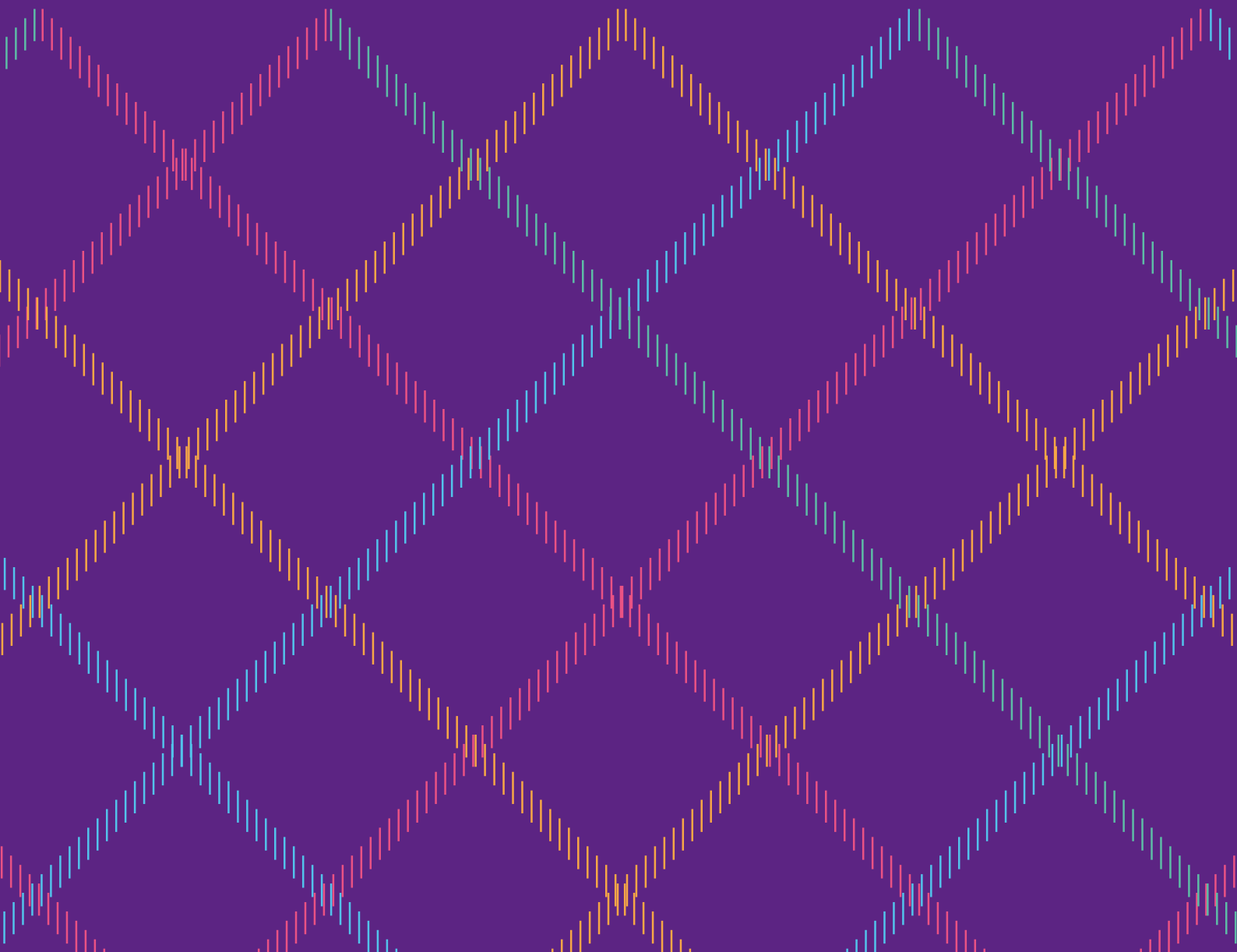
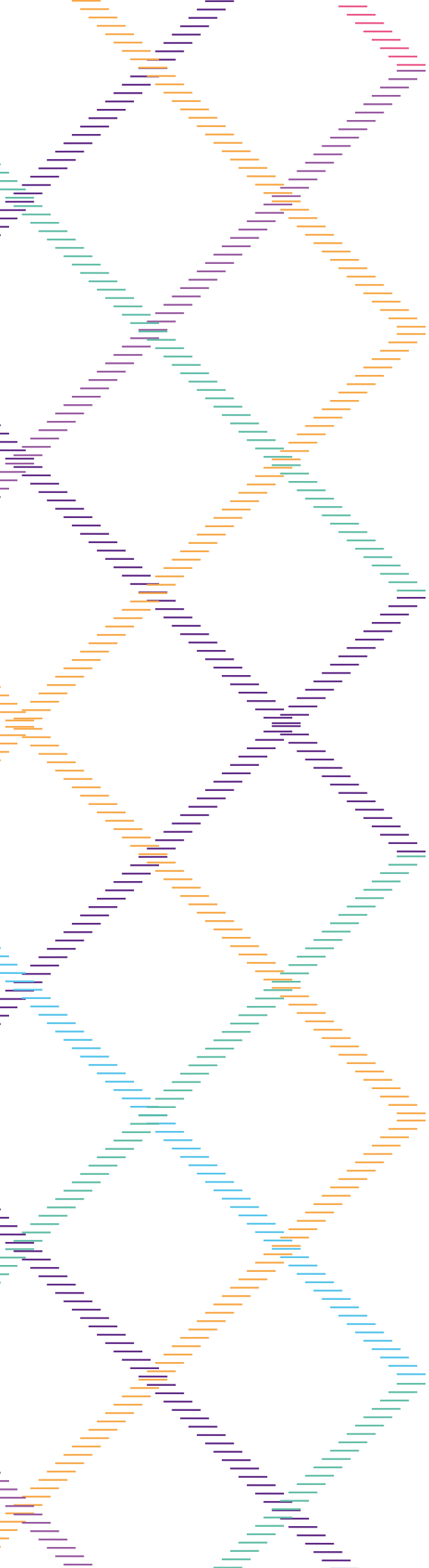
Alzheimer Scotland
Action on Dementia

Delivering Fair Dementia Care For People With Advanced Dementia

The Fair Dementia Care Commission





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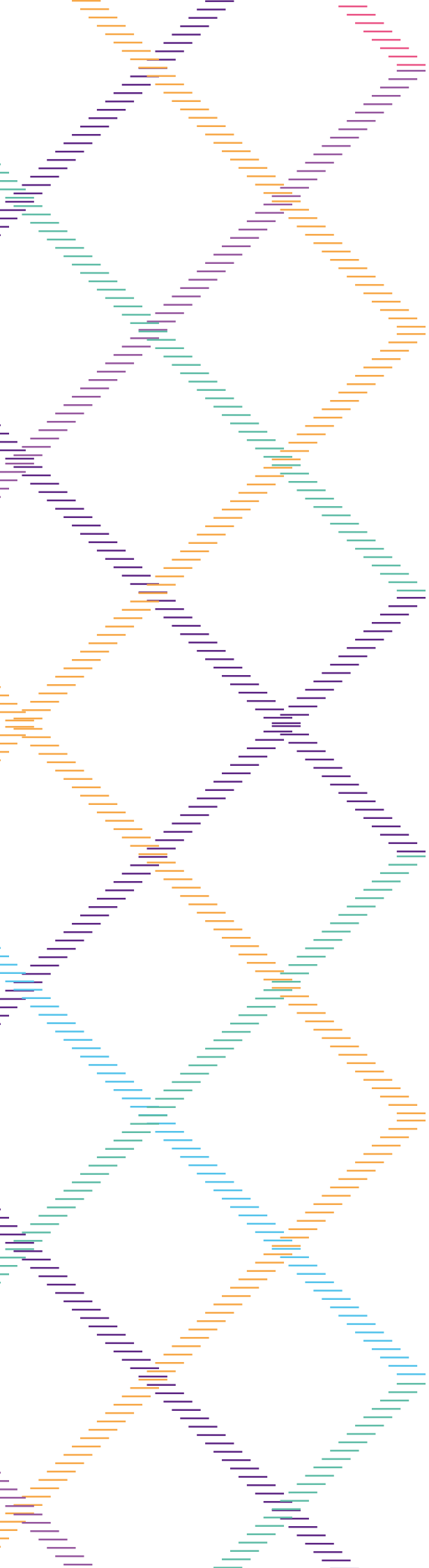


About the Fair Dementia Care Commission

Following on from the publication of Alzheimer Scotland's Advanced Dementia Practice Model, we decided to establish an expert group led by Henry McLeish to work in partnership with Alzheimer Scotland, in order to explore in more depth the issues surrounding advanced stage dementia and our current health and social care system.

Commission members

Henry McLeish – Chair of Fair Dementia Care Commission

Prof Jo Armstrong - Economist and Researcher, Glasgow University

Robert Bain – Health Economics Data Intern, Alzheimer Scotland

Joanna Boddy – National Dementia Carers Action Network (NDCAN) member

Amy Dalrymple – Head of Policy, Alzheimer Scotland

Myra Lamont – NDCAN member and retired senior nurse (for initial meetings)

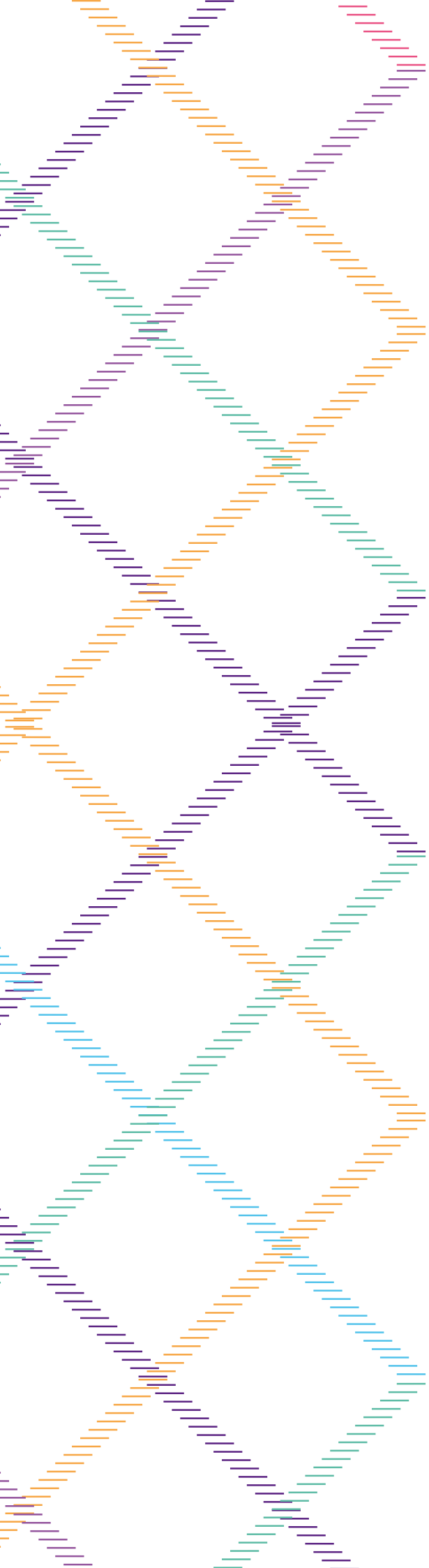
Owen Miller – Policy Officer, Alzheimer Scotland

Jim Pearson – Director of Policy and Research, Alzheimer Scotland

Dr Tom Russ – Consultant Psychiatrist & Honorary Clinical Senior Lecturer, University of Edinburgh

Prof Debbie Tolson – Director of the Alzheimer Scotland Centre for Dementia Policy, University of the West of Scotland

Kirsty Yanik – Communications Manager, Alzheimer Scotland



“This report has set out a definition of advanced dementia to identify those whose needs have become increasingly and primarily health care needs.”

Henry McLeish

Chair of the Fair Dementia Care Commission

Foreword
Henry McLeish

It gives me great satisfaction to present to you Alzheimer Scotland's Fair Dementia Care Commission report: Delivering Fair Dementia Care for People with Advanced Dementia. I would like to thank all the commission members for the commitment and expertise they have contributed, both individually and collectively, over the past 18 months.

As we discover more about dementia and develop a better understanding of the disease processes which cause dementia, it is crucial that we reflect on how we respond to the needs of people living with what is a progressive and terminal illness. Our understanding of dementia is changing. We have a better understanding of advanced dementia and the complex physical and psychological symptoms experienced in advanced dementia and at end of life. However, this understanding is not yet reflected in current policy and practice. As a result, the increasing health care needs of people with advanced dementia are not always recognised or met. Instead we continue to respond to the increasing health care needs through social care services. This creates two significant and obvious inequities. Firstly, people with advanced dementia do not have access to the health care they have a right to and secondly, they are disproportionately subject to charges for social care in their own homes or in care homes.

This report has set out a definition of advanced dementia to identify those whose needs have become increasingly and primarily health care needs. By recognising and identifying advanced dementia we can work towards ensuring that people living and dying with advanced dementia can have equity of access to the health care they need on an equal basis to those who have other progressive terminal illnesses, and which is free at the point of delivery.

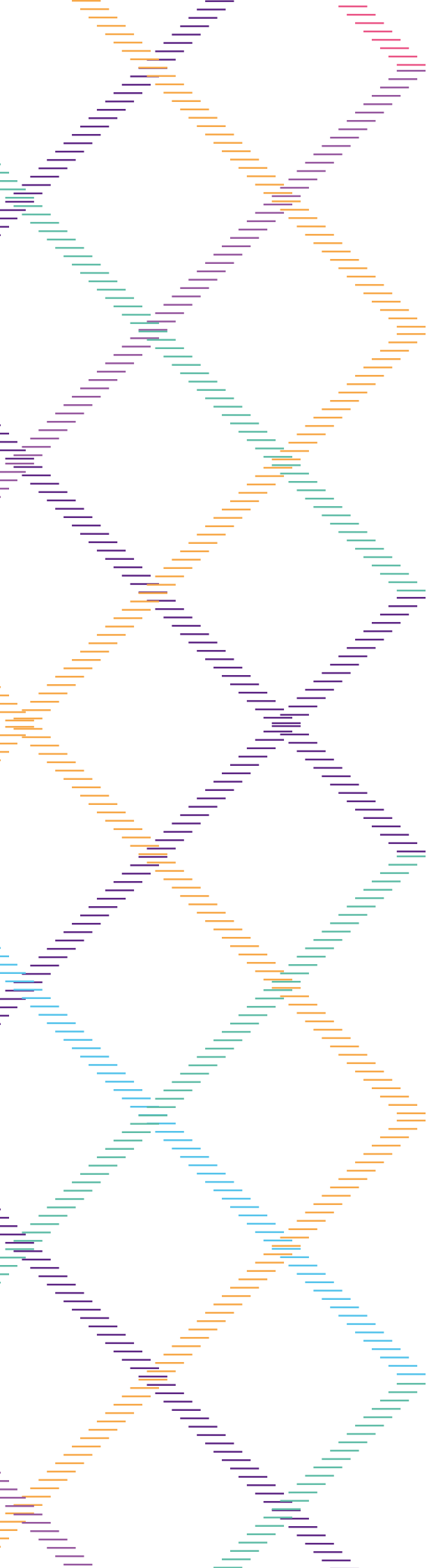
The report also highlights the unnecessary complexity, variability, and lack of transparency in the processes for social care financial assessments, particularly for non-residential care. For most members of the public these must appear as an impenetrable jungle, impossible to navigate. The fact that there are 32 different charging policies across Scotland which cannot easily be compared, or understood, by those who are subject to them is inherently wrong. We can, and we must, do better than this.

Scotland is internationally recognised as having some of the most progressive dementia policy. In many respects Scotland has made good progress. However, there is still much to do to close the gap between the aspirations of national policy and the lived experience of people with dementia, their families and carers. Ensuring that we end the inequities highlighted in this report will be significant progress towards achieving that.

On behalf of Alzheimer Scotland and the members of this commission, I ask that Scottish Government accept and act on the recommendations set out in this report so that we can work towards delivering fair dementia care for people with advanced dementia.

Henry McLeish

Chair of the Fair Dementia Care Commission



“We ask that the Scottish Government lead the way by committing to starting the journey towards delivering fair dementia care for those with advanced dementia in Scotland.”

Henry Simmons

Chief Executive, Alzheimer Scotland

Foreword
Henry Simmons

Firstly, I would like to express our sincere gratitude and thanks to the chair of the Fair Dementia Care Commission, Henry McLeish, and to all of the members of the commission who dedicated their commitment and time to fully exploring the complex issue of fair dementia care, resulting in this detailed yet concise report. I would also like to thank the people living with dementia, carers, professionals and members of Alzheimer Scotland who have helped us understand the lived experience and current difficulties within our system for people with advanced dementia.

It is often the case that something which is so obvious and so clear often goes unnoticed by the many people and organisations who are best placed to effect change. It is clear from this Fair Dementia Care report that this is the case for the many thousands of people living with advanced dementia, their carers and their families. Every day they are dealing with the complexity of their changing needs. The physical, emotional and psychological challenges that they are experiencing are so clear and so obvious to them and those professionals supporting them. Yet, despite this, we do not appear to have seen this. Within our current policy and practice construct there is no evident understanding of advanced dementia, the changing nature of individual needs do not appear to have been properly understood and it would seem very clear that once diagnosed with dementia, people are boxed into an ongoing social care construct which they subsequently pay for on an ongoing basis.

It is understandable that, if there is no agreed definition or construct of advanced dementia, the flow of appropriate person-centred policy and practice will be disrupted. In truth, form will always follow function and we believe that this lack of agreed definition within our policy context has had a significant part to play in driving people with advanced dementia into what is very obviously an unequal and subsequently unfair position when compared with other progressive terminal conditions.

This report sets out a definition of advanced dementia. It highlights how, in the absence of this. our system has reacted without any clear guidance and what the problems are because of this. It offers a way forward; a way of rectifying this unintended inequality - a way which is progressive and fair for people with advanced dementia, their carers and families.

Now that we have a detailed understanding of this inequality and can see very clearly that people with advanced dementia have, in fact, very complex health care needs it would be entirely wrong not to fully review how we support and care for this group of people which includes the vital topic of how their care and treatment is paid for. We need to build a new form around this function.

Whilst we understand that it will require significant effort and dedication to fully transform our system, we ask that the Scottish Government lead the way by accepting the definitions and recommendations in this report and commit to starting the journey towards delivering fair dementia care for those with advanced dementia in Scotland.

Henry Simmons

Chief Executive , Alzheimer Scotland

Executive summary

Dementia is a condition associated with diseases such as Alzheimer's disease which are progressive terminal illnesses. Advanced dementia means living for months, sometimes years, with complex health care needs before reaching the terminal and end of life phase of the illness. There is growing evidence that the current application of a predominately social care model, at this stage in the illness, is failing to meet the specific health care needs of people living with advanced dementia. Consequently, people with advanced dementia 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 is clearly an inequality that needs to be addressed to align the experience of people with dementia with other progressive and terminal conditions.

The Fair Dementia Care Commission was established to review how we understand and respond to the complex health care needs of people living with advanced dementia in Scotland. Specifically, the Commission sought to:

1. Determine how advanced dementia is defined and recognised in practice
2. Estimate the size of the population of people living with, and dying from, advanced dementia in Scotland
3. Examine and describe the current charges and cost framework of advanced dementia care
4. Make recommendations on what needs to change for Scotland to lead the way in achieving fair dementia care from diagnosis to the end of life.

What we did

The commission used a combination of desk-based research methods to review current literature and existing data. We facilitated two meetings to elicit ideas and opinions of expert health care practitioners and family carers on how to define advanced dementia and how to recognise advanced dementia in practice. A managed democratic approach to the discussions was adopted based on the nominal group technique.

What we found

- Dementia is caused by progressive neurological disease processes, such as Alzheimer's disease
- Advanced dementia produces complex health and nursing care needs
- People with advanced dementia do not currently have equality of access to the health care they need – instead advanced dementia remains essentially a social care response
- People with advanced dementia are disproportionately subject to social care charges for what are primarily health and nursing care needs
- People with advanced dementia are paying an estimated £50.9m per year in social care charges for care which doesn't provide the health or nursing care they require
- The current system of social care charges is complex, lacks transparency and is variable across Scotland

The current provisions for mitigating social care charges such as free personal and nursing care do not address the health care needs of people with advanced dementia – nor do they equate to the actual cost of care.

Recommendations

- That the Commission definition of advanced dementia is used and implemented in practice
- That advanced dementia is recognised as a continuum which includes, but is not confined to, end of life and dying
- The Scottish Government commits to recognising that the needs of people with advanced dementia are health care needs and ensure equality of access to appropriate health and nursing care, which is free at the point of delivery
- The Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia
- The Scottish Government, COSLA and Integration Joint Boards commit to ending the current lack of transparency, complexity and variability in current non-residential care charging provisions across Scotland
- That the recording of dementia (including advanced dementia) prevalence across all health and social care settings is urgently required to support better understanding of demand, allocation of resources and improved care and support
- That all local authorities/health and social care partnerships make local charging policies accessible and readily available.

Chapter 1 Introduction

1.1 Background

Alzheimer Scotland is Scotland's leading dementia charity. We have over 8,500 members and every week almost 2,000 people living with dementia or caring for people with dementia access our support and community activities. Our 24-hour Freephone Dementia Helpline and e-helpline also reaches approximately 5,000 people every year. Through all of the interactions with people with dementia, their carers and family members, paying for care is one of the most common issues we are asked about. The complexity and lack of transparency of financial assessment processes for social care charging is a major concern and most people who seek information don't understand how the process works, how the charges they are asked to pay are calculated, or why, unlike other progressive conditions, they are even subject to charges for the care they need. This is further compounded by inadequate and difficult to access appropriate health care in advanced dementia. Alzheimer Scotland consider this to be inequitable and in dialogue with our members agreed that we would explore the issues around paying for care in advanced illness.

In November 2015, Alzheimer Scotland published 'Advanced Dementia Practice Model: understanding and transforming advanced dementia and end of life care'. The report sets out a comprehensive and integrated approach to providing care and support for people with advanced dementia and at the end of life with dementia. The Advanced Dementia Practice Model followed two years of extensive research and consultation, informed by the experiences and expertise of people living with dementia, those who care for them, professionals and academics across health and social care. The report highlighted the inequality in access to the health care needed in advanced dementia compared to the access that exists for other progressive illnesses. A key recommendation of the report is that:

"The Scottish Government accept and recognise that on the basis of this report, there is clear evidence that once a person has reached the advanced stage of dementia, all their needs are health care needs." (Alzheimer Scotland, 2015, p.9)

The implications of this recommendation are clear. People with advanced dementia do not have equal access to the expert health and nursing care services that they need. Consequently, people with advanced dementia are disproportionately subject to social care charges for what are primarily health and nursing care needs, and which should be free of charge.

1.2 The purpose of the Fair Dementia Care Commission

Alzheimer Scotland established the Fair Dementia Care Commission in 2017. The commission was asked to consider the above recommendation and review available evidence to provide an informed description of how we currently respond, cost and pay for advanced dementia care in Scotland, and to make recommendations to address the current inequalities.

1.2.1 Fair dementia care

Fair dementia care recognises that when a person is in the advanced stages of illness, all their needs should be considered health care needs. It is right and fair that people living with advanced dementia have access to free health care - this would be no different from the expectations of people living in Scotland with any other type of advanced illness. However, the reality is that our current care system and cost frameworks do not respond to dementia as an illness, and this anomaly gives rise to serious and unacceptable health care inequalities.

1.3 Why is this important?

Dementia is a neurodegenerative condition caused by illnesses such as Alzheimer's disease. There are over 90,000 people living with dementia in Scotland, and the rising numbers of people with a diagnosis makes this a public health priority. There is currently no effective treatment and no cure. Although there has been recent emphasis on living well with dementia, the progressive nature of the underlying causes lead to advanced illness that ultimately shortens life. Dementia is the second leading cause of death in Scotland; accounting for 11.3% of all deaths, and the leading cause of death among women.

Dementia symptoms in the later stages are complex and although the term 'advanced dementia' is widely used, there is a lack of clear definition in practice, policy and research literature (Hanson et al 2016). At the advanced stages of dementia health care needs are complex and requirements for skilled nursing and other expert health care input increase. It is widely recognised that the interplay and combination of psychological and physical health symptoms require substantial health care input (Alzheimer Scotland 2015). Unfortunately, there is also evidence to show that these progressive health care needs may not be met and, at worst, are overlooked in what some describe as the application of the inverse care law; that is to say that those with the greatest health care need may receive the least (Tolson et al 2016).

An urgent rethink is needed as to how Scotland administers care and treatment for people with advanced dementia. Particular attention needs to be paid to the validity of asking people with advanced dementia living in the community to pay for their own care when those needs are clearly health care needs.

1.4 Policy imperative

In the past decade dementia has become widely acknowledged as one of the most pressing public health priorities in Scotland and beyond. It is estimated that, of the 90,000 people with dementia in Scotland, over 3,000 people are under the age of 65. Every one of those individuals, their carers and families are living daily with the profound physical, psychological, emotional and financial impact of this illness.

Dementia policy in Scotland sits within a broad context of dementia specific and other related public policies, and legal provisions. These include Health and Social Care Integration, Primary Care Transformation, National Clinical Strategy, Palliative and End of Life Care Strategic Framework, The Carers Act and Self-Directed Support.

Scotland's third National Dementia Strategy (Scottish Government, 2017b) builds on the 2010 and 2013 strategies. Scotland's national dementia strategies and other wider policy frameworks share the common themes of delivering better personal outcomes, more preventative and integrated support and a greater emphasis on supporting people within their community. The strategies are underpinned by the human rights-based approach set out in Scotland's Charter of Rights for People with Dementia, their Families and Carers (Alzheimer Scotland, 2009). This human rights-based approach has informed all aspects of the national dementia strategies and is reflected in the Standards of Care for Dementia in Scotland and the Promoting Excellence Framework, a training framework which sets out the knowledge, skills and behaviours of all health and social care staff who work with people living with dementia. High quality person-centred care

throughout the illness, from diagnosis to end of life, which supports the personal aspirations of those living with dementia, is the manifestation of a human rights-based approach.

This prioritisation has delivered significant progress and Scotland is globally recognised as having some of the most progressive national dementia policies. However, despite the progress which has been made in Scotland, there remains substantial gaps between the policy aspirations and the lived experience of too many people with dementia and those who care for them.

The Advanced Dementia Practice Model (Alzheimer Scotland, 2015) highlights the current and unacceptable inequality in access to the health care needed in advanced dementia compared to the access that exists for other progressive illnesses. If the aspirations of Scotland's national dementia strategies, and related health and social care policy, are to be realised for people with dementia, their families and carers in Scotland, it is crucial that we end these inequalities for people with advanced dementia.

Chapter 2 Defining advanced dementia

2.1 Why a definition is needed

The progression of dementia is often separated into mild, moderate and severe (corresponding to early, mid and late stage). Late stage dementia is often narrowly associated with death and dying, and this has focussed attention on end of life care (Hanson et al 2016). However, it is now recognised that as moderate dementia progresses, a more nuanced understanding of the so-called later stages of advanced dementia is needed.

Dementia symptoms in the later stages are complex and although the term 'advanced dementia' is widely used, there is a lack of clear definition in practice, policy and research literature (Hanson et al 2016). Notable exceptions are Alzheimer Scotland's Advanced Dementia Practice Model (Alzheimer Scotland, 2015) which sets out an integrated and comprehensive approach to providing care and support for people with advanced dementia and at end of life with dementia and Palliare (Holmerova et al 2016), a European practice initiative which supports people with advanced dementia who do not yet require end of life care. Both of these frameworks recognise that people can live with advanced dementia for months and sometimes years with dementia-specific extended palliative care needs associated with diseases such as Alzheimer's.

At this advanced stage of dementia, health care needs are complex and requirements for skilled nursing and other expert health care input increase. It is widely recognised that the interplay and combination of psychological and physical health symptoms require substantial health care input (Alzheimer Scotland 2015). Unfortunately, there is also evidence to show that these progressive health care needs may not be met and, at worst, are overlooked in what some describe as the application of the inverse care law; that is to say that those with the greatest health care needs may receive least (Tolson et al 2016).

To address these health care inequalities, it is imperative that in policy and practice we can recognise and respond to health care and other needs associated with advanced dementia. To this end the Fair Dementia Care Commission is seeking a definition of advanced dementia that embraces the extended palliative care phase in addition to the terminal end stage of life.

Put simply, we need to be able to recognise the point at which a person is deemed to have advanced dementia to ensure that they receive the expert health and nursing care services that they need, on an equal basis to other NHS services – free at the point of use.

2.2 Defining advanced dementia

Defining when a person has reached advanced dementia is complex and it is important to recognise that there can be fluctuations in a person's health and that the pattern of declining cognitive and physical function is neither fixed nor predictable (Alzheimer Scotland 2015).

The following definition draws upon the recent European Palliare Project (Holmerova et al 2016) and was developed through a managed democratic process involving expert health care practitioners and family carers:

"Advanced dementia is associated with the later stages of illness when the complexity and severity of dementia-related changes in the brain lead to recognisable symptoms associated with dependency and an escalation of health care needs and risks. Addressing advanced dementia-related health needs requires expert health care, nursing and palliative care assessments together with insights provided by family carers and others, particularly when the person has

difficulty communicating their own needs and emotions. Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying.

The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and other factors relating to health, personality, biography and socio-economics."

We believe that this definition should form the basis of establishing a consensus on the purpose of future policy and practice development.

To apply this definition in practice we need to agree defining features and identify or develop tools for practitioners to use to promote consistency. As we progress we need to be mindful that family carers occupy a central position in decision-making about the person with advanced dementia, particularly during the later stages of the illness (Shulmann et al 2017). In addition, the sustainability of family caring, where this exists, for a person with advanced dementia will be a critical factor within this decision-making process.

Features of advanced dementia

As highlighted in the Advanced Dementia Practice Model, there is no typical set of symptoms experienced in advanced dementia and it is not inevitable that people will experience certain symptoms. There is a pattern of physical decline with the loss of communication skills in many people, and some people can experience severe cognitive impairment ahead of physical decline.

The different illnesses causing dementia give rise to both shared and unique problems and an illness-specific understanding of the anticipated advanced dementia experience is important. However, such a nuanced and clinically detailed description is beyond the scope of the Commission's work. Instead we note key features that highlight the need for health, nursing and palliative expertise to:

- Anticipate and prevent, as far as possible, occurrence or escalation of health problems
- Alleviate commonly reported advanced dementia symptoms
- Optimise comfort, a sense of well-being and promote the best living and end of life experience possible
- Sustain and enable family caring.

Some of the most important aspects of the advanced dementia experience include: neuropsychiatric symptoms, disorientation, communication problems, multiple functional impairments, immobility, incontinence and weight loss. The cumulative impacts of these complex health needs are profound and impact on all care needs.

Findings

- A definition of advanced dementia is required to inform practice, policy and planning
- Advanced dementia involves living, sometimes for years, with advanced illness and the advanced dementia continuum includes the terminal stages of death and dying

- A person living with advanced dementia has complex health care needs including neuropsychiatric symptoms, disorientation, communication problems, multiple functional impairments, immobility, incontinence and weight loss
- The experience of advanced dementia is unique to the individual and dependent on the aetiology of the underlying illness, comorbidities and a multiplicity of factors. It is evident that, at this stage, individual need transitions from social care to health care
- Sustainability of family caring for a person with advanced dementia is important given the centrality of family care within the person's experience of life and living with dementia.

Recommendations

- That the Commission definition of advanced dementia is used and implemented in practice
- That advanced dementia is recognised as a continuum which includes but is not confined to end of life and dying.

Chapter 3 Estimating the prevalence of advanced dementia

3.1 Why is this important

Estimating the numbers of people living with advanced dementia is crucial to understand both the resources needed to respond to their health and nursing care needs and to estimate the current costs, to them, in social care charges.

The place of advanced dementia care varies for the individual and may include non-residential care provided in the family home or community services including day care, or residential care such as care homes.

This section provides an estimate of those living with advanced dementia in care home settings and those receiving non-residential care social care within the family home or other community setting.

3.2 Care home and non-residential care population

The Advanced Dementia Practice Model (Alzheimer Scotland, 2015) highlighted the difficulty in reliably estimating the number of people with advanced dementia. The Advanced Dementia Practice Model estimated that two thirds of all people with dementia live at home, and one third live in residential care settings.

A more detailed and accurate estimation is required to calculate costs and this requires data on the prevalence of people with advanced dementia receiving and paying for social care in residential or non-residential settings. However, there is an insufficiency of robust data with the exception of the study by Lithgow et al (2011), which estimated the prevalence of advanced dementia within Scottish care homes. Lithgow et al (2011) randomly selected every sixth resident from every care home in Glasgow, giving a reasonably representative estimate of the prevalence across the whole of Glasgow. The Glasgow study concluded that 31% of all residents had severe dementia. The study also found that almost 90% of people in these care homes had some form of dementia. We can conclude from this that 35% of those residents with dementia are in the advanced stage. This figure of 35% has been used in cost estimations presented later in this report.

We found a lack of accurate data in recording the numbers of people with dementia in receipt of non-residential care in Scotland. Dementia is under-recorded in social care information management systems and people with dementia are likely to be recorded under any of the categories of older people receiving non-residential care (Scottish Government, 2017a). Dementia is also known to be under-diagnosed (Rait et al., 2010). The lack of reliable data means it is equally difficult to determine an accurate estimate of the prevalence for advanced dementia in the community and the costs of non-residential social care charges.

There are currently an estimated 90,000 people living with dementia in Scotland, of whom 98% are 65 years of age or older (Scottish Government 2017a). In all the studies, we see a rise in the number of people with advanced dementia as they age (Herbert et al., 2003; Andersen, K. et al., 1997; Lucca et al., 2015). Estimates suggest that between 25-30% people with advanced dementia are aged 80 years or above. The impact of age, and older age, is particularly important as people

with advanced dementia are among the most likely to meet non-residential care eligibility criteria and potentially be subject to social care charges.

We know that some 160,000 people are in receipt of non-residential care (Scottish Government 2017a). Of this group we know that there are 11,180 reported to have dementia which equates to 6.9%. If we assume that, based on access and eligibility criteria, this population of people with dementia are likely to be in the advanced stages this equates to 18.6% of the overall 60,000 people living with dementia in the community.

This is similar to findings in a Danish study of non-residential and other dementia care which estimated the prevalence of advanced dementia across all settings to be 14% (Andersen et al 1997). A more recent study in the USA estimated 21% of people with dementia, living in the community, to have severe dementia (Herbert et al 2003). It is important to note that definitional variation and different social care systems make direct comparison or extrapolation of figures available for non-residential care problematic. Nevertheless, given the lack of accurate data it is necessary to make the best estimate of those with advanced dementia who are in receipt of non-residential social care.

Therefore, to calculate an estimated proportion of non-residential care social charges for those people with advanced dementia, this report uses the 6.9% figure which provides an estimate of 18.6% of the 60,000 people living in the community to give estimated potential costs.

Findings

- Dementia is under-recorded in national data sets. Consequently, data on the prevalence of dementia (and advanced dementia) in different settings is potentially inadequate
- Dementia remains significantly underdiagnosed
- People with advanced dementia represent an estimated 35% of people with dementia resident in care homes
- The best assumption based on current evidence available on the prevalence of advanced dementia among all older people receiving non-residential social care is 6.9%.

Recommendation

- Better recording of dementia (including advanced dementia) prevalence across all health and social care settings is urgently required to determine a better understanding of demand and allocation of resources and subsequently provide better care and support.

Chapter 4 Counting the cost

4.1 About this section

This chapter of the report estimates the total charges and costs to people with advanced dementia for residential and non-residential care. To estimate this, we have applied the prevalence of advanced dementia to the known income from social care charges for residential and non-residential care. A full breakdown of the calculations is contained within Appendix 1.

This report focuses on the portion of social care charges, paid by people because of their advanced dementia, which arise from local authority financial assessments for care homes and non-residential care. People with dementia, their families and carers may privately arrange and purchase care. Whilst any privately purchased care is likely to equate to a substantial cost, it is impossible to analyse this as the information is not currently available.

Self-funding residents in independent sector care homes are likely to pay in excess of the national care home contract rate. Our calculations are based on the gross average costs reported in the Scottish Care Home Census (ISD Scotland, 2018b) and therefore include the additional costs incurred by self-funding residents.

4.2 Calculating the costs to people with advanced dementia in care homes

According to the Scottish Care Home Census (SCHC) breakdowns (ISD Scotland, 2018b) 31,233 older people (aged 65 or over) were recorded as long stay residents in care homes as of March 2017.

People with dementia represented 19,318 of that number. The commission estimated total annual costs of £350m in care home charges to the 19,318 residents with dementia. If we apply the findings from the Lithgow et al 2011 study which, as stated earlier, estimate 35% of people with dementia in care homes had severe dementia and apply this to the estimated 19,318 people with dementia in care homes this would equate to 6,761 people. If we also apply the 35% to the total cost for all care home residents with dementia the estimated annual cost to those with advanced dementia is £122.6m.

The commission is concerned with the portion of care home costs which relate to a person with advanced dementia's care, rather than accommodation or hotel costs. This information is not readily available, However, The Future of Residential Care in Scotland report (Scottish Government & COSLA, 2014) provides information from care homes in England which estimated that care costs represented 35% of costs in residential care and 45% in nursing care. The average of these two percentages is around 40%. Based on this average, it is possible to breakdown the net costs for advanced dementia and estimate the net proportion representing care costs for care home residents with advanced dementia as being **£49m per year**.

4.3 Calculating the costs to people with advanced dementia receiving non-residential care

The Social Care Services in Scotland report (Scottish Government, 2017a) estimates the total number of people aged 65 or over receiving non-residential social care services in 2016/17 at 160,020. The number of people with dementia aged 65 or over was recorded as 11,180. However, as

highlighted in Chapter 3, the report acknowledges that dementia is known to be under-reported in social work information systems and people with dementia are most likely to be recorded as 65 or over.

However, if we use the current reported figure and assume that this group will be people in the advanced stage of the illness this provides a figure of 6.9%.

COSLA's non-residential care guidance 2016/17 (COSLA, 2016) estimates that total income from social care charges was £51m. This was amended by Social Work Scotland to take account of both over and under-recording in local authority financial returns to the Scottish Government by some authorities. COSLA estimates that the proportion of income from charges to older people in 2013/14 was £28.2m. This represents the most up-to-date information relating to income from social care charging by client groups.

The total costs for people with advanced dementia in non-residential social care charges is therefore estimated at 6.9% of £28m, which equates to **approximately £1.9m**.

4.4 Total individual costs of advanced dementia in social care charges for both non-residential care and care homes

The combined total estimated proportion of costs for social care charges for care homes (£49m) and non-residential care (£1.9m) is therefore approximately £50.9m.

Findings

- People with advanced dementia living in care homes are paying an estimated £49m per year in social care charges for the health care needs arising from advanced dementia
- People with advanced dementia receiving residential care are paying an estimated £1.9m per year in non-residential social care charges for health care needs arising from advanced dementia
- The total estimated annual costs to individuals with advanced dementia in both care homes and non-residential care settings is approximately £50.9m
- It is difficult to estimate accurate costs given the lack of precise recording of the prevalence of dementia in all settings and exact recording of social care charging.

Recommendations

- That the Scottish Government recognises that the needs of people with advanced dementia results in complex health care needs which should be free at the point of delivery
- That the Scottish Government commits to investigating the costs of implementing appropriate and free health care for those living, and dying, with advanced dementia
- That the Scottish Government, COSLA and Local Authorities commit to more accurate recording and reporting of income from social care charging.

Chapter 5 Social care charging frameworks

5.1 Charging frameworks

This section describes the current frameworks for social care charges and highlights the complexity, variability and lack of transparency in social care financial assessment processes.

People with advanced dementia don't currently have equality of access to the health and nursing care which they need. Instead they are more likely to receive social care which is subject to charging. This report is essentially concerned with the disproportionate impact of charges on those with health care needs arising from advanced dementia. It does not make a case for the abolition of all social care charges. Nevertheless, social care charging processes, and people's poor experience of them, remain amongst the most common issues raised daily to Alzheimer Scotland.

Social care charges fall into two broad categories - charges for non-residential care (including all options under Self-Directed Support) and charges for care home accommodation. The legal provisions underpinning both categories are distinct. The provisions for non-residential social care charges allow for individual local authorities to establish their own financial assessment process. Social care charges in care homes are covered by a national legal framework which prescribes how all local authorities carry out financial assessments for care home residents.

The purpose of financial assessments in both care homes and non-residential care is to determine if a person has sufficient financial resources to pay the full cost of the care. If so, they are regarded as self-funding. If not, then the process calculates the charge to the individual towards the costs of care.

5.2 Non-residential care

Non-residential care generally means care provided to support people to live at home.
This includes:

- Care at home (including supported accommodation, supported living, and housing support services)
- Sheltered housing or extra care housing support services
- Day care and day opportunities
- Community alarms and Telecare
- Short breaks and respite breaks
- Laundry services
- Lunch clubs
- Aids and adaptations
- After-care services for people with a mental illness
- Care and support services for those who have or have had a mental illness (either within our out with hospital)
- Transport
- Support provided through Self-Direct-Support

The Social Work (Scotland) Act 1968 provides for, but does not require, local authorities to charge for non-residential care. Under section 87 of the 1968 act, local authorities have the authority to

charge those who avail themselves of a non-residential care service (Social Work (Scotland) Act 1968). The act essentially requires local authorities to determine two things:

- That the individual has insufficient resources for it to be reasonably practicable for the person to pay for the service
- The amount is practicable for the person to pay towards the cost.

Beyond these parameters, local authorities are free to establish their own financial assessment for non-residential care. COSLA issues guidance to local authorities which aims to create greater consistency of non-residential care financial assessments across Scotland. Despite this there continues to be 32 different charging financial assessment processes across Scotland.

It is almost impossible for individuals to compare the costs of non-residential care in the local authority area they reside with that of any other area. That is because non-residential policies have several variables which impact on the outcome of financial assessments. These include:

- Differences in charges for non-residential care services
- Different capital limits
- Different tariff income from capital above certain limits. These vary significantly across Scotland
- Variations in charging thresholds and buffers
- Different treatment of income (different disregards)
- Disability related expenditure - additional costs related to a person's disability can be disregarded from assessable income, however there is no consistent approach across Scotland
- Treatment of a couple's resources – local authorities can only charge the person who receives the service based on their own resources but routinely take account of both members of a couple's incomes. It is appropriate in some circumstances to include a proportion of a partner's resources, but this should be considered on a case to case basis. Some charging policies continue to refer to the "liable relatives rule" (S42 of the National Assistance Act 1948) more than ten years after it was repealed by the Adult Support and Protection (Scotland) Act 2007 (ss. 62(1)(a) Adult Support and Protection (Scotland) Act 2007)
- Tapers – this represents the amount in every pound over income thresholds that a person is expected to a pay. These vary from 15 to 100 pence in the pound with some having lower tapers which step up as income increases.

Local authorities use these variables to manage their financial resources. However, the number of variables contributes to unnecessary complexity and lack of transparency which make it difficult, if not impossible, for people to understand how a charge has been calculated, or to compare the charging policy of their local authority against those in other those of areas of Scotland. This is further compounded by the variation in the accessibility of charging policies. Charging policies are not always easy to find on local authority websites, or read. Some merely provide summaries with little information, and many appear to be several years out of date.

5.3 Care homes

Section 22 of the National Assistance Act 1948 makes provision for a person to be charged for accommodation provided, or treated as provided, under part III of the 1948 act.

With the exception of the first 8 weeks, local authorities are required to charge for a stay in residential accommodation. The act requires local authorities to carry out a financial assessment where a person is unable to pay the standard rate for the accommodation. National regulations prescribe how a person's income and capital (including heritable property) are treated in the financial assessment (National Assistance Assessment of Resources (Scotland) Regulations, 1992). The regulations prescribe which types of income or capital, including heritable property, are counted in full, partially disregarded or fully disregarded. The Scottish Government's Charging for Residential Accommodation Guidance (CRAG) (Scottish Government, 2018c) provides statutory guidance to local authorities on how to apply these regulations.

The national legal framework for charging for care home accommodation provides for greater consistency of charging than non-residential care charging policies. Nevertheless, for many people care home costs may be among the most substantial expenditure they have ever incurred. The financial assessment process is complex and causes great anxiety for people moving into a care home, along with their family. The process can take a number of weeks to be completed during which time people with dementia, and their families and carers, have no indication of how much care costs will be, and the potential impact on their income, savings, home or other property. This is particularly true when one member of a couple moves to a care home and the financial assessment results in a charge which means the person remaining at home may be left with a substantially lower level of income or savings. The financial assessment for residential care often happens when a person is moving to, or has moved, to a care home as an emergency. This is a difficult and emotional time for individuals and their families. All too often the financial assessment process, and the lack of good quality information adds another layer of unnecessary stress.

The complexity and variability of current charging arrangements create distress, inequity and financial hardship for some individuals and families at what is already a difficult time and, in some cases, can reach tens of thousands of pounds.

5.4 Free personal & nursing care and provisions for terminal illness

There are two main provisions which aim to mitigate the impact of social care charges; free personal care and provisions for people who are terminally ill.

Free personal and nursing care was introduced by the Community Care and Health (Scotland) Act 2002. Free personal care applies to people aged 65 or over who are assessed as needing personal care. Free nursing care applies to those of any age who need nursing care. The Scottish Government plans to extend free personal care to people under the age of 65 from April 2019 (Scottish Government, 2018d). The 2002 act requires local authorities not to charge for social care which falls within the definition of personal care or personal support. Free personal care provisions differ from non-residential and care home charges. For people in care homes, free personal and nursing care are provided as a financial contribution towards the cost of the care home. From April 2018 the rates are:

- £174 per week for personal care
- £79 per week for nursing care for those assessed as also requiring nursing care

These rates do not equate to, or cover, the actual costs of the personal or nursing care provided, or, needed by those living in a care home. Free personal and nursing care payments for people

in care homes provide a non-means tested financial contribution towards care home costs but personal care is not free, as the name suggests. In addition, any person who is entitled to Attendance Allowance (the care component of Disability Living Allowance or daily living component of Personal Independence Payment Daily Living) cannot receive those payments if they are resident in a care home which is wholly or partly paid by public funds. This includes free personal care payments. Those payments of £82.30 or £55.10 (2016/17 rates) are suspended. Free personal care payments of £174 per week actually have a net value of £91.70 or £118.90. We have estimated that there are 5,989 people with dementia self-funding their care home place who have free personal care payments. Assuming they are entitled to the higher rate of £82.30 of disability benefits, this represents an additional annual cost to them of £25.6m in the suspension of benefit payments. It should be acknowledged that free personal care payments were increased to take account of those benefit suspensions in 2002 when they were introduced. However, it is not widely known or explained that free personal care payment amounts take account of suspension of these benefits.

In non-residential care local authorities cannot charge for any assessed personal or nursing care needs. However, non-personal care services remain chargeable. For those whose assessed needs are solely personal care there should be no charge. Those assessed as needing non-personal care services or a mix of personal and non-personal care may still be required to pay a charge subject to a financial assessment. The financial assessment determines the level of charge based on the individual's financial resources. Although the charge must not be more than the actual cost of the non-personal care service, those assessed as requiring a mix of personal and non-personal care may see no benefit from free personal care provisions.

Non-residential care charging guidance issued by COSLA includes provisions to waive charges for those with a terminal illness and who are in the last six months of life. These provisions mirror those provided under special rules for disability benefits such as attendance allowance. This is potentially helpful for people living with dementia. However, this generally requires the person, or someone acting on their behalf, to apply for the waiver but the provision and the process for claiming is not well known or promoted. In addition, there is real difficulty in identifying that a person with advanced dementia may be in the last six months of life; as the trajectory of the disease is less predictable than for some other diseases, such as cancer. The six-month rule is perhaps an anomaly that is not possible to apply fairly in advanced dementia for people who may have prolonged complex needs arising from advanced dementia.

Findings

- Financial assessment processes are complex and the process is the cause of significant anxiety for those who experience them
- Non-residential care financial assessments are unnecessarily complex and difficult to understand or compare the charges to other areas
- Non-residential care charging policies are not consistently or readily available to the public, nor are they easy to understand
- Provisions to mitigate against charges for personal care, nursing care or end of life care do not fully cover the costs of care.

Recommendations

- That the Scottish Government, COSLA and Integration Joint Boards commit to ending the current lack of transparency, complexity and unfairness in current non-residential care charging provisions across Scotland
- That all local authorities/health and social care partnerships make local charging policies accessible and readily available
- More comprehensive information and support mechanisms are required to encourage a better understanding of the processes of financial assessments.

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Appendix

1 Residential care (care home) cost calculations

1.1 Scottish Care Home Census (SCHC) (ISD Scotland, 2018a) Excel Table 8 – number and percentage of long stay residents with a characteristic, by main client group (older people) and area (Scotland)

- Number of long stay residents (older people) 2016: 31,223
- Total people with dementia: 19,318.

1.1.1 Gross average weekly charges

SCHC excel table 15 – Average gross weekly charges with and without nursing care, total long stay residents in care homes for older people

- Publicly Funded with nursing: £637
- Publicly Funded without nursing: £548
- Self-Funded with nursing: £870
- Self-Funded without nursing: £798
- All Funded with nursing: £749
- All funded without nursing: £659.

1.1.2 Breakdown of those requiring and not requiring nursing care

SCHC Excel Table 8 – Number and percentage of long stay residents with a characteristic, by main client group (older people) and area (Scotland):

To apply these gross average weekly charges to the cohort with dementia, a proportionate breakdown for self-funded/publicly funded and those qualifying for nursing care payments is needed. Taking first nursing care:

- According to the Scottish Care Home Census (ISD Scotland, 2018b) 20,272 long stay residents (older people) qualifying for nursing care payment.
- This represents 65% of all 31,223 residents (20,272/31,223 63%)
- Therefore, 35% of all residents do not qualify for nursing care payments.

Applying this 65/35 ratio for nursing care/no nursing care for specifically people with dementia:

- All people with dementia: 19,318
- People with dementia receiving nursing care payments nursing care payments: 12,557 (65%)
- People with dementia not receiving nursing care payments: 6,716 (35%).

1.2 Free personal and nursing care, Scotland, 2015-16 (Scottish Government, 2017c)

1.2.1 Breakdown of self-funded and publicly funded residents

The SCHC does not provide a breakdown for the proportion of residents with dementia who are publicly funded or self-funded. This breakdown can be found in the Free Personal and Nursing Care, Scotland, 2016-17 report (Scottish Government, 2018d).

This shows the total number of those aged 65+ receiving free personal and nursing care payments who are self-funders in care homes. In 2016-17 that number stood at 9,870. The report states that all older people (65+) in care homes receive free personal care payments, and a proportion receive nursing care payments. Assuming all self-funders receive personal care payments, this will represent the total number of self-funding residents in care homes. Proportionally, this is 31% of all long stay residents in care homes for older people in the SCHC.

Using the total numbers of people with dementia in the SCHC, and applying the 31/69 split for self-funded and publicly-funded residents, respectively, we arrive at the following figures:

- Total number of residents with dementia: 19,318
- Dementia self-funded: 5,989 (31%)
- Dementia publicly-funded: 13,329 (69%).

1.2.2 Breakdown of self-funded free personal and nursing care payments

ISD Scotland, (2016a) also states that 6,050 (61%) of self-funding residents who receive free personal care payments also receive nursing care payments, applying this to the numbers of self-funded residents with dementia:

- Self-funded residents with dementia receiving nursing care payments: 3,653 (61% of 5,989)
- Self-funded residents with dementia not receiving nursing care payments: 2,336 (39% of 5,989).

The value of free personal care payments for 2016/17 are (Scottish Government, 2018d):

- Personal care: £171 per week
- Nursing care: £78 per week.

Applying these rates to the numbers mentioned above, we get:

- Dementia value self-funded personal care: £1,024,119
  - £171 * 5,989
- Dementia value self-funded nursing care: £284,934
  - £78 * 3,653.

Total free personal and nursing care payments: £1,309,053.

1.3 Charges estimations for self & publicly funded residents

Together, these payments total in weekly deductions of £1,309,053 to the gross charges for all residents with dementia who are self-funded.

These have been applied to the proportional breakdowns for publicly funded/self-funded & nursing care/no nursing care dementia numbers to the charges listed above in section 1.1.2 for those respective groups. Doing that, we get average charges of:

1.3.1 Publicly funded dementia residents

- Value publicly funded with nursing care: £5,518,872
  - (13,329 * 0.65) * £637
- Value publicly funded without nursing care: £2,556,502
  - (13,329 * 0.35) * £548
- Value all publicly funded: £8,075,374 (per week)
  - £5,518,872 + £2,556,502.

1.3.2 Self-funded dementia residents

- Value self-funded with nursing care payments: £3,386,779
  - (5,989 * 0.65) * £870
- Value self-funded without nursing care payments: £1,582,593
  - (5,989 * 0.35) * £755
- Value all self-funded: £4,969,372 (per week)
  - £3,386,779 + £1,582,593.

1.3.3 Public & self-funded residents with dementia

- Value self-funded and publicly funded: £13,044,746 (per week)
  - £8,075,374 + £4,969,372.

1.3.4 Net charges, public and self-funded residents with dementia

The true cost for both local authorities and residents is the net cost. This is calculated as the total gross charges minus the relevant deductions; based on the proportions of self and publicly funded residents, and those receiving and not receiving nursing care payments.

For self-funded residents, the deductions on their gross charges represents free personal and nursing care payments as above (1.2.1) at £1,309,053.

For publicly-funded residents, charges vary based on the outcome of a financial assessment. The Local Government Benchmarking Framework (Improvement Service, 2017) provides an average weekly local authority cost per resident of £375. Multiplying this figure by the total number of

publicly-funded residents with dementia (13,329) provides an average weekly cost of £4,998,375 to local authorities. Adding the value of free personal and nursing care payments to self-funding residents with dementia £1,309,053) provides an average total weekly cost to local authorities of £6,307,428 (£1,309,053 + £4,988,375).

Subtracting the total weekly cost to local authorities from the total gross charges of £13,044,746 (– £6,307,428) provides and average total weekly of £6,737,318 (per week) net charges to residents with dementia.

1.4 Total costs – residential care all dementia

- Aggregate Weekly:
  - Costs to Local Authorities: £6,307,428
    - (publicly funded contributions + self-funded with Free Personal and Nursing Care payments)
  - Costs to people with dementia: £6,737,318
    - (publicly funded + self-funded with or without nursing care payments)
- Aggregate Annual:
  - Costs to Local Authorities: £327,986,256
    - £6,307,428 * 52
  - Costs to individuals with dementia: £350,340,536
    - £6,737,318 * 52.

1.5 Estimating prevalence and cost of advanced dementia in residential care

To estimate the costs for individuals and local authorities for people with advanced dementia in residential care, it is important first to estimate the number of people who may have advanced dementia. An estimate can be obtained from the study by Browne, Lithgow, and Jackson (2011). The authors sampled every sixth resident randomly selected from every care home in Glasgow and estimated the severity of a diagnosis of dementia based on SMMSE and FAST scores. Overall, it was found that 31% of all residents had severe dementia. Adjusted for those already with dementia however, the prevalence sits at 35%.

Applying an estimated 35% prevalence of advanced dementia as a percentage of the total costs for all care home residents with dementia provides the following estimated total costs to local authorities and individuals;

- Local Authority Cost: £114,759,190
  - £327,986,256 * 0.35
- Cost to individuals with dementia: £122,619,188
  - £350,340,536 * 0.35.

1.6 Extracting the care element of care home costs

The Fair Dementia Care Commission is concerned with the portion of care home costs which relate to a person with advanced dementia's care, rather than accommodation or hotel costs. This information is not readily available and is perhaps considered as commercially sensitive by care homes providers. The Future of Residential Care in Scotland report (Scottish Government & COSLA, 2014), provides a breakdown of average care home fees per resident per week in England. According to this data care costs account for 35% of all charges for residential homes, and 46% for nursing homes.

The average of these two percentages is around 40% which we use to estimate the proportion of charges which represent the care element. Based on thus we estimate the care element of charges paid by care home residents with advanced dementia to be 40% of the total charges the pay in care home charges.

- Cost to individuals with dementia: £49,047,675
  - £122,619,188 * 0.4.

The net total annual costs to care home resident with advanced dementia is therefore estimated at £49,074,675

2 Non-residential care cost calculations

2.1 Number of people with dementia using non-residential care services (Scottish Government, 2017a)

- Total 65+ social care services client base: 160,020
- Number of clients with dementia: 11,180.

This Scottish Government report acknowledges that dementia is under recorded in social care information systems and that that dementia is likely to be recorded under any of the categories of older people. Given this under recording we have assumed that all 11,180 are people with advanced dementia. This represents 6.9% of the total 160,020 people, aged 65 or over, receiving non-residential care services.

2.2 Individual cost for people with advanced dementia

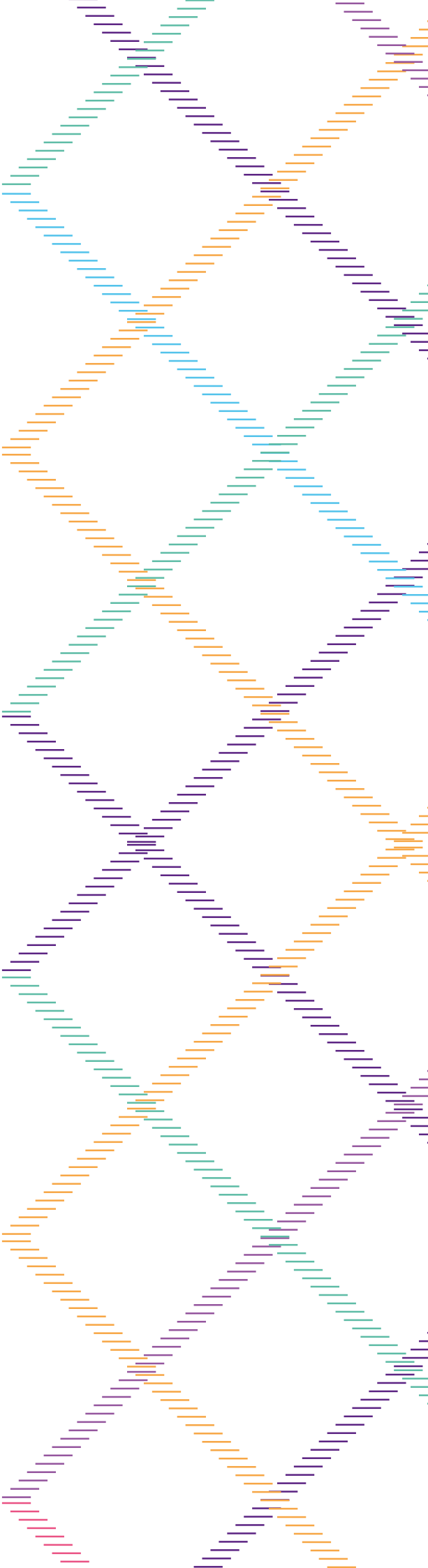
Figure 2 1 provides a breakdown of non-residential social care charging income for Scottish Local Authorities in 2013/14. This shows that charging income in that period represented £28m.

We have therefore assumed that the estimated total non-residential care charges paid by people with advanced dementia represents £1.9m per year (6.9% of £28m).

- Total individual costs of people with advanced dementia £1.9m
  - £28m * 0.69.

Scotland	Children and Families	Older Persons	Adults aged 18-64	Adults with physical disabilities	Adults with learning disabilities	Adults with mental health problems	Adults with other needs	**TOTAL ADULT SOCIAL CARE**	**TOTAL SOCIAL WORK (ex CJSW, Service STRATEGY)**
	£'000	£'000	£'000	£'000	£'000	£'000	£'000	£'000	£'000
Direct Payments (SDS Option 1)	27	670	5,783	1,600	3,660	523	0	6,453	6,480
Managed Personal Budgets (SDS Option 2)	0	34	739	713	25	2	0	774	774
Home Care	19	17,557	8,364	1,895	5,056	1,229	184	25,921	25,940
Day Care	1,695	2,752	1,693	166	1,470	55	2	4,445	6,140
Equipment and adaptations	2	3,090	300	275	16	9	0	3,390	3,392
Other non-residential services	749	4,169	3,282	931	1,720	333	298	7,451	8,200
TOTAL NON-RESIDENTIAL CHARGING INCOME	**2,492**	**28,272**	**20,162**	**5,580**	**11,947**	**2,151**	**484**	**48,434**	**50,926**
Charging income as % of Gross Expenditure	0.4%	3.3%	2.3%	3.1%	2.4%	1.8%	0.8%	2.8%	2.2%
Total Gross Non-Residential Expenditure	**616,554**	**853,476**	**859,833**	**182,563**	**495,409**	**121,733**	**60,128**	**1,713,308**	**2,329,862**

Figure 1 2013/14 Non-Residential Care Charging (COSLA, 2016)



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