



A Vision for a Whole Life approach to Social Care in Scotland

Evidence to the Independent Review of Adult Social Care in Scotland

November 2020

Foreword

The Life Changes Trust welcomes this opportunity to contribute to the review of adult social care in Scotland, chaired by Mr Derek Feeley. The report draws on our evidence base and focuses on what we see as the key areas for improvement in adult social care in Scotland. We hope to amplify the views and voices of thousands of people living with dementia, and unpaid carers, many of whom have responded to this review in their own right.

When the Trust set out a strategy for its dementia programme in 2014, we built it around priorities identified and endorsed by people living with dementia and unpaid carers. These five priorities are highly relevant to a review of adult social care, as is evaluation evidence from work we have funded under each priority.



We know from our work with people with dementia and unpaid carers that three things matter deeply to them:

- Rights and fair treatment
- Independence
- Choice and control

COVID-19 has brought these themes into sharp focus and the picture has not been encouraging.

We hope our contribution is useful and we look forward to discussing it with the Chair of the review in due course.

Anna Buchanan
CEO, Life Changes Trust

What is a 'whole life approach'?



In summer 2020, the Life Changes Trust published a five-volume resource entitled 'Dementia: a whole life approach'.¹ When someone receives a diagnosis of dementia it impacts their whole life and cannot be easily compartmentalised into 'social care needs' and 'non-social care needs'. All needs in all aspects of life are inter-related and determine how well a person can live with dementia. Many people with dementia do not receive formal social care at the point of diagnosis or, indeed, for many years after diagnosis.

The Scottish Government's National Dementia Strategy promises every person with a new diagnosis at least one year of post-diagnostic support.² The vast majority of people with a new diagnosis of dementia do not receive this support.

The latest figures available, from 2017/18,³ show that around 18,000 people were diagnosed with dementia. 7,600 people (42%) were referred for dementia post-diagnostic support. Of those referred, around 5,500 received one year of the promised post-diagnostic support.

This means that approximately 10,400 people newly diagnosed with dementia did not receive this policy-led support. It may be that many of this number were diagnosed in the later stages of dementia, however, they would still be entitled to support. We are sure that a good number of them will have benefited from community-led support.

¹ See <https://bit.ly/3jHqWl2>

² See <https://bit.ly/3kPxfUO>

³ Published April 2020, see <https://bit.ly/35YfrAl>

We know from our evidence that once a person has had a year of post-diagnostic support, or if they have not been fortunate enough to receive it, they will turn to four sources to try and find it:

- family and friends
- charities/community organisations
- statutory services
- peer support⁴

Family and friends can provide some level of support; this support will be at its best when people are well-informed about dementia and can access the information and advice they need. Family members or friends who become unpaid carers need particular support to enable them in their caring role. There are currently around 850,000 carers of people living with dementia in the UK. They save the state around £14 billion a year in care costs, but many say that they do not have the services and support they need.

Since 2013 the Life Changes Trust has funded and worked in partnership with more than 218 **charities and community organisations** that support people with dementia and unpaid carers. The work of these organisations has benefited around 30,000 people with dementia and unpaid carers, directly, to date. Countless others have benefited indirectly. The vast majority of these organisations receive no statutory funding and rely on independent funders, community fundraising and their own ingenuity to continue operating. They, too, save statutory services many millions of pounds each year.

When people with dementia enter into the self-management 'zone', which can last many years, they find little help from **statutory services**.

“(Self-Management) is a person-centred approach in which the individual is empowered and has ownership over the management of their life and condition. The role of health and social care providers is to support the person’s journey towards living well in the presence or absence of symptoms.” Gaun Yersel’, 2008⁵

⁴ Scottish Social Attitudes Survey – Dementia Module, 2018, ScotCen
<https://bit.ly/3mJjiMY>

⁵ Gaun Yersel’, The Alliance, <https://bit.ly/2HUrQ06>

A group of people with dementia, known as The Alumni, had often heard professionals, service providers and policy makers using the term 'self-management' when talking about the lives of people living with dementia, but they did not know what it meant in practical terms. After first receiving their diagnosis, many of them had been left largely alone to self-manage their lives and condition.

They spoke with other people living with forms of dementia in different circumstances in Scotland and found that very little guidance or support for this stage of their lives was available.

They wrote a booklet in order to take control of the debate around issues which affect their ability to continue to live fulfilling lives with independence and confidence. The booklet can be found here: <https://bit.ly/2JsvCPh>.

Their research with other people living with dementia found that:

- Many people interpreted self-management as 'you get on with it and ask for help when you need it' or they didn't understand what it meant
- Professionals don't tend to mention self-management or where to go for support
- Self-directed Support is key to self-management but very few meet the criteria to get it

The issue of Self-directed Support is discussed in more detail below.

People with dementia and unpaid carers will also turn to each other for **peer support**. The Trust has invested heavily in peer support because only people with dementia and unpaid carers really understand what it is like to walk in their shoes. Peer support can be in the form of support groups or one to one relationships; it can also come in the shape of useful resources that help and encourage one another.

'Dementia: a whole life approach' emphasises a holistic, rights-based approach to social care in the broadest of senses. A diagnosis of dementia is not just about the individual and those closest to them; it is about the response of the community to that individual's diagnosis.

The approaches and evidence set out in 'Dementia: a whole life approach', and the series of evaluation reports, webinars and updates

that accompany it, identify the current problems with social care in Scotland and provide **solutions**. We hope that these solutions will be considered by the review.

A whole life approach means looking at more than immediate and critical needs; it means looking at **all** elements of a person's life, asking how dementia affects them and recognising how prevention and early intervention in certain areas can delay or even avoid more expensive forms of crisis intervention and social care further down the line.

This is by no means a new approach, however, implementation of such an approach will require renewed efforts to:

- better support unpaid carers;
- better fund and work in partnership with local charities and community organisations;
- provide transparent statutory services with criteria that are not confined to crisis intervention only;
- recognise the value of small amounts of money provided through Self-directed Support or an equivalent mechanism;
- fund people with dementia and unpaid carers to support each other – very low cost and very effective; and
- take a much broader view across ALL statutory portfolio areas to determine ways in which changes in one area of service provision could take pressure off demand for social care

Anticipation, prevention and human rights-based strategy

Before we look at the areas outlined above, it is helpful to remind ourselves of the aims and principles already established for social care. The Scottish Government's website defines social care broadly, as supporting people to:

- live independently
- be active citizens
- participate and contribute to our society
- maintain their dignity and their human rights

Further, the Government says that it is committed to supporting people to stay at home or in a homely setting, with maximum independence, for as long as possible.

Self-directed Support is the means by which social care is currently provided to people living in the community. The Government's Self-directed Support Strategy and Implementation Plan⁶ outlines its aspirations:

"Social care support is essential for many people in Scotland to be able to fulfil their human rights. That means being able to participate in communities, make choices about work and study, and live as independently as possible for as long as possible. It means having a life beyond caring if you are an unpaid carer.

Both Scottish Government and COSLA are committed to self-directed support: people's right to direct their own social care support, across all age groups and regardless of the reason that support is needed. People must be fully involved in all decisions about their care support, and their expertise should shape the system itself. At the local level, councils, third and independent sector organisations and hundreds of thousands of professionals continue to work together to realise this vision for self-directed support in effective and innovative ways."

⁶ See <https://bit.ly/34g0pXj>

People living with dementia and unpaid carers feel that these aspirations are far from being realised.⁷

Section 4(1) of The Public Bodies (Joint Working) (Scotland) Act 2014 sets out integration planning principles for health and social care. Two of these principles are that IJBs should 'best anticipate needs and prevent them arising'⁸ and 'make the best use of the available facilities, people and other resources'. We do not see this happening.

Over the past twenty years Scotland has undertaken a considerable amount of work at policy and practice level with the aim of embedding a human rights-based approach to the care and support of people who live with dementia. Almost every piece of social care legislation that has been passed by the Scottish Parliament has had a core set of human rights principles at its heart. Scotland has also been a pioneer in embedding a human rights-based approach in relation to dementia. In 2009 the Scottish Parliament adopted the Charter of Rights for People with Dementia in Scotland which used the PANEL Principles⁹ as their basis. Therefore, the intention to take a human rights-based approach is undoubtedly present in Scotland.

However, the intention is not always translated into practice. One reason for this is lack of awareness and training amongst those who deliver human rights at a grassroots level; much depends on the culture of the organisation for which a person works. Another reason is the mistaken belief that law, policies and charters are sufficient. They are necessary, but not sufficient. Human hands deliver human rights.

⁷ For example, see Community Catalysts' Self-directed Support in Scotland report <https://bit.ly/3oNC57G>

⁸ An approach built on the original Social Work (Scotland) Act 1968, s.12:

"General social welfare services of local authorities

(1) It shall be the duty of every local authority to promote social welfare by making available advice, guidance and assistance on such a scale as may be appropriate for their area...

...and...assistance may be given...in kind or, in exceptional circumstances constituting an emergency, in cash, where the giving of assistance in either form would avoid the local authority being caused greater expense in the giving of assistance in another form, or where probable aggravation of the person's need would cause greater expense to the local authority on a later occasion."

⁹ PANEL stands for Participation, Accountability, Non-discrimination, Empowerment and Legality. See

https://www.scottishhumanrights.com/media/1409/shrc_hrba_leaflet.pdf

This is why the Life Changes Trust has funded the Rights Made Real in Care Homes project in partnership with Scottish Care¹⁰ and My Home Life.¹¹ The overall aim is to improve the quality of life of those living in a care home and to help support staff to not only recognise but embed human rights into their everyday practice. See <https://bit.ly/2HWm6mX>.

COVID-19 has highlighted the lack of a human rights-based strategy for social care. The Scottish Human Rights Commission recently reported that the removal of care plans during COVID-19 has had a direct and detrimental effect on people's rights, including potential unlawful interferences and non-compliance with rights contained in the European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities. Rights affected include people's rights to physical and psychological integrity, to private and family life, and to independent living in the community.

“We do not think (our) rights are being upheld. We are ‘living’ but only just! The quality of our lives has been significantly impacted because of COVID. All the things we would normally do to keep ourselves stimulated, purposeful and meaningfully occupied are being denied to us. While we understand the need for this because of the pandemic we want you to know that we need more balance in our lives. We may not die of COVID but we are seriously at risk of dying of melancholy, depression, suicide and prematurely as our dementia will likely progress much more quickly without the stimulation that would be available with a ‘normal’ social life.”

Group of people with dementia and unpaid carers, evidence to Independent Review of Adult Social Care

For a more in-depth discussion around human rights and dementia see 'Dementia: a whole life approach' Volume 1 at <https://bit.ly/35WduoA>.

¹⁰ <https://scottishcare.org/>

¹¹ <https://myhomelife.org.uk/>

“Community”

In our work, we are often involved in conversations where ‘the community’ is distinguished as a separate entity to government agencies or health and social care organisations. We understand what people mean when they adopt this framework, but it is problematic because it somehow suggests that government agencies or health and social care organisations are not part of the community. It is our view that the integration agenda will never work to its full potential while this distinction is made.

A term commonly used is ‘community-based’ services. While ‘community-based’ is good, ‘community-led’ is better. Community-led starts with the idea that everyone who lives in the community has a role to play and has abilities to bring. People with dementia are part of the community, carers (paid and unpaid) are part of the community, as are third sector organisations, sports clubs, the Chief Executive of the local authority, the Lead Officer for Health and Social Care, care home managers and children in the local school. It is not about health, social care and the community; it is about the community, which includes health and social care (and many others).

Funding received by IJBs is, in essence, a whole community resource. It is the job of the IJB to work with other members of the community to decide how a proportion of these resources should be allocated to achieve the best outcomes in the short and longer term for people who need the support of their community to live their life. Equally, when third sector organisations receive funding from independent sources these should be seen as a contribution to the community pot and celebrated as such. Often, match funding from statutory sources will leverage in funding from other independent sources (and sometimes vice versa) thus increasing the overall amount available to the whole community.

The framework for social care in Scotland is already primed for this approach because this is what the integration agenda should be about – all that is needed is for individual organisations to loosen their grip on ‘their’ budget where to do so would secure greater success for social care strategy aims.

Where there is not enough money in the pot to meet social care aims and outcomes, this should be a matter of frank and realistic discussion and decision for the wider community not just statutory budget holders.

Audit Scotland notes in its 2018 report 'Health and social care integration: update on progress'¹² that:

- Financial planning needs to be integrated, long term and focused on providing the best outcomes for people who need support. Without this, the ability of Integration Authorities to improve the health and social care system will be limited.
- Financial pressures across health and care services make it difficult for Integration Authorities to achieve meaningful change. Integration was intended to help shift resources away from the acute hospital system towards preventative and community-based services. However, there is still a lack of agreement about whether this is achievable in practice – or whether rising demand for hospital care means that more resource is needed across the system. (COVID-19 will not have helped this scenario.)
- Strategic planning needs to improve and several significant barriers must be overcome to speed up change. These include: a lack of collaborative leadership and strategic capacity; a high turnover in leadership teams; disagreement over governance arrangements; and an inability or unwillingness to safely share data with staff and the public. Local areas that are effectively tackling these issues are making better progress.
- Significant changes are required in the way that health and care services are delivered. Appropriate leadership capacity must be in place and all partners¹³ need to be signed up to, and engaged with, the reforms. Partners also need to improve how they share learning from successful integration approaches across Scotland. Change cannot happen without meaningful engagement with staff, communities and politicians. At both a national and local level, all partners need to work together to be more honest and open about

¹² See <https://bit.ly/3jpmFCM>

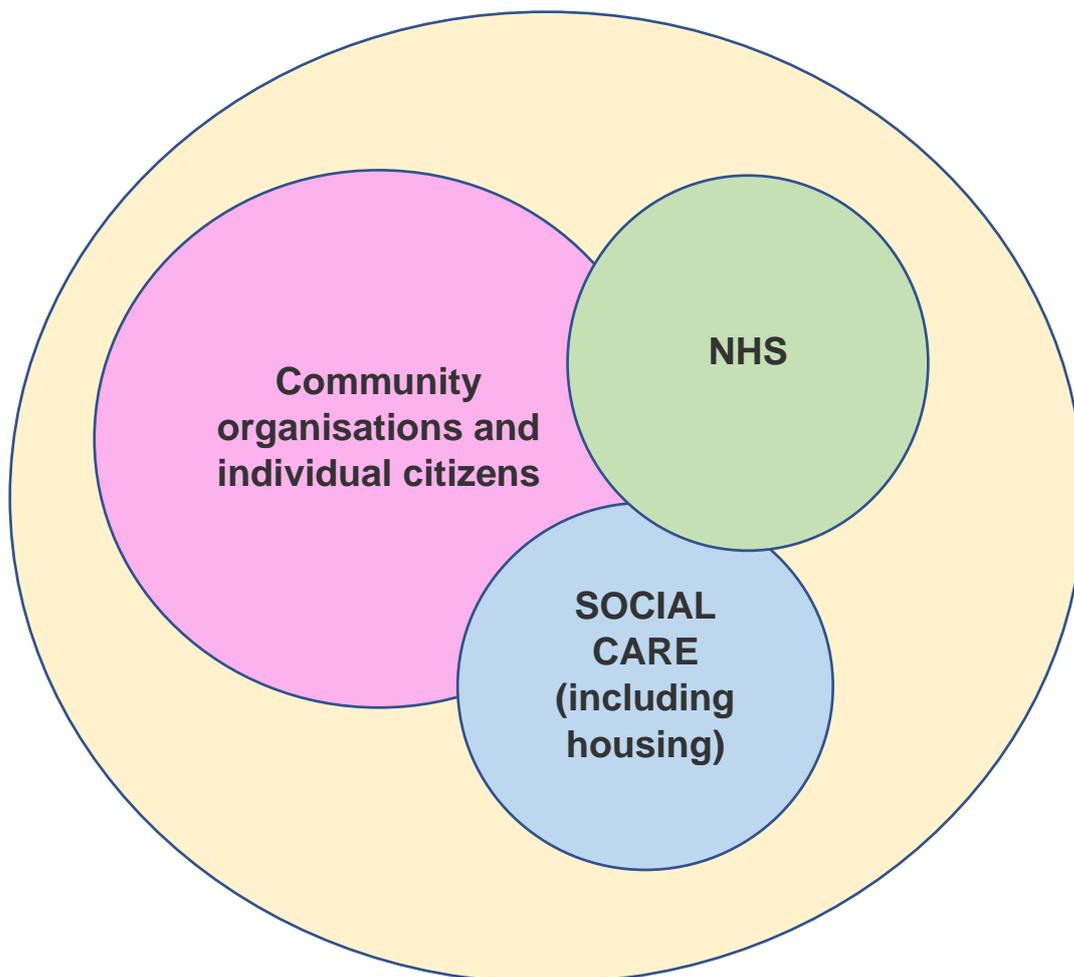
¹³ We would suggest that 'partners' should be wider than just health and social care

the changes that are needed to sustain health and care services in Scotland.

Reflecting on these findings of Audit Scotland it would seem that introducing yet another approach to social care may not be the answer, but implementing the existing approach with stronger leadership and collaboration may be. Whatever happens, very strong leadership and vision will be required to navigate social care through the current murky waters.

In the remainder of this report we highlight a number of lower level social care initiatives that could work alongside more formal statutory offers of social care support and help delay, mitigate or even eradicate many of the costs of late or crisis intervention.

COMMUNITY



Better support for unpaid carers

Carers tell us that caring for someone with dementia can, at times, be challenging, isolating and exhausting but it can also be very rewarding. The Carers (Scotland) Act 2016¹⁴ was designed to give more support to carers, including younger carers. The Act gives unpaid carers a right to support to help them look after their own wellbeing. Their needs and the needs of the person they care for may not be the same. Local authorities have a duty to offer carers a personalised support plan and carers also have the right to request one. This plan will identify what is important to the carer. If any of their needs for support, as identified in the plan, meet the local eligibility criteria then they have a right to support to meet those needs.

However, during COVID-19 this right to a personalised plan has been temporarily suspended in some areas where it would mean a delay in people getting the support they need. Some local authorities have taken this to mean that the right to support is suspended (not just the right to a personalised plan). This flies in the face of the ethos of s.16 of the Coronavirus Act 2020:

“A local authority (in Scotland) need not comply with a provision mentioned in subsection (2) to the extent that the authority considers that—
(a) it would not be practical to comply with that provision, or
(b) to do so would cause unnecessary delay in providing community care services to any person.”

The reason for dispensing with a personalised support plan should be to avoid impracticalities or prevent delay in provision of support, not to remove the support entirely.

Carers have expressed a need for better training and support in their caring role as well as for them personally. The needs of unpaid carers of people with dementia are distinct and they greatly appreciate peer support from those who have walked in their shoes. The Life Changes Trust has funded a number of events and initiatives to provide peer

¹⁴ See <https://bit.ly/34Ow7vn>

support to unpaid carers in Scotland. We have hosted two 'By Carers for Carers' conferences¹⁵, funded peer support projects¹⁶ and peer to peer resources¹⁷, and funded **tide** (Together in Dementia Everyday) to empower carers of people with dementia, helping them recognise that they are experts by experience.¹⁸ **tide** works closely with carers to help them understand that, as experts, their voice matters, and can be used to bring about real change. They also provide carer development courses which are rated as excellent by those who attend them.

These events, projects and resources allow unpaid carers to be supported in ways that statutory services do not provide. They provide places to talk, let off steam, and discuss difficult subjects that dementia carers would only talk to other dementia carers about. They help with the exchange of information and tips. Statutory services should continue to deliver the rights contained in the Carers (Scotland) Act 2016, but they should also commit money to help fund these other activities that draw unpaid dementia carers together. The cost of an unpaid carer no longer being able to care is enormous compared to the small sums of money needed to provide this regular community support.

“When do we have the chance to feel safe enough to share our personal experiences – and cry if the tears come – knowing that everyone there would understand? That was a very special experience for me.”

“Although our journeys on this road may be different, we all understand and just ‘get it’, without need of explanation. We understand that, sometimes we just need someone to be there, not to fix anything or to do anything in particular but just to let us feel that WE are also cared for and supported.”

Carers commenting on their attendance at the Trust’s By Carers for Carers Conference¹⁹

¹⁵ See <https://bit.ly/34ONTOZ>

¹⁶ See <https://bit.ly/3jHQ23e>. The Peer Support initiative is being evaluated by the University of Stirling; report due in early 2021.

¹⁷ See <https://bit.ly/3jHQ23e>, Peer to Peer Resources

¹⁸ www.tide.uk.net

¹⁹ For the full report from the East Lothian conference, see <https://bit.ly/34NYcD6>

Better funding for, and partnership working with, local charities and community organisations

Some areas in Scotland are better than others at realising the community approach set out at pages 11-13. There are very few, if any, who have mastered it.

As noted earlier, integration was intended to help shift resources away from the acute hospital system towards preventative and community-based services. If this is indeed happening, we are not seeing it in respect of services for people living with dementia. Statutory investment in preventative approaches and early interventions that anticipate, delay or even eradicate future cost is almost non-existent.

The Trust has invested in a number of initiatives that demonstrate the benefits of community-based interventions at an early stage.

Dementia Friendly Communities

Since 2015, the Life Changes Trust has funded more than 40 dementia friendly communities (DFCs) across Scotland. Several of these communities have produced further DFCs. The communities are a mixture of geographical communities and communities of interest. They are not exclusively for people with dementia, although the majority of people who attend have dementia. They are about inclusion rather than separation.

We have reported regularly on the progress of these communities and an independent evaluation is currently being carried out by HammondCare.²⁰ The final evaluation report will be available in 2021.

DFCs are an important component when considering social care for people living with dementia and unpaid carers because they open up the world again after a diagnosis of dementia, providing immediate support and complementing any statutory support that is needed. In a very sad way, COVID-19 has underlined the importance of these communities in stalling the progress of dementia. We have seen many people's dementia advance during lockdown, and since, because they are no

²⁰ <https://www.hammond.com.au/>

longer able to be part of these communities to the extent they were previously involved. The DFCs themselves have made many changes to the way they work in order to maintain relationships and activities, and they have also made connections with people who they had previously not reached, but they have been shocked by the rapid decline of some people who had been the life and soul of the party prior to lockdown.

“We need life to get back to normal and live with the risk of COVID 19. We are likely to die at a much earlier age than we would have hoped for so we need quality in the time we have. We are also in a situation that if we lose the use of our brains and physical functionality we will not be able to regain it. In our worlds we believe that support for social, intellectual, psychological and emotional stimulation are as important as addressing our physical needs. The role of ‘essential key worker’ needs to legitimately encompass these facets of our lives.”

People with dementia, evidence to Independent Review of Adult Social Care

DFCs provide a service that is comparatively low cost; they help sustain unpaid carers in a variety of ways, such as providing respite or providing direct support to the carer. They engage the person with dementia in a way that lifts their mood and allows them to use their gifts and abilities in a way that traditional services do not. They provide a sense of value, meaning and purpose that seems to delay decline and they uphold many of the rights set out in the United Nations Convention on the Rights of Persons with Disabilities.

In 2017, the Life Changes Trust gathered together a wide range of DFCs across Scotland for a two-day retreat. At this retreat, the DFCs discussed how their communities differ in order to reach a wide variety of people living with dementia. They also agreed a set of nine principles that provide unity to their approach. These are outlined below.

Until the funding of the Life Changes Trust, DFCs focused mainly on the physical environment. The physical environment does need to be enabling, but people with dementia and unpaid carers have said very clearly that what makes something dementia friendly are a) the

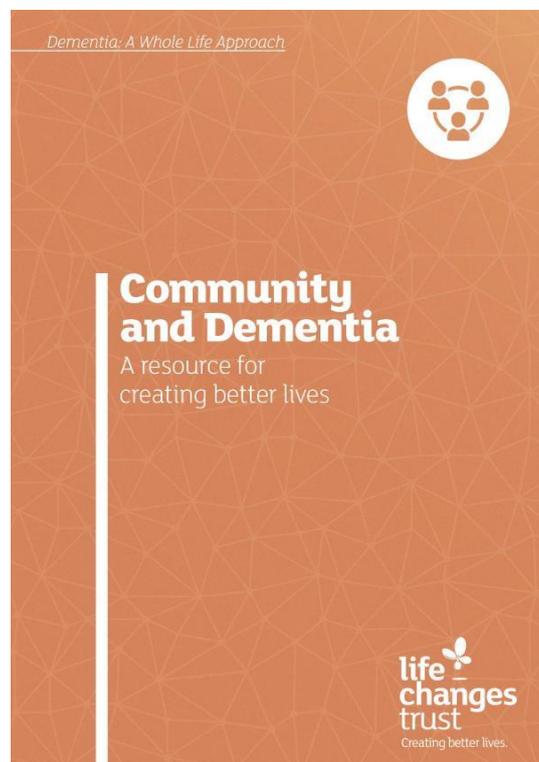
relationships that they have with the people they meet in DFCs; and b) the opportunity to shape the community to which they belong.

For a far more in-depth understanding of the work of DFCs in Scotland, see:

- DFC documentary produced by the Trust in 2018/19 <https://youtu.be/dn9SoC3kCl8>
- Dementia Friendly Communities Toolkit <https://bit.ly/2GgLQtw>
- Dementia Friendly Communities in Scotland Report 3 <https://bit.ly/2TKaAxk>

A full evaluation report, with examples of social return on investment, will be available in 2021. The first conservative SROI calculation has shown that Dementia Orkney creates positive social value for multiple stakeholders that is greater than the cost of the investment: £5.14 for every £1 spent.

Please also see Volume 2 of 'Dementia: a whole life approach', which can be found at <https://bit.ly/3edfv3v>.



PRINCIPLES EMERGING FROM DEMENTIA FRIENDLY COMMUNITIES

Dementia Friendly Communities work best when:



They adopt a social model of disability, rather than a medical model.

They take an assets-based approach that identifies and mobilises individual and community 'assets', rather than focusing only on problems and needs



People with dementia and carers have a significant say, that places them at the heart of the community so they can shape it



They are multi-generational



They enable people with dementia and carers to do what really matters to them



They provide appropriate training to staff and volunteers that goes beyond awareness raising



They meet with other communities so they can learn from each other

They collaborate with others and work in partnership to maximise use of resources and skills



They mentor new communities, who mentor new communities



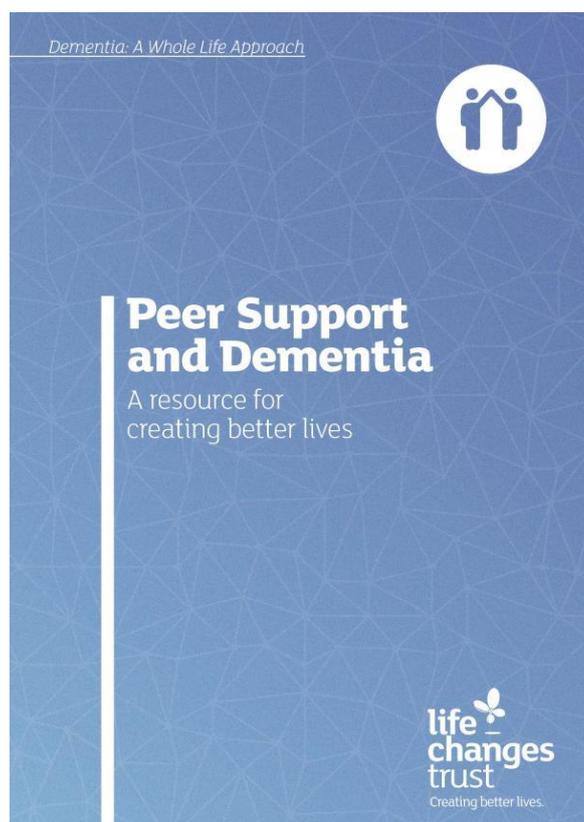
Befriending

Befriending²¹ is a fairly traditional approach to social care in the community but it is effective. It is particularly good when working with people who have more advanced dementia. The Trust has funded seven befriending projects across Scotland which are being evaluated by Faith in Older People (final report due in early 2021). The projects have been running for almost five years on a diminishing funding model.

Peer Support

The Trust has also funded five-year peer support projects (diminishing funding model) in five locations in Scotland. These projects are being evaluated by the University of Stirling with a final report in early 2021.

For a more in-depth exploration of peer support in the context of dementia see Volume 4 of 'Dementia: a whole life approach' at <https://bit.ly/3jNiqko>.



²¹ See <https://bit.ly/3oMzTNv>

Dementia-inclusive singing groups

The Life Changes Trust and the Baring Foundation support Scotland's Dementia Inclusive Singing Network, which is run by Luminate.²² Supported by Age Scotland, Scottish Care and Making Music, the nationwide network aims to ensure that people with dementia and carers have the opportunity to sing (in non-COVID times) in a choir or singing group in their local area.

Research has already shown that the benefits of participating in singing with a community of others can include improved mental health, social and emotional wellbeing, increased confidence and improved quality of life.

Choirs also provide the opportunity for fun, friendship, feeling happier, feeling worthwhile and valued. Singing can give a sense of belonging as well as a sense of pride in the group and its achievements, and individuals can do something they enjoy where dementia is not the focus.

Luminate provides small grants, supports the establishment of new dementia inclusive choirs and provides guidance to existing choirs on how to become dementia inclusive.

This work is being evaluated by the University of the West of Scotland. In the meantime, see <https://bit.ly/37ZYf0j> to better understand the benefits of singing groups.

Get Outdoors projects

Dementia causes difficulties which can lead to people withdrawing from day-to-day activities and routines. Lack of independence can lead to isolation and loneliness for both the person who has dementia and those who care for them. Maintaining confidence and independence is vital to sustaining a good quality of life for people with dementia and their carers, and it is important that ways of sustaining and building their confidence and supporting their independence are explored and established early on in the dementia journey.

²² <https://singing.luminatescotland.org/>

Scotland's Health and Social Care Standards²³ state this outcome for people receiving care:

"I can choose to have an active life and participate in a range of recreational, social, creative, physical and learning activities every day, both indoors and outdoors."

Getting outdoors is not something that immediately springs to mind when people are commissioning community-based services for people with dementia. The Life Changes Trust supported six projects to better understand what is needed to support people with dementia in outdoor spaces. The physical activities encouraged by the projects were varied and included walking around woods or attending community gardens and allotments, playing bowls, using equipment and materials to build bird boxes and planters, and refurbishing tools and equipment.

The evaluation report by Outside the Box²⁴, due to be published shortly, found that activities clearly improve physical and mental wellbeing. They help rekindle old memories and create new memories, with carers noting an improvement in alertness and cognitive function after the person with dementia has been outdoors. (Sadly the opposite was observed during lockdown.) People connect through music and song, and eating together outside. Those that made things felt a sense of purpose.

In addition to friendships and social connections the activities give people a safe, unjudgmental space in which they can share their concerns and issues with other family carers, sharing experiences and comparing notes or sometimes offering one another tips and solutions. Another outcome from the friendships and peer support was the way in which the groups also helped to reduce the stigma of living with dementia.

For some of the projects, there was also the chance to discuss informally more medical or clinical issues with staff such as the occupational therapist present at some sessions.

See <https://bit.ly/383BEjM> a video from the Evanton Woods Get Outdoors project.

²³ <https://bit.ly/324XAHf>

²⁴ Outside the Box <https://otbds.org/>

Work with minority ethnic communities

Very little work on dementia has been done with minority ethnic communities in Scotland. Stigma around dementia and social care is strong in many minority ethnic communities. The Trust funded work with four minority ethnic communities: Eastern European (Aberdeen); Cantonese speakers from Hong Kong (Edinburgh); South Asian, Chinese and East Asian, African and Caribbean, Polish and Eastern European communities (Falkirk, Stirling and Clackmannanshire); and South Asian – Pakistani, Indian and Bangladeshi communities (Glasgow).

The evaluation of these projects is being carried out by Blake Stevenson and will be published in the next month. The report's key recommendations should help decision makers develop better local responses to dementia services and care, improving access and the experience of services for people affected by dementia from minority ethnic communities.

An online learning event will be held on 9 December 2020.

Work with the LGBT Community

LGBT Health and Wellbeing has been carrying out work to raise the voices of lesbian, gay, bisexual and trans (LGBT) people affected by dementia to better understand and access services and support. The project will increase understanding for commissioners at a local level of what quality of life looks like for older LGBT people who are living with dementia or are an unpaid carers.

The project is also working with Alzheimer Scotland and other key stakeholders to develop a toolkit for professionals looking at their practice when working with LGBT people.

See <https://bit.ly/3oNf4lf>.

Transparency about statutory services and criteria that are not focused on crisis intervention only

Self-directed Support

Self-directed Support is the means by which social care is currently provided to people living in the community. People with dementia rarely qualify for any form of Self-directed Support but, when they do secure it, it makes a huge difference. The amounts of money that people with dementia require are relatively small. The principles of SDS are aspirational but there are four problems with its delivery:

- when assessing needs, 'social care' is interpreted very narrowly and traditionally - not in the creative, empowering way for which Self-directed Support was intended;
- from the evidence we have,²⁵ Self-directed Support is not, on the whole, being used to help people with dementia realise "their strengths and assets, their right to live fulfilling lives, their right to be included as active citizens, their right to be full participants in assessing their own needs and also their right to exercise choice and control over any support provided"²⁶;
- there is little transparency about how SDS is administered, which means that many who could benefit from such support miss out;
- it is impossible to track how much money is 'in the system' or available to individuals for funding SDS.

If Self-directed Support was being implemented as intended, there would be less need for this review of adult social care.

Work funded by the Trust on SDS struck many barriers, the first being a very real lack of awareness amongst people with dementia of their right to apply for social care support in this way.

²⁵ From: Rights, responsibilities and respect project, MECOPP <https://bit.ly/3oMCRBO>: Self-directed Support in Scotland, Community Catalysts <https://bit.ly/3oNC57G>: anecdotal evidence from Dementia Friendly Communities

²⁶ Scottish Government <https://bit.ly/35Spzv1>

Therefore, the work we were funding swung in the direction of providing information, guidance, training and legal advice.

See:

- Challenging Social Care Decisions in Scotland: a legal guide <https://bit.ly/3jiNI2c>
- Dementia, SDS and promoting individual autonomy <https://bit.ly/3kgXUK0>
- Self-directed Support in Scotland <https://bit.ly/2Hj4dyw>

“Only one of our members has Self Directed Support. Accessing this proved to be a cumbersome and lengthy process. This needs to be speeded up and made much more straightforward for people living with a diagnosis of dementia. By the time this was put in place the person could no longer cook her own meals and the personal assistant’s role is to microwave ready meals. If that support had been in place earlier then the personal assistant could have supported the individual to continue to cook her own food and do this with her. This would be a much more effective way of maintaining skills and independence than relying on ready meals.

Information about Self Directed Support is not generally made available by ‘services’. People tend to find out about it by other people who have accessed it. It would make much more sense to us if we could access Self Directed Support at the point of diagnosis when we could use it as a means to maintain skills and abilities and prevent decline.

So often assessments for ‘social’ care focus on physical needs. In our situation we are quite fit so are not able to qualify for input. We would like assessments to be more holistic and take into account that our need for support with sequencing activities like cooking, shopping and travelling are as meaningful as not being able to wash and dress ourselves.

What members...have also experienced is phone calls to discuss their care packages, including SDS, at 0900. This is not generally a good time of the day for people living with dementia as they often need a bit of space in the morning to attend to their basic needs. What would work better would be a letter sent in advance of a call to say contact needs to be made and to give options for communication. In our experience people would prefer a face to face visit where they can have family or a friend present for support."

"If I hadn't been persistent with them I wouldn't have got anywhere with it. I faced resistance all the way...(although) it was very positive...the process to get there was very complicated and difficult.

Things could change on a day to day basis, the direct payment was so flexible, it just allowed us to react to what Mum needed. I don't think any of the other SDS options would have worked in the same way."

Dementia Enablement Project – Care and Repair

Sometimes adjustments to the home are vital for helping a family member continue in their caring role. This issue was raised time and again with the Trust and carers said that they could not secure assistance through the usual statutory means, i.e. equipment and adaptations. It was also clear that some carers were having to relinquish their caring role and move their partner or relative to a care home because they could no longer cope. Yet through other work carried out by the Trust (Individual Awards – see below) we knew that timely interventions can make an enormous difference.

Following a conversation with Care and Repair²⁷ the barriers to timely support became more obvious:

- qualifying criteria are designed to meet critical need only;
- qualifying criteria are more favourable towards physical disability and do not take account of neurological conditions to any great extent;²⁸
- 'red tape'²⁹ means need cannot be met quickly; and
- there is usually no or little budget for preventative work.

These led to the Trust funding the Dementia Enablement Project (DEP) in partnership with Care and Repair Scotland to see what benefit could be gained if these barriers were removed, particularly with dementia-related Post Diagnostic Support (a government policy commitment) in mind. Four local Care and Repair services delivered the pilot projects in their areas: Aberdeen, Angus, Lochaber, and Lochalsh & Skye. The pilot started in February 2016 and ended in July 2019 in all areas except Lochalsh & Skye, where the project completed in January 2019. For a full understanding of this work see the report from Blake Stevenson³⁰ who evaluated the work: <https://bit.ly/34LRsFB>.

As well as exploring the benefits for people with dementia and unpaid carers, Blake Stevenson looked at the cost-effectiveness of the pilot project to see if this preventative service could also bring benefits and lower costs to wider statutory services (if statutory qualifying criteria were amended). The evaluation looked at the average cost of the DEP across the four pilot areas (£886.17 per client) against some of the benefits achieved.

The DEP was by its nature an early intervention and the high care costs of dementia on the wider statutory services may not be experienced for several years. The evaluation found evidence that the work of the DEP

²⁷ <http://careandrepairsotland.co.uk/>

²⁸ Not taking account of the impact that dementia has on sensory perception and interpretation, which can lead to the home becoming a frightening place if not adapted to suit an individual's particular needs. See <https://bit.ly/3223toO>.

²⁹ For example, a six-week process for checking in and out a handrail intended for use in a house in the same area; or procurement restrictions that prevented bulk buying certain items, even when bulk buying would bring about clear savings.

³⁰ <http://www.blakestevensonresearch.co.uk/>

supported people living with dementia to live safely at home for longer, therefore it should delay the time when a person living with dementia needed residential care and it most likely reduced emergency hospital admissions. It was not expected or possible to find a reduction in the short term of the publicly borne costs of supporting and caring for the people affected by dementia, however, it is useful to explore the future costs that could be avoided.

The evaluation considered what costs needed to be avoided to make the project cost neutral. To do this it looked at how effective the project would have to be at preventing the costs of residential care and emergency hospital admissions for people living with dementia. The standard rate for residential nursing care in Scotland is £714.90 per week or £37,277 per year. This only represents the amount of publicly funded support for people living with dementia below the lower capital limit and not the true cost of care. The evaluators took this conservative estimate of the cost of residential nursing care for people living with dementia and calculated that, to be cost neutral across all four areas, the DEP would have to reduce the average amount of time spent in residential nursing care by nine days for each person living with dementia who was supported by the DEP. This amount of time varies when we consider the individual areas. In Angus, for every person living with dementia who was supported by the DEP, the amount of time spent in residential care needed to reduce by seven days to make the project cost neutral. In Angus this was eight days, in Lochaber 16 days and Lochalsh & Skye it was 19 days.

Alternatively, whilst an estimated cost of an emergency hospital admission related to dementia is not available in Scotland, in England in 2017/18 the cost of such an admission was £4,516. This means that the costs of the project in Aberdeen would be covered if, for the 504 people supported in Aberdeen, there were 77 fewer emergency admissions amongst those people living with dementia. Similarly, for Angus, the costs of the project would be covered if amongst the 545 people living with dementia there were 87 fewer emergency admissions. In Lochaber, the equivalent figure would be 54 fewer admissions and it would be 35 fewer admissions in Lochalsh & Skye. Among the 1,281 people

supported across all four areas combined, this figure would be 252 fewer emergency hospital admissions to make the DEP cost neutral.

If we consider the lower future costs alongside the impact on the quality of life of those supported by the project, with clear examples of prevented or delayed need for care home or hospital admission, schemes like the Dementia Enablement Project are a worthwhile investment and should be explored as part of commissioning contracts.

The report also makes recommendations about the role of the Dementia Enablement Project in Post-diagnostic Support.

Recognition of the value of small amounts of money provided through Self-directed Support or an equivalent mechanism

Individual Awards

The Life Changes Trust has shown that small amounts of money can go a long way to delaying or reducing more costly social care interventions. In 2014-15, the Life Changes Trust ran an Individual Awards Pilot Scheme in Argyll & Bute and Edinburgh.³¹ This scheme offered £500 to individuals living with dementia or unpaid carers of people living with dementia. They could use the £500 for anything that a) mattered to them; b) would make their life better; c) they would be unable to do without the Award.

The evaluation report for this pilot phase showed how carefully people thought about how they would use the money. It also demonstrated the sometimes difficult or dire circumstances some families living with dementia face, with no social care support.

The very readable pilot project evaluation report can be found here: <https://bit.ly/380l2sS>.

The scheme was rolled out to other areas in 2018/19 and evaluated by The Lines Between³². That evaluation report will be launched at an online learning event in December 2020. It demonstrates that receiving just £500 or less can make a wide-ranging, long-lasting and far-reaching impact. Although the Awards represented a relatively small amount of money and were often spent on a straightforward and practical need, the initial and immediate impacts had ripple effects. They led to positive impacts for family members, and connected people with other forms of support. Impacts were often greater and more wide-ranging than expected, encompassing emotional, quality of life and relationship improvements and potentially avoiding or delaying a need for more costly support.

There are clear parallels to be drawn between the Individual Awards Schemes and the potential for SDS to be used for prevention, not just

³¹ Evaluation report is available here: <https://bit.ly/3oTFlhZ>

³² <http://www.thelinesbetween.co.uk/>

crisis intervention. This is something that we will draw out more at the learning event in December 2020.

“I was starting from scratch at about 73 years of age.”

When his wife developed dementia, Murdo from Argyll & Bute described himself as taking on a new role as a homemaker and learning a whole new set of skills. He hoped to keep his wife at home for as long as possible and her well-being is very important to him. Now responsible for the housework, as well as caring for his wife, he had begun thinking about how he was going to cope with the future and what needed to change to make everyday household tasks more manageable. When the opportunity of an Individual Award came up it was “a real help and a real incentive to move quickly”. He was able to replace the carpets in the bathrooms with vinyl flooring making it easier to maintain hygiene, and to buy a tumble dryer which had been timely given a period of particularly wet weather. These changes have made a great difference to Murdo, making caring for his wife significantly easier and making things feel more manageable. This has made him feel more positive about his caring role and has helped his emotional resilience. “It’s proved a boon, I can assure you”.

Funding for people with dementia and unpaid carers to support each other

Peer to peer resources

The idea of people with dementia and unpaid carers being funded to support one another is perhaps not one that would be considered usually in a social care context. However, this has proved to be one of the most fruitful lines of investment, in relative terms, that the Trust has made.

It began with Agnes Houston, in collaboration with other people living with dementia. Agnes approached us with a request for a small amount of funding to produce a book on dementia-related sensory challenges. Agnes was frustrated when professionals did not recognise that dementia is more than memory loss and that misconnections in the brain can also lead to misinterpretation of data in the brain. For example, some people with dementia find their sense of taste completely changes and so reject certain types of food. This can be interpreted as a refusal to eat or 'being awkward' whereas, in reality, they no longer like that meal. If not recognised, this can lead to significant weight loss or illness.

The Sensory Challenges booklet (<https://bit.ly/380Bk5d>) has made carers, professionals and others sit up and take note of what people with dementia are saying. It has influenced the re-writing of training and guidance from professionals in a number of organisations and has been incorporated into the health and social care curricula of several universities. The long-term benefits to health and social care policy and practice are clear.

A very conservative estimate would say that the booklet has been read by at least 33,000 people in Scotland alone. To date it has been translated into Czech, Welsh, Chinese, French and Japanese. It has also been distributed in Australia, Canada, Jersey, Guernsey, Hungary, Belgium, Spain and Slovenia.

Agnes went on to write a further book 'Talking Sense' with HammondCare (also available as an audio book).³³

³³ See <https://bit.ly/2HUvFTi>

Since then, people with dementia and carers have produced more peer to peer resources, including:

- Loud and Clear – a book that explores two decades of involvement, voice and activism by people with dementia in Scotland³⁴
- Alexa and Me - A Dementia Responsive Guide To Your Amazon Virtual Assistant³⁵
- Dementia and self-management³⁶
- The Recipe for Life – a recipe and poetry book that raises awareness about dementia³⁷
- This Rain – an EP music record that explores the therapeutic benefits of music for carers³⁸
- Driving and Dementia – what it is like to give up driving following a diagnosis of dementia³⁹
- Core principles for involving people with dementia in research⁴⁰
- Living and Learning with Dementia film⁴¹
- For Carers By Carers – easy-read self-management and resilience resources for dementia carers⁴²
- Come and Sing Café Video – how to set up a choir⁴³
- Urdu/Punjabi dementia awareness resource video⁴⁴
- BSL videos on the different types of dementia⁴⁵
- Travelling safely with dementia⁴⁶

These can all be viewed on the Life Changes Trust's website:

<https://bit.ly/326aYL8>

³⁴ <https://bit.ly/3oPAAWt>

³⁵ <https://bit.ly/3kUe901>

³⁶ <https://bit.ly/3oOWjOi>

³⁷ <https://bit.ly/3oPAZYZ>

³⁸ <https://bit.ly/325UgMc>

³⁹ <https://bit.ly/2TO9KQb>

⁴⁰ <https://bit.ly/35UO5vo>

⁴¹ <https://bit.ly/381AEfU>

⁴² <https://bit.ly/3oTQ8so>

⁴³ <https://bit.ly/34Ra0Eh>

⁴⁴ <https://bit.ly/3oQZ9Cv>

⁴⁵ <https://bit.ly/2Hwx0Eg>

⁴⁶ <https://bit.ly/3oV0zM7>

A broader view across ALL statutory portfolio areas to determine ways in which changes in one area of service provision could take pressure off demand for social care

A whole life approach to dementia means that statutory organisations should look across all statutory portfolios to determine whether there are changes that can be made that would help reduce or delay the requirement for social care.

There are five key areas worth considering initially.

Housing

In our experience, the role of housing is often overlooked in social care planning by Integration Joint Boards. In 2016/17, the Life Changes Trust funded a report on housing and dementia. The Trust had organised a number of events bringing together housing practitioners, health and social care professionals, the private and the voluntary sector to help identify housing's contribution to supporting people with dementia.

A small project group was set up to consider what could be done to support the housing and voluntary sector to develop their contribution. The report was produced by an interdisciplinary project team, comprising practitioners and academics, led by the Alzheimer Scotland Centre for Policy and Practice at the University of the West of Scotland. The final report entitled 'Being Home' was launched at the Scottish Parliament: see <https://bit.ly/324ex4J>.

The findings would encourage local authorities and other relevant bodies to:

- Add practical detail to independent policies and guidance in Scotland about housing and dementia.
- Give more consideration to housing and planning guidance about meeting the needs of people living with dementia, with particular attention to the majority of older people who live in owner-occupied housing, which has high levels of disrepair.
- Start developing accommodation appropriate to the diverse needs of people with dementia.

- Identify gaps in the knowledge of those who work within housing services, including practitioners, support and maintenance staff, and train them to know how to support a person with dementia and their family.
- Improve collaboration within health and social care integrated teams to fully realise and include the housing contribution.
- Give people living with dementia and their family information about general housing advice, support and funding.
- Consider home adaptations and equipment as early as possible, to ensure the needs of people with dementia are person-centred, well planned and can promote living well at home for as long as possible. Home adaptations should address the cognitive and psychological needs of people living with dementia as well as physical support.

Transport

“Only one person in our group can still drive. The rest of us have to rely on public transport which sadly is not always dementia friendly. One complicated journey can ruin confidence which means we don’t go out again.”

Person with dementia, evidence to Independent Review of Adult Social Care

If people cannot get out and about, their independence and confidence reduces. A reduction in independence and confidence can have psychological and physical implications, for example, depression, loss of mobility and falls. This can lead to greater need for health and social care. While someone in the later stages of dementia may find that the ability to walk or stand is affected by the condition, this is not always the case and many people in the earlier stages of dementia want to keep active.

Many people diagnosed with dementia will need to give up driving. This can be a difficult and emotional time for that person and their closest family and friends, particularly if they live in a rural area. For a personal account of how this feels, from the perspective of someone living with

dementia, see the booklet 'Driving and Dementia' by James McKillop: <https://bit.ly/3oMflVt>.

Go Upstream⁴⁷ is an organisation that develops training for mobility service providers, such as train and bus companies, based on insights learned from people living with dementia and other conditions. They have used a wide range of creative and interactive methods to understand the barriers people with dementia face when they travel and how these could be addressed.

You can read about their work here <https://bit.ly/3mlqB3y> and on their website www.upstream.scot.

Signage

If people with dementia cannot find their way around and are confused by signage and symbols, they will not go out and about. This is a problem for the reasons cited above. Public authorities and providers of commissioned services should consider upgrading their signage to dementia inclusive symbols that have been designed in Scotland in collaboration with people living with dementia and other people who do not have dementia.

The first of these symbols, the 'any disability' symbol, was launched at the UK Parliament last year and is now in use. The British Standards Institution is now considering whether the symbol set can be recommended as an ISO standard.

See: <https://www.inclusivesymbols.com/thestory>.

Scams

People living with dementia are at great risk of falling prey to scammers, and families are often worried about how to prevent their relative becoming a victim of a scam, particularly in the early stages of dementia.

East Renfrewshire, Angus and South Ayrshire Councils worked together to develop, pilot and evaluate a preventative approach to protect people

⁴⁷ See <https://bit.ly/324UW4h>

with dementia from financial scams, so that they better maintain their confidence and ability to continue living independently at home.

The project tasked itself with making people with dementia feel safe and protected from harm, reducing the current rate of financial loss and personal harm as a result of scams.

This work involved the development and delivery of a package of preventative measures to offer people with dementia an individualised, person-centred approach to safeguard them from financial exploitation on the doorstep, by telephone, mail or online, including practical solutions and assistive technology, for example, call blockers and 'no cold callers' badges for their front door.

The councils also produced awareness-raising materials and a training programme for organisations working with people with dementia, developing a good practice model which can be used across Scotland.

The evaluation of this project was complete in summer 2020 and can be found here: <https://bit.ly/3mAZjMm>. The evaluation, which was carried out by the Social Value Lab,⁴⁸ showed that for every pound of investment in the scams project £10.30 social value was created.

Technology

The Life Changes Trust recently held a webinar⁴⁹ on Dementia and Technology following the publication of a literature review and research project on the subject.⁵⁰ Scotland has a Digital Health and Care Strategy which states "This strategy is about how care for people in Scotland can be enhanced and transformed through the use of digital technology. It is not specific to individual specialisms, groups or organisations: it encompasses the whole range of health, social care and wellbeing services commissioned and provided by Health Boards, by Integration Authorities and by Local Authorities and their third and independent sector partners. Importantly, it extends as well to informal care, self-care, prevention and public health."

⁴⁸ <http://www.socialvaluelab.org.uk/>

⁴⁹ Webinar: <https://bit.ly/3kNgWlr>

⁵⁰ Report: <https://bit.ly/35XxarY>. The research was funded by the William Grant Foundation.

This statement assumes that, increasingly, people with dementia and unpaid carers will use technology to help them with informal care and self-care.

In early 2018, the Life Changes Trust conducted a preliminary scoping exercise to see what the evidence base was around dementia and use of technology. There was some evidence that technology that would assist professionals had been evaluated, for example, technology that helps with the administration of medication or to make sure a person had not left their room.

There was a lot less evaluation of technology that **enables** the independence and confidence of the person living with dementia or the unpaid carer living in the community. The evidence base seemed to focus on medical solutions more than social solutions and treated the person as a patient rather than a citizen with rights and freedoms.

Therefore, an important element of the study, which was funded by the William Grant Foundation, was to better understand the evidence base on the effectiveness of assistive technology for people with dementia and carers living in the community.

People with dementia, their families and friends have often reported anecdotally that assistive technology is enhancing their quality of life and their independence. It is also helping carers to care for longer, which means that people with dementia can stay at home for longer.

To delve into the findings of this study and other work like it, watch the webinar. However, statutory bodies should consider the following in the context of social care:

- Technology should enhance human relationships, not replace them
- Assistive technology for people with dementia needs to be the best option available. If there is a non-technological solution that works well then people are less likely to try an assistive technology device that would perform the same function.
- People want a product that addresses a problem experienced by the individual with dementia or the carer. What became very clear from

the research focus groups was that for each device discussed, one participant could see it being useful and in the same group another could see no need for it. So, one size definitely does not fit all.

- Technology must be used with consent, where that consent can be given
- There are considerable ethical issues around the use of monitoring technology and these need deeper exploration
- Scotland's Digital Health and Care Strategy needs a stronger evidence base to undergird the ways in which it says it will support people with dementia and unpaid carers. The Strategy needs to be enabling and not just focused on risk reduction. We understand that there was no equality impact assessment of this Strategy that might have identified benefits or negative impact for people with dementia.

Measuring success – scrutiny and accountability

There are many monitoring mechanisms in place in Scotland for measuring progress against stated outcomes. It is our view that the quality of these measures could be greatly improved.

For example, the Scottish Government's Dementia Benchmarking Toolkit (related to the National Dementia Strategy) has five 'key challenges' to be monitored:

- **Fear of dementia that means people delay in coming forward for diagnosis**

Performance indicators: number of patients on the Quality and Outcomes Framework dementia register; proportion of people in Care Homes with a medical diagnosis of dementia versus non medically diagnosed.

- **Information and support after diagnosis for those with dementia and their carers is poor or non-existent**

Performance indicators: the percentage of patients diagnosed with dementia whose care has been reviewed in the previous 15 months; prescribing rates for dementia drugs per 1,000 population (65+); patients and carers on the dementia research register per 1,000 population (65+).

- **General healthcare services do not always understand how to respond well to people with dementia and their carers, leading to poor outcomes**

Performance indicators: number of acute admissions for people with dementia per 1,000 population over 65; percentage acute readmissions within 365 days; proportion of patients following home>hospital>home (Path 1) versus home>hospital>care home (Path 2); Average Length of Stay (Acute).

- **People with dementia and their carers are not always treated with dignity and respect**

Performance indicators: Number of Dementia Guardianships; Number of people with dementia receiving home care; Prescribing rates for antipsychotic drugs per 1,000 population (65+)

- **Family members and people who support and care for people with dementia do not always receive the help they need to protect their own welfare and to enable them to go on caring safely and effectively**

Performance indicators: Number of psychiatric admissions for people with dementia per 1,000 population over 65; Percentage psychiatric readmissions within 365 days; Average Length of Stay (Psychiatric)

The mismatch here is obvious between the fairly qualitative 'key challenges' and the performance indicators which are in some instances, frankly, inappropriate. Any new or revised social care framework **must** collect performance data that is a) relevant, b) appropriate, and c) cross-referenced between health and social care in order to build a true picture of performance. These current indicators tell us almost nothing about how the 'key challenges' are being addressed.

Scotland's nine National Health and Wellbeing Outcomes⁵¹ are good and the key measures and indicators are better. It would be very helpful if performance in relation to dementia was somehow melded with the Health and Wellbeing Outcomes.

More generally, people with dementia and unpaid carers will want to be involved in providing their perspective on the performance of any new or revised approach to social care. We are keen to know how that will happen.

In April 2019, About Dementia: Shaping Our Worlds Together – Scotland's forum for improving lives was launched. About Dementia works with people affected by dementia to make changes to the things that are most important to them. A lot of good work is being done around Scotland both nationally and locally, but many people affected by dementia are still struggling to get the support they need when they need it. About Dementia believes that people living with dementia and unpaid carers are in the best position to say what is and isn't working and how to do it better.

About Dementia brings together people affected by dementia, and organisations who are interested in working for change, to look at how

⁵¹ See <https://bit.ly/3kV1VEw>

we can improve policy and practice across many different areas of life. This will include various aspects of social care.

See: <https://bit.ly/38fkXC3>

Alongside About Dementia is the BOLD (Bringing Out Leaders in Dementia) school of leadership. See <https://bold-scotland.org/>. BOLD is an innovative programme providing free leadership opportunities across Scotland to help those living with dementia to flourish. The project brings together people living with dementia, family members and friends, professional carers, NHS staff, artists and people from all walks of life.

The project wants to ensure that our communities can all make a positive contribution to support people living with dementia in Scotland.

Both BOLD and About Dementia should be a valuable resource when it comes to rolling out the review's recommendations and tracking progress. Please do not hesitate to contact them.