

## South West Dementia Partnership



Improving domiciliary care for people with dementia: a provider perspective

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## Document details

Title	Improving domiciliary care for people with dementia: a provider perspective
Description	This report has been produced by the United Kingdom Home Care Association for the South West Dementia Partnership. It offers a provider perspective on the current models for the delivery of care and support to people with dementia. It looks at innovative practice and identifies key messages for providers and commissioners on how to move forward with the delivery of services for people with dementia in the future.
Version	Final
Date	01.09.2011
Author	Jennifer Roberts RGN on behalf of UKHCA
Publisher	South West Dementia Partnership United Kingdom Homecare Association
URL	<a href="http://www.southwestdementiapartnership.org.uk/domiciliary-care/provider-perspective/">www.southwestdementiapartnership.org.uk/domiciliary-care/provider-perspective/</a> <a href="http://www.ukhca.co.uk/downloads.aspx?ID=339">www.ukhca.co.uk/downloads.aspx?ID=339</a>

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## 1. Introduction

Dementia is one of the most important issues we face as the population ages. There are estimated to be over 750,000 people in the UK with dementia<sup>1</sup>, 79,236 is the current estimate for the South West Region and numbers are expected to double in the next thirty years<sup>2</sup>.

The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is progressive decline in multiple areas of function. Although dementia is primarily a condition associated with older people, there are also a significant number of people (currently around 15,000) who develop dementia earlier in life. Direct costs of dementia to the NHS and Social Care are in the region of £8.2bn annually<sup>1</sup>.

*'Living well with dementia - a National Dementia Strategy'*<sup>1</sup> was published in February 2009. It set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at whatever stage of the illness and in whatever setting.

Raising the quality of care for people with dementia and their carers is a major priority under the new Coalition Government. In line with this, the Government is committed to ensuring there is a greater focus on accelerating the pace of improvement in dementia care, through local delivery of quality outcomes and local accountability for achieving them. This is a new outcomes-focused approach, a key element of which is ensuring greater transparency and provision of information to individuals. This enables people to have a good understanding of their local services, how these compare to other services, and the level of

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<sup>1</sup> Department of Health (2009) *Living well with dementia: A National Dementia Strategy*. London, Department of Health.

<sup>2</sup> SHA dementia prevalence and diagnosis rate: South West SHA

[http://alzheimers.org.uk/site/scripts/directory\\_record.php?recordID=1262](http://alzheimers.org.uk/site/scripts/directory_record.php?recordID=1262)

quality that they can expect. The new approach is set out in the document '*Quality outcomes for people with dementia*'.<sup>3</sup>

The South West Dementia Partnership (SWDP) oversees the delivery of the National Dementia Strategy in the South West, and the South West Implementation Support Programme, brings together organisations from health and social care, the voluntary sector and people using dementia services to drive forward improvements.

The United Kingdom Homecare Association (UKHCA) is the professional association of home care providers from the independent, voluntary, not-for-profit and statutory sectors representing more than 1,900 members across the UK.

The South West Dementia Partnership has commissioned the United Kingdom Homecare Association to research and deliver the findings of this important report '*Improving Domiciliary Care for People with Dementia: A Provider Perspective*'.

Home care providers from a variety of backgrounds and geographical locations across the South West had input into the research. This was complimented by organisations and key people with knowledge and experience in the field of dementia from other parts of England.

With the future of health and social care under the microscope, this opportunity to look at how home care can rise to the challenge of providing person-centred care and support for people with dementia and their families, could not have come at a more critical time.

The project has been designed to show how providers are meeting the challenge of supporting people with dementia and their carers, and how they can deliver person-centred care and support in the future.

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<sup>3</sup> Department of Health (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. London, Department of Health.

The experiences and aspirations of providers and care workers shared in this research are crucial in helping to tackle the difficulties that exist today and implement the changes needed to enable home care to meet the challenges ahead.

The aim of the project has been to identify:

- The challenges homecare providers face;
- What is working well from the homecare providers perspective and across all sectors of care;
- Initiatives, best practice and models that can set the benchmark for future care and support;
- How we can move things forward to improve and develop future dementia services.

### **1.1 Research methodology**

Members of the UKHCA in the South West and the rest of England were invited to take part in the research through an email survey, focus group or telephone interview.

Key organisations and individuals with knowledge and experience of dementia care – not connected to the UKHCA but interested in participating in development work – were also invited to take part.

E mail survey participants were asked 44 questions focusing on:

- A person's journey with dementia and the help and support delivered by home care;
- Models and types of care and support;
- Organisational arrangements;
- Workforce development;
- The cost of delivering care and support;
- Links with other community networks and services;
- Support for family and other informal carers;
- What providers need from commissioners.

Focus groups were held in Bristol on May 10, 2011 and in Exeter on May 11, 2011. The theme for these groups was: What would a good, flexible and responsive person-centred dementia care service look like?

Reference points for discussions in the focus groups were:

- At what stage on the person's journey with dementia do home care providers engage with and provide a service and support;
- What models of care are working? Where are the challenges? What elements are required to provide a flexible, responsive person-centred service? How can home care develop its workforce to meet future needs?

The telephone interviews were designed to gather information on:

- Current dementia care and support delivered in the community;
- Models of care and support and organisational arrangements;
- Pilot or new care and support projects;
- Case studies and best practice.

## **1.2 Response**

Seven completed email surveys were received, 18 people attended focus groups and 10 contributed via telephone interviews. Survey returns were considered low. However, the research covered two significant groups, generic home care providers and services specifically focussed on dementia. In broad terms it was felt the providers who responded, represented a range of geographical locations, and offered in-depth responses that appeared to reflect the wider, generally accepted, homecare provider perspective on the challenges and the developments needed to take dementia care services forward.

## **1.3 Context**

Home care is facing its greatest ever challenges in an era of change, uncertainty – and opportunity. It features highly in plans for the transformation of social care – from playing an increasingly important role in caring for and supporting people with dementia to being pivotal in turning the aspirations of personalisation into reality.

The expected steep rise in the number of people with dementia over the next decade presents the biggest health and social care challenge of the 21<sup>st</sup> century.

Added to this are providers who feel under immense pressure to provide more responsive flexible person centred care, whilst being asked to work with local authorities who are operating within a programme of austerity cutbacks and budget reductions. This combination is having a wide range of effects that impact on workforce recruitment, training, service development and employment costs.

Services are being affected by rising fuel costs adding to the pressures to provide support for people with dementia, who may live in more rural or isolated areas, and there is concern about the reliance on family members and 'informal carers' who are being asked to provide more care and support.

Providing person-centred care and support for the increasing number of people with dementia is a daunting prospect for home care providers, and has raised many concerns about the resource levels and whether personalisation is actually working in terms of providing people with the ability to have real choice and control over the care and support they receive.

There is also growing concern about the prospect of working with a greater number of individual budget holders rather than one client (i.e. a local authority) which may present significant changes to administration and management structures for many generic home care providers.

However, the predicted increase in dementia offers all home care providers the opportunity for real change in the way care and support is delivered from early intervention to palliative and end of life care.

## 2. The Provision of Dementia Care: The Current Position

In seeking to find new and innovative ways to move forward and develop dementia care services, it is important to reflect on the progress made by providers towards delivering person centred outcome-focussed care, and the challenges and areas of concern that have been raised as part of this research.

Taking into consideration the dementia care pathway, and the document *Living Well with Dementia*,<sup>4</sup> home care providers were asked how and when they were providing services for people with dementia. Two different pictures emerged related to the source of funding.

### 2.1 Private care

Home care providers generally engage with people paying for care from their own funds at a very early (or pre-diagnosis) stage. The earlier providers can start to build a relationship with a person with dementia and their family the more likely they are to build up a rapport, learn about their life history and what is important to them. The care worker has time to adapt and change along with the person with dementia, to meet the range of complex needs presented by someone with dementia and avoids crisis management, unnecessary medication interventions and inappropriate admission to care homes and hospitals.

### 2.2 Local authority commissioned care

As local authorities increase eligibility thresholds for care to 'critical' or 'substantial' levels, home care providers are generally not providing care for council-funded clients until they are at a much later stage along their pathway with dementia.

Consequently, the opportunity to develop a good relationship with people with dementia (through getting to know them at an early stage and building valuable life histories) becomes more challenging. In many cases, care workers are first coming into contact with people when they need complex packages of care, which are generally 'time and task' orientated and achieve poorer outcomes. Ideally investment in early intervention and

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<sup>4</sup> Ibid 1.

prevention work would be beneficial. However, an area largely populated by the third sector offers some alternatives.

Life story work and creating memory boxes are methods by which valuable personal information can be captured and is seen as a positive step in developing a person-centred approach. Family relationships, employment, hobbies, and a range of personal preferences play a large part in our lives. They all contribute to who we are, how we think and our likely responses to situations. As a person's journey with dementia progresses and verbal communication becomes more difficult, it can become harder to gather this personal information, so the earlier we can start or encourage others to do this the more likely we are to achieve better outcomes for the person with dementia.

### 3. Challenges: Commissioning Practices

#### 3.1 Diagnosis

Early – and better – diagnosis of dementia is a priority in England’s *National Dementia Strategy*.<sup>5</sup> Home care staff are often the first to identify cognitive difficulties (and probable dementia) but the experience of many providers is that it is often difficult to influence or achieve a diagnosis for their clients. Earlier diagnosis leads to better personalisation of care.

*‘Diagnosis of dementia can be difficult to achieve. It is not easy to get doctors to come out to see someone. The person showing signs of dementia can perform brilliantly for the 10 minutes the doctor is there...and then fall apart afterwards.’*

Whilst accepting that commissioners do not diagnose, home care providers look to care managers to assist and provide support in this process.

#### 3.2 Assessments and reviews

Initial care assessments provided to home care providers by local authority care managers are criticised as *‘frequently inadequate’* and *‘light on real detail’*. People showing obvious signs of cognitive decline can be described as *‘confused’*. Assessments carried out that capture a short moment in time (where the person with dementia may be performing either unusually well or poorly) may lead to inaccurate conclusions being drawn. In many cases the home care provider or family member could provide valuable contributions about the persons abilities based over a longer time period.

There is considerable concern over the time taken by some local authority care managers to carry out *‘urgent reviews’* of people’s care needs. Providers said:

*‘They don’t review even though we have to put in extra time to provide help that is needed, you sometimes have to wait three weeks for an urgent review of someone’s needs to be carried out.’*

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<sup>5</sup> Ibid 1.

### 3.3 Palliative and end of life care

Many home care providers are not involved in palliative or end of life care for people with dementia. However, a small number have been involved with providing personal care through schemes spearheaded by Marie Curie. The vast majority of people needing palliative care end up in a hospital or care home. Home care providers said many of the people they care for would prefer to die at home. This is supported by a YouGov survey carried out on behalf of Marie Curie Cancer Care that suggested that 64% of people would prefer to die at home as opposed to 4% who would prefer to die in hospital and 23% who would prefer to die in a hospice.<sup>6</sup>

Providers feel they have the skills and abilities to assist with palliative care, but many find it difficult to get commissioners to consider them at this stage of the person's journey with dementia.

*'I would like the opportunity to say this is what we (as a home care provider) can do. Whether it's not happening because of trust, speed or finance, I don't know.'*

### 3.4 Live in care as an option

The live in care model is not often considered as an option or an alternative to residential care.

*'Far too few social workers and other professionals in decision-making positions consider or offer people with dementia the option of live-in care. People with dementia often find themselves looking at the residential care option without realising there may be an alternative. This can cause great distress and if used as an option at the wrong time, can have considerable effect on the wellbeing of the person with dementia and their family.'*

### 3.5 Delivering quality dementia services

Dementia is a complex condition by nature and each experience is an individual one.

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<sup>6</sup> Marie Curie Cancer Care (2004) Views about dying at home: survey of the views of the UK general public. London, Marie Curie Cancer Care.

Delivering a quality service based on personalisation with a focus on outcomes is difficult to achieve when the current quality measurement systems are based on process and formal systems and structures best suited to block contracts and existing quality assurance programmes.

Many concerns were raised during the research around increasing levels of bureaucracy that seem to be in place around all aspects of care provision from assessment to care management, service delivery and reviews. There is a great desire and willingness for more autonomy, responsibility and accountability to be placed with the home care providers, which is felt, would result in more responsive, flexible, cost effective service management and delivery.

### **3.6 Dementia awareness**

Home care providers felt their level of knowledge and awareness about understanding dementia and the associated complexities of managing reviewing, planning and responding to dementia service users needs was greater than some of the commissioners and care manager's they were working with. This created challenges that ultimately affected the care and support received by the service user.

### **3.7 Time and task focussed commissioning**

There was a lot of discussion around the link between additional time and cost pressures that caring for people with dementia present for home care providers, these were identified as:

*'The initial assessment for a person with dementia takes longer, giving them and their 'informal carer' time to contribute and shape their plan of support and care. The following support planning is often more complex to ensure that the plan meets the needs of the person with dementia, ensures their desired outcomes are met and builds in flexibility to cope with a change in their abilities or aims.'*

Often people with dementia (unlike others with more consistent conditions) by the very nature of the condition, require more reviews to meet the changing needs and abilities during their progress with dementia.

Staff providing support and care often require more in terms of supervision, advice and support when caring for people with dementia. This in turn may well impact on the requirement for more out-of-hours support, in terms of management availability and accessibility, all with service cost implications.

To achieve a good quality dementia care service, based on a person-centred approach, communication is a key element. Providing this service for people with dementia increases the time spent both internally amongst managers and staff as well as externally linking with professionals, families and specialists.

There are a range of cost pressures related to training and workforce development that have already been mentioned but add to complete the picture in this section.

### **3.8 Personal budgets**

This research shows that personal budgets were largely welcomed by home care providers as a way of moving forward. However, concerns were expressed that commissioners would influence how the money would be controlled, budgets may be reduced in value and that in some areas there was an unwillingness or reluctance to support service users to take up personal budgets.

### **3.9 Framework agreements**

Some authorities have used this type of contractual arrangement and significantly reduced the number of providers they are working with. Reducing the numbers of providers raised concerns about diminishing social care capacity, which has a direct impact on retaining care workers and delivering consistency in service delivery.

To ensure care delivery, providers within the framework agreement may subcontract with providers outside of the agreement. However, this can create difficulties as they are not signed up to the framework price and require time in managing, coordinating, monitoring and supervision. In addition, as commissioners change contracting processes, service users may find themselves in the position of having to switch providers thereby losing consistency

and continuity in their care. The effect this has is that valuable relationships developing between care workers and the service user and person-centred knowledge is lost.

## **4. Challenges: Provider Issues**

### **4.1 Organisational arrangements and costs**

Home care providers have to adopt different organisational arrangements that can be adapted to suit the delivery of care and support to a variety of homes and set of circumstances that are completely different to other care settings. This can present a whole range of challenges that are often overlooked e.g. entry, lone worker issues, security, building relationships, environmental issues, health and safety issues.

Many home care providers report they are in a state of transition, moving from a range of systems structure, software and support mechanisms previously adopted to support block contracts, cost and volume contracts, spot purchasing and grant funded arrangements to implementing a person-centred approach based on individual needs and focusing on outcomes. Understanding and moving towards a more outcome-focussed approach is proving challenging. An additional challenge comes when the provider is further along that journey than the commissioners they operate with.

Difficulties have been expressed around the management and administration required e.g. planning rotas, fulfilling care workers expectations, guaranteed hours etc. to develop a more personalised approach. Some home care providers expressed concern over the increase to the financial administration and management costs, the increased risks of non-payment and increased costs in relation to credit control for delivering person-centred care.

Providing a service for people with dementia who live in isolated or more rural areas, can create additional organisational pressures in terms of time, cost, travel and flexibility. This type of service may require a different approach to urban areas.

## 4.2 Workforce

### **Recruitment and Retention**

Home care is renowned for having dedicated workers, but recruiting and retaining good staff is a continuing problem.

The words of Mike Padgham, Chair of UKHCA (quoted in *The Guardian* on May 29 2011) demonstrates why:

*'When companies recruit, they have to say: "Come and do this job which has quite anti-social hours and is not highly paid and we can't guarantee how many hours you are going to do." It is not exactly an attractive offer. It's a stressful job. It is early-morning work, evening work, Christmas Eve, Easter and weekends. And sometimes you arrive and people don't want the care. They may be doubly incontinent. They may be physically or verbally aggressive. It might be a dark night driving up a farm drive. It's not all sweetness and light. You have to be resilient, very skilled.'*

Lack of continuity of staff was a clear concern. Home care providers reported that retaining staff can be difficult for a number of reasons: levels of pay; terms and conditions of employment; levels of responsibility and commitments required of care workers; using their own vehicles with cost implications; poor perception, recognition and appreciation of the care workers role, knowledge and experience, particularly in the field of dementia. Concerns were also raised about the practice of 'poaching staff' and the development of personal assistants (PA).

### **Training**

Achieving good quality dementia services requires investment in training the workforce and providing on-going support to implement the training into every day practice. This involves shadowing and managers providing time for mentoring, support and reflective practice.

Home care providers report concerns about the lack of funding available to support external training and qualifications to achieve this quality standard. Somerset Care is introducing 'Dementia Care Mapping' (DCM); this initiative, alongside their basic training for all employees, is estimated to cost £1,000 per person.

Whilst the reduction in regional and national funding has led to improvements in the internal development of very good models for training, there was still concern that access to experienced external training was paramount to ensuring the development of knowledge and quality dementia services to support internal developments and obtaining qualifications.

### **4.3 Links with other professionals and services**

The launch of the Think Local Act Personal (TLPA) partnership – to continue the momentum of the Putting People First agenda – has put the emphasis on local authorities, health organisations and care providers:

*‘Working more collaboratively to personalise and integrate service delivery across health and adult social care, and make vital public funding go further.’*

Access to information, advice and support is seen as a crucial part of developing a dementia care pathway that includes the home care sector. Concerns were expressed around the lack of consistency in approach across the region to provide this network of support. Building networks and relationships was seen as a very individual, more personal-based experience rather than using established recognized structures and systems.

Home care providers reported a breakdown of links that were developing as a result of cutting back on coordinators and key contacts and the centralisation of the district nursing service.

### **4.4 General concerns expressed**

#### ***Perception of Home Care***

Home care providers felt strongly that the sector and the people who worked within it were not treated as equal partners by commissioners and other community and professional staff. Many had experienced a lack of respect, professionalism and sense of value of the services they provided, their expertise, the training and knowledge possessed by their workforce, and their ability to provide a valuable and often critical contribution to the care and development of services for people with dementia both now and in the future was not often recognised.

In general terms, home care providers felt that third sector providers were viewed differently than the independent sector providers by commissioners and received a different approach. They were seen as *'adopting a more altruistic rather than a profit-led approach'*. Consequently, commissioners appear to be more open to allowing a third sector provider to have more flexibility, take management decisions and act on their experiences because there is no profit motive.

Interestingly this was viewed as unfair by both sectors, with the third sector highlighting that many excellent (private sector) home care providers operate with the highest standards and integrity.

### ***Perception of Dementia***

Approximately 60% of people with dementia live in the community. They may be living alone or with their 'informal carer' and support structure. Many do not have a diagnosis and those that do often struggle with the 'dementia label'. Home care providers said they can encounter many problems in this area. Dementia is seen as a loss of hope, a change forever with only one ending and not much good happening in-between. Many families are in denial, blaming problems simply on old age, other medication or a condition that they will 'get over'. This can cause great problems around the language used in care planning, communication and delivery of care. It also prevents the person with dementia receiving the right type of support, appropriate medication and access to a range of services and support structures that would help both them and their family.

## 5. Current Progress and Developments: What's Working

### 5.1 Personalisation

Progress is being made in adopting the personalisation approach, but it is inconsistent across the region. This research enables us to pull out and highlight what is working, and encourage and promote these developments to help homecare providers and commissioners to move forward.

By delivering and providing care directly into a person's own home, home care providers are more naturally predisposed to developing good relationships between service users and their families, from the initial referral through to assessment, delivery of care and review.

### 5.2 Person centred care and building relationships

#### *Communication*

Good communication, particularly the ability to listen, is seen as key in supporting the individual, family and other unpaid carers of people with dementia. Good communication and building relationships are inextricably linked.

Home care providers say the following works well:

- Helping the individual and family to understand the condition, listening, not having all the answers but knowing where to get them or pointing them in the right direction i.e. Alzheimer's society;
- Making sure they have a key contact within the organisation;
- Ensure that the family and other informal carers feel part of the caring team by adopting a team approach that includes the care worker, manager, person with dementia and family or informal carer;
- Ensure the person with dementia and family feel they have all the information to make an informed choice and can influence/contribute and change the care and outcomes;
- Developing a culture of mutual trust and respect achieved by listening and providing a reliable consistent service that meets the needs of the person with dementia and supports the informal carer.

The following comment taken from our research sums this up very well:

*'We see the provision of care for dementia service users as being very much an exchange of ideas to create a scheme that works for the service user and their family.'*

### **5.3 More autonomy**

When providers are given more autonomy to manage and make changes to care that meets the service user's needs, the delivery of service is seen as more responsive and reduces crisis or emergency situations arising.

*'The system works best when coordination, management and responsibility for care rests with the person receiving care, their family or care worker. This leads to delivering a more responsive flexible service based on trust that meets their needs.'*

*'Get things right from the start of the package. Spend time listening and taking on board what the person with dementia and their carer is saying. Regularly check with them to ensure we are meeting their needs, take on board feedback and ideas they may have for change. Be friendly and genuinely interested in speaking to them and visiting them rather than completing tick box sheets. Build up a relationship built on trust.'*

### **5.4 Phasing out of block contracts**

Phasing out of block contracts was seen as a vital change in commissioning to enable a more person-centred approach to be adopted. It is seen as moving away from a task and time driven approach and the start of achieving more flexible options for commissioning home care services.

### **5.5 Market movement and development**

In some areas, changes made by local authorities to eligibility thresholds or through measures to reduce public spending has seen a shift in more people seeking privately funded care and support (either as individuals or as part of a family support package).

*'With fewer cases being approved for assistance, we have benefited as those refused care are purchasing it on a private basis, and we are able to charge economic rates and work more flexibly with service users.'*

## **5.6 Personal Budgets**

Home care providers in the South West are keen to implement personal budgets and see them as crucial in bringing about flexible, outcome-based care and support. Where they are being used, they encourage a stronger role in support planning, with the person using their services and support in a more flexible way.

Providers feel there is greater flexibility for people paying for care through personal budgets. They believe personal budgets are *'putting service users in the driving seat'*, and nurtures an environment of friendship and support rather than an "I carer – you client" situation. *'If someone is feeling unwell, you can go back the following day and put extra time in to do the things they want done.'*

The following comment provided during our research illustrates this:

*'We draw up the care plan with the client and his/or her family or friends. The care plan is not just about the help with personal care that is required but stresses the need to support the person with maintaining their interests and activities. This could be trips out or friends for tea. It could be helping them to maintain their interest in playing bridge or gardening. Risks should be assessed but never used to limit people's lives. The outcomes identified are those which add to their quality of life, not just the quality of care.'*

It was interesting to hear what people on personal budgets are choosing to spend their money on. The following provides some examples:

- *'Keeping themselves at home – getting things done. There's more emphasis on socialisation than normal packages, helping make sure they get to day centres or just as a chaperone type call and doing things with them in the day. Also there is a focus on good nutrition to maintain a healthy person who can make the most of their life.'*
- *'Purchasing different amounts of care on different days and perhaps not to purchase care on days when family members can help instead.'*

- *'Blocks of hours over a mealtime and to give time to go out for a walk or a coffee. To give family a break.'*
- *'Support with personal care.'*
- *'Purchasing live-in care so that they can retain their activities and independence as well as having the personal care they need.'*

### **5.7 Purchasing blocks of time with inbuilt flexibility**

Planning care in 'banks of time' rather than allocating set times for care and support to be delivered is effective in supporting flexibility of provision in enabling service users to express choice. The following example – from a large private home care provider – demonstrates how a simple change, can make a difference:

*'A service user with 'memory issues' had three care visits a day (in the morning, at lunchtime and during the evening or bedtime). Part of the lunchtime visit involved making a sandwich for later and leaving it in the fridge. The sandwich was still in the fridge when the bedtime visit was made – because the client had forgotten it was there. After some discussion, it was decided to change part of the visiting time to allow a support worker to make a 'pop-in' visit in the afternoon to make a fresh sandwich for immediate eating. The client was happy – and there was no additional expenditure involved.'*

## 6. Initiatives and Best Practice Models

### 6.1 Service delivery

#### *Creating consistency and continuity in care provision*

The majority of home care providers are caring for people with dementia (pre and post-diagnosis) as part of their mainstream services. Traditionally, they divide up the service delivery and management in the following way.

#### *Field based work*

Providing care and support, carrying out service user assessments and reviews, drawing up care plans, and providing staff supervision and support.

#### *Office based work*

Setting up care plan rotas, coordinating and matching care workers to service users, providing support and information to care workers, processing and checking invoice, pay roll, information and expenses claims.

A person-centred approach requires the person with dementia to be central to their care and support. One development that has moved this approach forward is to have a nominated manager who is responsible for all aspects of care service delivery and coordination of a team of care workers. This incorporates the traditional field and office based roles as described above into one, with smaller manageable case loads. This improves understanding of the changing needs of people with dementia, helps create better relationships between the person receiving care, the manager and the care worker and reduces the amount of internal communication, liaison and reporting time between field and office.

Many home care providers are achieving this consistency and continuity by operating 'key worker' or 'named carer' systems or by maintaining a core group of 4 – 5 care workers for each service user.

*'We use a main/key carer for each case where it is relevant. They can act as an advocate. Maintaining continuity of office staff has a bearing on this. Encouraging team work by supporting carers and office staff and having team activities seem to make a difference.'*

*'We try to build a small team of 4 or 5 which seems to work well as the service users don't have to meet a stranger if their most regular carer is on holiday or off sick unexpectedly.'*

### **Computer rostering systems**

These are playing a key role in managing and planning care rotas. A rostering tool that automatically allocates the care assistants who have been with a service user in order of time spent (all other things being equal) has proved very useful.

### **Management of out of hour's services**

Many home care providers suggested they are operating longer office opening hours and increasing the use of the office base for staff to manage out-of-hour services. This has benefits for managers in accessing information and support and for care workers to update paperwork and discuss service users care plans (please refer to the Crewkerne pilot project on page 32).

### **Generic homecare providers**

In order to support managers and care workers, many home care providers have identified and nominated a person within their organisation to develop a specialist dementia knowledge base (i.e. appointing dementia mentors or 'champions', link workers or dementia managers). When an expert knowledge base is developed, home care providers report that care workers and managers feel better equipped and supported to undertake and deliver care.

Within the generic home care model, expertise has been developed by creating specific dementia care teams that can operate as part of a mainstream model.

### **Good Practice Model**

#### **Gloucestershire based Model**

A Gloucestershire-based charity (a generic care provider specialising in supporting people with dementia) has risen to the challenge of providing innovative care and support, from early interventions to palliative care.

*‘We have cared for a number of service users at home with dementia at the end of their lives – usually they have impressed upon their families that they do not want to go to care homes under any circumstances.*

*‘Four visits a day with two care assistants is our usual maximum package, but at end of life we can put in other support, such as sitting and domestic tasks.*

*‘We are involved in a lot of short term packages, holiday cover, home from hospital etc. and we frequently become involved when the partner of a person with dementia needs respite or is unwell/in hospital themselves. We have cases where we go in to sit with and keep a service user company while the partner plays golf or goes shopping.’*

#### ***Specialist dementia homecare providers***

Home care providers who have chosen to specialise in a particular field i.e. dementia, have identified the following benefits as key to their model:

- It gives an organisation focus and direction into the development of their services, both in terms of direct delivery and in models of support for the family and informal carers of people with dementia, i.e. carers support groups, dementia café;
- Offers service users much needed clarity and reassurance about the organisations area of expertise knowledge and services.

## **Good Practice Model**

### **Alzheimer Society Model**

The Alzheimer's Society, are providing social 'light touch' or early intervention support to council and privately funded clients (as well as people on personal budgets) across the South West. The Alzheimer's Society model of support – the charity works in partnership with home care providers who provide personal care – is widely acclaimed. The charity's home support workers use their specialist dementia knowledge to support people with dementia and family carers through regular respite help and facilitating support groups.

### **Early intervention**

Dementia takes many forms and is a condition that brings about deterioration over a period of time, during which home care providers report the benefits gained by early intervention. This is an area largely populated by the third sector. The type of help and care offered varies greatly and depends on the point at which a person has been diagnosed with dementia. It is generally targeted at helping people with dementia to maintain daily living activities, continue hobbies and interests and make best use of their abilities.

Early support and intervention can assist with people coming to terms with dementia and accepting more help as their needs increase. It also ensures they receive the right type of help, information and support and can start to develop links that will support them on their pathway with dementia, i.e. dementia advisors.

Early intervention works by focussing on preventative work, developing support structures that enable people with dementia to feel in control and to operate within their capabilities and looks to improve quality of life.

The Alzheimer's Society home care model benefits from specialist dementia training and research carried out by the charity, and also through:

- Its highly informative website;
- Factsheets on the common challenges of dementia;
- Talks and newsletters aimed at raising awareness of dementia.

For further details contact:

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### **Short Visits**

Short visits of around '15 minutes' are widely regarded as inappropriate and ineffective as far as care for people with dementia is concerned.

*'You can't deliver what is needed in 15 minutes, particularly if the person has dementia, it might take five minutes to get in the door, and then you try giving them breakfast, boiling the kettle takes four minutes. You want to support and encourage them to eat and drink, have a chat (you may be one of the few people they see all day) but you haven't got time. The service user may be having a bad day and as the carer you feel rushed, you have to get to your next service user and the stress can be transferred from the carer to the person you are caring for, and then we leave them. Is this person centred care? How are they left feeling?'*

However there is a place for short visits (i.e. in helping to turn or lift people in beds, to make safety checks or to assist an older person with medication), but only when used to complement person-centred dementia care and support already in place (please refer to the Crewkerne Pilot project on page 32).

### **Telecare**

Increasingly telecare options are being used to avoid the need for routine short visits just to check or help manage medication. Whatever the system is, it is critical this is linked to existing home care or reliable alternative support systems to ensure a timely and appropriate response when help is needed. Appropriate use by a home care agency can ensure staff time is focussed on achieving outcomes via quality interaction and care, and crisis responses if needed, rather than spent on 'pop-in' calls.

The following good practice models illustrate the benefits of service providers working in partnership with telecare.

### **Good Practice Model**

#### **“Just Checking” Model**

“Just Checking” helps people with dementia or poor memory to live independently in their own home. It monitors the movement of a person in their home and generates a chart of activity, on-line.

Care professionals use the system for assessment and planning care. “Just Checking” highlights what a person is able to do for themselves in the familiarity of their own home, and the effect of care services.

Families use it to 'just check' that a family member is following their usual pattern of life, without intruding or undermining their independence. It provides a real insight, so that you understand how best to offer support, and when to make social rather than 'checking' visits.

### **Good Practice Model**

#### **West Midlands Automated Pill Dispenser Pilot**

Home care visits and telecare services, such as telephone prompts are some of the ways used to ensure medication is taken. Devices such as dosset boxes, calendar clocks, blister packs and talking labels are also common. But the West Midlands Telehealthcare Network found the most successful solution cited by customers and carers was the Pivotal automatic pill dispenser.

The device is programmed to dispense pills up to 28 times a day. At the pre-programmed times, the internal pill cassette rotates, the alarm sounds and the correct dosage comes into view through the opening in the lid.

Once the alarm has sounded the pills are released by tilting the dispenser allowing them to fall into the hand or a suitable container. It can be used as a standalone device or linked to a control centre. The latest version of the device can also transmit text messages and e-mails to notify designated contacts (typically family members) if medication has not been dispensed from the device at the medication time. This enables appropriate action to be taken to check on the well being of the individual before a potentially adverse event occurs which might otherwise require a paramedic or ambulance call.

***Live in care as a positive, viable option***

Live in care as a model of home care provides an option to deliver a more flexible care support plan that enables a person to live well with dementia, throughout their journey. The care worker has more flexibility around time, so activities can be undertaken when it best suits the service user, and the support plan can be adjusted to meet their changing needs without the person leaving the familiarity of their own home. Providing the service user's accommodation was suitable to support a live in carer, the feedback was positive and in some areas considered comparable to the cost of residential care.

A live in provider illustrated an innovative approach developed between the live in provider and hospital to maintain consistency of care and support for a person with dementia admitted to hospital:

*'The live-in carer working alongside the ward staff provided assistance with personal care and eating and drinking. This ensured the relationship and understanding between the carer and the service user was maintained whilst the person with dementia was in an unfamiliar environment.'*

### **Good Practice Model**

#### **Live in Care Model**

##### **At point of diagnosis**

Support and reassurance is offered to the person with dementia and relatives are pointed in the direction of further advice, information and links to local support groups.

##### **Post-diagnostic support**

On-going support is offered throughout the day and, to an extent, at night. The maintenance of skills and activities is encouraged to minimise cognitive decline and dependence. Advice is given on measures to prevent accidents within the home, with occupational therapist involvement recommended, if appropriate. As both physical and/or cognitive support needs increase, care workers receive advice and support from their managers, and care plans are changed to reflect changing needs. Carers are also trained in the skills they need to provide more advanced care.

##### **Responding to a crisis or emergency support**

There is a degree of flexibility to provide additional care staff to support the live-in care worker on a short term basis to cover respite or emergencies. In some areas, when a person with dementia has been admitted to hospital the live-in carer can provide continuity of care in the hospital by assisting with washing, dressing and eating.

##### **Supporting a person with dementia at the end of their life**

Live-in care aims to keep people in their own homes for as long as they wish and to provide end of life care. Specialist providers have care workers skilled in end of life care. Providers work with other agencies and the family to provide the support needed. Two live-in carers or more can be provided to provide 24-hour care (if the client's home can accommodate two or more carers).

##### **For further details contact:**

Anne Challenor-Wood, Care Provider (Convivium Care Ltd)

Tel: 01761 239029 / 01761 232689

### **Response services**

A pilot project developed by local authority commissioners and home care providers has been operating for three years in South Somerset. The scheme offers a more flexible and responsive approach to service delivery and could provide the foundation for future council-funded care. It illustrates the benefit of moving the responsibility, accountability and management of support and care closer to the service user. The home care manager has the ability to make decisions enabling people to retain their independence and stay in their own homes. The scheme demonstrates that a one-hour night visit can help people to stay in their homes 24 hours a day and avoid unnecessary hospital admissions.

#### **Good Practice Model**

##### **Crewkerne Model of Initial, Rapid Response and Night Services**

The project is designed to provide home care and support to enable people to remain in their own homes. The service is provided for residents in a 15-20 mile radius of Crewkerne.

The initial and rapid response service is purchased by social services as blocks of hours per month. Referrals are made by social services following an assessment of need. The service, provided by two home care providers, including Care South, is designed to:

- Assess and support people following hospital discharge;
- Prevent hospital admission;
- Provide services for people receiving care for the first time.

Initial response operates between 7am and 10pm

Response time is within 48 hours of referral. Home care co-ordinators are sent the assessment and request for care based on the person's needs. The two home care providers decide between them who is best placed to provide the service (with decisions based on capacity, availability and skill sets). Care is provided by an individual care worker unless two are required for mobility reasons. The service provision covers a range of social support and care needs (i.e. nutrition and rehydration, dressing, personal hygiene and social support) designed to enable a person to return to everyday activities.

## **Good Practice Model**

### **Crewkerne Model of Initial, Rapid Response and Night Services**

#### **Rapid response operates between 7am and 10pm**

Rapid response is provided on a rota basis by the two providers, working on alternate weeks. There is a dedicated phone number. Referral details and needs are provided and a care worker has to be with the person needing help within two hours of the call being received.

Care is provided by an individual care worker. The service provision is more likely to be meeting emergency needs or crisis management to stabilise a situation as opposed to a more controlled approach adopted by the initial response service (i.e. a person being discharged from hospital without any care or support being put in).

#### **Night response service**

This is also purchased by social services in blocks of hours per month. Referrals come via social services. GPs or other members of the community team who want to refer have to go via a central social services manager. The service is designed to provide night support critical to keeping people in their own homes and prevent inappropriate admission to hospitals.

#### **Management of the service**

The social care manager makes the referral, ensuring the home care provider has access to all the critical information needed to provide the care.

Care workers operate from the office as their base. They start and finish their shift there as well as having access throughout the night. At the beginning of the shift they have a report on the clients and pick up the relevant paperwork for the calls they will be making.

The support they provide includes:

- Turning people in beds to prevent pressure sores;
- Changing incontinence pads and taking people to the toilet;
- Well-being checks for people who are wandering or unsettled;
- Helping people to resettle in their homes after being discharged from hospital.

### **Good Practice Model**

#### **Crewkerne Model of Initial, Rapid Response and Night Services**

Depending on needs, visits can be made once or more per night. Decisions on the number of visits (and thus the flexibility and responsibility for managing the support) are left with the home care night team. Initially, this was not seen as a long term scheme. However, the reality is that some clients are remaining with the service on a long-term basis.

Lone worker safety is covered by:

- Care workers going out in pairs;
- A tracker system being placed in vehicles, enabling managers to locate them via GPS or computer if they are late, have missed a call or are lost.

Access to clients' properties is via a key safe system (with a key kept in a box outside clients' homes).

Clients' needs are regularly updated. Care workers keep a record in clients' homes and update office records. There is a dedicated phone line for the service and all care workers carry mobile phones. Care is monitored by a manager who liaises with social services.

There are regular three-monthly meetings to discuss cases and a twice a year meetings to discuss the development of the service and evaluate its progress and success.

## **6.2 Workforce development**

### ***Recruitment and retention***

Tough economic times often lead to the best innovations and home care providers are taking the initiative in recruiting, developing and training their workforces to help them provide the best care and support for people with dementia and their families. Tried and tested and new models of training and workforce and development, from Alzheimer Society's 'key worker' system to 'Dementia Care Mapping' and high quality in-house training, are being developed.

Providers say that different approaches have been tried with staff recruitment, illustrated by the following comments:

*'More creative advertising for care staff – looking outside the usual parameters. Many of the best people have been/are working in completely different fields. It's not what qualifications they have but whether their hearts are in the right place and then giving them the skills to build on.'*

*'We need to remove the stereo typical, perceived images of dementia i.e. these clients will be aggressive. We need to send out positive messages about dementia to service users and staff and promote a sense of pride and passion in this type of work.'*

*'We encourage service user input into staffing and care worker teams.'*

Home care providers say that staff are more likely to stay with a provider if the following are taken into consideration:

*'It is important to provide flexible working arrangements to accommodate the needs of part time staff, i.e. around family arrangements or their change in circumstances.'*

*'Providers need to create a positive working environment where managers and care workers feel respected and valued, and develop a culture where praise and recognition of good practice is encouraged.'*

*'Care staff perform better when there are good support structures in place (in some cases counselling and access to occupational health services ), a career development path is available through training, gaining qualifications and taking on specialist roles (i.e. dementia champions and ambassadors, dementia nurses and dementia advisors).'*

### **Training**

Investment in training has never been more important. The reduction in public funding for external training has resulted in an increase in home care providers training staff in-house – and they are encouraged by the results. It is proving to be cost-effective and critically gives staff direct experience of looking after 'real people needing real care'. One provider says:

*'It works for us because we can focus the training on our clients and the challenges they are facing. Instead of theoretical clients, they get to hear about real people and real problems.'*

#### **Good Practice Model**

##### **Train the Trainer packages**

Train the trainer packages enable information to be cascaded across an organisation via internal training courses and as part of case meetings.

Home care providers believe that everyone should have a basic knowledge about dementia but this needs to be combined with practical experience in the workplace and on-going support to ensure best practice is maintained and developed as illustrated below:

*'Training goes beyond attending a course. It needs to be relevant and applicable to a work situation, with regular time set aside for reflective practice to see if techniques/methods work and, if not, what can be done to change to improve the situation. Training needs to be more practically focused to change, improve and maintain good practice.'*

#### **Good Practice Model**

##### **Supervision**

Maintaining and supporting staff to implement training and improve on best practice are achieved through reflective practice, work shadowing programmes and supervision.

It is important that training includes managers, supervisors and office teams; this helps them to develop leadership skills and drive forward the person centred approach as illustrated by the points raised in this research:

*'Office teams are trained to challenge care staff in terms of respecting people's independence and their needs and right to remain in control, and to advise them if there is any indication that this is not happening.'*

*‘Supervisors and managers have completed a Dementia Link Worker course so this is passed on informally all the time, but we are planning to include short training sessions at team meetings using the experience of our care staff.’*

*‘Support staff develop by approaching specialist units, learning about best practice and develop specialist’s skills by working with them through joint training and developing support structures.’*

### **Good Practice Model**

#### **‘Dementia Care Mapping’ for home care**

Dementia Care Mapping – used as a focus for staff training and development in hospitals and care homes and as an aid to care planning – is to be incorporated into home care by a major South West provider.

Somerset Care at Home, part of one of the largest care providers in southern England, is introducing ‘Dementia Care Mapping’ in August 2011 to put themselves at the forefront of providing person-centred care and support for people with dementia.

Designed by the Bradford Dementia Group to evaluate quality of care from the perspective of a person with dementia, it is widely used in care homes to monitor the needs of residents and make appropriate changes to care and support. Somerset Care at Home plans to train eight community managers and deputy managers as ‘Care Mappers’.

Their role will be to:

- Visit home care clients;
- Observe care and support provided;
- Discuss their thoughts with clients and care workers;
- Offer praise and encouragement for care and support that is working well;
- Offer constructive thoughts and ideas on improving care and support.

### **Good Practice Model**

#### **‘Dementia Care Mapping’ for home care**

The ‘Care Mappers’ will provide a vital link in liaising with teams responsible for delivering care packages, and play a pivotal role in ensuring the consistency and continuity of care, ensuring that it meets the needs of clients.

The company began its journey towards delivering person-centred care in Somerset Care’s 26 residential care homes in Somerset and Gloucestershire (experience that should prove crucial to home care). Initially, all staff including managers, clerical staff, cooks and domestic operators attended a basic three-day dementia awareness course. In putting what they learned into practice, they noticed significant changes, not only to how care was delivered and interactions between staff and residents but in the way people were thinking and approaching care. Managers were also supported in their role by attending ‘inspirational leadership’ training.

Somerset Care at Home care workers presently learn about dementia from a 12-week distance learning course and are supported in putting what they learn into practice by managers and other care team members. Dementia awareness is a basic requirement for all staff, but there is recognition that specialist teams who can support and provide care for more complex care packages are integral to providing high quality dementia care.

#### **‘Dementia Care Mapping’: the way forward**

‘Dementia Care Mapping’ is a tried and tested model in hospitals, care homes and day care in more than 20 countries worldwide. Generally used in formal settings, it is proving a highly effective way of promoting a holistic approach to care and Somerset Care at Home should be applauded for introducing it to home care. Adapting it to this new environment could produce a definitive way forward for dementia care and support.

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### 6.3 Multi-agency working / links

#### *Integrating community services*

One home care provider is working closely with a local care home to break down traditional boundaries and be better able to meet the needs of local people with dementia and their families.

#### **Good Practice Model**

##### **Shared facilities**

Facilities at the care home have been made available to the local community. Home care clients can visit to have their hair done, see a chiropodist, have an assisted bath or join the residents for activities and meals. The initiative is helping to provide respite for carers and help people overcome isolation and loneliness, particularly those who live on their own around difficult times such as Christmas.

This approach is seen as a moving away from day care to a more community based day club, enabling people to have greater choice to pop in for an hour or so rather than all or part of a day. In addition, the care home supports the home care provider by offering short stay help when needed. Care workers can move freely between people's own homes and the care home, improving the continuity of care and allowing them to share experiences with care home staff.

This joined up approach enables:

- Home care workers and the care home to develop and share resources;
- Service users to have more choice over where and how they receive support and care;
- Consistency and continuity of care.

***Links within the community to support people with dementia***

Home care providers in the South West are keen to develop good community support networks and have access to health expertise that can help them to provide care and support for people with dementia and their families.

The following models and links are proving successful in moving this development forward:

**Good Practice Model**

**Local Involvement Networks (LINKs)**

‘Local Involvement Networks (LINKs) aim to give citizens a stronger voice in how their health and social care services are delivered. Run by local individuals and groups and independently supported, the role of LINKs is to find out what people want, monitor local services and to use their powers to hold them to account. A LINK exists in every area. Many providers reported the benefits of joining such schemes.’

NB. LINKs will evolve into new "Healthwatch" organisations from October 2012, and some will be renaming themselves before this.

**Good Practice Model**

**Local ‘learning hubs’**

Local ‘learning hubs’ have been set up to enable those providing support to share experiences, develop partnerships, build relationships and develop practices, models and ideas that will benefit future customers. Home care providers found that when engaging with these groups they were positive and brought together a large number of providers operating in the community (i.e. care homes, home care providers, nursing homes, and community staff). Sadly, care managers and discharge planners were not represented.

### **Good Practice Model**

#### **Crib Sheets**

The development of a simple 'crib sheet' designed to go with a person as they travel through the health and social care system, including questions framed as 'Are you aware that...? With space for important information to be added (i.e. health conditions, likes and dislikes and home support, if any, received).

### **Good Practice Model**

#### **'This is me'**

The Alzheimer Society's 'This is me' leaflet has proved a very beneficial mechanism for sharing information between community and hospitals around the admission and subsequent care of a person with dementia (also see the Alzheimer Society Model of Care on page 28).

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Many beneficial networks made between professionals, other home care providers, specialist providers and specific advisors are being made both formally and informally.

## 7. Moving Forward

### 7.1 Achieving an outcome-focused approach

This was identified by home care providers as an area where more help was needed. To start we need to understand that essentially, it's not what a service does that matters, but what difference it makes to the life of the person who receives it.

When an outcomes-focused approach is adopted it can resolve many of the challenges home care providers face, and makes a positive impact on the perception of the sector and those who work within it.

The benefits this has for care workers include:

- Being clear about what they are trying to achieve and celebrating the achievement of goals with service users;
- Being able to use their own initiative – work is more interesting and engaging;
- Their views being taken seriously – they will know about progress in achieving outcomes and new potential outcomes so communication with a supervisor/manager will be seen as critical;
- Being regarded as, and feeling, a more important part of the team;
- Experiencing improved quality of relationships and achieving continuity of care.

The benefits this has for home care managers and supervisors are that it:

- Develops their vision, strategy and leadership skills;
- Makes their role more professional – not just responding to pre-specified care plans;
- Enables them to become active participants in influencing, contributing and enabling service users to achieve their goals and outcomes;
- Improves on their ability to manage and control risk;
- Creates an opportunity to develop an information database and effective networks.

This approach improves staff retention, creates a more interesting and fulfilling role and creates a culture where the relationships in care matter. When service users and their

families work together with home care providers, and outcomes are achieved it creates a positive spiral of increased confidence and increases aspiration.

The benefits this has for service users include:

- Better choices of care and support and a feeling of being in control of their life;
- Better relationships with care workers, building trust and confidence in them;
- Being treated as unique individuals and with dignity.

Changing the way we think and deliver care and support can be challenging, particularly when the routines and methods are so familiar. It can be useful to have a framework to help you plan for an outcome. For example:

Service user needs	Inputs (what we invest)	Outputs	Outcomes
Wants to get around the home better (expressed in their everyday language)	<ul style="list-style-type: none"> <li>• Time</li> <li>• Money</li> <li>• Training</li> <li>• Physiotherapy</li> <li>• Occupational Therapy</li> <li>• Planning and management</li> </ul>	Discuss the options with the service user and help them choose	Slow progress at the start but improvement seen by the end of a 6-week period
		Provide home care with sufficient time to encourage and practice mobility	Service user feels much more confident moving around their home
		Occupational Therapy provides handrails and non-slip edges to steps	Service user feels more cheerful and in control of their life
		Physiotherapy assessment plus four sessions of exercise	Home care reduced as service user's abilities increase
		Monitor progress	

Computer tools can also provide a framework as illustrated by the following comment:

*'We have an outcomes report that adds on to our database,'* says one home care provider.

*'This can be filled out as decided at the outset. This means at each review the supervisor will work out where they are at that point and record this. This has to be with the person with dementia and also probably the main carer present.'*

## **7.2 Opportunities for home care**

### ***Growth in the private market***

To make the most of this area of growth, the UKHCA Personalisation Toolkit says home care providers need to think about the following:

#### *Marketing*

Presenting and selling their services, as opposed to completing tender documents for block contracts. Focusing on USPs, developing a range of marketing material to address different customer needs and creating good quality websites.

#### *Building on existing services*

Talking to existing service users who may be opting for personal budgets about the options they can provide in meeting their needs. Discussing choice, consistency and flexibility of care and support services and how service users can make use of personal budgets, direct payments and top-ups (private funds).

#### *Promoting the benefits of using a regulated home care provider over personal assistants*

This includes explaining to providers the burden of being an employer, vetting workers before engaging them, training their workforce to a high standard and replacing workers when they are absent, sick, on holiday or leaving to work elsewhere.

#### *Developing and providing different services*

Introducing a specialist service (i.e. for people with dementia), enabling resources to be focused on one area, streamlining thinking and service development (in terms of knowledge, training, management, roles and responsibilities) to create a valuable network and resources in a specific sector.

Home care providers could also look at making the most of existing skills and resources by:

- Facilitating or brokering care and support for people with individual care budgets;
- Offering training for personal assistants, or a back-up service to people who normally employ a PA;
- Helping with recruitment and vetting of PAs and organising payroll service for people employing a PA;
- Collaborating or working in partnership with other organisations.

This research addressed the challenges faced by home care providers in developing dementia services within a personalisation context and has provided us with a variety of models, case studies and development of good practice which is moving us all closer to achieving the aims and objectives set out in the personalisation agenda. Best practice and innovative thinking develops from experience and lessons learnt.

Throughout the process, but in particular in the discussions held during the focus groups and the telephone interviews, many thoughts and ideas were shared about what is required to move the development of flexible good quality person centred dementia care services forward.

## **8. Key Messages for Commissioners**

### **8.1 Dementia care pathway**

- Support and work more closely with homecare providers to achieve a referral and diagnosis of dementia;
- Explore and develop homecare providers' capacity to deliver more person-centred care and support throughout the person with dementia and their carer's pathway;
- Work closer with homecare providers around early diagnosis, interventions, palliative and end of life care;
- Building up a relationship with providers will increase greater understanding and recognition of the knowledge and abilities of the sector and the people who work within it.

### **8.2 Person centred service delivery**

- Develop a partnership approach that includes homecare providers and informal carers to achieve a more accurate assessment of a person with dementia's abilities;
- Utilise the skills and knowledge of providers in the care review process;
- Delegate more responsibility for care closer to the point of delivery, giving providers more autonomy;
- Aim to reduce unnecessary layers of bureaucracy, by working more closely with homecare providers;
- Planning care in 'banks of time' rather than allocating set times for care and support to be delivered is effective in supporting flexibility and choice;
- Short visits i.e. '15 minutes' only have a place in when used to complement person-centred dementia care and support already in place.

### **8.3 Funding**

- Develop and facilitate a relationship with homecare providers that allows for alternative funding options, approaches or solutions to be explored;
- Reduce confusion by simplifying or clarify the terminology and range of language that is being used regarding funding;

- Build in greater flexibility around finance and monitoring processes;
- Encourage, support and promote the uptake of personal budgets for people with dementia and their families;

#### **8.4 Contracting clauses**

- To improve on the provider's abilities to deliver flexible care and support, remove punitive penalty clauses i.e. missed or late calls or visits;
- Take into consideration the effects on the homecare sector of using framework agreements or similar contracting arrangements, in terms of potential reduction in providers and social capacity and the ability to provide consistent flexible services.

#### **8.5 Costs**

- Foster closer working relationships with homecare providers to improve understanding and recognition of the true cost and implications beyond direct service user contact time of delivering good quality person-centred care and support for people with dementia.

## 9. Key Messages for Providers

### 9.1 Personalisation

- Encourage and support people with dementia to take up personal budgets;
- Clarify frameworks to deliver outcomes (thinking about identifying needs, inputs, outputs and outcomes);
- Develop monitoring and quality assurance systems that support a person-centred outcome-focussed approach.

### 9.2 Service delivery

- Diversify and support growth in the private market;
- Build on existing skills and resources;
- Develop more flexible and responsive person-centred care and support, based on individual needs;
- Address how you can provide more flexible weekend, evening and overnight services to support people with dementia.
- Consider extending office opening hours and use it as a base for on-call managers and staff to work from improving access to information, communication and support to care workers;
- Organise staff into smaller teams, adopt a key worker structure and consider merging traditional field and office management roles into one;
- Move towards developing new community based service initiatives and partnerships including assistive technology.

### 9.3 Workforce development

- Look for staff from other sectors with comparable skills, life experience and the right approach;
- Invest in developing specialist dementia knowledge and training.

#### **9.4 Links and multi-agency working**

- Continue to develop and maintain links that support managers and care staff to provide services for people with dementia.

Everyone has to change if we are to truly achieve outcomes-focused, person-centred care and support for people with dementia. Home care providers have the opportunity to take the lead in personalisation – and should not wait to be given permission to move forward or to follow someone else’s vision.

## 10. Conclusion

There is no doubt that both homecare providers and commissioners are working towards delivering services for people with dementia within the personalisation context. Whilst there are some challenges that are getting in the way of best practice, providers have found innovative ways of meeting the challenges, delivering services and managing and developing the workforce to provide good quality care to people with dementia and their carers.

Flexibility, consistency, choice and time are words that sum up what providers believe are required to deliver person-centred care. There is a genuine willingness amongst providers from all sectors to develop more joint working partnerships with commissioners, community support networks and dementia expertise, so that together we can meet the growing challenges that dementia presents.

It is crucial that commissioners and providers continue to build on and develop good working relationships. To achieve this, both partners must have:

- Trust – the belief that each of them is doing what they say they are doing and honouring the commitments they made to each other;
- Joint commitment to success;
- A shared focus on results;
- Good and open communication;
- An agreement to share risk.

Ultimately the aims and objectives of both commissioners and providers is to deliver the best quality individual service we can to support and meet the needs of people with dementia and their carers both now and in the future.

## 11. Further Information

### 11.1 Author and contributors

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## 11.2 Resources

### ***South West Dementia Partnership***

For more information about the work the South West Dementia Partnership please use the following link: [www.southwestdementiapartnership.org.uk/](http://www.southwestdementiapartnership.org.uk/)

### ***United Kingdom Homecare Association***

For more information about the United Kingdom Homecare Association (UKHCA) please use the following link: [www.ukhca.co.uk](http://www.ukhca.co.uk)

A copy of the UKHCAs Personalisation: A toolkit for Independent homecare providers is available to download free to UKHCA members. To purchase a hard copy please use the following link: [www.ukhca.co.uk/productdesc.aspx?ID=24](http://www.ukhca.co.uk/productdesc.aspx?ID=24)

A copy of UKHCA of Specimen Terms and Conditions Relating to the Supply of Care Services is available to download free to UKHCA members only. For membership details please go to: [www.ukhca.co.uk/joining.aspx](http://www.ukhca.co.uk/joining.aspx)

***National Dementia Strategy*** [www.dh.gov.uk](http://www.dh.gov.uk)

### ***Bradford Dementia Group and Dementia Care Mapping***

[www.brad.ac.uk/health/dementia/DementiaCareMapping/](http://www.brad.ac.uk/health/dementia/DementiaCareMapping/)

***Think Local Act Personal (TLAP)*** [www.thinklocalactpersonal.org.uk](http://www.thinklocalactpersonal.org.uk)

***YouGov*** [www.yougov.co.uk](http://www.yougov.co.uk)

**LINKs** For more information about LINKs please use the following link:

[www.nhs.uk/NHSEngland/links/Pages/links-make-it-happen.aspx](http://www.nhs.uk/NHSEngland/links/Pages/links-make-it-happen.aspx)

***Alzheimer's Society*** [www.alzheimers.org.uk](http://www.alzheimers.org.uk)