



“The longer you
are involved with
a family, the more
you become part
of their lives”

The impact Shared Lives Moray has on
older people and those living with dementia

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The impact Shared Lives Moray has on older people and those living with dementia

Foreword

Shared Lives is a form of social care which historically has been used for people with learning difficulties and mental ill health. The model has evolved over its 35 years of use in Scotland and now meets many care needs. There are 15 Shared Lives schemes in Scotland; eight managed by in-house teams at local authorities, and seven managed, on a commissioned basis, by third sector providers. Services include live-in arrangements, provision of short breaks, and day support. The unifying feature is that Shared Lives carers are self-employed, and the caring arrangement is supervised by a registered Shared Lives scheme, regulated by the Care Inspectorate.

Shared Lives Plus commissioned social work consultant, Charlie Gracie, to examine and document the impact of one scheme, Moray Shared Lives, on the people they support who live with dementia and their family carers. Moray Shared Lives has grown to support 120 people in 7 years.

This work is supported with funding from the Life Changes Trust. The Trust is funded by the Big Lottery.

Executive summary

Shared Lives Plus commissioned this study to illustrate the impacts of the work of Shared Lives Moray on older people with dementia and their family carers, including information on the use of Self-Directed Support.

The resultant narrative report is based upon a series of semi-structured interviews with people living with dementia, their family carers, Shared Lives carers and members of Moray Council staff.

There is evidence of Shared Lives' positive impacts on the wellbeing of people living with dementia. This includes ongoing connectedness to their communities; increased emotional wellbeing; and the ability to delay moving into residential care.

Most participants in the study felt that the relationship between the person with dementia and the Shared Lives carer is at the heart of these positive impacts.

There is also evidence of positive impacts on family carers. This includes increased ability to cope with the pressure of caring for a relative, which is key to enabling them to sustain their caring role; and greater consistency in support.

Family carers report having positive and sustained relationships with Shared Lives carers. This ensures that the changing needs of people living with dementia continue to be met and builds trust between both types of carer.

Shared Lives carers are self-employed and most compared this positively to other employment options. This, and the Qualifying Care Tax Allowance, enables Shared Lives carers to have a flexible approach to work alongside a good income.

Shared Lives carers offer good quality, person-centred support in a way that can meet people's specific needs. This is made possible by the processes in place to provide the service:

- A detailed assessment of potential Shared Lives carers, with a panel of managers from Health and Social Care Moray making final decisions about recruitment
- referrals to Shared Lives Moray are followed up quickly, with a service being provided typically within six weeks of referral;
- an assessment meeting to clarify the needs as defined by the person living with dementia and their family carer;
- careful matching with a Shared Lives carer who has the skills and interests to meet the needs of the person living with dementia;
- monthly activity reports provided by Shared Lives carers and regular reviews ensure changes to the service can be made as needed.

The Health and Social Care Partnership in Moray (Health and Social Care Moray) has identified clear potential improvements in the day care service offered to people living with dementia by Shared Lives Moray. The Partnership are planning to introduce live-in Shared Lives services for younger adults with a broader range of needs, with significant financial savings forecast alongside improvements in support and care.

The commitment of the Head of Adult Care and other managers, working alongside Shared Lives Plus, was essential to the development of Shared Lives Moray.

Key Messages

The benefits of Shared Lives for people living with dementia

- Shared Lives services improve the self-esteem of people with dementia and increase their social interaction
- A good match will last: this means less emotional disruption for the person living with dementia and less anxiety for their family carer. Cost-effectiveness is increased due to reduced need for repeat matching and reduced disruption for people living with dementia and their family carers
- The experience of Shared Lives Moray as a stimulating service was shared by almost all participants: this included rediscovering a sense of themselves that had been lost through their dementia

The benefits of Shared Lives for family carers

- Shared Lives sustains the energy and wellbeing of family carers, reducing stress and increasing the length of time people with dementia can remain in their community
- Shared Lives services build the trust of family carers and people with dementia – consistency and responsiveness are key to this trust
- Professional colleagues trust the Shared Lives service because of the high quality of support provided and the response to referral

Running Shared Lives as a Health and Social Care partnership

- Strong leadership in the agency is necessary for a Shared Lives service to develop
- Clarity about the financial aspects is important for people with dementia and their carers
- It is vital that systems are in place to ensure that the self-employed nature of Shared Lives carers is understood and taken into account
- Shared Lives day care offers a more personalised service, with little in cost savings for a local authority
- Shared Lives can support people to live at home for longer and delay accessing residential care
- Live-in Shared Lives services can offer significant cost savings



'Shared Lives is helping me stay well enough long enough to prevent my wife going into care.'
– Family carer

Introduction

Background

The adult care system is often described as unsustainable, with greater numbers of people needing care and support, rising costs and public bodies' budgets becoming increasingly stretched. In addition, agencies involved in social care are increasingly looking to offer more flexible and person-centred care and support.

Those caring for vulnerable friends and relatives have consistently received insufficient respite and other support, despite growing understanding that family carer breakdown and fatigue are significant factors behind many hospital readmissions and older people needing residential care. To address this, the Carers (Scotland) Act 2016 placed newly defined duties on local authorities to provide support for unpaid and family carers.

Shared Lives Plus is a membership organisation that is the UK network for Shared Lives carers, Shared Lives schemes, and Homeshare. It provides its 5500 members with support, and operational advice and guidance. It provides strategic advice and support to policy makers and commissioners.

In 2011, Moray Council worked with Shared Lives Plus to develop Shared Lives Moray. The service sits within Health and Social Care Moray, managed under the auspices of the Moray Integrated Joint Board that has responsibility for a range of adult services delegated by Moray Council and NHS Grampian.

Health and Social Care Moray's Joint Dementia Strategy 2013-2016 expressed an ongoing and strong focus on increasing the level of support for people living with dementia to remain within their own communities for as long as possible.

Shared Lives Moray offers support to vulnerable adults to remain in their own homes, or with family carers, for as long as possible. Although the service supports adults with learning disabilities, the main focus of has been with older people, the majority of them living with dementia. In Shared Lives services in general, a person needing care or support goes to live with, or visit on a regular basis, a paid Shared Lives carer. From there, they take part in community activities. In Shared Lives Moray, the type of service for people living with dementia is mostly day care, with some short break respite also offered. (In the six years of service operation, four Shared Lives carers have offered short break respite for a small number of people with dementia and people with learning disabilities. This has not been consistently available due, in the main, to the availability of the Shared Lives carers).

The service has operated since 2012. It is registered with the Care Inspectorate as an adult placement service and received scores of 6, the highest possible, in 2016 and 2017. It has a current staffing complement of six people: 1.0 FTE Shared Lives Officer, who manages the service on a day to day basis; 1.0 FTE Clerical Support Worker; and 3.5 FTE Community Care Assistants who directly support the Shared Lives carers. In June 2018, 30 Shared Lives carers were supporting 117 people, offering 880 hours of support per week. At the time of the study, 68 older people living with dementia were supported by the service.

Methodology

In early 2018 Shared Lives Plus commissioned Charlie Gracie, an independent social work consultant, to study the impact of Shared Lives Moray on older people living with dementia and their unpaid carers. He was asked to write a narrative report that would evidence this impact and to describe the service model.

The approach taken was to have semi-structured interviews with people living with dementia, their family carers, Shared Lives carers and members of staff from Moray Council. This happened over four days in June 2018, with:

- Six people living with dementia
- Six family carers
- Nine Shared Lives carers
- Five members of the Moray Shared Lives team
- Three managers from Moray Council, including the Head of Adult Services
- Two social workers from Moray Council.

Ten people living with dementia in the West area of Moray and their family carers were approached by the Shared Lives team and agreed to take part in the study. Of these, six were available to participate. 19 Shared Lives carers working with people living with dementia agreed to take part; from these, three were chosen randomly by Charlie Gracie, with a further six being present at an informal Shared Lives carers' meeting which he attended.

The number of participants might appear to be a limitation of the study; however, this report supports the broader research that was the foundation for Shared Lives Moray and it is clear that this model of service provides the positive impacts reported. Evidence from Care Inspectorate reports from 2016 and 2017 also backs these findings (PPL 2017).

To protect their privacy, the names of people living with dementia and their family carers have been changed. They are referred to in the formal 'Mrs', 'Ms' or 'Mrs', reflecting how the majority of people preferred to be addressed during the study. Where Shared Lives carers are named, their first names are used, again reflecting how people living with dementia and their family carers referred to them.

The term 'participant' refers to anyone who took part in the study. The quantification of participants' views in the narrative adheres to the following convention: almost all – over 90%; most – 75% to 90%; majority – 51% to 74%; half – 50%; less than half – 15% to 49% few – up to 15%.



What are the benefits of Shared Lives for people living with dementia?

Key messages:

Shared Lives support is built best on a relationship between a person with dementia and a well-matched Shared Lives carer who understands, and is able to meet, their needs. Shared Lives services must place strong emphasis on this relationship.

Shared Lives services improve the self-esteem of people with dementia and increase their social interaction.

Structured and regular review of the service, involving people with dementia and their family carers is essential for this to work.

Relationships with Shared Lives carers

Shared Lives Moray focuses strongly on matching the skills of Shared Lives carers with the needs and interests of people living with dementia.

'My [Shared Lives] carer is a Christian and that's important to me. The other [Shared Lives] carer [not a Christian] is good too.'

'I asked for someone that would take [my partner] Brian on walks as that has been important to him. It felt like Elaine was hand-picked.'

Mrs Ralston, whose mother, Mrs Franklin, receives a service, said:

'It was a very good match as Shirley had dogs and loves art, just like mum.'

Mrs Franklin added:

'I love it too.'

Relationships are a key part of the service. Everyone living with dementia who took part in the study communicated their pleasure at the company of their Shared Lives carer.

Mr Graham, who speaks very little, communicated through his eyes brightening at his relationship with his Shared Lives carer, Mike. Mr Graham's partner, Ms Timm, explained that Mike takes Mr Graham and another person with dementia out for walks together.

'Brian and the other man have no joy in each other, due to their dementia, but Brian has joy in Mike.'

Once a potential Shared Lives carer is identified, a taster session takes place, where the Shared Lives Team member takes the person living with dementia to the proposed Shared Lives carer's house. This session is flexible in time and focus, allowing the two to get to know each other and to decide about whether to proceed. This part of the process makes sure that what the person with dementia needs is matched with what a Shared Lives carer can offer. It is also important that they feel a connection with each other.

'The taster session was important for checking that the energy was okay; Brian's point of view was the one that counted.'

Shared Lives carers expressed pride in their ability to offer good, person-centred care. Many had worked with people from early in their diagnosis until they became too ill or had to go into residential care.

Many of the Shared Lives carers have developed a closeness to the family carers too. Mrs Ralston spoke about her and her mother's relationship with the Shared Lives carer.

'The familiarity has become important for us.'

Part of what seemed to build good relationships was the commitment offered beyond the defined service. One Shared Lives carer spoke of a person with no social support:

'I take her to hospital appointments. I juggle things; it's not a Monday to Friday 9-5 job.'

Ms Timm spoke of her surprise at the Shared Lives carer sending her and her partner a postcard from his holiday. Mr McVitie, Mrs Patrick and Mrs Chisholm all commented on the importance of a consistent person offering care to their relative.

The Shared Lives Team emphasised the matching process as vital to the overall quality of the service. With the growth in numbers in the last six years, there is a range of Shared Lives carers with specific interests and experiences to choose from. Following a referral, a visit is made by a member of the Shared Lives team.

It is at this meeting that the Shared Lives team begins to understand the needs of the person living with dementia by talking to them and to their family carer. From there, discussion takes place at the weekly Shared Lives team meeting about potential Shared Lives carers.

It is clear that matching Shared Lives carers to the needs of people living with dementia is a central part of the process, and one that Shared Lives Moray has prioritised.



A key strength here appears to be the discussion of people's needs and potential Shared Lives carers at the weekly team meeting, thereby bringing the knowledge of as many team members as possible to bear on the decision. Given that the matching is based on initial referral, a Shared Lives service visit, the weekly team meeting, then a taster session, there are a number of opportunities to ensure that the needs and wants of a person living with dementia can be understood and prioritised.

A good match will last: this means less emotional disruption for the person living with dementia and less anxiety for their family carer. Cost-effectiveness is increased due to less need for repeat matching and reduced disruption for people living with dementia and their family carers. The importance of a good initial Community Care assessment was emphasised by one of the social workers who took part in the study:

'Social workers need to really understand the reality of dementia, of that person's needs and attitudes.'

Social interaction

Most of the participants talked about the importance of people living with dementia remaining connected to their communities and to the interests they had before they developed dementia.

Mr Orr, a family carer, praised Moray Council's structured approach to offering good day care:

'Loneliness is a terrible thing. Shared Lives extends the natural way to connect and provides a mechanism for that.'

Elaine and two of the people she supports, Mr Chisholm and Mr Banks, have a favourite coffee spot. It is a popular café with a good atmosphere and a mix of families, young people and older people. This type of connection is fundamental to Shared Lives practice, ensuring that people living with dementia remain part of mainstream activities in a natural way:

- Mr Patrick enjoys going to the Men's Shed in Elgin
- Mr Graham continues to visit the library
- Mrs Franklin takes part in pottery painting

A number of the Shared Lives carers and the people they support share activities. The majority of participants saw this as a positive chance for people living with dementia to interact together, but without the pressure to do so if they did not want to.

Mrs Patrick appreciated the chance for her husband to interact with other people with the support of the Shared Lives carer, Reg:

'It's great that he goes out with Reg and another man. This gives him good company. It gets better the more he and Reg get to know each other.'

For Reg, this is central to his role:

'We support our service users to access community-based services designed for people living with dementia. I get them there and help them to relax so they can take part. Shared things are key. I also support people to go to mainstream community-based things.'

Mr Chisholm's wife saw it as positive that her husband meets other people and does new things, but also stressed the need for an element of routine:

'It's important that he's got to know the carers and the places they go; this is a good part of the service.'

Both the social workers who took part in the study felt that, while 'traditional' day care offered a good service for some, Shared Lives offered a more person-centred and responsive service:

'It's more interactive, with more one to one time.'

'Traditional day care can be intimidating, and accentuate the disability.'

It is a common feature of Shared Lives Moray for two people living with dementia to be offered support together, where matching indicates that this will meet people's needs.

Participants spoke about the relationships between people receiving support together. There needs to be good communication between Shared Lives carer, family carer and the people living with dementia, to make sure that these relationships are working. In Mr Graham's case, his main focus is with Mike rather than the other man living with dementia. For Mrs Franklin, she actively enjoys the company of the other woman she meets when with her Shared Lives carer.

Mrs Franklin and her daughter laughed when they explained that she knows she has had a good time, but can't remember why. For both, the important thing was that Mrs Franklin was happy; this makes her and her daughter's lives better.

People living with dementia sometimes have different Shared Lives carers on different days of the week. Normally this is to ensure that particular needs are met; at other times it is due to a Shared Lives carer not being able to increase the number of days' support. The Shared Lives Team is conscious of the need to balance practical considerations of running a service with the primary need for consistency of support that meets the needs of each person with dementia.

Dementia is an isolating condition, and Shared Lives Moray ensures that people living with dementia have opportunities to continue with the activities they enjoyed before their illness, to enjoy new activities and to meet other people in as natural and normal way as possible. This is a focus at the assessment and recruitment stages for Shared Lives carers and is emphasised during their induction and training processes.

Shared Lives carers are required to complete monthly activity sheets. These are monitored by the Shared Lives team. Six-monthly review meetings give the chance for fuller discussion about the Shared Lives carers' work. The service offered to people living with dementia is formally reviewed after the first six weeks and at least every six months after that. These approaches ensure that changes in a person's care needs or the dynamics of the care relationships are picked up quickly.

Wellbeing, self-esteem and happiness

For Mr Patrick, it was important to have fun with his Shared Lives carer:

'I'm happy. Reg is happy. Good laughs.'

Mrs Patrick was positive about the level of care her husband receives from Shared Lives:

'My husband goes out twice a week, with Shared Lives. He also goes to a day centre. The carers in both services are great, but the Shared Lives service is better because he's getting out and about, going places that he wants to. It's more stimulating.'

This experience of Shared Lives Moray as a stimulating service was shared by almost all participants: this included rediscovering a sense of themselves that had been lost through their dementia.

Mrs Chisholm described the impact of the Shared Lives carer on her husband's creativity:

'He used to draw but stopped when he got ill; since he has been going out with the Shared Lives carers, he has started sketching again.'

Mr Chisholm has now started teaching Elaine, one of his Shared Life carers, to draw:

'I have my wee sketch book and he has his big one, I've learned a lot from him.'

This type of joint effort was not apparent across all participants, but there was a clear sense among Shared Lives carers that they too gain a positive sense of wellbeing from carrying out the role.

One reflected:

‘The whole point of caring is to help people take some risks and get as much out of their day as possible. The day always flies by and I enjoy it too.’

Another had left employment in a care and support job to become a Shared Lives carer:

‘Why would I work out of an office when I can do this for a living?’

The Shared Lives carers described a number of ways to promote the wellbeing and self-esteem of the people living with dementia. For the majority it was walking, others visiting old haunts, others taking part in services like Screen Memories and Musical Memories run by Alzheimer Scotland. Mr Orr, a family carer, was clear what worked for his wife:

‘The social aspect gets over the risk of isolation. My wife gets to go to an environment where she feels warm and valued.’

Shirley, a Shared Lives carer, said:

‘I know I’m doing a good job when I see the look on people’s face when I arrive to pick them up. I know some women who have started wearing lipstick again, thinking about what they’ll wear, since they’ve been coming out with me. Before, they’d lost sight of themselves.’

The positive impact of activity and social interaction on the wellbeing of people living with dementia is well understood. Shared Lives carers are required, as part of their service provision, to engage with the people they care for in an active and person-centred way. One outlined this in straightforward terms:

‘I get to know what my service users like to do and enable them to do it.’

This reflects the starting point for all good social care: understanding what people need and designing a service around it. Shared Lives Moray has shown good ability to be person-centred and responsive in the types of activities and social interaction offered to people living with dementia. A Care Inspectorate report in 2017 highlighted two examples that illustrated the importance of proper person-centred care that increased people’s sense of wellbeing:

- a man who had previously been a fisherman benefitted hugely from regular visits to spend the day at the harbour he had worked in, watching boats and chatting to the fishermen
- a woman living with dementia took up knitting again after being introduced to a ‘knit n natter’ group

What are the benefits for family carers?

Key messages:

Shared Lives sustains the energy and wellbeing of family carers, reducing stress and increasing the length of time people with dementia can remain in their community;

Shared Lives services must build the trust of family carers and people with dementia – consistency and responsiveness are key to this trust;

Professional colleagues trust the Shared Lives service because of the high quality of support provided and the response to referral.

A vital break from caring responsibilities

The Shared Lives service is usually offered for four to seven hours per day, two days per week. A number of family carers felt that this compared positively to some other forms of day care:

'I was offered two hours by another service, but that's hardly time to properly relax before doing anything else.'

For all family carers, the break from direct caring gave them a chance to catch up on leisure activities, on other responsibilities like shopping or, in a few cases, supporting other people. The words of four of the family carers illustrate this:

'No matter how much I love him, I need time on my own away from him. I become a nicer person due to the outlet; otherwise I'd be a grumpy old woman. I love music, the theatre, walking.'

'I can spend time with my daughter, who I also care for.'

'My husband has a [Shared Lives] carer for five hours, two days a week. It's a great service. We have support from other places too. It gives me a wee bit of space.'

'He can be a bit sarcastic now, argumentative, and he was not like that before. The Shared Lives service gives me a break. I feel refreshed. I get uptight and this lets me unwind and be calm for him. It helps me cope.'

Support for family carers can also lead to a reduction in people living with dementia going into care. The report, "An independent review of Shared Lives for older people and people living with dementia" (PPL, 2017), commissioned by Shared Lives Plus, emphasised the clear link between family carer wellbeing and "hospital admissions, readmission and delays in the transfer of care". In their "State of Caring 2016" report, Carers UK notes the importance of "replacement care", without which "carers are often pushed to breaking point which can result in them having to give up work, stop caring, or potentially going into care themselves." (Carers UK, 2016)

Diane McLeary, Shared Lives Officer, stressed the importance of family carers having a break so they could feel more able to continue supporting their relative living with dementia.

Jacqui Short, Home Care Manager, felt that all of the people living with dementia who have Shared Lives support would most likely be in traditional residential care or at risk of that happening imminently.

This is reflected in what a number of family carers expressed:

‘Shared Lives is helping me stay well enough long enough to prevent my wife going into care.’

‘I would never let my mum go into care, but Shared Lives gives her social interaction. She really needs that and without it our home situation would be more difficult. We’re very isolated where we live.’

‘Without the support, Tom would be in a home. My blood pressure goes sky high. Shared Lives gives me a break, means that I can pick it up again.’

Shared Lives Moray is trusted by family carers

Family carers expressed a high degree of trust in Moray Shared Lives. This is also reflected in feedback from participants employed by Moray Council and in the Care Inspectorate reports of 2016 and 2017.

Mrs Ralston felt that the personality and manner of her mother’s Shared Lives carer gave her a feeling of trust very quickly. She also trusted Moray Council’s processes. Having gone to her GP to discuss the pressure she was under with caring for her mother, Mrs Ralston was quickly referred to Moray Council’s Access Team. They referred her in turn to Shared Lives. The speed of the response, the care taken to learn about her mother and the way the Shared Lives carer was matched all added to the sense of trust.

This feeling that Moray Council had robust processes made people with dementia and their family carers feel more secure in the service.

Mrs Patrick talked about her husband’s safety:

‘I know Hugh is safe with his [Shared Lives] carer.’

For Ms Timm, it was also about the Shared Lives carers’ personal qualities:

‘They have pleasant manners. Moray Council must have a good system to employ them.’

Mrs Orr, a woman living with dementia, explained:

‘When Michael [her husband and family carer] arranged the carers, I wasn’t sure about it; now I’d never say no.’

Mr Orr felt that the process of finding the right Shared Lives carer was crucial to his wife’s wellbeing:

‘The care taken with matching was paramount at the time.’

Shared Lives Moray understood the need for family carers to feel that their relative is safe. When Shirley, a Shared Lives carer, offered weekend respite for Mrs Ralston’s mother, she gave her a written account afterwards to ensure she understood and felt happy with her mother’s care. Usually, verbal feedback is given; however, due to Mrs Ralston’s mother’s vulnerability, the Shared Lives carer and the Community Care Assistant who supports her decided that written feedback would be of particular help. This enhanced Mrs Ralston’s view of the service and ensured that she will seek it again. Shirley reflected:

‘The longer you are involved with a family, the more you become part of their lives, get to know them, what they need.’

Flexibility is built in, and all Shared Lives carers talked about changing plans for weather or if the people they support felt unwell or reticent. One talked about the ongoing risk assessment when out with people who like to walk, noting the incline of paths, the potential for weather changing. Another recorded television programmes for the people he supports if they don't feel like going out or the weather is bad.

Reliability was central for Mrs Patrick, and was a factor that made Shared Lives stand out from other providers:

'He comes when he says he will and it's always the same person. We had another service, but they weren't consistent, often cancelled close to the time and we never knew who was coming.'

A social worker from Moray Council's Access Team (the initial point of contact for all adult Community Care services), explained that:

'Trust and reliability are the things that informal [family and other] carers need most.'

Shared Lives Moray is trusted by professionals

Family carers have made clear that the trust they have in Shared Lives Moray is based on two factors: the quality of the people offering the service and the processes in place to run it. These factors are also central to a service's reputation among professional colleagues.

Around half of referrals to Shared Lives Moray come from social workers with existing service users and around half from social workers in Moray Council's Access Team.

New referrals to the Access Team are accepted from potential service users and their families as well as other agencies. The Access Team's comprehensive assessment process allows for a speedy response to most referrals.

Referrals from the Access Team to the Shared Lives service are discussed at each weekly team meeting, with a member of the team allocated to carry out an initial visit. A fuller discussion, including about matching, takes place at a weekly meeting once that visit has taken place.

This makes it possible for the service to respond to referrals quickly, and taking into consideration all the important factors; availability of the person needing the service, their family members, Shared Lives staff and Shared Lives carers factors. There is a waiting list, which tends to fluctuate. The average time from referral to Shared Lives Moray to a match beginning is about six weeks.

Shared Lives carers are assessed by members of the Shared Lives Team and the information presented to a panel for final decision. This panel is made up of managers from across the Health and Social Care Partnership including the Home Care Organiser (also the Registered Manager) and Team Managers in the areas of mental health, fieldwork and learning disability. The panel, chaired by the Service Manager for Provider Services, makes decisions based on presented information. As noted above, when Shared Lives carers have been approved by the panel and begun supporting people, they present monthly reports to the Shared Lives Team and have six-monthly reviews to ensure scrutiny and support Shared Lives carer development.



Running Shared Lives as a Health and Social Care partnership

Key messages:

Strong leadership in the agency is necessary for a Shared Lives service to develop;

Clarity about the financial aspects is important for people with dementia and their carers;

It is vital that systems are in place to ensure that the self-employed nature of Shared Lives carers is understood and taken account of;

Shared Lives day care offers a more personalised service, with little in cost savings for a local authority;

Live-in Shared Lives services can offer greater cost savings.

Establishing and developing the service

Jane Mackie, Head of Adult Care, showed strong leadership in driving the development of Shared Lives Moray. She brought knowledge and understanding of Shared Lives from her work in England. She accepted that the motivation for any local authority to introduce Shared Lives has to include an understanding of the financial benefits, but her main driver was to ensure that services better meet people's needs. She currently chairs the Shared Lives Plus Champions Network in Scotland.

Jane had considered commissioning a voluntary sector organisation to develop and deliver Shared Lives; however, her experience elsewhere confirmed her sense that a local authority should see itself as being a service provider as well as a commissioner.

A commissioned service may have been easier to manage; however, her view was that such type of Shared Lives service would have struggled to survive recent rounds of budget cuts. In addition, growing the service in-house enabled the local authority to develop a greater sense of closeness to service users and family carers.

One challenge for a local authority is to understand and respond to the needs of Shared Lives carers as self-employed people and develop processes that take account of their legal status (this is established through HMRC arrangements for Qualifying Care Relief).

John Campbell, Service Manager for Provider Services with oversight of Shared Lives, stressed the importance of senior officer leadership in introducing new services like Shared Lives to an area.

Given the rural nature of Moray, it has been important for Shared Lives Moray to develop in a way that meets the needs of people in more remote or less well-served areas. The single team that was established across the local authority area became two teams, East and West, to better ensure that Shared Lives carers were supporting people locally. This split has allowed the Shared Lives team to concentrate on developing the numbers of Shared Lives carers in the two areas where the needs of people with dementia require and the availability of Shared Lives carers fluctuates; this indicates a positive level of responsiveness to the needs of people, ensuring that, as far as possible, support is delivered as locally as it can be.

How the finances work for people with dementia and their family carers

All family carers who participated were happy with the financial elements of the service.

A full financial assessment is carried out for all people referred to or receiving a service from Moray Council Adult Services. These are carried out by social workers in Moray on initial referral and repeated at least annually.

When a referral is being made to Shared Lives Moray, the social worker discusses Self Directed Support options with the person with dementia and their carer. It was anticipated that this report would document that different forms of Self-Directed Support were used and supported in Shared Lives Moray. While all options are available, and systems are in place to support them, to date only one person across the whole Shared Lives service has used Option 1 of Self-Directed Support, the others using Option 3.

The costs of Shared Lives carers transporting people from their own homes to the Shared Lives carer's home (their work-base) are covered by Moray Council. Mileage above that figure is invoiced by the Shared Lives carer to the family carer. The matching process carried out by the Shared Lives Team takes account of geography to ensure that mileage costs are kept down. Meals and snacks given in the shared Lives carers' home are charged to the family carer on a standard basis as defined by Shared Lives Moray. People being supported pay for their own drinks and snacks when outside the Shared Lives carer's home.



How the finances work for Shared Lives carers

Shared Lives carers are self-employed. They are eligible for Qualifying Care Relief from HMRC (HS236). This relief defines qualifying amounts as tax-free: these are a fixed amount of £10,000 for each household per year and a weekly amount of £250 for each adult who cared for.

Almost all Shared Lives carers felt that their contract arrangements added to the positive balance being between lifestyle, work satisfaction and income.

How the finances work for Moray Council

The cost for day support for Shared Lives is broadly comparable with more traditional forms of day provision (PPL, 2017). Savings are achieved through supporting people living with dementia to live at home for longer, delaying entry into residential care. The standard weekly rate across Scotland for residential care is £593, and £690 for nursing care, typical costs for day care are between £8.50 - £9.17 per hour (PPL 2017).

The Service Manager for Provider Services explained that Shared Lives delivers person-centred day care support better than other services. The Service Manager and Home Care Manager, Jacqui Short, felt that the Shared Lives service has laid the ground for a broader shift in support for people. Shared Lives Moray brings only small cost savings in comparison to 'traditional day care and respite'; however, a plan is now being considered to build on this work and offer more longer-term placements for vulnerable adults. As outlined in the 2017 PPL report, this will bring positive practice elements to bear as well as saving costs.

- They agreed that the positive reputation of the existing service has been necessary for the Integrated Joint Board to confidently support further developments. Longer-term, live-in placements are likely to lead to greater financial savings and it is believed within Adult Services that Shared Lives can offer many people a service more tailored to their needs than existing residential services.

- Research carried out by Social Finance in 2013 identified significant savings for live-in Shared Lives arrangements. "On average, the net cost of long-term Shared Lives arrangements was 43% cheaper than alternatives for people with learning disabilities, and 28% cheaper for people with mental health needs, saving an average of £26,000 and £8,000 per person per year respectively."

"Expanding a scheme by 75 placements, 50 for people with learning disabilities and 25 for people with mental health needs, requires around £250,000 of up-front investment and should generate savings of around £1.5 million per year once the scheme reaches full capacity." (Social Finance, 2013)

PPL, in their 2017 review of Shared Lives for older people across the UK, outlined the initial role requirements to set up a new Shared Lives service:

- Shared Lives manager
- Shared Lives worker
- Additional admin support

Other set up costs would include

- Staff training
- Carer recruitment
- Advertising
- Mileage

A copy of the full review completed by PPL is available on the Shared Lives Plus website.

Conclusion

Shared Lives Moray offers a high level of good quality support to people living with dementia and to their family carers. Feedback from people living with dementia and their carers has been consistently positive, as seen in evidence gathered in this study and in reports from the Care Inspectorate. Their success, with a low density rural population, demonstrates the viability of the model.

There are indicators that more people living with dementia are being sustained within their communities than would be the case had Shared Lives not been available. At the heart of this service is the relationship between the person with dementia and the Shared Lives carer.

This is supported by a set of referral, assessment and review processes that concentrate primarily on the needs of people with dementia and match those needs carefully with a Shared Lives carer that can properly meet them. The service also continually seeks, and responds to, the needs and views of family carers.

The service has continued to develop responsively to the needs of people across Moray. As the service has grown, so the structure has been adapted to meet the needs of people living in more rural and less well-served areas from within their own communities.

The commitment of the most senior managers in the local authority has been vital to the development of the service, alongside colleagues in the Health and Social Care Partnership.

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SharedLivesPlus

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