



healthwatch
Dudley

Exploring experiences of Shared Lives with Camphill Village Trust

September 2025



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Healthwatch Dudley

Healthwatch Dudley listens to people's views on health and social care. We aim to hear from all communities, including those who may find it more difficult to have their voices heard. We share feedback with people who have the power to improve services.

What we did

Camphill Village Trust (CVT) invited Healthwatch Dudley to capture feedback from Shared Lives Carers and people accessing the service.

We were not commissioned to complete this piece of work, we wanted to listen to the experiences of people who don't often have their voices heard, including carers and the people they care for.

We met with CVT staff to plan the project and explore how we could work together. Our aim was to better understand how the Shared Lives approach supports adults with learning disabilities, autism and mental health needs and to hear directly from those with lived experience.

We set out to explore:

- The benefits of Shared Lives placements.
- Any challenges or areas for improvement.
- Peoples experiences of accessing wider support including: respite care, health services and social care pathways.

Listening to people's expereinces

Who we heard from:



3 carers and 2 people accessing support spoke to us in a focus group



7 carers completed a survey online.



We completed case studies with 3 carers and 2 people accessing support.

Camphill Village Trust

Camphill Village Trust is a national charity that supports adults with learning disabilities, autism, mental health needs and complex support needs.

Across England, Camphill Village Trust encourages people they support to live their best, most independent lives through various projects, including their Shared Lives scheme.

Shared Lives

Shared Lives is a scheme designed for the adults they support who wish to live or spend time in a family home.

Camphill Village Trust match individuals with trained Shared Lives Carers who provide support in their own homes, friendship and stability.

People can:

- **Live full-time** with a Shared Lives Carer(s).
- **Stay for short breaks** when they or their family need it.
- **Spend the day** or a few hours with a carer for support.

Dudley Borough

Right now, there are 68 Shared Lives Carers in Dudley, supporting 50 people aged 18 to 65. Carers open their homes, providing safe, stable homes where people can live with choice and a sense of belonging.

Around 1125 adults in Dudley are known to have learning disabilities and/or autism (2021 local authority data).

How are people supported to pursue their interests?

People who use Shared Lives told us what they like to do. Their experiences highlighted how the Shared Lives scheme supports and encourages people to develop their own interests and take part in activities and opportunities that are meaningful to them.

Michael told us he likes to go on holiday, especially cruises, as he likes the food and entertainment. Kath also likes going on holiday.

“There was a time when Kath wouldn’t go out the front door without holding my hand. Now she can catch a bus on her own. She’s like a different person!”

The consistent, trusted support afforded by Shared Lives Carers can help people to reach their full potential.

One person who uses Shared Lives, now works for a local disability charity, supporting a social activity group and delivering Oliver McGowan* training.

Michael loves to attend football matches and is a season ticket holder. His carers say he loves the atmosphere at the match, regardless of who is playing.

“Football means the world to Michael, it is everything to him.”

“Kath would say if there’s something she wants to do. She has tried many activities such as: horse riding and rock climbing. However, physical challenges can sometimes hold her back.”

**Oliver McGowan training: training on learning disorders and Autism. The training was set up after Oliver McGowan died in hospital in what may have been a preventable death.*

Day centres

People who use Shared Lives told us about using day services or day centres.

“Michael enjoys attending Discover U and Happy Hours day services.”

However, carers told us that changes to funding have impacted day services.

“[Activities] are not as consistent as it once was when people attended centres.”

“We had issues getting a day placement for Rich.”

Carers and clients mentioned day centres and the role these facilities play in supporting independence, providing social and engagement opportunities as well as respite for carers.

“When the day centres closed down, parents were having more of a patchwork week.”

“We’ve had issues with getting a day placement for Rich, as the manager said they were not double funding him. He goes to the Emily Jordan foundation three days a week now.”

“I do gardening and bikes and I tell jokes – What’s bad for your teeth? A brick wall!”

Not having access to day centres or funding impacts the wellbeing of both carers and the people they care for.

“[Without day centres] you have to entertain them 24/7. If you want them to go somewhere, it’s £90 a day to come out of their money.”

Provision varied between people “there is a lack of consistency, as some people may have a bigger pot of money to do something with.”

“If I say to Michael ‘You’re going to have to pay for your day centre, he couldn’t because he’s a massive football fan, he has a season ticket and buys all the shirts. If he had to take that passion away just to pay for that day centre he’d be depressed.”

Individual care

Placements are arranged according to the needs of the person receiving care and the experience of the Shared Lives Carers.

“Each placement is matched between the family & the individual. The individual and family’s choice is paramount.”

“Shared Lives is very individual. The person we care for was only placed with us after an extensive matching process.”

This approach means that carers can offer support tailored to the clients needs.

Some people who use the Shared Lives service require a higher level of support than others.

“Rich is terrible at remembering to shower and wash his hair. We’ve put visual aids in the bathroom, but he still comes out of the shower and puts his pyjamas on while he’s still wet. I have to keep reminding him. He has placed a plastic bowl on the cooker and tried to get bread out of the toaster with a knife.”

Shared Lives Carers provide support on an individual basis and adapt to the needs of the person they care for.

“We focus on the things Rich can do around the house. He loves to put the bins out and helps the neighbours out.”

Life as a Shared Lives Carer

Shared Lives Carers told us how the role can be both incredibly rewarding as well as incredibly challenging.

Being a carer was described as “a vocation not a job” and some carers described the person they care for as family.

“Kath is our daughter.”

“The best thing about being a Shared Lives Carer is seeing the people you care [for] develop. It makes a difference to their lives and helps them to reach their potential. Having long-term placements means we really get to know the people staying with us.”

However, being a Shared Lives Carer can be challenging. Carers emphasised the 24/7 nature of the role “we get calls from services during the day because there has been an issue [...] We have even had calls when we are on holiday.”

Supporting people to lead independent lives and meet their unique needs and wishes requires Shared Lives Carers to “wear so many hats.”

“We are carers, self-employed and landlords “

Carers often end up helping the people they care for apply for benefits and “deal with the many departments within the Department of Work and Pensions.”

CVT told us that they provide training and support to enable carers to remain in post and provide the best care to the people they support.

“We access mandatory training, support and monitoring. We know that support from the team is only a phone call away.”

A carer told us that he has learnt a lot from CVT, including record keeping and the training is “really good”. However, one carer said the training modules can be overwhelming.

“I have 16 outstanding online training courses to complete. It can be overwhelming and as a carer, I often have other priorities.”

Why do people become a Shared Lives Carer?

29% of carers who completed our survey said they became Shared Lives Carers after seeing an advert.

Other people joined for various reasons:

- Continuing care for someone they fostered as a child.
- Indeed job posting.
- Recommendation from a social worker.

James has cared for Kath for 17 years, initially in a foster care placement before moving to a Shared Lives placement when she became an adult.

Another carer said they looked into Shared Lives when the person they fostered turned 14.

"I fostered Rich since he was about four years old. I saw Shared Lives advertised in the fostering network book when Rich was about 14 years old."

Two carers had previously been involved in a different model of care where adults with additional needs lived together in a large house and House Parents provided care. When Shared Lives was developed they wanted to be able to provide more personal care.

"We have stayed in this caring role through various service changes."

Carers said the Shared Lives model provides financial, practical and emotional support that is not afforded by other models, such as the 'Staying Put' model.

"In the Staying Put model, there is no financial support for carers."

A “rewarding career”

“It is very rewarding although it is a full on job.”

Being a Shared Lives Carer was described as a rewarding and fulfilling career. Despite the challenges faced when caring for a person with additional needs, the individual approach leads to carers forming close relationships with the people they support.

“Seeing the difference we make to the lives of those we support”.

Being a Shared Lives Carer was described as a vocation as opposed to a job and making a difference was important to them.

“I want to make a difference in someone's life by utilising my spare room to support someone who needs my support.”

People spoke about how Shared Lives is a diverse environment and they get to meet new people. They can also form connections and get support from other carers.

“It is a rewarding career, and a multicultural environment where you meet different people from different backgrounds who come together and have one voice in delivering competent services to vulnerable people.”

“Meeting new people with diverse cultures and also companionship. ”



Is respite needed and supported?

Funding for activities and respite care was mentioned by Shared Lives Carers and the people they care for. Respite was incredibly valued by some carers and they see it as essential in their role. However, some carers and the people they care for do not want to use respite care.

“We now have to take unpaid leave. Previously, we had four weeks paid respite per year. Now, it is unpaid. This can make us reluctant to take breaks as loss of earnings has to be considered.”

“I am aware of [other carers] who do not take any time out. This can easily lead to burnout.”

“Long-term placements mean we really get to know the people staying with us. It is a unique experience with 24/7 support with tailored choices.”

The nature of Shared Lives means being a Shared Lives Carer is a “full-time job”. One survey respondent said “paid respite” would help them.

“The ability to recharge without losing income, as it used to be before Dudley Council changed the pay structure.”



Why is respite so important for Shared Lives Carers?

One Shared Lives Carer shared the importance of respite for the two adults they care for, as well as themselves.

"The carers need a bit of a break during the day. The people we care for don't want to be with us 24/7, especially when we are encouraging independence. Cam comes back from seeing other people and he's clearly lifted."

"Tim and Darren go on their own holidays, they want to do things away from us."

One carer we spoke to said they have never really used respite care "we've always looked after them like they were our own kids." The woman they care for had a previous negative experience with respite care, which was not provided by Shared Lives:

"We told the respite carers not to close the bedroom door at night, and they did. Kath was only given five minutes to shower and no choice of the food she had to eat. I had to make a complaint."

Due to the complex nature of the challenges faced by clients and the individual care they receive, handover to other care or support services can be daunting for both Shared Lives Carers and clients.

Two carers told us they now plan for potential issues to improve handover. They shared experiences where they had informed respite carers about potential issues.

e.g. one client likes to sign into accounts on electronic devices and place orders. He also likes to take the devices apart. In one instance, the respite carer allowed the client to gain access to accounts and they had run up a large bill.



What support is offered by Camphill Village Trust?

Overall Shared Lives Carers feel they get a “good level of support from CVT.”

“The support from CVT is good, compared to what we received previously.”

“CVT are more thoughtful, friendly and approachable compared to other agencies where you can just feel like a number. Things don’t just get brushed aside, even when something is difficult.”

The personalised, supportive nature of CVT is highly valued by Carers.

“It is person-centred family life and each individual is placed with, in our case a family after an extensive matching process.”

“[We get] full support including monitoring visits and access to advice over the phone.”

Shared Lives Carers suggested areas for improvement:

- Providing up-to-date information

“The directory of services could be improved.”

- Including clients in decision making.

“We want the people we care for to be included, and their voices heard.

- In-person training and support.

“We would have meetings attended by social workers and community nurses which was great for networking.”

“I prefer training to be face-to-face.”

- Reinstating paid respite

“We provide support 24/7. When CVT took on Shared Lives, they negotiated 28 days paid holiday for carers. This was welcomed by all and it was a bitter blow to have this withdrawn after two years.

Reinstating this would be appreciated.”

“Thoroughly supported.”

Shared Lives Carers told us that they receive training to support their role.

“I receive a good level of support from CVT staff and Kath is actively involved with the organisation and often supports their work.”

Joe explained that he undertakes training from both agencies that he works for.

“I have 16 outstanding online training courses to complete. It can be overwhelming and as a carer I often have other priorities.

Sometimes it can feel like it's not joined up, as I have to do duplicate courses because of being a Shared Lives carer and a foster carer.

Some courses are really useful. I have completed 18 weeks of training about managing behaviour that was really helpful.”

Andy said that they have learned a lot from CVT and that the training is really good. He told us CVT is organised and they helped him to learn the non-caring aspects of his role, including financial and medical record keeping.

“We receive physical, psychological, social and emotional support [from CVT].”

“We access Mandatory Training, Support & Monitoring as well as having the knowledge that support from the team is only a phone call away.”



Experiences of health & social care

Shared Lives Carers and people who use the service told us their experiences of using other health and social care services.

Their experiences were mixed and people appreciated personalised care and had concerns about waiting times.

“Access to health services in Dudley is quite often difficult for us as carers and very nearly impossible for the people we support.”



Accessing GP services

“Our experience at the surgery varies depending on who we see, they seem to have a lot of trainee GPs.”

We spoke to people about their experiences of accessing health and care services outside of CVT.

People spoke about the lack of consistency in who they see for health care and how this has a greater impact on people with learning disabilities and/or autism.

“In the past we had access to a named and trusted GP, who could give the individual a person-centred appointment, addressing the many aspects of their disability and medical needs. Now we have to make upwards of five appointments, with separate nurses and doctors, who haven’t first-hand knowledge of the patient in front of them.”

Andy felt GP services have changed since COVID and they are being offered less face to face appointments.

Changes to GP booking systems and delays in getting an appointment can add additional pressure to those with caring responsibilities.

“Recently we were unable to use the online system and were advised to phone the surgery at 8am each morning for someone to fill in the form for us – which would take upwards of 10 minutes!

This impacts us as carers and the people we support. 8am is the busiest time of the day. We cannot always be on hold for 30 minutes in the hope that we are not told the surgery has reached capacity.

We should be supporting people to get to day provision, get ready and maintain a personal routine.”

Michael attends his annual health check, but does not need to see a GP as he is generally well.

How do Shared Lives Carers advocate for the people they care for?

“Michael had to wait three to four weeks to be seen as an emergency. He was referred to a dentist in Birmingham and they sent reports with recommendations to Dudley, but these haven’t been followed up.”

James supports Kath at all of her appointments and often stays with her as she can become very anxious.

Waiting times were mentioned by some of the carers and how they feel the need to advocate for the people they care for, particularly with complex healthcare systems and long waiting times.

James told us Kath is waiting for a number of things:

- She attended an ECG appointment seven months ago and had not received test results.
- A referral was made to a consultant several years ago for pain and they have not heard anything.

“It’s not fair, she is in pain.”

Lisa and Jed said they stayed to advocate for a person they cared for during an inpatient hospital stay. They felt some nursing care “**did not happen and some was poor**” because staff expected them to provide care themselves.

“Carers are not always seen as professional people, they just think you care for someone and you don’t always feel listened to.”

One carer shared a positive experience at a local hospital where adjustments were made to accommodate the person they care for.

“Tim went to the hospital as he needed a procedure as a day patient and was very nervous.

The people who sent the invite knew his circumstances. We visited before to talk through the procedure and they gave him a picture book and we walked around the department and could ask questions.”

How do people access financial support?

“The complex system requires carer support with Universal Credit.”

“She sends emails and does not always receive a response, it makes her anxious.”

“Universal Credit is not very accessible.”

Carers were vocal about the difficulties they faced obtaining the support and benefits the person they care for is entitled to, with one describing themselves as a “welfare advisor”.

“We’ve had a lot of trouble with Universal Credit. With Shared Lives they pay rent to their carer. We have to go back and forth. It’s all done online and you don’t have one contact with someone.”

“You can’t just message [the Department of Work and Pensions] you can only respond to what they’ve asked you.”

“You need to have an understanding of Universal Credit to help the people you are advocating for.”

Shared Lives Carers expressed concerns that the complex system negatively impacts people with additional needs and they worry that the people they care for may not receive everything they are entitled to.

“They were asking Rich about how much capital he has and he hasn’t got a clue.”

“It’s really stressful and I would put money on it that there are people who don’t get what they are entitled to because they just don’t know.”

“It’s not geared up for people with a disability, especially a learning disability.”

“It took six months to sort out Universal Credit when Kath transitioned from foster care to Shared Lives. She had to go to nine appointments. Some carers would not have been able to cope financially.”

How do carers offer support when the services aren't there?

"Everything takes so long."

People shared the challenges they face getting social care.

"Social workers have the freedom to refer someone but are now constantly assessing what is the cheapest model."

Carers said they have to "chase up" social workers. However, they understand "social workers have a lot of stress and a lot of cases".

"You can go back and forth, they've got too much on their plate."

Carers told us in previous years each person was assigned a social worker and a community nurse.

"Now there are no community nurses and fewer social workers."

This, in addition to the reduction in day services has increased the need for people who use Shared Lives to access health and social care services. It has also increased the workload on carers who are often responsible for arranging and supporting at health and social care appointments.

Lisa and Jed shared that Joe was referred for bereavement support as a relative has received a terminal diagnosis. They felt that preparation for Joel was important. He was referred to a men's health group and was provided with a workbook that was inappropriate for his needs.

"We have been waiting two years for bereavement support for Joe. We were told he needed to go through the natural grieving process, which takes around a year, before they would do something."

Filling the gaps in health and social care places additional pressure on Shared Lives Carers who already feel as though they are wearing "many hats".

"Helping with grief is something outside of my expertise."

What is it like for carers to access care?

As carers is it important to look after their own health. We asked Shared Lives Carers what it was like for them to personally access health and social care.

Lisa experiences challenges with getting a GP appointment.

"It has taken me four appointments with the GP to resolve one issue."

She also had a negative experience getting prescribed medication.

"I have had issues being prescribed special medication and nearly had to go days without my medication, as they couldn't provide a prescription for what I needed following an operation."

Some carers make use of multiple services to support their wellbeing.

"I use social, community and health services to manage my own wellbeing."

A Shared Lives Carer said that more commitment was needed from services to improve support for carers.

"Support and commitment from relevant bodies. would help make the role of a carer easier."



Recommendations

The recommendations from this report primarily relate to other services and wider healthcare systems.



Respite

- Explore ways to offer respite for carers in a way that does not financially impact them.
- Consider providing day activities or care to offer shorter respite for carers.



Training

- Consider joining up training with other roles.
- Provide training on a case-by-case basis rather than making all courses mandatory for all Shared Lives Carers.
- Provide face-to-face training, that can offer opportunities for Shared Lives Carers to connect with each other.



Personalised care

- People who use Shared Lives appreciated when healthcare services took the time to understand and adapt to their needs.
- People appreciate consistency in GPs so that their doctor understands their needs.



Learning from good practice

- Services should listen to what works well, and build on the good practice shown by other services to improve care.
- *For example, when Charlie was invited to visit a hospital ward prior to receiving treatment (page 16).*

Response from Shared Lives



Training

Shared Lives Carers have access to training both online and in bespoke face to face sessions.

We understand online learning can be overwhelming. Training is needed to maintain best practice and we can support those who need additional help.



Respite

Shared Lives schemes are funded by Local Authority, Dudley Council do not provide funding for respite. We encourage and support carers to identify opportunities for natural breaks in support to allow respite.



Providing feedback

We encourage Shared Lives carers to regularly share their views, including areas that we could improve. We value an open, honest and transparent working relationship with the Shared Lives Carers.



Health and social care

We recognise the pressure health and social care services are under and the impact this can have on those we support and their carers. We encourage Shared Lives Carers to seek support from their area co-ordinator if they are having difficulties accessing health and social care.



Benefits, Universal Credit and welfare.

We have developed a range of resources to support Shared Lives Carers and the people who live with them. The Shared Lives team can provide financial advice and support.

Thank you

Thank you to the people who use Shared Lives and the Shared Lives Carers for sharing their experiences with us. Thank you also to Camphill Village Trust for their openness and cooperation throughout the project.

“More people need to be aware of Shared Lives, and to get involved in it. We need effective networking to reach more people, so that more people come on board. More variety, as you have to match personalities.”

“My experience is excellent.”

**Comments and quotations may have been clarified for clarity. All names and identifying details have been changed to project the anonymity of the people we spoke to.*



If you would like this report in another language or format please contact us.

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**Committed
to quality**

Healthwatch Dudley is committed to providing a quality service, from how we collect data, to the information we provide. Every three years we perform an in-depth audit, in conjunction with Healthwatch England, to ensure we meet this high standard.