action has been taken on its implementation. The Coronavirus pandemic has highlighted the desperately poor state of our social care system in Wales. Ensuring the system has enough funding to survive has to be the bare minimum.
- The next Welsh Government to create a social care system to match the NHS – free at the point of need and funded to match. The creation of such a system is vital to the wellbeing of the nation, and particularly those with dementia, who currently pay an average of £100,000 for their care. This disparity means that families and carers for people living with dementia often struggle to fund care that is appropriate and matches the person's needs. Creating a free at the point of need system would enable these worries to vanish and drastically increase the wellbeing of carers and people living with dementia.
- The next Welsh Government to bring pay scales in social care in line with those of the NHS. Social care staff have been chronically underpaid for a number of years, providers are having issues filling staff vacancies, and staff turnover is incredibly high. Paying social care a wage commensurate with the work they do will encourage staff retention, allow vacancies to be filled and reward staff for the incredibly hard work they have undertaken pre-pandemic, during the pandemic and post pandemic.
- All of Wales' Health Boards to sign up to the newly published Dementia Standards. These standards, produced by Public Health Wales in consultation with people living with dementia, carers, dementia professionals and health and care charities, have been designed to ensure an equality of care across Wales. They are designed to give everyone diagnosed with dementia the choice to access services within certain timeframes following diagnosis.
- All of Wales' Health Boards to sign up to the Hospital Charter. This charter, developed by the National Dementia Action Alliance in collaboration with people living with dementia, carers, dementia professionals and health and care charities, has been designed to drastically improve the hospital experience for people living with dementia. We strongly believe that an improved hospital experience will lead to an improved care experience.



Northern Ireland national and local recommendations

- Each of Northern Ireland's Integrated Care Partnerships should implement the Regional Dementia Pathway and interact with the 11 Local Councils 'Community Plans' in order, through greater use of multidisciplinary teams, to support people with dementia with their care plans. People with dementia often require support across sectors, and care can be disjointed when these sectors don't work together and share information. The Dementia Navigators in each Health Trust across Northern Ireland should also collaborate in sharing knowledge and skills.
- Department of Health and bodies such as the Patient Client Council and the Commissioner for Older People should support people with dementia and their carers who use social care to have their voices heard during the ongoing reform of adult social care.
- The Health and Care Board should commission cognitive rehabilitation services and make these available to people with dementia, including those supported by social care, to help address the impact of cognitive impairment on an area important to their daily life. This could take place in a community setting for people supported by homecare, and should also be considered in a care home setting where this may be of benefit.
- The Department of Health should work with the Care Home sector to ensure that there is a greater uptake of the 'Care Partner' model within the sector and give the Care Home resident and family members greater entitlement to set the visiting arrangements for their residence.
- The Department of Health through the Regulation and Quality Improvement Authority (RQIA) should ensure that advocacy arrangements are in place for residents in Care Homes who do not have a designated 'Care Partner'.



Introduction

In this discussion paper we start the conversation on what social care reform needs to deliver in order to meet the needs of people with dementia, to allow them to live their lives the way they choose, in the places they call home, in communities where we care about and support one another.

We will look at:

- **Delivering quality dementia care** – what are the hallmarks of quality dementia care?
- **Stability of provision** – how can we ensure that care workers are able to deliver these benefits for people with dementia?
- **Sustainability of the system** – how does the system need to be built to deliver these benefits for people with dementia?
- **Support for all** – are people affected by dementia able to draw on the care they need when they need it?

This is the first step in our work looking at this issue. Over the coming months we will be engaging with people affected by dementia to learn more about their experiences of care and what quality care means to them, and using this research to provide a framework for our understanding of what social care should look like. This will build on our recent reports examining the impact of Covid-19 in ‘Worst hit: dementia during coronavirus’, the quality of health care people receive through the NHS Well Pathway in ‘From diagnosis to end of life’, and the support available for family carers and their right to respite in ‘The Fog of Support’.

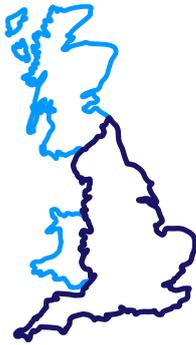
At least 70% of people in care homes³ and 60% of people supported by homecare workers have dementia⁴. People with dementia will often be supported by a care worker whilst living in their own home. Many people want to live in their own homes for as long as possible and this support is essential in enabling them to do this for as long as they feel able. For many people with dementia, their needs will increase to a point where residential care is required, and they will then receive support from care workers in a care home setting, relying on this care to support them through to the end of their life.

It is therefore essential that the social care system delivers the high-quality care we would all want to see for ourselves and for our loved ones throughout their journey, and that people in residential care can make that place their home – we all want to live in the place we call home, in communities where we support one another.

Currently social care for people with dementia falls short – the Care Quality Commission (CQC) describe a lack of high quality, person-centred homecare and a lack of suitable residential care provision for people with high support needs, including those with dementia⁵. Social care reform is desperately needed and people with dementia must be at the heart of this reform. We all want to live in the place we call home, with social care helping us weave a web of support and relationships that we can draw on to live our lives the way we choose to. For that to happen, the Government must make good social care a priority and begin investing more in it.

In England, the Prime Minister has repeatedly committed to a plan for social care which has been subject to a series of delays. In Wales, it is positive to see the three main political parties make commitments to social care reform ahead of the May 2021 elections, but we need to ensure these commitments include the necessary detail and that, crucially, they are delivered on by the new government. In Northern Ireland, consultation has been held on a new vision for a future system of care and support followed by Health and Wellbeing 2026: Delivering Together proposals⁶, but these have been subject to interruptions and delays.

Over the last year, the Covid-19 pandemic has had a disproportionate impact on both people with dementia and the social care system.



In England 27% of all deaths from Covid-19 between March and June 2020 were of people living with dementia⁷.



In Wales 28% of Covid-19 deaths in March to May 2020 occurred in care homes⁸.



In Northern Ireland, 36% of those who died with Covid-19 from March to September 2020 also had dementia⁹.



In the UK at least 40% of all deaths from Covid-19 in March to June 2020 were in care home residents¹⁰.



In Northern Ireland, 40% of all Covid-19 related deaths in the year 2020 occurred in care home residents (occurring either in care homes or in hospitals)¹¹.

At the beginning of the pandemic it became clear that action was not taken quickly enough to provide social care with the protection it desperately needed. There was a failure of timely action to provide the necessary measures such as supplying personal protective equipment (PPE) and testing for care homes, and we saw unsafe discharge of patients from hospitals to care homes, which further put residents at risk. As the height of the Covid-19 pandemic hopefully ends, with the roll out of vaccines, the social care system emerges with many problems that existed prior to the pandemic having been exacerbated and further neglected.

When organised well, social care helps weave a web of support and relationships that we can draw on to live our lives the way we choose to, no matter our age or stage in life. For that to happen, Governments must make good social care a priority and begin investing more in it. And more local councils need to urgently start working alongside and supporting local people and organisations to bring these ideas to life by organising and funding social care differently. The pandemic has shown the need for reform is urgent.

The challenges people with dementia face with social care span across three separate but interconnected issues. People with dementia struggle to access the care they need, face catastrophic costs to pay for care, and often receive poor quality care that doesn't meet their needs or provide effective outcomes. Alzheimer's Society's longstanding view is that people with dementia must be able to access the care they need when they need it, that they must not face unfair costs, and that care must be of good quality and meet their needs.

Section 1:

Delivering quality dementia care

Here we look at what social care should be delivering for people with dementia and the hallmarks of quality dementia care. What are the outcomes that social care should be supporting people to achieve? What should be our vision for the purpose of social care?

It is vital that policymakers understand the answers to these questions so that social care reform designs and delivers a system that works for the people who use it and is sustainable for the future. We support a vision of care that focuses on what is really important to people, what gives them meaning in their life, and what makes life worth living.

Currently people's experience of social care is that it is often based on receiving help with things that are essential to daily functioning, also described as 'personal care' – care directly relating to the person and within the person's place of residence.

The activities of daily living (ADLs) that personal care supports someone with include:

- **Personal Hygiene** – Bathing, showering, hair washing, shaving, oral hygiene, nail care
- **Continence Management** – Toileting, catheter/stoma care, skin care, incontinence laundry, bed changing
- **Food and Diet** – Assistance with the preparation of food and assistance with the fulfilment of special dietary needs
- **Problems with Immobility** – Dealing with the consequences of being immobile or substantially immobile
- **Counselling and Support** – Behaviour management, psychological support, reminding devices
- **Simple Treatments** – Assistance with medication (including eye drops), application of creams and lotions, simple dressings, oxygen therapy
- **Personal Assistance** – Assistance with dressing, surgical appliances, prostheses, mechanical and manual aids. Assistance to get up and go to bed. Transfers including the use of a hoist¹².

The current system is often focused on meeting these kinds of needs, providing support for the basic tasks of feeding, washing and dressing – tasks to solely keep someone alive and safe.

The Adult Social Care Outcomes Framework (2019/20)¹³ shows us that for over 65s in England:



61.5% were extremely or very satisfied with their care and support.



86.1% said the services helped them feel safe.



71.2% felt as safe as they would like.

However, while personal care is essential to daily functioning, alone it will not necessarily give people a good quality of life, which everyone should have the right to. Often described as ‘personalised care’, a truly personalised and person-centred approach should be much more expansive and bold in its vision.

Personal care is...

Support with essential tasks – often called activities of daily living – for someone to stay safe and healthy on a day to day basis

Personalised care is...

Care that upholds our right to be recognised for who we are, and for our diagnosis not to define or limit the life we lead, as the Dementia Statements show.

A more expansive vision for social care that places greater emphasis on personal agency, choice and control, built on the underlying assumption that people are ultimately best placed to make decisions on their care, support and wellbeing. A belief that social care and care and support services are not a destination in themselves but should be capable of supporting people to find purpose, meaning and connection in their daily lives.

We have reviewed many of the standards and frameworks that define quality care or drive improvement from leading bodies across the social care sector which underpin the delivery of the legislation. The table below shows a number of themes that we identified were common to many of the frameworks and standards we reviewed, and which also map to the Care Act 2014 and to the Dementia Statements. We can also see that two categories emerge: one around basic needs and rights (safety, dignity, and caring), and one around person-centred care which is both a theme on its own and can be linked to others: control and choice, responding to changing needs, actively seeking feedback, and encouraging/supporting independence.



Theme of care	Mapping to Wellbeing Principle in the Care Act	Mapping to Dementia Statements
Personalised	<p>The importance of beginning with the assumption that the individual is best-placed to judge the individual's wellbeing.</p> <p>The individual's views, wishes, feelings and beliefs.</p> <p>The need to ensure that decisions about the individual are made having regard to all the individual's circumstances.</p> <p>The importance of the individual participating as fully as possible in decisions relating to the exercise of the function concerned.</p>	<p>We have the right to be recognised as who we are.</p> <p>Our diagnosis should not define us.</p>
Safety	Protection from abuse and neglect.	We have the right to... receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us.
Dignity	Personal dignity.	We have the right to be respected.
Caring	Personal dignity (including treatment of the individual with respect).	We have the right to... receive evidence-based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us.
Responsive to changing needs	The importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist.	We have the right to be respected and recognised as partners in care.
Control and choice	Control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided).	We have the right to... make choices about our lives.
Actively seeking and acting on feedback from people using the service	The importance of the individual participating as fully as possible in decisions relating to the exercise of the function concerned and being provided with the information and support necessary to enable the individual to participate.	We have the right to be respected and recognised as partners in care.
Encouraging/ supporting independence	The importance of preventing or delaying the development of needs for care and support or needs for support and the importance of reducing needs of either kind that already exist.	We have the right to continue with day-to-day life and family life.

The need for personalised care is reflected in the legislation which underpins care. In the current system, in England the Care Act 2014 is the key legislation relating to care and support for adults and support for carers, setting out what care should be delivered and how. The Social Services and Wellbeing Act (2014) performs a similar function in Wales. In Northern Ireland provision of social care is determined locally by individual Health and Social Care Trusts. National legislation on social care in Northern Ireland lags well behind the other nations, with the most recent legislation being in the Carers and Direct Payments Act (Northern Ireland) 2002.

The ‘Wellbeing Principle’ of the Care Act in England sets out the quality of care that should be experienced. The principle puts wellbeing at the heart of care and support, which in this context includes:

- personal dignity
- physical and mental health and emotional wellbeing
- protection from abuse and neglect
- control by the individual over day-to-day life
- participation in work, education, training or recreation
- social and economic wellbeing
- domestic, family and personal relationships
- suitability of living accommodation
- the individual’s contribution to society.

The wellbeing principle also includes a strong focus on a person-centred approach, including:

- the importance of beginning with the assumption that the individual is best-placed to judge the individual’s wellbeing
- the individual’s views, wishes, feelings and beliefs must be regarded in particular
- the need to ensure that decisions about the individual are made having regard to the individual’s circumstances
- the importance of the individual participating as fully as possible in decisions relating to the exercise of the function concerned¹⁴.

The Social Services and Wellbeing Act in Wales sets out very similar principles and definitions of wellbeing to that of England’s Care Act. It’s five core principles are wellbeing, voice and control, prevention and early intervention, coproduction, and collaboration.

The principles of personalisation in legislation such as the Care Act in England and Social Services and Wellbeing Act in Wales are clearly positive and reflect many of the key elements of personalised care, but aren’t clear enough on a vision of care that puts the individual and what matters to them front and centre.

We must ensure that the opportunity presented by social care reform is used to set out a clear vision of what people can expect from social care.

This needs to be a vision that meets the needs of people who draw on the social care system for support to live well and one that has support from staff working on the frontline and national and local organisations across the sector.

We believe that social care must be personalised and help people to live their best lives, by focusing on what matters to people.

We have found personalised care emerges as a key theme across the sector. This approach should start with a discussion about the goals the person wants to address in their life and what is important to their quality of life, before identifying the care and support that can help them to achieve this. This can be better not only for the person with dementia but for the care worker too. Instead of carrying out tasks for the person, they work with them towards achieving goals, which can be more rewarding, interesting, and varied.

These are some examples of how this is conceptualised by some of the frameworks:

- Department of Health and Social Care's Quality Matters says: **'high quality person-centred care supports people to live the lives they want to lead'**, and describes an approach where **'the person using care and support is at the centre of the way care is planned and delivered'**¹⁵.
- Think Local Act Personal's Making it Real framework states that: **'personalisation is rooted in the belief that people want to have a life not a service'**, and **'conversations with people are based on what matters most to them'**¹⁶.
- The first condition critical to success in the Enhanced Health in Care Homes model is personalised care: **'putting the needs of the person at the centre through "what matters to you" conversations and personalised care and support planning processes'**¹⁷.

This more expansive view of what social care needs to be is also captured well by the movement Social Care Future in their vision: **'Don't we all want to live in a place we call home with the people and things that we love, in communities where we look out for one another, doing the things that matter to us?'**¹⁸.

The Local Government Authority (LGA) also calls for 'people first' in the first of their seven principles for social care reform. They state 'Whatever emerges post-COVID-19 should be rooted in, and guided by, what works for people, not what works for systems or structures' and 'It must help support the realisation of the Think Local Act Personal 'Making it Real' framework that articulates what quality, personalised and community-based support looks like from the perspective of people'. The principles also call for additional funding to 'not simply be used for "more of the same", but instead used 'to help us move to a more person-centred and preventative model of social care that is rooted in supporting people's wellbeing in line with the Care Act and building resilience in our local public services and communities'¹⁹.

We have already seen plans for personalised care for the NHS, with the NHS Long Term Plan stating that personalised care will become business as usual²⁰. This includes giving people choice and control over their physical and mental health, and personalised care and support planning to manage long term conditions – a process which includes recognition of the things that matter most to the person. For some people making personalised care arrangements is also greatly helped by having a Personal Health Budget, which gives them greater choice and control, particularly when taken as a direct payment, though some people are unable to manage a direct payment alone. The NHS Long Term Plan includes accelerating the roll out of Personal Health Budgets, and expanding the offer to a number of groups, including people receiving social care support. The roll out of social prescribing also plays a key role in personalised care, where link workers give people time, focusing on 'what matters to me', and taking a holistic approach to people's health and wellbeing'. People who need social care should be treated with this same approach: with care that gives people time, and focuses on what matters to them. A consistent approach taken by both systems is also vital for integration of health and social care: for as long as the two don't share the same vision this is another barrier to integration, which is essential for people with dementia who often receive support across both the NHS and social care, as well as from voluntary or community based organisations.

A vision of social care that is more personalised, supports people to make decisions and have choice and control over their own care and to maintain and strengthen their relationships, is crucial to enabling people affected by dementia to live well with the condition as part of their communities.

What does ‘living well’ mean for people with dementia?

Social care needs to look to the evidence for what living well means and how social care can help people to live well, alongside how outcomes can be measured. This must incorporate evidence from both research studies and also innovations from the frontline which are shown to be effective.

The IDEAL (Improving the Experience of Dementia and Enhancing Active Life) programme²¹ looks at the factors that influence how people with dementia are able to live well and represents the largest study on living well with dementia in the UK.

By examining influences on quality of life and wellbeing for people living with dementia and family carers, it identifies a range of individual factors that may impact on quality of life for people with dementia, and which have been grouped into the following five life domains:

- psychological characteristics and health
- social capitals, assets and resources
- social situation
- physical fitness and health
- managing everyday life with dementia.



The researchers found that all of the above domains were important for living well, but that the psychological domain was the only independent predictor of 'living well'. This means that all domains of life contribute to psychological health, which in turn underpins the potential to 'live well' with dementia.

Individual factors within the psychological characteristics and health domain that were linked with ability to 'live well' were:

- Optimism
- Self-esteem
- Positive attitudes to ageing and feeling younger than your age.

Factors that made it harder to 'live well' included loneliness and depression

The model produced from these analyses provides a map that allows us to think broadly about what is important for living well for people with dementia as a whole group across each of the life domains. It can also be used to help identify what may be supporting or undermining the capability to 'live well' for each individual with dementia.

The Government needs to do more to support and enable evidence in social care, by improving funding for research into how quality care is defined, evaluated and improved in social care, as well as supporting innovations in practice. For people with dementia current evidence indicates that psychological factors including optimism, self-esteem, loneliness and depression contribute to living well.

Staff on the frontline with a good understanding of the needs of the people they are supporting can be best placed to come up with new ways of delivering quality care. Support for this could build on the evidence-based principles to be effective at adopting innovation set out by the NHS Accelerated Access Collaborative (AAC) and the CQC, which includes developing a culture where innovation can happen. Social care can look to the impact innovation has had in the NHS, which a report from the AAC states has delivered benefits of over 12,000 fewer hospital admissions and a saving to the NHS of over £50million²².



Always involved, stories of experts by experience involved in the IDEAL study

Based at the University of Exeter, with Alzheimer's Society funding and involvement from other organisations and universities, IDEAL follows people's lives over several years. The researchers do this using face-to-face interviews and questionnaires. A group of people affected by dementia has been advising on different aspects of IDEAL. Called ALWAYSs – short for 'Action on living well: Asking you' – the group's members draw on their personal experiences, skills and expertise to do this.

Julia, who cared for her late mother, recognises on the importance of 'asking you' – **'That's what it's all about, it's getting the questions and answers that are important to people. I have a real sense of involvement.'**

Keith, who was diagnosed with Alzheimer's disease in 2010, feels that the IDEAL study can help change how professionals approach dementia. **'Medication is tried and tested, so sometimes they play safe with that and stay away from the support side. I don't think there's anything quite like IDEAL anywhere, so it can really make a difference.'**

The ALWAYSs group has influenced the various ideas that the study is based upon, as well as its themes and ambitions.

'We had a big discussion about that and found things that were far more important than what was already there' – Monica, a former carer.

'We're hoping it brings a better understanding of the experience of dementia – how do you make it so that everyone is at the more positive end? This group understands how bad dementia can be, but we're about looking for solutions.'
– Jane, a former carer.

David, who cared for his late wife and mother-in-law, says the IDEAL project provides **'a positive message in the open arena'** that he can pass on to anyone diagnosed with dementia.

'I like the idea of being at the forefront of research. We're helping researchers from an early stage with our experiences.' – Julia, a former carer

The importance of relationships to health and wellbeing

In the IDEAL study, social situation and social capitals, assets and resources also feature as factors important for quality of life, with social situation being the second strongest predictor of living well, after psychological factors.

The Covid-19 pandemic has shone a spotlight on just how important contact with family members and other loved ones is to the health and wellbeing of people with dementia. Early on in the pandemic face-to-face visits of loved ones to care homes were banned and the restrictions left many people with dementia without face-to-face contact with loved ones for months. The impact of this lack of meaningful contact has been linked to deterioration in the condition, worsening of symptoms and possibly even deaths. Our own enquiry found that 79% of 128 care home managers surveyed reported a lack of social contact was causing deterioration in the health and wellbeing of their residents with dementia²³. Whilst basic care needs were being met, many people were being left without what matters most to so many of us – seeing people they love. A care home is not just a roof over someone’s head, but is the place many call home.

In a commentary from the International Long-Term Care Policy Networks resources in response to Covid-19, Associate Professor Lee-Fay Low explains the role that family visitors play in:

- providing love and company
- helping with eating
- keeping cognitive and communication skills sharp
- grooming and recreation
- advocacy
- and timely detection of changes in health²⁴.

Without visits, residents are more likely to become lonely or bored, which may be expressed through increased agitation or social withdrawal. Lack of physical activity may lead to loss of strength, and reduced cognitive stimulation may lead to greater cognitive decline.

In our recent report, ‘Worst Hit: dementia during coronavirus’, we called for informal carers to be recognised as an integral part of the care system. **We must learn the lessons from the pandemic on just how vital meaningful contact with loved ones is to the health and wellbeing of people with dementia.** Social connections – supporting people to build or strengthen relationships with loved ones, family members or people in their community – must be fundamental to caring about people with dementia. For people in care homes, this means regular meaningful visits from loved ones and informal carers being treated as partners in their care.

In summary, social care should be there to help people with dementia live their lives the way they choose to by:

- Delivering truly personalised care that puts the individual at the centre, setting their own goals that focus on what matters to them
- Having a positive impact on psychological factors
- Strengthening social connections which are vital to health and wellbeing

Section 2:

Stability of provision

This section looks at how we can ensure that care workers are able to deliver these benefits for people with dementia.

Good quality care starts with the staff delivering care having the necessary skills and knowledge, including understanding of the frameworks of quality care and how they can implement these in practice. Care workers can't be expected to support someone with dementia without having an appropriate level of understanding of dementia, what it is and how it affects someone, and how best they can meet the person's needs. Care workers also need an understanding of relational and personalised care, what this means, and how they can deliver it. Training and development is therefore essential. Evidence suggests that currently, social care staff don't always receive the training they need to support people with dementia. Our Fix Dementia Care: Homecare report (2016)²⁵ found that whilst one third of homecare workers receive no dementia training, and only 2% of people affected by dementia say homecare workers have enough dementia training, 86% of homecare workers believe that dementia training would help them to provide better care. Current data on training levels²⁶ provides some context. Data suggests that in England there are nearly 1 in 5 direct care staff who do not have a relevant social care qualification and have not engaged with Care Certificate (the identified set of standards for health and social care workers to adhere to in their daily working lives)²⁷. Skills for Care reports that 44% of all workers had training in the category of dementia recorded, however this does not indicate the level of this training, and so could include only basic awareness of what dementia is rather than skills in providing care²⁸.

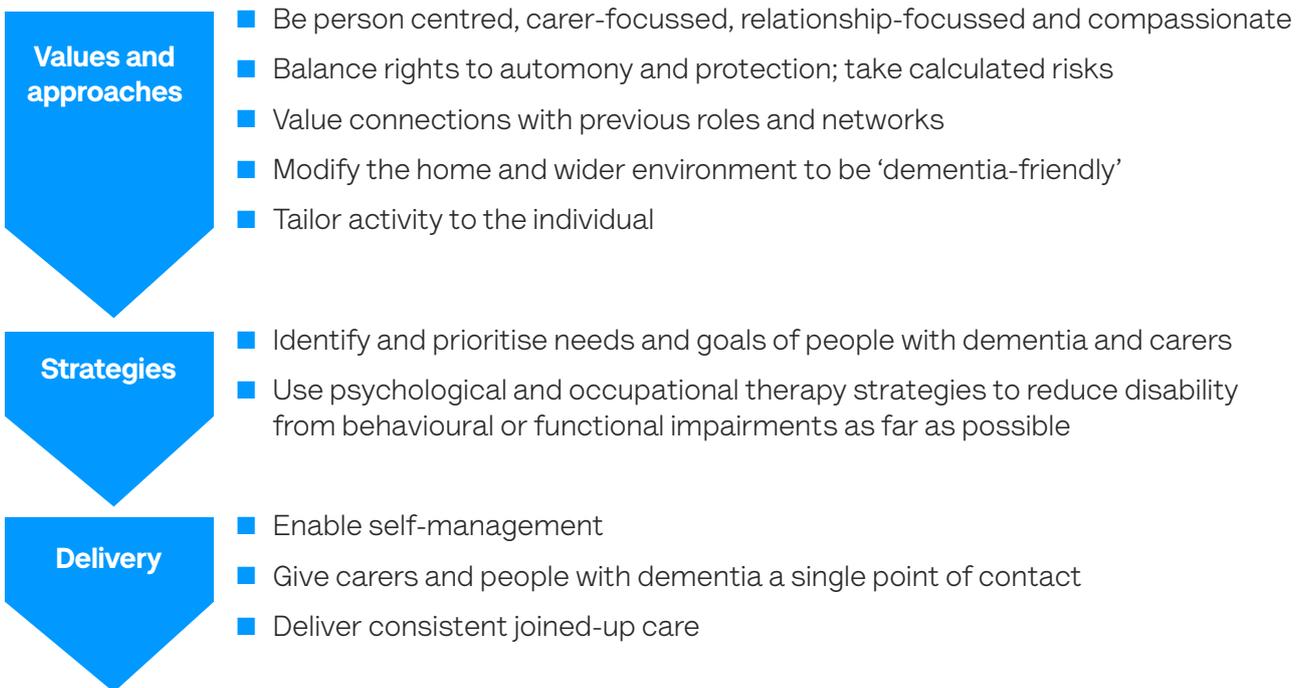
It is important that training is evidence based. **Shockingly, researchers have found in a review of 170 training manuals for person-centred care in dementia that only four had evidence that they worked when tested in a research setting²⁹.** We must ensure that wherever possible practices within social care are based on evidence of effectiveness and improving outcomes.

Here we provide examples of evidence-based training in dementia that might improve quality of care.



Training for homecare staff – NIDUS

The NIDUS (New Interventions for Independence in Dementia) study³⁰ has developed a training programme for homecare workers supporting people with dementia as well as one for family carers. Starting with a systematic review of over 40 papers on what good support for people living at home looks like, it found a key recurring theme of supporting independence, which is one element identified from our review of policy frameworks. They used their review to develop a theoretical model of how to support independence.



A key part of the model is relationships: approaches should be relationship-focused, developing a strong relationship between the carer and person with dementia; and social connections of the person with dementia (to loved ones, family members, and others in their community) should be valued. Informal carers are also vital within the model, and should be involved as a partner in care planning.

NIDUS is now piloting their training for homecare workers. This consists of six sessions, focused on delivering person-centred care using real examples, and with family carers involved in the study also receiving support through the 'NIDUS-Family' programme. The 'NIDUS-Family' co-produced programme looks at family carers and/or people with dementia to select personal goals. These goals most commonly related to getting out and about and increasing activity or hobby participation; carer wellbeing; managing physical complaints; meal preparation and cooking; and reducing irritability, frustration or aggression. The qualitative findings indicate building connections and improving communication between people living with dementia, wider family and professional networks facilitated goal directed change and was an important outcome in itself³¹.

We know that personalised care is vital for people with dementia and that training of care staff can help achieve this. Future results of NIDUS will show whether this training programme for care staff is effective in improving quality of life and whether it is feasible for wider roll out.

Story of Michael, an expert by experience involved in the NIDUS study

‘I enjoy taking part in research, it makes me feel useful and as if I’m being listened to and not just being written off. I also think if no one asks ‘us’, how will anyone ever know what it’s really like to have dementia and how can anyone ever do anything about it – to put it right?’

I live on my own and don’t want to go into care. If I’m going to stay on my own, I may need help at some point and I want it to be the sort of help I want, not what other people think I want. Anything that is to help make things better for people with dementia is valuable. If you have to have people come into your house to look after you, they need to know about dementia and know what they’re doing. The only way they can know this is to talk to people with the condition. If the ones who are doing the caring get it right, that will help people living with dementia.

Through taking part in this project I realised that there needed to be some changes in the way care is given and I noticed that the ones who took part in this project from the carers wanted to get onboard with it, but at the end of the day they had to get their managers and owners to get onboard and then it’s down to the financial cost to train the staff.

I did enjoy taking part in this, and I felt pride when I would give my views on things and I was listen to and not judged, and it give me the feeling, yes I have dementia, but I still have a voice and I can still contribute in these studies and projects.’

Michael, Expert by Experience, Centre for Dementia Studies, University of Bradford.

Training for care home staff – WHELD

The ‘WHELD’ (Wellbeing and Health for People Living with Dementia) study³² has developed a training programme for care home staff and involves:

- Training in person-centred care
- Review of antipsychotic medication
- Social interaction
- Exercise

The study started with a review of the existing evidence on psychosocial interventions for people with dementia in care homes and existing training manuals, finding that in many care homes residents have as little as two minutes of social interaction per day. They found strong support for person-centred approaches to care and, using findings from their review, adapted the most effective approaches to develop an optimised intervention.

The programme delivered benefits, including:

- Significant improvements in quality of life
- Reduced mortality
- Reduced agitation and overall neuropsychiatric symptoms
- Reduced use of anti-psychotics
- People had fewer emergency or routine hospital admissions and fewer GP visits
- Cost savings saving up to £4,000 for each care home over the 9 month study; or up to £2,000 when the cost of delivering WHELD is taken into account

Follow-up with staff in some of the homes 9-12 months after the project finished showed that many of the elements from individual’s learning from the programme continued to be used as a routine part of the home’s practice.

The researchers are now working on a new online adaptation, in response to Covid-19, drawing on the most successful elements of WHELD to develop a digital version of the training programme.

These quotes are from care home staff who took part in the WHELD training.

‘I think it was important, it gave us insight about spending more time and giving our time more to our residents... then tasks could be done, you know, you could have plenty of time for tasks. But the main priority was our residents and how to make them feel better and how to spend that quality time with them... the main important things are our residents... and making them feel better.’

‘It has helped in an area where we sort of do more one to one activities with people. Like with groups, and that person is not interested in it, she doesn’t want to do anything, like now it has sort of moved on to identify individuals and what interests them so we do one to one with them, it helps them.’

‘You know that lady never used to even come out of her room. And from that sort of friendship [with staff member] she was able to... The lady didn’t used to like to get... her clothes washed either... but from that relationship, [staff member] introduced her to another member of staff who could do the washing.... There’s been other things, in one unit particularly they’ve actually taken quite keenly to the baking... [staff member] has sort of taken to... doing cakes with them which is kind of the highlight of a Monday.’

Person-centred care training toolkit – VIPS

Care Fit for VIPS³³ is a web-based toolkit that enables practitioners to assess the person-centredness of their organisation across 25 different indicators, to pinpoint areas for quality improvement and find up to date web resources to support quality improvement cycles. It is fully evidence-based and maintained by Professor Dawn Brooker and the University of Worcester Association of Dementia Studies. The toolkit can be used in training, and has elements that apply to different levels of roles within the social care setting including tailored content for leadership, shift leaders, and direct care staff. The model highlights the importance of leadership in the delivery of person-centred care and the importance of leadership in enabling learnings from training to be implemented, and to be effective in changing and improving care.

The ‘VIPS’³⁴ model defines person-centredness as care that:

- **Values** – values and promotes the rights of the person
- **Individual needs** – provides individualised care according to needs
- **Perspective of the service user** – understands care from the perspective of the person living with dementia
- **Supportive social psychology** – social environment enables the person to remain in the relationship

Evidence based interventions in person-centred care for people with dementia

There is emerging evidence on the benefits of cognitive rehabilitation in care home settings. The ‘GREAT’ (Goal-oriented cognitive rehabilitation in early-stage Alzheimer’s and related dementias: a multi-centre single blind randomized controlled trial) study, led by Professor Linda Clare at the University of Exeter, provided evidence for the benefits of GREAT cognitive rehabilitation in the home setting and has been further developed in an implementation study, GREAT into practice (GREAT-iP).

Cognitive rehabilitation (CR) uses an individual problem-solving approach to address the impact of cognitive impairments in areas the person with dementia themselves has identified as the most important things that they want to manage better. The person with dementia and the practitioner then work together to plan how to meet their goals. The practitioner helps them to identify where difficulties arise in the particular task and they work together to develop specific strategies to overcome obstacles to achieve the goals. Cognitive rehabilitation for people with dementia has been adapted from a well-established approach for people who have cognitive impairment that has resulted from a brain injury.

The NICE dementia guideline³⁵ recommends considering offering cognitive rehabilitation to support functional ability in people living with mild to moderate dementia in their own homes, but new evidence from GREAT-iP may suggest that it could also deliver benefits for people with dementia in care home settings.

The ‘GREAT-iP’ study³⁶ involved four care homes, two of which had an Occupational Therapist deliver 20 hours of cognitive rehabilitation while the other two had cognitive rehabilitation delivered by existing staff without additional hours (Senior Care Assistants or Activity Coordinators). Cognitive rehabilitation was delivered to each resident twice weekly in one hour long sessions for ten weeks.

Each person with dementia identified a goal to work on and rated current ability in relation to the goal on a scale of 1-10 from ‘cannot do or am not doing successfully’(1), to ‘can do and am doing very successfully’(10). A care partner and the CR practitioner also rated the person’s ability. Prior to the intervention, people with dementia on average rated attainment for their chosen goals as 2.71, and this increased to 7.27 after the cognitive rehabilitation. For care partners, ratings changed from 2.50 to 6.50. For CR practitioners, ratings changed from 2.83 to 7.50. Additionally, 40% of residents improved in level of wellbeing and 30% of residents improved in cognitive functioning. A larger scale study is now needed to see if results will be replicated.

Case study of cognitive rehabilitation in care homes

One lady, Esther*, was becoming distressed because she couldn't find her way back to her bedroom on the first floor. She was increasingly agitated, which led to her not wanting to leave her room.

There was also a risk that she would become socially isolated, added to by the fact that some other residents were starting to avoid her because they didn't know how to help.

Esther worked together with the Activity Coordinator, who was trained as a GREAT Cognitive Rehabilitation (CR) Practitioner, to develop her goal:

'I will be able to find my way to my room whenever I want'.

The goal was broken down into four stages and a number of different techniques were used. The first stage was being able to use the lift to get to the first floor. To help with this, they decided to initially place a coloured dot next to the correct floor number, which was discreet enough to not cause her any embarrassment with other residents but meaningful to her – especially as she chose her favourite colour, red. She also used a mnemonic with the helpful alliteration of 'reach for the red'. The last stage involved identifying the correct door for her room, which was helped by a picture of a cat on the door and a matching picture in the basket of her rollator walking frame.

As her confidence grew, Esther became less distressed and was proudly telling the other residents about her achievement. She became able to find her room whenever she wanted to, not only achieving 100% of her goal but also raising her wellbeing as she felt once more part of the community.

*name has been changed to protect confidentiality

Section 3:

Sustainability of the system

In this section we look at how the system needs to be built to deliver these benefits for people with dementia.

Social care reform needs to deliver a new system that is designed to deliver high quality personalised care for people where they live, and is sustainable for the future. There are fundamental system changes that are needed, without which we risk not fully resolving the current issues, and not delivering the care that we want and need to see. It would also pose a risk to integration: for true integration of social care and the NHS, there needs to be parity of the two systems.

People

Care staff themselves need to be valued for the work that they do. **Care staff need to feel supported in their job and have their own wellbeing supported in order to support others' wellbeing.**

As the previous section discussed, learning and development is vital to equip staff with the skills they need to provide good quality care, but there are other working conditions that have an impact on the care that staff are able to provide. Social care reform needs to set out new working conditions for staff and to provide the conditions that will facilitate good quality care and that will value care staff for the work they do. This is long overdue, but particularly when we have seen how hard care staff have worked during the pandemic, putting their own lives at risk to help others, it is time to see them sufficiently rewarded. Parity of the social care workforce with the NHS workforce is also essential for integration.

Reform for quality of care can't happen without reform for the workforce. In October 2020 Wales published a ten-year workforce strategy for health and social care in *A Healthier Wales: Our Workforce Strategy for Health and Social Care*³⁷. This is a very positive step: an integrated workforce strategy, based on extensive stakeholder engagement and public consultation, with valuing staff at its heart. We need to see England and Northern Ireland governments publish their own strategy or People Plan for social care.



Beyond the argument of treating staff fairly, the social care sector is currently facing huge numbers of staff vacancies: **in England adult social care vacancies currently total around 112,000 (a 7.3% vacancy rate)**³⁸. Given the impact the Covid-19 pandemic has had on the wellbeing of staff, this number may well grow. 7% of social care staff hold EU nationality, which may further increase pressures on the sector³⁹. If the number of people requiring support from social care increases in line with population growth then 32% (520,000) more jobs will be needed by 2035⁴⁰. **Annual turnover rate is also high: for care workers it is 38.1%**⁴¹. The sector needs to transform if it wants to attract staff to fill vacancies and reduce turnover.

Skills for Care have carried out considerable analysis of factors that affect staff turnover, which may provide insight into the factors that support people working in the sector (making staff more likely to stay) and those that make working difficult (making staff more likely to leave)⁴².

This includes:

- training and qualifications (the average turnover rate was 8.1 percentage points lower amongst care workers that had received some form of training, and, of those that had received training, those that had more opportunities also had lower turnover rates)
- job progression (turnover rates for care workers were almost twice that of senior care workers)
- culture (research with employers with a turnover rate of less than 10%, found 92% said embedding values of the organisation contributed to success)
- leadership (turnover rates were higher when the registered manager had been in their post for less than one year)
- feeling valued (research found a trigger for leaving included not feeling valued for the role they do)
- and levels of pay (Age UK recently reported that care workers earn 24p less an hour than shop assistants)⁴³.

Training and support, career progression, a culture of respect, good leadership, and appropriate pay are basic principles that help create a working environment where people can flourish and do their job well. Delivering on these principles is better for staff and better for people receiving care. These are also basic principles that many people take for granted from the job they do and failing to provide these conditions for staff in social care reflects the undervaluing of both the sector and their work.

Registration can be one step in improving workforce conditions for staff and improving quality of care. Northern Ireland introduced mandatory registration for the social care workforce in 2016, where workers being on the register demonstrates that the worker is compliant with the standards of conduct and practice, though it is not tied to possession of qualifications. Evaluation has found 2 out of 3 social care workers said it had improved their confidence in what they do and 73% of employers thoughts that it improved the quality of service delivered⁴⁴. Social Care Wales is in the process of implementing a mandatory qualifications-based register with CPD schemes under which all registrants must demonstrate fitness to practice.

Care staff also learn about values and practices from other people, including leaders in their social care setting. There is evidence on the important role that leadership plays in embedding good quality care. For example, a study looking at implementing an evidence based tool ('Dementia Care Mapping') designed to improve quality of care found that the biggest factors that influenced whether the tool led to benefits were manager support for the tool, manager understanding of the tool, choice of staff to lead, manager stability, and manager engagement with the tool⁴⁵. There is also evidence from a 2018 CQC report⁴⁶, which looked at how nine services that had received an 'inadequate' rating had turned their performance around to achieve a 'good' rating. They found common themes from the services of strong leadership focused on valuing and empowering staff, seeking ideas from all staff, and working collectively as a team to drive improvement towards a shared vision of high quality personalised care.

Section 4:

Support for all

This section looks at how people affected by dementia are able to draw on the social care support they need when they need it, and what needs to change to ensure everyone who needs it can get the support to live their lives the way they choose. Even when care is of sufficiently high quality, many people struggle to access that care – while legislation sets a strong foundation it has often not been fully implemented due to a lack of **‘appropriate levels of funding’**⁴⁷.

In England, the Care Act (2014) is the legislation that sets out how adult social care should be provided and principles for delivery of care. However, the Care Act is not clear on a minimum set of national standards and eligibility criteria for accessing care to properly support people affected by dementia – while it outlines core outcomes people should be supported to achieve, it is not sufficiently clear on at what stage someone’s condition means they have an entitlement to support. Similar legislation exists in Wales with the Social Services and Well-being Act (2014). There is even less clarity in Northern Ireland, where individual Health and Social Care Trusts retain discretion to decide whether or not to provide a service to meet a need identified in a care assessment.

Local authorities in England have faced cuts of 38% in real terms in grants from central government between 2009/10 and 2018/19⁴⁸, significantly reducing their budgets and meaning they have gradually stripped back the care that they are able to provide⁴⁹. Wales and Northern Ireland have faced similar challenges with reduced budgets leading to reduced access to care, resulting in more and more people going without their care needs being met.

In England, the Local Government and Social Care Ombudsman has:

- Shown a 140% increase in social care complaints over the eight-year period since 2010 and indicated that social care assessments are now among **‘the biggest areas of complaint’** in their 2018 annual report⁵⁰
- Found 68% of complaints on assessment and care planning are upheld in their 2019/2020 Annual Review of Adult Social Care Complaints⁵¹
- Found some councils at fault **‘for raising eligibility thresholds to qualify for services, particularly in adult social care, as a means to save money. Instead of starting by assessing needs, developing a care plan and then meeting eligible needs, councils have made resource-led decisions, sometimes missing out the care plan stage altogether’**⁵²

Whilst not dementia specific, it is clear there is a growing level of unmet need, in particular among over 65s – while requests for support from over 65s has increased by 3.3% between 2015/16 and 2018/19 (with some people requesting support multiple times), the number of older people receiving support decreased from 587,000 to fewer than 550,000 despite an increase in the older population⁵³. This is partly because the national means-test has ‘got meaner’⁵⁴. In England, the means-test threshold for social care has not kept pace with inflation since 2010/11 – the current threshold of £23,250 should be around £27,759 in 2020/21, meaning everyone with savings between those points has effectively lost the entitlement to publicly funded care due to inflation⁵⁵.

This has had huge consequences for people with dementia. Too many are being left without support from the government to help them live the lives they want at a time when it could help to prevent their condition deteriorating, and instead are only being able to get support at a point of crisis.

Research from 2019, using figures from 2015, has estimated that in England there are:

60,800 

people with severe* dementia with care needs who receive no support from the professional social care system and rely on unpaid family carers⁵⁶.

8,600 

people with severe dementia don't have support from family carers nor professional carers.

43,000 

people with moderate dementia receive no support with their care needs at all.

93,100 

people with moderate dementia with care needs only receive care from an unpaid informal carer⁵⁷.

Whilst the reasons for not receiving social care will be specific to each case and may be for a range of different reasons, this helps provide some indication of the scale of people whose needs are not being met by the current system. This is important, because not meeting the needs of people with dementia is associated with the progressive worsening of cognitive and functional deterioration, resulting in the loss of levels of autonomy and the capability to satisfy their own needs⁵⁸.

Reduction in formal support also often results in care being picked up by family members or friends, which can lead to increased stress or exhaustion of these informal carers, and greater risk of crisis. Moreover, our recent report 'The Fog of Support' found that although the Care Act (England) 2014 and Social Services & Wellbeing (Wales) Act 2014 require local authorities to identify and consider the needs of carers themselves, **'there is still the chance of (1) not identifying carers due to them being in hidden populations; and (2) not identifying, assessing and supporting carers if they do not appear to be actively engaging with the local authority (which may be due to the complexity of their situation rather than not wanting or needing support)'**⁵⁹.

It is clear that not everyone who would want to draw on support is enabled to do so. With unmet need growing among over 65s, we must take the opportunity of reforming social care to deliver a clearer expectation for what social care means and what a well-organised system can do to nurture an ecosystem of support and relationships that can be drawn on to help people live independently and well. National standards must provide greater clarity on the care people can expect to receive if their condition means they are unable to achieve their specified outcomes, or the outcomes are significantly impacted. We need to see people's rights to care assessments upheld. During the Covid-19 pandemic, the Coronavirus Act introduced easements to the Care Act in England which legally removed the rights for people affected by dementia to have their needs assessed and have their eligible needs met, for councils which applied them. While few councils eventually applied the easements, we must nevertheless reinforce the importance of people's rights to care always being upheld.

*In this research care needs were identified based on measures of independence/dependency, and mild, moderate and severe dementia were defined using MMSE (Mini-Mental State Examination) scores.

This needs to include clearer national guidance for assessors on establishing when people with dementia cannot meet these outcomes so that people understand their entitlements regardless of where they live. It is important that assessors have an understanding of dementia and how it affects someone, including its impact on their mental capacity and ability to communicate their needs. For example, a person with dementia may state in an assessment that they don't want or need support, when in reality they aren't coping at all and require services but are unable to communicate their need. Currently, there is no requirement for assessors to have specialist training, which can mean people with dementia having their needs assessed by someone without an understanding of their condition. Assessors should be specialist roles with training in dementia and cognitive impairments. An example of where this has been implemented is the Autism Act 2009⁶⁰, which requires the assessor to have training and a good knowledge of the condition.

Care needs assessments should involve the carer and recognise them as an essential part of someone's life, but the provision of professional care should not hinge on whether or not a carer is already providing support. No one should be expected to provide care. Support should start with the person and what they can do for themselves (with or without technology and aids); before broadening out to reflect the possibility for the contribution of personal networks and available community support.

For this to happen, the government must make good social care a priority and begin investing more in it. Local councils in England and Wales, and Health and Social Care Trusts in Northern Ireland, need the investment to enable them to meet nationally assured entitlements to care, so that everyone who is assessed as having care needs can access this care, and without delay. Councils and Trusts also need to work alongside and in support of local people and organisations to bring these ideas to life by organising and funding social care differently.



Conclusion and next steps

We must ensure that the opportunity presented by social care reform is used to set a new vision for social care. We believe that everyone should be able to live in the place they call home, doing what matters to us, in communities where we support and look out for one another – social care can provide the vehicle via which people can live the lives they chose, if it is personalised and focuses on what matters to them. For people with dementia, this evidence suggests that the support that people can draw on from social care providers should address psychological factors to improve living well and support people to build or strengthen relationships with loved ones, family members or people in their community. New training programmes could increase standards, and innovations such as cognitive rehabilitation can provide benefits within certain settings.

A new social care system must be designed to deliver on this vision, with the necessary investment and structures, leadership and accountability. We believe that this can and should be happening everywhere and for everyone.

These are just the first steps in the conversation on how we improve the quality of social care for people affected by dementia, and clearly set out an evidenced based perspective on what real quality care looks like. Alzheimer's Society will use this paper as a basis to further explore best practice and what can help to provide that care. Most importantly, we will be engaging with people affected by dementia and staff working in the care sector to learn more about experiences of good care and what personalised care means to them, furthering the themes of this initial analysis. This paper has provided the framework for us to understand and conceptualise personalised care. People who use social care must always be at the heart of reform. Moving forward we will be helping ensure that the voices of people with dementia are heard, building on our work on how to bring the latest research evidence into policy and into practice, in future targeted work on the specific themes of personalised care which matter most to people affected by dementia.

This is the first stage of our project on delivering quality personalised social care for people with dementia. If you would like to be involved and have evidence or research for us to share, please contact policy@alzheimers.org.uk



Appendix 1: Methodology

We carried out literature reviews of policy and research sources addressing questions including:

- What does good quality social care look like for people with dementia? What are the outcomes in social care that are important to people with dementia?
- What evidence is there on the quality of social care people with dementia are currently receiving? What evidence is there on the outcomes for people with dementia in social care?
- Is there evidence of particular factors that lead to higher or lower quality care, and better or worse outcomes in social care for people with dementia?

Sources looked at included:

- Standards, frameworks, reports and statistics from think tanks, charities, campaigning organisations, providers, and the Government and arms-length bodies
- Research from Alzheimer's Society supported Centres of Excellence and from other studies that Alzheimer's Society have supported. Additional studies from a search of PubMed, Google Scholar and Science Direct for the latest research articles using a combination of search terms such as: 'Domiciliary' OR 'residential' AND 'dementia' AND 'quality of life' (limited due to the high volume of results)

Research review

- Our review of relevant research literature identified further elements of quality care that are important to people with dementia. We also looked at research emerging from Alzheimer's Society supported Centres of Excellence, which are groundbreaking initiatives developed to address areas of dementia care in urgent need of more research. We would like to thank the researchers who we interviewed as part of this project



Appendix 2:

Frameworks and standards reviewed

The table below outlines some of the frameworks and standards from leading organisations, with a summary of the purpose of the framework, how it is used, and how it was created.

Organisation	Framework and publication date	Purpose of the framework and how it is used	How the framework was created
NHS Digital	Adult Social Care Outcome Frameworks (ASCOF) (latest version 2019-20)	To measure how well care and support services achieve the outcomes that matter most to people. Data on measures is collected annually through the Adult Social Care Survey	Personal Social Services Research Unit (PSSRU) developed the Adult Social Care Outcomes Toolkit (ASCOT), which drew on a large scale study of people in care homes
Department for Health and Social Care	Quality Matters (2017)	To set out what high quality social care looks like. It is used to support commissioners and providers in high quality care. An 'action plan' reports on priority areas for improvement.	Collaboration across ADASS, Care England, the CQC, Local Government Association (LGA), NHS England (NHSE), NICE, Skills for Care, and other leading organisations in the sector
Care Quality Commission	Inspection framework	To assess quality of care, for regulation purposes, and to identify where care falls below minimum standards It is used to guide CQC inspections.	The framework has evolved over time through consultation with a wide range of stakeholders

Think Local Act Personal (TLAP)	'Making it real' framework (2018)	To describe what good, personalised care and support looks like from the point of view of people using the services. It is used by organisations who provide care and staff working in care.	Co-produced by people using services and by TLAP and Coalition for Collaborative Care, now known as Coalition for Personalised Care.
UK Homecare Association (UKHCA)	Indicators of quality care (within code of practice for members) (2016)	To present indicators of good quality care. It is designed to be used by homecare workers and providers.	Developed by the UKHCA and its members.
Enhanced Health in Care Homes (EHCH) (from NHSE)	Framework for delivery of model (2020)	To help areas implement the model to improve care in care homes.	From evaluation of vanguard sites implementing the model.
Independent Age (with Healthwatch Camden)	Quality indicators for a good care home (2016)	To help people in choosing a care home.	Developed with older people and families.
NICE	Dementia guideline Quality Standards for adult social care (2018)	To be used to improve quality of care.	Developed in collaboration with health and social care professionals, practitioners, and people using services, and based on NICE guidance.

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