Shared Lives and Dementia

Helping Shared Lives schemes develop their services to meet the needs of people with dementia and their families

Final report of the National Shared Lives and Dementia project 2010–2013

Innovations in Dementia

shared lives south west
SHARED LIVES AND DEMENTIA
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1. In 2010, two organisations based in the South West - Innovations in Dementia and Shared Lives South West - began a joint three-year national project examining how Shared Lives schemes might support people with dementia and their families. The project also asked people with dementia and their families what they thought of Shared Lives services and looked at how such services could be developed across the UK. The project was funded by the Esmée Fairbairn Foundation.

2. The project’s main purpose was to collate evidence showing whether Shared Lives could be a desirable service offer from a carer’s or person with dementia’s viewpoint and to support Shared Lives schemes to gain the confidence and skills needed to be ‘dementia ready’ – to be able to respond appropriately when asked to provide a service to someone with dementia. Activities included training, the development of resources and sharing of best practice information.

3. Over 18 months of the project, we collated information about 46 different instances where people with dementia came into contact with the four Shared Lives schemes that participated in the project at five sites. We gathered feedback from people with dementia, family carers and Shared Lives carers. We also collated the views of Shared Lives scheme staff and commissioners of services for older people.

4. Our evaluation showed us that family carers and people with dementia responded very positively to Shared Lives services. Those who used it felt it was very personal, reliable and that the person with dementia had had a great time. There were a few services that did not work out and broke down, where carers gave less positive feedback.

5. We found that Shared Lives schemes are well placed to develop services for people with dementia and that the core processes of matching and monitoring and supporting Shared Lives carers work well for any client group. However, the scheme must make crucial ‘tweaks’ to the way it provides services in order to deliver dementia services successfully.

6. From our wider interaction with Shared Lives schemes, it was clear that many schemes have already begun to develop dementia services on a small scale, often in response to an individual case where an existing service user with a learning disability has developed dementia or where a specific referral has come in which could be matched. In some cases, local authorities were asking their in-house Shared Lives schemes to become a generic service rather than learning disability specific.

7. The experience of our partner Shared Lives schemes and other schemes actively developing dementia services is that this expansion requires specific investment in knowledge and capacity within the scheme.

8. Schemes reported that there are people willing to become Shared Lives carers for people with dementia, usually because they have personal or professional dementia experience. Those doing this work are skilled care professionals working from their own home and remuneration needs to reflect this. They also need training, support, and access to assistance and an alternative service should a crisis arise.

9. We found the strong view that success of the service would be maximised where the relationship between a person with dementia and a Shared Lives carer starts relatively early in the service user’s journey. However, there is a mismatch between the need for early intervention and eligibility criteria for social and healthcare funding. This can prevent people with dementia accessing Shared Lives services at an
appropriate time. If regarded as an early intervention or preventative approach, Shared Lives could be very successful but there appears to be very little funding available for this type of service.

10. It was apparent that Shared Lives as a concept or service model is not well known in the social and healthcare sectors that predominantly focus on older people or people with dementia.

11. Shared Lives needs to establish a higher profile as an option for care among a wide range of health and social care professionals who work with people with dementia and their family carers.

12. Shared Lives is not necessarily cheaper than residential care but there is some evidence that it delivers better outcomes for people with dementia and their carers and might be preferred if it were available and funded. Further analysis and study are needed to identify specific longer-term savings gained by using Shared Lives as an early intervention service, but there is general evidence to suggest that early intervention services would reduce public expenditure in the longer term.

RECOMMENDED ACTIONS

1. Shared Lives must be seen as a core component in the local implementation of the National Dementia Strategy, and be fully included in the range of options commissioned for people with dementia in any area.

2. Local authorities and independent organisations must invest in local Shared Lives schemes to enable the development of the skills, experience and capacity required to deliver dementia Shared Lives services.

3. Shared Lives schemes must ensure that they are prepared to meet the needs of people with dementia using or wishing to use the scheme by ensuring that staff and carers have adequate training and support.

4. Shared Lives schemes must adapt their service to fully meet the needs of people with dementia and their carers - it is not the same as delivering a Shared Lives service for people with a learning disability.

5. Shared Lives schemes should engage with their local dementia health and social care professionals and the new Health and Wellbeing Boards to ensure that the dementia care ‘world’ is fully aware of the Shared Lives offer.

6. Memory service teams should be made aware of Shared Lives and be able to provide information to people with dementia and carers in advanced planning discussions.

7. Shared Lives schemes should find ways to engage with people with dementia and their carers early on in the dementia journey to overcome some of the concerns that carers have.

8. Shared Lives schemes should evaluate their services for people with dementia in order to develop the evidence base for the service.

9. Shared Lives schemes that are working with people with dementia should commit to sharing their learning with other Shared Lives schemes and with other providers of dementia care practice to improve overall dementia care and outcomes for people with dementia.
SECTION 1: INTRODUCTION

WHAT IS SHARED LIVES?

Shared Lives is an innovative form of social care that offers permanent or short breaks in the home of a local family. Shared Lives services are all about one household sharing their lives, families, home, interests, experience and skills with others who need help and support to live their lives to the full. The person is welcomed as a member of the family and supported by a Shared Lives carer who is checked and approved, trained and monitored by the Shared Lives scheme. Shared Lives focuses on what the individual wants and needs. It is highly personalised and delivered by the local community in the local community.

There are more than 150 Shared Lives schemes across England. Most are based in local authorities but some are run by independent third-sector organisations. Traditionally, Shared Lives schemes have supported people with learning disabilities but increasingly they are working with different user groups including people with dementia.

DEMENTIA FACTS AND FIGURES

There are approximately 800,000 people with dementia in the UK and the disease costs the economy £23 billion a year (Alzheimer’s Society, 2007, updated to reflect 2012 figures). By 2040, the number of people affected is expected to double and costs are likely to treble (DH, 2013).

Dementia describes a range of symptoms that progressively affect memory, cognition, decision-making, perception, reasoning and understanding. In the final stages, people can lose the ability to control movement, including sitting up, smiling and swallowing. Dementia occurs as a result of the death of brain cells or damage in parts of the brain that deal with thought processes. It is progressive, which means the symptoms will gradually get worse.

The most common cause of dementia is Alzheimer’s disease, which affects 62% of people with dementia, followed by vascular dementia (17%) and a combination of both (10%). A few other, rarer conditions also cause dementia. At present there is no cure for dementia, although some medication can slow its progress. Age is the greatest risk factor, with one in 14 people over the age of 65 and one in six over the age of 80 affected (Alzheimer’s Society, 2011). There are an estimated 17,000 younger people with dementia (under the age of 65) in the UK. However, the actual figure may be up to three times higher (Alzheimer’s Society, 2013).

LEARNING DISABILITY AND DEMENTIA

People with a learning disability are at greater risk of developing dementia as they get older compared to the general population (Cooper, 1997). As people with learning difficulties live longer and into old age, incidence of dementia is therefore increasing. Studies (cited in Kerr, 2007) estimate that 13% of those over 50 and 22% of those over 65 have dementia. For people with Down’s syndrome, the risks are even higher, with a rate of 75% in people over 60 (Lai and Williams, 1989; Prasher, 1995).

As many Shared Lives schemes currently support people with a learning disability on a long-term basis, dementia is an issue of relevance and importance to all Shared Lives schemes in the UK.

THE POLICY CONTEXT

Breaks for people with dementia and carers

In the context of an ageing population and increased incidence of dementia, responsive and appropriate support enabling people to live well with a diagnosis is now seen as essential. The need for reliable access to community-based respite and short-break support for people with dementia and their family carers has been highlighted in many government documents.
Section 1: Introduction

A Care Services Improvement Partnership factsheet (CSIP, 2008) asserted:

Short breaks are part of a spectrum of care to enable people to continue living in the community.

The National Carers Strategy (DH, 2008) stated:

In giving carers a break, we believe there should be a greater emphasis on the provision of planned breaks, which will provide carers with the time to take up the same work, education, leisure and training opportunities as anyone else.

NICE’s Dementia Quality Standards (2010) refer to the need for improved carer support and to the availability of suitable breaks for people with dementia and their families.

Living well with dementia: a national dementia strategy (DH, 2009) set new standards for dementia care, including increasing early intervention and developing flexible and reliable community support services responsive to the personal needs and preferences of each individual.

Support in the community

Two-thirds of people with dementia live in their own home in the community and one-third live in a care home; at least two-thirds of UK care home residents have dementia (Alzheimer’s Society, 2007).

Support. Save. Stay (Alzheimer’s Society, 2011) reports that people with dementia and their carers greatly value living on their own but many do not receive the care and support necessary to make this possible. Lack of support at home leads to hospital admission, entry to care homes and increased strain on carers.

The dementia report (Alzheimer’s Society, 2012) shows that, at the present time, people are not living well with dementia, although much work has been done to improve their quality of life. The Society’s respondents said they wanted services better designed around their needs and almost 50% thought their carer did not always get the support they needed to carry out their caring role. The Alzheimer’s Society recommends that resources are shifted from inappropriate residential care for people with dementia to the community setting. This would help to ensure that the right support, such as early intervention and respite care, would be available.

The report also found that most people with dementia and carers thought their local community did not understand dementia (Alzheimer’s Society, 2012).

A national movement of dementia-friendly communities has emerged in response to Prime Minister’s challenge on dementia (DH, 2012) and there is ongoing discussion about ways of keeping people with dementia connected to life in their local communities.

How Shared Lives fits with the policy context

Shared Lives services are all about one household sharing their lives, families, home, interests, experience and skills with others who need support to live their lives to the full. Shared Lives schemes are:

- Community-based alternatives to residential care for respite and short break opportunities
- Person-centred, individualised models of care and support, based on relationships
- Flexible and responsive services, which can support a family carer to care for longer
- Delivered in communities by communities, helping people with dementia remain connected to their neighbourhood

The model of Shared Lives could be seen to fit with the policy context of enabling people to remain living at home in their local community, not entering institutional or hospital care, and supporting carers to carry on caring for their loved ones at home.

There seems to be a clear synergy between the perceived benefits of the Shared Lives model and what carers and service users identify as lacking or poor in current service offers.
THE NATIONAL SHARED LIVES AND DEMENTIA PROJECT

The proposal for a national project was based on initial scoping work with Shared Lives schemes in England. A workshop held at a National Association for Adult Placement Scheme (now Shared Lives Plus) conference in 2009, attended by 40 Shared Lives representatives, raised issues about how Shared Lives might work for people with dementia. These included:

- A need for a shared strategic direction and collation of Shared Lives good practice for people with dementia
- Help with the practical and technical arrangements for delivery of Shared Lives opportunities to people with dementia, including recruitment of family providers
- The need for appropriate dementia training for Shared Lives carers
- The effective presentation of Shared Lives as a positive alternative to traditional models (residential and nursing homes) to commissioners of services

Project objectives

Based on the factors identified above, the following objectives were proposed for the national Shared Lives and Dementia project:

- Development of Shared Lives opportunities for people with dementia, including service models that may be replicated by other schemes
- Evaluation of the outcomes and impact of Shared Lives for people with dementia from the perspective of the person with dementia, their family carer, the Shared Lives carer, Shared Lives scheme staff and the commissioning statutory authorities
- Collation and dissemination of good practice for delivering Shared Lives to people with dementia
- Development of a range of training tools and support strategies for Shared Lives schemes to meet the needs of people with dementia
- Establishing links with national dementia initiatives where Shared Lives is considered to have relevance
Section 1: Introduction

In 2010, Innovations in Dementia and Shared Lives South West began a joint three-year national project looking at how Shared Lives schemes might support people with dementia and their families, what people with dementia and their families thought of Shared Lives services and how such services could be developed across the UK. The project was funded by the Esmée Fairbairn Foundation.

The project’s main purpose was to collate any available evidence that Shared Lives could be effective and was a desirable service offer from a carer’s or person with dementia’s viewpoint.

If so, there was a need to equip Shared Lives schemes with the confidence and skills to be ‘dementia ready’ – to be able to respond appropriately when asked to provide a service to someone with dementia.

The project has also collected evidence demonstrating positive outcomes for all those involved in providing or receiving a Shared Lives service for people with dementia, whether an existing service user or someone new to Shared Lives.

Project activities

The following activities were agreed:

- Evaluation of 45 cases studies relating to Shared Lives services for people with dementia
- Mentoring and support to five Shared Lives schemes that were partners on the project
- Delivery of three good practice days, with sharing and learning opportunities
- Delivery of two dementia training courses to Shared Lives schemes in six locations in the UK
- Production of a stand-alone Shared Lives and Dementia training pack
- Production of a film about a Shared Lives service from the perspective of the person with dementia, the family carer and the Shared Lives carer. *Pat and Roger’s story* is available on DVD or to view at [www.sharedlivessw.org.uk/dementia](http://www.sharedlivessw.org.uk/dementia)
- Development of a business case review of the costs and benefits of Shared Lives services for people with dementia (Association for Dementia Studies, University of Worcester, 2012)

Further objectives

As the project progressed, it became apparent that Shared Lives schemes in many areas were keen to engage with the development of services for people with dementia. Most of the difficulties and barriers they were encountering seemed related to awareness of the model by professionals working in health or social care services for older peoples and people with dementia.

The following objectives were therefore added as the project developed:

- Identifying barriers to the commissioning of a Shared Lives dementia service with older people’s commissioners
- Raising awareness of the Shared Lives model with professionals working in dementia health and social care and among family carers of people with dementia
REFERENCES


Department of Health website: www.gov.uk/government/policies/improving-care-for-people-with-dementia


National Institute for Health and Clinical Excellence (2010). Dementia Quality Standard

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Vera and Judy on a Shared Lives short break in Paignton, 2011
SECTION 2: THE EXPERIENCE OF SHARED LIVES: EVALUATION FINDINGS

SHARED LIVES SCHEMES AS PARTNER SITES

The project involved talking to four Shared Lives schemes working at five sites that were already working with people with dementia or planning to shortly. The aim was to track approaches and outcomes across all sites.

Each scheme was at a different stage of development: some were already running an established service; others were starting dementia work from scratch. The schemes met regularly with the national Shared Lives and Dementia project team to share experiences, work through solutions to tricky issues and offer mutual learning support.

Cornwall (Shared Lives South West)

The Cornwall team has been working with people with dementia since 2009, initially through a dedicated project in Newquay, which was funded as part of two-year pilot scheme testing out new pathways for dementia (part of the National Dementia Strategy). Services for people with dementia are now integrated into Shared Lives South West’s core services and operate across Cornwall.

Torbay (Shared Lives South West)

The Torbay team has been working with people with dementia since 2008, initially through a dedicated project funded by Carers Grant monies through the Torbay and South Devon, Health and Care NHS Trust. Services for people with dementia are now integrated into Shared Lives South West’s core services and are available in limited numbers in Torbay.

Lincolnshire (Adults Supporting Adults - ASA)

ASA has been working with people with dementia for the past 13 years, specifically providing an ‘at home’ day service in the homes of Shared Lives carers in the Grantham area of Lincolnshire.

Dorset (Dorset County Council Shared Lives scheme)

Dorset Shared Lives primarily provides a service for people with learning disabilities. During the lifetime of the project, the scheme has begun offering Shared Lives opportunities to people with dementia as part of its core services.

East Sussex (Supported Accommodation and Independent Living Solutions)

SAILS provides a range of long- and short-term support within the local community, including Shared Lives and day care opportunities for people with memory problems and dementia. During the lifetime of the project, the scheme has been working to establish Shared Lives opportunities for people with dementia.

EVALUATION FRAMEWORK

Collecting data

Working through our five partner sites, we used an evaluation framework to collect information from people using Shared Lives services (people with dementia and family carers) and the Shared Lives carers.

We were collecting evaluation data from users of a locally contracted service, so therefore applied for research ethics approval from the relevant research governance departments. Project information was given to families and Shared Lives carers, who were asked to ‘opt in’ to the project’s evaluation process by completing a consent form.

Those who agreed to participate completed several questionnaires about their experiences at certain points during the Shared Lives service. The data from the evaluation therefore represent a ‘snapshot’ of their views about Shared Lives at certain points in time (before the placement, during a regular placement and/or when the Shared Lives service came to an end) from the perspective of all those involved.
The process set limits to the interpretation of the evaluation data, as it only included completed questionnaires from those who agreed to participate and took the time to complete them. Not all respondents completed questionnaires at all stages of their experience intervals. Not all referrals resulted in a Shared Lives service being provided, so some pre-placement questionnaires were not followed up by during-placement questionnaires.

The questionnaires
Over a period of two years, we collected information on 46 people with dementia who in some way came into contact with one of the Shared Lives schemes that were partners on the project.

Our questionnaires were short and designed to invite open-ended, spontaneous responses (see appendix B). Shared Lives carers, family carers and, where appropriate, people with dementia were asked to complete questionnaires at intervals during the placements:

- Prior to any placement taking place (baseline questionnaire)
- At intervals during a regular placement (quarterly questionnaire)
- When a one-off or regular placement came to an end (final questionnaire)

Several Shared Lives carers also provided information about their hopes and expectations of working with people with dementia prior to a match being made (general questionnaire).

Seventeen Shared Lives carers and 12 family carers only provided pre-placement information about their hopes and concerns about Shared Lives.

Twenty-nine Shared Lives carers, 14 family carers and five people with dementia provided information about their experience of a regular or ‘one-off’ placement.

EVALUATION FINDINGS

A. PRIOR TO PLACEMENT

What were the hopes of family carers?
Carers were asked what they hoped to get out of using Shared Lives. Of the 12 family carers who completed baseline questionnaires, a large majority (92%) said they hoped Shared Lives would give them peace of mind and cause minimal disruption so they could enjoy a break.

Comments included:

- We are the sole carers for my sister-in-law and we all need some time apart to rest and refresh mentally and physically.
- I’m really hoping for peace of mind, knowing that my mum is happy in the place where she is receiving good care in a home setting.
- I hope that Shared Lives will provide a level of normality and some respite for me as her carer.
- I think it is far less disruptive to my mother’s routine and she actually said she really enjoyed her initial two-night stay. I hope she receives good care within a family setting, which minimises disruption to both herself and to us as a family.

In ranked order, the other hopes carers expressed were:

- Wanting the person with dementia to have fun and enjoy stimulating activities (mentioned by 75% of respondents)
- Opportunities for the person to live a normal, quality life, independent of their family carer (mentioned by 75% of respondents)
- The person with dementia experiencing love, affection and respect; being part of the Shared Lives family in a home from home (mentioned by 50% of respondents)
- The person with dementia looking forward to respite (mentioned by 25% of respondents)
- Shared Lives helping them maintain their relationship with the person with dementia
so care at home could continue (mentioned by 25% of respondents). One carer commented:

I really hope to see my wife have some sort of a life on her own without me being there, and for me to get some free time to relax without the constant worry of looking after her. I’m hoping she can interact with a female adult where she can talk about things that she is not comfortable talking to me about. I hope that by having a short weekly break she and I will have a less fractious relationship as her condition deteriorates.

What were the concerns of family carers?

Family carers were asked if they had any concerns about Shared Lives before experiencing a placement. While most did not express any concerns, there were a few:

- Are Shared Lives carers able to respond well as the needs of the person with dementia change?
- Is the service a ‘safe’ option? One comment was:
  
  My concerns are whether Shared Lives carers are fully aware of what is involved in supporting an individual in the later stages of dementia.
- How committed will they be?
- Can the individual remain in the placement till the end? One comment was:
  
  Do the host families know enough about dementia? Will they know enough about the specific needs and limitations of my mum?
- Is the service responsive enough to provide a Shared Lives carer at the time needed? One carer commented:
  
  My only concern is when the Shared Lives carer is ill or in some way unable to provide care due to illness. What happens then? What happens if we are away and can’t get back? Is there provision for alternative care?

What were the hopes of the Shared Lives carers who were offering the service in their homes?

Shared Lives carers were asked what they thought would be positive about working with people with dementia. Their hopes were wide ranging and went beyond Shared Lives being a reliable respite option. One hundred per cent said they wanted to provide opportunities for a full and good-quality life based on the person with dementia’s wishes.

Comments from Shared Lives carers included:

I want to help the person achieve their wishes, help her and her family feel she is getting the best she can with her life now.

I hope the person with dementia will have added interests in their life and a sense of being valued.

I want to ensure the person with dementia has the most normal and fulfilling life as possible so he may actually enjoy it.

I believe that sometimes people with dementia are treated as second-class citizens and I think through Shared Lives you are able to give individual attention and respite.

In ranked order, the other hopes were:

- To provide respite for the family carer (mentioned by 76% of respondents)
- To provide Shared Lives opportunities to the person for as long as possible (mentioned by 65% of respondents)
- To learn about the person and gain experience of dementia (mentioned by 58% of respondents)
- To share day-to-day family life with the person with dementia in a loving environment (mentioned by 53% of respondents)
- To maintain the person with dementia’s abilities (mentioned by 47% of respondents)
- To keep the person with dementia safe (mentioned by 35% of respondents)
Comments from Shared Lives carers included:

I want to observe and discover more about dementia for my own education and role as a carer.

I hope to gain personal insight into how dementia affects people’s lives and to learn to have patience and respect when dealing with clients.

What were the concerns of Shared Lives carers?

Shared Lives carers were asked if they had any concerns about providing support to a person with dementia. Many did not identify any concerns, citing the ‘good backup systems’ and knowing the Shared Lives scheme was always available for advice and support. Of the concerns expressed, the main ones were:

- Knowing enough about dementia and the needs of people with dementia. One Shared Lives carer commented:
  
  This will be a learning curve for me and I want to do well. I am reading about dementia and hope I can put into practice lots from the book, although I realise life isn’t a book! I will hopefully learn as we live together.

- Need for good information about the person with dementia prior to the placement

- Information about physical needs and what to do in the event of an emergency

- Practical impact of someone’s needs changing.

- Emotional impact of watching someone’s needs change

Comments included:

I need to have good knowledge of information about the needs of anyone I undertake to support.

I need to know about how to respond should an individual fall - a known occasional hazard. I’ll be monitoring the person’s unsteadiness and their safety.

It is a full-on job supporting someone with dementia, with very little or no respite. Where would he go if we can’t cope or he can’t use the stairs.

I worry that I will find it distressing as the person deteriorates and that there is very little hope of any improvement. I will find it hard as it becomes increasingly difficult to communicate and that she may become aggressive at times.

What were the views of people with dementia?

Five people with dementia completed questionnaires about their experience of Shared Lives, usually with support to do so. All were all very positive about their experiences. Here are two examples.

Norman

Norman goes for regular weekend breaks with a Shared Lives carer. Prior to accessing Shared Lives, Norman had attended respite at a residential care home. This had not been a positive experience. Norman said

I get on alright. I like the family and there’s a cat and a dog. I haven’t had any problems. We go out and she takes me out for meals. [The Shared Lives carer] is very nice. I’ve been out for breakfast and lunch. I haven’t got any worries about going there. I worry most days about what I am doing - but I don’t mind going there. I am alright. I am quite happy. It is much better than the other place I went to. I used to go there and put up with it.

Malcolm

Before his placement, we asked Malcolm what he hoped to get out of the Shared Lives service:

I hope to get out and about and meet other people. I want to see new places and have new experiences. It will let my wife have some respite too. I hope they will allow me to indulge my passion for photography and to take me places to do this. I hope Shared Lives will relieve boredom and I see things I would not get to see. It will allow my wife to have a social life too.
When we asked him about his experience after using Shared Lives, Malcolm said it had been very good and he was doing the things he hoped for – in his words “definitely a great improvement”.

**B. DURING THE PLACEMENT**

Most people with dementia using Shared Lives were accessing short-break support, which includes overnight stays, weekend breaks and occasionally longer stays. Some attended for a day on a regular basis. There was one long-term placement for a person with a learning disability who developed dementia.

**What were the views of family carers?**

Fourteen family carers completed questionnaires during a placement about their experiences of using a Shared Lives service. They were asked about what the person with dementia had been doing during the placement and whether they had any concerns.

In ranked order, the topics that appeared in their unprompted responses were as follows:

- The person with dementia is engaged in family life and activities and is being stimulated (mentioned by 71% of respondents)
- The person with dementia is happy/satisfied (mentioned by 57% of respondents)
- The family carer has had a good break and a well-needed rest (mentioned by 50% of respondents)
- The support delivered was high quality and individual (mentioned by 42% of respondents)
- The family carer had built a good relationship with the Shared Lives family (mentioned by 28% of respondents)
- The carer was glad the person with dementia was safe (mentioned by 28% of respondents)

Comments included:

- She has been thoroughly spoilt (in the nicest way) - lovingly spoilt. She loves going to see her Shared Lives family.

A bond was formed between mum and myself with the family and they came to her funeral. She experienced some different things and was happy. I felt the load was lifted for me.

I like that Simon goes to one person who can give him the attention he needs. I also felt that Simon would appreciate a home atmosphere where he could relax and feel part of a family. He gets secure, family support and encouragement to perhaps tackle new or forgotten tasks. It is good knowing he is safe and happy while I get a break. Simon is really enjoying himself. I think it has been one of the best things we have done. It is definitely better than I ever imagined. It felt right from our first meeting [with the Shared Lives scheme].

There were also a few concerns:

- The house not being set up appropriately for someone with dementia
- The length of time it could take to make an appropriate match between the person with dementia and the Shared Lives carer
- Availability, at the time of need, of appropriate Shared Lives opportunities

Comments included:

- The only problem with the service was that they had a lot of antiques around and I had to be so careful that my wife did not knock anything over.

I understood it would take a while to find an appropriate placement. However, this could be shortened by greater consideration and assessment of the personal limitations caused by dementia.

I have a mixed experience of Shared Lives, as what was originally promised did not materialise regarding longer term – weekend or longer – which would have been a much greater help. Although I was relieved to be able to hand over my wife to their care with confidence and with the knowledge she was happy.
What were the views of Shared Lives carers?

The Shared Lives carers were very positive about their experiences of working with people with dementia; all felt they learned a great deal from the person themselves. They identified the following qualities and approaches to be important:

- patience
- reassurance
- allowing plenty of time for discussion
- offering choices
- involving the person as much as possible
- knowing the person’s life story
- providing a stable environment and routine
- listening
- flexibility
- giving people every chance to decide what they want to do
- being in the world of the person with dementia
- keeping the pace of the person with dementia
- awareness of deterioration
- entering the family’s life early for the best results
- training about dementia to increase knowledge and understanding

Comments included:

You need to give the person with dementia every chance in deciding what they want to do and see. You need to keep at their pace - don’t rush them. Have lots of patience and see the person not the dementia.

I try to treat her like a good friend. I value her company and try to reassure her when she is sad. We enjoy each other’s company.

Always plan and be consistent, follow routine and the service user’s routine. Make time to listen and be flexible and tolerant.

C. AT THE END OF THE PLACEMENT

What were the views of family carers?

Nine family carers completed a final questionnaire as their use of Shared Lives came to an end.

Six said they would use Shared Lives again if the opportunity arose, one said they wouldn’t, and two did not answer.

Five carers said Shared Lives was worth the cost, two said the costs were too high and two did not answer.

I did feel the costs were high but, on consideration, the people prepared to have strangers with a difficult disease staying in their home are very special.

It was worth the cost for one-to-one care.

What were the views of Shared Lives carers?

Twenty-nine Shared Lives carers gave information about their experience of supporting a person with dementia in their own home after the placement had come to an end. Ninety per cent, unprompted, said it had been a positive experience.

In ranked order, other positive areas mentioned were:

- Spending time supporting people to maintain their abilities, providing personalised activities and stimulation (mentioned by 48% of respondents)
- Learning skills and approaches from the person with dementia (mentioned by 26% of respondents)
- Getting to know the person with dementia (mentioned by 24% of respondents)
- Belief that Shared Lives was slowing down the impact of dementia (mentioned by 10% of respondents)
- Keeping the person with dementia safe (mentioned by 10% of respondents)
- Building a relationship with the person with dementia’s family (mentioned by 10% of respondents)
One Shared Lives carer commented:

I originally thought it would be hard and depressing work. But once you can see the person first and not the dementia, it becomes positive. It’s positive having great results and seeing the person not deteriorating too fast – that they still have a life. I felt supported by Shared Lives, just knowing they were there if I needed them. I always know I can contact the office for advice.

Some carers were also concerned about the future. Worrying about the worsening of, or future worsening of, the person’s dementia (mentioned by 17% of respondents).

What were the views when Shared Lives didn’t work?

In six of the tracked cases, the Shared Lives placement did not work or the person with dementia did not receive the whole planned service – usually owing to the person with dementia becoming anxious and confused in the Shared Lives carer’s family home. This is one case:

Marcus enjoyed his afternoon out with my husband and I. On the afternoon he arrived we took him to a large garden centre which we looked around and then had tea. But it became difficult as he didn’t sleep at night – he took 20-minute naps and then he was wide awake. The lesson I learned was not to have people staying overnight unless you have built a relationship. But I would still like to support people with dementia in the future.

Of those placements that broke down or ended prematurely, four ended because the person with dementia went into a home, one owing to the person’s physical illness and one owing to a family difficulty.

In each of the above cases, the Shared Lives carer said they would be happy to support another person with dementia in the future.

CONCLUSIONS

From our evaluation data, we can say that Shared Lives is perceived to be of considerable benefit by people with dementia and family carers. Carers told us that Shared Lives offers them a positive alternative respite option in a stimulating and highly individualised family environment. Family carers can experience a break from their caring role knowing the person with dementia is enjoying their Shared Lives placement and is safe. People with dementia enjoy a range of opportunities more like day-to-day life than those offered by a traditional respite care service.

Some carers expressed concerns about the knowledge, skills and ability to respond of Shared Lives carers. These were worries that they may not have expressed about respite in a residential care setting.

Shared Lives carers say that providing a service to people with dementia has been a positive experience. Many feel they learned a great deal from the person with dementia. Even when the placement breaks down, Shared Lives carers say they would be happy to support another person with dementia in the future.

The following key points emerge from all the feedback from people with dementia, family carers and Shared Lives carers:

• Family carers need good information about Shared Lives for them to feel confident about using the service
• Family carers should be encouraged to share as much information as they can about routines, approaches and the person’s life story with the Shared Lives carer before placement
• Shared Lives carers should have knowledge of and skills in dementia care
• Shared Lives schemes need to provide good mentoring and support to Shared Lives carers
• Shared Lives works best when relationships have had time to develop, although some schemes have responded well to crisis/emergency situations
Esmee, aged 98 during Shared Lives Week 2012
SECTION 3: DEVELOPING YOUR SCHEME TO MEET THE NEEDS OF PEOPLE WITH DEMENTIA

INTRODUCTION

The most common question we have been asked by Shared Lives schemes during the project is: ‘How do we develop our services to meet the needs of people with dementia? What is the same as other Shared Lives services and what is different?’

There is no simple answer. We cannot give you a blueprint. So much is local and will depend on how your service is organised. However, over the past three years, we have picked up lots of ideas, concerns, issues and tips from those schemes which have been partner sites for the project, and from other Shared Lives schemes that have also been trying to develop services and have shared their learning.

Every scheme has encountered similar barriers to development and tried to find ways around them. This chapter summarises this collective learning and will give you an idea of the kinds of adaptations, investment and development your scheme will need to undertake to provide an appropriate service for people with dementia.

Successfully developing dementia services does not happen without up-front investment in staff time. It takes considerable time to establish a dementia service and it cannot reasonably be expected that a busy Shared Lives scheme can suddenly become ‘generic’. Dementia services are different in many respects from learning disability services. You will need to tweak your scheme with this in mind, particularly around:

- Carer training
- Involvement of family carers
- Funding and pricing of services

DEVELOPING YOUR STAFF

General awareness

If your scheme is new to supporting people with dementia, you will need to ensure that your staff know about dementia and share the person-centred values you want to see in dementia service provision. If this is a new departure, you will also want everyone to feel involved and to share the same values, perceptions and principles from the outset.

We recommend that all staff, including those in admin and finance, have dementia training. If Shared Lives carers, family carers and people with dementia phone the office or come to meetings, it is important that everyone is informed, aware of the issues and feels confident communicating with those directly involved. Even staff who have previously worked in a dementia care setting may have conflicting perceptions and it is worth making sure that everyone shares the same understanding.

Staff training

We recommend that all workers, as a minimum, complete SCIE’s e-learning Open Dementia Programme.

Further details are given in the Shared Lives and Dementia training pack or can be found at www.scie.org.uk/publications/elearning/dementia/index.asp

In addition, if you run the in-house training course developed for Shared Lives as a follow-up, your staff should take part in this.

Appoint a staff member to lead on dementia

In addition to ensuring that all staff have basic knowledge, we recommend appointing a Shared Lives worker to take a lead role in dementia-related issues, particularly if your scheme is predominantly a learning disability
service. While there are many aspects of Shared Lives services that will be common across all client groups, the needs of people with dementia are different and the support carers need is different. Ensuring that this is fully considered and championed and that the necessary adaptations are made to the service requires focused energy and commitment. Ideally, this person should have:

- Relevant experience of supporting people with dementia
- Passion for person-centred dementia support
- Links to or knowledge of dementia services locally
- Training skills

The lead person doesn’t need to be a new member of staff. Someone with existing knowledge of Shared Lives and its key processes could be ideal. They wouldn’t need to ‘do’ all the dementia work either – that wouldn’t work with geographical caseloads. Their role would be to act as an in-house expert/enthusiast/problem solver for all Shared Lives workers.

**Staff capacity**

If you are developing dementia services in a Shared Lives scheme previously aligned to learning disability, do not underestimate the challenge of offering services to a new client group.

There is a great deal of work to do before you start delivering a service: finding suitable carers, letting potential referrers and service users know you exist, adapting your key processes, training Shared Lives carers and staff. There will also be a whole new set of professionals to engage with. This all requires a lot of time before the first person with dementia starts using the service.

If staff have no spare capacity, you will make very slow progress.

**SHARED LIVES CARERS**

**General**

Your scheme may already be very good at finding, assessing, approving and supporting carers. You will want a carer to be compassionate, fun, welcoming, resilient, have some caring experience and person-centred values they put into action, and so on. The qualities you will look for will be the same for supporting someone with dementia as for supporting someone with a learning disability.

**‘Converting’ current carers**

There are two ways to find Shared Lives carers to support people with dementia. You could ‘convert’ some of your existing carers or you could recruit carers specifically to do this sort of work. It is worth asking your current carers if they would be interested in supporting people with dementia. As we know, Shared Lives carers are usually very flexible, resilient and creative when it comes to supporting people in their own home. These characteristics are just as valuable when supporting people with dementia.

Some of your carers may have had a care background or other relevant work experience. Some may have had relatives with dementia and informal experience. Even if people have prior knowledge about dementia, it is important you test this out to ensure your carers understand what is meant by person-centred care for people with dementia and share your vision for the service.

Using existing carers might require a change of status application to your panel if they are currently only approved to support people with learning disabilities. Read the section on approval panel processes.

**Recruiting new carers**

You could decide to recruit new carers instead of or as well as using exiting carers. The process might be very similar to the one you have now, though the role will be more clearly one for dementia and you might be asking for different skills and knowledge.
When recruiting Shared Lives carers specifically to support people with dementia, we ask for relevant previous experience – personal or professional. Not only does this give the Shared Lives carer more of an idea what to expect and how to cope in certain situations, it is also hugely reassuring to family carers and people with dementia when they are thinking about using our service for the first time.

Where to find suitable new carers? The million dollar question. People working with people with dementia in care homes often find it rather unfulfilling. However, if those care workers are enabled and encouraged to work in a more person-centred way, they can be very enthusiastic. It is tricky to poach good care home staff, but try advertising for Shared Lives carers in the places care homes advertise. Some local authorities publish a newsletter for their care staff; writing an article for these might also be effective.

We have found that former family carers can also make great Shared Lives carers. Some just want to leave dementia behind when their loved one dies or goes into long-term care. Others feel, having cared for a family member, they have skills, knowledge and great empathy with other family carers and want to put this to good use. Former carers who have received wonderful support often talk about wanting to give something back. Talking to carers groups, liaising with your local Alzheimer’s Society, finding out whether there is an existing support group for former carers are all good starting points.

However, there are potential drawbacks to using former carers. Although they may have skills and experience and will be highly motivated, they need to recognise that their loved one’s dementia experience was unique. How they cared might not be how you want them to approach the task as a Shared Lives carer. They will need to be open to different ways of looking at things, learning more about dementia and developing new skills.

Your local authority press department may be able to get editorial coverage of your new service in the local newspaper. Dementia is quite high up the priority list for local authorities at the moment. You may have a team or person with responsibility for carer support in your area. Talking to them about your service and where you might be able to find good carers might be helpful.

**The Shared Lives chicken and egg dilemma**

Clearly, you do not want to promote your service to family carers and service users until you have Shared Lives carers lined up. You could set up expectations you will not be able to meet. But you do want family carers to know about the service because, if you don’t get any referrals, your recruiting efforts will have been wasted.

This part of the Shared Lives chicken and egg conundrum is always difficult to negotiate. Our advice would be to try to get started and provide some service, so you can iron out any problems and talk about your successes in your carer recruitment campaign. Starting with a small number of existing carers who you have trained and supported to move into dementia care might be a route to larger-scale recruitment later.

**Carer assessment**

You should think about your current assessment process and how you will evidence someone’s suitability to support a person with dementia. Again, many of your current processes to check applicant values and motivation will stand you in good stead. It is useful to create a specific space in your assessment paperwork where you describe someone’s experience and the skills and characteristics specifically related to dementia they have demonstrated in the assessment process.

**Approval panel processes and training for panel**

As seen from the example on the next page, making sure your panel is on board is very important. Some schemes have reported that their panels find the whole concept of Shared Lives carers supporting people with dementia in their homes rather difficult. If members of
your panel are risk averse, assuming that Shared Lives carers would need far more knowledge and training than you can give or would not be able to cope, they are not going to readily approve carers for this role.

You may need to review your panel’s knowledge of dementia. If they are going to look at applications from Shared Lives carers and make recommendations, they will need some shared understanding about dementia in a Shared Lives context. You also need to be clear with your panel what your expectations of Shared Lives carers are and how you see the service working.

Here is what a panel chair in one of the partner sites felt she wanted to see in a carer assessment:

My mother-in-law had severe dementia and we watched her slowly deteriorate over a period of ten years. She eventually had to go into a care home. I am reflecting on what we looked for in the care home and what I learnt from the care she received once she was there. Some of the care was very good and some not so good.

I found that as a relative I became very emotional and guilty about what was happening to my mother-in-law. My father-in-law cared for her in the early stages but once he could no longer manage she went into a care home near where they lived in London. It was large and institutional with a staff group that changed regularly. She put on a lot of weight and became depressed. Once my father in-law died we moved her to a small home near us. The staff group was stable and certain members of staff developed a close relationship with Sadie and with me. This helped tremendously.

The staff were able to reassure me when I felt upset and guilty about the fact that I wasn’t caring for her. They took time to get to know her background and what she used to do. They allowed her to wander and sit the office and re-arrange papers. (She used to work in an office.) They didn’t try to ‘tidy her up’ and keep her contained. They allowed her as much freedom as possible. Once she began to wander and suffer from incontinence they had to be more careful but she was never permanently catheterised or made to feel ‘bad’. The qualities for a Shared Lives carer I would look for in an assessment would be:

- **Experience of dementia.** Understanding of the condition and the emotional impact of the slow deterioration on both the person with dementia and their family
- **Willingness to ask for help if the situation becomes too hard to manage.** Sometimes a care home becomes inevitable. This is hard for everyone involved but the right care home can make a huge difference
- **Non-judgemental.** It is easy to judge the relatives and find them at fault. It can be easier for someone who is not a relative to care for a person with dementia. The family can constantly be looking for the person they have lost or are losing. A good carer will accept the person for who they are at this moment in time and work with this
- **Patience and tolerance.** Not minding if routines get broken. Fitting in with the person with dementia rather than expecting them to fit in with you
- **Willingness to learn about what the person did in the past, their loves, likes and dislikes plus ability to form a new relationship with the person as they are at the moment**

*Cathy Toole, Shared Lives Panel chair
Shared Lives South West*
AN APPROACH TO THE ASSESSMENT PROCESS

When assessing the new carers specifically interested in supporting older people with dementia, we do a lot of discussion around how they might defuse a situation if it arose, how they would talk to the person who may be doing and saying unusual things and why they may be showing this behaviour.

I am looking for people who have empathy and a good understanding of person-centred care in the true sense of the word, put themselves in the other person’s place, and are able to understand their perspective. I know all the carers have to have a sense of this, but I personally think this is far more essential when working with people who consider they have no difficulties and at one time in their lives were in complete control. I therefore ask for more evidence around their ability to understand the communication being given through body language, behaviour, past knowledge of the individual and their interests.

With this in mind, the few new carers I have approved or am currently assessing have different skills from many of those already approved (although some of the existing carers have also worked with people with dementia and older people in the past). I try to check out they can think on their feet, keep calm, but still manage situations that may arise, and that they have good knowledge of risk assessment, recording and feeding back to the scheme.

From the panel’s perspective, our panel have primarily only had experience of learning disability, so when one of the new carers was presented, they initially found her very quiet and were concerned she may not be dynamic enough. However, I presented some training to panel about the project and the type of people we are looking for and they were very grateful to have a better understanding of the work we will be doing.

I feel it is very different work. The approaches are different, the matching process is much slower and has to be constantly adjusted to the needs of the person with dementia, but also there is a lot more involvement with the family carer. This continues with the Shared Lives carer after the matches are set up, so the carers have to be able to work from a person-centred perspective, but also alongside the family carers, almost offering them support in their own right.

As it turns out, the particular carer the panel thought was not dynamic enough is already providing a lifeline to one husband and wife and is in the process of being matched with another. This carer is gentle, calm and quiet, does not promote her own skills, but has lots of interests, loves being able to spend time with service users, supporting them in their individual ways.

Gloria Waskett, Shared Lives officer
Dorset County Council Shared Lives scheme
Section 3: Developing your Shared Lives scheme

Dementia training for carers

Shared Lives carers need to have some basic training about dementia before they begin to care for people with dementia. No matter what their background and experience of dementia (personal or professional) people have some common misconceptions about dementia.

The minimum level of training for Shared Lives carers recommended by Shared Lives South West and Innovations in Dementia is that all Shared Lives carers should have completed the SCIE e-learning Open Dementia Programme and have done in-house group training on supporting someone in their own home.

The SCIE course is excellent in that it explains what dementia is very well but more importantly also explains really well what it might feel like to have dementia and to receive support. It is not Shared Lives specific, which is why we have developed Shared Lives notes to support learners and developed a follow-up course to consolidate learning and apply it to the Shared Lives setting.

Instructions on using the SCIE programme and on how to run a one-day follow-up course in house for a group of carers are set out in the Shared Lives and Dementia training guide sent to every Shared Lives scheme in England. If you cannot access this resource, please call Shared Lives South West on 01626 360170.

Carer remuneration

This is covered in more detail in section 4 where we look at pricing of the service.

TELLING PEOPLE ABOUT YOUR DEMENTIA SERVICES

A new model

Our experience of talking to people working in dementia care and to carers and people with dementia is that they have never heard of Shared Lives services! Although well known in the learning disability field, Shared Lives is not commonly used to support older people or people with dementia. Even when presented with the model and its benefits, professionals are often sceptical about its suitability for people with dementia. Similarly, carers are often unsure about it and need convincing that it might work for their loved one.

Talking to care teams

The experience of all our partner sites trying to develop dementia services was that it felt like going back in time and starting from scratch. As a scheme for people with learning disabilities, you might have had great relationships with the learning disability teams, and they may know all about Shared Lives. But you may have had no relationship with older people’s teams, specialist dementia teams or health professionals supporting people with dementia. The chances are that these professionals will not have heard of Shared Lives and have no idea that it could meet the needs of people with dementia.

You will have to explain the key processes that make Shared Lives safe, high quality and dependable. Teams who are more used to funding a care home place and moving someone in quickly might find the matching process unnecessarily long and complicated. They may think the model unsafe and unsuited to people who wander for example. You will need to explain what your role is and what the care manager’s role is.

Using anecdotal evidence that Shared Lives can work and who it works best for is key to getting new care teams engaged. Use Pat and Roger’s story, a short, ten-minute film made by Shared Lives South West specifically about Shared Lives services for people with dementia. Pat and Roger’s story can be found on a DVD in your training pack or viewed at www.sharedlivessw.org.uk/dementia

You should also have your pricing clearly worked out and should be prepared for making a financial case for Shared Lives over other service options more familiar to care teams (see section 4).

We advise putting together a pack of information specifically for care teams,
explaining how the Shared Lives dementia service would work, and making this widely available.

**Talking to family carers**

One of the key issues Shared Lives schemes encounter is that people in the early stages of dementia are not eligible for social care funding; they can only use Shared Lives if they self-fund the service. You therefore need to be able to explain the service to your customer, and often that customer will be the family carer of the person with dementia.

Our partner sites have found that family carers can be suspicious of the Shared Lives model. It engenders difficult emotions and they may have reservations about its safety and professionalism. It took a while for the schemes to convince carers that Shared Lives could work for their loved one and was a safe and suitable service. Common reservations, concerns and questions include:

- Will it be safe? It’s just a normal family home with no locked doors
- Is the Shared Lives carer trained? Do they know about dementia? What experience do they have?
- Will the service be reliable?
- What if it gets too much for the carer and they want the person to leave but I am on holiday?
- Why is it that my husband goes to that family, has a lovely weekend and is no trouble, but I find him really difficult at home?
- Will the Shared Lives carer do everything as I want it done? Or will they undo all my routines and ways of doing things that help me to cope?

You need to have good answers to these questions. If carers do not trust the service they will simply not use it. We suggest a few answers on the next pages but only use them if they are true of your scheme!

The other useful thing to do with carers, for example at a carers meeting, is to use the DVD resource, *Pat and Roger’s Story*, a short, ten-minute film made by Shared Lives South West specifically about Shared Lives services for people with dementia.

*Pat and Roger’s Story* can be found in your training pack or viewed at [www.sharedlivessw.org.uk/dementia](http://www.sharedlivessw.org.uk/dementia)

**Answers to carers questions might include:**

Q Will it be safe? It’s just a normal family home with no locked doors.

You might say:

Locked doors are a last resort. We might consider door alarms if the person with dementia is at risk of leaving the home unnoticed. If there is a high risk of this happening, we would consider it carefully when matching someone to a Shared Lives carer. However, this is much less likely to be an issue with a highly personalised, one-to-one Shared Lives service, where the carer spends a lot of time with the service user engaged in activities and conversation. In a friendly home environment, our experience is that people feel comfortable and are unlikely to try to leave. All Shared Lives carers’ homes are checked for health and safety issues and carers are trained in these situations and how to support
Section 3: Developing your Shared Lives scheme

someone.

Q: Is this Shared Lives carer trained? Do they know about dementia? What experience have they got?

You might say:

All Shared Lives carers go through dementia-specific training as well as the training they receive as Shared Lives carers. They nearly always have care experience and specific experience of supporting someone with dementia. We make sure that they know as much as possible about the person they are supporting, which is key to providing high-quality dementia care.

Q: Will the service be reliable? What if it gets too much for the carer and they want the person to leave but I've gone on holiday?

You might say:

The aim of the service is to offer family carers a respite break where they can truly relax, in the confidence that their loved one is being cared for in a warm and friendly environment and having a good time. Resilience, ability to cope and a good understanding of dementia are things we look for in all of our carers.

Good matching is essential to ensure that our Shared Lives carer will be able to meet the person's needs. Gathering as much information as possible about the person with dementia is essential to make the service as effective and appropriate as possible.

In the first couple of stays, it is best that the person doesn't stay too long and their carer is at home in case things do not work out well. However, once established, our aim is that family carers are able to take a complete break. All Shared Lives carers are fully supported by the scheme and know how to access emergency support out of hours in the unlikely event of it being needed.

Q: Why is it that my husband goes to that family has a lovely weekend and is no trouble, but I find him really difficult at home?

This is always a difficult thing to respond to. You might say:

Shared Lives carers have a different perspective; all are trained and working as care professionals. This is quite different from being a family carer, with all the emotions and history that this involves.

Just because a Shared Lives carer seems to be able to cope does not make you a poor carer.

We ensure that Shared Lives carers have a very good understanding of what it is like to be a family carer and we ask them to work closely with family carers – Shared Lives supports them as well as the service user. Usually everyone has the same aim: to make the break as enjoyable as possible for the person with dementia.

Q: Will the Shared Lives carer do everything how I want it done? Or will they undo all my routines and ways of doing things that help me cope?

You might say:

Shared Lives carers have a good understanding of what it might be like to be a family carer. They understand that you know the person with dementia better than anyone else and will have lots of good ideas about how best to support that person.

We will communicate with you about people's routines, what they like and don't like and so on, to make their stay as enjoyable and stress free as possible. The more information we have, the easier it is for us. If we find new things that work for the person with dementia, our Shared Lives carers will share them with you – in a different environment with a different pair of eyes, useful things can come to light.

If we feel there are issues about care or routines at home we would raise this with you as sensitively as we could in the best interests of the person with dementia. We know that carers often get no help or information about how best to respond to some of the symptoms of dementia and we hope we could help carers by passing any knowledge on.
Dementia-friendly materials
If this is someone’s first encounter with Shared Lives you want them to know that you understand dementia and that this service is specifically there to meet the person with dementia’s needs.

The experience of schemes has been that using materials featuring people with learning disabilities is unhelpful when trying to talk about Shared Lives for people with dementia. It does not portray knowledge of dementia or that the scheme is designed for or has been adapted to meet the needs of people with dementia. Having specific information or leaflets about the dementia service within your Shared Lives scheme is therefore recommended – for professionals, for family carers and for people with dementia.

People with dementia should be as involved as possible in choosing their own support services and their own Shared Lives carers. Making sure you have information that is relevant to them is therefore important and can sometimes be understood better than talking about it.

SERVICE DELIVERY

Getting appropriate referrals at the right time
This has been one of the most difficult aspects of the service for schemes actively trying to support people with dementia. There have been several difficulties around referrals and the timing of referrals.

• Referrals have been slow to come in as the service is not well known in teams that might refer. This leaves recruited carers with no work which can be de-motivating for them or financially non-viable.

• Referrals have been for people whose dementia or physical care needs are too far advanced to be suitable for the Shared Lives model.

• Referrals have been appropriate but the person is a self-funder and the local authority cannot work out how to request payment or make a charge, so either refuses to offer the service or leaves it so long that the window of opportunity has passed and the service is no longer appropriate.

• Referrals have been appropriate and the person seems to be eligible for social care funding, but by the time funding has been agreed, the window of opportunity has passed and the service is no longer appropriate.

It can be slow to get a dementia Shared Lives service off the ground. In Cornwall, it has taken three years to get a steady trickle of referrals coming in.

Family carers who have had a positive experience with Shared Lives are often very effective at getting other people to try it out. In Falmouth one referral was received from a carers support worker. The experience was positive and the worker promoted the service to other workers and carers. The family carer themselves went back to their carers group and described the service as ‘brilliant’, so now more carers are enquiring.
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Accurate care plan/symptoms/behaviour/stage of dementia information

In order to effectively match the person with dementia to a Shared Lives carer, we need as much information as possible. Schemes found that this was quite often not available or as complete or accurate as it might be. Reasons included:

- The sort of information provided by care professionals was sometimes very focused on personal care tasks, as if for a care home referral, and did not say much about personal preferences, history and so on that would be more useful for a Shared Lives setting.
- Carers did not always want to reveal the full extent of issues caused by the person’s dementia, in case the service was then not offered. They felt that if they gave the full picture from the outset this might be off-putting to a Shared Lives carer. Although this might sometimes be the case, it was felt by Shared Lives workers and carers to be much better to have a full picture than to set up a service that was at high risk of failing, with the upset this caused all round.
- Some service users had little or no contact with social or healthcare services and no care plan or assessment had been undertaken. This was most often the case with self-funders, which made up a significant number of the service users we tracked.
- Some carers overstated the person with dementia’s needs or the risks they might present in a Shared Lives setting as they wanted to make sure the person with dementia would be safe and secure and not exposed to risks they felt were too high.

If your scheme is used to working with people with a learning disability, where there is often quite a lot of information available, you may find quite a difference when introducing a service for people with dementia.

When we discussed this with Shared Lives carers in Shared Lives South West, they felt they needed good information about the following issues in order to provide a short break:

- The person’s normal routines such as times of meals, getting up, going to bed,
- Their likes and dislikes about food, drinks, clothing and so on
- Information about the person: what they used to do as a job, their family, their interests
- Communication issues: how did they express
that they were happy or unhappy, or needed specific support

- Mobility support: when was support needed, what people were able to do for themselves in terms of moving about
- What might upset someone and what to do if they became distressed or anxious
- Personal care issues such as help with using the toilet, getting dressed, medication

Shared Lives carers were very aware that the main family carer would have a wealth of information about small details of the person’s life and that this would be invaluable in making someone feel welcome and at home. They felt it was important that the scheme captured as much of this as possible as part of setting up the placement.

Schemes might therefore devise a simple carer questionnaire before the placement starts to collect this sort of information. It needs to be pragmatic and focused on daily life.

Some family carers have developed life history books (as in Pat and Roger’s story) which they could leave with the Shared Lives carer.

Matching

A key component in the provision of any Shared Lives short break is the involvement of family carers in the decision to use the service. Often the main driver for having the service is the need for respite for a family carer.

This may be more so with a dementia service, where, until recently, the person with dementia, their partner and family has been living a normal family life with no need for interaction with the world of care services.

Family carers understanding and having confidence in the Shared Lives scheme and the specific carer are critical to the service going ahead.

You are not only matching the service user to the Shared Lives carer, you are also matching the family carer to the Shared Lives carer. You are trying to set up a strong and trusted three-way relationship and there are two parties (the family carer and the person with dementia) who have a vested interest in the service working for their own reasons. Managing this complex triangle of support requires great skill and sensitivity from the Shared Lives carer at times.

A short-break service for people with dementia will need as much maybe more staff input than other Shared Lives services from the outset, as the matching and introductory processes may be more complex.

Introductory stays

Although some people with dementia may have memory problems, which means they do not remember the Shared Lives carers or their home from one visit to another, family carers and Shared Lives carers alike felt that people did have a sense of familiarity, which was comforting and reduced anxious behaviour for some people. Whilst this is not supported by empirical data, it is a very interesting observation. It was felt that introductory periods had a very valuable role to play in gradually introducing someone with dementia to support through Shared Lives.

One feature of Shared Lives is the gentle way it can be introduced to people, as a visit to a normal family home to have tea with a friend. It is much harder to introduce someone gently to a care home environment.

Some breakdowns occurred when a service had commenced without sufficient introductory stays. These were quite traumatic for the person with dementia, their family and the Shared Lives carer.

The partner sites in the project have concluded that it is critical that introductory stays are arranged and that several stays take place with the carer remaining local. This gives the person with dementia an opportunity to get to know the carer and the place they will be spending time.

The family carer was not usually wholly convinced by the model until they could see it working. The introductory stays enable the family carer and the Shared Lives carer to
build a relationship and for the family carer to develop trust in the service. This was felt to be critical to the success of a longer-term regular service.

Introductory stays are also important for the Shared Lives carer. If the person’s needs are more complex than perhaps indicated, the Shared Lives carer will have an opportunity to find this out and change their approach if needed.

We would recommend that no regular service is commenced without at least one trial stay for a similar period of time. During that trial, family carers should remain local and be available should the Shared Lives carer need any information or the service breaks down.

Management of breakdowns

There is a perception that dementia services for Shared Lives night break down more often than other Shared Lives services. It is true that dementia is not a ‘stable’ disease. A person with dementia can have good days and bad days and may react differently from one day to the next. However, if the normal processes of Shared Lives are followed (good information collation, matching, introductory stays) and carers are well trained and supported to be resilient and flexible, the risk of breakdown may not be much higher than for any other client group.

From the Shared Lives carer’s perspective the scenario they worried about most was when the person with dementia arrived at the house in a much more distressed or anxious state than they had expected.

The experience of the partner sites was that if a breakdown was going to occur it usually happened within the first few hours, when the person could not settle in the Shared Lives carer’s home, became very anxious and distressed and wanted to leave.

In some cases, people with dementia have been matched with more than one Shared Lives carer for regular short breaks, which has enabled a more responsive and flexible service to be provided.

Changes in the person’s wellbeing occurring after the service has been arranged but before it starts need to be notified to the scheme. Again, family carers were sometimes reluctant to do this in case the service was then cancelled.

You may be developing this as a new service and working with a new group of care professionals. The experience of the partner sites was that, in reputation terms, any breakdown was seen very negatively, and often taken as proof that this unfamiliar and untested model could not support people with dementia safely and was too risky to be commissioned. Individual care workers were highly likely to never use the service again based on one negative experience. More importantly, they would suggest to their colleagues in the care team who had not yet tried the service that they should not use it.

This is not what is needed when you are trying to promote the model to family carers and people with dementia. It is therefore important to make sure that breakdowns are managed effectively and that successes are used to promote the service where possible.

After a service breakdown it is useful to be proactive and to work with any care professionals involved and the family carer to see why it broke down and how this could be prevented in the future. Shared Lives is not going to work for everyone but everything should be done to make sure that the service did all it could to make it work.

Questions to ask after a breakdown might include:

- Was a lot of information not given to the scheme at the time the service was set up, which if known would have meant the service was not offered or was set up differently?
- Were there sufficient introductory stays?
- Did the person with dementia have any specific issues that affected them for that stay but might not normally have been an
An example of where Shared Lives did not go well

A family booked a short break with Shared Lives over a weekend to attend a large family wedding some distance away. This was done at relatively short notice. The person with dementia was matched with an experienced Shared Lives carer who had recently started supporting people with dementia. The family provided quite a lot of information about the person with dementia, but did not feel it was necessary to pay for a lengthy introduction process. The scheme suggested this but did not insist.

The carers dropped the person with dementia off at the Shared Lives carer’s house and then left to go to the family wedding. Fairly quickly it became apparent that the person with dementia was very anxious and distressed, and did not want to stay at the Shared Lives carer’s home. They became quite agitated and aggressive. The Shared Lives carer felt they could no longer support the person and decided they would have to ask the family to come and take the person home. There was no back-up plan. The carer could not immediately contact the family but eventually did. The family had to leave the wedding and return home. They felt very let down by the service and by the Shared Lives carer, who they felt should have been able to cope with these very common symptoms of dementia, which the family dealt with every day. They felt the scheme should have done more to enable the Shared Lives carer to continue or found an alternative carer, as they were relying on the scheme for this break.

The family carers have relayed their experience to other carers in the area, describing it as unreliable, unprofessional and unable to meet the needs of people with dementia. As a result, other carers are very reluctant to give the service a try. The family, the Shared Lives carer, the worker involved and the person with dementia have all been very upset by this outcome.

issue (a urine infection; not having their hearing aid; not having been told they were going to the Shared Lives carer’s house until the last minute)

- Was the Shared Lives carer able to cope with the situation or did they panic at the first sign of difficulties?
- Were there other issues in the Shared Lives carer’s home, such as other service users, children or pets, that made the stay difficult?
- Was there a good back-up plan in place?

On-call support

If the scheme is offering short breaks for people with dementia, these can often happen over a weekend, for example where the carer needs a break to go to a family event. It is therefore important that the Shared Lives carer has access to support from the scheme or from out-of-hours teams who understand what Shared Lives is all about.

Schemes starting to develop dementia services should ensure that they liaise with out-of-hours teams, give them good information about the service and what might need to happen if a service breaks down.

Some Shared Lives schemes have their own on-call system (officially or unofficially) where scheme workers are available to carers out of office hours. This can be a very valuable support, as often a Shared Lives carer simply needs to check that their approach is correct or seek ideas about how to handle a particular situation, rather than asking for help to end the service.

If your scheme does not currently have on-call support, you may want to consider developing this specifically for the dementia service.
“I hope the person with dementia will have added interests in their life and a sense of being valued.”
SECTION 4: FUNDING, PRICING AND COMMISSIONING

INTRODUCTION

One of the main discussion points between Shared Lives schemes thinking of developing dementia services and the project related to how the service would be funded. How could a scheme price the service to make it competitive to purchasers but give Shared Lives carers reasonable remuneration and be viable to deliver?

Schemes also highlighted the issue of commissioners being unable or unwilling to commission the scheme or invest in it to develop dementia services. This is summarised in feedback from the Good Practice Day held in February 2012 with scheme managers and older people’s service commissioners.

CONCERNS RAISED BY SHARED LIVES SCHEMES

The Good Practice Day on commissioning was held as part of the national project with Professor Alistair Burns, National Clinical Director for Dementia in England. The focus of the day was on the commissioning context in which Shared Lives schemes deliver or might wish to deliver a dementia-specific service. There were opportunities for schemes and commissioners to share their perspectives on the issues they faced, and to discuss possible steps forward. There were two principle areas of discussion:

a) What do commissioners need to enable investment in Shared Lives services for people with dementia?

b) What do schemes need to do to get investment from commissioners in Shared Lives services for people with dementia?

The following issues were identified as needing to be resolved locally for Shared Lives schemes to develop services for people with dementia:

- Making links with the right people and organisations locally, including people with dementia and their carers who probably know very little about Shared Lives as an alternative model of social care
- The need for approaches that encourage people with dementia and their carers to see Shared Lives as relevant, especially in the earlier stages when respite might not be considered
- The need for good local networks and partnership working, so that Shared Lives is seen as an option amongst other more familiar options.
- Resolving issues around how local authority Shared Lives schemes are able to respond to self-funders
- Overcoming some of the complexities of funding to enable people with dementia to take up Shared Lives placements more quickly
- The need for Shared Lives to be seen as an early intervention opportunity, linking to the National Dementia Strategy, as one of the ways that people can continue to live well with dementia

The following commissioning issues were identified:

- Fair Access to Care Services (FACS) criteria acting as a barrier to people in the earlier stages of dementia (when the model might best be set up) because in most areas social care funding was only available at a critical or substantial level.
- Organisational change (particularly in local authorities) making it difficult to give attention to new areas of work
- The perceived risk of Shared Lives, which is relatively unknown and untested as a resource for people with dementia.
- The need for an evidence base and a business case before commissioners will invest in the Shared Lives scheme in order to create capacity.
This became an important focus in the national project. Shared Lives schemes were willing to undertake training with carers and make adaptations to their schemes to become ‘dementia ready’. However, they needed the support of commissioners and care teams for the service to be successful and most were not engaged with these groups of people.

In the later stages of the national project we worked with scheme managers and directly with commissioners to unpack some of these problems and find creative solutions. This is still a work in progress.

**ELIGIBILITY CRITERIA**

Eligibility criteria were seen as a main issue by schemes and a barrier to the funding of Shared Lives services for people with dementia in the early stages, when Shared Lives might be most effectively set up.

In at least three partner sites people with dementia in the early stages living at home with the support of family carers were ineligible for social care funding for any respite services. Shared Lives was therefore only available if the person or their family funded it themselves.

Carers were sometimes reluctant to start spending their own resources on a service when they had no idea what the future might hold in terms of the care needs of the person with dementia, and the possibility of needing to pay for long-term residential care some time in the future. They would rather cope themselves in the early stages until they felt an urgent need for a break.

This is a funding dilemma for all early intervention or preventative services in the dementia field. Although there is a very strong policy imperative for early diagnosis and support to people in the early stages, most of the people we spoke to during this project agreed that this is not currently matched by the availability of funds for early intervention services.

**Case study: Cornwall**

In Cornwall, funds were granted to Shared Lives South West by the Cornwall and Isles of Scilly Primary Care Trust to recruit new carers specifically to offer breaks to people with dementia in the Newquay area. This was part of their dementia pathways project with the DH. A part-time worker and some advertising and training costs were funded, as well as a small but significant sum of £22,000 to be used to pay for breaks for people with dementia living at home with carers, who were not eligible for social care funding but would benefit from the service.

The service was advertised via GPs and the new care teams working close with GP practices. People came forward or were identified as being able to benefit from the Shared Lives service. A process was agreed between health and adult social care that, when a person with dementia was deemed ineligible for funding, this source of funds could be accessed. This proved to be a difficult process. People with dementia in the early stages were not prioritised for assessments by the local authority, and therefore assessments to ‘prove’ that the person was ineligible took many months or did not happen at all. By the time the financial case had been made, the window of opportunity for the person to use Shared Lives had passed and service was no longer appropriate.

At the end of the two-year project very little of the funds had been spent. This was frustrating for all concerned but not the fault of any individual, more the funding systems. Since the end of the project, the funds have been retained and used to offer free ‘taster’ respite stays to enable carers and service users to find out about the service and build confidence in the model. If the person with dementia and their carer feel they would benefit from further Shared Lives services, they are helped to discuss funding with the relevant social and health care professionals. This is helping to unlock the funding dilemma.

Eight people have had free taster respite sessions, and six people have gone on to have further respite, of which four are self-funding. One person is still being introduced to the service. The other situation broke down irretrievably and the carer will not use the service again.
PRICING ISSUES

Local price comparators

Often the cost of a Shared Lives services for people with a learning disability is compared to a residential fee for people with a learning disability. Invariably, Shared Lives comes out looking like a cost-effective option.

EXAMPLE: Long-term learning disability
Shared Lives service compared to long term learning disability residential care.

In Shared Lives, a long-term service for someone with a moderate learning disability is charged at £380 per week (not including any management fee). This includes an amount the service user pays for their rent and household costs set at £150 per week and £230 care and support fees paid to the Shared Lives carer. The service user pays a small fairer charging contribution of £25 per week based on a financial assessment. The total net cost to the local authority is therefore £205 per week.

A service in an eight bed residential home for a person with a moderate learning disability is charged at £650 per week. The local authority makes a charge of £75 per week under its residential charging policy. The net cost to the local authority is therefore £575.

This substantial saving of £370 per week is one of the reasons why the Shared Lives model is seen as attractive. It is cost effective with good outcomes for the person. Even with the addition of a management fee, there would be a saving using Shared Lives instead of a residential care home service.

It is important to understand the local comparators used to establish cost-effectiveness in services for older people and how Shared Lives services match these.

Our experience has been that services for older people are generally accepted as being lower cost than services for people with a learning disability. If pricing for your dementia service is entirely based on learning disability service pricing, you may find you look expensive and uncompetitive.

When considering the support of older people, the local authority will set a maximum amount that it will pay for residential care. This can be considerably less than for a care home for someone with a learning disability. The same applies to respite care, where a respite/short-break service in a care home might be less costly than a Shared Lives service.

EXAMPLE: Weekend break in Shared Lives (dementia) versus weekend in residential care

The Shared Lives scheme offers short breaks for people with dementia. These are charged at a 24-hour period rate.

The person with dementia comes to stay from Friday at 2pm and goes home on Monday at 2pm. This is charged as three 24-hour periods.

The cost to the local authority purchaser is £87 (inclusive of management fee) per 24-hour period. The local authority makes a charge for residential respite of £10 per day to the service user under its charging policy. The net cost to the local authority is £231.

A local residential care home is asked to provide the same service.

The maximum amount the local authority will pay for residential care with no nursing element is £390 per week (£55 per day) and they use this amount as a top limit on what they pay for Shared Lives.

The care home charges for any part of a day when the person’s room would be occupied. It would therefore charge for four days at £55, totalling £220. The local authority charges £10 per day to the service user as a charge for residential respite.

The net cost to the local authority is £182.
The cost is less in residential care than in Shared Lives. However, there are key differences in the service offered.

- The person with dementia can only chose to go to a care home which the local authority will fund, unless they top up.
- This may not be a dementia specialist care home.
- The person would be staying in a more institutional setting in a larger group of residents.
- Care staff would be more numerous rather than in Shared Lives where you know who is going to care for the person with dementia.

**Topping up**

One option is for the person with dementia to receive their funds as a direct payment or as an individual budget to use as they wish, and with the option to top up the funding.

In some areas there are still no mechanisms up and running such as direct payments or managed budgets that would allow a service user with dementia to choose the service they want, from the provider they want and to top up from their own funds, although this is clearly the expectation in policy terms.

Given the choice, carers may well prefer to have a shorter stay in Shared Lives than a longer stay in residential care for the same amount of funding. They may have to top up whatever funding they get from the local authority but choose Shared Lives because they prefer the service. It is important to make sure that commissioners are aware of people with dementia’s and carers’ preferences to make their own purchasing decisions.

**Case study - why a carer chose Shared Lives**

A couple were offered the maximum financial help anyone is entitled to for respite care from their local authority, which was £399 per week for an agreed number of weeks. They chose to spend this on Shared Lives services for several reasons.

They could not get a care home for £399 and had always had to top up.

They had used two care homes prior to coming to Shared Lives and the husband (the person with dementia) did not like them – he doesn’t want to be in a care home. The care homes cost about the same as Shared Lives, so they were topping up by about £100 per week.

The husband has much preferred staying with Shared Lives carers. He is the early stages of dementia, remembers those care home experiences and remembers that he doesn’t like them. He is making an informed choice for himself and tells everyone how much he enjoys going to Claire and Allan’s house.

His wife says ‘**Even if we could find a care home for £399 we would still come to Shared Lives. You can’t put a price on my husband’s happiness.’**
Day services comparators

When considering day support services, you have to look at what might be charged locally for a buildings-based day services as the local comparator. In some areas, Shared Lives might come out favourably but in others this might prove more challenging.

**EXAMPLE: Dementia day support service in Shared Lives versus a day centre**

One Shared Lives scheme offered an ‘at home’ day resource where people with dementia would spend the day with a Shared Lives carer in their home. The carer could support up to three people at any one time. The cost of the service was £42.50 for a five-hour day. This was popular and seen as a cost-effective option.

Referrals to Shared Lives, however, dropped off with the development of a local day centre resource for older people. The support provided here costs just £10 per day plus lunch. Carers who have to pay for services have started to use this service instead of the much more expensive Shared Lives service, as their funds (direct payments or their own resources) will go much further. Professionals are also directing people with dementia to this service as it is significantly cheaper for the local authority to purchase.

However, the support at the day centre is quite different from that provided through Shared Lives.

It is a large group setting and designed as a social support service to older people, not a specialist dementia service. It is not registered with CQC and therefore cannot support people who have any personal care needs.

It is mainly staffed by volunteers with just one paid worker who manages the service. Activities are group based and there is little choice – you either join in or sit and watch.

Other comparators

Using nursing home rates as a comparator may appear useful as these rates tend to be higher and more reflective of the specialist nature of care for people with dementia. However, Shared Lives does not offer nursing care so this may not be understood as a relevant comparator.

**Banding level descriptors**

You need to understand what banding level descriptors are used for older people’s services and for services for people with dementia and how these might be used when setting a price for your service.

In Torbay, for example, there was a completely separate set of banding level descriptors for older people’s residential services than for learning disability services, using different terminology and different thresholds for moving into the next band.

Older people’s teams wanted to use their own residential descriptors, which were not really appropriate for Shared Lives, and much debate was had about what the two different groups meant by band level two.

In the end we had to rewrite Shared Lives banding level descriptors for dementia services to match the terminology so they could understand how our service compared to residential care and the support given and expected at each level.
Pricing day and short-break services

Our experience has been that most of the use of Shared Lives for people with dementia has been for short breaks, which also serve as respite for a family carer. There are a few examples where Shared Lives has been used as a permanent, longer-term placement as an alternative to residential care, but this requires sensitive matching and very good timing.

We saw earlier that the delivery of short breaks or day support in Shared Lives has different challenges than the provision of long-term services. This is also true of pricing short breaks and day support. If you only currently have long-term pricing, you will need to think about how to price short breaks and day support.

1. How will you charge – by 24-hour or eight-hour period?
2. What if the person’s stay goes into your next charging period for example, from 2pm one day to 6pm the next? Will you charge for two 24-hour periods or just one plus the additional hours? Have you got an hourly rate for additional hours?
3. What happens if the person is late being picked up?
4. If you have a management fee, how will you charge this?
5. Does the income you receive in management fees offset the extra staffing costs you will incur? Does it cover any additional admin or finance costs?
6. If you set the management fee too high (on top of carer fees) will the overall cost become uncompetitive with other options or out of the reach of family carers, commissioners or service users within their RAS (resource allocation system)?
7. What is the local charging policy for respite? How will service user contributions be collected and by whom?

Case study – Pricing a Shared Lives short-break service

In one area, initial prices for Shared Lives short breaks for people with dementia (about £87 per 24-hour period, totalling £609 per week minus any service user contribution) were based on our learning disability services. They were seen as unreasonably high as they were compared (unfavourably) with the fees that would be paid by the local authority for older people’s respite in a care home (top limit of £350 per week minus a service user contribution under residential charging).

Commissioners compared all alternative services in the area with the cost of care in a one star residential care home for older people. Fees for care homes for older people were historically quite low in the area due to a history of over supply, so we looked like an expensive option. They were very reluctant to agree funding for our service as it was so much more expensive than this comparator.

We did not think this was an appropriate ‘like for like’ comparison as many care homes did not offer respite in 24-hour period blocks, only in whole weeks. We also felt our service offered better support than basic non-dementia-specific care in a large care home.

Carers and people with dementia were not given the choice of four days of Shared Lives over seven days of residential care for the same money, but we felt many would have favoured Shared Lives if they could choose.

There was no system available at the time to allow the family carer to top up the funding available in order to choose a more expensive service, even where they felt the outcomes would be much better.

All these factors meant we had a very hard time getting our dementia service off the ground. Even when we had good referrals, panels were turning down funding as it was more expensive than the standard comparator, and as a new service we had no data on better outcomes to justify the cost.
REMUNERATION TO SHARED LIVES CARERS

Given the fact that commissioners seemed to pay less for a service for an older person with dementia than for a service for a person with a learning disability, you may need to review all elements of your pricing.

One of these elements is how much you pay a Shared Lives carer for the care, support accommodation and household services they provide. If you overprice the service no one will use Shared Lives as an alternative to residential care. If you underprice the service no Shared Lives carers may be willing to provide the service for the payment you offer.

Generally the carers we spoke to during the project were not willing to provide 24 hours of support to a person with dementia in their own home for less than about £60. Where the dementia was more advanced, there were complex issues or there was a need for high levels of personal care support, this was more like £75 per 24 hours.

One carer summed it up by saying that, given the skills, experience and personalised support she was offering, she could see no reason why she should be paid ‘less than it cost for someone to stay one night in a Travelodge.’

We think it is very important not to undersell Shared Lives in order to be price competitive, at the expense of the remuneration of the Shared Lives carer. What you are offering is a very personalised, small-scale, community-based service delivered by people with good skills and knowledge. It does not attract economies of scale or the ‘block’ advantages of a large care home, which may be attractive when funding is in scarce supply, but you need to make the case that this should not be the only or main consideration of purchasers.

You need to sell the combined benefits of price and outcomes for the service user - the value for money that people experience - and not just market the service on price.

THE LONGER-TERM COST-SAVINGS ARGUMENT

Carers UK estimates (Valuing carers: calculating the value of carers’ support. Carers UK, 2011) that carers (of all ages) are saving the UK economy £119 billion a year (or £2.3 billion a week). This compares to a total annual cost of the NHS of £98.8 billion (or £1.9 billion a week)

Providing services that carers feel confident about using and which meet the needs of both carer and person with dementia such as Shared Lives respite services may mean that informal carers are enabled to continue to care for longer at home, saving money from the public purse for longer. Further data and analysis is required to estimate the contribution Shared Lives might make to any saving.

The cost of one 24-hour day in hospital is calculated as £264 per bed (Reference costs 2011-2012, DH, Nov 2012). A week would therefore be £1,848. There are no empirical data available to demonstrate specifically that the use of Shared Lives prevents hospital admission.

Anecdotally, if having reliable support services early such as Shared Lives prevents crises of care, where the person with dementia or their carer ends up being admitted to hospital, there may be some tangible longer-term savings. Further data and analysis are required to estimate the contribution Shared Lives might make to any saving.

The Alzheimer’s Society report ‘The financial cost of dementia’ made reference to the National Audit Office report Improving services and support for people with dementia, (NAO, 2007) which found that services for taxpayers were failing to provide value for money for taxpayers.

NAO found that health and social services were spending significantly on dementia, but this spending was often late, with too few people diagnosed or supported early enough. They stated that early interventions known to be cost effective, and which would improve quality of life, are not being made widely available.
The case that early intervention in dementia is cost effective is further supported by the economic metric developed by Professor Sube Banerjee for the Department of Health and published as ‘Appendix 4 in “The clinical and health economic case for early diagnosis and intervention services in dementia, Transforming the quality of dementia care, (DH, 2008).

Banerjee identifies the potential savings to the public purse that could be achieved by early intervention and diagnosis that delays or prevents transitions to care homes. He refers to a number of studies that show reductions in institutionalisation through early service interventions, and notes that services that enable early intervention have been shown to have positive effects on the quality of life for people with dementia and their family carers.

Banerjee calculated that a 6% reduction in the number of people with dementia entering care homes translates to a cost saving of around £25 million in year four of a ten-year programme of service enhancement, increasing to £75 million in year ten. Taking the third of people who are self-funding rather than publicly funded, overall savings accruing to public funds and private individuals by a 6% drop in residential care admissions would save £150 million.

These calculations were based on assumptions about investment in early intervention services (memory clinics, support for community mental health teams and enhanced social services for older people with mental health problems) and the savings this would create over ten years. These investments have not necessarily been implemented as envisaged in this report, but these calculations support the view that early intervention has a long-term cost saving impact.

At the time Banerjee’s paper was written, Shared Lives would not have been included as an early intervention service; no empirical data exists to demonstrate that Shared Lives would reduce admission to care homes and thus save public funds.

However, it seems logical that a Shared Lives service which enables family carers to continue to care for people at home would at least contribute to this.

SELLING THE SERVICE TO SELF-FUNDERS

Many of the dementia services delivered by Shared Lives schemes during the project were for people who were self-funded, either from a direct payment or from the carer or service user’s own resources, as they were in the early stages of dementia and not eligible for social care funding, where the threshold was ‘substantial’ or ‘critical’.

In independent schemes, such as ASA in Lincolnshire or Shared Lives South West, this was feasible. However, in local authority schemes, this was creating a barrier to people accessing the scheme.

One example given at the Good Practice Day on commissioning in February 2012 was the case of a person with dementia wanting to access and pay for day support, but being denied because the local authority had no mechanism for creating an invoice for £45 for a self-funder.

Another local authority strongly suggested that Shared Lives services should be ring fenced for those service users with an assessed need who were eligible for funding as they had paid for the places through the provision of their in-house scheme and would not see any benefit if all the places were taken up by self-funders.

Most Shared Lives schemes are local authority managed at the time of writing. If most potential service users of Shared Lives services are not eligible for social care funding and the local authority does not allow self-funders to access its services, this may be a real barrier to developing Shared Lives for people with dementia. Local authorities can develop preventative and early intervention services which are accessible to self-funders. Shared Lives could be seen as and described in this way.

Many Shared Lives schemes feel that they cannot offer a service to someone with a direct payment as they are an in-house service.
This can be overcome by part of the person’s individual budget being managed within the local authority.

Some schemes are able to offer services to service users who are not eligible for funding but who would benefit from Shared Lives by making a 100% charge for the service.

The guide, *Enterprising councils - getting the most from trading and charging - 2012 edition* (Local Government Association, May 2012) sets out how a discretionary service might be offered to self-funders and charged for by a local authority. However, this has not been agreed or implemented in many areas, and there remains local legal argument about many issues including whether a local authority can make a profit by selling services.

**THE COST OF CAPACITY BUILDING**

In order to develop your service to meet the needs of people with dementia, we state that the scheme needs staff capacity up front to develop the new relationships that will be required, to market the service to carers and people with dementia, and to recruit and train carers and staff. All this has to happen before you are able to offer a service.

We have been asked what sort of investment in the Shared Lives scheme might be needed to create this capacity. We have looked at how much it might cost to do this (we are making many assumptions):

- The scheme already has an appropriate manager who is sufficiently knowledgeable and skilled to manage the expansion of the Shared Lives service to meet the needs of people with dementia.
- The scheme is currently compliant with the requirements of CQC and meets the good practice standards set out by Shared Lives Plus.
- The scheme staff and the local authority are committed to developing high-quality person-centred services for people with dementia and not just the cheapest service.

A scheme would need a budget to cover
- the lead worker for the dementia work
- some additional admin
- mileage and other expenses
- staff training
- carer training
- recruiting carers
- advertising the service

Each local area would have different views on how much this would cost, how much staff time would be needed and the budget available. The figures below are given purely as an illustration of how you might build a budget for a scheme to expand its services to meet the needs of people with dementia.

<table>
<thead>
<tr>
<th>Senior scheme worker with specific responsibility for dementia</th>
<th>Minimum three days per week @ about £25,000 pa plus on costs @ 18%</th>
<th>£17,700</th>
</tr>
</thead>
<tbody>
<tr>
<td>Additional admin/finance support</td>
<td>Minimum of five hours per week @ £16,000 plus on costs @ 18%</td>
<td>£2,518</td>
</tr>
<tr>
<td>Mileage</td>
<td>5,000 miles @ 45p per mile</td>
<td>£2,250</td>
</tr>
<tr>
<td>Additional staff training</td>
<td>For dementia training</td>
<td>£3,000</td>
</tr>
<tr>
<td>Specific carer recruitment</td>
<td>Advertising, public meetings, posters, leaflets</td>
<td>£2,500</td>
</tr>
<tr>
<td>Specific service advertising</td>
<td>Adverts, leaflets, stands at meetings for carer and service users, display materials</td>
<td>£2,000</td>
</tr>
<tr>
<td>Total per annum</td>
<td></td>
<td>£32,968</td>
</tr>
</tbody>
</table>

We would suggest a minimum of two-year funding for a Shared Lives scheme to enable carers to be found, assessed, approved,
Section 4: Pricing, funding and commissioning

awareness raised with referrers, referrals sent, matches made and services started with a reasonable number of people.

**Measures of the activity and success of the service could include:**

- number of potential Shared Lives carers enquiring
- number of specific carers recruited
- number of family carers/people with dementia enquiring about the service
- number of referrals
- number of matches
- number of short breaks delivered (service users/days of break/periods of break)
- number of day support services delivered (service users/days of break)
- feedback from family carers
- feedback from the person with dementia
- feedback from the Shared Lives carer
- estimates of cost compared to the local cost of residential care

**Making a case for funding**

If you are making a case that Shared Lives for people with dementia would be a worthwhile development in your area, these are questions you need to address in some way:

- What are the alternatives in your area that are used for short breaks for people with dementia and respite for carers?
- How do they charge for their services and how would your prices compare?
- Are you competing against services that use volunteers rather than paid staff?
- Do you have local evidence of demand for your service from carers and people with dementia? If not, how could you demonstrate this?
- Are local purchasers locked into current arrangements with block-booked beds in care homes or respite centres? Will this act as a barrier?
- As your maximum ‘staff ratio’ is capped at three service users to one carer, how does that compare to residential staffing ratios?

How would you make an argument to support this 3:1 ratio?
- How will you measure the outcomes of your service to provide evidence for future funding?
- Can you align the benefits of Shared Lives to the local dementia strategy implementation plan?

The paper in the next section from the University of Worcester goes further in gathering evidence to support the case for Shared Lives being a valuable and cost-effective resource for people with dementia.

**SUMMARY**

There are many funding, pricing and commissioning issues for schemes to consider when developing Shared Lives services for people with dementia.

1. Shared Lives services for older people may not be cheaper than other alternatives such as residential care based on our experience that this is the main comparator that commissioners and funders are currently using.

2. It is therefore crucial to use price and outcomes for family carers and people with dementia and their direct feedback when talking to commissioners about the benefits of Shared Lives.

3. Striving to make the service more cost competitive at the expense of giving reasonable remuneration to the Shared Lives carer may mean you will not get carers willing to undertake this work.

4. Although a limited sample, most carers and people with dementia would chose Shared Lives over residential care for respite and would be prepared to top up or have fewer days of service if there was a limit to funding rather than use a cheaper residential service.

5. There are no empirical data to suggest that Shared Lives as an early intervention service would certainly save money in the
longer term through reduction of admission to hospital or residential care. There is evidence to support the longer-term cost benefits of early diagnosis and service intervention in a more general way.

6. Anecdotally, during the project, family carers have stated that they think that Shared Lives would enable them to carry on caring for longer.
“You need to give the person with dementia every chance in deciding what they want to do and see. You need to keep at their pace—don’t rush them. Have lots of patience and see the person not the dementia.”
Section 5: Shared Lives for people with dementia: making a business case

Lead authors: Dr Simon Evans and Teresa Atkinson

BACKGROUND

This chapter has been prepared by the Association for Dementia Studies (University of Worcester) for Innovations in Dementia CIC and Shared Lives South West in relation to the Shared Lives programme for people with dementia.

Its main aim is to make the business case for Shared Lives in relation to dementia, and to demonstrate its value in both financial and human terms.

In outlining a business case, the paper draws on a wide range of resources, including research evidence, government policy and examples of good practice. An element of ‘horizon scanning’ is included to identify emerging initiatives and their potential impact on Shared lives and dementia.

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INTRODUCTION

Shared Lives is a form of social care that offers either permanent support or regular breaks in the home of a local family.

Shared Lives services are all about one household sharing their lives, families, home, interests, experience and skills with others who need help and support to live their lives to the full. The person is welcomed as a member of the family and supported by a Shared Lives carer who is checked and approved, trained and monitored by the Shared Lives scheme. Shared Lives focuses on what the individual wants and needs. It is highly personalised and delivered by the local community in the local community.

There are more than 150 Shared Lives schemes across England. Most are local authority based but some are run by independent third sector organisations. Traditionally, Shared Lives schemes have supported people with a learning disability, but increasingly schemes are working with different user groups including people with dementia.

From 2010 to 2013, a joint project between Innovations in Dementia CIC and Shared Lives South West has considered how Shared Lives services can best be provided across the UK to support people with dementia and their carers. Its main purpose has been to equip Shared Lives schemes with the confidence and skills to be ‘dementia ready’ – to be able to respond appropriately when asked to provide a service to someone with dementia. It has also focused on collecting evidence that demonstrates positive outcomes for those involved in providing or receiving a Shared Lives service for people with dementia. Activities have included:

- Working in partnership with four Shared Lives schemes to evaluate Shared Lives from the point of view of the person with dementia, their family carers, Shared Lives carers and the statutory authorities
- Producing training materials
- Sharing good practice and experience across all Shared Lives schemes
- Identifying barriers to and stimulating development of the Shared Lives and dementia service.

A major challenge in the provision of Shared Lives to people with dementia relates to local commissioning: accessing funding for individuals and promoting commissioner investment in the development of this new type of service. The project has engaged with a number of commissioners who recognise the value of Shared Lives as an effective model for people with dementia. However, to recommend investment, a commissioner must be able to demonstrate a good business case.

Innovations in Dementia CIC and Shared Lives South West will distribute an information pack sharing the learning from the project to schemes and commissioners in spring 2013. This will include the experiences of people with dementia and their families who have used Shared Lives. This paper offers additional evidence to commissioners of services in relation to dementia policy and considers the impact of dementia on the future costs of care.
DEMENTIA – A GROWING NEED

At times of austerity and public spending cuts, the challenge to commissioners and service providers is to achieve core strategies with limited and often diminishing resources.

The UK is experiencing a changing demographic landscape, with a substantial shift in the ageing population. The number of people aged over 65 is estimated to increase from 10.1 to 16.7 million over the next 25 years, while numbers of people aged 90 and 95 will triple and quadruple respectively (Counsel & Care, 2011). The group most likely to need care, those over the age of 85, has grown by over 250,000 since 2004/05 (Age UK, 2012).

The prevalence of dementia increases with age and stands at approximately one in five for those aged 85 years and over (O’Malley and Croucher, 2005). An estimated 820,000 people are living with dementia in the UK at present, at a cost to services of approximately £23 billion a year (Brooker, 2012). Yet low levels of diagnosis are the norm. The *World Alzheimer’s report* (Alzheimer’s Disease International, 2011) identifies this ‘treatment gap’ as an international issue. Only 20 to 50% of dementia cases are recognised in high-income countries and there is an even poorer picture in low-income countries such as India where as many as 90% of cases remain unidentified (Dias and Patel, 2009).

*The Prime Minister’s challenge on dementia* identifies better diagnosis as a key area for improvement, stating that an average of 42% of people in England with dementia have a formal diagnosis, ranging from 27% in the worst performing areas to 59% in the best (DH, 2012a: 8). This has a major impact on the capacity of people with dementia to ‘live well’ because, without the benefit of a formal diagnosis, people with dementia ‘do not have access to treatment, care and organised support that getting a formal diagnosis can provide’ (Alzheimer’s Disease International, 2011: 4).

This situation raises fundamental issues:

- **How can care be provided in the most cost effective way?**
- **How can people with dementia and their families access the care and support they need?**
Section 5: Shared Lives for people with dementia: making a business case

**SHARED LIVES: INDIVIDUAL ASPIRATIONS AND ALIGNMENT WITH GOVERNMENT POLICY**

In this section we consider how Shared Lives for people with dementia fits with a range of dementia policy initiatives.

The Shared Lives model for supporting people with dementia and their families offers a range of high-quality, personalised, affordable services. The approach accords with a broad range of policy drivers. For example, when the Department of Health launched *Living well with dementia: a national dementia strategy*, it set out the following challenge:

*The Department’s goal is for people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system.* (DH, 2009a: 21)

**What is Shared Lives?**

Shared Lives is a little known alternative to home care and care homes for disabled adults and older people. It is used by around 15,000 people in the UK and is available in nearly every area.

In Shared Lives, a Shared Lives carer and someone who needs support get to know each other and, if they both feel that they will be able to form a long-term bond, they share family and community life. This can mean that the individual becomes a regular daytime or overnight visitor to the Shared Lives carer’s household, or (for 4,500 people in England) it means that the individual moves in with the Shared Lives carer. These relationships can be lifelong. Shared Lives carers often say, ‘She/he is just one of the family.’

Shared Lives is used by people with learning disabilities, those with mental health problems, older people, care leavers, disabled children becoming young adults, parents with learning disabilities and their children, people who misuse substances and ex-offenders. People who use the schemes have often lived in many different institutions, and some have been considered too ‘challenging’ to live in an ordinary household, but many find, for the first time, a sense of belonging with the Shared Lives carer. They will go to family events like weddings with the Shared Lives carer and get to know their friends and neighbours.

Shared Lives carers are paid a modest amount to cover some of their time and expenses. But they are not paid by the hour and they do huge amounts without being paid: there is no ‘clocking on and clocking off’. Other forms of care for adults can be preoccupied with maintaining clearly defined professional boundaries in the ‘care giver/customer’ relationship. In Shared Lives, everyone gets to contribute to real relationships and the goal is ordinary family life.

Shared Lives carers are recruited, vetted, trained and supported by local Shared Lives schemes, which are regulated by the government’s social care inspectors. There are already 8,000 Shared Lives carers in the UK participating in 152 local schemes.
The UK is only just beginning to grasp the benefits of families and communities contributing to the wellbeing of people with support needs, and of those people being active, valued citizens. In 2010, England’s care inspectors rated 38% of Shared Lives schemes excellent (three star), double the percentages for other forms of regulated care. Care inspectors from the Care Quality Commission (CQC) logged 3,473 safeguarding alerts and 39,115 safeguarding concerns about social care provision in England. Of those, only 109 concerns and just one alert related to Shared Lives.

When people labelled ‘challenging’ have moved from care homes or assessment and referral units into Shared Lives households, annual savings of up to £50,000 per person have been realised. The average saving is £13,000 per person.

**Living well with dementia**

A recent Alzheimer’s Society report notes that people are not living well with dementia (Alzheimer’s Society, 2012: v), and presents a very unsatisfactory situation: only 22% of people say they are living very well with dementia and even then quality of life remains extremely varied (ibid: iv). Six life outcomes are identified as being very important to people living with dementia:

- Having personal choice and control/influence over decisions about themselves
- Services which are designed around them and their needs
- Support to help them live their lives
- Knowledge to get what they need
- An enabling and supportive environment
- A sense of belonging – of being a valued part of family, community and civic life.

People with dementia and older adults want to remain active, remain in employment if they choose to, have sufficient finances to pay for their care needs and to be able to stay in control of their own lives (DWP, 2010). People with dementia also benefit from stable environments. As cognitive abilities diminish, the need for consistency in support and place increases. Ageing in place is seen as desirable.

Shared Lives placements offer consistency and reassurance, supporting people with dementia to live their lives well. The service offers people with dementia access to accommodation where they:

- have control
- can have access at the times they wish
- can be involved in the family life of the Shared Lives carer.

Building on *Living well with dementia: a national dementia strategy* (DH, 2009a), *Prime Minister’s challenge on dementia* (DH, 2012a) commits to raising awareness of dementia, creating dementia-friendly communities, providing better and more timely information and diagnosis, and doubling overall funding for dementia research to £66 million by 2015.
Community support

Optimising the potential for mental health and wellbeing is particularly important for vulnerable populations. People with dementia benefit from the support of people who understand their needs and who are consistently present. ‘Improving support in the community, as well as increasing the capacity of communities to support people with dementia, are therefore essential components of meeting the aspirations of people with dementia to remain at home, remain active, be independent and enjoy a good quality of life’ (Alzheimer’s Society, 2012). Age UK recommends that systems should be ‘founded on a clear principle that care and support enable people to live with dignity, to be as independent as possible, to be part of a community and to maintain family and social relationships and that local authorities should be responsible for ensuring that care and support services are available to support someone at all stages of their needs, to manage transitions and following major life-changing events’ (Age UK, 2012: 3).

These statements align with the broad principles of the personalisation agenda and feature strongly in the coalition government’s *Vision for adult social care: capable communities and active citizens* (DH, 2010a), which takes personalisation as one of its six principles in enabling individuals, not institutions, to take control of their care.

Support for carers

Shared Lives offers an innovative approach to supporting carers of people with dementia. Ensuring the optimum level of care for people with dementia is key to their wellbeing. However, most of that care is provided through informal networks comprising family and friends, viewed as a cost-effective solution. There are negative consequences: people with dementia don’t want to burden loved ones with the responsibility of their care, and family carers come under huge pressure and personal stress, which may lead to ill health. The indirect effects of caring also have an economic cost: carers are likely to have less time, energy and financial resources and their ability to undertake paid employment is significantly affected (Oyebode, 2003).

There are an estimated 670,000 family members and friends acting as primary carers for people with dementia (Alzheimer’s Society, 2012), saving the nation nearly £7 billion a year (DH, 2012 b). Any kind of breakdown in this form of care and support can lead to short- or long-term admission to residential care or hospital, both of which generate high costs for funding bodies (Knapp, Lemmi and Romeo, 2012).

*Recognised, valued and supported: next steps for the Carers Strategy* (DH, 2010b) set out the coalition government’s vision for supporting carers and pledged an estimated additional £400 million via the NHS to provide carers, including young carers, with breaks from their caring responsibilities (DH, 2010b: 3). In some areas, this funding has been channelled through primary care trusts as a way of offering outreach for people with dementia with the ‘aim of preventing carer
Caring for someone with a long-term illness such as dementia can cause substantial stress, both emotional and physical, and can often lead to ill health. Approaches such as Shared Lives which offer family carers an element of respite can be extremely effective in reducing carer burden, improving carer wellbeing and preventing carer breakdown.

**An alternative to long-term care?**

A lack of support in the community has often meant that people with dementia are admitted to long-term and acute care settings earlier than necessary (Alzheimer’s Society, 2011). However, increasingly, the trend towards accommodating the majority of people with dementia in care homes is viewed unfavourably by older people and their families, who no longer see them as their accommodation of choice (Sanderson, 2012).

Government strategies, such as *Lifetime homes, lifetime neighbourhoods* (DCLG, DH and DWP, 2008) aim to enable people to remain in their own homes for longer through, for example, adaptation and assistive technologies that promote ‘ageing in place’. Such initiatives align with the aspirations of older adults and can also reduce the costs associated with care home placements.

Shared Lives schemes complement these initiatives seeking alternatives to long-term care. They ensure people with dementia and those who care for them are fully supported to remain either in their own homes with consistent respite available or for longer periods with a Shared Lives carer.
MAKING A BUSINESS CASE FOR SHARED LIVES FOR PEOPLE WITH DEMENTIA

In this section, we present evidence that can be used to make a business case for Shared Lives South West. We draw on sources that demonstrate the potential of the model to support quality of life for people with dementia, while also reducing costs. This evidence should be considered in the context of how Shared Lives operates financially (PSSRU, 2010).

As shown above, the Shared Lives approach aligns with and contributes to a range of statutory policy and practice goals in terms of supporting people living with dementia and their families. There is also clear evidence for the quality of the Shared Lives service. In November 2010, the Care Quality Commission (CQC), the government’s social care inspectors for England, rated 38% of Shared Lives schemes excellent (three star), almost double the percentage for other forms of care. Ninety-five per cent of Shared Lives schemes were rated good or excellent compared to 83% of all forms of support.

Further evidence of quality comes from Fox (2012a), who demonstrates that initiatives of the Shared Lives type produce ‘highly tailored, personalised responses to people’s individual needs, as well as building on individuals’ potential skills and contributions to adopting healthier, more fulfilling lives. By building on and extending people’s close relationships, they provide the potential to form bridges between the goal of individually tailored services and a desire to encourage communities to contribute more to the local health and care economy by becoming more supportive and inclusive.’ In addition, an evaluation of Shared Lives schemes highlights a range of positive outcomes, including having choice and being in control, living the life the person wants, and developing confidence, skills and independence (NAAPS, 2010).

Paying for the Shared Lives service

Shared Lives is registered as a community service, which means the people it supports can access the full range of benefits, including housing benefit and, in some cases, Supporting People funding. Personal care and support needs are funded through personal budgets, and service users’ contributions are assessed through Fairer Charging, a means test determining ability to contribute. Shared Lives carers can be considered for a disabled facilities grant if they need assistance with specialised equipment or adaptations to their home.

Payments made to Shared Lives carers comprise the following elements:

1. Rent, paid to the Shared Lives carer and usually funded by housing benefit
2. A fixed amount to cover food, electric, gas, etc, payable by the person in the arrangement
3. Care and support needs and management costs for the scheme, funded from the community care budget and increasingly through personal budgets.

The Shared Lives scheme is responsible for setting the levels for each of these elements. The first two are usually fixed for all placements. The care and support element is usually but not always fixed using some sort of banding level tool with descriptors.
The Shared Lives approach ensures that the person retains more of their income than if they were in residential care. It also increases their opportunities for using their money in the way they wish.

Evidence for the cost-effectiveness of Shared Lives is presented under four headings:

1. Economic analysis: published estimates of the economic savings Shared Lives can generate

2. Preventing the use of costly high-level services (such as hospitals and care homes)

3. Person-centred services: non-medical approaches to behavioural and psychological symptoms

4. Choice and control: offering flexible choices to service users, including personal budgets

**Economic analysis**

There are currently 8,000 Shared Lives carers in the UK, each saving on average of £13,000 per annum per person in comparison to residential care and supported living (Shared Lives Plus, 2012). Shared Lives was recently identified in the coalition government white paper, *Caring for our future: reforming care and support* (DH, 2012b) as an approach with good outcomes that also had the potential to save the health and social care system £155 million a year (Shared Lives Plus, 2012).

Ten new long-term arrangements made by Shared Lives generate annual savings of between £23,400 (older people) and £517,400 (learning disabilities). Developing a Shared Lives scheme to support 85 people requires investment of £620,000 over five years but generates savings of almost £13 million (Fox, 2011).

A report by NAPPS (2009) calculated the average unit cost of a Shared Lives placement to be £419 a week, including care and support, board and lodging and management costs. The care and support cost element was £293 a week.

The same report estimated that the Shared Lives service at that time could produce annual savings of £12.99 million by reducing the need for costlier services, most notably residential care. This adds to a growing evidence base for the cost savings that can be achieved through early intervention as a result of, for example, reduced hospital admissions (Evans, Means and Powell, 2013).

The case that early intervention in dementia is cost effective is further supported by the economic metric developed by Professor Sube Banerjee for the Department of Health and published as appendix 4 - *The clinical and health economic case for early diagnosis and intervention services in dementia in Transforming the Quality of Dementia Care*, DH 2008. Banerjee identifies the potential savings to the public purse that could be achieved by early intervention and early diagnosis which delays or prevents transitions into care homes. Anecdotal evidence suggests that interventions such as Shared Lives can reduce the need for other services, but more research is required in order to quantify the level of savings that can be made by using Shared Lives.
Preventing the use of costly high-level services

The Alzheimer’s Society (2011) emphasises that remaining in their own home is of crucial importance to people with dementia and their carers. However, people with dementia tend to stay in hospital for longer than others admitted for the same reason, and the Alzheimer’s Society (2009) also found that one-third of people with dementia admitted from their own home were discharged into a care home.

Preventative services can preclude the need for costly interventions such as hospital admissions and readmissions and discharge from hospital to care home (British Red Cross, 2012), with a minimum return on investment of over three and a half times the cost of the preventative service intervention. For example, support delivered to a service users suffering with a urinary tract infection and dementia after discharge from hospital prevented possible further hospital admission through non-compliance with the medical regime, resulting in an estimated saving of £729 (British Red Cross, 2012: 5).

A national evaluation of the 29 Partnerships for Older People Projects (PSSRU, 2010), funded by the Department of Health, found that every £1 spent on low-level preventative initiatives led to a saving of £1.20 on emergency bed day use. Overnight hospital stays were reduced by 47% and the use of accident and emergency departments by 27%. Reductions were also seen in the use of other services, with a total saving of £2,166 per person. These efficiency gains were achieved without any adverse impact on the use of social care resources, and the preventative interventions were found to have improved the quality of life of services users.

Person-centred services

Shared Lives is recognised as an ‘established, small-scale, personalised, community-based service’ (Brookes, Netten and Callaghan, 2012:3) offering several types of service to support older adults: outreach/day services (to support the person in their own home), long-term/permanent placements (with a Shared Lives carer), and short-term placements such as respite and recuperative care. The schemes are based on a person-centred approach to supporting people with dementia, which includes closely matching the needs of people using the service with Shared Lives carers. It is important to reach people with dementia at as early a stage as possible to enable them to build a relationship with their Shared Lives carer.

A growing body of evidence suggests that providing services for people with dementia based on person-centred approaches can improve quality of life while reducing costs, including those for antipsychotic drugs. It has been estimated that 180,000 people with dementia in the UK are prescribed antipsychotic medication for the treatment of behavioural and psychological symptoms such as aggression, agitation and psychosis (Bannerjee et al, 2009). Serious concerns have been raised about the extent of this prescribing. While these medications can offer short-term benefits in the treatment of aggression and psychosis, there is no evidence they are effective in the treatment of other behavioural symptoms or that they work when prescribed over longer periods (Ballard et al, 2009). In addition, the potential benefits of antipsychotics need to be balanced against a range of substantial side effects and adverse outcomes, including reduced mobility, Parkinsonism, increased
risk of stroke, cognitive decline, pulmonary embolism and death (Ballard and Corbett, 2010).

Fossey et al (2006) demonstrated that caring for people with dementia using a person-centred framework could reduce the prescribing of antipsychotics by over 40%. This can be achieved without any increase in behavioural or psychological symptoms and result in improved wellbeing and social engagement (Ballard et al, 2009). It has been estimated that the £80 million a year currently spent on antipsychotic drugs for people with dementia could be reduced by two-thirds, leading to savings of nearly £55 million a year (Alzheimer's Society, 2011).

**Choice and control**

Shared Lives offers people with dementia and their families a flexible service, giving considerable choice over the type of respite they receive and when and where they receive it.

There is growing recognition that people with dementia can express opinions about their quality of life and want services and support that do more than simply meet care needs (Alzheimer's Society, 2011). With the benefit of better access to information, people with dementia now have greater choice of the type of services they receive, where they receive them and how these are funded.

A report published by the Social Care Institute for Excellence (Carr, 2010) focuses on the potential for personalisation, including self-directed support and personal budgets, to lead to cost efficiencies and better productivity, as well as improving care and support services. Evidence supporting the potential for cost savings included:

- Personalised, ‘low-level’, community-based approaches to integrated adult social care and support can result in crisis prevention and avoiding admission to hospital or residential care, particularly for older people (PSSRU, 2008; DH, 2009b).
- The use of personal budgets can be preventative, particularly in relation to mental health (eg Glendinning et al, 2008) and reduce hospital admissions (Audit Commission, 2009).
- An Individual Budgets Evaluation Network (IBSEN) study evaluating individual budget pilots reported a small advantage in cost-effectiveness over standard support arrangements for younger physically disabled people and people with mental health problems (Jones and Netten, 2010).

The report also gives specific examples of how personal budgets and direct payments can reduce inefficiencies, including waste and overheads, improve value for money and lead to better outcomes for both service users and carers.

Another key factor is the role of external support, planning and brokerage in implementing personal budgets and direct payments for people who may not be confident or have support from carers, family and friends. User-led organisations offering peer support are an important part of the infrastructure. In addition, greater involvement with and access to community networks and support has been shown to have a preventative effect against the use of more intensive services. The report identifies alternatives to traditional day centres, such as smaller community hubs providing personalised activities and learning opportunities, as a way of
delivering efficiency savings. Shared Lives schemes are specifically mentioned as delivering high-quality person-centred support at a relatively low price.

**HORIZON SCANNING**

While Shared Lives has operated successfully for some time as a resource to support people with learning difficulties, it is underused by older adults. There are currently 4,310 people living long term in Shared Lives arrangements in England, a figure that has doubled in six years, yet most areas make no use of Shared Lives as a long-term source of support for older people (Fox, 2012b). Work by Brookes, Netten and Callaghan identifies potential barriers as being a lack of awareness about the potential of Shared Lives for older adults and the need for a ‘clear steer’ from commissioners about what they would like the scheme to provide (Brookes, Netten and Callaghan, 2012: 6).

A range of policy initiatives in the early stages of development at the time of writing may help make the business case on a local basis. We list some of these below and we suggest that Shared Lives stakeholders monitor them, with an eye to influencing developments in their local area.

**Health and Wellbeing Boards**

The integration of local services across health, housing and social care is a high priority for the government, viewed as a way of both improving service quality and promoting cost-effectiveness. The development of Health and Wellbeing Boards is key to achieving integration and is specified as a statutory responsibility for local authorities in the recent Health and Social Care Act.

Membership of Health and Wellbeing Boards comprises representatives from adult social care, public health, the NHS and children’s services, and includes elected representatives from HealthWatch. Their role includes setting local priorities and commissioning appropriate services. Most local authorities are still in the early stages of developing their boards, but it seems likely that they will be key forums for raising awareness of the Shared Lives model. All local authorities are expected to have shadow boards in place by April 2012, with the aim to become fully operational by April 2013.

**Joint strategic needs assessment**

Health and wellbeing boards will also have responsibility for assessing the needs of the local population by carrying out a joint strategic needs assessment (JSNA). This will be used to agree a local health and wellbeing strategy that acts as a framework for commissioning local services. Some boards are involving voluntary and third sector organisations in this process, thus offering an opportunity to raise awareness of the needs of people living with dementia and the advantages of the Shared Lives model.

**Localism and the Big Society**

The broad ‘localism’ agenda emphasises local solutions to meeting local needs. The Localism Act, introduced in April 2012, enables voluntary and community organisations to trigger a procurement process by expressing an interest in providing a council service. This offers an opportunity to increase coverage of the Shared Lives model as a form of respite care. The Big Society concept is perhaps
less tangible and more challenging to engage with. Nevertheless, its focus on
tapping into social energy and goodwill at a local level to promote health and
wellbeing fits well with the aims of Shared Lives. More practically, Big Society
Capital, the organisation established as part of the Big Society agenda, provides
funding for social sector organisations tackling ‘major social issues’.

**SUMMARY AND RECOMMENDATIONS**

**Summary**

In making the business case for Shared Lives in relation to people with dementia,
this paper has drawn on a wide range of sources including economic analyses,
service evaluations and national guidance. In purely financial terms, the evidence
suggests that a Shared Lives placement leads to an average saving of £13,000 per
person compared with care homes and other forms of care and support. Shared
Lives also aligns closely with a raft of government policies, including the National
Dementia Strategy for England, the Carers strategy and the personalisation
agenda. More importantly, Shared Lives can achieve substantial cost savings while
at the same time offering high quality person-centred support, dignity, consistency
and reassurance for people with dementia and their families.

**Recommendations**

We believe this paper supports greater use of the Shared Lives model as a cost
effective way of supporting people with dementia and their families. This will
require sustained awareness raising and promotion of the many benefits of the
model.

We also recommend that commissioners, providers and other stakeholders should
be alert to the opportunities that recent changes in the health and social care
sector provide for promoting and funding Shared Lives in relation to people with
dementia. These include Health and Wellbeing Board, the localism agenda and big
society capital initiatives.

Finally, we suggest that there is a pressing need to add to the evidence base
through more research into the impacts of the Shared Lives model on the quality of
life of people with dementia and their family carers, and the extent to which it can
reduce the need for more costly services such as hospital admission.
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Department of Health (2012b). Caring for our future: reforming care and support.


Section 5: Shared Lives for people with dementia: making a business case


APPENDIX A: USEFUL INFORMATION AND OTHER RESOURCES

ACTIVITIES FOR PEOPLE WITH DEMENTIA

NAPA (National Association for Providers of Activities for Older People) is a national membership organisation for those interested in activities for older people. Although the focus is on activities in care settings, a lot of the ideas could be adapted for a home setting. NAPA provide training and publications.

www.napa-activities.co.uk/

Increasingly people with dementia are continuing to use computers and ICT or are interested in doing so. There is a useful factsheet produced by the Social Care Institute for Excellence about using computers with people with dementia


‘We can do IT too: using computers in activity programmes for people with dementia’
London: Speechmark. (Savitch & Stokes, 2011)

A practical book with detailed advice on using computers for recording people’s lives, making things, communicating with friends and family and personal planning. Can be purchased from www.speechmark.net

BBC Archive has themed collections of radio, TV and photos from the 1930s onwards
www.bbc.co.uk/archive

ASSISTIVE TECHNOLOGY

There are simple and more developed technologies available that can help people with dementia to live more independently. For a guide to help you identify the technologies that could help a person visit:

www.atdementia.org.uk

DEMENTIA SERVICES

Alzheimer’s Society provides a range of local services, information and support for people with dementia and their carers. Find your local Alzheimer’s Society here:


The national Alzheimer’s Society provides a wide range of written information about living with dementia. It also runs a national helpline for telephone enquiries.

www.alzheimers.org.uk
Telephone: 0300 222 1122

Memory or Alzheimer’s cafes are a social place of contact for people with dementia and their carers. Find your local memory cafe here:

www.memorycafes.org.uk

DEMENTIA TRAINING AND CONSULTANCY

Jackie Pool Associates develops and sells specialist dementia leadership programmes and training materials for the health and social care sector.

www.jackiepoolassociates.org

Dementia Care Matters has an evidence-based approach to developing dementia care in organisations. Its team of expert consultants and trainers apply a model consisting of 12 core beliefs and achieving 36 outcomes in dementia care. This approach is based on over 30 years’ experience in developing dementia care in the UK, Ireland, USA and Canada.

www.dementiacarematters.com

Innovations in Dementia CIC provides help to organisations around the involvement and support of people with dementia. It can provide support about the best ways to write for an audience made up of people with dementia. It also provides a range of high-quality training opportunities tailored to suit the needs of your service.

www.innovationsindementia.org.uk
The Bradford Dementia Group was established in 1992 by the late Professor Tom Kitwood. Bradford Dementia Group is a multidisciplinary and multiprofessional group committed to making a difference to policy and practice in dementia care for people with dementia and their families. Bradford Dementia Group delivers a wide range of training courses, undergraduate and postgraduate programmes (by distance learning), and conducts research on dementia.

www.bradford.ac.uk/health/career-areas/dementia-care/

PUBLICATIONS

The Journal of Dementia Care is a bimonthly journal aimed at those working with people with dementia. It also organises dementia conferences around the country. To find out about subscribing to the journal visit:

www.careinfo.org/journal-of-dementia-care/uk-jdc-subscriptions

GET INVOLVED IN NATIONAL AND LOCAL DEMENTIA INITIATIVES:

Dementia friends is an Alzheimer’s Society network aiming to give people an understanding of dementia and the small things they can do to make a difference. To become a dementia friend visit:

www.dementiafriends.org.uk

Local Dementia Action Alliances are collections of stakeholders brought together to improve the lives of people with dementia in their area. They would usually include a range of organisations within a community and examples would include bus companies, taxi firms, police forces, fire and rescue services, high streets, local authorities, charities, care providers and health trusts, faith groups, local associations and schools. To find out if there is a Dementia Action Alliance near you visit:

www.dementiaaction.org.uk/local_alliances
APPENDIX B: THE EVALUATION FRAMEWORK
QUESTIONNAIRES

THE QUESTIONNAIRES

During the project, we gathered feedback from people with dementia, Shared Lives carers, family carers and schemes about their experience of Shared Lives services. We used the following questionnaires to capture this feedback.

• General questionnaire (1) - Shared Lives carer
• Initial questionnaire (3) - person with dementia, family carer, Shared Lives carer
• Quarterly questionnaire (3) - person with dementia, family carer, Shared Lives carer
• Final questionnaire (3) - person with dementia, family carer, Shared Lives carer

These questionnaires can be used by Shared Lives schemes to capture information from participants, as you develop your scheme to meet the needs of people with dementia.

The general questionnaire can be used with ALL Shared Lives carers planning to support people with dementia.

The initial questionnaires would be used at the beginning of each individual service, whether a one-off period of respite, or an ongoing respite arrangement or a long-term service. The quarterly questionnaire is used to capture ongoing feedback for the duration of a service. It could be used more frequently. The final questionnaire is used when a service comes to an end.

TIPS ON USING THE QUESTIONNAIRES

• Make service users and family carers aware that you are collecting feedback and would like them to participate. Participation cannot be mandatory.
• Try to incorporate them into the normal setting up and monitoring processes of your service so they are not seen as an chore.
• Give people a simple means of returning the questionnaires once completed, for example using pre-paid envelopes.
• Ensure one person in your scheme is responsible for receiving the questionnaires and logging all the data.

QUERIES

If you have any queries about the use of the questionnaires, please contact Rachael Litherland at Innovations in Dementia: rachael@myid.org.uk
Shared Lives dementia project

Shared Lives carer (general questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

INITIAL QUESTIONS about providing support to people with dementia.

1. Why do you want to work with people with dementia?

2. What do you think will be positive about working with people with dementia?

3. Do you have any concerns or worries about supporting people with dementia?

Shared Lives carer general questionnaire
4. What are the main things you think you will do with people with dementia?

5. What do you hope will happen as a consequence of supporting people with dementia?

To be completed by office:

**Code** ..........  

Shared Lives carer general questionnaire
Family carer (initial questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

INITIAL QUESTIONS about receiving a Shared Lives service.

1. What do you hope to get out of using Shared Lives?

2. Do you have any concerns or worries about using Shared Lives?

3. What are the main things you hope your family member will be doing in Shared Lives?
4. Why did you choose to use Shared Lives?

5. What do you hope will happen as a consequence of this placement?
   (This might be consequences for you or consequences for the person with dementia)

To be completed by office:

Code ............

Family Carer initial questionnaire
Shared Lives dementia project

Shared Lives carer (initial questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

INITIAL QUESTIONS about providing support to a person with dementia.

1. What do you think will be positive about supporting this person with dementia?

2. Do you have any concerns or worries about supporting this person with dementia?

3. What are the main things you think you will do with this person with dementia?
4. What do you hope will happen as a consequence of this placement?

(This might be consequences for you or consequences for the person with dementia)

To be completed by office:

Code ............
Shared Lives carer initial questionnaire
Shared Lives dementia project

Service user (initial questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

INITIAL QUESTIONS about receiving a Shared Lives service.

1. What do you hope to get out of using Shared Lives?

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2. Do you have any concerns or worries about using Shared Lives?

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3. What are the main things you hope you will be doing in Shared Lives?

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Service user initial questionnaire
4. What do you hope will happen as a consequence of this Shared Lives service?

To be completed by office:

**Code**  ..........  

Service user initial questionnaire
Shared Lives dementia project

Family carer (quarterly questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

QUARTERLY QUESTIONS about receiving a Shared Lives service.

1. What have your experiences been of using Shared Lives?

____________________________________________________________________________________
                                                                                     
____________________________________________________________________________________
                                                                                     
____________________________________________________________________________________
                                                                                     
2. Do you have any concerns or worries about using Shared Lives?

____________________________________________________________________________________
                                                                                     
____________________________________________________________________________________
                                                                                     
____________________________________________________________________________________
                                                                                     
3. Has your family member been doing the things you expected in Shared Lives?

Family carer quarterly questionnaire
To be completed by office:

**Code** ...........

Family carer quarterly questionnaire
Shared Lives dementia project

Shared Lives carer (quarterly questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

QUARTERLY QUESTIONS about providing support to a person with dementia.

1. What has your experience been in the last three months of providing support to this person with dementia?

2. Do you have any concerns or worries about supporting this person with dementia?

3. Have you done the things you set out to do with this person with dementia?

Shared Lives carer quarterly questionnaire
4. Have you done anything differently than you planned?

5. Do you have any lessons to share about providing support to people with dementia?

6. Is there any additional support [the Shared Lives] scheme or others could provide to help you? (e.g. training, advice, information etc)

To be completed by office:

**Code** ............

Shared Lives carer quarterly questionnaire
Shared Lives dementia project

Service user (quarterly questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

QUARTERLY QUESTIONS about receiving a Shared Lives service.

1. What have your experiences been of the Shared Lives service?

   2. Do you have any concerns or worries about using Shared Lives?

   3. Are you doing the things you hoped you would be doing in Shared Lives?

Service user quarterly questionnaire
4. Is there anything else you would like to be doing in Shared Lives?

5. Has Shared Lives made a difference to your life?

To be completed by office:

Code .............

Service user quarterly questionnaire
Shared Lives dementia project

Family carer (final questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

FINAL QUESTIONS about receiving a Shared Lives service, at the end of a placement.

1. What have your experiences been of using Shared Lives?

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2. Why did you stop using Shared Lives?

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3. Will you use any other service instead of Shared Lives?

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Family carer final questionnaire
4. Did your family member do the things you expected in Shared Lives?

5. Do you have any views on the cost of Shared Lives? Is it worth the cost?

To be completed by office:

Code ............

Family carer final questionnaire
Shared Lives dementia project

Shared Lives carer (final questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

FINAL QUESTIONS about providing support to a person with dementia (at the end of a placement).

1. What were your expectations about supporting a person with dementia?

2. What was positive about supporting this person with dementia?

3. Was there anything difficult about supporting this person with dementia?
4. What kinds of things did you do with the person with dementia?

5. Did you notice any changes in the person with dementia between the beginning and end of the placement?

6. If you noticed any changes, are you able to say what these were due to?

7. Overall, did you feel supported by [the Shared Lives scheme] during your placement?

8. If you did feel supported, what did the scheme do to make you feel supported?
9. Is there any additional support [the Shared Lives] scheme or others could provide to help you? (e.g. training, advice, information etc)

10. Do you have any lessons to share about providing support to people with dementia?

11. Would you like to support people with dementia in the future? Please give a reason for your answer.

To be completed by office:

Code .............

Shared Lives carer final questionnaire
Shared Lives dementia project

Service user (final questionnaire)

Thank you for taking the time to answer these questions. This will help us to look at the best ways of providing Shared Lives opportunities to people with dementia.

More information about the project is available in a separate information sheet.

**FINAL QUESTIONS** about receiving a Shared Lives service.

1. **What have your experiences been of using Shared Lives?**
   
   __________________________________________________________
   __________________________________________________________
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2. **Why did you stop using Shared Lives?**
   
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3. **Will you use any other service instead of Shared Lives?**
   
   __________________________________________________________
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4. **Did you do the things you expected in Shared Lives?**
   
   __________________________________________________________
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To be completed by office:

**Code** ............
Service user final questionnaire
Shared Lives and dementia
Final report of the National Shared Lives and Dementia project 2010-2013

Helping Shared Lives schemes develop their services to meet the needs of people with dementia and their families

Shared Lives South West and Innovations in Dementia
May 2013