

Business Case: Why Shared Lives works for family carers

Introduction

Shared Lives remains a little known form of social care which has been mostly used for people with learning disabilities and mental health issues. There are 121 schemes across England, of which 119 are member of Shared Lives Plus. In response to a recent survey of Shared Lives schemes, (England) schemes reported they offered services to some 1,600 people aged 65 and some 320 of whom have dementia as their primary support reason. The number of people with learning difficulties is 7710, 820 people with mental health problems and 282 people with physical disabilities. Despite some well-established older people support, the number of schemes offering arrangements to older people is growing but is nowhere near its full potential. Shared Lives schemes in Moray in Scotland and in the South West of England provide substantial services for older people and those living with dementia and have demonstrated what can be achieved using the Shared Lives model for these groups of people. This paper looks at the potential benefits to family carers, commissioning authorities and to the wider community and explores the business case why Shared Lives works for family carers.

Shared Lives

Shared Lives is a regulated form of social care delivered by Shared Lives carers who are approved by a Shared Lives scheme which is registered with CQC. Shared Lives enables people to live life to the full in their community, without having to live alone or in a care home. Individuals who need support are matched with compatible Shared Lives carers and families who support and include an adult in their family and community life. In many cases that person moves in, to become a permanent part of a supportive household, although Shared Lives is also used as day support and as regular short breaks for unpaid family carers.

Shared Lives carers are recruited and approved through a rigorous assessment process which is itself subject to quality assurance by an independent panel. Shared Lives carers help people to develop independent living skills, friendships and roots in their community. Shared Lives always involves the Shared Lives carer sharing their home and family life with the person using the service. It can be offered to anyone aged 18 or over.

Shared Lives care may include:

- Long term accommodation and support
- Short breaks or other time limited live-in support, such as intermediate care
- Day care provision
- Reablement or intermediate care

Why Shared Lives works for family carers

There have been a number of surveys and investigations of carers' needs undertaken by both voluntary organisations and government agencies. A growing body of research evidence suggests that the following are areas which enable carers to cope and to continue to care, and where Shared Lives could make a significant contribution. These are:

Opportunities for short breaks

Short breaks can be used as a temporary alternative to a person's usual care arrangements. People who care for someone often carry on without realising how tired or tense they have become. A break or holiday can help them relax and recharge their batteries. Short breaks may also be needed in other situations; for example, the carer might have to go into hospital or might have other important commitments.

Short breaks are offered in the Shared Lives carer's home and can be anything from a few hours a day on a regular basis to overnight stays by arrangement for an agreed length of time. At the heart of Shared Lives is the relationship between the person using the service, and their family, with the Shared Lives carer and their family. The time spent on making sure that the match between the service user and the Shared Lives carer is a positive and happy one and means that using short breaks or day care can provide more peace of mind to family carers.

Improving carers' own health

Representative surveys have confirmed that carers' own health suffers as a result of caring. This includes not only physical health such as back pain caused by moving or lifting the person they care for, but also depression and stress-related illness, particularly in cases where carers have not been able to take a break from caring.

Graham is a 53 year old man living with dementia. Until 2012 he was in a temporary placement at a residential care home for older people. Prior to this, Graham lived with his wife and children in their family home. People close to Graham knew that a residential home wasn't a suitable placement for him but because of his age there were no specialist dementia care placements.

Graham's social care practitioner contacted the Shared Lives team to ask whether the Shared Lives scheme could help him. Following the usual matching process, a Shared Lives carer who lives very close to Graham's family home was identified.

After an introduction to the Shared Lives family, and a number of 'getting to know you' visits, Graham moved in with his Shared Lives carer Yusreen and her husband Fahim in March 2013. Graham's family also provided support through this time and continue to play a significant support role.

Living close to his family enables Graham to visit his wife and children several times a week, which is a very important part of his life. Yusreen and Fahim also welcome Graham's family into their home. Twice a week, Graham is supported by another Shared Lives carer Keith for day support. Keith lives very close to Yusreen and this enables Graham to undertake activities that he enjoys in familiar surroundings.

Graham's wife Sue is very happy knowing that Graham is being well looked after by people who care for him and because he is living locally, she can remain very much a part of his life. She has said Yusreen and Fahim are very lovely people who are very welcoming and supportive of her.

Shared Lives offers on-going support through providing relief for family carers by looking after the person they care for in a home from home setting. Through establishing a safe, on-going relationship with both the service user and the other important people in their life, Shared Lives can ease a lot of the emotional pressure on the family carers, as well as providing personal care during a day care session or a short break.

Emotional support for carers

Having someone to talk to is greatly valued by carers. Shared Lives can enable family carers to access the support they need by providing a break so they can get out to a group or just have a coffee with a friend. Furthermore because Shared Lives is about providing a family environment for the service user, the family carers become part of the extended Shared Lives family, and remain a part of the care provided by the Shared Lives carer.

Recognition of the role and contribution of family carers

It is essential that carers are involved in plans for care. A survey by Carers UK found that half of carers felt their comments and concerns were not taken into account.

Shared Lives offers a holistic approach that embraces all aspects of the service users' life, particularly their family carers but also their wider family and friends, embeds them in the wider community through hobbies and interests. There is a recognition that it is the family carers who know the service user best, who understand their needs and wants and in some cases, how to interpret these. Family carers are encouraged to remain central to the service users' life, even if a live-in arrangement is in place.

Supporting older family carers in Scotland

The Supporting Older Family Carers project in Scotland was a two year project, funded by the Scottish Government. The project worked in partnership with families, their older carers and organisations, to establish the evidence base for the service and best practice guidance, leading to the development of more support and choice when planning for the future.

Older family carers were defined as people over 50 and usually parents looking after a son or daughter at home and worried about the future. The project found that the gradual matching process in Shared Lives allowed for successful short breaks to take place. The development of a supportive relationship with the Shared Lives carers gave peace of mind to family carers who were worried about what would happen when they were no longer able to provide hands on care.

See more at: <http://www.sharedlivesplus.org.uk/research-in-scotland/46-older-family-carers-project#sthash.fpY6C8wf.dpuf>

Evidence of need

Traditionally Shared Lives schemes have worked predominantly with people with learning disabilities and mental health problems, but there are examples where successful arrangements have been made with people in later life and those living with dementia. The Shared Lives sector has not previously engaged significantly with family carers as an interest group, but could make an important difference for many family carers if they were aware of the service.

1 in 8 adults (around 6.5 million people) are unpaid carers.

- By 2037, it's anticipated that the number of unpaid carers will increase to 9 million
- Every day another 6,000 people take on a caring responsibility - that equals over 2 million people each year.
- Over 1 million people care for more than one person.
- Carers save the economy £119 billion per year, an average of £18,473 per carer
- Over 3 million people juggle care with work, however the significant demands of caring mean that 1 in 5 carers are forced to give up work altogether.

People providing high levels of care are twice as likely to be permanently sick or disabled

- 625,000 people suffer mental and physical ill health as a direct consequence of the stress and physical demands of caring.
- Over 1.3 million people provide over 50 hours of care per week.

Black, Asian and Minority Ethnic (BAME) Carers

- The 2001 Census showed that there were 503,224 BAME carers in England. Caring varies between ethnic groups - Bangladeshi and Pakistani men and women are three times more likely to provide care compared with their white British counterparts.
- An analysis of the 2001 Census also showed that black and minority ethnic carers overall are also statistically more likely to be providing between 20-49 hours of care a week.

(Statistics above provided by Carers UK, March 2014)

Older carers

- There are 2.8 Million people aged over 50 providing unpaid care in the UK, including 5% of people aged 85 and over.
- A quarter of all carers aged over 75 provide 50 or more hours of informal care a week.

(Age UK 2014)

The financial case for Shared Lives and family carers

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 and their families often contribute much which is unpaid: there is no clocking on and clocking off. The Shared Lives carer is paid for the care they provide by the Shared Lives scheme from the individual's social care budget, which may be expressed as a personal budget. Their personal budget can be taken as a cash Direct Payment where support is purchased from an independent Shared Lives scheme, but for council-run schemes, a managed fund will be used. Payments to Shared Lives carers for live-in arrangements also include rent and a fixed amount to cover food, fuel etc. There is also sometimes a management fee for schemes that are independent of the local authority. This approach often results in people retaining more of their income than if they were in other forms of care, particularly residential care. People may be charged for the care they receive using Fairer Charging rules which apply to all social care provision.

Costs vary between Shared Lives schemes according to what care is being provided, where the service user lives (London and the South East are often more expensive than other parts of the country), and how complex the care requirements are. However, Shared Lives is

considerably cheaper than other forms of regulated care and short breaks in particular can be much more affordable than using residential care. For example, in some London boroughs Shared Lives can cost £100 a night for a short break compared to over £200 using a standard residential home. Breaks in specialist dementia facilities, where they are available, are considerably more expensive.

A recent independent report demonstrated that Shared Lives saves local authorities on average £26,000 a year for a full time arrangement for someone with learning disabilities, compared to the costs of care homes and supported living arrangements, and £8,000 for someone with mental health problems (Social Finance: Investing in Shared Lives 2013). Even though the tangible savings for short breaks services are likely to be smaller, the better outcomes associated with Shared Lives suggest there may be notional savings through less need for other expensive services. This requires more research.

Shared Lives has enormous potential to grow in all sectors, especially for older people, people living with dementia and people with mental health issues as well as extending the offer into intermediate care and reablement. To do this effectively, Shared Lives needs to engage more directly with family carers at an earlier stage than is typically the case. However there are challenges, including changing some of the Shared Lives culture around:

- **Finances:** Shared Lives schemes have relied on referrals from local authorities of people who are eligible for financial support. As fewer people become able to access this funding through the tightening of eligibility criteria, Shared Lives schemes need to offer more services and work more closely with self-funders. This is particularly important for people with degenerative conditions such as dementia, as the matching process with the Shared Lives carer is most productive when the service user is fully engaged with the process.
- **Marketing:** As with financial support, Shared Lives schemes have relied on the introduction to family carers being undertaken by statutory agencies supporting the service user. Marketing is usually directed at the recruitment of Shared Lives carers, not introducing Shared Lives to family carers and potential service users.
- **Engagement:** Although Shared Lives workers and carers work with, encourage and support the family carers of the people using Shared Lives, there has been little direct engagement with carers groups and organisations to promote the service, particularly outside learning disabilities. There has also been very little work done to attract self-funders. As an alternative for day care and short breaks, Shared Lives has much to offer family carers and the people they care for, but remains a well-kept secret.