

SharedLivesPlus

THE UK NETWORK FOR SHARED LIVES AND HOMESHARE

A Shared Life is a Healthy Life

How the Shared Lives model of care can improve health outcomes and support the NHS.

Foreword by

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A Shared Life is a Healthier Life.

The role of Shared Lives care in delivering positive health outcomes

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Foreword

This is a time when we need to think about new and radical options to support people with health needs, making use of community based solutions which can be more cost effective than traditional institutional care. An option where people can receive the treatment they need whilst remaining in their community, living amongst family and friends, and thus have the best chance of building long-term health and resilience.

Shared Lives offers an alternative approach for people who need support, where trained Shared Lives carers share their own homes and family lives, after a careful matching process. This approach has a strong track record as a social care service going back many years.

There is real potential for new partnerships between the NHS and agencies which provide and commission Shared Lives. This report is a starting point for that dialogue, which could lead to many more people receiving the kind of care they want, where they want it, and challenge assumptions about what can be delivered in an ordinary family home.

Simon Stevens, Chief Executive, NHS England.

What is Shared Lives?

Shared Lives is a uniquely holistic approach, not only breaking down barriers between health and social care, physical health and mental wellbeing, but also combining the personal and professional; paid and unpaid.

In Shared Lives, an adult (and sometimes a 16/17 year old) who needs support and/or accommodation moves in with or regularly visits an approved Shared Lives carer, after they have been matched for compatibility. Together they share family and community life. Half of the 12,000 UK citizens using Shared Lives are living with their Shared Lives carer as part of a supportive household; half visit their Shared Lives carer for day support or overnight breaks.

Shared Lives is also used as a stepping stone for an individual to possibly become fully independent. The outcomes can be startling, with people reporting feeling settled, valued and like they belong for the first time in their lives. They make friends and get involved in clubs, activities and volunteering.

Shared Lives is used mainly by people with learning disabilities, but also by 1,000 people with mental health problems, 1,600 older people, including those living with dementia. There is also a small number of care leavers, young disabled adults, parents with learning disabilities and their children, ex-offenders and individuals who have misused substances. It is being developed as a home from hospital service, an acute mental health service and a form of respite for family carers.

There are nearly 8,000 Shared Lives carers in the UK. They are recruited, trained and approved by 153 local schemes, all of which are regulated by each home nation's care inspectors, who consistently rate Shared Lives as an exceptionally safe and high quality model.

Shared Lives is lower cost

Shared Lives is cheaper than other forms of care: the cost for an individual with mild to moderate learning difficulties to use Shared Lives instead of another form of regulated care could be on average £26,000 cheaper per year (around £8,000 for people with mental health problems).

Much higher cost reductions can occur when people with learning disabilities and additional, complex needs move from expensive, medical or out-of-area services into Shared Lives. The cost comparison between Shared Lives (typically costing £250 - £450 per week for a live-in arrangement) and a hospital stay is also more favourable, especially for types of care less associated with Shared Lives eg. acute mental health care.

These figures are cash savings and do not include any additional monies or efficiencies which often come with a Shared Lives match. The examples below highlights common outcomes of Shared Lives including; a reduction in hospital admissions and visits to A&E as well as a reduced

reliance on community based health services.

'Alan', 23, who has Asperger's syndrome, had moved between several expensive 'out of area' services after his family and then a local residential service had found his behaviour and excessive drinking too challenging to manage. When he first met the South Tyneside Shared Lives scheme, Alan said, "I hate it here and want to get out". Alan was carefully matched with approved Shared Lives carers and lived with them successfully for 12 months, accessing community education and rebuilding relationships within his community. Alan's move to a Shared Lives household saved £49,000 before a successful move to his own tenancy, with occasional funding, which reduced the cost of his support still further.

Shared Lives improves people's health

Over 200 Shared Lives carers responded to a 2015 survey, which asked about how the health of the people they supported had been improved by being part of a Shared Lives household.

The survey discovered that 73% had received positive feedback from an NHS colleague about the difference their support was making to an individual's health. Comments included:

- "I offer respite care to someone with bi-polar disorder. The community psychiatric nurse noted that since beginning her stay with me, her need for formal support from the mental health team had decreased."
- "Her dentist of 40 years had never seen an improvement until she came to live in Shared Lives."
- "The GP stated that my care was remarkable and hoped I would continue to support this person."
- "The mental health nurse reported that the person concerned was a changed woman: more confident and happy. The nurse said that she thought it was wonderful how this lady was finally able to voice her own opinions."

87% of people who responded said that Shared Lives has had a positive effect on the mental health of the person/s they support.

"Khalid is a young man who after his third stroke was unable to return to live alone in his flat. The social worker was hopeful that he would not end up in a nursing home at such a young age. Instead, he was matched with a Shared Lives family originally from the same city in Pakistan as his own family. Being able to talk to the Shared Lives carers in their own language, and feel a sense of support so similar to what he would receive from his own family, is invaluable. Also, it has meant that he is able to maintain his previous social circle. He is keen to return home and live on his own again, and we are working towards this as a long-term goal." Newham Shared Lives scheme.

Some of the most common reported health outcomes were:

Healthier lifestyles

Many Shared Lives carers support people with learning disabilities who have struggled to live healthily in the past. Shared Lives carers told us:

- “I am helping someone go to the gym twice a week as she is currently overweight. She went by herself for the first time yesterday.”
- “One lady has lost five stone in weight in five years. Her BMI is perfect and she has much more energy to enjoy things she loves, like dancing.”
- “Before coming to Shared Lives, one man used a wheelchair to go to the shops. However he is now using physiotherapy and orthotic shoes to help with pain management and posture.”
- “Her diabetes is controlled through diet now, rather than medication. Weight loss has been achieved through exercise and healthy eating.”
- “Both our long term residents have now been discharged from asthma clinics and have lost four and a half stone between them.”
- I helped him to achieve his aim of giving up smoking after being a heavy smoker for 40 years.

Karen has Down's syndrome and lives in a Shared Lives arrangement with Pauline and Joe from Lancashire. When Karen came to live with Pauline and Joe six years ago, she was overweight and a size 20. Karen didn't speak often and only communicated via Makaton (a form of sign language). Following support from Pauline and the local Learning Disability Team, Karen learned about healthy eating and was given support to make her own choices. Karen is now a size 12. Pauline says that Karen “loves herself now” and “likes who she is – she didn't before”.

Tackling misdiagnoses and reducing unnecessary medications

Health professionals can find it difficult to listen to and communicate with people with learning disabilities and other conditions, leading to misdiagnoses:

- “When ‘S’ came to us she was on a lot of medication. I asked the doctor if we could review it, which they did. She came off three medications and is now much more awake.”
- “She had been on epilepsy medication for thirty years – for no obvious reason - before she came to us. She has no seizures.”
- “They thought she was deaf until I found that she hadn't had her ears syringed for over five years. This was easily sorted by a visit to the practice nurse at our surgery and her hearing is fine now.”
- “This person was in a wheelchair due to being over-medicated because his doctors thought he was very severely epileptic, and subsequently over-medicated. We found out that most of his 'seizures' were behavioural, and they gradually reduced his epilepsy medication. From having around 4 'seizures' per day, he hasn't had any for 12 months. He now walks and attends college. The GP stated that this was directly attributable to care we had put in place.”

Shared Lives reduces pressure on health services

When people are living well and feel like they belong, they experience fewer crises and rely less on hard-pressed services. Here are some of the main ways in which Shared Lives carers told us this happens:

Improved health and wellbeing leads to reduced use of NHS services

We hear time and again that NHS professionals see remarkable improvements and feel confident to take a step back. Shared Lives carers told us:

- “The gentleman who is with us has now finished six monthly hospital visits and just sees the nurse once a year.”
- “All of the people we support have been signed off from community support nursing because their conditions are monitored and controlled while in our care.”
- “Neither gentlemen have needed A&E, whereas under their previous arrangement, they had needed to use it four times in two years.”
- “One gentleman was admitted to hospital around once a month, but not at all whilst he lived with us.”

Shared Lives carers spot symptoms of undiagnosed conditions

We were told that people with communication difficulties and those with a range of health conditions were at particular risk of serious illnesses going undiagnosed. This included several instances of cancer. Shared Lives carers told us:

- “We alerted our GP to early cancer symptoms that we had spotted.”
- “We were told he received treatment for cancer “just in time!””
- “One person had prostate cancer. We recognised the symptoms (that he must have had prior to moving in with us!) we supported him throughout all his treatment and getting to and from hospital.”

“Eric had rented a room for many years. Following his dementia diagnosis a friend provided him with informal care and friendship as well as a place to live. When the friend was diagnosed with a terminal illness Eric moved into a council-run ‘Elderly people’s home’ on a temporary basis while a long term plan was made.

As Eric is still physically active and was used to family based method of care, Shared Lives was the perfect solution. A little while later he moved into Shared Lives carers’ Pete and Sam’s home, who supported him to:

- *Visit the dentist for the first time in many years and get dental care including a new set of teeth!*
- *Visit the optician and get new pair of glasses which has improved his mobility.*
- *Register with a new GP.*
- *Regain his independence with personal care tasks and he is now shaving himself.*

Sadly Eric’s friend died but the Shared Lives carers supported Eric to ensure he could visit daily during her last week.” Leicester Shared Lives Scheme

Improved mental health and self-esteem

When people with learning disabilities develop mental health needs, service responses can include highly expensive and institutionalised ‘special hospitals’ such as Assessment and Treatment

Units. Shared Lives carers are experts at helping people to build self-esteem:

- Providing secure, peaceful home environment has enabled service users to gain and maintain healthier mental health with less anxiety, anger and depression.
- One service user practiced unsafe sex for many years, to an extent that she had a regular monthly appointment time at the local sexual health clinic. After discussing at length and researching different diseases and their effect on human health, the service user has had a steady partner for years and has needed no medical intervention.
- Because they have a busy and enjoyable life their medication has been reduced.

'Dave' is a man in his fifties. He sustained head injuries inflicted by his father as a child and has experienced a lifetime of mental health difficulties. These have often presented themselves in the form of symptoms of bipolar disorder, which Dave is not able to recognise and manage himself. Dave has never been able to live fully independently and has spent many years living in various hostels and shelters, where he was seen as "looking like a tramp" and was very vulnerable. He has been living within Shared Lives for nine years in two very successful arrangements. Although it is possible he may never live completely independently, Dave now has a network of positive friendships and relationships and attends the local football club with the son of his previous Shared Lives carer. He dresses smartly and manages his personal care with support, receiving regular medical and dental treatment. When his mental health deteriorates this is noticed and appropriate treatment is sought. He saves money and has had several holidays.

Shared Lives reduces inequalities in health service provision

People with learning disabilities, mental health problems or dementia are amongst those who can experience inequalities of access to high quality, personalised health care. Shared Lives carers, who collectively support nearly 1,200 people, said they had supported 48% of those people to access the NHS, reducing health inequalities for people with learning disabilities and other vulnerable people and ensuring earlier access to essential treatment. They also played a key role in making self-care achievable, telling us:

- "I aided one lady to dress her own ulcers, rather than relying on the district nurse and GPs."
- "Helping 'M' who is autistic independently visit the doctor by writing down for him what he needs to say so that he is able to go on his own."
- "Because of their significant learning and communication needs, the people I support would be unable to access the mainstream NHS services otherwise and there would be considerable distress and challenging behaviour."
- "I support someone who has learning disabilities and mental health issues by following programmes suggested by the specialists in the mental health/learning disability team, support in attending appointments and in taking medication."

I am currently caring for someone with Korsakoff (dementia) who I have cared for for nearly 7 years. Her dementia was very bad, she had mobility problems and weight loss (7kgs). She was told she had to go to a nursing home, but I agreed to accept her as part of my family. I worked very hard to develop strategies to help her to remember things; using prompts, signs, memory book, lots of walking and getting her out daily. She now goes out on her own, she gained weight and is now over 10 stones. She is a happy, totally different person.

Working with NHS staff to improve patient experience

Where people using Shared Lives need to access health services, Shared Lives carers and their families work hard to make the experience more successful and pleasant for everyone:

- “When he spent time in hospital my husband stayed with him apart from the time he was asleep at night.”
- “I supported a young lady when she had scoliosis surgery. Over the four weeks I lodged in the hospital to support her 24 hours. Staff said that they would have had a hard time doing their job without my being there to help and support her.”
- “I accompanied him to the hospital for a surgical procedure and was told by staff that without my help, knowledge and support of him, they would never have been able to carry out the operation.”
- “When ‘B’ was hospitalised, staff struggled to understand him and his ways and were grateful that we stayed the whole time. When his social worker offered to stay to enable me to pop home for a bath, they had to ring, as they were struggling with his behaviour.”
- “The nurse said “it’s obvious he is confident and comfortable with me as they have not been able to do this procedure successfully before”. We are very proud of him and his progress.”

‘P’ grew up with his mother, who has a number of personal challenges and his disabled brother. P developed renal failure and underwent a kidney transplant aged ten. He requires a specialist diet and medication alongside regular dialysis. He spent the latter part of his childhood in foster care, then moved into an independent flat with a small support package. However, at this time, both his mental and physical health deteriorated and he misused substances, stopped medication and suffered serious renal failure. P became homeless and when he was referred to a rural Shared Lives scheme he was thin and frail, feeling very alone and overwhelmed, unable to contemplate a future. P moved in with Shared Lives carers, Fred and Joan, who have a wide experience of working with people with mental health difficulties. Support with diet, health and fluid intake led to P regaining weight and thinking more positively. When P suffered a life-threatening infection, Joan and Fred ensured that he gained rapid medical attention and helped P work with health professionals and make informed decisions and choices about his in-patient and post-discharge care. P is planning for his future. The arrangement costs the NHS £275 per week.

Shared Lives: a future health service

There are Shared Lives schemes in most areas in England, Wales and Scotland. Traditionally, Shared Lives has worked mainly with people with learning disabilities and mental health problems.

However, there are growing numbers of successful examples of arrangements for other groups including, people in later life and those living with dementia. Shared Lives has rarely been designed as an intermediate care or reablement service in the past, but there is growing evidence that Shared Lives can work as home-from-hospital care.

One of the key benefits of Shared Lives is that it offers trained and professional care, as part of a regulated service, without taking people away from their friends, families and communities, instead helping people to maintain and widen their social support networks.

Shared Lives is being developed as a health service in a number of ways:

- Intermediate care and reablement
- Holistic care for people with a number of conditions e.g. people with learning disabilities and substance misuse issues
- Support for people using NHS continuing healthcare
- An alternative to in-patient mental health care
- An alternative approach to end of life care

The Herts Partnership Foundation Trust run a Host Families scheme for service users who are acutely unwell to stay with a local family for a few weeks, as an alternative to inpatient care. The service users get involved in all aspects of family life, from walking the dog to cooking family meals. They can go out if and when they want to and can meet up with family and friends when they like. Both hosts and guests get intensive support from our Crisis Assessment and Treatment Teams (CATT) and hosts are not expected to provide care or treatment, just a welcoming, caring environment. Hosts receive £600 a week to cover the costs of taking in a guest.

Next Steps

Shared Lives is growing and diversifying, without sacrificing its unique values and ethos.

Shared Lives schemes are changing the way they recruit and train Shared Lives carers in order to reach new groups effectively, with the support of Shared Lives Plus through business planning support, training materials, and guidance, such as 'How to make your Shared Lives household dementia-friendly'. Shared Lives Plus and its partner organisations are available to support local and national developments (see Contacts below).

Here are our recommendations for developing Shared Lives as a mainstream health service.

Government should:

- Raise awareness of Shared Lives within the NHS and ensure that regulation and commissioning infrastructure are Shared Lives friendly.
- Include Shared Lives and other community-based approaches in training programmes.

Health and care providers and commissioners should:

- Meet to discuss the benefits of integrated health and care Shared Lives support.
- Support existing Shared Lives schemes to develop partnership with the NHS which will enable them to reach new groups and offer effective health interventions.

- Explore new specialist health Shared Lives schemes where there are gaps which cannot be met through developing existing provision.
- In particular, work with the Shared Lives sector to develop the Shared Lives model of intermediate care, rehabilitation and reablement.

“We provided intense end of life day support to a man with a physical disability and a deteriorating medical condition. He was literally wanting to die when we first met him. Through her persistence, and over time, his Shared Lives carer developed a hugely positive working relationship with him and he started to take a real interest in life again. The hospital consultant contacted us to say, “B told me that it would not have been possible to live this last year of his life so well without his Shared Lives carer’s support. I would like to know how I can refer another of my patients to your service.” South Gloucestershire Shared Lives scheme

Contact

Shared Lives Plus is the membership organisation supporting the 153 schemes across the UK; over 4,000 Shared Lives carers have also chosen to be members. We provide support, information and training for schemes in all aspects of providing the service, including regulatory and good practice, and work to influence policy makers to expand Shared Lives to bring the benefits to more disabled and older people.

Working with our sister organisation Community Catalysts, we can offer:

- Advice on new models of care and safe and effective Shared Lives practice.
- Support to review services and develop costed development options.
- Guidance and training to staff.
- Access to social investment via the Shared Lives Incubator, hosted by Community Catalysts (www.CommunityCatalysts.co.uk).

For help and advice, contact Shared Lives Plus on: **0151 227 3499**

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NOTES:

