

MAKING IT REAL

for people with dementia

MAY 2013



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About Making it Real

Think Local Act Personal (TLAP) launched *Making it Real: Marking progress towards personalised, community-based support* on 17 May 2012. This resource aims to help organisations move towards more personalised and community-based support by providing them with practical steps to make personalisation a reality.

The *Making it Real* programme was developed and co-produced with members of TLAP's National Co-Production Advisory Group, which is made up of people with experience of using services and carers from across the country. The resource consists of a series of 'I' statements, which describe what people might say if personalisation was working well for them.

Making it Real is divided into six themes:

- **Information and advice:** having the information I need, when I need it
- **Active and supportive communities:** keeping friends, family and place
- **Flexible and integrated support:** my support, my own way
- **Workforce:** my support staff
- **Risk enablement:** feeling in control and safe
- **Personal Budgets and self funding:** my money.

Each theme is supported by 'in practice' statements, which are examples of good practice or service features that show an organisation is making good progress towards personalisation.

Introduction

A considerable number of organisations have already signed up to *Making it Real*. To support them TLAP has been asked to provide more help and advice on how *Making it Real* can work in practice for people living with dementia and their families and carers.

TLAP is certain that person-centred approaches work for people with dementia, as good practice is already evident in the best care homes, domiciliary services and community-based supports. However, it wants to ensure that the ideas in *Making it Real* are accessible, practical and easy-to-use for everyone.

This document aims to show how *Making it Real* can be a useful tool for commissioners, providers, families and communities to help ensure that people with dementia can live well and independently for as long as possible. The work was developed with a cross-sector steering group of experts including carers and people with care and support needs.

The context

Making it Real aligns with other national policy and initiatives around dementia. The National Dementia Strategy (DH 2009) sets out 17 key objectives to support people to 'live well' with dementia. These include:

- ◆ Raising awareness of dementia and reducing stigma
- ◆ Early diagnosis and support for people and their carers
- ◆ Better information and access to improved and flexible support services, including peer support
- ◆ A more informed and effective workforce
- ◆ Joint working between health and social care.

The Prime Minister's Dementia Challenge (2012) sets out three key areas of action:

- ◆ Improving care and health services
- ◆ Improving research into dementia
- ◆ Creating dementia-friendly communities.

Making it Real in the community

There are 800,000 people with dementia in the UK, and this is set to rise to one million by 2021. Two thirds of those are living within the community (Alzheimer's Society statistics 2012).

This document therefore tries to strike a balance between making personalisation work in more traditional settings like residential care, and new and innovative ways to support people in the community. It also looks at how everyone can play their part in nurturing truly 'dementia-friendly' communities.

One theme running throughout this document is the need to look beyond health and social care services. For most of us, living a full life is often dependent on our ability to access and enjoy local facilities and activities. However many people with dementia face barriers to carrying on as they did before they developed memory problems. We need to look at housing and the wider built environment – including transport, parks, leisure, libraries and community activities, as well as the private sector – shops and businesses.

Another theme is the importance of social networks and interaction with others. Being connected and having social support is vital for everyone's wellbeing, Wilton (2012) gives an overview of the literature. It is of added importance to people with dementia, as there is evidence that having contact with relatives and the wider community can slow cognitive decline (Zunzunegui et al 2003). Some research has even suggested that being isolated could double the risk of cognitive decline (Yevchak et al 2008).

Making it Real for busy managers

One of the positive aspects of *Making it Real* is that it is not being forced on anyone. It is being driven by the sector and was developed by people with experience of using and running services. Most organisations that initially signed up to *Making it Real* were not able to tick all 26 'I' statements to begin with – they are aspirations. Signing up to *Making it Real* just means you are committing yourselves to moving in the right direction. Many organisations describe their work around *Making it Real* as a 'journey' towards personalisation. It is a tool that can help you to think about the strengths in your organisation or community and build on them, as well as identifying areas for improvement.

Everyone who has been involved in developing this publication has agreed that the original 'in practice' statements in *Making it Real* are relevant to people with dementia. However, some could be more challenging to implement than others. For example, it was felt that care homes might find it difficult to achieve the outcome: '*I can plan ahead and keep control in a crisis,*' as often, a move to a care home can be the result of a crisis. Another challenge identified was the issue of implementing personalisation in domiciliary care when some commissioners are still using traditional 'cost and volume' service specifications rather than thinking about quality outcomes.

Both issues demonstrate that one organisation or individual cannot necessarily achieve all the aspirations in *Making it Real* on their own. The whole system needs to change and take the messages on board. The first issue highlights the need for early diagnosis and support so that people and their families are able to plan for the future. The second shows that commissioning needs to change to reflect the needs and wishes of people with dementia. *Making it Real* encourages you to do your bit and to try to get others to do theirs. Locally, investing time in partnership-working to influence others might end up being an important element of your action plan, if that is one of the main barriers to progress.

Making it Real also recognises that people with dementia are not a single group and may have multiple health issues or different cultural needs.

People in later life have varied experiences, but assumptions are often made about them that do not reflect reality. Some people live independently in the community into their 80s and beyond, whereas some younger older people need assistance relatively early in life.

– Audit Commission 2008

Making it Real and co-production

Just because people have dementia this doesn't mean that they don't know what they want.

– Sally Percival, Carer and member of the National Co-production Advisory Group

Co-production is an essential part of *Making it Real*. It describes both the practice and philosophy of working closely with people with care and support needs to ensure that services are designed and tailored around what they want. Put simply, organisations providing a service can only achieve so much on their own. For the service to work, the mutual co-operation of people both using and providing the service is essential. There is growing evidence that this type of approach leads to better, more efficient and more cost-effective services, as well as happier, more motivated staff. More importantly, it leads to better quality of life for those supported (Wilton 2012 and Building Community Capacity).

Effective communication is essential to co-production and whilst there may be communication challenges in co-producing with people with dementia, it can be achieved.

Many of the case studies in this publication highlight ways that people with dementia and their families and carers are being involved in decisions about their care or in how their community

can be more 'dementia-friendly'. Other case studies show how organisations are investing in their staff and promoting person-centred practice in the way people with dementia are supported.

People with dementia have told us about the very real impact of their increased reliance on others when they have been used to some freedom and self-determination. When they seek help, it is more effective when they feel that help is offered by staff who understand their difficulties, but also their need for self-determination and the right and freedom to make their own choices.

– Steve Milton, Innovations in Dementia (Local Government Association 2012)

Communication is of course more than just words. People can communicate what they want through behaviours, body language and key words. Building relationships and reflective practice is vital – as is always questioning why someone is behaving in such a way. It is also important to see the person's whole life, their memories, past experiences, skills and interests, as well as their current needs and abilities.

Life history is important – if you don't understand the person you're looking after, you can't look after the person.

– Ian Turner, Registered Nursing Homes Association

Our expert panel also wanted us to stress that working with families, carers and communities to support a person with dementia can be described as 'co-production' – as long as the person supported is at the centre. Many of the case studies in this publication describe creative ways to engage families and carers.

Making it Real in practice

The following sections take you through the six themes of *Making it Real*. There are suggested additional statements to describe what good ways of working look like 'in practice'. These aim to complement the original *Making it Real* statements.

Each theme is enhanced by case studies and personal stories to show how personalisation can work for people with dementia. The 'top tips' come from comments made by our expert panel during a series of workshops that TLAP held to develop this publication. A useful list of resources is also available on the *Making it Real* website to support this document.

Information and advice: having the information I need, when I need it

This generation is going to be more knowledgeable and better prepared than previous generations, and people will be diagnosed or will acknowledge their condition earlier. The information needs to be there to support them to make more informed choices for the future.

– Marjory Broughton, Carer, Co-chair of Think Local, Act Personal and member of the National Co-Production Advisory Group

People told us that a community could become more dementia-capable by... [providing] more accessible information about local services and facilities... There is a lot that can be done to make the physical environment easier for people with dementia by making signage and directional information simple, clear and uncluttered, and by improving lighting and use of colour contrast.

– Local Government Association, 2012

What this would look like in practice:

- ◆ People with dementia and their carers are able to access a range of quality information about dementia and the supports available
- ◆ High quality support planning and advocacy is available from diagnosis
- ◆ Information about the benefits of staying connected to others is promoted
- ◆ Information about community activities, leisure and transport is available and accessible in a range of formats, and not just relying on a website
- ◆ There is a strategic approach to providing information as part of creating a dementia-friendly community. This involves making all information that people need to live an independent life accessible. For example, how to use a bank or navigate a shop
- ◆ The role of people working on the front-line is recognised, and awareness training is provided – for example, in shops and community facilities as well as for health and social care staff.



Case study: Advice and brokerage (dementia advisers)¹

The role of support planning and brokerage for people with dementia is crucial. It helps people navigate the care system and promotes the benefits of maintaining connections with friends, family and the wider community and supports them to do this.

The Alzheimer's Society has developed a dementia adviser service which has been piloted in 22 areas across England. The service was set up following the publication of the National Dementia Strategy (DH 2009), which recommended that all people with dementia should have access to a dementia adviser following their diagnosis.

The role of the dementia adviser includes:

- ◆ Providing ongoing advice, information and support to people with dementia and their carers
- ◆ Developing a personal and tailored information plan with people with dementia and their families
- ◆ Connecting people with dementia to support and / or services
- ◆ Helping people to navigate the system successfully.

One carer who used the service in Central Lancashire said that the adviser was, '*like her lifeline, and she would not know who to talk to if she wasn't there*' (Alzheimer's Society 2009).



Case study: Information that is important to people with dementia²

Innovations in Dementia is a Community Interest Company (CIC) working nationally with people with dementia, partner organisations and professionals. Their aim is to develop and test projects that will enhance the lives of people with dementia. In 2009 they ran the 'Start Making Sense' project, which aimed to:

- ◆ Look at how information can be presented in a helpful way for people with dementia
- ◆ Encourage people with dementia and their allies to ask for accessible information
- ◆ Raise awareness of the rights of people with dementia to accessible information.

They recruited a group of people with dementia from London and the South East to discuss what information they needed to live independently. The conversations centred around information on shopping, using public transport and going to sports, leisure or arts venues. It wasn't just about health and social care. This showed that a broader approach to 'better information' is needed.

¹ www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=1083&pageNumber=2

² www.innovationsindementia.org.uk



The group also identified different sources of information that they use. These included newspapers and magazines, advertisements, flyers, leaflets, maps, TV and radio, and friends and professional advisers. This highlighted the importance of providing information in different ways to ensure that everyone is able to access it – rather than just posting something on a website.

The group stressed that each person is different. They also agreed that some issues are more difficult for some people than others, like using the internet. Many people had given up using activities that they found too confusing – for example, using public transport or going to the theatre. Others found that staff in their local shops were very helpful – especially if they were told that their customer had Alzheimer's disease. However, some people felt that asking for help could be difficult if staff didn't have the right attitude or training.



Case study: Care homes as 'brokerage hubs'

St David's Care Home in Norfolk is using its communal areas as 'brokerage hubs' for people in the local community. Sheringham is a rural area with many isolated older people. This initiative helps to bring them together in one place so they can get support from peers and access information and advice about self-directed support, personal budgets and other social care, household and leisure services. They have also held open days and tea parties, which have attracted people from the local community. By providing a useful local information service, the initiative also helps to link up the people living there and the activities happening outside.

Other care homes around the country also offer free meeting rooms to local groups to encourage more interaction with the local community.



Case study: Bringing organisations together to share knowledge³

Home Instead Senior Care Wimbledon and Kingston took an innovative approach to improving the availability of information and communication between organisations in the local community.

Rather than focus entirely on developing her own service, which could be expected of a relatively new provider, owner Clare Jefferies and her team organised an event for the community that got people together to make connections, share information and build relationships with each other. They hired a local church hall halfway between the two councils and invited local branches of voluntary organisations, local service providers such as mobile meals and solicitors, and the police, health colleagues and local councils to set up information stands. Their aim was to help local people better understand the local resources that are available to them. In total, 25 exhibitors took up stands.

Not only was this initiative very useful to members of the public who were potential service users, but an unexpected benefit was the wonderful atmosphere of co-operation and pleasure in meeting and getting to know potential colleagues during the course of the day.

– Home Instead Senior Care Wimbledon and Kensington



TOP TIP: Making sure your staff have the right information to pass on⁴

A good way to ensure that information on community resources is available is through 'community mapping' training for staff. The National Development Team for Inclusion (NDTI) has developed practical training for front-line staff and teams. It shows how staff can map and build links with existing community groups and how team managers can get people to work together to share information with one another and develop 'specialisms' in areas they are interested in – for example, sports groups, hobby groups, coffee mornings, and arts and crafts.

³ www.homeinstead.co.uk/wimbledonandkingston

⁴ www.ndti.org.uk/how-we-do-it/training/inclusion-programme/community-mapping



Case study: Whose Shoes? Interactive e-resource⁵

Whose Shoes? is an interactive tool that is widely used across health and social care settings to open up ‘crucial conversations’ about personalisation. It aims to help people work together for positive change by allowing them to ‘walk in other people’s shoes’, and is aligned to Making It Real themes and ‘I’ statements. By discussing difficult issues in a relaxed environment, people can work through the practicalities of Making It Real and co-produce local solutions.

The tool looks at issues from different perspectives and contains many scenarios that are relevant to people living with dementia and their carers. Any new material is co-produced with a wide range of partners, often through discussion at Whose Shoes? workshops, in a true spirit of co-production.

One group that has contributed is the EDUCATErs group (Early Dementia User’s Co-operative Aiming To Educate). This multi-agency project includes NHS Stockport, Pennine Care NHS Foundation Trust, Stockport Council’s Adult Social Care, Age Concern and the Alzheimer’s Society. But most importantly, it puts ‘experts by experience’ at the centre of dementia training and policy formulation. Gill ran a Whose Shoes? session with the Dementia Champions group in Stockport, which included a group of EDUCATErs, as part of Dementia Awareness Week. The EDUCATErs told the group what it is like to live with dementia and discussed issues specific to younger onset dementia.

5 <http://nutshellcomms.co.uk>

Active and supportive communities: keeping friends, family and place

We need to think more broadly than family, and look at engaging with programmes such as volunteer befriending schemes and faith groups.

– Clenton Farquharson, Co-Chair of Think Local Act Personal and member of the National Co-production Advisory Group

The ability to create and develop relationships with others is crucial to our well-being... There is nothing about dementia that changes this: indeed, the increasing dependency on others, which inevitably accompanies dementia, emphasises rather than detracts from the need for supportive relationships with others.

– Nuffield Council on Bioethics

One of the key elements of delivering the best possible care and support to the client with dementia, is knowing and understanding the person in front of you... to discover what they like/dislike, what they like to eat, what their hobbies are, where they used to live and work, etc. By gathering this vital information over the weeks, our care workers build a good understanding of the person they are caring for and this enables us to make their care unique and personal. It also helps them to interact with their clients on a personal and social level.

– Bipin Patel, Managing Director, Caremark Wokingham & Bracknell

What this would look like in practice:

- ◆ There is a strategic local approach to making the community 'dementia-friendly'
- ◆ Local facilities and services are accessible and people with dementia find it easy to get out and about and live independently and well for as long as possible
- ◆ Local groups and businesses are welcoming to people with dementia and people with dementia are able to make a contribution to their community

- ◆ It is part of the role of support services, including in residential care, to support people with dementia and their carers to make and maintain friendships and connections in the community
- ◆ People's history, interests and links with carers, family and friends are at the heart of support packages for people with dementia.



Case study: Developing 'dementia-friendly' communities⁶

The Local Government Association's Ageing Well programme commissioned Innovations in Dementia to work with two councils in England – Sheffield and Hampshire – to support them in developing dementia-friendly communities. They worked closely with people with dementia in these areas to explore what a dementia-friendly community might mean and what it would take to achieve.

Their report (Local Government Association 2012) defines a dementia-friendly community as one where:

- ◆ The greatest number of people with dementia are able to live a good life
- ◆ People with dementia are enabled to live as independently as possible, to continue to be part of their community and are met with understanding and given support where necessary.

During the project, people with dementia said that dementia should be 'normalised', and that others needed to know more about it. They said that a community could become more dementia-friendly if there were local groups for people with dementia and their carers, and more accessible information about local services and facilities. They also believed it was necessary to make mainstream services and facilities more accessible for people with dementia.

Crucially, when asked what they were interested in doing, they did not mention accessing traditional services. Instead, they wanted to:

- ◆ Pursue hobbies and interests
- ◆ Go out more
- ◆ Make more use of existing local facilities
- ◆ Help others in their community by volunteering.

The report stresses that basic dementia-awareness training is needed for all staff working in front-line roles in services such as housing, customer centres, leisure services, libraries, transport, adult education and in local businesses. For customer-facing staff in leisure and retail premises, this awareness-raising might be as simple as being trained to know what to look out for and how to help, whereas other staff might need more training, depending on their role. A toolkit with a business case, engagement methods and tips on awareness-training is included in the report.

⁶ www.local.gov.uk/ageing-well

Dementia-friendly communities are also ones where the built environment is sensitive to people's needs, for example, where signs in town centres, shops and other public places are easy to understand. The report highlights this: '*lighting, colour, layout and shape affect people's cognitive ability to understand where they are and what they should be doing*' (Local Government Association 2012).



Case study: Supporting and nurturing skills in the wider community⁷

Community Catalysts is a CIC established by the charity Shared Lives Plus. It works with councils, PCTs and service providers to stimulate and support the development of small scale, non-traditional models of care and support. It is currently supporting a gardening project in the East Midlands called the Ace of Spades Community Gardening Company. Dave and Sarah started the company as they have both a passion for gardening and skills and experience in delivering care services. They offer support to people to get involved in gardening and horticultural activities. The service promotes physical and psychological well-being by supporting people to work outdoors, to interact with the natural environment and maintain what may have been a lifelong hobby or interest. The service is also provided in care homes as a way of engaging the people living there who may have an interest in gardening at the same time as keeping the gardens well maintained.

Community Catalysts' role is to identify and nurture people with great ideas like Dave and Sarah's, and help them get their idea off the ground. This makes the most of passions and talents in the local community that can be harnessed to help people with care and support needs.



TOP TIP: linking with national initiatives like Dementia Friends⁸

The Alzheimer's Society has recently launched its Dementia Friends initiative. The scheme aims to make everyday life better for people with dementia by changing the way we all think and talk about dementia and by encouraging citizens to offer help and support to people in their community with dementia. They are aiming to recruit a million people across the country by 2015. Dementia Friends will be a friendly face in the community and can offer a range of support where necessary from helping someone who might be struggling to get on the right bus to volunteering on a more regular basis. Dementia Friends will also have a role in raising awareness locally and could be really useful assets for home care, NHS staff and other formal support services to link in with.

⁷ www.communitycatalysts.co.uk/case-studies/innovative-people-with-an-ace-up-their-sleeve

⁸ www.dementiafriends.org.uk



Case study: Peer support networks⁹

Community Catalysts and Walsall Council are supporting the development of a dementia support group in Streetly. Local resident Diane Cleary, who has been supporting her sister who has dementia, started the group. She wanted to provide an opportunity for people with dementia and those who care for them to meet up and offer each other support. She also wanted them to enjoy a range of activities together, where people could feel like families and not just carers.

It's a real role reversal. She's my big sister who used to look after me. It saddens me that a part of my sister and our relationship is lost. But this is why I wanted to set up a group to help support myself, my sister and others in our situation.

– Diane Cleary



Case study: DemenShare social media resource¹⁰

DemenShare.com is an online social media resource and peer support network. It is designed for people who have been diagnosed with dementia, their carers, families, friends, professionals or anyone with a personal interest in dementia in central and eastern Cheshire.

DemenShare.com provides access to information and online help 24 hours a day. It aims to build local peer support networks and allow individuals to find and share information and resources to help those living with dementia to remain independent and enjoy an improved quality of life. It was launched in October 2010 and by April 2011 had 281 registered users.

One example of how helpful it has been is that of a lady whose husband has dementia. She posted a message on the site saying that she was worried because her family was coming to visit and the grass needed cutting. Another member replied and recommended someone to cut the grass who lived nearby and was very trustworthy. This not only took the pressure off the carer, but also reassured the wider family that she was able to cope.



Case study: The Good Care Group and reminiscence work

Recently, James, from the Good Care Group worked for two weeks with a gentleman called Doug, who is living with dementia. James understands that people with dementia rely heavily

⁹ www.communitycatalysts.co.uk/case-studies/streetly-dementia-support

¹⁰ www.DemenShare.com

on past memories, and that reminiscing can be a very positive and healthy activity. He noted that Doug often seemed 'lost' during the day, and struggled to maintain conversations about things that were happening here and now. James realised that when he brought out photographs found in an old drawer, Doug was able to talk animatedly about some of the people or places in the pictures.

He spoke to Doug's family, who were able to fill in even more of the blanks. In fact, they named people and places that were captured in the photographs, and prompted Doug's memory of these treasured past events.

James bought a photograph album, and spent an hour each evening with Doug, gluing the photographs in place and giving them labels that were meaningful to Doug. He found that Doug had particular favourites, which seemed to spark 'glory stories' about the 'good old days'. He noted that Doug would go back to these photographs over and over, never tiring of telling James the tales he remembered. He put gold star stickers next to these very special photographs, so that other carers or family members could guide Doug to them and elicit these wonderful stories, which helped him to come back to life.



Case study: Nursing home in Yorkshire is a community resource

Stamford Bridge Beaumont Nursing Home in East Riding (Yorkshire) strives to be seen as a community resource, with the older people who live there regarded as active citizens in their local neighbourhood.

They have created a cafe for the community to use, where the home's catering team is supported by people who use services with dementia to bake cakes and make, serve and sell soup, tea and coffee. There have been three pilot days linked to special events in the home and the success of the enterprise has led to plans for a regular fortnightly opening.

In addition to this the consultant psychiatrist uses the home as a base for a memory clinic, the Alzheimer's Society uses one of the lounges for regular Singing for the Brain sessions that welcome individuals from the whole village, and York University has allocated nursing students to the home to produce life story books with individuals on a dementia journey and these collections have been published. The home has worked with schools to develop children's books – Visiting Gran's/Grandad's New Home – that help young children understand dementia and why their grandparent might need the support of a nursing environment. The home also offers flexible day care to support families who care for older people at home and need short breaks during the day for appointments, shopping and social meetings. These can be from one hour upwards and can be booked at short notice in case of emergencies.

Flexible integrated care and support: my support my own way

We need to work with commissioners and the wider system to get it right.

– Tom Owen, My Home Life

The personal health budget contains an allowance for osteopathy for my mother, as well as gloves and aprons for the personal assistants. It also includes funds to buy a laptop for the personal assistants to use, enabling them to input information systematically about my mother's food and fluid intake, her blood pressure and temperature. Before the laptop, this was arduous and all written by hand. The budget also enables us to pay a suitable nursing home to care for my mother so I can take respite for a few days when I really need it.

– Mary from West Sussex shares her story about having a personal health budget,
Personal health budgets

The key word here is integrated. The co-ordinated involvement of Doctor, District Nurse, Day Centre and charity support (Alzheimer's Society), all falls within the remit of a quality homecare agency. We ensure there is constant feedback from care workers on the ground in addition to regular assessments of our clients' requirements. All this is essential to keep pace with the progress of an illness such as dementia. By anticipating changes and communicating them clearly to family, the changes, when they do occur are likely to be less shocking.

– Carl Ward, Managing Director, Caremark Kingston

What this would look like in practice:

- ◆ There is easy access to a range of care and support services
- ◆ Services are joined-up and work seamlessly together
- ◆ People with dementia and their carers are involved at every stage of the support planning process



- ◆ People's changing needs are regularly reviewed and monitored – care provision is not just seen as the end point
- ◆ Assessments take people's strengths and assets into account as well as their needs. This ensures they can maintain as much independence for as long as possible
- ◆ Organisations have a culture of 'giving it a go' and staff are encouraged to have confidence to enable and support people, rather than simply having a set of tasks to do.



Case study: Larry deals with Early Onset Dementia

Larry Gardiner's life changed drastically after he was diagnosed with vascular dementia at the age of 50. A busy father of three with a highly paid international career, Larry and his family and colleagues had noticed that his memory was going. He began to forget about projects he was working on and he would become intensely frustrated by forgetting simple things such as where he had parked his car.

My wife began to notice I was having problems. I was being clumsy and I felt very tired and confused all the time. After a series of mini-strokes and subsequent health complications I ended up in a wheelchair in my bedroom, isolated from everyone and thoroughly depressed. It was no life for anyone. My wife needed a partner, a husband, a lover and a co-parent. My children wondered where their father had gone.

Larry has totally turned his life around and now campaigns tirelessly across Europe for others who have dementia. Larry decided to resist symptom progression by stimulating his brain – he enrolled in Ruskin College, Oxford where he became a residential law student. The College

adapted a room especially for his needs and provided a room across the corridor for his much needed Personal Assistant, Jesse Reed, who has saved his life on several occasions.

I've been a struggle trying to fight for a life worth living, instead of just living a long goodbye. I have a sense of urgency to help others nationally and internationally living with dementia, as I know time is running out.

We can live full lives and make choices for ourselves: 'no decision about us, without us' is what I'm campaigning for. Although it's not easy getting what you need, it's one of the best kept secrets trying to access the right care and support from your local council.

Larry would advise anyone finding themselves in this position to push their local council for a formal Social Care Assessment. The Citizens Advice Bureau can help you find your local Independent Advocacy Project.

I can remember things clearly from a long time ago, but what I did this morning is a different story, and it's very sketchy. I attend the memory clinic at the John Radcliffe Hospital, Oxford, and have developed some useful tools to help me with my memory. These include:

- ◆ *Electronic memory recorder, with a screen and microphone*
- ◆ *Smart Phone with a touch screen*
- ◆ *Wall board, and Wall Calendar – which I update with my PA*
- ◆ *Special pharmacists boxes with reminders for medication*
- ◆ *Text messages and reminders for appointments.*

Larry now definitely lives life to the full and receives one-to-one support from Young Dementia UK. He is currently chair of the Oxfordshire Dementia Empowerment Group and has previously been a trustee for Oxfordshire Advocacy, an adviser to the Alzheimer's Society, and a Non-Executive Director for Dementia Adventure.

Larry has even found time to have a 'dementia romance', as he calls it:

It's hilarious having a dementia romance as I can be waiting in one restaurant for my date and she's in another one. But we're having fun and life can be joyful and delightful.



Case study: Multi-agency working in the JackDawe service in Nottingham¹¹

Nottingham City Council's dementia service, also known as JackDawe, was set up to deal with the unique needs of people with dementia living in the community.

¹¹ <http://nottinghamcity.gov.uk/index.aspx?articleid=1488>

Kate Fisher and her team of home care workers, mental health nurses and occupational therapists provide person-centred care and aim to support people with dementia to be as independent and live as fulfilling a life as is possible. All staff have a particular interest in people with dementia and are specifically trained in this area of work. The team covers the whole of the Nottingham City area and provides a service to approximately 200 people.

A major strength of the service is its emphasis on integration and joined-up working within teams and between agencies. The inclusion of health professionals within the team has been extremely beneficial as they can be effective in linking back to GPs and NHS consultants – for example, in persuading a GP to make a home visit.

Many opportunities to improve practice are created through the discussion of particular cases at joint meetings with clinicians, drop-in sessions for managers, fortnightly meetings of home care managers and their staff, and links with hospital discharge facilitators. People who are supported by the service are reviewed and discussed on a regular basis so that the support provided is tailored to the progression of their illness or fluctuations in their condition. People with dementia are supported and family carers are encouraged to participate in routine decision-making and activities.

They also have links with the Nottingham On Call centre, which monitors and answers telecare calls, the Fire Service and the Alzheimer's Society at an operational and individual case level.

Feedback about their service is consistently good.

We managed to keep mum in her own home up until four weeks before she sadly passed away, surrounded by her children and grandchildren. We would not have been able to do this without the dedicated and devoted care given to mum by your team. I cannot begin to let you know how much we appreciate and respect the amazing group of people we have met over the last few months. With love and respect.

– A Relative

The service was evaluated in 2008 in the International Journal of Geriatric Psychiatry. The study found:

The specialist service helped reduce carer stress and prevent crises. These outcomes depended on the configuration of the service, including multidisciplinary health and social services input, care worker autonomy and independence, continuous reassessment of clients' circumstances and preferences and the capacity to develop long-term relationships, through care worker continuity. The standard service, which used a task-orientated approach, lacked these characteristics.

– Rothera et al 2008



Case study: Dementia Action Alliance Plymouth¹²

Plymouth is the first place in the country to have a Dementia Action Alliance. Launched in May 2011, it brings together businesses, statutory and civic organisations, including emergency services, and voluntary groups to help improve understanding and awareness of dementia and develop supportive communities.

Councillor Mary Aspinall, Chair of the Plymouth Dementia Action Alliance said: *We already have some great support in the city from organisations including the Council, Plymouth University, the Navy and Plymouth Raiders... We will be asking others to sign up and support the principles of improving their organisations' understanding of dementia, supporting staff who may be family carers and training staff to respond effectively to customers with dementia.*

The local paper reported an, 'overwhelming sense of positivity around Plymouth's attitude towards dealing with dementia,' at an awareness-raising event in September 2012.

Plymouth is leading the way because of the determination and energy of the Dementia Action Alliance Steering group with city organisations and businesses. Their one aim is to ensure that individuals with dementia and their carers in Plymouth don't feel isolated and feel included in the life of this city.

– Ian Sherriff, Plymouth-based Alzheimer's Society trustee.

¹² www.plymouth.gov.uk/plymouth_dementia_action_alliance.pdf



Case study: Reading Museum resources aid memory and reminiscence work¹³

Flexible, integrated care can mean using the resources and facilities in the local community to support personalisation. As part of a new Reminiscence Service, Reading Museum has created Memory Boxes from the museum's collection that could spark memories. They have over 30 Memory Boxes covering a range of themes including 1950s Home Life, A Night Out, Royalty, Holiday and Home Medicine. Original objects, photographs, documents, smells and sounds draw the user back in time and place.

The museum offers training to care home staff in how to use the boxes.

I found this to be some of the best training I have had, as it puts you in the position of the person, seeing objects that provoke a memory or feeling inside of you. A simple shopping basket handed round to a group of people from all backgrounds and workplaces, produced many different memories and feelings, some good, some sad. For some there was no memory, it was just a basket. This is the way for a lot of things – each item in the Memory Boxes will affect different people in individual ways, which is what makes them so unique.

Our first attempt was looking at the Cookery Box. We simply laid the items on the table and let people pick them up and talk about them. This was amazing and many stories came out of this such as baking for church fetes, what mum used to do with it, rationing to get foods, plucking birds for Christmas and someone's dad being away at war. One lady who can't communicate verbally how she felt was smiling and holding objects. Later in the week the same group did a cooking session, making pastry with items similar to ones from the box plus some modern day items on the table. The lady who couldn't talk started singing as she rolled out pastry, 'If anyone under the apple tree...!' She used some of the items adeptly and made the loveliest decorations on her tarts using a tool that I had no idea how to use.

– Rebecca Craker, Optalis, Suffolk Lodge Care Home, Wokingham

¹³ www.readingmuseum.org.uk/get-involved/reminiscence

Workforce: my support staff

It is essential that support is tailored to the person and their personal interests and specific needs, encouraging independence and choice in the decisions they make.

– Skills for Care and Skills for Health 2011

If you get the culture right, you can actually find staff have more time to spare, because they are doing what they want to do e.g. serving food in a different way, eating together.

– Ian Turner, Registered Nursing Homes Association

You can't have personalisation without listening to your staff.

– Clenton Farquharson, Co-chair of Think Local, Act Personal and member of the National Co-production Advisory Group

If learning and development has been positive, staff will return to the workplace determined to implement some of the aspects learned.

– Skills for Care 2012

Working with dementia every day, we understand the impact the illness can have – not just on the client, but on the family as well – and the need to offer appropriate support, alongside any other treatment... true person centred care, which makes such a difference to a client suffering with dementia. This starts with gathering vital information about the person, and organising it into a very good care plan, which can be understood by the care workers... This individualisation of care is all about meeting a person's needs and making them feel good... By ensuring continuity, quality and consistency in the care provided, our clients are able to enjoy a better quality of life, which in turn brings comfort and reassurance to their families

– Bipin Patel, Managing Director, Caremark Wokingham & Bracknell

What this would look like in practice:

- ◆ Front-line health and social care staff work in a person-centred way with the people they support. They appreciate the history and experiences that people with dementia bring with them and are encouraged to be reflective – for example, asking ‘why is that person behaving in that way?’
- ◆ Staff and key workers are matched carefully with the people they support and are encouraged to build relationships rather than working in a task-based way
- ◆ People with dementia are supported to engage in meaningful activity, doing something that they enjoy or are interested in. This can be as simple as undertaking everyday tasks such as cleaning or cooking together or more formal activities – for example, participating in a choir or swimming group
- ◆ Organisations invest in dementia training for their staff and use person-centred thinking tools with staff as well as the people supported by their service
- ◆ Organisations tap into and nurture skills in the wider community and unpaid ‘workforce’ – for example, linking with community groups such as ‘time banks’, and supporting families and carers.



Case study: Micro enterprise provides highly personalised home care¹⁴

Companions, a small business that was founded by Susan Shaw and supported by Community Catalysts, operates in a rural part of Oldham. Sue had varied experience of providing care and support. She was inspired to start her own service due to her frustration as a care worker that certain tasks laid out in a person’s care plan had to be stuck to. Care was often rushed and impersonal when what people really wanted was a chat.

Companions offer reassurance and help with everyday activities both inside and outside the home to people with care and support needs, including people with dementia. They help people to get out and about and can also provide support to attend medical appointments. They organise activities for people, including shopping expeditions, theatre trips or meals out, in small groups of like-minded individuals. Companions staff always accompany groups, and they can be an ideal way for a full time carer to get a much needed day off.

Sue’s staff generally work part-time and as a result are happier and can fit work into their own lives. Staff are matched to the people they support as much as possible and staff changes are kept to a minimum. They are encouraged to go that extra mile. Remaining small has enabled Sue to stick to her values of providing a person-centred service – one where the customer really feels like they care.

¹⁴ www.communitycatalysts.co.uk/case-studies/companions



Case study: Person-centred thinking transforms life in a care home¹⁵

Person-centred approaches are at the heart of the support provided by Wren Hall Nursing Home in Nottinghamshire. Everyone who lives there has an individual support plan. Staff are trained in the Butterfly Approach™ by Dementia Care Matters, which was highlighted in the recent BBC Two series Can Gerry Robinson Fix Dementia Care Homes. Staff are encouraged to be like ‘butterflies’, making sure they have 30-second interactions with different people throughout the day. They are given freedom and permission to be spontaneous. They fill the space with a variety of objects such as domestic items, comfort items like dolls, prams, soft

¹⁵ www.dementiacarematters.com/d4.html

toys, rummage items like boxes of jewellery, cognitive items like shopping catalogues and poems, musical items, and everyday items like socks to pair up. Having these objects on hand means that staff don't have to set up an activity for someone. It's about going with the flow and seeing where the mood takes the people they support.

Staff are also matched to support people at different stages of their illness. For example, some staff are best at talking and reminiscing with people. They tend to work with people in early-stage dementia. Other staff are more spontaneous or better at going with the flow, and they tend to work with people who are living in a different reality.

The approach has unlocked hidden talents among the residents and transformed people's lives. For example, one man was very quiet when he arrived at Wren Hall and just used to sit in a chair. One day, a box arrived that contained a flat-packed garden ornament. He said, 'I had one of those', and set about putting it together. Now, he puts all sorts of furniture together and fixes things around the home, and is a changed man.

One man, whose wife died when his daughter was seven, lights up when children come in the home, finding a football to play with or getting down on the floor to play with them. Another man was supported to run a Bowls group for other people – he used to be a leisure centre manager and gets so much out of doing what he used to do.

Staff satisfaction has rocketed. Teams cover each other, stay longer and people are being creative about how they work. One of my staff said to me the other day: 'I absolutely love my job. When I'm not in I find myself wondering if everyone is OK'.

– Anita Astle, Managing Director of Wren Hall



TOP TIP: tools to help make personalisation real¹⁶

There are a number of useful tools to help providers and their staff work in a person-centred way with the people they support, which can be useful in both residential or domiciliary care settings.

The **learning log** is a diary that staff fill in to report on something interesting or useful that happened when they were supporting someone. Some learning logs are available to read on the *Making it Real* website but for example, one entry reads:

Winifred was singing as she washed up, lots of hugs and cuddles. Telling Winifred often what a good job she is doing really motivates her and gives her joy!

16 www.helensandersonassociates.co.uk

Winifred was reluctant to take a break and have a sit down when cleaning. Winifred is happier to take a break if you walk arm in arm and sit down together.

Beryl to talk to Lisa about Winifred's request to do some baking & knitting.

A **One Page Profile** is a summary of information about someone that can help support staff get to know them quickly, or to ensure they are providing support in the way that person wants. A one-page profile typically has three sections: an appreciation about the person, what is important to that person from their perspective, and how to support them well.¹⁷



Case study: Personalised support for carers and people with dementia from BME communities¹⁸

Crossroads Care Bexley has developed a dementia service to support people in early stage dementia and their carers. The service is open to everyone, but particularly targets those from black and minority ethnic (BME) communities. They were initially funded by The City Bridge Trust to identify people who may need support but who are not receiving any 'funded' care. The Dementia Development Officer then visits the person to build a personal history profile and discuss options for support.

Professionals, partner organisations and carers refer people to the project, and the service is advertised through leaflets and posters across the borough in GP surgeries and community centres. The Dementia Development Officer also spends time visiting individuals, groups and events in the community to raise awareness of the service and to reduce the stigma of memory loss and dementia. With the help of individuals from particular communities, leaflets and presentations have been translated into other languages such as Punjabi and Bengali, to ensure that the information is accessible to a wide audience.

To further extend the reach of the project, volunteer Community Dementia Champions are currently being recruited, particularly from BME communities. The aim is for volunteers from different ethnic groups to raise awareness of dementia within their own communities and to gather feedback and insight from those communities.

¹⁷ Winifred's One Page Profile is on the Helen Sanderson Associates website.

¹⁸ www.crossroadscarebexley.org.uk/services/dementia

Risk enablement: feeling in control and safe

Sometimes it is necessary to reassure family and carers about risk – this is possible when the relationship is based on mutual respect and trust.

– Dame Philippa Russell, member of the National Co-Production Advisory Group and Chair of the Standing Commission on Carers

...Family members may worry about their loved one's risk level increasing considerably through carrying out even simple daily activities. Our view is 'why should a client who has always been free to go shopping be prevented from doing so, for fear of them wandering?' ... By enabling them to take agreed risks, mishaps and danger can be minimalised, and the person's dignity is left intact.

– Carl Ward, Managing Director, Caremark Kingston

People with dementia emphasise that being able to make small decisions on a day-to-day basis adds to their wellbeing and quality of life. Life stories and other biographical approaches can help establish how people with dementia have developed an approach to risk over their lifetime.

– DH 2010

What this would look like in practice:

- ◆ There is dialogue, debate and reflection with staff on dilemmas about safeguarding so that they have permission to take calculated risks to provide personalised care
- ◆ Providers support each other around safeguarding and personalisation – for example, developing communities of practice
- ◆ Support plans are based on what is important to people as well as health and safety.



Case study: Getting a taste for adventure¹⁹

Dementia Adventure is an award-winning social enterprise based in Chelmsford, Essex. Established as a CIC, it provides adventure travel and short breaks for people living with dementia and their carers.

Whether people live in care homes or in their own home, Dementia Adventure offers everyone the opportunity to connect with nature and meet others in the local community. The enterprise works alongside care providers, local green space and leisure providers, local authorities and health services to help them support people living with dementia to get out into nature as much as possible. The adventures they offer are diverse and range from park walks to holidays in locations such as Cornwall, Essex, the Isle of Man and Turkey. For example, they have run many all day woodland celebration events in Essex, East Sussex, Gloucestershire and Scotland with the Woodland Trust. These 'mass participation' events of up to 89 people have seen people living with dementia, families, paid carers and volunteers sharing lunch, activities and walks in woodlands together.

The organisation was started by Neil Mapes and Lucy Harding, who have backgrounds in dementia advocacy, clinical psychology and international adventure travel holidays. Through their experience, Neil and Lucy have found that people living with dementia – especially those living in care and hospitals – often have limited access to outdoor green spaces. Their work is based on a vision of a society where people live well with dementia and have contact and connections with nature.

One man with dementia who recently went on a sailing holiday with Dementia Adventure said: *I never thought I would have such a chance and I have learnt so much from being on deck with the experienced crew. The sailing was excellent – it was all great.*

Two sons who went with their father who has dementia said: *What a week and what a team! It was brilliant to meet everyone, to see the beautiful river estuaries, to survive a day of rough seas and high winds, to keep laughing and to learn about the boat and its history. Above all it was so good to see Dad joining in and gaining confidence day by day.*



Case study: 'Memory-aware' town centres^{20, 21}

Innovations in Dementia and the Ageing Well programme have proposed the piloting of 'memory-aware' high streets, to make it easier for people with dementia to get out and about and feel safe using local facilities. They stress that there is a strong business case for this as people with dementia will choose to spend their money elsewhere if they find staff unfriendly or a shop too confusing.

Other similar schemes are in use around the country for people with learning disabilities, but the idea of one for dementia is relatively new. A 'memory aware' high street scheme would include:

19 www.dementiaadventure.co.uk

20 www.local.gov.uk/ageing-well

21 www.innovationsindementia.org.uk/resources.htm



- ◆ Awareness raising training for people in front-line roles, including in shops and businesses
- ◆ A card that people with dementia could carry to explain how other people can help them, which is personalised to the specific needs of the person rather than a generic 'top tips' approach
- ◆ Posters advertising the scheme for shops and businesses to display
- ◆ Marketing of the scheme.

Plymouth was the first city to introduce the idea of a dementia-friendly high street scheme. It was developed through the local Dementia Action Alliance and has achieved a lot of support from local businesses, with 400 signing up.

The Ageing Well programme stressed that all of the above should be done in partnership with businesses and people who have dementia to ensure widespread ownership of a scheme. A strategic approach is also important. A scheme could be supported through existing structures and resources such as town centre managers and older people's partnership boards. This is an area that would benefit from a joined-up approach and where councils, businesses and user-led organisations could all play their part (DH 2010).

For a comprehensive guide to issues regarding risk for people with dementia see the Department of Health 2010 guidance *Nothing Ventured, Nothing Gained: Risk Guidance for people with dementia*.

Personal budgets and self-funding: my money

We got a personal budget for my mum so she could move back into the community. She is in control of her staff and tells them what time she wants to go to bed. Although we had to try a number of different agencies to find the right one we got there in the end.

– Sally Percival, Carer and member of the National Co-production Advisory Group

Three years on, we employ four members of staff who have all worked for us for at least two years. My dad no longer attends the day centre and spends more time at home. He enjoys doing things that HE chooses, more often, like feeding the ducks, going for walks, listening to music and going to football matches. He uses his personal health budget to rent a flat so that he can enjoy some peace and quiet watching the TV programmes of his choice with a single personal assistant who understands his needs and wishes...and much, much more!

– People Hub case study

By involving a responsible homecare agency early in the diagnosis of dementia, one begins a relationship between the family, their client and the agency, which is based on understanding and trust.

– Carl Ward, Managing Director, Caremark Kingston

What this would look like in practice:

- ◆ There is transparent pricing for support services to enable personal budget holders and self-funders to make informed choices
- ◆ Managed personal budgets and Individual Service Funds (ISFs) are used to ensure people have personalised support packages even if they don't want to or are unable to manage their own budget or direct payment
- ◆ There is proactive awareness raising and good information available for people with dementia and their families about personal budgets, ISFs, direct payments and the types of support available at the earliest stage.



Case study: Sally's mum

As a young woman my mother was an actress and had an active life. She became a music teacher and the headteacher of a very busy Cambridgeshire school. She became a widow about 30 years ago but managed to bring up me and my sister alongside her career. A very determined woman!

Mum had a very active life (gin and bridge parties) and carried on teaching music even after retirement. One day she fell over and as quickly as that she lost her independence. She remained in hospital for a year, having lost her mobility. Her muscles deteriorated and she began showing signs of dementia.

It was decided for the family that she should be placed into a care home. This was a rushed process and mum was very unhappy. She lost her independence, was put to bed every night at 3:30pm and had no choice of what she could eat. The dementia got worse and she kept using her buzzer, which the staff didn't like, so they took it away.

My son has a personal budget, so I fought to get my mother one too. We finally used this budget to bring my mum home. She is back in the community so she can keep in touch with her neighbours and they form part of her emergency plan. She is in control of her staff and tells them what time she wants to go to bed. Although we had to try a number of different agencies to find the right place we got there in the end.

Mum feels safe in her home and is in control of her finances. She just needs a little help to make sure things run smoothly. We use technology, mobile phones and neighbours and are quite creative about how we can ensure she is safe.²¹



Case study: A care home enables people to get out and about

Stockport Council and Borough Care Ltd wanted to see how far they can go with personalising residential care. At Bruce Lodge, a residential care home supporting 43 people living with dementia, they have developed the use of Individual Service Funds (ISFs). ISFs give each person two hours of individual one-to-one staff time each month to spend however they want doing something that is important to them. Lisa, the manager of Bruce Lodge, and Gill, from Helen Sanderson Associates, spent time with each person – and their family, where possible – to find out what people had enjoyed in the past and what they would do if they could in the future. They also changed the way staff rotas and time was organised to support people in this personalised way.

Annie now gets to go to Ashton market and likes to have tea and cake or a meal whilst out. John enjoys going out on a boat. Bessie is going to make a scrapbook of her life and travels, which her daughter Barbara is helping with. Doreen was an assistant verger at Norbury Church in Hazel Grove. She was also a member of the Mothers' Union and wants to go to a church service there. Van has later stage dementia and after thinking with her and her family, everyone's best guess is that she would enjoy going out to the park and sitting by the bowling green to have an ice cream or to have someone read aloud to her – Danielle Steele was always a favourite author.

– Gill Bailey, Helen Sanderson Associates

²² Case study provided by Sally Percival, Chair of the National Co-Production Group

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Resources

WEBSITES

Ace of Spades Community Gardening Company: www.communitycatalysts.co.uk/case-studies/innovative-people-with-an-ace-up-their-sleeve

Ageing Well: www.local.gov.uk/ageing-well

Alzheimer's Society statistics 2012: www.alzheimers.org.uk/statistics

Building Community Capacity: www.thinklocalactpersonal.org.uk/BCC

Butterfly Approach: www.dementiacarematters.com/d4.html

Community Catalysts: www.communitycatalysts.co.uk

Community Mapping: www.ndti.org.uk/how-we-do-it/training/inclusion-programme/community-mapping

Companions: www.communitycatalysts.co.uk/case-studies/companions

Contented Dementia Trust: www.contenteddementiatrust.org

Crossroads Care Bexley: www.crossroadscarebexley.org.uk/services/dementia

DemenShare: www.DemenShare.com

Dementia Action Alliance Plymouth: www.plymouth.gov.uk/plymouth_dementia_action_alliance.pdf

Dementia Adventure: www.dementiaadventure.co.uk

Dementia Care Matters: www.dementiacarematters.com

Dementia Friends: www.dementiafriends.org.uk

Helen Sanderson Associates: www.helensandersonassociates.co.uk

Home Instead Senior Care Wimbledon and Kingston:
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Innovations in Dementia: www.innovationsindementia.org.uk/resources.htm

JackDawe: <http://nottinghamcity.gov.uk/index.aspx?articleid=1488>

Making it Real: www.thinklocalactpersonal.org.uk/Browse/mir

National Development Team for Inclusion: www.ndti.org.uk/how-we-do-it/training/inclusion-programme/community-mapping

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Nuffield Council Bioethics: www.nuffieldbioethics.org/dementia

One Page Profile: www.helensandersonassociates.co.uk/media/71301/how%20to%20opp.bmp

People Hub case study: www.peoplehub.org.uk/?p=228

Personal health budgets: www.personalhealthbudgets.dh.gov.uk

Reading Museum: www.readingmuseum.org.uk/get-involved/reminiscence

Shared Lives Plus: www.sharedlivesplus.org.uk

Streetly Dementia Support: www.communitycatalysts.co.uk/case-studies/streetly-dementia-support

Stockport Borough Council: www.stockport.gov.uk/services/socialcarehealth/adultsocialcare/workinginpartnership/myhome

The City Bridge Trust: www.citybridgetrust.org.uk/cbt

The Good Care Group: www.thegoodcaregroup.com

Think Local Act Personal: www.thinklocalactpersonal.org.uk

Walsall Council: www.walsall.gov.uk/dementiaservice

Wren Hall: www.wrenhall.com

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Think Local, Act Personal is a sector-wide commitment to moving forward with personalisation and community-based support, endorsed by organisations comprising representatives from across the social care sector including local government, health, private, independent and community organisations. For a full list of partners visit www.thinklocalactpersonal.org.uk