



INNOVATIONS IN DEMENTIA

edited by Martin Routledge, Helen Sanderson and
Gill Bailey

commissioned by In Control on behalf of Alternative Futures Group

in  **Control**[®]



**ALTERNATIVE
FUTURES GROUP**

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INTRODUCTION

COMMUNITY-BASED SUPPORT FOR PEOPLE WITH DEMENTIA AND THEIR FAMILIES: THERE MUST BE A BETTER WAY

There is a great deal of understandable concern about how people with dementia are currently supported, all the way from diagnosis and early post-diagnosis support through to assistance for people with late stage dementia. We hear terrible examples of poor care in people's own homes through to awful examples of lack of care in residential homes.

Many people have considered ways of improving this position. They have proposed solutions including higher spending on social and healthcare support for people with dementia, better trained and qualified staff, better commissioning, inspection and regulation, and the introduction of person-centred approaches to support.

Beyond these approaches to service improvement are others at a broader community or cultural level – such as dementia-friendly communities and dementia friends. People have developed these latter approaches at a time when public resources available to people with dementia (as other groups) are declining; due in particular to cuts in grants to local authorities. These cuts, alongside the current and predicted growth in the number of people with dementia, have led to a search for approaches that rely less on direct provision of traditional forms of support to people and families.

Austerity is not the only force leading us to look for new approaches to support. For some, the traditional forms of support and models of delivery are deficient because they maintain a largely institutional, even inhumane, response to dementia. This leads them to look for different ways of supporting people – sometimes combining person-centred practices¹ and approaches with a range of new or adapted service support models. At one end of the continuum this might mean adapting or improving existing models by introducing person-centred practices to change how people experience a service, or shift the culture of providers.

<http://www.youtube.com/watch?v=LlPLj8etSYU&sns=em>

At the other end it might involve either new service forms or the adapted or expanded use of forms previously developed for other uses. New approaches may also involve different forms of service organisation that stimulate or exploit greater entrepreneurship and energy amongst those delivering them.

These developments, however, remain at an early stage, with few operating at scale and a general lack of powerful impetus for their expansion.

CONTEXT

In considering the prospects for introducing different approaches to supporting people with dementia, we must bear in mind the strategic context, including policy and resources, and more local policy and practical considerations. Nationally, there is a high level of public and media interest in dementia, which is reflected in political interest and concern. We can see this at the highest level in the direct interest and involvement of recent prime ministers, and the resulting policies requiring the development of strategies and improved support at a local level. This policy affects primary and other healthcare commissioners, local authorities, health and wellbeing boards and the providers of domiciliary, residential/nursing and specialist care. Providers of course are often third sector or private organisations and there is a significant, mixed role played by major organisations seeking to represent and support older people and people with dementia – notably Age UK and the Alzheimer’s Society. This high level of political and public interest and complex local pattern of responsibilities and delivery adds both challenge and possibility to the goal of changing how people are supported.

There are policy and political drivers that could offer opportunities, in particular the policy drives towards integration and personalisation. Though there is inevitable party political nuance, there is a broad political consensus on both. So whether we are talking about New Models of Care vanguards, Integration Pioneers, Better Care Fund, Whole Person Care or Integrated Personal Commissioning, the direction is towards stronger joining up of health and social care around people. There are CCG, Local Authority and HWB strategies regarding people with dementia and in respect of relevant broader groups (such as carers) and forms of service (such as homecare). The challenge of course is to make this work at a local level at a time of powerful pressure on the finances of the individual players and policy, financial flows and regulation that continue to make it easier to deliver services separately, in silos.

An important question then is whether and which alternative forms of support can:

- **Deliver tangible improvements to people with dementia and their carers.**
- **Meet national policy and local strategy expectations – ideally those that cross sectors.**
- **Be delivered at the same or lower cost than current approaches.**
- **Be scaled up reasonably quickly.**
- **Be delivered in a context of massive system pressure.**

One additional consideration here is where the initiative for the introduction of change comes from – including investment and risk. Traditionally there is an assumption that it comes from commissioners, but we must consider

“we always felt there must be a different way of doing things”

the possibility that there are other sources of innovation, especially in the development stage. Innovators may include providers and consortia/ partnerships of providers who decide to develop alternative offers and bring them to commissioners and others, including personal budget holders and self-funders. Initiatives may also not be limited to traditional care providers but include, for example, housing providers and community organisations. Whatever the source of initiative, we need to see greater co-production with people and families in identifying the problems that need to be solved and the solutions to these problems.

THIS E-BOOK

This E-Book has been edited by In Control and Helen Sanderson Associates. It was commissioned by Alternative Futures Group who are interested in the best practice across the sector for dementia support. It offers concrete ideas and examples to those interested in driving a radically different approach to supporting people with dementia and their families. We have explored a number of approaches with people who have been leading their development. We have been keen to look at both approaches that emerge from working directly to improve support for people with dementia and others that have different roots, but we think are potentially very transferable. None of the approaches is yet being used at any significant scale. Our view is that if this were to happen, sometimes with adaptation, they offer the potential for a dramatically different and better future for people and families. At this early stage of exploring innovations in dementia our aim has been to bring to readers' attention approaches and examples that may have promise - often described by those leading them. We have not attempted to evaluate the projects and examples described, though some of the authors have quoted relevant research. In considering selection, we looked for approaches that appear to be attempting to solve the problems we have identified in support for people with dementia - using our own connections and those of trusted advisors in the field. Our expectation is that readers will know of other similar examples and of approaches we have not yet considered. We hope that our contribution through this e book can assist in the exchange of information, ideas and examples.

This e-book does not attempt to tackle the question of how to achieve the shift to the incorporation of these approaches at scale, though you will see some chapters do explore barriers to this. The focus here is on bringing these approaches to readers' attention - the innovators describe them and make the case for their use. The e-book format allows readers to choose issues and approaches that are of particular interest to them and also to use the links provided to follow up their interest in much more detail via additional material and contacts. We hope that they provide food for thought but more importantly, action.

We start with the current situation for people living with dementia, and then explore a range of ways to address this.

Helping people to receive good support:

- **Living with and being supported by another family with Shared Lives.**
- **Three different examples of housing and support: Extra Care housing at Seafarer's Way, Sunderland; in Fiona Gardens, Trafford; and at Amblecote Gardens, Salford.**
- **Care at home in a community setting from Belong, Warrington.**
- **Enhanced healthcare in Coalfields, Sunderland.**
- **Improving health and wellbeing in Eccles.**
- **Reablement support for people coming out of hospital in Oldham.**
- **Holidays provided by Mede and Seaward House.**

Then we look at enabling people to have good days:

- **Each Step, Blackley provides holistic dementia care.**
- **White Gables, Bromley offers flexible day and evening support.**
- **The Healthy Living Club, Stockwell offers flexible support through the day.**
- **Dementia Adventure provides outdoor activities and holidays.**

Then we look at connecting people in their community:

- **Small Community Enterprises.**
- **Local one-point resource from Local Area Coordination.**
- **Partners in Policymaking work to include people and carers in support planning.**
- **Community Circles facilitate self-sustaining support around a person.**
- **Community Catalysts encourage small community enterprises.**
- **Volunteering through Volunteering Matters (formerly CSV).**
- **And finally,**
- **Personal budgets that enable people to have choice and control over all areas of their lives.**

We are grateful to the organisational representatives who were interviewed or provided material for chapters. Thanks also to those who directly authored chapters: Jemma Mindham (Volunteering Matters), Helen Turner (Community Catalysts), Ralph Broad (Inclusive Neighbourhoods), Julie Stansfield (In Control). Special thanks to Gill Phillips (Nutshell), Alex Fox (Shared Lives) and Ian McCreath (Alzheimers Society).

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The current situation for people living with dementia

Before we look at and discuss innovation, we must first examine where we are now and why it is needed. This chapter examines what the challenges are for people living with dementia, as a result of either current service provision or a lack of an alternative. For every issue raised here, we suggest a potential solution described in a chapter of this book.

15 minute support visits are not enough to provide quality care

The majority of older people with dementia continue to live at home after their diagnosis [Alzheimer's Society, 2014]. To ensure that people who choose to remain at home receive the care they need to stay safe within their home, adult social services provide domiciliary care through direct payments or personal budgets. However, in 73% of local authorities [Unison, 2013] this support provision is mostly based upon 15-minute calls. An amount of time that has been criticised as being too short, considering that so many people living with dementia live alone or with a carer of the same age who cannot provide any additional care they might need.

Research carried out by Leonard Cheshire demonstrated that neither disabled nor non-disabled people were able to get out of bed, go to the toilet, shower, brush their teeth, get dressed and have breakfast in less than 40 minutes [Leonard Cheshire, 2013] and yet the vast majority of domiciliary care in the UK allows nearly two-thirds less time than this. That this is a huge disparity has become increasingly obvious as some news reports have suggested that many older people are having to choose between being fed and being bathed [Donnelley, 2015]. Frail people cannot move quickly and the likelihood that older people are being put at risk by carers who have to rush to do their jobs is high.

Research from Unison [2013] also shows that carers worry that they do not talk to the people they support enough. Whilst trying to wash, dress, feed and tidy for a person, all in 15 minutes, carers say that it is hard to engage in conversation. However, carers might be the only visitors an elderly person or someone living with dementia sees for the entire day.

Another issue is the number of different staff who go into a person's home, with little opportunity to build relationships or get to know people.

In Northern Ireland, research by the Patient and Client Council [2012] showed that almost a fifth of older people felt that the care they received only improved their quality of life "a little", even though they may rate their care of basic needs as "good". Reasons given for this included short duration of visits, little continuity as regards care staff and inconvenient or irregular call times. They felt that while the care they received did cover basic needs, a lot more support was needed in order to achieve a good quality of life.

"a lot more support was needed to achieve a good quality of life"

We know that neither homecare [domiciliary care] nor residential care currently consistently ensures that older people live well in their own homes, maintaining and growing their connections with their local community. Many recent reports by CQC and the Equality and Human Rights Commission find failings of basic quality and safety: the EHRC said in 2012 that “the poor treatment of many older people is breaching their human rights” and identified “pervasive social isolation and loneliness experienced by many older people confined to their homes who lack support to get out and take part in community life” [EHRC, Close to Home, 2012].

Innovations that relate to this can be found in these chapters:

Homecare and Individual Service Funds (personalised homecare using a personal budget)

Good days: Flexible services, White Gables, Bromley

Good days: Holistic dementia care, Each Step, Blackley

Connecting people: Circles of Support, England

Choice and control: Personal health budgets, In Control, England

Many older people are isolated and lonely

Many older people experience loneliness and isolation, which in turn have a detrimental effect on their health and wellbeing. Loneliness has been identified as an epidemic for older people by [The Campaign to End Loneliness](#)² and others. The Centre Forum's 2014 report [Ageing Alone](#)³ shows that nearly half of over-85s admit to experiencing loneliness some or most of the time and highlights research showing that one in ten people visit their GP because they are lonely. Research also suggests that lonely adults are more likely to undergo emergency hospitalisation and early admission into residential or nursing care. Lacking social connections is a comparable risk factor for early death to smoking 15 cigarettes a day, and is worse for us than well-known risk factors such as obesity and physical inactivity.⁴ Indeed, there is evidence that socially engaged older people experience less cognitive decline and are less prone to dementia, and the risk of Alzheimer's disease more than doubles in older people experiencing loneliness.⁵

We also know that people living with dementia very often become lonely and/or socially isolated as a direct result of their condition. In their recent report, [Dementia 2013: The Hidden Voice of Loneliness](#),⁶ The Alzheimer's Society presented a number of alarming statistics in relation to how dementia can affect people's connections and relationships. The report found that 33 per cent of people living with dementia said they lost friends following their diagnosis. Furthermore, 39 per cent of people surveyed said they felt lonely as a result of their condition, and 62 per cent of people who live with dementia who live on their own admitted to feeling lonely.

Isolation can additionally lead to early admission into residential care, which for many is either unnecessary or should only be for a short period of time rather than a lasting arrangement that drifts into permanency. There

is a high financial cost to this as well as a cost to the individual in terms of their independence and sense of worth and wellbeing.

Shaping our Age, a Lottery-funded three-year research and development project by the Royal Voluntary Service, the Centre for Citizen Participation at Brunel University and the Centre for Social Action at De Montfort University, began in 2011 with a nationwide consultation and research programme with older people individually, in focus groups and via an evaluated involvement programme. **The second of its seven key findings⁷** is: “social connectedness was by far the most strongly voiced and frequently mentioned aspect shaping wellbeing”. It recommends that services consider how existing relationships within health and social care provision can be made “more humanistic and more closely tied to how older people may define their own wellbeing.”

Given the extent and serious impact of loneliness and the lack of evidence that conventional support approaches have any realistic prospect of tackling it, it is perhaps surprising that government and service planners have not done more to explore and research alternative models which address the issue.

Innovations that relate to people being lonely can be found in these chapters:

Housing and support: Shared Lives, UK-wide

Good days: self-directed community, Healthy Living Club, Stockwell

Connecting people: Circles of Support, England

Connecting people: Supported Volunteering, Volunteering Matters

Most care and support services for people with dementia are inflexible and fragmented

Service systems in the UK make it difficult for people with dementia to live good lives in their community and to have significant choice and control over the support they receive. Services are fragmented and people don't know where to go – they are sent from pillar to post. Family members often feel unsupported, with few links. Additionally services tend to function in traditional ways that expect older people and people living with dementia to fit into a box where one size fits all.

Traditional care homes often have institutional models that feel alien to the person with dementia. People are often living with large numbers of others without any attention paid to matching the people who are living together or the staff providing support. There appears to be a culture of professionals in charge whose purpose is to keep people safe. There is too little recognition that people are from different backgrounds, will have different preferences, different physical abilities and families, and there is little consideration that the person with dementia is on a journey that's going to change along the way. With all this added into the mix, people with a dementia and their families are generally not happy with the options available to them: stay at home for as long as possible with traditional homecare support, or go into residential care.

Key people and agencies often do not work collaboratively or in partnership. People and families in crisis need help and support but really struggle to access it due to red tape and feeling that they do not have the right or confidence to challenge policies and procedures that have always been in place. Often there is a simple solution if the key people work creatively together.

Innovations to the current situation can be found in these chapters:

Housing and support: Extra Care, Seafarer’s Way, Sunderland
Housing and Support: Homes with support, Belong, Warrington
Good days: holistic dementia care, Each Step, Blackley
Good days: flexible services, White Gables, Bromley
Connecting people: Local Area Coordination

A lack of personalised support at home for people with dementia

There is a lack of personalised, round-the-clock support to people living with dementia in their own homes in the community. This often results in a crisis leading to admission to residential care. Because it is a crisis, no forward planning takes place and the person living with dementia and their carers are often left feeling disempowered.

Local Authorities are under pressure to make efficiencies and savings and this can result in reductions in support – perhaps to just a ‘pop-in’ – which makes people more isolated. Support focuses on the task rather than on who the person is and what is meaningful and important to them.

The Commission on Residential Care A vision for care fit for the twenty-first century commented that “Career structures, or lack of, often lead to high turnover in ‘care’ roles leading to inconsistency of support. Too often working in care is seen as a ‘job’ that is temporary and low skilled. There is little career progression; society attaches a low value and low pay to the work, unlike the value it attaches to those working in the NHS.”

This lack of adequate and personalised support comes at a time when many more people are living longer and the numbers of people being diagnosed with a dementia is significantly increasing. Although there has been some progress in awareness of dementia, the reality is that many people are still isolated, unhappy, and not receiving the right support for them.

Though there are many acts of hospitality, human kindness and great care, they are drowned out by stories of shocking abuse across the UK. This results in fear and trepidation for both people living with dementia and their families when they require housing with support.

The Commission on Residential Care said, “For most people, going into residential care is synonymous with an end to independence, of loss. Personal independence is wrongly linked in the public mind with remaining

in one's own home. In the UK and around the world we have seen great examples of how residential care can reinvent itself. It is no longer a last resort, but a respected part of a continuum of 'housing with care', which is enabling people to lead bigger and more fulfilling lives. Rebranding residential care as a part of a spectrum of housing options with care is a prerequisite of delivering the twenty-first-century care system we want to see."

Another result, also pointed out in the report, is of the lack of support and understanding for people with dementia that means many people lack purpose and direction in their life. For example, people are often labelled as wandering aimlessly around a building and families and staff need to understand what this means, what people are looking for, and how to respond.

There has been some positive work done towards creating dementia-friendly communities and neighbourhoods, focusing on local shops, banks, supermarkets, etc. but this is the exception rather than the rule. This leaves many people still facing discrimination (although it is not always intentional) due to lack of understanding and empathy.

We clearly need to work with the people we support to provide truly personalised support.

Innovations to the current situation can be found in these chapters:

Housing and support: Extra Care, Fiona Gardens, Trafford
Choice and control: Personal health budgets, In Control, England
Homecare and Individual Service Funds (personalised homecare using a personal budget)

The increasing impact of dementia on people and services

The impact of living with dementia both for the individuals affected and their families and carers has been well publicised in the national media over recent months. Sadly, the diagnosis is often perceived to be life limiting by the individual, their families and carers, and practitioners involved in providing service and support. Given some of the limitations around existing service provision, compounded by some of the taboos associated with dementia (often as a result of a lack of awareness), the negative reaction to a diagnosis is not surprising.

As a consequence, the diagnosis of dementia often leads to significant stress for both the individual and their families. The all too frequent perception is that the quality of life will be extremely limited as a result of a diagnosis, with few options around accommodation, maintaining independence, treatment and the availability of care and support. There is often a withdrawal from the community or scheme where the individuals live. Many carers cope with undiagnosed dementia or the individual copes on their own, exhibiting increasingly risky behaviours in an inappropriate

residential setting. In addition, the combination of an inappropriate living environment, lack of truly integrated person-centred care and limited interaction with the wider community exacerbates the isolation further, often causing dementia to deteriorate rapidly.

The impact of dementia on health agencies and partners is hugely significant with over 250,000 people estimated to be living with dementia in the Greater Manchester region alone. With an increasingly ageing population this number is set to increase greatly.

Treatment is often focused at the clinical end of the treatment process with far less emphasis on early intervention and treating people living with dementia in a more holistic way. Shifting the emphasis from the reactive to a more preventative model requires a level of upfront investment, which may be difficult to justify in the current financial climate. However it is only by tailoring services to the individual, with an increased focus on living with dementia in a more positive way, that some of the current challenges can be met.

Put simply, it is recognised that current systems, processes and the ways of delivering services to those living with dementia often aren't working. Whilst this is clearly a matter of great concern, it also presents an opportunity for partners to consider potential innovations either delivered through traditional partners, through new ones (like Registered Housing Providers) who are playing an increasingly more prominent role in the world of health and social care, and in collaboration with third sector partners who will often have resources and expertise in this area.

Innovations to the current situation can be found in chapters:

Housing and support: Extra Care, Amblecote Gardens, Salford
Housing and support: breaks away from home, The Mede and Seaward House

People with a dementia living with inadequate support in high-rise blocks

City West Housing Trust has a concentration of older people living in their stock in the Eccles town centre. City West has one high-rise block that is let to customer's aged 18 and over. It also has 11 high-rise blocks within a confined geographical area, each containing between 56 and 84 properties that are let to customers aged 55 and over. Two of the 11 high-rise blocks are designated sheltered schemes, each containing 84 apartments, with on-site scheme managers and communal space including laundry, lounge, kitchen, and scooter store.

The age-banding of these high-rise blocks has resulted in significant numbers of older people living in high-rise properties, with many customers over 80 and living with dementia, particularly in the Eccles centre. There is a predominance of single-person households living in the high-rise stock and previous research established that there is a high incidence of family

breakdown with the customers living in these properties. Over the past five years City West has extensively invested in a regeneration programme, bringing the properties up to a high quality modern standard.

The visits that took place as part of the investment works and housing management work highlighted high numbers of vulnerable customers living in the high rise and sheltered stock in Eccles. There is a wide range of vulnerabilities including differing levels of mental health, high levels of alcohol dependence, high levels of loneliness and isolation, high levels of anxiety and depression, poor social connections, drug dependence, poor general health, high incidence of long-standing health conditions, poor mobility, poor diet and nutrition, low income and poor life skills leading to poor living conditions. There are a number of customers with a dementia diagnosis, but it is anticipated that there are many more customers living with dementia without a diagnosis.

Peoples' situation is compounded by a number of factors: longstanding low income, lack of family connections and support, poor general health, isolation in their homes, their mental health conditions not meeting the criteria for an assessed need for support, and reduced local authority care and support provision due to austerity cuts.

Innovations to the current situation can be found in the chapter:

Housing and support: health and wellbeing, Eccles

Discharge from hospital too often leads to a crisis move into a care home

People living with dementia are often offered the traditional default option of moving into a residential care home on discharge from hospital. This is frequently seen as the only viable financial option, mainly due to the fact that there is little understanding that people with a dementia can be supported to stay at home longer and that there are a number of options around housing with support besides a care home.

There appears to be a lack of focus on supporting independence, community connections and self-reliance when a person is referred for social care support on discharge from hospital. Consequently people with dementia feel swallowed up in services rather than living a life that makes sense in their community, and services are not as efficient and effective as they could be.

We hear stories of people with a dementia who have a fall or become sick, stay in hospital a long time and lose touch with their links in the community. Health and safety will often have dictated life in hospital, and people consequently become deskilled – perhaps no longer able even to make a cup of tea. The service systems often take control and the person is no longer at the centre of decision-making, in particular when it comes to risk issues. Reablement can really help here.

There appears to be a lack of specialist reablement teams assessing people living with dementia. Such teams could proactively support many people living with dementia and their carers and prevent avoidable crises, crises which would likely result in reactive, unnecessarily expensive service responses that would not be in the interests of the person involved or their families – such as immediate referral to residential care.

Related to this lack of specialist reablement teams assessing people with dementia is the fact that people who need support on discharge from hospital have to go through too many uncoordinated assessments. People tell us they are asked the same questions many times and have to meet a lot of professionals at a time when they are at their most vulnerable. People feel like they are on a conveyor belt and that carers are interested in their needs but not in who they are as a person, often because they are on a tight timescale to complete tasks in the allotted times. Why, in a civilised society, would we expect someone who has just come home from hospital to fare well with a 15-minute support call?

“All these different people tramping through my front door, I don’t know who they all are but they keep asking me the same things all the time. It’s so tiring,” says Joan, who receives support.

There is also a misunderstanding that assistive technology is about replacing people with machines, whereas in fact it supports a person’s independence in another way – it may be as simple as having a mobile phone, a sensor mat or an alarm pendant.

The government’s programme to transform social care services by offering personalised support means that people and their families should be offered choice and control in how they achieve outcomes, with support to exercise that control as needed and with much greater transparency of information. These principles should run throughout all services. Research suggests this isn’t happening as well for people living with dementia as it is for other groups of people.

Innovations to the current situation can be found in the chapter:

Housing and support: hospital to home, Reablement, Oldham

People with dementia are often excluded from communities, have low expectations, and few support options

Families who move into the new role of carer or who become recipients of care often describe themselves as like Alice – “it’s like falling into a whole new world which I didn’t know existed”. They feel they need to fit into this new world that they find is built in silos and entirely based on diagnosis. A [Mori survey](#) reported most people would not want to be moved into care homes but would prefer to stay at home for as long as possible. However, entering this strange world often makes common sense approaches almost impossible to attain.

The challenge of enabling people who receive support to live as independently or as interdependently as possible is a big issue for people living with dementia. For people and their carers this fitting into limited and traditional service provision comes at a cost, often to the whole family. Unhappiness with this kind of parallel world is not limited to people who experience it. Providers, support workers and commissioners also want to break open the silos. They are themselves frustrated by difficulties in achieving positive change and often feel they lack partners for such change amongst local people using public services: they are too often stuck in unproductive tensions and conflicts with the very people with whom they could co-operate.

While the term 'co-production' is now common within the care services field, people still often don't feel listened to, don't feel they have the right information, and don't know the jargon they need to get the best options for themselves or people they support. This also makes it harder to develop more creative community asset-based solutions, but what can we do about this?

The Prime Minister's Challenge on Dementia launched in March 2012⁸ rightly emphasises the importance of ensuring that 'people with dementia, their carers and their families can be active citizens with the potential to live well with dementia at every stage of the condition'.

However, this ambition sits within a public policy context where the focus has traditionally (and understandably) been on the need to improve health and care services for people with dementia. Whilst the Dementia Friendly Communities initiative clearly recognises the need for community inclusion, there has perhaps been less emphasis on the need to sustain people with dementia in making positive contributions to their communities, or looking for new opportunities to do this while they are still able to. Perhaps all too often, people with dementia are seen as passive recipients of care and not as active citizens, with skills, assets and the desire to play a part in community life.

Being able to make a positive contribution through giving back to others is increasingly recognised as a key means of promoting and maintaining wellbeing [NEF, Five Ways to Wellbeing]⁹ for all citizens, regardless of age or health status. However, an Alzheimer's Society report (2013)¹⁰ highlighted that 66% of people with dementia felt they could not make a contribution.

Innovations to the current situation can be found in chapters:

Good days: outdoor activities, Dementia Adventure, UK-wide
Connecting people: friend, family and community support, Partners in Policymaking
Connecting people: Circles of Support, England
Connecting People: Transforming Community Based Support for People with Dementia
Connecting People: Supported Volunteering, Volunteering Matters

There are few local, small-scale services for people with dementia

The national health and wellbeing partnership, Think Local Act Personal says, “Small-scale voluntary and independent sector ‘micro providers’ and social enterprises can offer community-based, affordable and niche support to individuals or small groups”.

A key problem in transforming community support for people with dementia is the current lack of choice of local, small-scale support and services for people with dementia and their families. This is highlighted by the Alzheimer’s Society, which says “The market is not yet fully developed to deliver a range of different types of dementia services”.

The Alzheimer’s society report goes on to say that where people have access to a personal budget there may not be the services available to meet their needs, or the options may not deliver the personalised, flexible care and support that is needed.

Many older people using personal budgets, including people with dementia, still have them managed by their council. However, when the National Institute for Health Research (NIHR) looked at how personal budgets worked it found that older people most value “having a small team of carers during the week; close relationships they were able to develop which allowed them the flexibility to request [or workers to offer] extra off care plan tasks.” All too often these council contracts with community-based support providers restrict creativity and make it more difficult to deliver that flexible care and support which people with dementia so need.

Innovations to the current situation can be found in chapters:

Connecting People: Transforming Community-Based Support for People with Dementia, Community Catalysts, UK

Connecting People: Transforming Community Based Support for People with Dementia

In the next section of this book we look at a wide range of innovations relating to housing and support. We start with the Shared Lives scheme, where older people with dementia live with or visit their Shared Lives carer, receiving appropriate care and taking an active role in the carer’s community.

- ¹ <http://www.helensandersonassociates.co.uk/>
- ² <http://www.campaigntoendloneliness.org/loneliness-research/>
- ³ Ageing alone: Loneliness and the 'Oldest Old', Kempton, J. & Tomlin, S. Centre Forum April 2014
- ⁴ Holt-Lunstad J, TB, Layton JB. 2010. Social relationships and mortality risk: a meta-analytic review. PLoS Medicine 7 [7]
- ⁵ Wilson RS, Krueger KR, Arnold SE, Schneider JA, Kelly JF, Barnes LL, et al. (2007). Loneliness and risk of Alzheimer disease. Archives of General Psychiatry 64[2] <http://www.ncbi.nlm.nih.gov/pubmed/17283291>
- ⁶ The Alzheimer's Society (2013) Dementia 2013: The Hidden Voice of Loneliness
- ⁷ Involving older age: the route to twenty-first century wellbeing, Shaping our Age partnership, June 2013: http://www.royalvoluntaryservice.org.uk/Uploads/Documents/SoA_Closingprojectreport_final_web_v2.pdf
- ⁸ Department of Health (2012) The Prime Minister's Challenge on Dementia – delivering major improvements in dementia care and research by 2015, London, Department of Health
- ⁹ New Economics Foundation Five Ways To Wellbeing <http://www.neweconomics.org/projects/entry/five-ways-to-wellbeing>
- ¹⁰ Dementia 2013; The Hidden Voice of Loneliness The Alzheimer's Society (2013)

HOUSING AND SUPPORT



HOUSING AND SUPPORT: SHARED LIVES, UK-WIDE

Current situation: many older people are isolated and lonely

Many older people live alone, with a diminishing social circle as friends become frail, ill, or die, and as it becomes harder for them to get out and about. If they have no family or their family plays little part in their life, they may see no one from week to week. If an older person develops dementia, their isolation is likely only to increase.

This can lead not only to older people with dementia feeling isolated, but also to them feeling unable to contribute to friendships and communities.

The innovation: Shared Lives

In Shared Lives, an adult (and sometimes a 16/17-year-old) who needs support and/or accommodation moves in with or regularly visits an approved Shared Lives carer, after they have been matched for compatibility. Together, they share family and community life. Half of the 12,000 people using Shared Lives are living with their Shared Lives carer as part of a supportive household; half visit their Shared Lives carer for day support or overnight breaks. Shared Lives is also used as a stepping-stone for someone to get their own place. The outcomes can be startling, with people reporting feeling settled, valued and like they belong for the first time in their lives. They make friends and get involved in clubs, activities and volunteering.

“outcomes can be startling”

Shared Lives remains a little known form of social care that has been mostly used for people with learning difficulties and mental health issues. There are 121 registered Shared Lives schemes across England, of which 119 are members of Shared Lives Plus. The schemes have approved nearly 8,000 Shared Lives carers.

In response to a 2014 survey of Shared Lives schemes, schemes in England reported they offered services to some 1,600 people aged 65 and over. Many of those are older people with learning disabilities but over 300 came to a Shared Lives scheme primarily for dementia support. There are already some well-established older people support schemes. Shared Lives schemes in Moray in Scotland and in the South West of England provide substantial services for older people and those living with dementia, and have demonstrated what can be achieved using the Shared Lives model for these groups of people.

Shared Lives is delivered only by Shared Lives carers who are assessed and currently approved by a registered Shared Lives scheme. It always involves the Shared Lives carer sharing their home and their family (or community) life with the person using Shared Lives, and it is arranged and monitored by

the local scheme. Shared Lives which involves personal care is a regulated form of social care, further defined by the regulators of each home nation.

Shared Lives may include:

- **Longer term accommodation and support.**
- **Short breaks or other time limited live-in support such as intermediate care.**
- **Daytime support involving the Shared Lives carer sharing their home and family (and/or community).**

No more than three people are accommodated or supported at any one time by a Shared Lives carer; the Scottish care regulator and some schemes elsewhere in the UK further limit the number supported to two. This is to ensure that the household feels like an ordinary family home rather than a care service. Shared Lives arrangements always involve the following processes:

- **Matching: Shared Lives arrangements are formed using a matching process. The process involves participants getting to know each other at their own pace, before making any commitment to sharing their home and family (and/or community) life.**
- **Monitoring and safeguarding by the Shared Lives scheme: the registered manager of the Shared Lives scheme remains ultimately responsible for the quality and safety of care and support in every Shared Lives arrangement.**
- **Self-employment: Shared Lives carers are self-employed and can access the Shared Lives tax break. Shared Lives carers are not paid by the hour and do not work to a fixed schedule but are paid in line with the expectations set out in a Shared Lives arrangement agreement.**
- **Shared Lives carers are under no obligation to agree to any care and support arrangement offered.**
- **Shared Lives carers do not employ staff to help them provide care.**

Shared Lives is unique in adult care and support in that it combines paid and regulated personal care provision with an equal focus on friendship, family life and being part of the community. Typically, those areas of support are seen as separate realms with social care services providing personal care on a paid-by-the-hour basis, from professionals who work within tight time constraints and strict professional boundaries, providing a set list of support tasks for their 'clients' or 'customers'. Care managers see it as acceptable and indeed inevitable that older people may spend long periods of time on their own, either at home between twice daily support visits of as little as 15 minutes, or in a care or nursing home whilst staff attend to others. Where people are offered support with staying connected to others and feeling a part of their family and community, it is usually done through voluntary sector action, often provided by volunteers as part of insecurely grant-funded local charities.

In contrast, Shared Lives carers are paid, vetted and trained professionals, approved to work under contract to their local CQC-registered scheme. But they are not paid by the hour and contribute much which is unpaid, also encouraging their family, friends and neighbours to provide unpaid companionship, friendship and informal support. So Shared Lives can often result in added value through the unpaid contributions from the Shared Lives carer's family and friends. As one Shared Lives carer said at a recent event, *"My kids pop in on the lady I support on their way home from school."*

This becomes possible because of the matching process at the heart of Shared Lives, which ensures that all participants wish to spend time with each other, rather than individual 'clients' being allotted by managers to available staff. Typically an individual will receive all of their support from a single individual and their family, which contrasts sharply with many services that employ staff on a rota that can be subject to high staff turnover and use of agency staff.

What do Shared Lives schemes cost?

Shared Lives schemes are not expensive to set up, need very little capital and as Shared Lives carers are self-employed, they are only paid when they are actually working for the scheme. In general the main resource elements and payments that make up a Shared Lives scheme are:

The payment to a long-term Shared Lives carer, which comprises:

- **An accommodation payment (from housing benefit).**
- **Payment for board and utilities (from the person's benefits), typically: £40 p.w.**
- **Payment for care (from the social care budget), £150-450pw, on average, £240 p.w.**

The payment to a Shared Lives carer for a short break is calculated on a 24-hour rate that doesn't include rent, and for day support it is based on an agreed daily or hourly rate.

The cost of a Shared Lives service to a council comprises:

- **Payments to carers for care, including cost of 28 days' (minimum) breaks (less any contribution under Fairer Charging).**
- **Cost of any day services/support.**
- **Scheme costs (ranging from £90-£125 p.w. excluding wages), including:**
 - One coordinator per 25 long-term arrangements (more if providing short breaks).
 - Recruiting, vetting, training, approving, supporting carers.
 - Marketing, overheads, etc.

Shared Lives carers are self-employed and get a tax break for using their own homes. This applies to short breaks as well as live-in arrangements.

How is Shared Lives being used with people living with dementia at the moment?

In the report “What Next for Shared Lives?”, Nadia Brookes says, “Shared Lives promotes social inclusion, integration into communities, gives consistency of people and place and allows the continued use of life skills.”

Shared Lives provides highly personalised arrangements where decisions about support and care are made in partnership with the service user and their family, with participants often describing a sense of partnership between the two families, rather than just the two individuals. The highly personalised approach also ensures that wherever possible the service user and the Shared Lives carer share the same interests and the Shared Lives carer can support the service user to pursue their hobbies and interests and help them remain part of the community. In a recent survey that asked 500 Shared Lives users what they had done for the first time, over 90 per cent said they had made at least one new friend and 34 per cent had made five or more new friends.

To achieve this balance of safe and effective care coupled with support that enables older people and their family to make and maintain friendships and community connections, good Shared Lives provision for older people is characterised by the following qualities and practices:

- **Schemes recruit Shared Lives carers specifically to work with older people.**
- **The matching process takes into account service users’ wishes on where they want to live and the type of household they want to live in.**
- **As in any Shared Lives arrangement, the Shared Lives carers and individual get to know each other gradually and have to feel there is a ‘match’.**
- **The older person visits the Shared Lives carer for day support or overnight breaks.**
- **The Shared Lives carer uses their home as a base, going out into the community as the individual wishes. They may also visit the individual in their home.**
- **The Shared Lives carer’s family and friends get to know the older person. The older person may enjoy meeting the Shared Lives carer’s children or grandchildren for instance.**
- **The Shared Lives carer encourages the older person to meet new people, and to keep up with their existing interests and activities.**

One consistent finding from research and the experiences of Shared Lives schemes is that it is important to develop supportive relationships early on in someone’s dementia, to establish a familiar home-from-home for short breaks or day provision, reducing the confusion caused by new environments. The Shared Lives carer and their family need to become well known to the service user. When this happens support arrangements can last into the later stages of dementia, but early referral is not the norm,

partly due to low awareness amongst families and referral agencies, and partly because older people with low level support needs are not always deemed eligible for support.

Community Care magazine reported on dementia support using the Shared Lives model: "Celia is generosity itself. She and Roy get on like a house on fire," says Mary Willis of the relationship between her husband and their short breaks Shared Lives carer, Celia. "She includes Roy in everything the family do; he gets a front seat at the Highland shows they go to. Her husband is a good musician and Roy plays the African drums so there is a connection there. Celia takes him out a huge amount and he is treated like one of the family."

Daphne, who is aged 93 and has a personal budget, is a user of Shared Lives through a Shared Lives scheme in Lincolnshire called Adults Supporting Adults (ASA). A typical week for Daphne starts by using the At Home Day Resource, which is a weekly activity (10.00 am to 3.00 pm) where Daphne visits Julie, a Shared Lives carer, at her home. The two of them play games and enjoy a break from the norm.

When Daphne's family goes on holiday she is able to stay with Viv, a short breaks provider. This is a holiday in itself for Daphne, who wanted to stay over during her first meeting with Viv. Her lovely home and friendly cats won Daphne over immediately. These breaks throughout the year allow Daphne's daughter and son-in-law to visit their grandchildren, enjoy short holidays and catch up with personal affairs.

The family were able to meet providers to decide whether or not they, along with Daphne, were happy with the match provided by ASA. This gave them the peace of mind and gave Daphne independence and choice.

How does Shared Lives reduce isolation and loneliness in people living with dementia?

With National Institute for Health Research funding. In 2013-14 Kent University's PSSRU unit researched the costs, benefits and processes of Shared Lives for older people. [Their preliminary findings](#)¹¹ are that older service users and their family carers say that Shared Lives has made a positive difference to their lives, with the main benefits for older people being greater independence, the family setting, involvement in activities outside of the home and the reassurance of familiarity with Shared Lives carers. Two-thirds of family carers experienced increased rest and relaxation, with many saying that they were confident that the care was high quality. Half cited the importance of relationship-based care: "being made to feel part of a family gives me confidence and a feeling of being wanted and not alone."

Reciprocity

[JRF research](#)¹² into the wishes and needs of older people with high support needs found that older people, including those labelled 'frail elderly', not

only placed a high value on maintaining existing family relationships and friendships, but wished to make and contribute to new friendships. One of the least heard pleas of older people with high support needs may be “I feel useless”, perhaps because ensuring that someone is and feels useful to others is diametrically opposed to the aims of most services.

Government policies have started to explore the idea of reciprocity for people who require support. Whilst in 2007, *Putting People First* and related policy documents¹³ discussed the need to build ‘social capital’ mainly in terms of the contribution that volunteers and other community members could make to the care of vulnerable people, its successor, the Think Local, Act Personal partnership and the White Paper and subsequent Care Act have a stronger narrative around reciprocity in which community action includes the active citizenship and family life of people with support needs.

Funding

Shared Lives support helps older people and their families to live good lives whilst also reducing financial pressures upon public service budgets. Shared Lives has been demonstrated to be significantly cheaper than residential care for working age adults: it is on average **£26,000 a year cheaper**¹⁴ for people with learning disabilities and £8,000 per year for people with mental health problems.

Scheme costs for a live-in arrangement for an older person range from £150 to £300 per week, depending on their support needs. Individuals will then contribute an agreed amount towards food and utilities out of their personal benefits and towards rent, usually from housing benefit. Short breaks are usually £50 to £100 per 24-hour period. This is a little higher than the typical weekly rate because there is no rental contribution from the person taking the break, whereas this is part of the Shared Lives carer’s income when the person using Shared Lives lives in the household under a licence to occupy.

An illustrative cost comparison was carried out as part of Shared Lives South West and Innovations in Dementia’s national project on Shared Lives and dementia. The scheme in question was offering short breaks and respite to people with dementia:

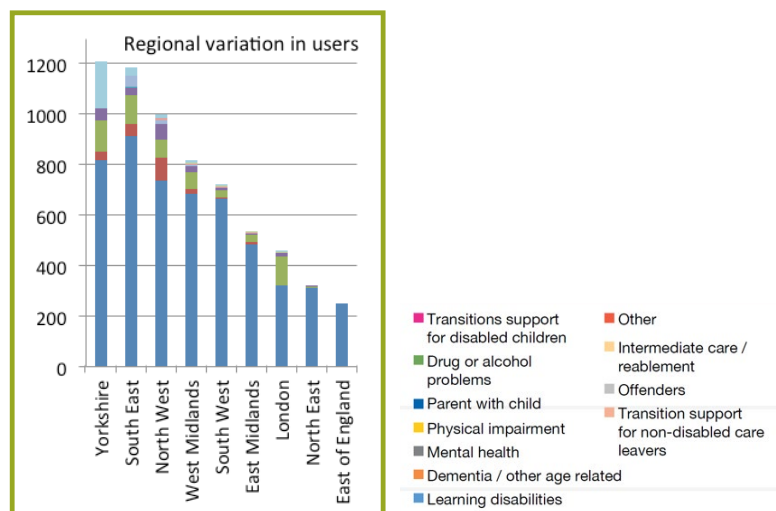
The Shared Lives scheme has a weekly charge of £450 per week. The total cost of a four-week respite stay would therefore be £1,800. An alternative four-week break in a care home specialising in dementia in the same area would cost £7,000 per week, which would be a total cost of £28,000.

If a local authority were purchasing this service from Shared Lives on behalf of the person with dementia and they made a residential respite charge of £70 per week to the service user, the total cost to the local authority would be £1,320. If the local authority imposed an upper limit on funding comparable with residential fees of £420 for dementia specialist care, the net cost to the local authority would be £1,400 and the service user would have to top up by £200.

If the person with dementia and their carer wanted to purchase this four-week break package directly from their own resources, Shared Lives would be £1,000 less expensive than the residential care.

[From the Final Report of the National Shared Lives and Dementia project 2010 – 2013]¹⁵

There is significant variation in the use of Shared Lives nationally, both overall and specifically as support for older people. The table below shows that Yorkshire and the South East make around five or six times as much use of Shared Lives as the North East and the East of England. Shared Lives is used mainly, or in some regions almost solely, for people with learning disabilities (dark blue), followed by people with mental health problems (green). Yorkshire and the Humber is the most significant region for Shared Lives as support for older people, where 30 per cent of around 1,200 Shared Lives arrangements are for over 65s, whilst in the North East, this is only 2.1 per cent of a total of around 300 Shared Lives arrangements. In Sheffield, 2 per cent of older people who receive any social care support are supported through Shared Lives arrangements; replicated across England this would result in Shared Lives reaching an additional 17,200 people.



From State of Shared Lives in England report, Shared Lives Plus 2014.

Where to go for more information

You can find your nearest Shared Lives scheme at:
<http://sharedlivesplus.org.uk>

Contact

info@SharedLivesPlus.org.uk
susan@SharedLivesPlus.org.uk
[older people's and family carer support lead]
T. 0151 227 3499

Shared Lives Plus offers membership to individual Shared Lives carers and to local Shared Lives schemes. Its sister organisation, Community Catalysts (www.CommunityCatalysts.co.uk) provides strategic support to commissioners and new provider organisations to develop the Shared Lives model.

Some reading that may be useful

'What next for Shared Lives? Family-based support as a potential option for older people 2013', Brookes N, Callaghan L, *Journal of Care Services Management* 7 3 87-94

'Good Practice: Time to Share scheme for dementia patients', Natalie Valios, *Community Care*, October 28, 2010

¹¹ 'Outcomes, processes and costs of Shared Lives' interim findings Kent University 2014: <http://sscr.nihr.ac.uk/PDF/ProjectOutlines/PO30.pdf>

¹² A BETTER LIFE - WHAT OLDER PEOPLE WITH HIGH SUPPORT NEEDS VALUE; JRF, November 2011: <http://www.jrf.org.uk/publications/older-people-high-support-needs-value>

¹³ Putting People First, HM Government, December 2007

¹⁴ Investing in Shared Lives Social Finance, July 2013

¹⁵ Final Report of the National Shared Lives and Dementia project 2010 – 2013, May 2013, Shared Lives South West and Innovations in Dementia: [http://sharedlivesw.org.uk/wp-content/uploads/2013/09/Final-report-FINAL-draft-for-printing.pdf](http://sharedlivessw.org.uk/wp-content/uploads/2013/09/Final-report-FINAL-draft-for-printing.pdf)

HOUSING AND SUPPORT: EXTRA CARE, SEAFARER'S WAY, SUNDERLAND

Current situation: most support for people with dementia is inflexible

Most traditional domiciliary care models are extremely inflexible: carers work to a strict timetable and the person receiving care has to fit in with this schedule. This doesn't reflect the reality of most people's daily lives, nor does it work well when someone has a condition such as dementia that means their need for support will change over time.

The innovation: extra care housing for adults with Alzheimer's or a dementia diagnosis

Seafarer's Way is a new-build 38-apartment dementia specialist extra care scheme in Hendon, Sunderland, built next to an existing listed building – The Old Orphanage – which has also been refurbished. The scheme was built by Inclusion Housing, a community interest company. Housing and Care 21 (H&C21) are the managing agent and care service provider. It has been designed to enable people with dementia to live independently in an extra care setting. There is a mix of one and two bedroom apartments, which are situated behind progressive privacy doors, ensuring residents' security.

Within each apartment there is a range of dementia-friendly equipment and adaptations (to the usual provisions in extra care):

- **Coloured toilet seats to enable identification.**
- **Open kitchen cupboards and shelves so that necessities can be visually identified and traced.**
- **Sockets and switches with coloured rocker switches to assist with visual identification.**
- **The “unnecessary” doors in each hallway (cupboards, etc.) have been painted in plain colours to match the walls whilst essential doors – bathroom, bedroom and living space – are wood panelled, with contrasting frames to aid visual identification.**
- **Ground floor apartments have French doors opening onto a secure garden with winding paths, raised beds and lots of visual connections to the rest of the scheme.**

Each resident is issued with a pendant detector and each apartment has a response system with a red cord should anyone need assistance.

Although there is limited telecare hardwired into the building there is potential within each apartment for the addition of telecare equipment, depending upon the needs and aspirations of each resident.

Within the communal areas of the scheme the spaces have been kept domestic in size and décor as far as possible, with a keen attention to detail in the colour scheme, fabrics and wallpaper designs to ensure they are as dementia capable as is possible. There is a participation kitchen within the main dining room so that residents can cook together with staff support if needed. There is also an exercise suite with adapted fitness equipment.

The artwork throughout the scheme is designed to be familiar and to prompt reminiscence, with many local scenes and old photographs from the 50s, 60s and 70s.

Social and participation opportunities and activities will be available within the range of shared communal areas on the ground floor and in the garden areas. Inclusion Housing will manage the housing scheme and H&C21 will provide the on-site care and support service, which will be on-site 24 hours a day, every day of the year.

“spaces have been kept domestic in size and décor”

The scheme is located close to local amenities and community facilities in Hendon. The front of the building will be for community use and will accommodate the East End Community Association, and H&C21 will provide a care shop to enable people in the wider local area to gain access to advice relating to care and support services.

Many local people have been employed to work as care staff in the scheme, ensuring that there is a real community involvement, and they are beginning to build a dementia-friendly community in Hendon.

Phase 3 of the work at Seafarer's Way will see the completion of Dovecote Meadow, which will be completed in March 2015 as part of the larger extra care scheme. Part of Phase 3 is a 17 apartment dementia specialist wing. The apartments are one bedroomed and open plan with lots of visual connection throughout the space to support orientation and familiarity. There is only one door in each apartment, which is the bathroom door. The wing is situated over two floors and each floor will have a small communal lounge and dining area to provide for social interaction. There is also a beautiful roof garden and a safely enclosed outside space to support activities and walking.

The wing is part of a much larger scheme at Seafarer's Way, which has 175 apartments in total, and whilst the 17 apartments will have some additional measures to ensure residents are safe and protected, the residents of the 17 dementia specialist apartments will be invited and welcome to join in with all social activities and communal facilities within the rest of the scheme – supporting ongoing meaningful citizenship.

H&C21 are building links with the Alzheimer's Society locally, who are relocating their day service to Dovecote Meadow whilst their own building is refurbished. H&C21 are also working with Age UK and their Essence

Service to support advanced planning, activities, inclusion and involvement for people with dementia.

Whilst H&C21 are developing specialist dementia-friendly apartments and schemes, it's important to remember that a large number of new and existing residents have some level of dementia or other cognitive impairment and therefore it is the behaviours and culture across the whole of Seafarer's Way which are so important in providing innovative dementia care.

There is a real focus within H&C21 on moving away from task and time and other institutionalised practice at Seafarer's Way. There is a culture of confidence and strong leadership that supports staff to be flexible.

This is a new model of working with Sunderland Council, which in itself is quite innovative because Seafarer's Way is not actually contracted with the local authority. The service provision agreed is for people to pay for the H&C21 service with an individual service fund. Some people move in with a social care assessment and a traditionally planned care package consisting of so many hours dependent on their needs, but Seafarer's can change the care package either to increase by two hours or decrease by two hours.

Without a formal contract, H&C21 and the local authority's partnership is based on trust built over years of working on the model together, and a shared vision and understanding of delivering personalised support. They have had to work hard with the monitoring systems they use to capture the flexible hours worked as they have shifted to this way of working – strong relationships and partnerships have made this approach possible.

How does Seafarer's Way work?

Flexibility is crucial to the success of this model. A domiciliary model is very traditional and inflexible, and it's the flexibility within the service at Seafarer's that makes the difference.

“Staff teams think differently here. If you go up and see Mrs Smith at 8.00 - because that's what time our breakfast call is planned - and she's not ready to have her breakfast, then you just go and provide the service to somebody else and pop back later at a time that's convenient for Mrs Smith.

If on a particular morning a resident doesn't eat their breakfast and a cup of tea in 15 minutes, that's absolutely fine: the staff member will spend a bit longer with them. H&C21 are looking to move away from task and time and flexibility is built into its ethos. Everybody who is in the scheme knows that if they specifically need us to call at a particular time of day for whatever reason, we will do our level best to get there.

People have the option of receiving as much or as little assistance as they need, in the knowledge that they are in a secure environment. People can choose to live independently in their own home. But if they want to be in a community setting and mix with others, or have more calls than they normally have, that option is there as well for them. H&C21 can therefore provide people with more support than they would receive if they were not living within the scheme, but still ensure an independent environment.

Promoting individual wellbeing is at the heart of our philosophy and has challenged both commissioners and H&C21 to look afresh at how we do things. This has led to the flexibility we can now offer in terms of funding the number of hours required by a person living at Seafarer's."

[Link to the Housing 21 pilot with the Kings Fund](#)

How does Seafarer's Way help people with dementia?

H&C21 provides a minimum of one person awake overnight on every scheme, and usually at least two. This means that whatever their needs, people are assisted to remain within their own home.

The extra care model is flexible in that it's not tied to specific times, and there's someone on call at all times for any potential issue.

People have the option of as much or as little assistance as they need, while knowing that they are in a secure environment.

The extra care scheme is community-focused, so it's not seen as a locked environment where only people with dementia live. People live in individual apartments, and people living with dementia use all the facilities and the wider services of the larger extra care scheme in the same building.

Often, if one member of a couple has dementia and has had to leave home and go to a residential care service, they become extremely distressed, and the carer is also further distressed. There are many examples of people that have been married for 60 years who have been separated. That won't happen within this model. People will still be able to live together with the relevant amount of support.

Where to go for more information

www.housingandcare21.co.uk

Contact

Victoria Barclay, Regional Director

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Claire Charlton, Locality Manager

Claire.charlton@housingandcare21.co.uk

HOUSING AND SUPPORT: EXTRA CARE, FIONA GARDENS, TRAFFORD

Current situation: a lack of personalised support at home for people with dementia

Many people with dementia receive a homecare package that has been determined for them by other people. The person who needs support is rarely enabled to make choices and decide the care they want, or to choose to receive care among other people, and this is especially the case when someone's needs become complex.

The innovation: an extra care scheme that includes people with and without dementia

Fiona Gardens is a new and different extra care scheme in Trafford. This innovation was created by a housing provider, Trafford Housing Trust (THT) and a social care provider, Imagine, Act and Succeed (IAS) and taken as a proposal to the local authority. Our two organisations shared common values and brought our expertise together to work as true partners.

We held a Visioning Day with all the key people. We brought learning from the sector but the main focus was on learning from what everyone was saying. The participants included people who had lived in extra care schemes, family members, housing providers, social care providers and the local authority. This was to ensure we set off in the right way by learning from real experiences. The day had a real sense of co-production. The day was captured and recorded with graphics and we produced a poster. We refer to this regularly and it helps us to hold ourselves to our vision.

This process allowed transparency about the purpose of Fiona Gardens from the start. Our focus was on THT being the housing provider and IAS the social care provider, working hand in hand to ensure people's wellbeing. People who were interested in moving in were absolutely clear about what they were signing up for: not just a nice apartment but an ethos of true community and long-term sustainable relationships.

IAS and THT created the "wellbeing charge", an innovation that relates to the funding of the care at Fiona Gardens. The Local Authority has welcomed the charge as it significantly reduces the cost to them and gives a greater quality of life to the people who live at Fiona Gardens. People moving in and their families, whether or not they have any care and support needs, see this as a positive in their new home. Even if a person does not need care, the wellbeing charge offers them security and the reassurance that they will have a home for life should they ever need care in the future.

The wellbeing charge funds part of the 24/7 on-site care provider. The role and expectations of the support team are key to making Fiona Gardens a great place to live. It was agreed there would be no staffroom and that when staff members were not providing individual support they would have a social presence. This was not to say they would always be on the go, but when having a break they would be in the restaurant or in the lounge having a drink and a chat with someone. This has helped build relationships and connect people.

The team at Fiona Gardens use the Five Ways to Wellbeing (www.neweconomics.org/publications/entry/five-ways-to-wellbeing-the-evidence) as evidence of improvements in people's health. We begin in the initial assessment period prior to a person moving in and identify the reasons why people need extra care and what is important to them. We review this to ensure we are maintaining and improving people's wellbeing.

We have planned dementia awareness sessions for people who live at Fiona Gardens who do not have dementia. These sessions have also been opened up to family members, staff who work at the restaurant and hairdressers. This is to help people to develop empathy and understanding so that they can interact positively and confidently with the people who have dementia around them.

Approaches we are using at Fiona Gardens¹⁶

Circles of Support (Community Circles)

We held an awareness session at Fiona Gardens and offered to support people to establish a Circle. This is taking off slowly and three people are now in the process of planning their Circles. We have Circle facilitators waiting to be matched up with people as more people take up this offer.

Progress for Providers

This tool helps providers to check their progress in delivering personalised support for people living with dementia. IAS and THT are working together using this tool and it helps us focus on the service as a whole rather than from just a housing or care and support perspective.

Reablement and Just Enough Support

Reablement means ensuring that people have the right support at the right time.

Dignity in Dying

We are currently planning training in relation to how we support people tactfully and appropriately with this. We will be using the Living well thinking tool.

One-page profiles¹⁷

All staff and people who have moved in to Fiona Gardens either have or are in the process of developing their one-page profiles. We were very conscious about how we introduced and explained these, but people have been happy to share information and have seen their benefits.

Working Together for Change

This is a structured approach to engagement with people using services to review their experiences and determine their priorities for change. We have agreed that we will use this process to bring people, families, staff, the local authority, and the community together and this will take place in January 2015. Co-production like this is at the core of our commitment to ongoing learning.

How does this approach work in practice?

The first people started to move in to Fiona Gardens in June 2014 and although lots of positive work has happened we will continue to learn and develop together.

One-page profiles⁸

When we helped Kathryn to develop her one-page profile it became apparent that she was not happy with her current care package as she felt she had no control over it. As a result she has now changed provider and has her support at times that suit her. Kathryn has a sensory impairment and her guide dog Isla is one of the most important things in her life. Kathryn chose her apartment based on this and Isla now has her own enclosed outdoor space.

Kathryn was extremely anxious when moving in to Fiona Gardens and was worried about how she can come across when she is feeling anxious. She was also worried about how other people would interact with Isla. Her one-page profile has this information included and she feels confident sharing this with people she lives with to help her to explain.

Effie is a lady who was clearly struggling when she moved in. This was due to her dementia and to her and her family not receiving the right support. We helped Effie to develop her one-page profile and supported her to share this with people that she was living with so that they could see who Effie is as a person and what is important to her. We carried out a wellbeing assessment with Effie and this highlighted the need for a [person-centred review](#).¹⁹ Her family were involved in this and are now in the process of setting up a care package and a Circle.

Encouraging people to develop and share their one-page profiles has had a real positive impact. It has helped people understand what people may be going through and the best way to respond. It also gives an insight to who someone is and what is important to them.

Wellbeing assessments

We supported a married couple when they moved in to look at how they could potentially benefit from the wellbeing charge. They did not have or currently need a care package, but the lady was in the early stages of dementia and her husband did not want to leave her for any length of time. He said he had not had any kind of life for the past year due to supporting his wife. He now has time to himself twice a week when he goes out and does not have to worry about his wife. He plans this with the staff who periodically check that his wife is ok and encourage her to get involved in anything that is going on that day.

How does the extra care scheme help people to receive more personalised support?

Fiona Gardens offers a number of people, who might otherwise be supported in isolation, an alternative. It can also be a resource-effective way of meeting high and complex needs while creating opportunities for building friendships and community.

The Commission on Residential Care [referenced earlier] said, “We share a common belief that great care can liberate people, enabling them to maintain, even regain, their sense of worth, purpose and connection. Housing with care can offer a life and laughter, fun and friendship.” We share this vision for Fiona Gardens.

One-page profiles,²⁰ wellbeing assessments, Community Circles, etc. are all contributing to helping people identify what good support looks like for them. These approaches help us plan training and awareness sessions for staff, families and people who live and work at Fiona Gardens and in the community, resulting in more empathy and understanding for people living with dementia. We develop a person-centred culture within our staff teams by ensuring we apply the principles of person-centred practices to them as well as to people living in the scheme. This results in a workforce who feel valued and have a shared vision with the leaders of the organisation.

“we tailor individual support to meet their needs”

Using person-centred tools and approaches helps us to see people as individuals – without this information their dementia is likely to be seen first.

Using Progress for Providers and focusing on the environment as well as the person helps us to ensure as much as possible that people have a home for life as their dementia progresses, because we tailor individual support to meet their needs.

We place a strong emphasis on the social aspect of our staff's role and how we can connect people. This has been invaluable in terms of building up positive relationships between people who move in, and their families, regardless of whether they have any care or support needs. We really believe that this has been key in creating the welcoming and positive atmosphere at Fiona Gardens that many people say they feel when they are here. We also know that many people can move in to extra care and find a beautiful environment but remain just as lonely or isolated. The team at Fiona Gardens are extremely conscious of this and work with people and their families to include and connect them in a way that feels ok for them.

The wellbeing charge significantly reduces the cost to the local authority but does not affect people's quality of life. We are able to provide what are traditionally referred to as “pop-ins”, but we are able to do this in a much more person-centred way. Having a 24/7 presence enables us to be flexible and the information people have shared with us helps us to know them and provide meaningful support when they need it.

Real partnership working between care provider, housing and health is key to the future success and wellbeing of people.

Where to go for more information

www.imagineactandsucceed.co.uk

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¹⁶ <http://www.helensandersonassociates.co.uk/>

<http://apple.co/1FdX7g9>

¹⁷ <http://www.helensandersonassociates.co.uk/>

¹⁸ <http://www.helensandersonassociates.co.uk/>

¹⁹ <http://www.helensandersonassociates.co.uk/>

²⁰ <http://www.helensandersonassociates.co.uk/>

HOUSING AND SUPPORT: EXTRA CARE, AMBLECOTE GARDENS, SALFORD

Current situation: the increasing impact of dementia on people and communities

Services for people with dementia often focus on immediate care needs but pay little attention to people's desire to stay active, engaged and healthy within their community.

In addition, formal care services for people with dementia are frequently provided apart from other resources so that people with dementia become disconnected from the wider world, and the people around them see them as somehow separate and no longer part of their community.

The innovation: extra care schemes for people with higher support needs. In this dedicated co-funded scheme staff focus on service coordination, signposting, inter-agency liaison and reducing loneliness and isolation.

City West Housing Trust is developing its service for older people with higher support needs on our extra care schemes, based on two key principles:

- **Providing a high quality living environment with excellent care and facilities based on an intentional communities principle, whereby the new scheme at Amblecote Gardens (AG) is integrated with the wider community, and can draw on support from that community and is also used by the community. It is worth noting that our new 66-unit scheme is based within an area that is also subject to significant regeneration with 78 new units now completed, bringing much needed housing and investment to the area.**
- **Complementing the high quality accommodation, we have developed and are delivering a more integrated and person-focussed model of service on the new scheme through dedicated staff employed by City West who work on the scheme alongside the site care provider, colleagues from the Council and other agencies.**

These specialist staff [Scheme Coordinator and Scheme Officer] are employed directly by City West but have been jointly funded by City West and the Council's Supporting People Fund, which has contributed £25k per annum at a time when Supporting People budgets are being dramatically reduced. We see this contribution as a significant commitment to the new roles and wider partnership working around Extra Care in Salford. The primary focus of these posts is on promoting the integration of the individual within the scheme and the wider community, and by doing

so, reducing loneliness and isolation. Creating the posts ensures a more prominent and proactive role for City West in our role as landlord on the scheme compared to previous models on Extra Care schemes.

The role of the Scheme Officer has been developed by the Senior Managers within our Independent Living Service (ILS.) The Scheme Officer oversees service delivery in relation to older people as well as leading our work on safeguarding vulnerable adults and the operational delivery of our action plan to increase awareness of dementia amongst our staff, customers and wider communities within West Salford.

Work to develop the role has been undertaken collaboratively with Salford City Council's Adult Commissioning Teams. Given the joint funding arrangements, this post is in effect a partnership role, which joins up commissioning and delivery effectively with intended benefits to our "shared" service users who previously have often been treated separately by partners.

We are hugely excited by the new role as we believe it presents an opportunity to deliver services and activities to customers who have a dementia in a different way, with an emphasis on reducing loneliness and isolation and actively engaging the wider community. It is anticipated that one of the main intended benefits will be significant improvements to the quality of life for individuals living on the scheme (and their families and carers).

We are developing some measures through which we measure life satisfaction of both service users and their families and carers as a result of their interactions with the service whilst living in Amblecote Gardens.

How does this approach work in practice?

Amblecote Gardens in Little Hulton has an excellent range of facilities including a café offering a freshly prepared two course lunch each day, assisted bathing provision, a hairdressing salon, social activities (coffee mornings, quizzes, healthy hips and hearts session, gardening club, chess club, bingo, etc.) as well as visiting health initiatives such as flu jabs. The scheme has large gardens and a generous communal lounge.

At Amblecote Gardens, which opened in September, there are 66 units of self-contained accommodation. People referred for Amblecote Gardens by the Adult and Social Care team from Salford City Council must have an assessed support need and usually have a care need. We aspire to have a mixture of people with high, medium and low needs once the scheme is fully occupied. A significant number of the customers for Amblecote have dementia or a moderate mental health issue. Salford CC co-funds two posts at Amblecote; one being focused entirely on building social opportunities, events and activities for customers.

The importance of food at Amblecote Gardens

The facilities at Amblecote Gardens, in particular the food, could be offered to other customers in the community, with people either coming into the café or having a meal delivered to their home. The catering provider at

Amblecote Gardens could use the facilities there to offer food that could be delivered at our sheltered schemes nearby, or be served at the existing luncheon club, providing better food for a more affordable charge.

Improved diet and nutrition supports better health across the board. The catering provider at Amblecote Gardens celebrates all occasions – Easter, Mother’s Day, Halloween, sporting events like the Olympics or Wimbledon. This helps isolated customers engage with the calendar, know what is going on in the wider world outside the scheme and interact socially with their neighbours and family. The food at Amblecote has already promoted social interaction, with customers all coming down for their lunchtime meal between 12 and 2, usually sitting up to four at a table and chatting over their lunch. Family members have also joined their relative for lunch, offering an opportunity to chat and share a meal, something they had not done for a long time.

The catering provider, along with the scheme coordinator, engage the customers both in menu planning for the four-week cycle of menus and individually in their meal selections, establishing the customer’s likes and dislikes and involving them in what they will be eating over the coming month.

Case study: Mr and Ms Brown

Mr and Mrs Brown, a couple in their eighties, moved into Amblecote from a larger City West property a few miles away. As a couple they were very insular at their previous property and did not take the meal provision, mix with their neighbours or attend any of the social activities. They were very resistant to moving to the new extra care scheme and did not feel they needed the additional support.

At the point of moving Mr Brown was in hospital as he has a number of serious conditions including cancer. Mrs Brown was fully supported in packing up and moving across to the new scheme. They had both amassed a large amount of belongings and staff assisted her in packing and labelling the boxes. Staff also committed to helping Mrs Brown go through a box per week to clear some of the belongings. Mrs Brown was supported in getting to know the scheme and encouraged to come down to the café for her lunchtime meal, sitting and mixing with her neighbours, which she seemed to really enjoy.

Mr Brown has since been discharged from hospital, has joined his wife in taking the lunchtime meal, is mixing more with his neighbours and has started to spend some time each day in the communal lounge. They are both eating well and mixing more than they did previously. Mr and Mrs Brown have now been assessed as having a care need due to their failing health, and are happy to receive this in the new setting at Amblecote Gardens. Their son has said he feels reassured that they are eating well, securely housed and enjoying the support of extra care housing.

Other facilities at Amblecote Gardens

The assisted bathing and hairdressing facility can be offered to customers nearby, for a charge, and the customer can come into the scheme with their carer and enjoy a bath, a visit to the hairdresser and even stay for lunch.

The regular activities that take place can be extended to include older and vulnerable customers living nearby. The member of staff with responsibility for social activities will be tasked with contacting social workers and establishing customers aged over 55 locally who would benefit from being able to use the facilities at Amblecote. The Alzheimer's Society could be invited to host coffee mornings or other activities on-site to bring customers living nearby with dementia and their carers into the scheme. Local church groups have been contacted to come and visit the scheme and potentially signpost some of their regular attendees to the facilities at Amblecote.

The gardening space at Amblecote is a great facility and could be used by other volunteer groups to develop a grow-your-own scheme, encouraging City West customers to be involved to a level they can manage. The catering provider is keen to support this scheme and to use locally produced vegetables in its meals. The garden space could also be used to provide a link with local schools, with children and customers working to plant up some of the garden planters.

Long-term outcomes

We will capture the numbers of individuals whose conditions stabilise and whose support packages can be maintained at low or medium need (or high need but still able to maintain independence on the scheme without the need for residential care or hospitalisation).

We will also measure reductions to hospital admissions and an increase in tenancy sustainment once customers move into Amblecote Gardens. Through the last measure, we can demonstrate the positive impact of providing a physical environment and services that enable people to live independently for as long as possible with the consequential benefits of keeping customers out of costly residential care and/or hospital settings.

How is the service being developed?

Working alongside the Scheme Coordinator, the on-site care provider, individual carers and the full range of other support providers, the main remit of the Scheme Officer role is to organise and develop activities and opportunities for social interaction for customers residing on the scheme. By doing so it is hoped that mental wellbeing will be maintained or improved as a result of loneliness and isolation being reduced and as a result of better coordination of service provision.

How is Extra Care living more effective than existing services?

Amblecote Gardens has already had a positive impact on customers' health. It is anticipated that some customers coming in with assessed high needs will be reassessed as medium in the short term due to them eating better, being able to get around their property and bathe without requiring assistance, increased social interaction, opportunities for light exercise and/or activities that stimulate them.

If we further develop the range of activities we offer to encourage the widest range of customers to get involved, our service will benefit a larger number of people and create a vibrant environment at Amblecote Gardens. We are encouraging organisations such as Alzheimer's Society, Age UK, Singing for the Brain and other specialist groups to bring their activities and their customers on-site, to both promote an understanding and greater awareness of customers living with dementia and provide a positive environment for their carers to enjoy. Extending our activities will also allow us to offer a service to customers with dementia living in the community.

We will explore the potential for offering similar food and other services out of some of our other sheltered and extra care scheme facilities. Possibly such services could be delivered by a local social enterprise.

The new role and services delivered by the Scheme Officer alongside a range of partners will reduce the loneliness and isolation of people living with dementia in the extra care setting. There is significant potential for the services and activities to be offered to the wider community, so that those living in the wider community who may be living with dementia may also benefit.

We anticipate that by establishing a dedicated role responsible for social activities and wider community integration, the wellbeing of people living with dementia will be improved. As well as reducing the pressure on families and carers, we will be able to mitigate the rapid onset and deterioration of conditions that occur when people are isolated and excluded.

By aligning the role of the Scheme Officer to the provision of care and support, as well as significantly improving the quality of life of those people living with dementia, we aim to support individuals to live independently in Extra Care settings for as long as possible.

With our ability both to reduce the burden at the acute end of dementia care by having a more effective preventative focus, and to increase levels of support as need increases, we can potentially not only transform the lives of individuals for the better but also reduce the strain on health and social care budgets.

Where to go for more information

<http://www.citywesthousingtrust.org.uk/case-study/amblecote-gardens>

Contact

Margaret Madden, Head of Independent Living

T. 0161 605 7751

Lorri Holding, Independent Living Service Lead

T. 0161 605 7829

Margaret and Lorri are lead officers for the development and ongoing delivery of the range of services at Amblecote Gardens. They will be happy to provide any further information and will also be able to provide relevant documentation as required.

In addition the scheme has attracted significant publicity from local media following a high profile launch event where the scheme was opened by Andy Burnham MP, the Shadow Minister for Health.

HOUSING AND SUPPORT: HOMES WITH SUPPORT, BELONG, WARRINGTON

Current situation: care and support services are impersonal and inflexible

Belong's services have evolved to offer an alternative to traditional models of care and support and better meet the needs or desires of people living with dementia and their carers. Specifically, Belong set out to reverse a situation where the person with dementia is presented as the problem and looked instead at the way systems are set up and what's available being the problem.

The innovation: mixed housing and support for life

Belong is an organisation founded on a vision that older people and those living with dementia have the right to enjoy the same community belonging and richness of experience that they have always known. Belong's ambition is to offer a radically different alternative to the host of support available.

When the Belong model was being developed, the organisation went out to stakeholders and did some market research with social workers, older people and traditional care home customers. What were their desires and aspirations for an older age? And if they needed to live in care or support to live their lives, Belong asked, "What would you still want and what would be important to you?" Their answers informed how Belong moved forward with the vision.

As a result, Belong has a strong set of values that underpin how it works. A sense of belonging is central to the vision of Belong. It wants people to feel at home in the villages, with all the security, contentment and fulfilment that the word 'home' signifies.

Belong villages are places where privacy and community go hand-in-hand, offering intimate and natural settings where people can build meaningful and long-term relationships with other residents, employees and visitors. By opening facilities to the wider community, Belong villages welcome all age groups, creating a place where children can play, families can unwind and people living with dementia receive the support and respect that they deserve.

The Belong lifestyle is a proactive choice – people may want support, variety or independence. People can be secure in the knowledge that staff are always nearby to assist with any arising needs, but people are free to pursue hobbies and interests. Every decision at Belong is made in

partnership with people using the service, a relationship that is at the core of their philosophy.

Belong also provides support to relatives as their loved one's dementia progresses, and offers access to dementia training workshops for those who are interested in understanding more about supporting people with dementia.

Belong villages offer four key services that cater for a range of support needs, from minimal to continuous:

- **Apartments which can be bought or rented and where people continue to live independently.**
- **Households offering 24-hour care for people who are living with dementia or older people who need some degree of personal or nursing care: at Belong Warrington 70 per cent of people living in the households have dementia.**
- **A village centre with a range of facilities open to the public, and where a specialist day support service is provided – known as Belong Experience Days.**
- **The Belong at Home domiciliary care, which is also used in the wider community to support people in their own homes.**

Some people live in the apartments and don't need any support; some people receive support in their apartments and Belong also provides support to people living in their own homes in the wider community.

People living in the Belong apartments may receive some respite care or if a person's support needs increase, they may then move in to one of the six 12-person households at Belong Warrington. The availability of both households and independent living apartments in one complex is often attractive to married couples who have different levels of support needs. It is often preferred to alternatives where both must live in residential care or struggle to cope at home with care packages.

How is Belong's approach being used with people living with dementia at the moment?

The Belong village at Warrington has 18 apartments where people can live entirely independently. This allows people to plan for a time when they may begin to need some help. For example, they may initially choose some very simple help from the bistro to make sure they have a hot meal every day, or ask for maintenance on their home: living in the Belong village means they have someone to turn to for support.

People living in the Belong village can buy a Belong at Home service, where Belong staff go into their apartments to provide support. The Belong at Home staff also go out to support people living with dementia in the wider community.

Quite often people are then tempted to join in with the Experience Days, our daytime service. There is a vibrant activities and events programme, which is promoted to Belong customers as well as people living in the community. We design Experience Day activities to match interests of the group of people taking part. Experience days are supported and chargeable.

The Experience Days enable people to use the village facilities and to make friends, with the support of Belong staff members as necessary. In the main, Experience Days run between 9.00am and 4.00pm Monday to Friday, and there is the flexibility to provide weekend and evening support if the demand is there.

People who attend the Experience Days might choose to have coffee in the bistro. Friendships are often made there, people arrange to meet, and they may then choose to join in one of the activities together. With our Experience Days we aim to reach out to people at home or their carer who is wondering what else is out there. Alzheimer's groups also pass on information about what is available to people and their carers on behalf of Belong.

A number of customers who have full capacity and have gone on to move into Maple Court [Belong apartments] have certainly found the transition very easy. They have been able to make an informed decision about their future care and have found visiting the village through Experience Days has given them an opportunity to make friends and 'try before they buy' so to speak.

One person who used Experience Days enjoyed them very much and increased the number of days he came along; he also had a respite stay. Due to an emergency situation that left his wife unable to care for him, he moved in to the village. This worked very well because he was as familiar with Belong staff as they were with him, so they could support and reassure him at this very stressful time. Belong was his home for two years until his death.

Most Experience Days customers use the service for between 12 and 18 months. They tend to start with one or two days then increase them, and some have respite stays as well. A number of people then move into the households and their familiarity with the environment and staff at the Belong village eases the stress of their move. There is also a carers' support group that was set up to support family members during the difficult time when their loved one moves out of their family home into the residential service.

All Belong village members have access to an exercise studio specially equipped to meet the exercise and activity needs of older people, including those living with dementia. A qualified fitness instructor designs personalised training programmes to improve mobility and wellbeing, working in conjunction with other health professionals where appropriate. Scope also exists for Belong staff to support rehabilitation programmes, helping restore confidence and independence to residents wherever

“there is a vibrant activities and events programme”

possible. People from the wider community can pay by the session to use the gym, or they may buy a membership.

Belong as an organisation is clear that the people it employs are key to making the difference. It invests in [person-centred approaches](#)²¹ to training, is an Investor in People and has a Practice Development Facilitator at every village, who acts as a coach and mentor to staff working on the households.

The household model is relatively intimate, with a ratio of one to four most of the time and this encourages positive relationships, where residents are well known to the staff supporting them. The open plan design of the households also enables staff to observe people in an unobtrusive fashion. As far as possible, people living and working in households are matched based on personalities, backgrounds and experiences. Each household tends to develop its own culture and atmosphere reflecting this. The idea is to create a home for the people living there and a sense of second home for staff and carers who visit.

Tracy Paine, Belong Operations Director, is involved with the Housing Dementia Research Consortium. Belong would like to participate in some research to look in particular at hospital admissions, prescribing of antipsychotics and to examine the impact of exercise programmes on wellbeing, mobility and fitness, as well as outcomes such as reduction in falls and the use of hoists and wheelchairs.

How does Belong provide personalised care and support for people living with all stages of dementia?

Belong can provide support right through a person's journey from diagnosis of dementia through to end of life. This is a home for life and there are very few places that people living with dementia and their carers can go and know this. Belong makes clear its intention to continue to be there for people regardless of how advanced their dementia may be.

Through the apartments, Belong offers housing to people with a dementia [or not] who are presently not needing support, though experience suggests that it's rare that somebody will move in without having done some thinking about the future.

People moving into Belong Warrington can get information and advice, and there are options for support during the day via our Experience Days. We offer support for people living at home in the community, and this service does not undertake calls under 30 minutes in duration. We also offer respite stays and residential support in our households.

There are also options that help people living with dementia and their families to remain connected and close to each other within the Belong village. For example, even where a person is in the later stages of their dementia, their spouse can continue to live in the apartment if the person with a dementia moves into a household.

We can therefore deliver personalised support to people from diagnosis right through to end of life, and have moved away from the fragmented service systems we see generally in this country.

Having choices and options to support people in living an ordinary life offers recognition that people can live well with dementia, that life still goes on, and this appears to provide comfort and wellbeing to people.

Belong supports people who have been around the system, in and out of hospitals, and in and out of assessment centres, because there appears to be little support available for people who are still very active in their dementia. Belong's facilities enable people to remain active in its gardens, gyms, bistro, and exercise classes, and this helps us to provide solutions by learning what works for each person.

Living in a Belong community addresses many older people's experience of loneliness and isolation because we look to build friendships, and together, the services we provide enable us to create a vibrant hub at the heart of the community, and a continuum of services that gives people consistency and familiarity through their journey.

The core of the village is open to the public, and openly promoted to the local community, our aim being to have a vibrant community that all sorts of people of all ages enjoy coming to. This in turn means those who live in the village continue to feel very much part of the community.

Where to go for more information

www.belong.org.uk
www.pozzoni.co.uk

Contact

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²¹ <http://www.helensandersonassociates.co.uk/>

HOUSING AND SUPPORT: ENHANCED HEALTHCARE, COALFIELDS PROJECT, SUNDERLAND

Current situation: poor access to healthcare for people living with dementia

The Coalfields project is a response to British Geriatrics Society research that suggests people living with dementia in extra care and in care homes have poor access to quality healthcare, and poor health outcomes.

The innovation: the Coalfields enhanced healthcare project

The Coalfields project [Coalfields is an area within Sunderland] came from the findings of research carried out by British Geriatrics Society and is led and funded by Sunderland Clinical Commissioning Group.

The Coalfields project aims to provide enhanced care centred on primary care. We use a multidisciplinary approach bringing together the GP, therapy inputs, podiatry, a community geriatrician from the city hospitals, community nurses from the South Tyneside Foundation Trust, alongside some pharmacy support.

The Coalfields project covers 13 local care homes and an extra care scheme, Bramble Hollow, which has 50 apartments with 48 people living there, including a number of people who are living with dementia. This number is increasing, because more and more people move in without a diagnosis of dementia, but go on to develop a dementia.

The GP provides one or two sessions a week (a session being four hours of care) at Bramble Hollow. They carry out preventative care rather than the acute care GPs more often provide, which is why it is termed “enhanced care”.

Health professionals work collaboratively with the patient and their family, developing and putting emergency healthcare plans in place. The GP reviews medications, and the pharmacist follows up as well to check that people are on the right types of medications, and to assess if there are any improvements to be made.

We have a focus on getting to know people and their families, and on seeing what kinds of self-care plans are in place and how they can be improved.

If somebody is admitted to hospital, the GP reviews what happened to cause that hospital admission and how it might be prevented from happening again. The GP will then follow up and review those patients.

Similarly, if there's a death, the GP reviews it and makes a judgment about whether the person died without unnecessary pain or distress, and what lessons can be learned.

How does the project help people living with dementia?

Many people living at Bramble Hollow have only ever received reactive treatment from the GP, whereas they now have a review, including a conversation with the GP or nurse and their family, to talk about what emergency healthcare plans they may be interested in developing. The health professionals then pass on clinical advice about how the patient's health needs are best managed to the care staff. They have conversations about medications and the best way to support people to take them, and share ideas to help staff with what may be perceived as challenging behaviours.

The GP, care staff and link nurses [all of whom have a community matron or district nurse background] meet each week and share information, contacts and advice. They are building up relationships between health professionals and people living and working in the schemes and family members, and they are asking the GPs and the nurses for advice.

Care staff are receiving training from Tyne & Wear Care Alliance that enhances their confidence and competency.

Social workers hold surgeries within Bramble Hollow for people who live there and their families, and as a result they have much broader information about people because they are more involved. In addition, they are actually taking their service into the scheme rather than providing it on an ad hoc basis or when a crisis hits. They learn more about the person's life story, and think about how they can contribute to the person's health. Again the multidisciplinary approach is key.

A key focus of the multidisciplinary approach is that everyone involved is working to make sure that they recognise what personalisation means and that part of their role is to support each person to live the best possible life they can.

If someone's move into extra care or on to residential care is planned, the multidisciplinary team share all the information they have collated with those who will be providing support. This means people don't have to continually repeat their stories. One example of the effectiveness of our sharing was the way we worked with a woman whose behaviour was seen

by staff as challenging. The support staff described how she had been a landlady of a rough pub in the local area so when she was in the day room and she thought it was closing time, she got everybody out. Initially staff found this challenging, but by stepping back and looking at her life and her history, they understood better why she does it and how they can support her. We share the information with new supporters and this will have a positive effect on this woman's support. We use one-page profiles to share information and have a good process for reviewing them constantly to ensure they are up-to-date.

How does enhanced healthcare improve the health of people with dementia?

The enhanced healthcare scheme can provide round-the-clock support to a group of people who might otherwise be supported in isolation. It can also be a more resource-effective way of meeting high and complex needs while creating opportunities for building friendships and community. The Coalfields project has highlighted the scale of the problem and brought it to the fore. There are residents who live in the extra care scheme whom you would have expected to be living in residential care homes. Some would probably be receiving nursing care, and some have continuing healthcare funding and have nursing care. But they are all still able to live at Bramble Hollow with the help of the enhanced healthcare scheme.

The scheme has helped its professional participants too. For example, previously the GP practice was being called frequently, and now their regular presence within the scheme means fewer unplanned visits. This works better for people living at Coalfields and for their carers too.

Where to go for more information

Contact

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Penny Davidson, Locality Commissioner Manager, is senior management lead for The Coalfields Care Home Project at the Sunderland CCG.

HOUSING AND SUPPORT: HEALTH AND WELLBEING, ECCLES

Current situation: people with a dementia living with inadequate support in high-rise blocks

City West Housing Trust has a concentration of older people living in their stock in the Eccles town centre. There are a number of customers who live in the tower blocks with a dementia diagnosis, but it is anticipated that there are many more customers living with dementia without a diagnosis.

The situation of these customers is compounded by a number of factors: longstanding low income, lack of family connections and support, poor general health, isolation in their homes, their mental health conditions not meeting the criteria for an assessed need for support, and reduced Local Authority care and support provision due to austerity cuts.

The innovation: Alternative Futures

City West have worked with Alternative Futures Group, a large and well respected support provider, to develop and start to deliver a pilot in Eccles centre to address some of the issues highlighted as affecting our customers. We hope to improve our vulnerable customers' overall health and wellbeing through this partnership.

Following the extensive refurbishment of the two high-rise blocks of sheltered accommodation, City West have created a new suite of self-contained offices on the ground floor of one of those blocks at College Croft. College Croft is located in the centre of Eccles, immediately adjacent to excellent local transport links, a wide range of shops, a large supermarket and all the other facilities of a town centre. The new office suite has its own frontage onto the main street and space for up to six members of staff to work comfortably. City West have offered this accommodation and adjacent parking free of charge to Alternative Futures Group. This is an offer of accommodation to the value of approximately £15,000.

Alternative Futures Group operates a range of services in the Greater Manchester region. It has floating support and on-site support contracts across Trafford, Tameside and Manchester. College Croft gives Alternative Futures Group modern, good quality, central office space with good transport links to base themselves in to manage their various contracts in the region.

In return for the office provision, Alternative Futures brings their key skill of extensive experience of providing support to vulnerable customers and in-depth knowledge of supporting customers with dementia.

How will the partnership help people living with dementia?

City West and Alternative Futures are developing a pilot support and signposting service for City West's customers in our two sheltered high-rise blocks, College Croft and Kemball, which is a short walk away from College Croft. Using their staff presence in the block and together with City West Independent Living Service staff, they will get to know the residents at the two blocks, identify areas where support needs exist, signpost customers to existing services, scope out low level support for customers requiring that, develop new ideas for social interaction and activities at the two schemes and provide advice and assistance on referring customers who require higher levels of support through the appropriate channels.

Alternative Futures will support City West staff in further developing their skills and knowledge around supporting customers with dementia to continue to live independently in their own homes for as long as they possibly can.

How will the service provide appropriate support for people living in the high-rise blocks?

The pilot scheme in Eccles, linking City West and Alternative Futures Group, will give the customers in the two sheltered blocks, a total of 168 households, better access to support.

Having a concentration of staff from two organisations regularly on-site and interacting with the customers should allow us better to observe customers in the early stages of dementia. This enables us to make earlier referrals to the appropriate medical professionals as well as to providers of low-level support.

Significant numbers of customers suffering from lower-level mental health issues such as anxiety and depression will have access to support and advice that they would not ordinarily meet the criteria to receive. Early access to support, advice and assistance will help those customers to improve their social interaction, diet, general health, wellbeing and quality of life, and to attend health appointments. Customers with drug and alcohol dependence issues will have a regular interaction with a member of staff who understands their condition and can support and signpost them effectively.

There will be an opportunity for Alternative Futures staff to develop an informed overview of the key issues and challenges City West customers are facing in the two identified sheltered schemes. Working with Alternative Futures, City West will be able to build staff knowledge and experience around identifying and supporting customers with low level support needs. Alternative Futures staff will be able to provide training for the site-based City West scheme management staff to broaden their skills in support and dementia awareness. Creating an overview of the issues and needs from

both schemes will provide City West with more detailed information to influence the services, activities and partnership links developed for those blocks into the future.

The staff involved in working on the pilot will have the benefit of learning about how each organisation works with customers and developing a broader understanding of supporting vulnerable customers to retain their independence.

Where to go for more information

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HOUSING AND SUPPORT: HOSPITAL TO HOME, REABLEMENT, OLDHAM

Current situation: discharge from hospital too often leads to a crisis move into a care home

When an older person with dementia is discharged from hospital they are all too often assessed as unable to cope at home and make a crisis move into a care home. This not only fails to consider what they actually want and need, but also fails to draw on the person's own networks and those of their community. It can therefore lead to the person's social isolation, loss of independence, at considerable financial cost.

The innovation: reablement for people with a learning disability

www.imagineactandsucceed.co.uk/Agenda/IAS-New-Reablement-report

Based on the success of our reablement project working with people with a learning disability, we are exploring reablement's potential for people with dementia.

Imagine, Act, Succeed (IAS), a provider organisation in the north-west of England has implemented a different model of social care service with Oldham Council. We acknowledged some radical thinking was needed to prevent a conveyor belt of long-term and increasingly paid support for people, which not only risked escalating expenditure, but also increasing the social exclusion of those individuals.

IAS believed paid support could, in some scenarios, be enhanced or replaced by richer, natural and more sustainable support networks and community connections, and people could be supported to enjoy a better life. *Person-centred thinking*²² was central to our approach and as an organisation IAS had a deeply rooted person-centred ethos, but we also found it beneficial to shake up our thinking around reablement by using the principles of 'just enough support'.

Eight key principles of the New Reablement Journey

- 1. Reablement is a journey rather than a service and is not limited to six or eight weeks.**
- 2. Reablement can be appropriate for anyone needing social care support.**
- 3. People should be able to self-direct their reablement - able to exercise choice in how they are supported to achieve short and longer-term outcomes.**
- 4. There should be one person-centred 'harvesting' of relevant information.**
- 5. Support planning should include outcomes that strengthen natural support networks and community involvement.**
- 6. Plans to achieve short-term goals should be person-centred; people will be involved in decisions about their support and will own the planning process.**
- 7. People should have information about the resources available and agree a time frame to achieve specific outcomes.**
- 8. People have a seamless experience with minimal 'hand offs' between professionals or services.**

Regular communication between the reablement service and the Council care management team is an essential part of the joint working arrangement between the two parties and enables both to provide the best service to individuals and their families. At the outset it was agreed that for the sake of simplicity and efficiency there would be one point of contact between the two and therefore the reablement team leader and Senior Practitioner meet weekly to go through the referrals, update on progress and alert the Council if it is felt that anyone is likely to need support beyond the reablement period. The trust mentioned above is of course critical in this respect and it is accepted that the reablement team will have explored every way to reduce the need for paid support; their recommendation is trusted and a care manager will be allocated to commence a full assessment and start the process of setting up a Personal Budget.

Establishing not only a new service but also one that took such a bold and radically different approach to supporting people with learning disability would not have been possible without positive leadership throughout both the Council and IAS. The reablement service questions accepted wisdom about the way that support should be provided to people. Positive leaders who are confident in people's capacity and who are able to enthuse, motivate and instil in others the importance of building the person's own confidence and self-esteem, are a vital component of any service like this.

At all levels, from the Adult Services Director and the IAS CEO, Operational Manager and Reablement team leader, Senior Practitioner in the Council and individual care managers, a belief in the importance of reducing dependency and of keeping the person at the heart of decision making, managing risks and expectations openly and positively has been critical.

Such leadership needs to communicate a true belief and instil a positive attitude in others regarding the potential for communities to support people through natural networks of friendship and reciprocity.

Critical factors for success

The model of service has been shown to work but the critical success factors listed below would need to be present in any replication of the model.

- **A person-centred culture and a belief in people's capacity**
- **Partnerships and trust**

A spirit of trust, shared involvement and understanding between all key partners was an essential success factor. The trust and shared vision that exists between the Council and IAS was instrumental in designing and developing the service and remains critical to its ongoing success.

- **One point of contact with the local authority**
- **Just enough support**

The concept of 'just enough support' is well established within IAS and builds on the organisation's culture of [person-centred practices](#),²³ partnership working and community connecting.

- **A positive approach to risk**
- **Pace and a focus on outcomes**

Working within a flexible six week window changes the dynamics and focus of the service. Knowing that the success of the service depends on outcomes being achieved within that short time frame means that there is a pace to the work that requires a different approach to that inherent in long-term services.

- **Keeping it small and purposeful**

The small size of this service means that it remains person-centred and not led by the needs of the organisation with regard to such things as the level of bureaucracy in place, matching workers and agreeing times for support.

- **Leadership**

Will reablement work for people with dementia?

There is evidence that this model is successful for people with learning disabilities, as it has been delivered through a specialist learning disability reablement team in Oldham. The evidence can be found on the [IAS website](#).²⁴

We are therefore suggesting that a similar approach for people living with dementia could be a good option. The success of this pilot service and the enthusiasm to apply such an approach to other areas of service delivery is infectious.

What happens on the reablement journey?

The specialist reablement team takes referrals directly from the Council contact centre or the social work/hospital discharge team. The team makes contact within 24 hours and a meeting is arranged within a week (unless they are informed that the situation is more urgent).

At this first meeting we begin to create a one-page profile with the person, capturing important information that we build on over the coming weeks. We use the working/not working tool to summarise the current issues and reasons for referral. We agree short-term outcomes with the referrer, the person and their family and agree a plan.

A key part of this process of gathering information is to identify the assets and strengths that the person has, their social capital, gifts and talents. This information is key in developing a short-term plan that builds on these resources and is therefore more likely to result in the person needing less paid support.

Identifying resources also includes knowing what exists in the person's own community - organisations, groups, clubs, facilities, etc. and what assistive technology, aids, grants, etc. are available.

We use all the information gathered using the person-centred thinking tools to agree and implement a short-term plan. We identify a small team to work with the person and to implement the plan. As they get to know the person better and implement the plan they are able to update the information about what is important to the person and what good support looks like, and to review the outcomes.

After the initial reablement period, during which the rich information is gathered, we develop a robust support plan (reflective of how the person wants to live and be supported, plus clearly showing how the money will be spent) unless the person needs no further paid support. We regularly review progress informally through conversations and at a six monthly [person-centred review meeting](#).²⁵

A specialist reablement team of people who understand dementia is more likely to be effective than a generic service. If local people are employed their local links are a great advantage in connecting the person living with dementia to their local community.

At whatever point it is felt likely that the person will require support beyond the initial reablement period, we make a referral for Care Management involvement if this doesn't currently exist (e.g. if the person has been referred through the Contact Centre). All the information learned with the person about what good support looks like is used to develop a Support

Plan with them that would be funded through a Personal Budget. We also support the person through the Council's Self-Assessment process and, through dialogue with the Senior Practitioner in the Council at weekly meetings, the plan is refined and agreed and the Personal Budget confirmed.

Circle of Support

IAS are also developing Circles of Support at Fiona Gardens, an extra care scheme in Greater Manchester. If a person does not already have a Circle when they are admitted to hospital, the Circle coordinator would look to match the person with a Circle facilitator. This could begin prior to discharge and continue afterwards, which is especially crucial where people have no family and few friends or have lost touch with friends. IAS are exploring how Circles of Support could help older people and people living with dementia who live at Fiona Gardens.

How will reablement help people with dementia?

The reablement approach helps people to avoid being swallowed up in services rather than living a life that makes sense in their community.

It stops us jumping in with the fix and makes us step back and reflect with the person and their allies on where they need support, with a focus on positive risk taking.

IAS is demonstrating through its reablement service that by taking a different approach to supporting people with learning disability, it is possible to prevent or lessen the need for paid support in people's lives. Paid support is enhanced with richer, natural and more sustainable support networks and community connections, with a focus on enabling people to 'get a life' rather than a service – this would be a welcome and innovative approach for people living with dementia and their carers.

The new Deprivation of Liberty Safeguards (DoLS) are all about least restrictive practice. Reablement helps us seek out the least restrictive practices and also has a focus on what people can do – supporting the view that a diagnosis of dementia is life changing but not life ending. Reablement can support people to regain links and skills that they have lost during a stay in hospital.

The person is in the centre of the decision making when receiving support from reablement, whereas in a care home the service systems often take control.

In the current financial climate we need to consider whether services are as efficient and effective as they could be. The reablement approach helps address the extreme pressures in adult social care funding and presents ideas for a new service model. We need a new model to prevent people finding themselves on a conveyor belt of long-term and increasingly paid support that not only escalates expenditure, but also increases social exclusion.

This approach builds on a person's independence, confidence and self-reliance through short-term paid support. It aims to provide 'just enough' support but to avoid creating dependency.

Reablement is an innovative service development founded on a strong culture of working in partnership, sensitively building independence through positive risk taking, and stretching people to take new steps to take control of their lives.

A team with specialist knowledge of dementia can help people to make effective use of assistive technology and resources that can keep them safer in their own homes for longer.

A specialist team can give people information that is truly relevant to them about the resources available to them, and support them to plan and make decisions.

The aim of reablement is to maximise people's independence and strengthen their natural support networks and community involvement. These goals would be embedded in all support planning and reviews and not just confined to the first few weeks of the person's journey.

As part of the reablement journey we harvest relevant information about the person with their full involvement and consent, and this can then be drawn upon for a range of organisational purposes.

Where to go for more information

www.imagineactandsucceed.co.uk

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²² <http://www.helensandersonassociates.co.uk/>

²³ <http://www.helensandersonassociates.co.uk/>

²⁴ <http://www.imagineactandsucceed.co.uk/Networks/Oldham/News/Reablement-Successes!.aspx>

²⁵ <http://www.helensandersonassociates.co.uk/>

HOUSING AND SUPPORT: HOMECARE, INDEPENDENT SERVICE FUNDS/OPTION 2

Current situation: people with dementia may struggle to use personal budgets

Personal budgets give individuals the chance to decide what care and support they receive, when, and who from. However, people with dementia will need varying degrees of support to use a personal budget, and this support must be personalised if it is to mean anything.

The innovation: Individual Service Funds and support at home

The Care Act [2014] requires fundamental changes in the way people think about support and wellbeing. This includes a strong focus on outcomes that are based on aspirations as well as needs, and a requirement that people are offered personal budgets to purchase the support that works for them. One way to have a personal budget is through an Individual Service Fund, or Option 2 in Scotland. An ISF is one way that individuals can have greater choice and control through a personal budget. Rather than the individual, their carer or a public sector organisation holding the individual's budget, the money is instead managed by a provider organisation on their behalf. Sam Bennett, director of Think Local Act Personal describes what ISFs are here: <https://www.youtube.com/watch?v=IHOyIZLxqms> and this is a useful short film by Simon Duffy: <https://www.youtube.com/watch?v=fqcdTirYHks&sns=em>

The Guidance for the Care Act states that the local authority should:

- 1 Provide people with information and advice on how the ISF arrangement works and any contractual arrangements.**
- 2 Explain how the provider(s) will manage the budget on behalf of the person.**
- 3 Provide advice on what to do if a dispute arises.**
- 4 Give consideration to using real local examples that illustrate how other people have benefited from the ISF arrangements.**

These principles are starting to be introduced into homecare services for older people, including people living with dementia.

Individual Service Funds means that people are in control of their service, in the following ways:

WHAT “I can use my hours/budget flexibly and can choose what I am supported with.”

WHERE “I am supported where it makes sense for me, at home and out and about.”

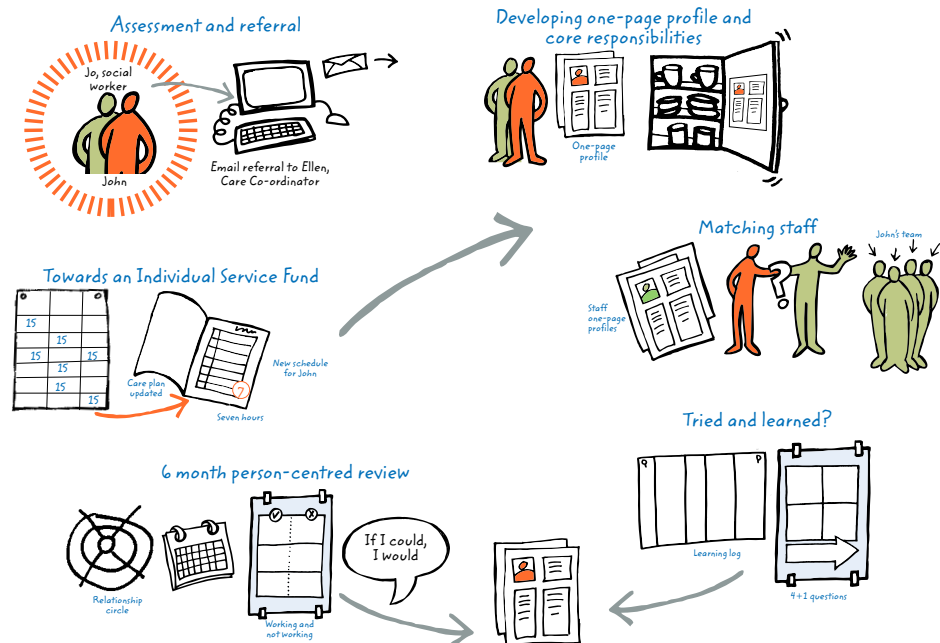
WHO “I choose who I want to support me, my support worker knows me and I know them.”

WHEN “I get support on the days and at the times that are right for me.”

HOW “I choose how I am supported and my support workers know this is important to me.”

COPRODUCTION “I am fully involved in decisions about my own support and how the wider service develops.”

ISFs are much more than simply breaking down the funding available to each person and giving them theoretical power over how this is spent. They do not work unless the person is supported to both understand their allocation and to make meaningful decisions over how it is used. For many people this can be a daunting process, but even more so for those whom others find difficulty in communicating with and/or who do not have capacity to make decisions over all aspects of their lives. What is required is a person-centred process which guides the person through the different stages of the ISF's development and which uses recognised **person-centred thinking tools**²⁶ and practices to engage people throughout.



The ISF process mirrors the process for developing personal budgets – starting with an upfront allocation of resources (which could be in money

or hours). The next step is developing a support plan to decide what the person wants to change in their life, and what they want their life and week to look like, and this will include how they want to 'spend' their allocation. This is then agreed and recorded, then implemented. The implementation will result in further learning, and then the allocation, support plan and most importantly the impact of these on the person's life, are reviewed through a [person-centred review](#).²⁷

How are ISFs being used in homecare for people living with dementia at the moment?

Homecare packages can require multiple visits during the day and night, but there are many older people and people living with dementia who are supported to live in their own homes through a few hours per week. Often this homecare complements support provided by their families, networks and community organisations such as faith communities and voluntary organisations. Due to the current eligibility and charging processes people who receive such support will pay for this care themselves. Being clear about the money is only one element of enabling people to have greater control over their care.

This chapter illustrates how ISFs are being used with people living with dementia through Hilda's story, and then how a commissioner and provider in Scotland are introducing ISFs.

HILDA'S STORY



United Response, a national provider, wanted to explore how ISFs in homecare could work with people living with dementia. They worked with Hilda, who had early onset dementia, to learn together what good practice could look like.

Helen and Nick met Hilda for the first time with her niece, Gill, to begin the process of delivering person-centred homecare to Hilda. Hilda called this her 'personal shopper'. Hilda was 92 at the time and a fantastic film buff. She lives by herself near the coast, is registered blind and now is in the early stages of dementia. Gill, and Gill's daughters Barbara (Babs) and Rachel support her and stay over a couple of nights a week. She has great neighbours too, Jean and Brian, who call in every day. Hilda's daughter Joan lives in the States, in Pittsburg, and while we were there, Joan phoned Hilda to see how the meeting was going. For Gill and Joan, and for Hilda too, there had been one too many near misses on the road to Asda, and Hilda needed help with her weekly shop.

On their first meeting Nick and Helen met with Gill and Hilda, to learn about her and what she wanted from a service. They learned about Hilda, through purposeful conversation, and from being introduced to her family through the array of precious photographs in the lounge and kitchen. They found out she has a great sense of fun, is incredibly organised and tells it like it is! All the rich information collected from the session was added into Hilda's one-page profile, and to 'matching staff'. With these tools filled Nick was able to go off and find the right people to help Hilda.

Some might ask why go to the trouble for a weekly contract worth less than £30 per week? Well, three reasons. We want to demonstrate what the most person-centred homecare could look like, and this simply is the way we do business whatever the size of the contract. We also want to build trust with Hilda. If we can provide her with staff that are well matched to her, and support them to do an excellent job, then as Hilda needs more support (as we all will at some time in our future) then we would like to be her first choice to provide that. Thirdly, if Hilda and her family are very happy with their service, they are likely to mention it to other people.

After some thought, Nick identified Linda as being the best match to provide Hilda with some support. Linda and Nick had studied Hilda's one-page profile and Linda had developed her own, prior to visiting Hilda. They had also looked at Hilda's service specification and thought about how this will be delivered to achieve her outcomes, and when the service to support Hilda would begin, providing of course that Hilda and Linda connected well together when they met:

Here Babs, Hilda's great-niece, picks up the story: *"Aunty Hilda was busily preparing a plate of biscuits and setting out a tea tray when I arrived - Nick and Linda were due to call in 30 minutes. She pointed out to me that Nick likes biscuits so we will put plenty on.*

I was a little surprised as I expected her to be anxious about the "conference" as she called it, but absolutely not! I can only put this down to the fact that she had felt very comfortable and involved during Nick's prior visit with Helen.

Nick and Linda arrived and it was a really comfortable meeting. Aunty Hilda was the hostess setting out the tea and biscuits. Linda had clearly paid good attention to Hilda's one-page profile and led conversations around all of Hilda's favourite topics. They clearly had a great connection by the end of the meeting and my sense of relief was overwhelming! We had been so worried about finding ourselves in the world of needing social care and until it is your personal experience, it is hard to empathise with the fear of leaving a vulnerable loved one with a stranger".

During the meeting it was agreed that Linda would initially support Hilda, but in around 10 weeks two further staff members would be introduced. This would be her consistent team of supporters for the foreseeable future. It was also agreed that each new team member would be introduced to Hilda in the same way as Linda, understanding and agreeing key ways of supporting Hilda consistently by using her one-page profile and service specification as their job description. Therefore ensuring Hilda had the things that mattered to her when being supported, that she was safe and that she was consistently supported regardless of which of her team was providing that support.

When asked how she thought the meeting had gone, Hilda said: *"Well it wasn't like when they came from the social services asking me all them questions and filling out forms. Linda is very nice, she won't boss me about I can tell."*

Even with Hilda feeling happy to have Linda be her support worker, she still shared some anxiety about going out and about just the two of them being together for the first time. It was agreed that Babs would join them on the first visit. Hilda was more than happy with this and consequently had a good afternoon. Hilda said she enjoyed it and was looking forward to going out with Linda the following week. Linda had put Hilda at ease chatting with her about movies and Hilda told her more about her family in America.

The following week Linda and Hilda went out together and Hilda said how lovely it was that she had all the shopping she needed and had paid her paper money at the newsagents. Not paying her papers weekly was something that created great anxiety for her. She would often ring Gill to check which day she was going over because her paper money was due. So clearly Hilda gained enhanced choice and control from her time spent with Linda.

Linda was on leave one week and Hilda said she would give going out a miss but would think about going out with somebody else in the future on weeks when Linda wouldn't be able to support her. She was further reassured that Linda will be with her as she is introduced to a new person. It was recognised that it will not be practical to rely solely on Linda, and there is a hope to build a team of three people supporting Hilda, but at her pace.

It is great to hear how much Hilda looks forward to going out with Linda and chatting with Linda about Lucy and Trevor, Hilda's grandchildren, and hearing how Linda's little girl is doing. They have a great relationship so different to the task-focused care culture that is often seen.

The key sign that things were working well was when Hilda said she and Linda have a lovely chat over a coffee and cake when they get back from shopping. Hilda is now obviously comfortable enough to invite Linda to sit with her. Babs has recently moved to the USA for several months – being supported by United Response has filled that gap a little for her. Hilda's verdict so far: *"it's going beautifully, me and Linda can chat for England!"*

The homecare package worked well for Hilda in a number of ways. She reported an increase in her overall wellbeing as she had the security of knowing that she could get out every week. She felt comfortable with her support worker, and often they had a coffee together which was a real highlight for Hilda. She also arranged specific things with her support worker around what they do together, for example they went to the pharmacy for Hilda's medication check on one visit, which gave Hilda peace of mind. Her positive experience led to a number of word of mouth referrals through her and her network's contacts.

Key to the improvements in Hilda's support was the flexibility of her support worker, who was willing to change the days that she worked to respond to Hilda's preferences and to be a direct point of contact for the family. The support worker also tried to fit in with Hilda's existing home processes, for example capturing reminders on her calendar in big writing. One issue that did arise was that Hilda became anxious about another supporter being introduced and preferred to cancel the call if her regular supporter was not available.

Sadly Hilda has since died. However it was important that she was given the opportunity to have more control over her support over this period, especially as it turned out to be the final few months of her life.

How commissioners and providers are introducing ISFs with older people including people living with dementia

Commissioner Geoff Marks, in Dumfries and Galloway, is working with a range of care at home providers to support them to introduce the principles of ISFs, or Option 2 as they are known in Scotland.

They are starting by making the existing process more person-centred, and then at the person-centred review process they are looking to introduce Option 2 where the person and provider work out how to use the time/ service that the person is allocated. By approaching it this way, the individual, provider and social work colleagues build trust in each other and the process. In the future, the ISF will be part of the assessment, and the outcomes will be agreed before the service starts.

Geoff and colleagues are blogging about their experience in introducing this way of working, and you can follow their progress at: <http://transforminghomecare.org>

Where to go for more information

There is a free App that is available for iPads called Individual Service Funds that describes how ISFs can be developed in homecare and residential care [<https://itunes.apple.com/app/id976643751>]. The App can also be accessed on the home page of the Helen Sanderson Associates webpage <http://www.helensandersonassociates.co.uk/>

Some reading that may be useful

Blog: <http://transforminghomecare.org/>

The Individual Service Funds Handbook (2015) Helen Sanderson and Robin Miller. Jessica Kingsley Publishing. London, UK

²⁶ <http://www.helensandersonassociates.co.uk/>

²⁷ <http://www.helensandersonassociates.co.uk/>

HOUSING AND SUPPORT: BREAKS AWAY FROM HOME, THE MEDE AND SEAWARD HOUSE

Current situation: people with dementia and their families struggle to take breaks together

Sallie Rutledge set up the Mede because her father-in-law, John, had Alzheimer's and her mother-in-law, Sheila, had started to ignore her own health and to become physically and mentally exhausted. John and Sheila stopped seeing many of their friends, and the things that they looked forward to doing together were difficult and sometimes no longer possible. Sheila said she would often wake up at 3 o'clock in the morning and wonder what sort of day she was going to have. She worried about getting through the day and dreaded what it might bring. Every morning was the same, with its daily routine of washing, dressing, cooking meals and providing twenty-four hour care for John. There appeared to be little support in place that would work for Sheila and John. Eventually John went into a nursing home.

The innovation: supported breaks for people with dementia and their carers

Sallie always wondered whether if Sheila had had a few days off or nights away, either together with John or apart, it might have given her more strength to support John to live at home longer.

Before John went into the nursing home Sallie had started to look for somewhere they could go on holiday with support in place, but as she found nothing she decided to set one up herself.

Sallie's daughter says: "I really wish we had found somewhere like The Mede to go to with my Grandpa before he went into a nursing home. Instead the holidays we attempted to continue with were stressful, returning to places we thought he would remember but he didn't and that was sad. It was just not the same.

It would have been so nice to have gone somewhere different, where Grannie did not have to worry about the cooking or constant care. We could have taken it in turns spending time with Grandpa, but also maybe going out to supper with Grannie knowing he was being well looked after."

Suzu supports her mum. Here she describes the kind of support they have been offered, and what they would like: *"We are a family of six. My Mum lives with dementia and I live with her, my Dad, my husband and our two children aged 5 and 9 years. We have been offered conventional support such as respite care [a local care home for older people] and sitting services*

[often offered by services that do not offer good dementia training] to give us a break from our caring role. At this time we do not feel that respite for Mum is something we want because we feel strongly that moving Mum from her home environment would be detrimental. We don't want a break from Mum; we want to be supported to enjoy time with Mum."

Sallie is a qualified nurse and she has a good understanding of dementia and how important it is for carers to have a holiday. She bought The Mede and set it up as a place for carers and the person they care for to relax and have precious time together, with as much or as little support as they require.

Sallie has found that people who stay at The Mede, both carers and people living with dementia, sometimes just want to know there is somebody nearby or on the end of a phone if they need her.

The Mede is a three-bedroom bungalow in Topsham, on the edge of the beautiful Exe Estuary near Exeter in Devon. It has a wet room and level access so is suitable for people with poor mobility. Meals can be provided, and a sit-in service is available and personal care from local agencies can be organised.

Carers can contact Sallie direct to make arrangements. The Mede is not restricted to summer time but offers all-year-round support.

Sallie has also set up Seaward House, an activity day club for people living with memory loss. People visiting The Mede may feel their relative would benefit from spending a few hours there, leaving them free to have some time to themselves. Seaward House is open every Monday from 10.00am to 4.00pm [except bank holidays]. Staff are trained in understanding memory loss and the use of evidence-based approaches like Cognitive Stimulation Therapy [CST]. The main aim is to keep minds active, reduce boredom and engage people in meaningful activity. It also gives carers a day to do as they wish.

Visits to Seaward House and The Mede can be paid for by social funds; people are advised to check with their local authority about funding.

Suzy says: *"We feel very privileged to have found a family respite home in Topsham, Devon. I use the word home because it is not a unit or a dementia hotel, it is home from home. The service is run by a wonderful woman, Sallie Rutledge, who understands why the service she provides is essential for families [she has experience of caring for a family member with dementia]. The facility is well supported by the local health and social care community with secure links to domiciliary care and a local GP surgery. Sallie herself provides bespoke care, offering meals, breaks for the carer and importantly a listening ear. More recently Sallie has bought a new property that offers more accommodation and a day service provision available to the family staying at either home."*

How do The Mede and Seaward House help people living with dementia and their carers?

Sallie says respite care is important when looking after someone with dementia. She understands how families may need time together or apart and can organise support tailored to suit individual needs.

The sit-in service enables carers to have time on their own, perhaps to go and have a coffee in Topsham or go for a walk along the canal or estuary.

Everyone has different needs and wants different things when they stay at The Mede. There is always an opportunity before people arrive to discuss what they may require.

Visitors are never just handed the key and expected to cope on their own. If Sallie is needed she is on the end of a phone and can pop round when required.

Sallie describes how seeing families get together on holiday is a lovely thing when they start to relive some of those precious moments and rekindle some of those feelings they used to share. They can be a husband and wife again and the role of carer is changed.

One of the many questions asked by potential visitors to The Mede is about respite for a short time. Sallie previously offered a sit-in service of three to four hours or accompanied a couple on trips out to give the carer a break from being the carer. Now with Seaward House next door she can offer up to six hours, from 10.00am to 4.00pm, of cognitive stimulation therapy for the person with dementia while the carer gets a day to themselves. The wife of a man who has a dementia commented: *"It was wonderful to just have those few hours off and walk on the beach or go shopping and just relax so that I could enjoy his company again. He really seemed to enjoy your company too and would talk about little things that had happened. He could not remember specifics but this morning he said "the party was really good" and "the people really looked after you."*

Sallie has tried very hard to keep costs down to a minimum. They always depend on how much support is required. Many families worry about costs in the future and may be concerned about paying for a holiday as it is seen as a luxury. However giving a carer a supportive break can recharge their batteries and make a huge difference.

What difference do holidays together make to families living with dementia?

Suzy says: *"Only a year ago my Dad sat looking at his suitcase and said 'You can have this, we won't need it again.' We thought family holidays had come to an end. Taking Mum away was becoming a challenge. Then we found The Mede. We enjoy holidays as a family again, creating memories, wonderful!"*

Sallie's daughter says: *"I have seen people come and go visiting The Mede and they all are so grateful for the tailored care and attention my mum provides.*

I wish my Grannie had had this opportunity to enjoy some last holidays with Grandpa."

Perhaps if Sheila had had a few holiday breaks along the way she would have felt more able to support John.

Where to go for more information

www.themedede.org

Contact

Sallie.rutledge@yahoo.co.uk



GOOD DAYS

GOOD DAYS: HOLISTIC DEMENTIA CARE, EACH STEP, BLACKLEY

Current situation: dementia services are inflexible and fragmented

For the most part services for people with dementia are fragmented, each element being provided in isolation and with little overall sense of the person being supported. Not only does this mean that care rarely reflects the individual or their life till now, but it can also lead to someone with dementia quickly becoming isolated from the community they live in.

The innovation: one-stop care for every step of the dementia journey

Each Step, Blackley is a North Manchester based dementia care service that offers a holistic package of support each step of the way, in people's own homes or through other specialist services - homecare, day care, respite care and residential and nursing support.

Based on recommendations from the National Dementia Strategy, Each Step aims to offer options for support from diagnosis on. People are able to develop relationships with others who live, work or spend time in Each Step so as the dementia progresses and they may require different support they are not having to start again, rebuilding, and going through the same conversation over and over, because connections are already there. Relationships can be built gradually with people with a dementia diagnosis and their families. If in the future the person requires more intense support, the relationship is there. People can dip in and out of the support provided at Each Step, and whatever issues arise for them we offer a number of options.

Each Step has a Costa community café based in its building which equally benefits the people it supports and opens the service up to the local community. This has helped realise the service's ambition to bring together the people supported at Each Step and their local community. Having such a familiar brand based there draws people in and has proved a great asset in terms of community involvement.

People living with dementia and/or family members may drop in to Costa in order to simply get a feel for Each Step or to seek advice and information, often through informal conversations in the café. They learn about the options available to them such as support to live independently for as long as possible in their own home, daytime support at The Club, short or longer respite breaks, and the option of moving into the residential or nursing sections of the housing with support which we also offer at Each Step. Each Step includes a large spacious specialist dementia day care service

called The Club, which can accommodate up to 25 people at a time and is open seven days a week. The Club has been specially designed to be accessible for people with dementia and offers a wide range of activities to fulfil every member's interests. The Club offers a great way to remain active, meet and make friends, and have fun. Mental stimulation and social interaction have great health benefits for people with dementia too, so accessing a specialist dementia day care service offers fantastic support for staying independent for longer.

Dementia day care can also help family or other carers, allowing them to take some time out of their caring routine whilst knowing that their loved one is well supported and enjoying a great day out.

Each Step is committed to developing a [one-page profile](#)²⁸ with every person supported and their family and friends, in order to capture rich information about what is important to the person, what others appreciate about them and how best to support the person from their perspective. Each Step works actively with family members to ensure the rich contribution they have to make is also captured.

The Club is typically open from 8.30am until 6.00pm and aims to be flexible to all of its members and their commitments – because of this, it offers a range of sessions that run from three hours to a full day.

How does Each Step help people living with dementia at the moment?

Being a part of The Club introduces people living with dementia and their carers to the wider community at Each Step, and if they require support at home or support to go out shopping, they are supported by familiar staff they have already met via The Club.

For example, The Club has two people carrier vehicles, which can support members living across Greater Manchester who need transport to and from The Club. These people carriers are driven by carers who work for The Club, meaning that people will always be picked up by a familiar face. Even if somebody is not feeling great when our supporter calls for them, because the supporter is somebody with whom they already have a rapport they are generally more likely to come along to The Club. This is really important to carers too, particularly if they are going to work or have other commitments.

The Club is very flexible in terms of when people attend, so if somebody isn't up to coming one day they can attend on a different day rather than losing their day – flexibility is central to our ethos.

The Club is very much based on friendship from the moment a friendly supporter knocks on your door and asks you if you're coming. The Club gives people with dementia the opportunity to spend a day enjoying entertaining and engaging activities with company. People can eat breakfast, lunch, afternoon tea and an evening meal at The Club with their friends and it's a great way to meet new people, have fun and spend some

time away from home in a new environment. The Club makes it easy to remain active and helps people to live an ordinary life. It consciously seeks to enhance the public's awareness of dementia: people who attend The Club may go out walking, on visits to parks, orienteering, and use maps to follow nature trails at Chadderton Park and other people see them doing this. Our activities are based on what we know people enjoy and look forward to.

A couple of people who attend The Club are keen ramblers and walking has always been a big part of their life. One lady has walked all over Europe, another would often get up into the Pennines and the Peak District. With The Club they continue to enjoy walking together. Even though our activities may be on a smaller scale to those people used to pursue, they are still in keeping with people's previous experiences and are meaningful to them – and friendships flourish when they are based on shared interests.

CASE STUDY: BEATRICE

Beatrice attends The Club three times a week. Staff call for Beatrice at her house and bring her in. She loves nature and being outdoors, and she also loves going shopping in Manchester – Marks and Spencer is her favourite shop. She also has outreach support four days a week for two hours on a one-to-one basis provided by Each Step; this is part funded by a personal budget and part self-funded. Without this support Beatrice would not be able to get out and about on her own, or shop in Manchester – she would be very isolated as the only contact she has besides The Club and her outreach workers is a visit once a week on a Sunday from her god-daughter.

Prior to receiving support from Each Step, Beatrice would take herself up to her bedroom in the morning and she'd spend all day in bed – not because she was tired, but because she was bored and isolated.

The Club can also help family or other carers, allowing them to take some time out of their caring routine knowing that their loved one is well supported. If carers need to go away for a night or more there is the option for the person they care for to stay over in housing with support at Each Step.

Our outreach service is bespoke: we do what people want us to do and individual wellbeing is at the heart of what we offer. We make sure this happens by using the person with dementia's one-page profile to define their outreach worker's job description. Our service also meets the needs of carers, for example by supporting their loved one at a hospital appointment or taking them out for a social engagement.

How does Each Step address the challenges people with dementia face?

Each Step offers support from beginning to end. It avoids the fragmentation of services which means people don't know where to go and

are sent from pillar to post. Each Step can provide advice, information and support from the start. Located in a built-up area of Manchester, it's easy for people in the community to call in and get information and signposting.

Demystifying dementia

The local community uses the premises for meetings and groups, or simply to enjoy a drink and a snack in the Costa café. Mums meet here sometimes after dropping their children at school, and they often have younger children with them. A lot of people who live at Each Step or attend The Club also use the café, so there is a real mix of people coming together, building relationships between young and old.

Sometimes if people come in for some information or signposting, we sit down with them and use the café computer. Others come into the café specially to use the computer because they don't have online access elsewhere. It sometimes feels like an internet café being used by people from all generations.

People from The Club who have a dementia go out and about doing the things that we all do – the way we use our centre greatly breaks down the stigma society has associated with dementia

“When it was first announced that a service supporting people with a dementia was going to be provided at Each Step, some local people were anxious, having extreme or distorted perceptions of what dementia is and how it might affect them personally. We now see these same people coming by for a coffee and in fact many are now powerful advocates for the service.” Manager

The building is used by a number of other people besides those calling in to the Costa café. The community mental health team run sessions at the centre. There are three local councillors for this area, and each week they hold a surgery for the community and people come along here to meet them. Graham Stringer, the local MP, holds his surgery each month on a Saturday morning at Each Step and people from the community come in and meet him here. This is very much a place that is used by the local community as well as those who are simply passing through the town.

When the local community were going to lose their swimming pool, Each Step supported them by enabling them to hold their group meetings in the building and offering them advice and support. This went on for over a year and eventually the community focus group were able to work with Manchester City Council on securing the very first community swimming pool and leisure centre and they continue to hold meetings at Each Step

By supporting various community groups Each Step has become a valuable resource. We hope that the more people are comfortable about coming to the centre, the more we break down barriers and our centre stops being perceived as a mysterious place for people with dementia behind locked gates.

Where to go for more information

www.each-step.co.uk

Contact

michelle.phillips@c-i-c.co.uk

Manager

Some reading that may be useful

Living well with dementia: a national dementia strategy: <https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy>

²⁸ <http://www.helensandersonassociates.co.uk/>

GOOD DAYS: FLEXIBLE SERVICES, WHITE GABLES, BROMLEY

Current situation: support for people with dementia is time-restricted and inflexible

In south-east London commissioners of services are still not giving people with dementia the level of support and understanding that they need. There is a significant difference between dementia and other long-term conditions because dementia sits between health and social care, often with social care taking the lead. Though dementia is a disease, commissioners often see it as part of ageing. They feel that the needs of people with dementia and their carers are less than those of people suffering from cancer, which is treated as a medical condition with greater support needs.

Older people's services in the community usually run from Monday to Friday and offer advice, support and activities. In Bromley we have consulted with a number of people with dementia and their carers, and they have told us that it is out of hours when carers are under most pressure. They tell us that because traditional support services are not operating then, carers are more likely to call the emergency services.

We clearly need to work with the people we support and to provide truly personalised support.

The innovation: flexible services day and night

White Gables began as a day service provision operated by the Alzheimer's Society in Bromley, London, but in recognition of the differing needs of people living with dementia and their carers it now opens its doors from 8.00am to 10.00pm as a pilot project. During the course of a day 25 people living with dementia attend and if their carers choose to stay with them, we welcome them too.

White Gables offers a more personal and flexible service running through the day and into the evening. People may go for a meal, join in specific activities, or spend a few hours there. We charge people per hour according to how much they use the service each week. People attend at different times and the most popular slot is 10.00am to 2.00pm.

There is an open door policy: the team at White Gables carries out an assessment and then approaches the local authority. Approximately 40 per cent of people attending are self-funders, and 60 per cent use a personal budget from the local authority.

How does the service at White Gables help people living with dementia?

High quality person-centred training

At White Gables we recognise that being truly person-centred is an ongoing and continuous process that we must support every day. Each person with dementia has very different needs and experience so to support people appropriately, we need high quality training and understanding of their communication needs.

Activities people want to do

Commissioners do not always recognise that responding to what matters to a person is a good outcome. However, the people developing the model at White Gables recognised that people want to do the things they want to do, not typical 'activity' sessions.

At White Gables, if somebody is passionate about football, they watch football on Sky Sports: one man loves football and once he is immersed in watching a game his shaking reduces and he goes home happy.

The team at White Gables creates an atmosphere that says we have lots of jobs to do: a potato peeler, potatoes and a saucepan may be left on the worktop, baskets of laundry wait to be folded, and in this way we encourage people to do the things they wish to do.

“we encourage people to do the things they wish to do”

White Gables' evening services give people with a dementia who are much more active in the evening a place to go to meet others and get involved in things.

The team are hopeful they may progress to a 24/7 service in response to the number of people who become most active during the night, often putting additional strain on the carer. One member had been admitted to hospital and became distressed during the night as nursing staff continually tried to help him back into bed. His wife explained that she had altered her own routine so that it worked for her husband and they slept during the day and stayed up through the night.

How does White Gables provide a flexible, personalised service?

The people using White Gables drove the way the service evolved. The team listened to people and their carers through one-to-one conversations, focus groups and carers' meetings. They listened to what people said about needing more flexibility and recognised that if you meet one person with dementia you have met one person with dementia – everybody's experience is unique to them and we have to individually design support around each person.

Some carers drop a person off at 8.00am and then go to work: this helps them to maintain important routines in their own lives whilst knowing the person they care for is in a place where they get to do the things that they enjoy and are well supported. People come in and go home at different times, creating an organic feel to the day.

We are constantly evolving the service with the people who use it, and carers have a place where they can meet others in similar situations and can also seek information and advice from the White Gables team.

The flexible model we use meets the needs of people with dementia more appropriately than most services where times are restrictive and do not reflect people's support needs as their dementia progresses.

Where to go for more information

www.alzheimers.org.uk

Contact

Jo.Vavasour@alzheimers.org.uk

This model was developed by the Alzheimer's Society and as such the model is protected under our intellectual property.

GOOD DAYS: SELF-DIRECTED COMMUNITY, HEALTHY LIVING CLUB, STOCKWELL

Current situation: people affected by dementia are socially isolated

There are not enough places for people with dementia and their carers to go to meet others and do things together.

Simona who runs Healthy Living Club explains further: “The very idea that people with dementia should have their need to socialise met by a service is disempowering. The concept of service incorporates the notions of ‘providers’ and ‘recipients’, of ‘us’ and ‘them’. And I think that these notions perpetuate the stigmatising assumption that people with dementia are only able to participate in relationships as ‘receivers’, thus contributing to the widespread perception that people with dementia are, essentially, a burden on society.

The truth is that receiving a diagnosis of dementia does not, in itself, prevent people from engaging in community life as equals. It is the stigma attached to dementia that tends to confine people in their own homes, thus preventing many from forming relationships with people other than their caregivers. These relationships are, to an extent, asymmetrical by nature.

The process of losing one’s independence tends to induce fear: people fear becoming a burden. Consequently it is logical, and not uncommon, that people with a recent diagnosis of dementia are reluctant to accept any care offered to them.

As symptoms progress, those affected gradually lose awareness of their diagnosis and related care needs. Thus carers can become resentful and relationships become strained – a situation that affects the mental wellbeing of both the person doing the caring and the person being cared for.

Against this background, I would say that the Club provides respite from both the experience of caring and that of being cared for. It provides a safe space where people with dementia and their carers can step out of their roles as ‘givers’ and ‘receivers’, and interact with each other and everybody else as equals.”

The innovation: a Healthy Living Club

The Healthy Living Club is a self-directed community group promoting the wellbeing of its members – people with dementia, their carers and friends – by giving them a strong sense of belonging, but also a sense of purpose: all members contribute to the functioning of the Club to the extent that they are able.

The Club meets weekly at Langham Court around a programme of activities designed to alleviate the symptoms of dementia and/or to help arrest, or reverse, cognitive decline. We run the Club with a team of volunteers and some sessional contributors, led by a paid coordinator. We see it as a blueprint for future dementia care in the community. It is free to attend.

We do not train or insure volunteers to provide personal care, so people whose care needs are high are welcomed into the group, together with a person able to meet such needs and willing to participate in the group's activities as an equal member of the Club, regardless of whether they are a family member, a friend or a paid carer.

Simona points out: *"I cannot stress strongly enough that we are a community of individuals who help each other when we meet, but our motivation for meeting is not to provide or receive care. Therefore we are not care providers, and it is this that makes the Healthy Living Club a model of self-care."*

The Club began as an opportunity to explore and evaluate what having a day a week with a socialisation and activity focus did for people. It offers a place for people to come together, rather than a place where people drop a family member off and then go away again, so it provides a place of connection for families and carers.

The key to the Club's success is that it's about creating a vibrant atmosphere. It's about people being together. It's about inclusion.

Our decision to develop the "product" collaboratively with the people for whom it was intended was wise because the process of choosing the activities – with everybody expressing their likes and dislikes – turned out to be a community-building exercise in its own right: it endowed participants with a strong sense of ownership. Everybody having a one-page profile further supports this.

The people with dementia and the carers who participate are never referred to as "users" of a "service" provided for them. Everyone who takes part in the Club experiences it as their community. The fact that some members have job or role descriptions [e.g. coordinator, workshop leader, support volunteer] does not necessarily mean that their input is greater than anybody else's and this is not just because the members who have dementia also contribute to the group's functioning to the extent they are able [e.g. by helping serve lunch, fetching chairs, reciting poems and singing songs to the group]. One of the group said, *"It is especially because our members with dementia and their carers contribute in ways we can't:*

they provide each other with peer support, and us with their insight into the disease. Through sharing their stories they very often also provide us with a source of inspiration, while improving our understanding of people from other generations, and of the past."

A volunteer told us, "In other words, our community produces relationships of exchange, with everybody being a giver as well as a beneficiary, and the currency which is exchanged the most is warmth."

Two crucial outcomes of the relationships inside the Club are the sense of wellbeing and the ability to adapt. Wellbeing flows from the warmth and reciprocity among participants, a warmth which is sustained partly by the slow turnover of members: almost all of the same people come, week after week and the rhythm of activities is largely constant, excepting special events and guests. The abilities and needs of people with dementia can change unpredictably; the flexible co-production approach enables the mix of activities to adjust and for new needs to be met through one-to-one interactions or small-group sessions in separate rooms.

Volunteer hours are credited as part of a wonderfully imaginative local time-banking scheme. The reciprocity is fantastic – for example the Time Bank arranges insurance and CRB checks for Langham Court volunteers, and the extensive range of opportunities at Langham Court benefits other Time Bank members.

We have developed further local relationships through our membership of the local currency, the Brixton Pound [B£]; Project Dirt, a local gardening, food and sustainability network; the U, a short-term project with Loughborough Junction; and UCL/ the North-East London NHS Trust. We also have relationships with health policy and funding bodies.

The model here grew over time, starting with a focus on activity and evolving as we brought in things like the exercise group, quizzes, music and art sessions. I think we became what we are through the people who started attending the [UCI] meetings, so the membership created what our model has been.

How does the Healthy Living Club help people living with dementia?

The community at the Healthy Living Club is not dissimilar to any other group or association of people who meet regularly to pursue a common interest, or to engage in their chosen leisure activity. Its only peculiarity is that 30 or so of the members [the majority] have dementia, and that the activities we engage in are designed to meet their needs. HLC is about building a community, and it's the people who form that community who determine its shape and form.

The Club is supported by the time and energy of its volunteers and by donations and grants. Its most substantial support is a grant from the Guy's and St Thomas's Charity made through the College of Medicine, itself a charity with objectives very similar to our own. HLC has been invited to join the College of Medicine's Innovation Network.

The Club has a bit of everything – effective community development, peer support, and reciprocal collaboration with other local organisations.

HLC tries to find material that meets the backgrounds of each person who attends, such as singing the Kingston “ackee” a Jamaican song very much appreciated by many group members, or Greek dancing for the Greek contingent. The one-page profiles also help ensure what is offered is relevant to people as opposed to the “standard activity” you meet in so many clubs.

The programme at HLC reflects the needs and interests of the actual people in the group, and by conducting home visits in advance of the first meeting the volunteers develop an idea of what this looks like for each person. The programme is developed incrementally to incorporate the needs, including cultural needs, of new members. The Club is self-governing and adapts to the changing needs of its members as their condition progresses.

Muriel is a typical example of how volunteers get involved with HLC. It is five years since her sister died, and she’s carried on going along because it’s simply a great place to have fun and connect with people.

Muriel said, “It’s very good at HLC because there’s such a happy atmosphere. When you come in they make you so welcome. Somebody waits outside to welcome you, which is nice. It was a real highlight for my sister coming here: she struggled to enjoy things after she was diagnosed with dementia but she always loved coming here. The other places we tried during the day for her didn’t like us to stay, there was nothing for her to do in those places and she would come home very distressed. But after HLC we both used to go home uplifted. It’s the atmosphere alone, there’s something about here, that it just feels as though everybody’s loved, and that’s the secret when it feels like family.”

HLC values relationships between all the people who attend. We actively facilitate and encourage care that is centred on relationships by helping people to feel a sense of security, belonging, continuity, purpose, achievement and significance.

Members’ comments when asked, “What do you enjoy about the Healthy Living Club?”

“It is really good. It doesn’t matter whether you’re black, white, brown or yellow, everyone talks to each other, no one has anything to hide, everyone is good company.”

“It is very important to me that I come each week, I would be sad if couldn’t come.”

“The Club helps me remember certain things. I feel good coming here, I don’t think about the dementia, I don’t feel confused here. It helps keep my mind strong, I think about the goodness – the club brings goodness to my life. People say I look good after coming here – I feel good too.”

"It's made a real difference to me – I'm shining. I'm talking to so many more people now, at the Club and on the street, both young and old."

"I like it here. It is a very happy place, very kind, they cheer me up, make me feel happy. It is something to get up for."

"The club makes me feel better. I feel included here. It is unbelievable – a gathering of friends. It makes me smile."

"Everyone tries to help everyone, you know you are not on your own."

Impact report

We have used Dementia Care Mapping to evaluate HLC and its impact on members. Here is a snippet from the report:

"As described through some of the examples of personal enhancers listed later in the report, the skill observed from the contributors and volunteers was immense. The evidence shows participants were indeed truly enabled to live well during their times at the club, through good food and drink, fun and laughter, enjoyable exercise, and creative expression. Furthermore the warmth and compassion expressed to club members was evident in the data relating to every interaction."

More information around the dementia care map is available from simonaflorio.hlclc@gmail.com

How does the Healthy Living Club address isolation for people with dementia and their carers?

People with dementia and their carers suffer from loneliness and social isolation to a disproportionate extent, and their human need to connect with others is much more likely to motivate them to venture out than the prospect of participating in "activities". The Healthy Living Club provides a vibrant environment where people can truly connect with each other whilst joining in sessions they enjoy.

Carers and people with dementia are struggling with finding places to go where they feel comfortable and welcome. HLC is free and gives local people with dementia and their carers, who are often in a place of isolation, a social focus every week. It's a place where people feel OK to simply "be".

Usan talked about her mum who goes to HLC. She said, *"We've probably been coming for about two years now, and it's the only time my mum ever goes out. She's a very timid, frightened person. I know she enjoys it because she smiles. And the person I bring here and the person I take home are two different people. This is an absolute Godsend, because if I didn't have this place to bring her once a week I don't know what we would be doing – there is nothing, I mean, summers are all right. You can go sit in the park. I don't know what we'd do in the winter – nothing."*

Where to go for more information

www.healthylivingclub.org.uk

Contact

simonaflorio.hlclc@gmail.com

GOOD DAYS: OUTDOOR ACTIVITIES, DEMENTIA ADVENTURE, UK-WIDE

Current situation: limited outdoor opportunities for people with dementia

The problem which the founders of Dementia Adventure identified was relatively simple: they noticed that once people are diagnosed with dementia and their symptoms subsequently progress, all too often individuals spend too much time indoors. There is a resulting decline in the individual's health and wellbeing, and people have less choice and control over how they live their life.

People living with dementia don't want their lives to be defined by health and social care and their accompanying labels. People are increasingly at risk of isolation because support is based around buildings and they want a much wider range of things to do than what is currently available: there is a lack of genuine choices.

When people with dementia receive support primarily from services based in buildings, they are not getting fresh air and this is detrimental to their physical and emotional wellbeing. It is also difficult for them to connect with their community, or to take positive risks.

The innovation: adventure outdoors for people with dementia

Dementia Adventure was established in 2009 to connect people living with dementia with nature and to give them a sense of adventure in their lives. Founded by Neil Mapes and Lucy Harding, all their services have "nature in mind" and are designed to give people practical ways to continue to live well and to remain connected with the outdoors and the people and places which have previously kept them well.

The work of Dementia Adventure is grounded in the growing evidence base about the benefits of activity outdoors and connection with nature. It works with and supports people living with dementia of all ages and across the full spectrum of the condition. It enables every individual to connect with nature and have a sense of adventure in their lives at one of three levels:

- 1. by supporting activity outdoors (walking, sailing and more)**
- 2. by simply getting people out of buildings into the garden (for a dose of nature)**
- 3. by bringing nature in to people who find it extremely difficult to get outdoors.**

Every one of the 800,000 people living with dementia can be supported meaningfully and positively on one or more of these levels. The outdoors is the original multi-sensory environment and there are limitless ways that activity with nature can be supported and personalised both to the life history of an individual and their current wishes and needs.

Dementia Adventure is a community interest company and generates most of its income from training, research and consultancy services. These services indirectly enable more people to experience adventures with a range of experiential and practical training programmes such as Nature in Mind, Risky Business, Home Outdoors and Creating Outdoor Experiences. Any surplus money generated from these activities is used along with grants and other funds to subsidise the delivery of their direct adventure services. Dementia Adventure is supported by volunteers throughout the organisation, from governance roles on the board through to Park Walk and adventure holiday volunteers. They have a bank of ambassadors, including people living with dementia and family carers, who they consult with on an individual basis to ensure they continue to benefit the community and grow the organisation in the most effective way.

Dementia Adventure provides a range of bespoke and off-the-shelf staff support and development programmes to health and social care and leisure providers of all kinds. These are often delivered in beautiful locations with small groups and use an approach called “Thinking Differently about Dementia” where people are inspired by both inspirational and practical exercises, informed by Dementia Adventure’s own experience of providing adventures. Staff are re-energised and re-connected with a resource they can freely access every day [nature] and staff are then supported to generate personal action plans to start practically connecting the people with dementia in their care with nature.

Dementia Adventure conducts its own research, such as The Benefits of Green Exercise [2011] and Greening Dementia [2013], and writes research-related articles for publication to expand and build on this growing evidence base. It also supports universities to effectively deliver their own research programmes [such as No Limits Dementia].

The research highlighted above is available on the Dementia Adventure website [www.dementiaadventure.co.uk] along with video clips of holidays and outdoor activity via its YouTube channel.

How does Adventure Dementia help people living with dementia at the moment?

Dementia Adventure directly provides adventure experiences for people living with dementia. These range from short park walks through to walking, sailing and white water rafting holidays and international supported family holidays. They do not operate a brochure of holidays, although there are occasional off-the-shelf holidays that people can join. Instead a bespoke adventure service is provided that starts by asking

what people would like to do and gathering people with mutual interests and a similar level of ability to enjoy a break together with their carers and support from trained volunteers and members of staff.

In October 2013 three people living with dementia, their carers and three staff, set sail from Maldon with the Sea Change Sailing Trust.

Audrey spoke of the unbelievable impact the trip had on her and her husband Dennis, who has Alzheimer's disease: *"His mood lifted giving him a sustained energy to tackle many activities and socialise in a more positive way. I benefited from having a rest from caring for Dennis and was given an insight about how I must keep myself healthy, calm, caring and enthusiastic to keep our lives interesting and forward thinking even though we have to face the testing moments Alzheimer's throws up at us to test us both".*

Creating and sustaining Park Walks for people living with dementia

As part of a five year programme to expand Dementia Adventure Park Walks to 50 locations across the UK, People's Postcode Lottery has supported us to develop and deliver Dementia Adventure Partnership Workshops. 'Creating and Sustaining Park Walks for people living with dementia' was launched and we delivered the first of these workshops in March 2014.

Thinking differently about dementia

In January 2014, Neil, together with Andy Bradley of Frameworks4Change, introduced 155 participants at the Association for Dementia Studies, University of Worcester, to a powerful, inspiring and thought-provoking seminar about thinking differently about dementia. 'Thinking differently' involves sharing inspirational multi-media, the latest research and resources as well as expert facilitation and support in getting the best thinking and actions out of each and every individual on the course.

Greening Dementia is a partnership project between Dementia Adventure, Natural England and the Woodland Trust. The purpose was to produce an evidence report into the benefits and barriers to engagement with the natural environment for those living with dementia, and to develop project proposals to test a number of large-scale interventions that improve access to the natural environment for those living with dementia.

How does outdoor adventure improve people's lives?

Dementia Adventure helps people with dementia to remain connected with nature, to have regular opportunities for positive risk taking, and to re-connect with people, places and society. Through Dementia Adventure's outdoor adventures, people can maintain their wellbeing, maintain choices and remain in control and have a life worth living.

Where to go for more information

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CONNECTING PEOPLE

CONNECTING PEOPLE: TRANSFORMING COMMUNITY-BASED SUPPORT FOR PEOPLE WITH DEMENTIA, COMMUNITY CATALYSTS, UK

Current situation: people with dementia experience isolation and impersonal support

The majority of services designed to support older people with dementia at home are provided by organisations in the public or third sectors. Their traditional services are often quite formal, inflexible and impersonal and are based on short visits that give little opportunity for personal interaction. Because these services are provided in such a fragmented way by carers who spend little time in a person's home, someone with dementia is likely to become increasingly isolated. There is often little opportunity for the person with dementia to connect with the community they live in, although there may be many people around them with similar outlooks, lives and needs, and the willingness to offer support.

The Innovation: Small community enterprises, Community Catalysts, UK

What are small community enterprises?

Small community enterprises deliver co-produced and highly personalised support and services which help people stay strong and connected to their communities.

Small community enterprises can offer innovative, flexible and personalised services which help people with dementia remain part of their communities, retain a sense of identity, and engage in meaningful and therapeutic activities as well as providing support in their caring role to family and friends.

Community care and support enterprises are run by local people to support other people in their community who need some help to live the life they want to live. Some of these enterprises have no formal legal structure and make no charge for their services. The majority are run by 1 or 2 people who also deliver the service and make a charge that covers costs and allows

the people involved to take a wage. Most want to stay small and local. A few are more commercial and want to expand and grow. All need a little bit of help to get started and become sustainable, and Community Catalysts supports their development through local programmes and through its web portal Small Good Stuff.

What do small community enterprises do?

Community enterprises provide a very wide range of support and services, including many that fall outside traditional 'care' but are bought by people to enable them to have a good life. The best (and perhaps only) way to describe the value of their work is through individual people's stories:

Sam Edwards' vision was to set up a community support service for people with dementia that would be small and personal. She knew the importance of providing consistency of care when supporting people with dementia and wanted to make a real difference. Her work as a Local Authority First Contact worker had left her frustrated at how little time was available to spend with people and at how prescriptive home visits were. "Your hands were tied. You just couldn't spend the time with people you knew they wanted and, in particular people with dementia, needed so that they could get to know and trust you."

Sam went on to setup Senior Moments (www.senior-moments.info) with a start-up grant of £500 from Stevenage Council in 2011. Her aim was "to help people continue to do the things that they want to do and like to do. It is really important for people with dementia and their families to be able to rely and trust the agency and to know that there won't be multiple carers arriving." Sam states, "Finding out what is important to the person with dementia, their needs and preferences can be a difficult task at times, particularly when there are no family members to contribute."

Community entrepreneurs are drawn from all walks of life and include many people who themselves need some support to live a good life. Some community enterprises are set up by families when they are unable to find the right support for a family member, at the right time and in the right place.

S.T.A.R.S (www.starsdaycare.co.uk) is a small community enterprise set up by a family in Worcestershire when they were unable to find independent, flexible day support for their grandmother with Alzheimer's disease. They decided to respond to the gap by setting up a daytime resource to enable carers to have a break (even at very short notice) as well as providing an opportunity for social interaction and activities for the person with dementia. The service has been running now since 2012. Feedback has been very positive.

"When Dad has been to S.T.A.R.S he comes home with a smile on his face and is in a very positive frame of mind, despite his difficulties. The service at S.T.A.R.S offers Dad a sense of belonging to a small community within which he can contribute and operate. Being the main carer for a person with dementia is demanding on all levels - emotionally, psychologically, physically and spiritually - but the contribution made by the team at

S.T.A.R.S lighten and brighten this load considerably, both for myself and Dad."

Carer Catriona from S.T.A.R.S says, "We are a very small family run company and hope to bring that sense of family into our care. We want to care for each individual as we would have wanted our grandparents cared for and enable each individual to achieve their potential and maintain their sense of identity and value for as long as possible."

Community enterprise also challenges the boundaries between 'providers' and 'users' – people who have in the past been seen simply as people with needs are now getting help to use their often untapped gifts, imagination and knowledge through enterprise.

An example of what can be achieved with a simple mutuality-based approach to dementia care and support in the community can be seen in the Debenham Project in Suffolk (www.the-debenham-project.org.uk): a project in which a rural community has taken responsibility for the welfare and support of family carers and of meeting the health and social care needs of those they care for with dementia.

Lynden Jackson, Project Coordinator, states, "Apart from the GP and the Community Nurse, receiving health and social care involves travelling distances of up to 14 miles. For carers, and those they care for, this creates major difficulties, excessive pressure and distress. When someone is no longer able to live safely and securely in their own home, they have to leave the daily familiarity of their local community in order to move into an extra care facility several miles distant. Inevitably their relationships diminish in time and it is very difficult for them to develop new ones."

In Debenham, services and support have been developed through conversation with local people, using their skills and enthusiasm as volunteers and entrepreneurs. The volunteers are drawn from throughout the community and their skills are supplemented by professional support workers when specialist help is required. For example, the librarian attends the Info Cafe to advise on how to access information that is useful and accurate, and to bring books, material, etc. that are of interest to particular participants. A member of the Suffolk Dementia Advisory Service also attends the Carer's Club and Info Cafe. Many local people have become 'entrepreneurial volunteers', using their skills and resources to set up small enterprises such as the 'pop-up' restaurant which offers an inclusive opportunity for people with dementia and their spouses to enjoy a dinner out.

There are currently 100+ volunteers and the activity groups are near to full capacity offering about 200 person sessions per month. The Project is now providing support to over 60% of the approximately 100 families coping with dementia in the catchment area.

How is the innovation being used with people living with dementia at the moment? What evidence is there of the impact/potential impact?

The examples in the previous section demonstrate just a few of the ways in which local people are setting up community enterprises that offer support and services that help people with dementia stay connected and contributing.

Communication, building relationships and trust are all vital to providing good support for people with dementia. These take time to establish and are harder to provide through more traditional staffed services offering short programmed visits. Small community enterprises are in an excellent position to offer this “slow-care” – they share local links and have time to really get to know the person with dementia, their history, interests and relationships. They use their imagination, passion and gifts to create rich opportunities for people.

Positive Change has developed an arts based reminiscence approach to working with mixed groups of older adults and people with dementia.

Chris Laney from Positive Change had a vision to use her skills and talents as a life coach to create a service for older adults based on scrapbooks and reminiscence: hence the name Treasured Memory Sessions. People are able to sign up for the seven week course and are given a scrapbook to record old photographs and memories. Topics covered include “Getting to know you”, “Friendship”, “Hobbies”, “Travel” and “Family Celebrations.”

The sessions are open to people who are socially isolated to help them gain confidence, make friends, remember their past and celebrate who they are. Chris has also run specific sessions for people with more advanced dementia and there are plans to deliver them to people with early onset dementia in partnership with Alzheimer’s Society. Chris involves volunteers from the local community in running the sessions which has also enabled those attending to develop wider links.

“These sessions have unlocked memories helping us to understand what is important to the person, and their talents and skills. This has been of particular benefit to people with dementia and the staff that care for them” Chris explains.

“By bringing along photographs of themselves people with dementia have been able to recall stories and details about their past which have delighted the group.” Chris recalls, “One lady with dementia came with a picture of herself as a singer in a band. In spite of her memory loss she was able to lead the group in singing a selection of songs from her musical past, delighting everyone. Another lady with dementia was able to use her picture to talk about her work as a seamstress making beautiful dresses.”

Community Catalysts works hard with community enterprises to help them to be clear about the outcomes that they want to deliver and to find ways to demonstrate impact. Inevitably with such individually tailored services, people's feedback and stories are the most powerful demonstrations of impact. Some community enterprises become involved in larger programmes with more formal measures of impact.

Katherine Brown of the community enterprise Beauty and Utility Arts partnered with East Midlands Housing Association at an Extra Care scheme in Lutterworth, Leicestershire to deliver a time-limited intergenerational project involving frail older adults and people with dementia.

The project was designed to help reduce isolation and foster intergenerational relationships. It set measures of impact such as an increase in social activities, new friendships and neighbour recognition, as well as measures of wellbeing.

The project involved 10 children from a local Primary School for the first 4 weeks. Each pupil was asked to sit next to a resident and work with them for that session.

"From that point on, 'project buddies' became inseparable and relationships blossomed." Katherine Brown continues, "The children may only have worked with residents for a short period of time, but the impression they left will be everlasting."

"The young man I worked with wrote a postcard to me. It made me feel very emotional." Ron - resident. "We had a letter from a parent requesting to visit their son's buddy at the weekend." Support Coordinator

For the final 4 weeks, Katherine and colleagues worked with the resident group on artwork and video recordings inspired by a lifetime of memories including stories of gardens, holidays with family, school and riding on the back of motorbikes!

"Now that the project has drawn to a close I can look back and acknowledge that we tackled all of our anticipated outcomes around reducing social isolation, increasing participation and using lost skills, but it was the ones that nobody could possibly have dreamt of that will stay in all our minds; a young boy asking his Mum if he could visit his buddy in his school holidays; the school inviting all the St. Mary's participants to a special assembly and the clear evidence that such a small project has made such a huge impact on those involved," says Katherine Brown.

The Debenham Project developed a number of impact measures with the local community, reporting back on them regularly at community meetings. These include measures designed to demonstrate the level of 'dementia-friendliness' of the village and others around cost-effectiveness and cost-prevention.

The project leader says ‘there is really good awareness of the project and people now come forward to discuss and ask questions about dementia in a more open way than they might have done previously. In addition, more people in the village say that they feel confident and able to react usefully to someone with dementia. The project can demonstrate to the satisfaction of funders its cost effectiveness and the savings that it is delivering by preventing and/or delaying the need for hospitalisation, residential /nursing care, and crisis intervention.

How does the innovation address the problems we are trying to solve for people living with dementia, their carers, and services?

Small community enterprises can and do offer innovative, flexible and personalised services which help people with dementia (as well as lots of other people) remain part of their communities, retain a sense of identity, engage in meaningful and therapeutic activities as well as providing support to family and friends.

Think Local Act Personal²⁹ identifies the importance of *“Small-scale voluntary and independent sector “micro providers” and social enterprises [which] can offer community-based, affordable and niche support to individuals or small groups.”*

However these small-scale enterprises will only flourish in an environment that is supportive to micro-commissioning and community solutions. In many areas the environment created by procurement practices, legislation and regulation designed for larger services crushes innovation and creativity and dissuades local people from using their gifts, talents and passions to create enterprises that will benefit local people with dementia and their families.

There are, however, some encouraging examples of areas that have taken simple actions to support community ventures and enterprises co-produced with people with dementia and their families.

ADASS in “The Case for Tomorrow Facing the Beyond” [2012] suggests that Health and Social Care partners incentivise community-based care and wellbeing services by developing locally-based ring-fenced innovation funds (such as in Leicestershire <http://www.communitycatalysts.co.uk/wp-content/uploads/2013/03/Innovation-Challenge-Programme-Evaluation-Report1.pdf>) to develop ideas and alternatives to traditional services. Some of the community enterprises in this chapter have benefited from just such bursaries which have provided the “start-up” funding to grow those innovative ideas into an actual service.

A number of the enterprises in this chapter have also been supported, in different ways, by Community Catalysts through their micro-market development programme. This programme offers comprehensive advice and help organisations wishing to stimulate and support very small, family and community-based micro-enterprises in their area. For more information about the micro-market development programme see: www.communitycatalysts.co.uk

Where to go for more information

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²⁹ <http://www.thinklocalactpersonal.org.uk/>

CONNECTING PEOPLE: LOCAL AREA COORDINATION

Current situation: complex, crisis-focused systems give poor support

People with disabilities and mental health needs and older people – including people with dementia – often find it hard to understand the system that is supposed to support them. It rarely provides the support they want, and often only kicks in once a person has reached crisis point, leading to inappropriate and unnecessary levels of intervention.

The innovation: Local Area Coordination

Originally developed in Western Australia in 1988 for disabled people and subsequently developed across Australia and internationally, Inclusive Neighbourhoods and the Local Area Coordination Network are now leading the development of Local Area Coordination in England and Wales.

What is Local Area Coordination?

Local Area Coordination is a long-term, evidence-based approach to supporting people (children and adults) who may be isolated, excluded or vulnerable due to age or frailty, disability or mental health needs and their families. It helps them to:

- **Stay strong, safe and connected as contributing citizens.**
- **Build more welcoming, inclusive and supportive communities.**

Local Area Coordination is embedded in the system (building partnerships and nurturing systems change, integration and reform), but delivered/ embedded in the community alongside local people.

In operating and emerging areas in England and Wales, it is increasingly funded from a variety of sources, as part of integration and reform. This includes via CCG, social care, health, public health, fire service and various funding streams. It aims for a co-funded approach across service types.

What does Local Area Coordination do?

The Local Area Coordinator offers a local, single point of contact and helps people to stay strong, solve their own problems and build a good life as a member of their own community.

Rather than waiting for people to fall into crisis, assessing what they can't do and testing eligibility, Local Area Coordination starts in the right place – the start. It does not wait for problems to grow too big, it does not encourage dependency on service-solutions.

It begins by helping people to be as strong and as connected as soon as possible – preventing problems and crises.

The Coordinator takes time to get to know individuals, families and communities well, building a more personal, positive, trusting relationship.

They are a resource to anyone in the community for light touch information, advice or connections to local resources.

They support older people, disabled people and people with mental health needs and their families, and help them to:

- **Understand and nurture their gifts, skills, experiences and needs.**
- **Access accurate, relevant and timely information – choice and control.**
- **Build a positive vision and plan for the future.**
- **Build and maintain valued, mutually supportive relationships – reducing isolation.**
- **Be part of, and actively contribute to, community life – everyone has something to offer.**
- **Be heard through self-advocacy, advocating alongside people, advocating for people if no other options.**
- **Find practical, non-service solutions to issues and problems wherever possible.**
- **Access, navigate and control supports and services, if these are required.**

Local Area Coordinators support:

- **Local people not yet known to services to help build resilience and remain part of their community - staying strong.**
- **People at risk of becoming dependent on services to remain strong in their own community, reducing the risk of needing services.**
- **People already dependent on services to be heard, in control, become less dependent and more resilient in their own community.**

They also work alongside the local community to:

- **Understand, nurture and share the gifts, strengths and opportunities of the community.**
- **Build partnerships for a more welcoming and inclusive community.**
- **Build a positive vision and action for our communities.**

How do people find or connect with a Local Area Coordinator?

Local Area Coordination does not operate a “referral” system. Local Area Coordinators are embedded in their local communities as a local, accessible point of contact.

Rather than waiting for crisis, meeting eligibility thresholds, being referred to (and queuing for) services, people and families can make direct contact with their Local Area Coordinator in a variety of ways.

The recent Thurrock evaluation showed people connecting or being introduced to Local Area Coordinators via self “referral”, the Council’s initial contact service, social workers and support planners across all services including mental health teams, Third Sector organisations, Multi-disciplinary Team meetings [MDTs] based around GP surgeries, The Mayor of Thurrock Council and ward Councillors, direct from the community and meeting people at community events, Community Hubs, housing, police and fire services.

How is Local Area Coordination being used with people living with dementia at the moment?

Rather than focusing on specific service labels, deficits and service responses as the first solution, Local Area Coordination focuses on the strengths, contribution and aspirations of individuals in the context of their home, family, community life and circumstances.

In emerging areas, Local Area Coordination is being seen as a highly intentional approach to supporting people, including older people, to maintain and build supportive relationships, maintain independence, stay safe and build/share their skills and contribution.

Rather than being a time limited “intervention” for a “client”, Local Area Coordinators can both directly support the individual to stay strong and connected and/or support families, friends and neighbours/communities to solve problems and build local resilience, inclusion and contribution.

In some situations, supporting the family to maintain the caring/support role may be the most important support a Local Area Coordinator can provide.

In other situations, it might be important for the individual/family to have someone on their side as they navigate, access and control services they may need.

Sometimes, Local Area Coordinators will work in partnership with services to support and build on specialist interventions.

Instead of having to wait for a crisis for anyone to listen, or until problems get big enough to meet eligibility criteria, older people and their families will be able to talk with their Local Area Coordinator about:

- **What’s important.**
- **Feeling safe and secure in their home.**
- **Feeling confident in the future.**
- **Staying connected with people who are important to them.**
- **Things they would like to share – sharing their gifts, skills and interests with others.**

- **Things they would like to learn.**
- **Things they would like help with.**
- **Finding local, practical ways doing things they want or need to do, including solving problems.**
- **Accessing services.**

Local Area Coordinators know lots about the local community – other people with shared interests, local community groups and associations, community organisations and services. These will provide opportunities for friendship, contribution, support and fun.

There have been many studies and evaluations of Local Area Coordination over the past 27 years. These show that, where effectively designed and supported by strong, inclusive leadership, there are consistent positive outcomes for disabled people and more recently older people and people with mental health needs, their families/carers, including:

- **Increased social networks – reduced isolation and loneliness.**
- **Finding sustainable, non-service solutions to problems.**
- **Feeling more in control of their lives.**
- **Being better informed and able to make decisions.**
- **Feeling more informed about their local community.**
- **Feeling more engaged in their local community.**
- **Feeling more confident about the future.**
- **Feeling more in control of their health and wellbeing.**
- **Feeling more able to share their gifts and skills with others in their community.**
- **Families more able to continue in their caring role.**

Feedback from people has shown they highly value having someone alongside who will:

- **Take time to get to know them well.**
- **Listen, rather than tell or judge.**
- **Be accessible and approachable.**
- **Explore issues and possibilities together.**
- **Help people to find their own solutions, rather than try to fix them with services.**
- **Help imagine and plan a better future, rather than assess for services.**
- **Do what they promise.**

JOAN'S STORY: TAKING CONTROL, OVERCOMING LONELINESS (DERBY CITY COUNCIL)

Joan is a 72 year-old widow. Following the death of her husband two years ago there were numerous referrals and requests made to Adult Social Care for Joan, resulting in assessments and equipment provision.

Whilst on a visit, one agency worker raised concern about Joan's lifestyle and proceeded to refer her to a number of different services. This experience had a significant impact on Joan's confidence and resulted in her becoming increasingly dependent on the original worker, more withdrawn from her natural community networks, and less confident about making decisions for herself, often deferring to the worker for support.

Local Area Coordination was one of the services Joan was referred to. The Local Area Coordinator met Joan and spent time getting to know her. They started to talk about the things Joan wanted from life and they talked about the things that worried Joan, but the majority of the conversations focused on her gifts, skills and interests. Joan talked about the fact that she felt very lonely and so together they drew up a plan of action to address this.

This focus on strengths, interests, local resources and local connections meant that alongside the Local Area Coordinator, Joan was able to connect into local activities and develop relationships with neighbours, thereby reducing her reliance on workers to meet her social contact needs. Joan now attends a 'knit and natter' session in the local library and has been introduced to a neighbour who shares her passion for antiques.

Joan then worked with the Local Area Coordinator to think about her house and together they planned out what she wanted to do to make her home more secure and comfortable. Joan was able to call on her friends and neighbours to make some of this happen. The Local Area Coordinator still calls in on Joan every month for a cup of tea and a chat and Joan is happy to know that the Local Area Coordinator is still around. She also reports feeling more able to cope, knowing that the Local Area Coordinator is on hand should she need support.

"Before the Local Area Coordinator got involved it felt like Joan was being sucked into service world. She was becoming less confident in her own abilities and more reliant on the advice of workers. The Local Area Coordinator helped her take control of her life again and helped her find herself." [Derby City Evaluation, 2013]

At the point the Local Area Coordinator met Joan she was in discussions about moving into supported accommodation. After six months she no longer sees this as being appropriate.

How does Local Area Coordination help people find the support they want, before a crisis happens?

For many people, the service system can feel very complicated and controlling, waiting for a crisis to happen before stepping in to help. For others, as life changes, they can feel isolated and lonely, or find it difficult to contribute or cope.

A Local Area Coordinator is an accessible local person who takes time to get to know individuals and families, sees people as people not problems, has good connections in the community and with services and helps people to stay strong in their community.

Local Area Coordination:

- **Is a simple, friendly point of contact in the community.**
- **Helps local people and their families to:**
 - **Access information and support that may be helpful.**
 - **Stay connected with friends, family and neighbours – overcoming or avoiding isolation and loneliness through real relationships and shared interests.**
- **Helps people identify, nurture and share the gifts and contributions that ALL citizens have – a chance to be part of and contribute to community life.**
- **Finds practical local solutions to problems.**
- **Supports local communities to become even more welcoming, inclusive and supportive – citizens look out for each other.**
- **Helps people to access and control support and services if they need them.**

What people have said about Local Area Coordination

"It's nice to have someone on my side."

"It's really nice to be able to come and talk to the same person face to face."

"My Local Area Coordinator has listened to all the issues affecting me. Normally the Council want to pass me on to someone else; they have helped me deal with all of it."

"The Local Area Coordinator is genuinely interested in me and does not have an agenda. I feel completely in control and that the Local Area Coordinator is on my side. There are things that I have done that I wouldn't have been able to do without the support of the Local Area Coordinator."

"Local Area Coordinators take time to get to know us, our family, our community and our circumstances."

"They support and challenge us to do things for ourselves – this has helped me build confidence, to solve more of my own problems and to need services less."

Where to go for more information

Inclusive Neighbourhoods and the Local Area Coordination Network lead the development of Local Area Coordination in England and Wales. This includes working together to design and make it happen, and opportunities to be part of the emerging national network – building a community of practice.

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Some reading that may be useful

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CONNECTING PEOPLE: FRIEND, FAMILY AND COMMUNITY SUPPORT, PARTNERS IN POLICYMAKING

Current situation: people with dementia are often excluded from planning and policy

Although 'co-production' is often talked about by people involved in providing care and support to people with disabilities, it is rare for people with dementia and their families to be truly involved in care planning and policymaking.

People with dementia and their families have a great deal of experience and expertise to share that could inform better planning but they rarely feel they have a voice. They often feel excluded and have low expectations of the support available.

The innovation: true co-production that includes experts by experience

There are of course different ways of responding to this challenge. We believe that as part of the response, it is important to make an investment in local citizens who can become leaders alongside paid professionals, helping to co-produce local change and ground it in real people's experience, challenges and solutions. This is an initial investment that will pay off in the long term by growing strong, supportive local citizens who can play a range of positive roles with peers and professionals.

Historically it has been rare to make this kind of investment in local people using public services but it pays real dividends when it does happen, going far beyond consultation and stakeholder engagement. However while there has been a long-standing movement for inclusion and independent living for younger disabled people, sometimes leading to this kind of investment in groups of local citizens, this must now include older people.

Partners in Policymaking was developed in the USA in the 1980s by Colleen Wieck and brought to England in the 1990s by Chris Gathercole, Paul Taylor and Lynne Elwell. In 1996 the first Partners course was run in the North West of England, led by Lynne Elwell and supported by Owen Cooper, Martin Routledge and Julie Stansfield. The key innovation of the approach was that it went beyond a carers' course or a stakeholder consultation. It was designed deliberately to create a shared understanding of purpose between an expert by profession and an expert by experience. It aimed to

create a genuine power shift. Instead of the angry cries of “battling with services” or from professionals of “complaining and challenging families”, it focused on true co-production and really brought the meaning of “together we are better” into reality.

The Partners movement aims to:

- **Respect, use and build on the skills of those who are experts by experience as well as experts by profession.**
- **Change the relationship between citizen and state, which means changing how people needing support are seen by those who are paid to commission and provide services.**
- **Shift ingrained cultures, bottom up and top down.**
- **Find a new approach which sees people as whole people, with families and networks and as members of their own communities.**
- **Focus on investing time and money in people rather than systems.**

What is Partners in Policymaking?

Partners in Policymaking is an umbrella name for a suite of leadership development programmes for disabled adults, parents and carers of disabled children, professionals and other service providers working in education, health and leisure. It has developed over the past ten years into a range of programmes and a national network of more than 2000 people – champions who believe that all people should have the right to live the life they choose and who are available to support each other and others. The courses help people understand how the health and social care system works, find solutions to improve people's lives and give participants the confidence to work in partnership to enable them or their loved ones to have choice and control over their lives.

The programmes share common features and are based on the key goals and principles of co-production. Here's how the New Economics Foundation/Nesta defines co-production:

“Co-production means delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change.”

All of the courses bring people together for a number of group sessions, usually over a period of months (some are shorter), building relationships and covering a range of topics. All the courses have been developed to be as accessible, engaging and participatory as possible. We invite a variety of speakers, many of whom have graduated from our courses and share their stories on how they have used the skills they have learnt to make life better for their family and supported others to do the same. Each topic presented includes competencies, why it's important, concept highlights, ideas, suggestions, debates and then some ideas about how the world should work and what that would look like.

Content includes person-centred planning,³⁰ effective communication, personal budgets, options and possibilities in education, housing and health. The courses offer the latest information on policy and legislation that people can use to make a personal and local difference. They develop people's skills, offer tactics, and provide encouragement for people to plan solutions rather than get stuck on problems using effective change management approaches. We make the courses interesting and practical so that whatever a person's background or circumstances they develop ways to make a difference, individually and in groups.

There are variations depending on the local goals and resources of the programme. Some are for disabled people, or people with health issues and families – providing a safe space for people to learn and plan together – but also creating opportunities for them to engage with professionals and organisational leaders and test out their developed skills. Others bring together local citizens and service staff and leaders in order to break down “us and them” from the start, build personal relationships and work together to identify and solve joint local problems and take opportunities. These courses build relationships that have ripple effects long after the courses have finished. Following participation in the programmes, people become part of the national network that In Control supports. The network keeps people linked up to maintain their energy and mutual support. There are now several thousand graduates of the programmes who stay connected.

How is Partners in Policymaking being used with people living with dementia at the moment?

The Partners in Policymaking courses started in order to support people with learning disabilities and their families to escape the exclusion from society that they are vulnerable to. They helped them to build their sense of possibility for positive futures and to develop the skills, tactics and connections needed to achieve this. In recent years the courses have expanded their scope to include other groups, responding to demand from a wide range of people from women caring for their parents, to people with long-term health conditions. It is still rare for older people and people with dementia and their families to be invested like this. We believe, however, that the core principles and methods are very transferable and that with some content adaptation the programmes could make a real difference for people with dementia. The courses have been designed to include and support people whatever their disability, health condition or communication needs. This makes them adaptable to different groups.

There is clear evidence, for example from the [2012 World Alzheimer's Report](#), that people with dementia are very much at risk of exclusion from local communities, low expectations for their lives and limited and poor support options. They could benefit just as much as other groups from programmes that aim to build their influence, power, connections and aspirations. Recent courses have increasingly broken down barriers between groups of people – bringing together people who might have previously been trained or engaged with by different specialist parts of

local public services. Of course people and families don't often fall neatly into these categories anyway.

The versions of the programmes that bring local citizens and professionals together offer a very good opportunity for local people with dementia and carers to co-produce with health, social care and other local professionals and organisations. These courses could offer the opportunity to go well beyond the kind of consultation that typically takes place, which risks lack of creativity, fails to make best use of assets and produces solutions that are not popular or effective. The programmes offer the opportunity for local people with dementia and their families to become real ongoing assets offering a win-win for themselves and the system.

Some of the benefits the programmes have already achieved in disability and health seem strongly relevant to dementia, where formal resources are under great pressure and there are cultures of low expectation.

Shifting cultures

Without good co-production, service systems and families become polarised. Families often speak of battling with or for services and support. Systems follow a process routine which too often defines people by their condition rather than their whole life and which gets the balance between protection and enabling wrong.

There are two cultures that interact that are challenged by Partners:

- 1. The parental culture of services: Services and systems can take a duty of care to an extreme, and in effect take control of the person and their life. People describe being sucked into a care home. Once a person is fully reliant on only statutory support it becomes increasingly difficult for friends and even close family to retain a place in their life. Families describe feeling awkward when visiting people, feeling they have to gain a variety of permissions to enable any meaningful activity outside of the service.**
- 2. The dependency culture: This is where people feel it's the state alone's responsibility to care. They demand that the service looks after all aspects of a person's life so the person loses the opportunity to retain control of their life and build support that is meaningful to them as an individual in their community. Though it is very understandable that people may respond to their circumstances in this way, the result can be inappropriate support and lost opportunity.**

The courses take an asset based approach, encouraging people to look beyond services and system resources. Real Wealth is a concept that describes personal and family assets and resources, and helps people and families review and build these. It also encourages people to engage with community assets, directly and through working with local services and professionals. We map skills and knowledge, people, assets, participation and resilience, and plan how to maximise and exploit them.

CASE STORY: HARTLEPOOL COUNCIL

Hartlepool Council invested in a course specifically aimed at people with mental health-related conditions. The course consisted of 15 people (four staff, seven family members and four people who were direct recipients of support). Susan was one of the family members, who cared for her mum who was living with dementia. Whilst she came with the aim of learning how to support her mum better, within the first two sessions, it was clear to all including herself that her mum's support was actually very good: it was Susan herself who was not being cared for very well. She took on so much responsibility that she was in danger of becoming ill herself and if that occurred the whole support system around her mum would fall down too. As with many carers the need to look after themselves goes onto the back burner as the crisis develops around the person with the diagnosis. Susan was living a treadmill life and felt her life was consumed with dealing with a range of professionals for her mum and in effect fighting to maintain the support agency that provided her with both consistent staff (who had got to know her mum well) and preventing her mum "being put away" which she knew was against her mum's wishes.

Through some of the practical tools used such as solution Circles (a person-centred tool³¹ for change) Susan was able to develop a Circle of Support and a plan for what would happen if she was unable to care for her mum as a contingency, but also to allow her to take a holiday. The change in Susan when she returned for the update six months later was remarkable. Costing no more to the local authority, Susan remained in control of her mum's support, now had enjoyable lunches with her mum, and her own wellbeing had massively improved. She saw the ingredients for success as:

- **It gave me examples of what could be – ideas and inspiration to change the way I was living and caring for mum.**
- **It gave me a kind of permission to seek a Circle of Support for ME!**
- **It taught me that I need to look after myself if I want to look after mum for a long time at home.**
- **The network across the Partners network gave me a new-found confidence. What I didn't know, I would always find someone who would – I have a backup!**

One of the other participants, a trainee social worker, stated: *"This course should be our main training. I have learned more in this course than on any so-called 'dealing with families' courses! And I've learned that it's not about us and them, it's all about 'WE', 'our society' and how we want that to be for people we love who might need support."*

Another typical comment from a professional participant was: *"I have never in my professional training had such up-to-date and inspiring information as I did when I attended Partners."*

CASE STORY: LINCOLNSHIRE

Lincolnshire offers one of many examples where local people and professionals became true partners, identifying and acting on a significant local problem and building trust in the process. A group of 20 mixed participants all agreed the assessment process was not working well. The group consisted of people receiving services, family members and varied workers and professionals. Once we had identified the issue, we pointed out that the people in the room had the ability to redesign it. They did, and presented it to the director who adopted the new assessment method, making a real difference to everyone who came through the assessment process thereafter.

Belonging to a network

As well as direct local impact, graduates from all Partners in Policymaking courses become part of a strong local, regional and national network. This network consists of people who have the skills and confidence they need to help each other plan for the future in a positive way. Many graduates have gone on to get jobs, are using a direct payment or a personal budget and have helped to bring about change by getting involved in local politics, formed support groups, and most importantly have used their skills to make a difference in their own families. Partners graduates are people who are recipients of the service, family members, people who work in the services, work in senior management and executive roles, politicians, lawyers, GPs. The network is a rich and varied group whose focus is rooted in inclusion and people being able to live a full life.

How do Partners in Policymaking enable people with dementia and their families to be fully involved in creating good services?

How can Partners programmes help solve the problems we have identified – challenges faced by both people and families and by professionals and public services? These challenges are, we believe, fundamental if we are to have the public services that people want and need and that service staff want to be part of.

The courses equip people and families in a frightening new world of diagnosis, service and exclusion to:

- **Make a positive impact upon their own circumstances through being heard properly by those important to their lives and support (including families and services).**
- **Increase their ideas about positive and possible futures, not limited to what is currently available and on offer.**
- **Access knowledge and information about ways, means, approaches and mechanisms to get what they want and need in their lives.**
- **Gain skills and tactics allowing them to influence positively their own and others situations, including engaging effectively with services and professionals.**
- **Connect with others for mutual support.**

For professionals and services, Partners offers:

- **The opportunity to ground local strategy and service development in a deep understanding of the lives of people with dementia and their carers, based on co-productive exploration of issues and solutions and going well beyond consultation.**
- **The chance to build preventative and asset-based approaches through close engagement with people's lives and close exploration of better value approaches that would meet needs and aspirations in non-traditional ways.**
- **The development of cohorts of people who can play leadership roles in ongoing co-production with public services and act as exemplars and supporters for other local people with dementia and carers. They often provide an inspirational vanguard that can be the grit in the oyster for positive change.**

The courses and network offer a magic mix of information and inspiration. They erode the divide between experts by profession and experts by experience so all join together to focus on a local vision. To hear what graduates say about the programme follow this link: <http://www.in-control.org.uk/what-we-do/partners-in-policymaking/what-people-are-saying-about-partners.aspx>

Where to go for more information

Contact

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For more detailed information follow the links below:

About Partners in Policymaking
Volunteering: unlocking the real wealth of communities
Using real wealth to make plans
About coproduction
Barbara's story

The National Audit Office report on oversight of user choice and provider competition in care markets

Ipsos MORI survey of the experiences of users of personal budgets in adult social care

World Alzheimer's report 2012

³⁰ <http://www.igf.org>

³¹ <http://www.helensandersonassociates.co.uk/>

CONNECTING PEOPLE: CIRCLES OF SUPPORT, ENGLAND

Current situation: people living with dementia can become lonely and socially isolated

Whether they live at home or in residential care, people with dementia often become lonely: their condition can make it harder for them to maintain existing friendships and connections and other people may gradually stop including them in the social, family and community activities they enjoy.

This has implications not only for the person with dementia's emotional wellbeing: it can also lead them to rely on paid support even though there are plenty of people around them who would like to be involved in their life, and this paid support is rarely personalised.

The innovation: Circles of Support

A Circle of Support is a group of people who meet together on a regular basis to help somebody accomplish their personal goals in life and it can help someone living with dementia. The Circle acts as a community around that person [the 'focus person'] who, for one reason or another, is unable to achieve what they want in life on their own and decides to ask others for help. The focus person is in charge, both in deciding who to invite to be in the Circle, and also in the direction that the Circle's energy is employed. A facilitator is trained and matched to the focus person, and the facilitator becomes responsible for ensuring the Circle is working towards its purpose. A Circle of Support is a natural and human way of organising support that is of benefit to the person, to the people who participate in the Circle, and to the wider community.

Although the focus person's goals are the primary drive in everything the Circle does, the relationship is not just one way. Circles of Support are beneficial not only for the focus person, but to the other members of the Circle, who are also linked together through this collaborative network of support. The members will also all have diverse gifts and interests, and there can appear many new opportunities and possibilities that had not even been considered before forming the Circle. Because of this, an important function of the Circle is to regularly re-visit the plans they are working with, to keep the direction current in terms of what the person really wishes to achieve.

Most people who have a Circle of Support say that from the first meeting of their Circle their lives become so much bigger. People suddenly realise that they have a group of friends that have genuine interest in supporting them to reach and fulfil their dreams and aspirations. The difference between a

Circle of Support and a group of friends is that the Circle is focused on one person. Circles are particularly significant for those who might otherwise be isolated and find it difficult to build an informal, unstructured network of support on their own.

A Circle of Support can change a person's life by providing an individual with the confidence to dream and plan for the future. In a move towards personalisation, a Circle of Support uses person-centred thinking tools to support the Circle to achieve its purpose and carry out any actions that are decided upon. The approach of a Circle of Support differs from other schemes in that it empowers the person at the centre of the Circle: they are ultimately in control of the members of their own Circle and the shape and direction it will take. Circles adapt to individual, rather than just community, needs. This is a key reason why this method of support is so unique.

A Circle of Support is not a service or tool that can only be applied to a certain group of people. Circles are adaptable and are about seeing people as individuals who feel they need support in order to take more control over their own lives. A properly facilitated Circle of Support is empowering to all of the individuals involved and, unlike many service systems, does not reinforce dependence. Circles have supported disabled people, people with learning disabilities, younger people, people with mental health conditions, as well as people living with dementia. Because of their flexibility, Circles can be personalised to meet the requirements of people from a wide variety of backgrounds.

Circles have been given a variety of names and follow different models such as: 'Self-Directed Support Corporations', 'Microboards', 'Circles of Support and Accountability', and are similar to methods of organising like 'Family Group Conferencing'. While there are some important differences between these ways of organising, they're all based on a radical form of subsidiarity – taking decision-making power directly to the point closest to the people who will be affected by that decision. These methods have been shown to encourage independence, increase resilience and self-reliance, encourage creativity in planning, delivering support in a way that makes sense for the person, and also an increasing use of 'natural' supports.

Their flexibility means that Circles of Support can be in place to offer short-term, long-term or even life-long support. They also offer a cost-effective method because they build upon existing networks of friends, family members and volunteers; paid facilitators may or may not be included. The idea of a Circle of Support was developed in Canada, spread fairly quickly through North America and early Circles in the UK began in the mid 1980s. Between 2011 and 2014 we delivered the Circles of Support project in partnership with NDTi and Innovations in Dementia, who have both been central to its development and implementation, and we continue to work with people with dementia in our Community Circles pilot project. Delivery has taken place in partnership with many organisations in the involved site areas. We have also promoted partnership working through bringing different organisations and groups together, within this project, to discuss how they can work together to improve support and develop and embed preventative approaches for people with dementia within the project areas.

*“this is a
unique way
of working”*

Community Circles

In 2012, Community Circles adapted the Circles of Support model to explore how Circles could be developed at scale across the UK to provide even more people with the opportunity to develop their own Circle. The Community Circles model is not a radical departure from previous Circles work, it is an attempt to learn from the best that this work has achieved, and to apply this learning in the context of the movement towards personalisation in health and social care. Community Circles is an application of the Circles tradition in a new context, combined with a resolution to spread their benefits more widely, and using **person-centred practices**,³² as well as person-centred planning, to work towards positive change.

Community Circles recognises the powerful tendency in present day society to become socially isolated, and attempts to prevent it. The model recognises that people experience deep social isolation and loneliness even in circumstances where paid help, healthcare and support is present in their lives, as typically these paid interventions are focused on priorities other than the need for human connectedness. Community Circles has run a successful pilot project across the North West over the course of the last two years, developing Circles for people living with dementia who are living in residential care homes, as well as people with learning disabilities.

Community Circles employs Circles ‘Connectors’ to identify people who would like a Circle of Support, as well as to recruit and train volunteer Circle facilitators from a number of different areas. The model works on the understanding that when provided with the necessary training and support, facilitators can be recruited from across society and no prior knowledge of person-centred thinking is necessary. Facilitators are then matched to a Circle based upon a number of criteria, namely shared interests, availability and geographic location. By increasing the accessibility of Circles facilitation to those outside the world of services, Circles can be utilised much more widely across society. Indeed, in order to expand the outreach of Circle of Support into the wider community the Connector collaborates with other provider organisations, local and national businesses as part of their commitment to corporate social responsibility, universities, faith communities, care homes and other community groups. This unique way of working ensures that Circles aren’t restrictive in regards to who they are available to, and allows people from a variety of different backgrounds to become involved with Circles.

How do Circles of Support help people with dementia?

Circles of Support improve the accessibility and options for long-term social care by focusing on prevention, personalisation and partnership delivery. We have focused on working directly with people with dementia, alongside their families and friends, using person-centred approaches to help them develop Circles of Support, connect more with others and build their own networks. A key part of the approach has involved people with dementia identifying their goals and changes they want to make in their own lives that will help to support them to live well, and working with them in ways that they want to support them to meet these goals.

MARTIN'S STORY

One example of a person with dementia we have helped through a Circle of Support is Martin, who is in his early 80s and was diagnosed with dementia several years ago.

Although Martin had a great deal of loving support from his wife and family, he felt that he would like to take part in more activities locally – and also meet new people, especially during weekdays which were often quiet as most of the family were at work. Martin and his family have been involved in the Circles of Support project since their initial contact in 2012. Since that time, his situation has changed quite significantly. Martin's dementia has progressed and he now needs more support. Over the same time period, Sophie (Martin's wife) has had some serious health issues which has meant that she needs a much greater level of support in caring for Martin – and also in looking after her own health.

A member of the project team became a Circle member and facilitated links to information and local resources including other people in the area with shared interests and experiences. She also supported the Circle in coming together and identifying opportunities and resources to help Martin to continue to do the things he wants to, and more recently, help Sophie to get the support she needs to recover. Both Martin and Sophie have met new people and Martin is continuing to take part in activities with the Circle's (and other people's) support. The work of the Circle is ongoing – we are in contact with each other over time and able to adapt our approach to help to respond to Martin and Sophie's changing needs.

WILLIAM'S STORY

Another example of a person we have helped through a Circle of Support is William, who is in his 70s, lives with his wife Ann, and has memory problems and a number of physical health issues, including Ataxia, which affects his mobility and balance.

William became involved in the Circles project through a Memory Advisor and at our first Circles meeting, William told us: 'I'd like a mate'. William and Ann also felt that it might be helpful if they could find someone to go for a walk with William (and possibly the dog). This would allow them to spend short periods of time apart, doing things independently. We looked at different opportunities for William to meet and make new friends and talked about these at the Circle meetings.

The following areas have been progressed through William's Circle:

- **Alison (from the Circles project team) introduced William and his wife to Martin and his wife and daughter, who all then arranged to meet for coffee. Martin and his family had (as part of his Circle) identified that he would also like to meet new people.**
- **Linking William and Ann up to local volunteer organisations who offer one-to-one befriending support for William, accompanying him on walks.**

- **Joining the local ‘Self Directed Support’ (short term breaks) scheme where paid carers can be employed for up to 20 hours per quarter at a subsidised rate.**
- **Being involved in other projects and activities, including memory cafés and gardening clubs.**
- **Providing advice and support for Ann on the best approaches to use when caring for someone with memory loss.**
- **Making practical arrangements such as Careline, to help keep William safe at home when on his own.**

MIRIAM’S STORY

In Stockport, Community Circles has developed a relationship with a residential care home for people living with dementia, and has supported the development of Circles of Support for a number of residents. Miriam’s story shows how Circles can support people to engage with activities that are important to them.

The residential care home in which Miriam lives, enables people to have two hours each month to be supported by a staff member of their choice to go out and do something that matters to them. Miriam used her time to go to church, but she can only get there once a month. Miriam’s Community Circle provided an opportunity to increase the time that Miriam could spend doing the activities that she enjoys.

Through initial conversations between Miriam and the other Circle members, the conversation turned to drinking wine, singing and gliding, all of which are important to Miriam. Together, by conducting a person-centred review, the Circle worked out what it made sense to focus on. For Miriam, this could have been finding ways to support her to be a greater part of her faith community by going to church more than once a month; looking at taking up singing again; or finding a way to get into a glider!

It was decided that the Circle would focus on singing, and the first thing the Circle did was to think about people who could support them to achieve this. At the second meeting, the Circle got together to discuss the progress they had made since their last conversations. They had investigated some local choirs and discussed with Miriam the opportunity to attend a singing group at a local church. It was decided that Helen, the Circle facilitator, would join Miriam at The Stockport Community Choir on Sunday afternoon. Here we see the true reciprocity of a Community Circle. Not only has Miriam re-engaged with an activity that is important to her, but Helen has also started singing again, something that she may not have thought about until she became part of Miriam’s Circle.

LYNDA'S STORY

Lynda is a woman living with dementia in Rochdale. Lynda and her husband Alan heard about Community Circles at the Carer's Resource Centre in Rochdale, and decided that a Circle would be really useful to them both.

Lynda is warm, kind, welcoming and patient. She has been married to Alan for over 30 years, meeting as childhood sweethearts. They have two grown up sons and two grandsons. Family is really important to both Lynda and Alan and delight spreads across her face when she talks about them. One of the first things that Cath did in her role as Lynda's Circle facilitator was to develop a relationship map to help Lynda think about the people in her life and who she would like to invite to her Circle. As a result of the relationship map, Cath was able to call some of Lynda's friends and family to invite them to Lynda's Circle. At the first Circle meeting, the family joined in via Skype and friends came filing into the living room with a delightful energy that comes from people coming together for a common purpose. The purpose of Lynda's Circle is to maintain her friendships and support her wellbeing.

In the meetings that followed, the Circle has evolved and has led to some really positive actions that support Lynda and Alan in their everyday lives. Alan mentioned at a Circle meeting that one of the things he would like some support with is cooking. In the past, Lynda had done most of the cooking but it is a role that Alan has decided to take on. The Circle members chatted about what good support could look like for Alan, and have decided to develop a casserole club. This simply involves the Circle members making an extra portion of food for Alan and Lynda when they are cooking, that Alan can store in the freezer. The Circle members work together and swap recipes, a wonderfully simple yet inventive solution to Alan's cooking problems.

Lynda's story really captures the diversity and unique identity of Circle of Support: through simple discussions, positive, personalised support can be provided to Circle members, in a cost effective and very natural way.

Moreover, we know that two of the three key objectives of the National Dementia Strategy are 'Peer Support' and 'Improved range and quality of support services'. Circles of Support could help to improve outcomes in these areas.

Peer Support

One of our main findings has been the importance of connections in the lives of people with dementia and how crucial good connections are to the health and wellbeing of people living with dementia. Unfortunately, connections with others are often lost following a diagnosis of dementia and it can be very difficult for people with dementia (and their carers) to make new connections. As a result, much of our work within this project has been in supporting people to try and reconnect with people in their

lives, or make new connections – often people have identified that they would like to have closer connections with people who are living in the same situation as them.

As such, the project is contributing to developing peer support, not only directly for the people involved in Circles, but also by sharing the stories of how people have been supported to do this and by the wider lessons we are learning and sharing in how people with dementia can develop their connections.

Improved range and quality of support services

We have been involved with work to develop new groups or to help to strengthen and consolidate existing groups within the project areas, where these groups help people with dementia strengthen their Circles of Support, widen their connections and help them to take part in activities they want to do. This has increased the range and quality of support services available within the areas concerned.

Throughout the project, we have been supporting people on an individual basis within their Circles to benefit from support and opportunities that may have been available in their communities, but which they had either previously no knowledge of, or had been very difficult for them to access, often for very practical reasons. In these situations this has not involved increasing the range of support services overall, but it has increased the range of possibilities for those individuals by finding practical ways for them to be able to take part in activities or opportunities. We have also worked within each of the areas to connect different groups and organisations with each other where we feel that this will lead to mutual benefits and also support the longer-term development of different services and types of support for people with dementia.

Assessing the impact of Circles of Support

Our work has concentrated on finding out whether Circles of Support, or any of the elements often used in this type of approach, can help people with dementia to live well in their communities – and on identifying and achieving goals and changes which will help this to happen.

We have also been concerned with ascertaining how 'traditional' Circles of Support may need to be adapted or flexed to best help people with dementia to live well within their communities and enable their families and friends to support them in doing this. We have therefore been aiming to develop practical and useful models of supporting people with dementia within this work. Over the three years of the NDTi project [2011 to 2014] we have worked with 39 people with dementia and their carers, families and wider networks to try to develop Circles of Support. We have worked with 23 of these people on an individual basis and a further 16 within small group settings where we have explored how helping to develop and sustain groups can help natural Circles to form and support people with dementia to identify and meet goals/make changes they want to, while providing mutual support to each other.

We have also recently started to work with another organisation (Age UK Isle of Wight) who, as part of the 'Dementia-Friendly island building', are using Circles as an approach to help people to stay connected and improve the quality of life for people with dementia and their families.

In addition, we have been supporting the establishment and development of other groups which support people living with dementia, particularly through our work in Hampshire (where we have worked with the organisers of two groups for people with dementia and carers) and through our work with the Dorset Dementia Friendly Communities Teams to support the planning and establishment of groups within one locality. Prior to this project, Circles of Support, as an approach, had not been used extensively with people with dementia in the UK.

How do Circles of Support address the problems we are trying to solve for people living with dementia, their carers, and services?

Circles of Support are about empowering people to make positive decisions about the support that they receive in their lives. In the past, Circles have supported disabled and disadvantaged people in ensuring their voice is heard and that they are included in decisions about their lives. Circles of Support help those who are excluded or isolated, who live with physical disability, learning difficulties, mental health issues or disadvantage. A Circle of Support is a very simple idea but one that has far reaching impact and benefits for everyone involved. A Circle catalyses creativity, energy and commitment to help the focus person dream, dare and do, to overcome constraints and lead a rich and inclusive life. We believe Circles of Support are the most important tools we use to provide self-sustaining, emotional and practical support, problem solving and companionship. Through the project we have been tracking outcomes for each of the individuals and groups involved. Some of the outcomes that have been seen include:

- **People with dementia being supported to express their views and goals, and being supported to achieve them.**
- **People with dementia being supported to get out more and take part in activities they have identified they want to do, including one-off visits, regular activities and holidays.**
- **People with dementia and their carers being able to spend more time independently of each other, helping ongoing relationships, reducing carer stress, and supporting wellbeing for both the person with dementia and their main carer.**
- **Meeting and connecting with more people, particularly those in similar situations who can offer support, guidance and empathy.**
- **Families feeling closer, more supported in their roles and as a consequence better able to support the person with dementia and their main carer.**

- **Groups becoming established and more sustainable, providing ongoing support and opportunities for people with dementia, their carers and families, to live well.**
- **The influence of this work goes beyond the individuals who have been working to develop a definite 'Circle'. Staff feel that the Circles approach and the person-centred planning tools have helped them to think more holistically about other people who they support.**
- **Helping people make a start through one or two small changes (e.g. meeting one person, resolving a practical problem) has boosted confidence and given a sense of purpose to Circles of Support that has become established in later life.**

Where to go for more information

www.community-circles.co.uk

Facebook: Community Circles

Twitter: @C_Circles

Word Press: <https://communitycirclesblog.wordpress.com>

Some reading that may be useful

We have also written a number of research papers, which can be accessed through the following links:

Circles of Support and Personalisation - <http://www.imagineactandsucceed.co.uk/Agenda/Circle-of-Support-and-Personalisation.aspx>

Community Circles - <http://community-circles.co.uk/community-circles/>

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

CONNECTING PEOPLE: SUPPORTED VOLUNTEERING

Current situation: people with dementia are often excluded from communities

People with dementia have gifts, talents, enthusiasm and experience and many would like to play a part in their community. However, a diagnosis of dementia often seems to exclude people from volunteering despite the contribution they can make to all kinds of projects, and the value they derive from volunteering themselves.

What is supported volunteering?

Supported Volunteering enables people with dementia to use their gifts, skills, talents, experiences and passions as volunteers to make a valued contribution in their local communities.

Originally developed by Volunteering Matters with people with learning difficulties and disabilities, supported volunteering is increasingly seen as an approach available to any citizen with additional support needs, whatever their age or impairment.

Since 2013 Volunteering Matters has undertaken project work alongside In Control to consider how supported volunteering may work in ways that sit within today's person-centred social care system, where people with support needs have choice and control. This project is known as "Contribution Through Volunteering."

What is Supported Volunteering?

Supported volunteering seeks to enable those individuals who have additional support needs to take an active role in their communities as volunteers alongside their peers and thus:

- **Stay strong, safe and connected as contributing citizens.**
- **Help to build more welcoming, inclusive and supportive communities.**
- **Provide good outcomes as specified by those agencies responsible for citizens' health and wellbeing – the local authority and the NHS.**

What does Supported Volunteering do?

Supported volunteering offers a strong, supportive relationship between:

- **A project worker, usually a paid member of staff, employed by Volunteering Matters or a local third sector organisation with appropriate expertise in supporting volunteers. Their role is to**

initiate, lead, manage and review the project. They have overall responsibility for the recruitment and support of volunteers with and without additional support needs and for liaison with others with an interest in community action and support for people with dementia.

- **Volunteers with identified additional support needs.** The emphasis here is on the gifts, skills, talents, experiences and passions which a volunteer offers: the project works with the person to make the most of these gifts, skills, talents, experiences and passions, in order to find ways of bringing them to the surface and making use of them where they are needed. The “additional identified support need” concerned might relate to any form of physical, emotional or psychological impairment which makes it more difficult than otherwise for the person to make a valued contribution.
- **Volunteers without additional identified support needs, sometimes referred to as the support volunteer.** Once again the emphasis is on the gifts, skills, talents, experiences and passions which the volunteer offers: here the person is matched with one or more volunteers with additional identified support needs who have a similar set of gifts, skills, talents, experiences or passions. They then provide practical and emotional support, mentoring, advice and (where appropriate) training. Sometimes they share work in a volunteering setting with the person and work alongside them; sometimes they oversee and guide a small group of volunteers in a particular setting. They make sure things are progressing smoothly and seek to help to address any difficulties people may encounter.
- **Peer mentors in the role of support volunteer.** This is a potential progression for many individuals who have been supported previously, and enables them to further utilise their skills and experiences by mentoring someone else.

Supported volunteering assists people to consider how they wish to contribute to their community, whatever difficulties they may have or barriers they may face; and it seeks to identify opportunities for them to make that contribution.

It enables people with and without identified additional support needs to:

- **Understand and nurture their gifts, skills, talents, experiences and passions – as well as their needs.**
- **Choose where and in what way they can best make a contribution to their community.**
- **Build a positive vision and plan for the future.**
- **Build and maintain valued, mutually supportive relationships – reducing isolation.**
- **Be part of, and actively contribute to, community life – the clear and unambiguous message is that everyone has something to offer.**
- **Find practical, non-service solutions which “address needs” in innovative ways through supporting active contribution.**

It also provides a new set of talent for the wider community and showcases the contributions of people who are too often regarded as dependent.

Supported volunteering works alongside the local community to:

- **Understand, nurture and match the gifts, skills, talents, experiences and passions of citizens for the wider benefit of all.**
- **Enable people to regain and/or retain their health and wellbeing for as long as possible.**
- **Build relationships and partnerships between citizens from different segments of communities.**
- **Build a positive, welcoming and inclusive vision for community life.**
- **Inspire more community members to make a valued contribution.**

How are they being used with people living with dementia at the moment?

Supported volunteering projects are only just beginning to extend their reach to work with people living with dementia. For over 30 years, Volunteering Matters has supported people aged 50+ to engage in their communities through volunteering via RSVP (Retired and Senior Volunteering Programme), and in many instances this has included older individuals using their assets to support more vulnerable older individuals – with dementia becoming a more common condition for both the recipients of the support and the supporters themselves. As such, Volunteering Matters has piloted some work which focuses on volunteering and dementia, and which has led to the development of the supported volunteering approach within this field.

In Stockton-on-Tees, we consulted with volunteers on our Get into Reading programme, individuals with dementia, carers, carer organisations and the Dementia Collaborative Group regarding supported volunteering. Locally, Volunteering Matters has supported people with dementia through volunteers engaging in reminiscence and reading work. Evaluation of the three-year Get into Reading programme found:

'participants experienced cognitive activity and stimulation [in] at least 410 instances ... 392 instances of improved mood. Managers... noted positive impact on the wellbeing, memory and behaviour of the participants ...'

- **31 volunteers read with 85 people living with dementia.**
- **90% reported better concentration and social interaction.**

Every person consulted on supported volunteering for individuals with dementia felt that it was a good idea, best suited to those experiencing the early stages of dementia, and that the professional training of volunteers would ensure they could support the unpredictability of the illness. Unanimously, people felt that one-to-one support was crucial for consistency and to ensure the success of the activity: 'each individual requires support tailored to them'.

Volunteering Matters has further explored this approach to engagement in volunteering in the London Borough of Camden, where Volunteering Matters has a successful volunteering programme for older people – The Camden Networkers. It was identified that approximately 100 of our volunteers had been diagnosed with or were showing signs of developing dementia. They were all continuing to contribute to their communities through volunteering on this programme. However, several older people in the more advanced stages of dementia were not able to take up this opportunity. Volunteering Matters partnered with a local Dementia Care Home and carried out a small pilot to test how these individuals could be engaged, and if peer support would be effective and have benefits for both parties in the relationship. People just diagnosed with dementia or showing signs of developing dementia volunteered to provide support for a group whose illness was at a later stage within the care home. They were asked to identify activities with the residents and co-ordinate these, including opening them up to the wider community, family and friends to reduce stigmas around dementia – this was particularly effective within the minority ethnic communities we were working with.

Particularly successful activities were the games, a gardening group and music-based group events. Residents were able to participate as instigators of activities, not recipients, shaping and hosting them for their families and friends. In the gardening group, individuals reminisced about memories from their past, and shared them. Informal feedback showed that for those who were acting as volunteer mentors, the volunteering helped them to accept their diagnosis, removed fear and contributed to their wellbeing. For those who would have traditionally been the recipients of the activities, they were engaged, happy, involving family and friends previously isolated to them. In all, a positive image of dementia was being portrayed.

Volunteering Matters are now building on the learning from this work to ensure that the supported volunteering model works well for people with dementia. Where this model is in operation for other groups of people, independent evaluation shows:

- **90% of physically disabled volunteers felt happier and 66% physically better.**
- **93% of learning disabled volunteers had increased independence.**
- **65% felt more in control.**
- **58% of volunteers with mental health issues improved their mental health.**

Feedback from disabled people³⁰ on the importance of the support role: Talking about awareness in supporting people to understand what opportunities are available for them to get involved in disabilities: *“Being a volunteer gives self-esteem and confidence – a sense of purpose and makes me happy.”*

Talking about skills – it takes time to get to know individuals well and support them to identify their skills and assets, rather than focusing on what they can’t do: *“Help to build my skills up so I know what I want to do and how to do it – I want to do things properly and well.”*

Talking about the personal and listening rather than telling or judging, and enabling individuals to develop their own goals and identify their own volunteering possibilities: *"I need to be included in decisions; it's about what I want."*

Talking about how to be accessible and approachable, and support volunteer involving agencies to open up their opportunities in more accessible ways: *"I have learnt empathy, self-advocacy, understanding and how to support others."*

Talking about policy – rather than providing services, enable people to find/ contribute to their own solutions: *"I'm doing something I'm interested in and I want to pursue [my goals and dreams]."*

Stories – the experience of volunteering

These quotes are verbatim.

"I have Lupus and some other conditions, mainly related to effects of many years of medication. I am now nearly 70 and sometimes I am very worry about my memory, I try to keep active and reading, doing brain exercises. But the best for me is helping other people; it helps me to feel alive and is very rewarding when I can see the impact of my volunteering in other people's life. It change my life too, I forget about the pains. As I was worry about my brain I try to learn about dementia, I attended Volunteering Matters training in Camden and it was wonderful to be less afraid and be able to talk to other people about what we can do to help ourselves and keep our brain working but, above all to keep happy. I learn how important it is to have an end of life care plan, a will and a memory book. I received lots of information from our Coordinator and try to use them keeping an eye about stress, anxiety, healthy food. One of my best friend have dementia now, but I feel less afraid of it. " Volunteer

"I am 68 years, but am having problems remembering something done yesterday, when I was alone this condition worried me, as I did not used to keep remember the appointments I kept and so I missed them. But now, I am learning to keep the calendar – big in colour- I take the medication, try to keep busy, talking to people in my own language, try to learn new things, very practical ones and I enjoy doing some memory exercises and games that I learn with the volunteers group. I feel worry about my memory sometimes, especially because I am living alone." Volunteer

This individual was an active volunteer for many years, and the impact of her volunteering has led to the people she supported and volunteered with supporting her now: *"My mum is 87 and developed dementia. She is a happy women despite her memory problem, she used to attend the community events, she was volunteering with the dance group and enjoy every social with music and dance; sometimes she didn't recognise her friends but still she enjoy the group. Most recently she becomes more fragile after an operation and we have to move her to a care home. She is visited frequently by the volunteers and she enjoy singing and listening music with them. I appreciate that very much." Daughter of a Volunteer*

How do they address the problems we are trying to solve for people living with dementia, their carers, and services?

For many people a diagnosis of dementia can be frightening and sometimes overwhelming. Many feel isolated and lonely. Partners or family worry about “losing” the person they know and love.

And there is little doubt that society at large tends to the view that a diagnosis of dementia means the person is now and for evermore dependent on others for most if not all of their needs, and that their days of “making a contribution” are over.

When supporting someone with dementia to volunteer it is important that time is taken to get to know the individual and families, in ways that regard them as people not problems, with views, feelings and something to offer. It is also important to bear in mind that the person (and their partner or family) may not themselves start from this perspective: we are all subject to the received views of society at large.

In most cases, initial contact with the person and family will be through the paid project worker. It will be their job to match and to introduce the support volunteer to the volunteer they will be partnering with and their family, and to make sure that things are established on a sound footing and in due course are proceeding well. It will be for the support volunteer and their partner to establish a sound and supportive relationship. And it should by no means be assumed that support is all one way: many people in the early and middle stages of dementia remain willing and able to offer loving kindness to new people in their lives; and experience suggests that in many cases support volunteers benefit enormously from the relationship.

Supported volunteering will:

- **Provide a simple, friendly, open response to people with dementia, with a focus on those who are newly diagnosed; and perhaps invite them to think about making a new relationship with a support volunteer.**
- **Give people who are affected by dementia and their families the opportunity to reflect and plan:**
 - **Think back on their life to date, and take stock of their gifts, skills, talents, experiences and passions.**
 - **Make a plan for using these things to the benefit of others. This might be one element of a larger life plan, support plan or person-centred plan.**
 - **Take account of the views and comments of their partner and other family or friends in this process.**
- **Help people to find a place in their community where they are invited to draw on their gifts, skills, talents, experiences and passions for a wider purpose.**

- **Provide assurance that they are welcomed and understood by that place, that they are happy to be working there and that others are appreciative of their contribution.**
- **Support local people and places to become aware of the contribution made by these volunteers so they become even more welcoming, inclusive and supportive over time.**
- **Provide an eye on volunteers' challenges and achievements, check that they remain safe, well and happy and that appropriate action is taken where not.**

What people have said about supported volunteering:

"My confidence has improved and my social skills ...without [Volunteering Matters] I would not have got anywhere and would be sat at home bored with nothing to do."

"I am volunteering to be happy."

"Helping people makes me feel good."

"I feel a sense of achievement in doing something to contribute..."

Where to go for more information

www.volunteeringmatters.org.uk

Contact

jmindham@csv.org.uk

Jemma Mindham, Business Development Manager

T. 07724 069518

³³ Gathered from participants in a CSV/NDTi consultation event in the Disability Strategy in 2012 and seminars held by DRUK in 2013/14

A close-up portrait of an elderly man with his hands clasped, looking thoughtfully at the camera. The man has a gentle expression and is wearing a light blue shirt. The background is a soft, out-of-focus green. The text "CHOICE AND CONTROL THROUGH PERSONAL BUDGETS" is overlaid in the upper left quadrant of the image.

CHOICE AND CONTROL
THROUGH PERSONAL
BUDGETS

CHOICE AND CONTROL THROUGH PERSONAL BUDGETS: IN CONTROL, ENGLAND

Current situation: people with dementia often have services applied to them, rather than being in control of their own support

Currently many people living with dementia feel they have very few options for support. If their funding comes from the NHS the only options previously available to people have been through an agency, care or nursing home chosen by NHS staff. People have needed the support and felt obliged to take what was available but there were often difficulties.

With some home help support, people found there was such a great turnover of staff that they had no idea who would turn up. Every day different staff might come into their home to give often quite intimate support and people were often unsure what time staff might arrive, or staff arrived at inconvenient times for the family. This created added stress to the person, their family and their carers.

What is a personal health budget?

Personal budgets have been available in social care since 2008. There is a developing range of materials showing how they can be of benefit to older people and people with dementia. For more information see Getting Better Outcomes for Older People using Personal Budgets from Think Local Act Personal: <http://www.thinklocalactpersonal.org.uk/News/PersonalisationNewsItem/?cid=10549>

The Alzheimer's Society have also recently updated their factsheet:
– see http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=141

Personal health budgets are now being introduced by the NHS to help people with long-term conditions and disabilities manage their care in a way that makes sense to them.

A personal health budget is an amount of money to support your health and wellbeing needs. You are able to have a say over how this money is spent to meet your needs. You can have as much or as little choice and control as you want and you can use a personal health budget to pay for a wide range of items and services.

People have options of how to take and manage their budget. You can have:

- **A direct payment, which is cash in lieu of the service you would have received.**
- **A notional budget, where no cash exchange takes place but you know the amount you have to cover your health and care needs and work with your lead health professional so they can buy in the services you choose to meet your health and wellbeing outcomes.**
- **A third-party arrangement, where another person, group or organisation (independent of the individual and the NHS) hold the cash on your behalf; some people with dementia already have advanced directives to enable a formal trust to manage their affairs, others have chosen a set provider to hold their funds.**

The NHS is keen to make personal health budgets available to people who can benefit from them. As with anything new it is important to get it right, so their introduction is being phased in after successful testing. The first group of people to be eligible are those with NHS Continuing Healthcare needs. Since October 2014 everyone who is eligible for Continuing Healthcare has had the right to have a personal health budget, if they want one. Some clinical commissioning groups (CCGs) are already making personal health budgets more widely available and have extended the option of a personal health budget to a wider group of people with long-term conditions, which includes people with dementia. There are now requirements of CCGs relating to personal health budgets and eligible people using Continuing Healthcare, which include:

- **A duty to consider any request for a personal health budget.**
- **A duty to inform eligible people of their right to have a personal health budget.**
- **A duty to provide information, advice and support in relation to personal health budgets, for example:**
 - **What the eligibility criteria are.**
 - **What the local offer is.**
 - **What the process of getting a personal health budget is.**
 - **What support is available.**

Recent NHS planning guidance places expectations on CCGs to achieve a major increase in the uptake of personal health budgets and, where appropriate, personal budgets that cover both people's health and social care needs. Advice from [NHS England](#) sets out groups of people that might especially benefit from personal health budgets as this expansion rolls out. This includes people with long-term health conditions and high support needs – which could include many people with dementia.

How are personal health budgets being used with people living with dementia at the moment?

Personal health budgets have the power to transform services and lives. To do this though they must be introduced in the right way, giving people true choice and control. When people know how much their services cost and are given the opportunity to use the money differently, they have often found creative and very personal ways to achieve the outcomes they seek.

Over 80 per cent of people surveyed said a personal health budget has had a positive impact on their quality of life and in arranging their support, because:

- 1. They put you in control of decisions about your care and support.**
- 2. They should help you get a better, more personalised service from the NHS.**
- 3. Your care and support is delivered in a way that makes sense to you, rather than a one-size-fits-all approach.**
- 4. They allow you to combine your expertise and experience of what works best for you, with clinical expertise, to get the best health support to suit you.**

The evaluation of the personal health budget pilot programme is at: www.phbe.org.uk

Two case stories

MALCOLM'S STORY

Personal health budgets have already started improving the care and quality of many people's lives across England, especially those with the highest levels of ongoing care needs. Take Colin's Dad, Malcolm, for example. Instead of going to a day centre where he was not happy and the centre found his dementia hard to manage and relied on medication to calm him, his personal health budget allows him to be supported at home, to reduce his medication and specialist health input and to be calmer, safer and more content. There's a link to Colin's story at the end of this chapter.

LOUISE'S STORY

Louise is another example of someone who has been helped by a personal health budget. She has Alzheimer's disease and was diagnosed 15 years ago. She has great difficulty communicating her needs and is difficult to understand. She also has chronic physical health problems and as a result is totally dependent on others for her personal care and day-to-day needs. Before a personal health budget Louise needed frequent stays in residential homes. These tended to rely on agency staff who were, in Louise's daughter Mary's opinion, poorly trained and overworked. Mary was constantly worried about her mum.

Louise was very ill and wanted to spend her final months at home rather than in a nursing home. Mary contacted her primary care trust (now called a CCG) for help and they suggested a personal health budget. The budget has paid for a team of personal assistants (PAs) who cover shifts from 8.00am to 6.30pm every day at home and Mary and her husband care for Louise during evenings and overnight. A local user-led organisation helped with staff recruitment and payroll and advised on employment legislation. The budget also contains an allowance for osteopathy for Louise as well as a laptop for the PAs to use to record Louise's food and fluid intake, blood pressure and temperature, as well as respite care so Mary and her husband can have a break. Every four weeks the budget is transferred to a bank account for Louise as a direct payment.

Mary said: "Since my mother has had the personal health budget we have never looked back. Her quality of life has increased exponentially. Vivality, because of the expert care she receives, my mother has not required any emergency admissions to a nursing home or the hospital. All in all my mother now lives a fulfilled and contented life. She is so much happier."

There are many other stories like these; they are stories of people's lives and those of their families being transformed by having more control over their support. There is also evidence of some savings to the NHS or of much better value for money, which can be found in the national evaluation: www.phbe.org.uk.

Positive results for commissioners

As well as benefits to people and their families, PHBs can have positive results for service commissioners. People with a personal health budget were found to make less use of unplanned care than those receiving commissioned services, making personal health budgets a cost-effective way of delivering care. People also reported feeling more in control of their care with a personal health budget, and put much of the improvement in quality of life and psychological wellbeing that the evaluation identified down to this increase in control. Budget holders also reported being able to integrate their physical and mental health needs more easily with a personal health budget. Those who had a personal health budget for mental health reasons felt that their physical health also improved and vice versa and the evaluation team concluded that personal budgets were an important vehicle for integration between health and social care.

"her quality of life has increased exponentially"

How do personal health budgets address the problems we are trying to solve for people living with dementia, their carers, and services?

When people can use their funding flexibly, they can get the support they need without disrupting natural family support or being moved away from family and friends. One of the major dissatisfactions with traditional healthcare was the unreliability and inflexibility of care agencies and the lack of alternatives to residential care (Davidson et al, 2012). Though agencies and residential homes have to meet standards they rarely work to fit in individually with people's and their families' lifestyle. They cannot

guarantee the same staff at the same time of day, and therefore staff do not develop an enhanced relationship and knowledge about the person and their family.

When people use a personal health budget to buy their own team or equipment to support and enable better natural networks, they both retain control of their support and maintain that support and its consistency for longer. International studies have highlighted that from a family perspective, the core of good care comes from knowing the individual and family rather than formal qualifications [Doty and O’Keeffe, 2010]. This is backed up by Vidhya Alakeson, who looked at people who have directed their own services, and saw strong evidence that the approach is a cost-effective route to increasing their confidence and control, improving their satisfaction with services and increasing their quality of life. (She wrote about this in “Delivering Personal Health Budgets”.)

Where to go for more information

NHS England PHB delivery team have a huge range of stories, information and evidence on their website: www.england.nhs.uk/healthbudgets

In Control is a national charity that has pioneered the concept and practice of personal budgets and self-directed support. It offers a helpline to people needing advice or information on getting a personal budget. Contact: 01564 821 650 or info@in-control.org.uk

In Control also publishes a leaflet that includes frequently asked questions; you can get the leaflet at: communications@in-control.org.uk or telephone 01564 821 650.

People Hub runs a national peer network for people who have direct experience of personal health budgets either as an individual who has one or as a family carer.

The Health Foundation evidence scan collates more than 60 articles about personal health and social care budgets in the UK and internationally. The purpose is to provide a brief synopsis of evidence to help gauge the level of research in this field so far.

NHS Choices Davidson, J., Baxter, K., Glendinning, C., Jones, K., Forder, J., Caiels, J., et al. [2012]. Personal health budgets: Experiences and outcomes for budget holders at nine months. Fifth interim report. Department of Health / Personal Health Budget Evaluation team.

Clare Goodchild wrote a report on the challenges and solutions for personal budgets for people with dementia. This can be found at: <https://www.mentalhealth.org.uk/publications/personal-budgets-people-dementia>

Dr Benedict Rumbold and Vidhya Alakeson wrote the book Personal health budgets: Challenges for commissioners and policymakers. It can be found here: http://www.nuffieldtrust.org.uk/publications/personal-health-budgets?gclid=CJLg1_vC7MMCFWL3wgodDmQADQ

Vidhya Alakeson also wrote: Delivering Personal Health Budgets, a guide to policy and practice, and Putting Patients in control: The case for extending self-direction into the NHS.

Smith, G., O'Keefe, J., Carpenter, L., Doty, P., Gavin, K., Burwell, B., Williams, L. [2000]. Understanding Medicaid home and community services: A Primer. Retrieved October 18, 2011 from U. S. Department of Health and Human Services website: <http://aspe.hhs.gov/daltcp/reports/primer.htm#noteC1-25>

The National Institute for Health and Care Excellence (NICE)'s guidance

Colin's story: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2427&pageNumber=5