



Notes from Open Meeting

20 April 2024 on Zoom

Shared Lives

Welcome and introduction

Mary Pearson (Chair) welcomed everyone to the meeting, and began with some general announcements:

- The Camphill Families and Friends website is undergoing maintenance and is expected to be completed by mid-May. Unfortunately, during this time, we are unable to keep it up-to-date.
- It appears that some local authorities are not planning to increase funding in the upcoming year. We would like to invite members who are experiencing this issue to share their experiences with us.
- We are hugely grateful for the ongoing support of our members. We nevertheless recognise that many people are under financial pressure as the cost-of-living crisis continues. We don't want anyone to feel that they can't continue to be a member of Camphill Families and Friends because of this. Should you be considering cancelling your membership for cost reasons, please do get in touch in confidence with Mary, our Chair, to arrange a fee waiver. She can be contacted by email on fmarypearson@gmail.com.
- Our next online Coffee Morning will take place on Wednesday 5 June at 10.30am. Information on how to register will be circulated nearer the time. Our Coffee Mornings offer an online space for us to come together for an informal chat. There are no agendas or themes, no speakers, no minutes taken. This is purely an opportunity to drop in, meet others, say hello, or just listen. Join for as long as you want to.
- Mary extended a particular welcome to Dean Barnshaw, the Regional General Manager for Camphill Village Trust's Stourbridge Community and Shared Lives service. Recently, his responsibilities were expanded to include acting as General Manager for the Gloucestershire Communities.
- Mary drew members' attention to the [Our Life Our Choice](#) (OLOC) campaign which is challenging the Care Quality Commission (CQC). The CQC maintains that more than six adults living together is undesirable and therefore cannot be rated "excellent", although none of the research supports their position. OLOC is now launching a wider campaign with impressive backing and a conference in London on 24th October. Camphill Families and Friends has agreed to support this campaign and will circulate information to our members so that they can also offer support if they wish.

Mary then introduced the main topic for discussion in today's meeting: **Shared Lives**, a model of care which is increasingly popular with local authorities nationally, offering

support to up to three people with learning disabilities in each house, in a family setting.

In 2019, Camphill Families and Friends contributed £10,000 to support the recently-established [Esk Valley Camphill Community](#) in North Yorkshire. The community was created following a period of challenges and changes at Botton Village Community. A group of 30 co-workers created this community as an alternative to remaining in the new employee-model at Botton. Thirteen houses became Shared Lives households. These are located within Botton Village and rented from Camphill Village Trust, which runs Botton.

We welcomed Charlotte Buchanan, a co-worker from Esk Valley, who kindly agreed to talk to us about this Shared Lives community, and how they have worked with [Avalon](#), a Shared Lives provider in North Yorkshire. This relationship is coming to an end, and Esk Valley's Shared Lives provider is now [PSS: Person Shaped Support](#).

Charlotte shared her experiences, before we opened the virtual floor to questions from meeting attendees.

- Charlotte began with a short introduction to Shared Lives in general:
 - The idea of Shared Lives has been around since the 14th century, when people in Belgium decided that people with mental ill health should live in the community instead of an asylum. In the UK it's been going since the 1970s – many local Shared Lives schemes have run for 40 years on a small scale.
 - When the UK government started closing old 'institutions' for mental health patients in 1978, lots of older people had nowhere to go. Originally called 'Adopt a Granny', Shared Lives meant that instead of getting passed to another institution, these people could go and be supported in a homely environment by a carer and their family.
 - In 1984, the 'PSS Care in the Community Scheme' was created to support people with mental health difficulties in their communities – going against the general idea of the time that people with mental health difficulties should be institutionalised. This inspired and influenced this way of working in other areas of the country.
 - In 1992, PSS started what became the UK Network of Shared Lives schemes – back when they were called adult placement schemes. In 2010, this became Shared Lives Plus, reflecting the mutually chosen relationships that are at the heart of each shared life.
 - The network worked closely with UK governments to promote the value of very small, localised services, and ensured that legislative and regulatory requirements were appropriate and did not place unnecessary barriers in the way of people establishing and delivering local small-scale enterprises. It was instrumental in securing recognition by central and local government of the importance of micro social care to the successful transformation of adult social care.
 - Today, the Shared Lives scheme is a recognised government scheme, with around 9,000 people being supported. It matches people who need care and support, with an approved carer. The carer shares their family and community life, and gives care and support to the person with care needs. Each carer can support up to three people. This depends on the size of their house and facilities, the number of people in their family, and the extent of the carer's experience.

- Each Shared Lives carer goes through an approval process to get accepted, to ensure they meet the standards and have the skills. The application process can take between three and six months.
 - Shared Lives carers are self-employed and are paid a fixed fee rather than an hourly rate. They are paid by the Shared Lives scheme that they are registered with, which is usually funded by the local council or the NHS (the scheme keeps a small amount as a management fee). A Shared Lives carer can earn between £350 and £650 per week, per person living with them, depending on the level of care required.
- Shared Lives at Esk Valley has allowed their villagers to continue the life they were wishing to keep. Esk Valley was supported by Shared Lives Plus when they first started – they helped initiate the partnership with Avalon (their Shared Lives provider until very recently). Avalon provided training and set up an office – Avalon and Esk Valley built up a very good working relationship over the years. They had trust in each other, which was crucial.
 - Initially it was a challenge to adapt to the ‘three villagers per household’ rule, but spare rooms are now used for other things, such as a crafts, a music room or a library. Each house is now a separate business, and each carer is self-employed.
 - Carers have the right to decide who lives with them. There is a contractual agreement between each carer and villager, with the villager taking out a licence on their room.
 - It is believed that the opportunity for villagers to do meaningful work is vital, so workshops have kept going, which are free to villagers. The care fees received from the villagers, via the care provider, are pooled in a shared account for the use of the community. The co-workers propose a budget for the year for their personal needs which is then agreed by the community and covered from this pooled money. The money received for food and household from the villagers is not pooled but used by the house for its appointed purpose. Surplus money goes to support the running of the community, funding things like workshops and a fleet of cars.
 - There is a recruitment group to ensure volunteers from other countries are able to come and share the lives of each household. Usually there is one young volunteer per house, and they will assist with any tasks that aren’t directly related to regulated care work. They also bring knowledge, customs and music from their country, and help bring life and open up minds. Some villagers remain in contact with these volunteers for years afterwards.
 - There is ongoing paperwork for each carer to complete, but it isn’t too invasive. This has given the carers at Esk Valley the time to support ongoing workshops and community life in general.
 - They also run a health shop, as well as a market garden which provides most of the vegetables to feed the community and stocks their veg box scheme.
 - It has been seven years since Esk Valley started, and things are going well. It is time to reflect and look forward; they are keen not to rest on their laurels. They are making and maintaining connections to the wider community nearby; it is important not to become insular.

Attendees were then invited to ask questions and the following points were made:

- Dean Barnshaw explained that Camphill Village Trust were awarded the Shared Lives contract for Dudley in 2018, and later Wolverhampton in 2022. They have grown both schemes and currently support 74 people across the Black Country.

The residents are encouraged to get involved in the local community and some also make use of day opportunities at Ashfield Gardens. Although the houses aren't grouped together as they are in Esk Valley, he expressed that the beauty of Shared Lives is that community is created around each family household, and each resident becomes a part of family life.

- There was much praise for Esk Valley from parents of current villagers, emphasising the benefits of living in a community setting.
- Each Shared Lives carer pays tax annually, via a specific Shared Lives self-employed tax code. In Esk Valley, each carer hands their salary (the care fees) to the community, after tax – and then takes what they need from the central pot. Everyone is accountable to each other and feels connected to each other.
- The question was raised about arrangements for the future, for Esk Valley carers after retirement. They do pay National Insurance, and in months when the community is doing well, will also take a top-up to add to their private pension fund. So far, when a carer has needed to leave, the community has pulled together to enable them to achieve this and has felt a responsibility to do this.
- The switch from Avalon to PSS occurred following a tendering process. PSS is a much larger organisation.
- There was a discussion about the fact that room-sharing is no longer allowed for villagers, and they are also unable to assist with childcare within family households – but safeguarding rules must be followed.
- The question was raised as to whether the Esk Valley model could be replicated within Camphill Village Trust communities, but it was highlighted that it would not be possible, as the staff are employees, so work and do not live in the houses. Esk Valley developed out of a very specific set of circumstances, where a group of people were already living together in this way, and found Shared Lives as a tool to enable this to continue. There is also the issue of the physical houses in many Camphill communities being too large for the three-per-household model.
- Esk Valley was praised for managing to maintain free workshops for villagers. It was emphasised that dignity is an important concept to hold onto, and that meaningful work is all about being treated like an adult with responsibilities – something that used to be built into the Camphill way of life.
- The Care Quality Commission (CQC) approves of Shared Lives as an excellent model. They inspect the Shared Lives providers, with just a couple of households receiving a brief visit. They seemed impressed with Esk Valley.
- The CQC has a negative view of campus-style communities, and new ones are unlikely to be built today. This doesn't take away from the valuable lives being led in such communities. It is important to demonstrate to CQC that Camphill communities aren't insular, and that links are always developed within the local area.
- It was suggested that because everyone is different, the idea of a 'one size fits all' approach to care settings isn't a valid solution.
- Obesity isn't a problem within Esk Valley: people are mostly active and eat healthy meals, prepared and eaten together.

Mary thanked Charlotte and Dean for their contribution, and then opened the virtual floor for discussion of any other matters of interest.

- Camphill Village Trust has stepped back from acting as the benefits appointee for residents. It was suggested that a family member can be the appointee, or a (chargeable) alternative is to subscribe to [DOSH's Financial Advocacy scheme](#) – DOSH would become the appointee and provide financial advice.

- Regarding Camphill Families and Friends Open Meetings going forward, it was suggested that our annual in-person meeting be held in April (with better weather) and the annual Zoom-based meeting be held in the November. Trustees will consider this option.

The Chair closed the meeting and thanked everyone for attending.