Commission on the Future of Long Term Care in Scotland report

May 2024

Alzheimer Scotland
Action on Dementia


ELIF SHAFAK

Contents

Foreword
Henry McLeish

The future of long term care stands as one of the most pressing challenges confronting our nation today. Despite extensive debates and Scottish Government policies and initiatives such as the development of the National Care Service, there remain fundamental issues that demand our attention and require urgent action.

In an effort to address these challenges comprehensively, Alzheimer Scotland formed the Commission on the Future of Long Term Care, and it has been a great privilege to chair this vital piece of work. With members from across a broad spectrum, the Commission focused on what we consider to be the essential aspects of long term care for older people and people with advanced dementia.

Chief among these is a firm belief in championing the intrinsic worth and dignity of every individual in Scotland as they traverse through life, retaining their spirit and their sense of belonging within their communities as they age. It is imperative that our approach to long term care respects and preserves this fundamental aspect of our human rights.

The demands for care in this country will simply grow, and grow, and grow. We must consider what kind of society and care system we aspire to, and grapple with the ethical and moral dimensions inherent in these considerations. Central to this is the question of whom we serve - and how we serve them.

Our perspective on care is rooted in the principle that individuals should be enabled to access care and support that meets their needs but also reflects their wishes and preferences. This includes prioritising the ability to remain within familiar surroundings, to the greatest extent possible, and providing alternatives to institutionalised models of care where this may be incongruent with their life experiences and desires in later years.

The interface between health and care is of paramount importance, particularly in light of the challenges of co-existing health conditions, socio-economic disparities and an ageing population. We advocate for a significantly heightened level of integration between social and health care systems. It is untenable for individuals with complex care needs, such as those with advanced dementia, to be categorised as having solely social care needs when their requirements clearly extend into the domain of health care.

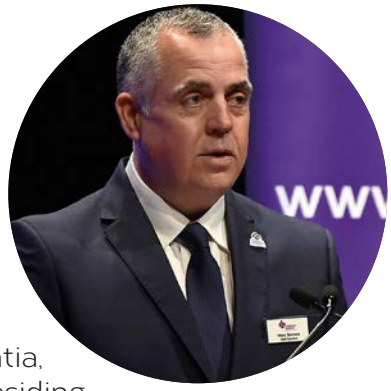
Drawing from the experiences of other models, we recognise the importance of learning from successful approaches and practices both domestically and internationally. While acknowledging the significance of cultural nuances, we should remain open and receptive to adopting effective strategies from elsewhere to improve the experiences of older people and people with dementia in Scotland.

Financial considerations loom large in the realm of long term care but we must still strive to deliver the vision of accessible, equitable care for all. For the first time, Scotland has engaged experts to explore innovative strategies for financing care initiatives and attracting investment into the sector. This presents us with an opportunity to re-think how we deliver and fund care, now and in the future.

I would like to thank all the Commission members for their commitment and expertise they have contributed, both individually and collectively. In presenting this report, we hope to spark meaningful discourse and Scottish Government action towards a future where long term care is not merely a response to needs, but a testament to a collective commitment to dignity, compassion and social justice.

Henry McLeish
Alzheimer Scotland Ambassador, Commission Chair

Foreword
Henry Simmons



I would like to thank the Chair, Henry McLeish, and indeed all our Commission Members, for their unwavering commitment and time to explore, consider and present this report on the future of long term care in Scotland.

There is an estimated 90,000 people in Scotland living with dementia, and according to Scotland's Care Home Census, about 19,000 are residing in one of the 1,000 care homes across the country – these numbers will only increase and despite this scale and the complex needs that arise as dementia progresses, Scotland lacks a national plan or strategy to address their long term care needs.

The absence of a coherent national plan means that we do not have a structured approach to ensure a range of long term care options and facilities are available locally to meet these needs. Instead, care home provision has largely been handed over to an open market, leading to a fragmented and crisis-prone system.

Today, many care homes are facing financial crises, with some areas at risk of collapse. This market-driven approach has resulted in a lack of strategic commissioning and planning, minimal engagement with local communities, and a disconnect between local needs and service design. Furthermore, it has stifled the development of innovative community-based long term care models, forcing a one-size-fits-all approach that does not cater to the diverse needs or wishes of people.

Many people feel they have no choice in determining their long term care. Once the cost of community care reaches the ceiling set by the National Care Home Contract, financial considerations drive decision-making, pushing thousands into care homes. This contract ceiling has led to a system where care decisions are financially driven rather than based on individual needs.

There is a public perception that care in this country is free. 'Free personal and nursing care' does not mean that all care is free, it is but a small contribution to the overall cost, which ranges from £1,200 to £2,000 per week. The truth is that everyone pays towards their care, including those who are considered publicly funded.

Many people with advanced dementia are paying thousands of pounds each week for care. Care which would be free if they had any other form of terminal illness. Care which is health care. Care which should be free at the point of delivery. This is fundamentally wrong and unequivocally unfair.

A fiscal challenge is not a good enough excuse for the Scottish Government to continue to allow this inequity to exist. It must end - and people with advanced dementia deserve much more personalised long term care options that reflect what they want and need, not what the budget ceiling dictates. They deserve what is right and what is fair.

We urge the Scottish Government to implement all of the recommendations in this report as a matter of urgency, and deliver fairness, equality and the best possible long term care to one of our most vulnerable communities in Scotland.

Finally, my deepest thanks and gratitude to the people with dementia and their families and carers who shared their views, hopes and concerns as part of the Commission's public engagement work. We care deeply and passionately about your voice, your choice and your future.

Henry Simmons
Chief Executive

Why do we need a Commission on the future of long term care?

Alzheimer Scotland recognises that people can live well at home with dementia for several years when they are able to access a timely diagnosis, high-quality post-diagnostic support and well co-ordinated, integrated community care services. However, we also recognise that accessing care and support that meets both the needs and preferences of people living with the complexities of advancing dementia presents significant challenges. Options around long term care begin to diminish as an individual's needs begin to increase and the current approach to commissioning, funding and the provision of care means that there is little choice, power or control for people living with advanced dementia and other complex health conditions. Care in care homes often becomes the default position for many older people and people with advancing dementia, irrespective of their personal preferences for receiving care and support. This is particularly the case where the current provision of community-based care and support can no longer meet their needs, or is viewed as no longer financially feasible, and in the absence of suitable alternative arrangements.

Alzheimer Scotland's Advanced Dementia Practice Model [1] demonstrates that the person-centred, multi-disciplinary care and support needed to manage the increasingly complex needs that arise in advancing dementia "does not exist in any meaningfully planned or commissioned way." Scotland's current care home estate is a mixed economy of care made up of local authority, not-for-profit and private sector providers, and has been founded on little or no strategic planning. Significant entrepreneurial activity in the private sector in the 1990s and beyond has seen the emergence of a largely market-driven approach to the delivery of long term care provision with a focus on financial investment and return rather than responding to a strategically planned system serving the specific needs of those who require care and support.
Large group living environments, based on the principles of economy of scale, have been the main offering for long term care provision over the last 30 years, and while there have been significant improvement programmes such as 'My Health, My Care, My Home' [2], very little has been done to explore or develop alternative approaches to long term care that meet the needs and reflect the wishes and preferences of older people, people living with dementia and those with complex care needs.

The experience of the COVID-19 pandemic has served to highlight the significant challenges that exist within the current approach to the delivery of long term care in care homes. The disproportionate impact of COVID-19 on people in care homes has raised concerns about the ability to ensure the safety and wellbeing of individuals in large, shared environments. This has even greater significance when considering the direct and indirect harms caused by the public health measures that were introduced in care homes in response to the pandemic. These challenges demonstrate the urgent need to consider how we best support people in Scotland with longer-term and complex needs in the future.

The delivery of high-quality, culturally appropriate long term care and support is also influenced by the cost and funding implications of service delivery. As Scotland's health and social care sectors face a challenging economic environment, we need to consider how care is both delivered and paid for. At present, there is a

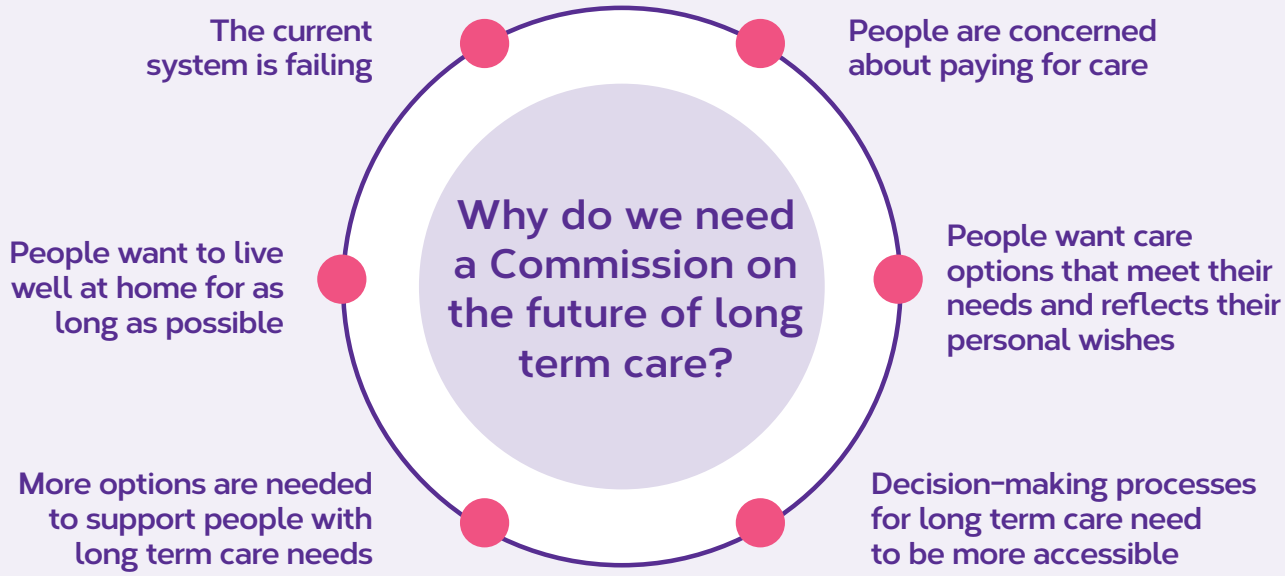


Figure 1 – Why we needed a Commission

systemic failure to acknowledge that care in Scotland is in fact not free, everyone pays something towards the cost of their care and some pay much more than others. The lack of an open and meaningful debate on who pays for care and what we actually pay for care perpetuates public expectations that their future care needs will be met without any cost to themselves, and the lack of innovation within health and social care systems limits opportunities for any meaningful future planning and early interventions that might provide better alternatives and ultimately mitigate the need for residential forms of care.

Current social care and support is unable to wholly meet people's needs. With an increasingly ageing population, more people in Scotland can expect to experience dementia and other long term, complex health conditions, and the proportion of people needing to access long term care and support will continue to grow. The lack of choice and control that people with advancing dementia and their families have means that few people experience care and support in the way that is right for them. People's rights, will and preferences are not being respected, and person-centred care is challenging to achieve with a 'one size fits all' approach.

The purpose of the Commission

The Commission has been brought together to consider how we tackle the existing lack of strategic planning and commissioning and how we address the future long term needs of older people and people with advancing dementia. We also wanted to explore the current inequalities that exist within long term care provision for older people and people with advancing dementia, and consider how their increasing healthcare needs are met and paid for in care homes in a fair and equal way.
As we look to the future, the Commission recognises that we must consider how approaches to care can respond more effectively to the needs, wishes and preferences of the increasing number of older people and those with advancing dementia in Scotland. The aim is to ensure the availability of high-quality care and support options when they are needed, delivered in a way that that older people, people with advancing dementia and their families believe can best meet their needs.

In recognition of the need for a new approach to care that is designed to meet the increasing needs of older people and people living with advancing dementia, the Commission has sought to establish a suite of national recommendations for Scottish Government and other stakeholders which sets out a new, fairer, more person-centred approach to sustainable policy and practice for the long term care of older people and people with advancing dementia in Scotland. Each of our recommendations has been underpinned by principles of human rights, fairness and dignity.

The Commission has considered what changes and improvements are needed in the current operational environment and the system levers which can be applied. It has sought to identify innovative, cost-effective, and affordable solutions for achieving any recommended changes to the current model of long term care provision. The Commission has considered alternative models of care for people with advancing dementia, with the aim of recommending a range of options that can meet the longer-term needs of people with advancing dementia within their communities.

Public views and perceptions of long term care

Alzheimer Scotland hosted a series of public engagement sessions [see Appendix 1] to hear the diverse voices, perspectives and views of people currently living with dementia and their families and carers to gather their opinions on current long term care options and their hopes for the future. While each view was as personal and unique as the individual who shared it, there were common themes which emerged from the discussions.

1. The current system is failing

People are concerned about the current system's ability to effectively meet their long term care needs. People shared experiences outlining the considerable difficulty they had in accessing the care and support they need, raising concerns about the lack of information available to them and the complexity of the processes and assessments which made them unattainable. We heard many examples of waiting lists and delays that prevented people from accessing the support they needed, when they needed it and from people reaching out for help and being told that their situation simply wasn't serious enough to be assessed and approved for help despite the urgency of their situations.

We also heard that current care and support packages are not working for people with dementia or their families. They feel that care is focused more on time and task rather than on achieving the outcomes that people who need care deserve. They do not feel enabled or empowered by current approaches to care. People are desperate for change and something better. They feel as if they are not being listened to or heard and that the care on offer does not, and cannot, respond to their needs as they arise. They feel that by failing to intervene at an earlier stage, it is too late to change the path that inevitably leads to a move to a care home – either because the person with dementia advances more rapidly without the type of care and support they need to prevent or delay the advancement of their condition, or because informal carers reach burnout and can no longer cope without the support they need to facilitate care at home.

> "It just isn't working. There's a different carer every day who pops in for five minutes and they're just rushing to get everything done so that they can move on to the next visit because they aren't allocated enough time to actually care."
>
> – Community member with lived experience

2. People want to be enabled to live well at home for as long as possible

For most people, staying at home for as long as possible is the most desired outcome since they consider living in a familiar environment, among a community of people that they know, to be of significant importance to enable them to live well. For most, moving to a care home is not a preferred choice and does not reflect how they want to live and be cared for as they age or manage an increase in care needs. People highlighted the perceived impersonal nature of care in large, shared environments, issues with limited workforce being able to deliver the desired quality of care and support, and a lack of local long term care options that enable individuals to remain within their own communities.

Nonetheless, people recognise that they need to able to access more support to enable them to continue to live at home. They recognise the need for flexible, innovative support that is tailored to effectively meet their unique needs and that a 'one size fits all' approach is neither helpful nor wanted. Current care provision is not responsive to their needs and the focus on delivering support to only those in critical need means that opportunities for prevention and early intervention are often lost. People want a person-centred approach to care that is focused on meeting their needs rather than focused on the cost, or the resources or time available. They specifically identified the need for high-quality care and support that:

- focuses solely on meeting the needs of individuals to achieve positive outcomes, including flexible options that can adapt to changing needs;
- is not allocated on the basis of arbitrary measures of time or money;
- enables the formation of relationships that promote positive experiences and outcomes for those receiving and providing care; and,
- is delivered by a knowledgeable and skilled workforce.

> *"I want to stay at home. I've built my life here and I don't want to leave everything behind."*
>
> **– Community member with lived experience**

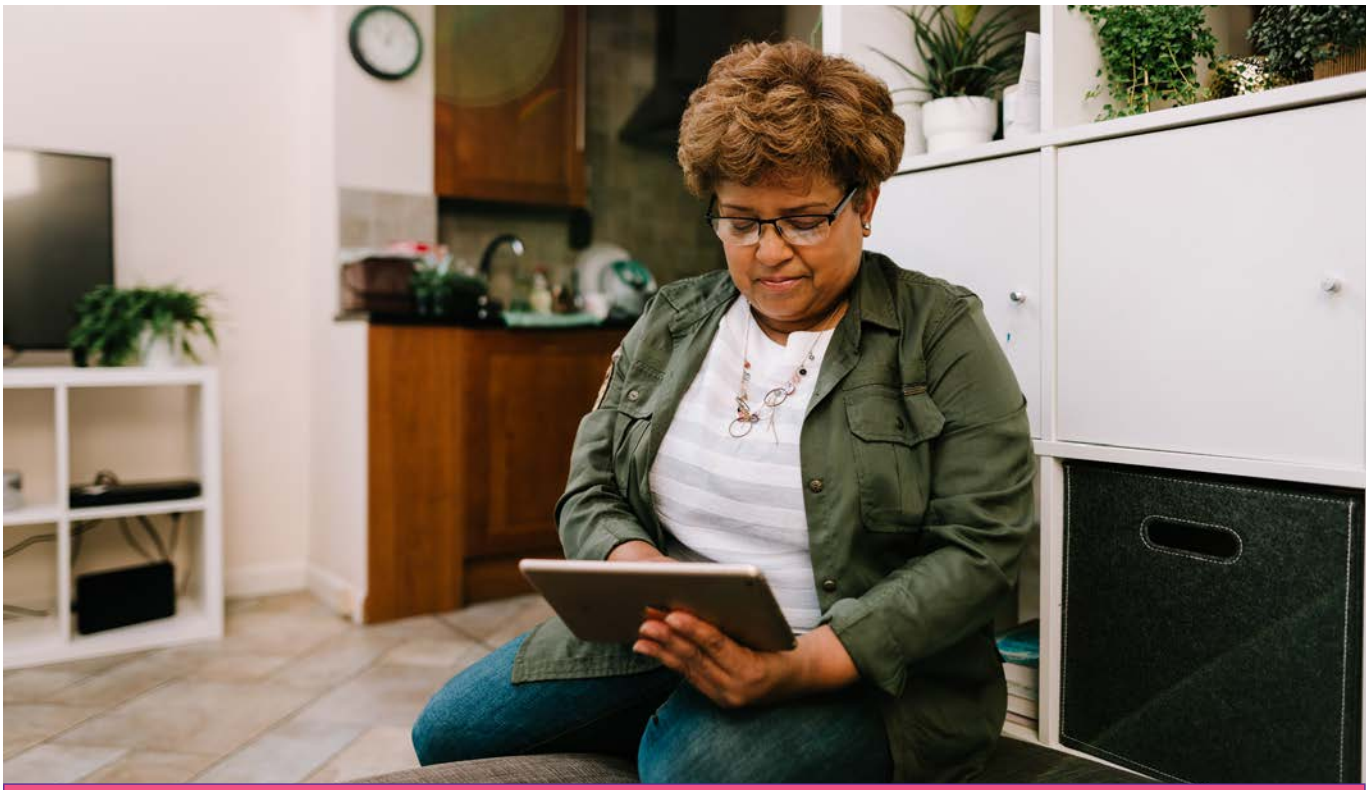
3. More options are needed to support people with long term care needs

The lack of choice around alternative long term care arrangements mean that many people feel they lack any power or control around how they access and receive care. People understand that once they have exhausted the limited support available to remain at home, there are no other alternatives to an admission to a care home. They believe that the decision to move to a care home is often made as a part of a crisis response and without considering their wishes or preferences. The overwhelming majority of people who participated in our public engagement sessions agreed that they would not choose to have their long term care needs met in a large group living environment such as a care home if there was a viable alternative.

There is recognition that care homes have a place in the long term care landscape and that they provide positive opportunities for social living arrangements, supported by the availability of a range of care and support. There are numerous examples of good practice in care homes which highlight excellent levels of care and support.

People want to have choice and control around their long term care and support options and are keen to explore opportunities for alternative approaches that might 'bridge the gap' between care at home and a care home. Approaches such as supported living arrangements (both independent and small-scale group arrangements), specific community living arrangements such as dementia villages, and more intensive care at home options supported by the availability of more flexible and responsive respite care were particularly popular choices among the group of individuals we engaged with on this issue.

> "The move from care at home to a care home is an enormous jump but there's no alternative. There's nothing to ease that transition or something that will help me to stay in my own home when I need more help."
>
> – Community member with lived experience



4. Decision-making processes for long term care need to be more accessible

Carers highlight the importance of being included in decision-making processes and the need to be listened to and heard throughout processes for determining eligibility and access to care and support. While the right to participate in decision-making is set out in legislation, we heard that people often feel excluded from these processes. A more inclusive approach to decision-making is required to enable people to express their views and to involve carers as 'equal partners' in care.

Current processes are often overly complicated, and people need assistance to be able to access the care and support they need. Processes need to be simplified to enable people with dementia and complex care needs to be meaningfully engaged in them. More information about care and support options is required since a lack of freely available information is a barrier to making positive choices and people are more able to question and explore care options when they feel more knowledgeable about their rights to care support. Care co-ordination through a single, dedicated point of contact was widely recognised as a hugely supportive approach to facilitating and enabling people to understand and navigate through systems and processes.

> "It's an absolute minefield. I don't understand how it all works but I don't know where to turn for help."
>
> – Community member with lived experience

5. People want care options that meet their needs and reflect their personal wishes

People want to access care and support that meets their unique needs, as well as meeting their individual wishes and preferences. Some people can find it difficult to express their specific preferences about what their future care and support should look and feel like. They are unsure about how their condition will change or their needs will increase while others find it difficult to imagine how their care could be delivered differently given the lack of creative examples of care. However, people are often able to articulate the type of care they do not want based on their experience of previous and current services and their views should be taken into account in decision-making processes.

People with dementia and carers are keen to see the development of new approaches to person-centred care based on human rights principles of dignity and respect. People with long term care needs want to be empowered to choose the type of care and support they would like.

> "I just feel like it doesn't matter what I want. I feel like everyone thinks they know what's best for me and my voice is drowned out. No-one listens to me and thinks about what I want."
>
> – Community member with lived experience

6. People are concerned about paying for care

Many people hold the belief that their care needs will be met by the health and social care system in Scotland and that there will be no direct cost to meet those needs. They assume that given healthcare is delivered free at the point of delivery by the NHS, and that the needs of people with complex conditions such as advanced dementia are primarily healthcare needs, then these needs will be met in a similar way. Most people are shocked and frightened by the scale of the financial contribution required to ensure that they receive the care and support they need.

On exploring the true cost of care, and the expected personal contribution to that cost, people often described it as 'unfair', 'unreasonable' and 'excessive'. Many people feel vulnerable when they think about the cost of care and are concerned about how they will meet the costs of long term care for themselves and their loved ones. They are concerned that they have not prepared to meet these costs and how they would find the resources to pay for their care, or the care of a loved one, given the financial burden that this would place on them. They also question what it would mean for the quality of care that would be provided if they were unable to afford it.

> "I thought the figure they quoted me was for a month. It was a shock to the system when they told me that was the weekly cost for my mum to stay in the care home. I'm not sure how we're going to pay for it, we're not well off. This has had such a huge impact on everyone."
>
> – Community member with lived experience

The current context of long term care

Across Scotland, long term care provision is struggling to meet current demands on the system. From increased waiting times for care needs and financial assessments to significant delays in receiving care services, the social care system is unable to respond to the complex, progressing needs of older people and people with dementia when they arise. Issues relating to inadequate funding and workforce challenges mean that the current approach to long term care provision is both inefficient and ineffective and there is concern that demand on services will only continue to grow as it deals with increasing complexity of care needs among an increasingly ageing population.

While existing legislation, including the Self-directed Support (Scotland) Act 2013 [3], sets out provisions for the planning and delivery of a range of choices for care and support, evidence indicates that it is not consistently applied across the country [4]. Limitations to the delivery of self-directed support reduce the extent to which people have choice and control since there is no true availability of all four options for accessing care and support.This also increases levels of bureaucracy, reduces transparency and accountability and limits opportunities for people with complex needs to be involved in planning their own care.

Additionally, the lack of investment and innovation in social care has meant that options for care and support are further limited. Since the introduction of the National Assistance Act 1948 [5], local authorities have assumed responsibility for the provision of social care, including the provision and management of residential care for older and disabled people. While these duties were largely carried out by local government in the early years of social care provision, shifting policy agendas have seen substantial, non-commissioned growth in the independent sector and local authorities have moved from being providers of care to being purchasers of care. As a result, some of the services on offer lack creative approaches to care that provide personalised, person-centred support designed to meet the unique needs of individuals and people often find themselves receiving traditional care at home services or in care home settings, even when this does not reflect their wishes or preferences.

Limited choice of community-based care options inevitably pushes individuals towards care homes, particularly where financial constraints are a primary driver for decision-making. The maximum level of community-based care is often dictated by a financial ceiling rather than by considering the preferences and outcomes for an individual. There is currently a potentially perverse incentive for local authorities to direct individuals towards care homes if the cost of meeting their level of need in the community exceeds the amount of the National Care Home Contract.
For individuals whose needs exceed the cost of supporting someone in a care home, there is a risk that local authorities might consider this cost financially unfeasible and conclude that the only alternative is a place in a care home. This reduces the cost to local authorities who would, depending on the outcome of the financial assessment, be required to pay at least any free personal and nursing care payment, or top up an individual's assessed contribution to the level of the National Care Home Contract standard rate. However, this financially-driven approach does not necessarily consider how this change in care provision will affect the individual's wishes, experiences or outcomes.

Private sector care home provision continues to be the main provider in Scotland while, by contrast, local authority-

owned and managed homes have declined in number over the past few decades, resulting in a prevailing market-driven model. Despite the requirement for health and social care partnerships to develop market facilitation plans or statements. [6] they have no authority to shape the care home market to meet the needs of the local communities they serve. The lack of commissioning or planning processes for privately funded care home provision means that new developments are established irrespective of the needs of local populations. Financial viability and return on such investments are the main drivers for what services and supports are available to people with long term care needs rather than focusing on any understanding of what people need and want to meet their long term care requirements. While local authority planning processes play some part in determining whether planning permission is granted for proposed care home developments, they do not appear to place any significant weight on, or requirement to, consult with health and social care partnerships or people with lived experience in the development of proposals. This has contributed to an imbalance in the provision of care home facilities, with an unequal provision in some communities, particularly in remote and rural communities across Scotland.

Currently, the challenging economic climate is leading to difficulties across the care home sector and there are increasing numbers of care home closures due to the significant pressure of increased costs. As the market fails, choices for long term care are squeezed and people are unable to access the care and support they need. As the landscape of available care and support changes, it is essential that we have a clear understanding of what support is available and how, and if, it is supporting the needs of local populations.

Commission recommendations

The Scottish Government urgently works with health and social care partnerships to undertake a full strategic assessment of the provision of long term care facilities and resources in each area. By undertaking an evaluation of existing provision we will have a greater understanding of the availability of, and potential gaps in the provision of, long term care options across the country. This information should be used to inform our understanding of current and future demand for care places.

The Scottish Government establishes agreed levels of care home and alternative care model places that should be equally available across Scotland. Data should be used to establish an accurate measure against which care places are provided. Care places should encompass a range of options that reflect the needs and preferences of local populations. Agreed levels should be subject to regular review to ensure that the availability of care places keeps up with demand.

A connected national and local strategic commissioning policy that offers innovative, alternative approaches to long term care provision is developed in Scotland. This will support the delivery of a range of long term care options that meet the needs of older people, people with dementia and people with complex needs. This includes the development of guidance and support that will enable health and social care partnerships to commission and engage services that are focused on positive outcomes for those who need long term care in their area.

Existing legislation, such as Self-Directed Support, should be fully implemented to support the delivery of greater levels of flexible, needs-led community care which is not limited by the ceiling cost of the current National Care Home Contract rate. This will enable people with long term care needs to access a range of community-based care provision that reflects their wishes and preferences about how and where they receive their care.

Human rights and long term care

While there is no explicit right to long term care set out in international or European conventions, broader protections for the rights of many older persons in need of long term care are addressed through the United Nations' Convention on the Rights of Persons with Disabilities (CRPD) [7] and International Covenant on Economic, Social and Cultural Rights (ICESCR) [8]. This includes protections for the right to the highest attainable standard of physical and mental health, independent living and autonomy and support for decision-making. Rights in Scotland are established through a legal framework underpinned by human-rights approaches such as those outlined in the principles of the Adults with Incapacity (Scotland) Act 2000 [9], the Mental Health (Care and Treatment) (Scotland) Act 2003 [10], and the Adult Support and Protection (Scotland) Act 2007 [11]. Nonetheless, there are significant gaps in the delivery of these rights and there remains concerns that there is an erosion of rights for people with complex, long term care needs. Findings from the European Network of National Human Rights Institutions (ENNHRI) [12] indicate that human rights are at risk across a range of settings including protections related to equal access to, and affordability of, healthcare, choice of long term care service, participation and social inclusion, and adequate standard of living.

There is a risk of 'missing the individual' without a commitment to enact even basic principles of human rights. The needs of individuals must be considered against a human rights framework based on the principles of maximising choice and control, prevention wherever possible, and early intervention where it creates the maximum benefit for individuals. This approach should be a key influence in the process of commissioning services that are designed to meet the needs of individuals.

Article 19 of the CRPD focuses specifically on the right to independent living and

being included in the community, including the right to choose where and with whom to live, and the right to access support to do so. The Article also promotes the end of all forms of institutionalisation, and emphasises the significance of personal choice, autonomy and control about how an individual chooses to live. Reflecting on the rights set out in Article 19, it is evident that some long term care arrangements for older people constitute institutionalisation, including environments often encountered in hospitals and care homes, and it is more challenging to enable people to live within a community under these conditions. Given that most people express a wish to continue to live in their own communities, it is clear that we are unable to achieve this through a model of long term care that is predicated on care home living as the default.

While long term care institutions for people with learning disabilities and mental health problems were being decommissioned and replaced with new, smaller, person-centred care models in recognition of how negative institutional care can be, new institutions in the form of large group living environments were being developed as the way forward for older people and those with long term, complex healthcare needs. While this approach to decommissioning has not benefitted everyone with a learning disability or mental health condition, it is evident that little consideration was given to smaller-scale, alternative models or more innovative, community-based supports that might better serve older people and people with complex health needs. Yet the United Nations recognises that there are clear alternatives to institutionalisation and provides a framework [13] for considering an alternative approach guided by the criteria set out in the Article. As we move forward from traditional approaches to care, we must consider how we move away from institutionalisation and consider how we can adopt a human rights-based approach to change and adapt existing models and consider new, alternative models of care that allow people to remain grounded in their communities.

Scotland has made clear its intention to shift its approach to supporting vulnerable individuals following the publication of the Scottish Mental Health Law Review [14] in 2022. For example, the focus of mental health incapacity law has moved from regulation and intervention by the authorities to implementing the rights of vulnerable individuals by concentrating on meeting their needs in the most appropriate way, at the right time. This approach must similarly be adopted to enable these individuals to access high-quality, long term care options.

Commission recommendations

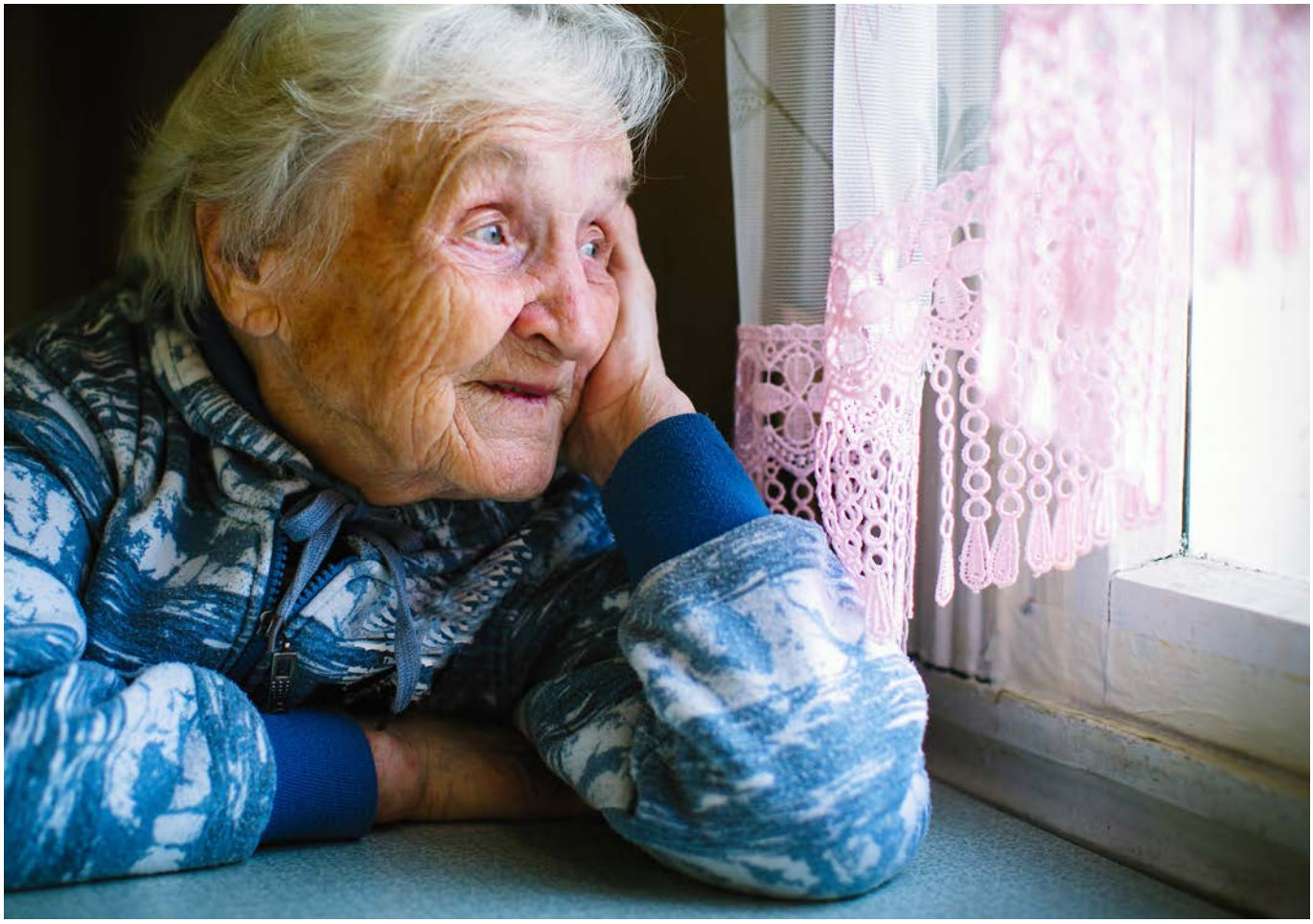
Human rights principles should be prioritised when developing ethical commissioning approaches and adopting new approaches to long term care and support. The focus of services and support, and the processes that enable their introduction and implementation, should be on meeting the needs of individuals in a way that also recognises their right to dignity and autonomy. Prioritising a human rights-based approach to delivering long term care options will achieve the best outcomes for people accessing care and support by promoting improved quality and effectiveness of services and increasing transparency and accountability for service providers.

The impact of Covid-19

The care at home sector was significantly affected by COVID-19, exacerbating existing challenges and creating new ones. It led to an increased demand for care services due to the impact of vulnerable individuals shielding or isolating at home, while simultaneously disrupting service provision due to restrictive practices for delivering care and an ever-changing regulatory framework. This strained resources and affected the continuity and quality of care. It also highlighted systemic issues within the sector including underfunding, workforce shortages and fragmentation of services and underscored the need for significant reform to strengthen the resilience and capacity of the sector.

Moreover, COVID-19 had a devastating impact on people living in care homes in Scotland. The fragility of care homes was uncovered by the pandemic as close living quarters in large care homes made vulnerable individuals, particularly those living with dementia, more susceptible to the spread of the virus resulting in high infection rates and increased mortality rates. [15] Evidence suggests that care home size and occupancy levels were significant risk factors in the spread of the disease [16], with large-scale care home environments at greater risk of experiencing outbreaks [17]. This confirms that safety is compromised in care homes during a pandemic.

The impact of restrictions to social support from family members contributed to social isolation and loneliness amongst care home residents. Other public health policy responses to the pandemic which resulted



in disruption to services saw emerging inequalities influencing care home residents' care. [18] These unintended harms added to the harm caused by the pandemic itself and has rightly led to ongoing work to safeguard the rights of care home residents, their families and carers.

The impact of the pandemic was also felt by service providers who had to deal with new challenges that tested their resilience in an already difficult landscape. Issues related to the recruitment and retention of staff, adapting to increased regulatory compliance and financial strain first emerged during the pandemic but now remain consistent features of care home providers' experiences.

The pandemic has undoubtedly put the challenges of delivering effective long term care and support in the spotlight. While issues relating to the infrastructure and processes around the delivery of care and support are longstanding, the experience of the pandemic has resulted in a fundamental change to relationships across social care and has renewed the need to consider a new way forward to deliver consistent care and support. The Commission recognises that future pandemic planning must incorporate learning from the experience of COVID-19 to enable effective responses that alleviate and minimise the risk to those who are most vulnerable. These experiences must influence wider approaches to commissioning and planning services to build a more responsive and sustainable approach to long term care for the future.

Commission recommendations

The Scottish Government and other key stakeholders explore alternative approaches to long term care that move away from traditional, large-scale care home environments. Evidence indicates that the size and scale of these environments present an unacceptable level of risk in the event of a pandemic or public health emergency so efforts should be made to ensure that the system is not reliant on accommodation of this type. Given the enormity of the impact of COVID-19 on people with dementia and people living in care homes, efforts should be taken to consider smaller-scale, community based models of care that prioritise personalised approaches to care and that minimise risk for those in receipt of care.

The Scottish Government develops a comprehensive policy response to building resilience across all parts of the care home and care at home sectors that reflects the experiences, needs and preferences of those who require long term care. A whole-system response that addresses the vulnerabilities exposed during the COVID-19 pandemic is required to reduce risk and unintentional harm to vulnerable individuals, particularly in the event of a further public health emergency. This includes a new approach to commissioning standards and requirements that reflects the need for sustainable infrastructure to meet the needs of those who access care, as well as a focus on the relationships that support the delivery of high-quality care and support and enable positive experiences of care.

Alternative approaches to long term care

Long term care in Scotland is principally delivered through traditional care at home approaches and residential care. For people with advancing dementia, care homes are often presented as the only available choice [19], but it is widely recognised that this model does not reflect societal needs nor the wishes of older people. As the sustainability of the current model of long term care provision is questioned, there is increasing evidence that new approaches to long term care with a focus on prevention and early intervention can go some way to resolving the negative experience and outcomes for people living with complex care needs. [20] There are many alternatives

Our research indicates the availability of at least 9 broad models of care and support [see appendix 2 for further information about these models] that can support people living with dementia and other complex care needs to live well for as long as possible. Many of the models share similarities, indicating the interconnectedness and complexities of long term care arrangements. These models deliver opportunities to maximise and enhance the autonomy and independence of individuals and use a range of environments and approaches to care to achieve person-centred outcomes for individuals. Features of these models include:

- **smaller-scale living environments.** These approaches seek to deliver more personalised care with a focus on homelike surroundings that contribute to greater comfort and wellbeing for residents. In addition, when compared with larger residential care homes, these smaller-scale environments support improved infection control and greater opportunities for independence.
- **the availability of targeted assistance and support.** Multi-disciplinary and integrated support lends itself to improving the overall experiences of people with long term, complex care needs. Residents can access facilities, as well as care and support services, from a range of providers to meet their complete range of needs.
- **engagement in meaningful and personalised activities.** Many models engage residents in tasks, hobbies and chores to enhance wellbeing, skills and resilience.
- **continuity of care across the whole life experience.** A continuum of care is required to enable people to access care that reflects the evolving nature of their needs, particularly for people living with progressive conditions such as dementia. A whole-life approach enables people to receive flexible, adaptable care that enables them to remain in their communities of support.
- **social and community integration.** Social inclusion is essential for promoting individual wellbeing and providing opportunities to participate fully in society to combat discrimination and reduce social isolation and loneliness. These approaches promote diversity and cultural sensitivity, as well as equality and equitability.
- **relational care.** Family and friends play an integral role in supporting and caring for people with complex care needs and these approaches make the most of family engagement to enhance the experiences of people with complex care needs.
- **improved design principles.** Housing can be more accessible and sustainable through the implementation of well-designed environments that enable people to live independently. This includes the use of technology, equipment and design features to support an individual to manage their specific needs.

to the current models on offer and the Commission has taken steps to understand the various approaches to care and support that are currently available internationally to explore their feasibility within the Scottish context.

While no one approach can meet the long term care needs and preferences of everyone, evidence suggests that there is a greater range of options that can support individuals to achieve positive outcomes than those currently on offer across Scotland today. These options provide a number of benefits including more personalised care and support and opportunities to engage within the community. Most significantly, the availability of these options represents the opportunity for individuals to express their own preferences and exercise their right to choice and control over their long term care options.

As Scotland moves towards a new approach to the delivery of social care through a national care service, establishing equitable access to high-quality care and support for people across the country should be the key objective for improving long term care. The feasibility of alternative approaches to care and support should focus on quality and improved outcomes rather than financial indicators but the Commission recognises the need for balanced, cost-effective approaches. Nonetheless, the measure of cost-effectiveness cannot just focus on the quantitative but must include the qualitative. Investment in new approaches to long term care can establish opportunities to prevent or reduce the need for costly hospital stays or residential care and treatment, and can maximise opportunities for people to live well, independently for as long as possible with access to the right care and support, at the right time. In turn, this whole-system approach can present a range of cost efficiencies and investment in new approaches should not be excluded on the grounds of the initial cost to establish a new way of working.

Commission recommendations

The Scottish Government establishes a citizens' assembly to engage across society on the type of alternative approaches to care that people want to access to meet their long term care needs. Actively including people with lived experience in planning and decision-making processes around the delivery of long term care will promote a greater understanding of their priorities and values and ultimately enable the delivery of more responsive approaches to care that meet the needs of people with complex needs and reflect their wishes and preferences.

The Scottish Government commits to secure and provide funding to test and pilot a range of new models of long term care. Informed and guided by people with lived experience, the finance sector, local authorities and providers should be encouraged to come together to explore and test innovative new approaches to long term care across the country. The availability of funding will promote opportunities for key stakeholders to explore new ways to deliver long term care.

Workforce issues

The social care workforce, supported by the invaluable contribution of informal carers, family and friends, deliver vital support to ensure that people receive the care and support they need to enable them to lead fulfilling lives yet they are consistently undervalued across society. The workforce is pivotal in being able to deliver the type of care and support that people would like to experience and only a knowledgeable and skilled care and support workforce can deliver care that meets the needs and preferences of those who receive it.
The social care workforce is often perceived as a low economic and policy priority and this significantly impacts on the recruitment and retention of social care workers to deliver the much needed care and support options required to enable the delivery of flexible, responsive approaches to care.

The failure to adequately reward the social care workforce results in the loss of expertise and potential talent and undermines key services – all of which jeopardises support for those who need it most. The changing nature of the social care workforce and the ongoing depletion of highly trained, expert workers who are skilled in the delivery of dementia-specific care and support will doubtlessly result in a widening skills gap that cannot be easily recovered. While the issue of fair pay for social care staff has gained some traction with the recent uplift of social care worker pay, people working in the sector do not believe that the Scottish Government has truly grasped the reality of what is happening in social care in Scotland and believe that this may not be sufficient to improve the workforce experience across the sector. The failure to provide fair pay, better working conditions and career progression undermines staff morale and impacts on the quality of relationships and consistency of support for the people in our communities who need it most.

The Commission recognises that investment in the social care workforce is necessary to support the delivery of improved approaches to meeting the needs of people living with complex, long term care needs. It is essential that the infrastructure for the delivery of long term care can support the workforce to respond more effectively to the changing needs of people who require care and support, and that the necessary resources are put in place to enable them to expand their delivery and meet the needs of everyone in Scotland.

Conversely, by expanding options for long term care provision, there are increased opportunities to attract, retain and create growth in the social care workforce.
New approaches to delivering long term care across a range of settings may serve to increase the appeal of employment within the sector and help to sustain the workforce and the services they provide.

While the Commission does not wish to replicate or duplicate the work of the Fair Work Convention Social Care Inquiry [31], it acknowledges the value and strength of its insights into the action needed to improve the experience of the workforce. We support the findings of this Inquiry and recognise that adopting its recommendations will create improvements for staff which will in turn see improvements in the experiences of people with long term care needs who are supported by the workforce.

Commission recommendations

The recommendations of the Fair Work Convention Social Care Inquiry are implemented in full and at pace. The social care workforce is vital to the delivery of high-quality, long term care options across a range of settings. It is essential that professional carers are recognised as, and supported to be, knowledgeable, skilled individuals and that they are valued for the role that they play. Improving the experiences of the workforce will serve to attract new talent to the adult social care sector and address the challenges of workforce shortages and high turnover rates that impede the ability to deliver consistent services, where and when they are needed

Paying for long term care

The cost of long term care in a care home is high. Figures show people in Scotland who are considered self-funding can expect to pay average weekly residential care home costs of £1160 while average nursing care home costs are £1410 per week [22], with many examples across the country of weekly care home fees in excess of £2000, and non-residential care charges remain in place. Those who receive financial support towards the standard rate set out in the National Care Home Contract pay most of their income towards fees. Everyone pays, yet the misconception that care is free persists.

Many people expect that their care is, or will be, free, based on their view and limited understanding of NHS care and the Free Nursing and Personal Care provisions currently available in Scotland. Given that healthcare provided by the NHS is free at the point of access, and the nature of advancing dementia means that people with advanced dementia have primarily healthcare needs, many people assume that their care costs will be met.
While Alzheimer Scotland's Fair Dementia Care Commission [23] calls on the Scottish Government to recognise that the needs of people with advanced dementia are health care needs and to ensure equality of access to appropriate health and nursing care, there remains no mechanism for people with advanced dementia to access the care and support that they need which is free at the point of delivery. The Commission supports the assessment that the needs of people with advanced dementia are unequivocally health care needs and that it is neither right, fair nor proper that they should be expected to pay for their care.

Additionally, the use of language around the availability of Free Nursing and Personal Care payments often reinforces the idea that care is 'free' in Scotland and members of the public assume that this is the case.

With a lack of transparency and clarity around the actual cost of care, it is then not surprising that many individuals are alarmed when they realise that they will be subject to financial assessment and may be required to make a financial contribution towards care costs or may even be required to self-fund their care. However, by the time this realisation occurs, it is often too late to consider planning for the cost of future care.

The policy of Free Nursing and Personal Care does not mean care in Scotland is free. It was aimed at going some way to address the financial burden of long term care for older adults and to mitigate the cost of social care.. Given that public expectations are that care is free, then now is the time to re-examine how care is funded in Scotland and how funding can be expanded to better meet the needs of those who require long term care.

The Commission acknowledges that meeting the cost of long term care is challenging and complex and that it is essential that sustainable approaches to funding long term care balance the need for affordable and accessible care with financial stability and viability of long term care systems. However, we recognise that current approaches to funding services are not sustainable to meet growing demand and we need to re-think how we address the challenge of financing long term care effectively. While no one mechanism can offer a perfect solution, options for consideration might include fresh approaches to public financing, taxation and new state-supported social insurance initiatives to develop a comprehensive approach to funding long-term care.

The lack of political will to consider how we fund and pay for long term care means that services remain inadequately funded, people have limited access to quality care and, ultimately, the quality of life for those in need of care and support is diminished.

It is the Commission's view that all opportunities for meeting the cost of care should be explored to address these challenges and improve the sustainability and effectiveness of care systems. At the current time, personal and statutory resources are often siloed and seen as separate yet a more creative approach to funding could bring these resources together to enable greater flexibility and choice for people when combining these means. Additionally, the insurance sector has the ability and will to offer a range of products that can insure against the cost of long term care, particularly where a cap or limit on thecost of care can be established. This presents an opportunity for the consideration of state-supported long term care insurance solutions which could enable individuals and families to take measures to protect themselves from unexpected care costs and provide them with the ability to exercise further choice and control over their care.

The Commission is also interested in going further by considering how improvements could be achieved through the development of a whole system approach by further integrating long term care funding with primary and acute care services.
It is our view that this would reduce the separateness of health and social care and promote continuity of care and enhance the overall equality and efficiency of long term care services, while increasing the value of social care. While this approach requires investment in care co-ordination infrastructure, health information technology and workforce development to support interdisciplinary approaches to care provision, there is scope to streamline care delivery, improve transitions and reduce duplicative services which will make this approach more efficient and effective.

Commission recommendations

The Scottish Government should engage in open, honest discourse around the reality of the current cost of care. Key stakeholders should set out that care is not free and should refrain from using language that suggests otherwise.

A process of in-depth public engagement around the issue of how we fund and pay for long term care should be established. A more candid approach to this issue would provide the conditions to enable individuals and families to undertake advanced health care planning and prepare for the potential cost of long term care.

The Scottish Government re-examines its commitment to implement a long term funding solution to expand current provisions for free personal care. The Scottish Government should clarify its position on meeting the cost of care. The expansion of free personal care to incorporate a broader range of social care and support, or moving towards the provision of care that is indeed 'free', will alleviate the financial burden of long term care on vulnerable groups and provide more equitable access to essential services and support.

The Scottish Government leads work to explore more robust approaches to meeting the cost of long term care. Re-thinking the approach to funding care is needed to provide a fairer, more sustainable approach to managing the costs that are met by individuals and families. This would include considering alternative approaches to funding long term care, including through taxation, or the potential role for the insurance industry to develop state supported long term care insurance solutions.

Individuals have access to an NHS-based assessment of their needs and those who are determined to have progressed to the advanced stage of dementia should have access to care and support that is free at the point of delivery. The Commission recognises that the complex care needs of people living with advanced dementia are health care needs. Equality of access to appropriate health and nursing care, free at the point of delivery, should be available to those in the advanced stages of their condition, regardless of the setting.

The wider recommendations of the Fair Dementia Care Commission are accepted and implemented, including the definition of advanced dementia. The failure to acknowledge the circumstances and experiences of people with advanced dementia means that they may be denied access to the expert dementia-specific health and palliative care required to meet their needs and are disproportionately subjected to social care charges. This inequality needs to be addressed to align the experience of people with dementia with other progressive and terminal conditions.

Conclusions and full recommendations

The Commission recognises that Scotland needs a comprehensive and sustainable approach to long term care that focuses on meeting the rights of people with complex needs. As we look to the future, it is clear that the current system cannot withstand the increasing pressures that it is experiencing and that the infrastructure, services and policies supporting people with long term care needs must be improved to build a more resilient and inclusive system. Investing in long term care now, particularly for people with dementia, is not only an ethical choice, but also an opportunity to future-proof our services to ensure that they are fit for generations to come.

While there are no easy solutions to resolving the challenge of meeting Scotland's long term care needs, a more strategic approach to planning and commissioning long term care provision will ensure that we can meet current and future needs. A well-considered approach to commissioning will support the equitable allocation of resources, co-ordination of services and cost efficiencies. It will also provide opportunities to promote innovation and, most significantly, improve the quality of services and supports available to people living with dementia and other complex care needs.

We cannot stop with making improvements to Scotland's long term care commissioning approaches alone. It is essential that we look at long term care in the wider policy context and seek to make improvements that can support the delivery of services that meet the needs and reflect the preferences of people with complex needs. In recognition of the social care workforce's invaluable contribution to the delivery of care and support, we must take steps to improve their experiences and encourage them to join and remain within the sector, contributing to positive outcomes for people with long term care needs. We must also take steps to address the increasing cost of care and the burden it places on individuals and families. We need to increase transparency around the cost of care and funding arrangements to ensure that people are informed about what they might be expected to pay.

The Commission seeks to open the debate on how people want to have their needs met and to engage key stakeholders and the public in a national conversation about how we provide flexible, responsive care where, when and how people want to access it, as well as how we pay for care. Person-centred approaches can only be developed by placing people at the heart of this dialogue, listening to their voices and hearing what they have to say.

This report is a call to action to take the steps necessary to improve the experiences of people with long term care needs now and in the future. Our recommendations act as a roadmap to transforming long term care that reflects the type of care and support that we all need and want.

Conclusions and full recommendations

1	The Scottish Government urgently works with health and social care partnerships to undertake a full strategic assessment of the provision of long term care facilities and resources in each area.
2	The Scottish Government establishes agreed levels of care home and alternative care model places that should be equally available across Scotland.
3	A connected national and local strategic commissioning policy that offers innovative, alternative approaches to long term care provision is developed in Scotland
4	Existing legislation, such as Self-Directed Support, should be fully implemented to support the delivery of greater levels of flexible, needs-led community care which is not limited by the ceiling cost of the current National Care Home Contract rate.
5	Human rights principles should be prioritised when developing ethical commissioning approaches and adopting new approaches to long term care and support.
6	The Scottish Government and other key stakeholders explore alternative approaches to long term care that move away from traditional, large-scale care home environments.
7	The Scottish Government develops a comprehensive policy response that builds resilience across all parts of the care home and care at home sectors that reflect the experiences, needs and preferences of those who require long term care.
8	The Scottish Government establishes a citizens' assembly to engage across society on the type of alternative approaches to care that people want to access to meet their long term care needs.

Conclusions and full recommendations

9	The Scottish Government commits to secure and provide funding to test and pilot a range of new models of long term care.
10	The recommendations of the Fair Work Convention Social Care Inquiry are implemented in full and at pace.
11	The Scottish Government should engage in open, honest discourse around the reality of the current cost of care.
12	A process of in-depth public engagement around the issue of how we fund and pay for long term care should be established.
13	The Scottish Government re-examines its commitment to implement a long term funding solution to expand current provisions for free personal care.
14	The Scottish Government leads work to explore creative approaches to meeting the cost of long term care.
15	Individuals have access to an NHS-based assessment of their needs and those who are determined to have progressed to the advanced stage of dementia should have access to care and support that is free at the point of delivery.
16	The wider recommendations of the Fair Dementia Care Commission are accepted and implemented, including the definition of advanced dementia.

Commission members

Alzheimer Scotland's Commission on the Future of Long term Care has been supported and guided by a broad membership of individuals who represent key areas of interest under the umbrella of long term care. This includes a number of professionals across the health and social care sector, as well as people with lived experience.

Henry McLeish, former First Minister and Alzheimer Scotland Ambassador - Chair

Henry Simmons, Chief Executive, Alzheimer Scotland

Jim Pearson, Deputy Chief Executive, Alzheimer Scotland

Bill Alexander, Member, National Dementia Carers Action Group (NDCAN)

Jill Carson, Policy Consultant, Alzheimer Scotland

Adam Daly, Consultant in Old Age Psychiatry, and Interim Associate Medical Director of Health & Social Care North Lanarkshire

Andy Elder, President, Royal College of Physicians of Edinburgh

Maureen Huggins, Member, National Dementia Carers Action Group (NDCAN)

Elaine Hunter, National Allied Health Professions Consultant, Alzheimer Scotland

Claire Lamza, Executive Director of Nursing, Mental Welfare Commission for Scotland

Donald Macaskill, Chief Executive, Scottish Care

Kenny Moffat, Member, Scottish Dementia Working Group (SDWG)

Sara Redmond, Chief Officer, Health and Social Care Alliance Scotland (the ALLIANCE)

Lee Robertson, Consultant in Old Age Psychiatry and Vice-Chair of the Old Age Faculty of the Royal College of Psychiatrists in Scotland

Cathie Russell, Co-founder, Care Home Relatives Scotland

Maureen Taggart, National Dementia Nurse Consultant and Executive Lead for National Post Diagnostic Support, Alzheimer Scotland

Debbie Tolson, Professor of Dementia and Director of the Alzheimer Scotland Centre for Policy and Practice (University of West of Scotland), Alzheimer Scotland

Tony Worthington, Member, Scottish Dementia Working Group (SDWG)

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Cathy Asante, Legal Officer – Rights Based Approach, Scottish Human Rights Commission

David Beddows, Member, Institute and Faculty of Actuaries

Jenni Burton, NES/CSO Clinical Lecturer, Academic Geriatric Medicine

Coalition of Care and Support Providers in Scotland (CCPS)

Ron Culley, Chief Executive, Quarriers

Angela Gregory, Policy Researcher, Alzheimer Scotland

Tom Kenny, Member, Institute and Faculty of Actuaries

Hugh Masters, Executive Lead, Brain Health Scotland

David McClements, Member, Law Society of Scotland

Scott McNeill, Member, Institute and Faculty of Actuaries

Maureen O'Neill, Board member of The Scottish Partnership on Palliative Care and Director of Faith in Older People

Jill Stavert, Professor of Mental Health and Capacity Law, Edinburgh Napier University

Phil White, Partnership Facilitator, South Ayrshire NHS/HSCP

Caroline Winchester, Policy Manager, Institute and Faculty of Actuaries

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Appendix 1

The process of public engagement

Four public engagement sessions were hosted across Scotland to gather the views and opinions of people living with dementia and their families and carers regarding long term care. In-person sessions were held in Alzheimer Scotland Brain Health and Dementia Resource Centres in Aberdeen, Kilmarnock and Kirkcaldy, and a further online session was hosted for those who were unable to attend the other sessions. Each session provided an opportunity for participants to consider what is important to them and what they would like to see and experience from long term care, now and in the future.

The delivery plan

A delivery plan was developed to support the engagement of people with dementia and their carers for each of the sessions. Consideration was given to the location, timing and process of engaging participants at each of the sessions to maximise the opportunities for people with dementia and carers to engage in discussion, taking into account their specific and unique needs and an inclusive approach to engagement was adopted to encourage wide participation. People with dementia and their carers were invited to participate in-person and online, and plans were implemented to enable the flexible delivery of each session to allow the needs of participants to be met appropriately.

A series of questions were formed to explore participants' views on long term care with the intention of informing the work of the Commission:

1. When thinking about your future long term care and support needs, what is important to you to enable you to live well?

2. What concerns you about your future care and support options?

3. What services and resources would you like to meet your future long term care and support needs?

4. What long term care and support options would not work well for you?

5. Is there anything else you would like to share with the Commission about your views on long term care and support?

Delivering the sessions

A total of 70 people attended across the four sessions, including 17 people living with dementia and 53 carers or former carers of people with dementia. Of the carers and former carers who attended the sessions, 5 were paid professional carers.

Alzheimer Scotland colleagues facilitated small discussion groups to encourage participants to share their thoughts and views through focused discussion and conversation. Participants were keen to share their experiences and represented a range a views based on their individual circumstances.

Appendix 2

Alternative models of long term care

1. Specialist housing

Specialist housing combines purpose-built accommodation with care, support and/or supervision to promote independence in daily activities and minimise risk. This model is often provided by the social sector and can be combined with technology to enable people with dementia to live at home for longer. Individual homes with their own front door are situated in the community, and communal spaces are sometimes available within the building to facilitate social activities and group dining. The aim of this model is to enhance independence and autonomy using a person-centred approach. Supported, sheltered, assisted, and extra care housing are all examples of specialist housing. Specialist housing models can be found in Canada, the UK, and the USA. Alzheimer Scotland's provision in Croftspar Place in Glasgow is an example of this model in Scotland.

2. Small-scale living

Small-scale living approaches provide family-style accommodation for a small number of residents (usually 6 -16). Each resident has access to private, individual bedroom spaces with either ensuite or shared bathrooms. Kitchens, living rooms and outdoor spaces are communal. Unlike residential care, small-scale living arrangements provide a greater focus on encouraging independence and enhancing skills by involving residents in household tasks and chores, as well as meaningful activities. Daily routines are collaboratively decided by residents and staff rather than being pre-determined by care professionals. These smaller facilities focus on a holistic, multi-disciplinary approach to supporting people with complex care needs ensuring that people get the right care from the right team, at the right time with the intention of preventing the cycle of failed placements. This model is well-known in the Netherlands and Belgium, and is also available in other parts of the world including the UK. Woodside Place in Telford provides an example of this model.

3. Collaborative housing

Collaborative housing represents a progressive approach to community living where individuals or families come together to create intentional, shared living spaces and where residents have shared control over where and how they live. This overall approach to living takes on many descriptions, including intergenerational housing, co-housing, co-operative housing, partially autonomous communities, community-led housing, and community-based living. This model emphasises community, shared resources and mutual support among residents through consensus-based decision-making and collective responsibility, and is designed to support individuals with varying levels of need. The design of collaborative housing prioritises inclusivity and accessibility, and the scale of this model depends on the type of community. Collaborative housing seeks to promote social inclusion, social citizenship and reciprocal support, and also fosters positive approaches to sustainability. Examples of collaborative housing can be found across Europe and Canada, including Share and Care Homeshare based in London.

4. Shared Lives

Shared Lives offers a unique approach to co-housing, respite and day care services where knowledgeable, trained individuals open their homes and lives to people who require additional care and support, accommodation and companionship. Shared Lives carers welcome individuals into their homes as valued members of their families, offering practical assistance, emotional support, friendship and a sense of belonging.
The co-housing aspect matches up to three people who require daily support with a

self-employed carer and daytime visits and/or overnight stays can also be arranged. This approach focuses on the concept of ordinary family life and arrangements for care and support vary depending on the needs and preferences of the individuals involved. The model aims to increase independence in the community, choice and autonomy. Live-in services are still being developed for people with dementia, therefore the current service is mainly day care. Shared Lives is available in the UK including in Moray.

5. Care Villages

Care villages are specific sites which provide enclosed, home-like accommodation within diverse neighbourhoods and communities which include facilities such as a supermarket, restaurant, theatre, and outdoor spaces. These residential developments include small-scale households which house 6-7 residents who are matched according to their preferences and background. Each household contains individual bedrooms with a communal bathroom and kitchen. This model of residential care and support is designed specifically to better support the changing needs of older people by providing high-quality care and support around the clock through pro-active early intervention and preventative action aimed at those with complex needs, frailty and dementia. This approach promotes inclusion and normalises life for residents with advancing dementia by supporting their unique needs, lifestyles and personal preferences for living, care and well-being, whilst moving away from traditional forms of institutionalised care. The focus is on what an individual can do and achieve rather than disability. First established in Denmark in the 1960s, examples of this model can be found in the UK, Australia, Canada and other parts of Europe. Plans to develop new care villages in the Scottish Borders were approved in 2022.

6. Care complexes/campuses

A care complex/campus is an integrated, community-based approach to delivering a wide range of health social care and support services to individuals with a wide range of needs which demonstrates a 'home for life' approach. Care complexes/campuses typically offer a variety of housing options to accommodate the diverse needs and preferences of individuals and bring together a multi-disciplinary team of providers within a centralised location or hub to create a collaborative, co-ordinated network of care and support, that can respond to the changing needs of residents to enable them to remain in their homes and communities, even as their needs increase over the course of time. Support on offer can range from health and personal care assistance to the provision of social services such as meal provision and laundry services, as well as group and community-based activities. This approach aims to provide a continuum of care, ranging from independent living to full nursing care, however, residents must be independent upon moving into the complex which necessitates advanced planning and early interventions to support the delivery of this model. This model includes specific approaches including care complexes, care campuses, continuing care retirement communities and life plan communities. This approach is countries including the UK, the USA, Germany, Switzerland, the Netherlands, and Japan, and is funded in a range of ways including through public funding and private insurance. Blantyre Life adopts this approach to reduce reliance on long-stay nursing and residential care.

7. Day services

Day services provide structure and meaningful activities to people with dementia and other complex needs to provide support, stimulation and socialisation during daytime hours. These services are typically offered in community-based settings away from home, such as adult day care centres or specialised facilities offered by health and social care providers, and provide a safe and supportive environment where people with dementia can be engaged in social activities while receiving support with daily living tasks while giving carers respite and support to manage their own needs. Care and support can be tailored to

the interests, abilities and stage of dementia of participants. Services can vary in scale and delivery from short sessions to long sessions and with varying points of focus. While this approach to care and support has been rolled back in Scotland, day services remain popular amongst attendees and carers of attendees. For example, in the Netherlands, a popular service called VanThuisUit (from home) runs day services seven days per week, from 10am - 8pm, and offers "guidance, treatment and various activities to meet, relax, experience, do and learn" to promote the ability of people with advancing dementia to live at home for as long as possible. Alzheimer Scotland conducted a pilot programme and refined an approach to Enhanced Sensory Day Care to support people living with advanced dementia in Scotland.

8. Home Care

Home care is team-based, collaborative care provided in the person's own home, or as part of a purpose-built setting such as a care complex. It encompasses a range of services and supports designed to promote independence, safety and wellbeing whilst also addressing their unique needs and the challenges that they experience. These approaches should be personalised and respect an individual's dignity, autonomy and preferences. The current focus of many home care services is assistance with activities of daily living, including personal care, medication management, mobility assistance and household chores, and care provision is designed to offer practical support and supervision to manage these activities. However, there is a recognition that home care should also offer opportunities for social stimulation, emotional support and companionship, and that a shift is needed from current time and resource-based provision to provision that is more driven by the achievement of positive outcomes. Home care must provide flexible, adaptable solutions to meet the specific needs of individuals and opportunities for care co-ordination and care management, carer education and support, and respite services must be explored to enable individuals to live at home for longer. This includes the use of virtual assistance and smart technology. Significantly, the successful delivery of high-quality care at home services can facilitate equal access for underserved communities. The Guiding an Improved Dementia Experience (GUIDE) Model is currently being tested in the USA to consider alternative approaches to home care services to support people with dementia to stay at home for longer.

Buurtzorg
The Buurtzorg model of neighbourhood care is a branch of home care which originated in the Netherlands. This model consists of small, autonomous, geographically-based nursing or multi-disciplinary teams. It extends home care by involving families, neighbours and communities. This sub-model seeks to provide person-centred and relational care. This sub-model has been adapted for use in Finland, Germany, Switzerland, and in the UK.

9. Future-proofing/inclusive living

Future-proofing and inclusive living involves adapting or repairing existing properties and new-build properties to accommodate varied needs, making housing accessible to all. This shifts the focus of housing from an individual responsibility to a societal and governmental issue. This model aims to prepare for an ageing population by using dementia design principles and making housing accessible and sustainable from the outset. It emphasises social connectedness, inclusion, independence, and wellbeing. This approach is being adopted in the UK, the Netherlands, Sweden, and Japan. A Scottish and international example is Designing Homes for Healthy Cognitive Ageing: Co-Production for Impact and Scale (DesHCA), a collaboration between The University of Stirling, Silviahemmet, a non-profit foundation in Sweden, and Mediva, a housing company in Japan.

Alzheimer Scotland
Action on Dementia

Prevent.
Care.
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Alzheimer Scotland
160 Dundee Street
Edinburgh EH11 1DQ
T 0131 243 1453

Twitter @alzscot
Facebook @alzheimerscotland
Instagram @alzscot

www.alzscot.org