



Wales Invaluable Report

Survey data from Shared Lives carers and Shared Lives schemes

2023





To skip to the section you're looking for, press CTRL and click to jump straight to it!

Contents

Contents	3
Executive summary	4
Introduction	6
How to use this report	8
Response rates and reference codes	10
Care fee benchmarks	12
Lowest average fee rates for live-in arrangements	14
Highest average fee rates for live-in arrangements	16
Board and lodgings contributions	18
Wales live-in fees and contributions graph	19
Shared Lives carer survey data	20
Summary	23
Recommendations	25
Appendix: Carer voices in Wales	27

Executive summary

The data in this report was collected in or before November 2022.

Fee rates are subject to change in the intervening period.

KEY DATA	There were 7 Shared Lives schemes in Wales in November 2022. All 7 Shared Lives schemes provided some form of data on care fees and board and lodgings. There are 9 data reference codes. This is because 2 schemes provided commissioning rate data for 2 local authority areas.
BANDINGS AND NON-BANDINGS	All 9 of the commissioning rates were banded according to the data provided by schemes.
LOWEST FEE RATES (LIVE-IN ARRANGEMENTS)	The <i>smallest</i> Welsh live-in fee of £161.00. The <i>greatest</i> Welsh live-in fee was £424.31. 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were below all other comparative fee rates for lowest fee rates for live-in arrangements.
HIGHEST FEE RATES (LIVE-IN ARRANGEMENTS)	The <i>smallest</i> Welsh live-in fee of £221.26. The <i>greatest</i> Welsh live-in fee was £532.00. 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were above all other comparative fee rates for lowest fee rates for live-in arrangements.

BOARD AND LODGINGS	The <i>lowest</i> B&L contribution was £25.00. The <i>highest</i> B&L contribution was £79.95. 5 out of 8 (63%) board and lodgings contributions were above both national and regional average for Shared Lives.
CARER SURVEY STATISTICS	Of the <u>25</u> Shared Lives carers in Wales who responded to the survey: ⇒ 72% stated that they were affected by cost of living. This is slightly less than the national average of 77% ⇒ 24% have considered leaving Shared Lives due to the cost of living. This is slightly less than the national average of 31% ⇒ 32% of carers said they felt not very or not at all valued, higher than the national average of 26% ⇒ 48% of carers stated that they felt highly valued or somewhat valued, although this was slightly higher than the national average of 47%
RECOMMENDATIONS	1. Commissioning organisations ensure that <u>at a minimum</u> they provide a lowest fee rate for live-in arrangements at or above the care worker minimum wage for Wales, £355.30. 2. Commissioning organisations ensure that <u>at a minimum</u> they provide a highest fee rate for live-in arrangements at or above the UK Shared Lives highest banded fee rate £433.14. 3. Commissioning organisations ensure that they provide a board and lodgings contribution at or above the UK national average £69.03.

Introduction

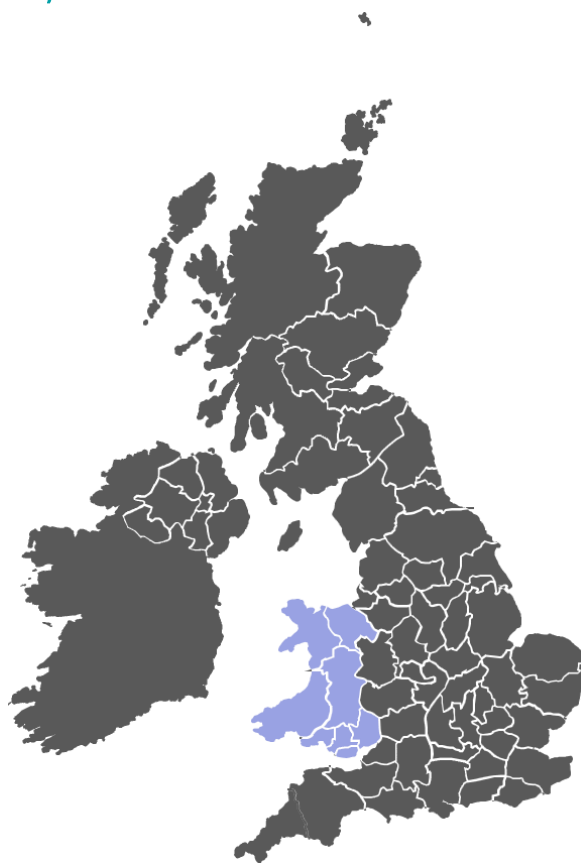
"[I enjoy] making a difference in someone's life. Seeing the changes - although slow, they are there: [like] changes in temperament, life satisfaction, and abilities. I get satisfaction knowing I have had a hand in this. I enjoy finding out about the person and their life and their family. The things that they like and the things that could be better. [I enjoy] finding out their aspirations and seeing them move closer to them."

Shared Lives carer, Wales

Shared Lives carers in Wales do amazing work by enriching the lives of the individuals they support, as well as the communities they live in. At Shared Lives Plus, we believe that the dedication of Shared Lives carers should be recognised and reflected in their earnings.

Shared Lives Plus has supported Shared Lives carers and Shared Lives schemes for more than 40 years. During this time, our organisation has primarily been involved in the good management of shared lives schemes, safe delivery of shared lives care, and fair treatment of Shared lives carers.

Although we know it is a cost-effective form of care, we also know that many of our Shared Lives carers are struggling. We know that the fees and board lodgings contributions provided by commissioning organisations to Shared Lives arrangement are not consistent. The data collected in the Invaluable surveys represents a step change in our understanding of care fees and board and lodgings contributions. It also centres Shared Lives carer voices, reflecting their feelings about fees, the cost of living, and their health and wellbeing.



In this report, you will find specific information about the highest and lowest average care and support fees, and average board and lodgings payments for commissioning organisations in Wales. Please note, **for this survey we limited our scope to asking about live-in support, since that is the predominant way in which people are supported.** You will also find recommendations for commissioning organisations improving these fees and contributions. We are planning to undertake more collection and analysis of respite and rent data, which is why you will not find that information in this report.

How to use this report

This report has been primarily written for Shared Lives carers and Shared Lives schemes. It draws upon data provided in the carer Invaluable survey, and as part of a data collection exercise conducted by Wales Development Manager Kathryn Morgan, and Scotland Development Officer, Nicola Watson. This report may also be of use to others, including commissioners and directors of adult social care.

A note about fees and bandings

Shared Lives is not a homogenous model. The data anomalies in this report reflect the differences between schemes who have evolved over time, and who also cater to the needs of individual supported people.

Shared Lives **live-in** arrangement fees should consist of three main elements:

- A care and support fee,
- A board and lodgings contribution,
- A rent contribution (not included in this report).

The **care and support fees** reflect the care required of the Shared Lives carer, as specified in a person's support plan.

Some commissioning organisations operate a system of bandings, which sets the rates for care and support fees.

There is no set number of bandings, and this can vary between areas. Some areas also provide an additional or extra fee on top of the banding fees. This can be at the discretion of commissioners and is based on the exceptional needs of an individual.

Several commissioning organisations do not work a banding system or have arrangements which are not within their banding system.

The board and lodgings contributions are not generally banded. In some cases, Shared Lives carers may receive a higher or lower board and lodgings contribution at the discretion of the commissioning organisation. For example:

- where a person has increased electricity usage through double incontinence, they may receive a higher contribution.
- Conversely, where a person is under the age of 25 and in receipt of lower benefits, their board and lodgings contributions may need to be lowered to make it affordable.

Lowest and highest fees

To compare data efficiently, this report compares only the highest and lowest care fees reported in the scheme survey. It compares both banded and non-banded data, for a clearer overall picture of fees in Wales.

Data report codes

Each commissioning organisation (such as a local authority/council) has been assigned a data report code, e.g., WSchemeA.

This allows commissioning organisations to remain anonymous, whilst enabling a regional and national comparison of fees.

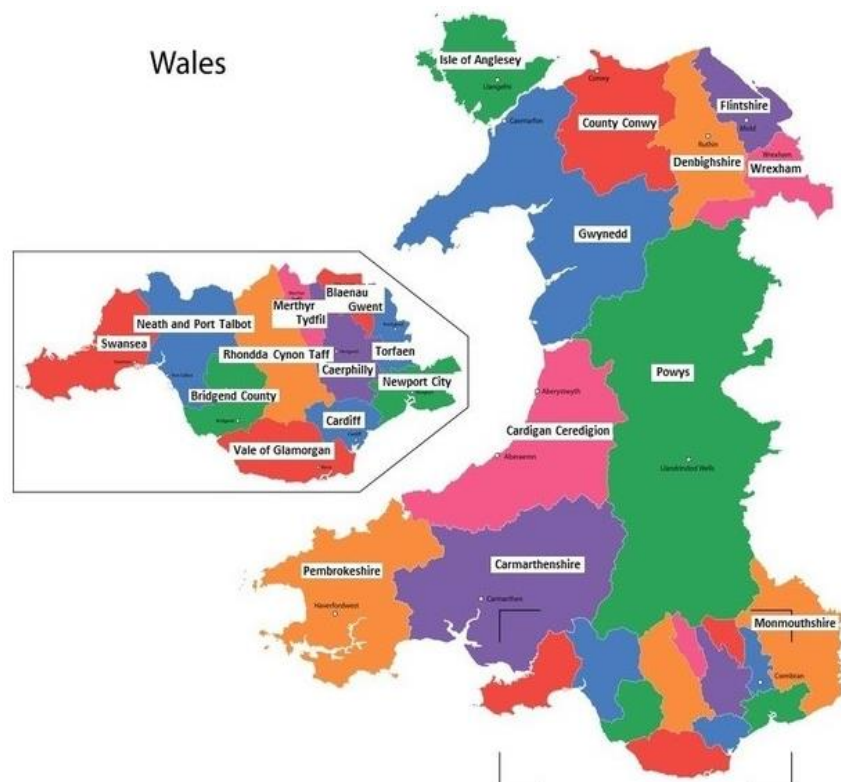
Shared Lives schemes will be provided with the data reporting code for the relevant commissioning organisations. If you are a Shared Lives scheme or commissioning organisation who does not have the code but would like one, you can contact us: membership@sharedlivesplus.org.uk

Response rates and reference codes

Shared Lives schemes response rate

There were 7 Shared Lives schemes in Wales in November 2022 who were registered members of Shared Lives Plus*:

- ⇒ Ategi Shared Lives
- ⇒ Gwynedd & Anglesey Shared Lives
- ⇒ Powys Shared Lives
- ⇒ PSS Wales Shared Lives
- ⇒ South East Wales Shared Lives:
- ⇒ Vale of Glamorgan Adult Placement
- ⇒ West Wales Shared Lives Scheme



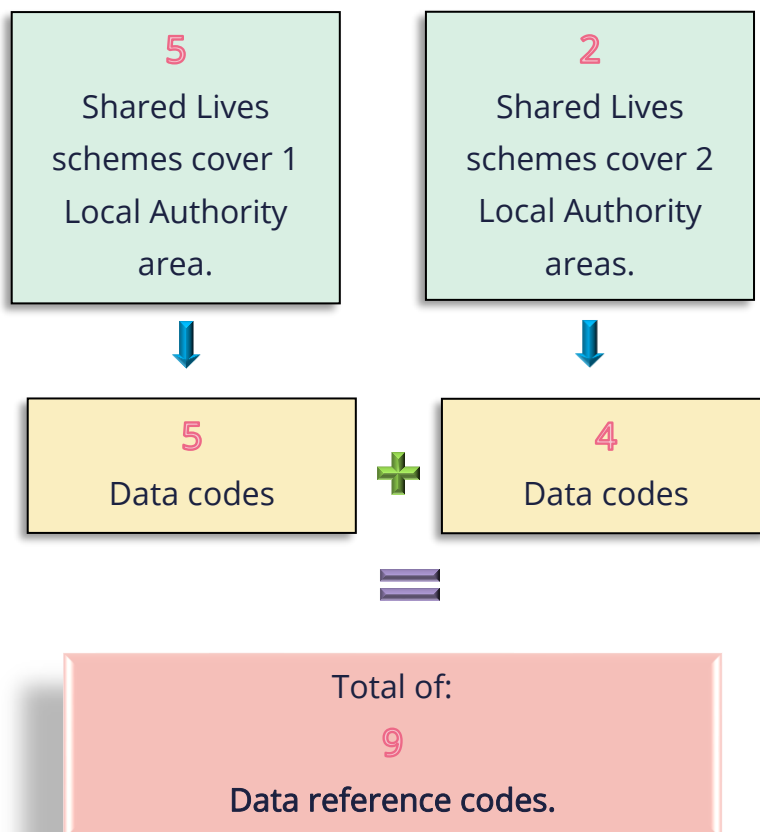
All 7 Shared Lives schemes provided some data on live-in fees and board and lodgings contributions.

There is a Shared Lives scheme in Denbighshire. However, they are not registered as members of Shared Lives Plus.

Data reference codes for commissioning organisations

There are **7** Shared Lives schemes in Wales, but there are **9** data reference codes to categorise information provided by schemes in this report.

This is because **2** Shared Lives schemes cover **2** different local authority areas. Each local authority has been given their own data reference code which reflects this e.g., *WSchemeE1* and *WSchemeE2*.



Shared Lives carers response rate

When this survey was conducted, there were **547** Shared Lives Plus carer members in Wales. Of these, **25** Shared Lives carers responded to the carer survey.

This equates to 5% of the Shared Lives Plus carer members in Wales.

Care fee benchmarks

Below are the benchmark rates used for each of the three comparative data sets: lowest care fees and highest care fees for live-in arrangements.

Lowest care fee benchmarks

Shared Lives lowest banded fee rate (Wales)

This figure is the average of the lowest care fee rates provided by Shared Lives schemes in **Wales**.

Shared Lives lowest banded fee rate (UK)

This is the average of the lowest care fee rates provided by Shared Lives schemes provided in **three nations**: Wales, Scotland, and England.

Shared Lives lowest non-banded fee (England only)

Shared Lives schemes in **England** also provided data of care fees which were **not set by a banding system**. To ensure a fair data comparison, the average of these figures for England have also been included in the data table below.

Care worker real living wage

The benchmark for the minimum care worker salary is taken from the. The figure below is based on full time equivalent (FTE) of 37 or more contracted hours a week.

The **minimum care worker salary** in Wales was £21,255 per annum or **£355.30** per week.

Highest care fee benchmarks

Shared Lives highest banded fee rate (Wales)

This figure is the average of the highest care fee rates provided by Shared Lives schemes in **Wales**.

Shared Lives highest banded fee rate (UK)

This is the average of the highest care fee rates provided by Shared Lives schemes provided in **three nations**: Wales, Scotland, and England

Shared Lives highest non-banded fee (England only)

Shared Lives schemes in **England** also provided data of care fees which were **not set by a banding system**. See previous page.

CCPS Scotland/Indeed Wales average.

The Coalition of Care & Support Providers in Scotland (CCPS) Scottish Social Care has set a higher recommended living wage. They set this at £12 per hour.

The Welsh National Commissioning Board (Bwrdd Comisiynu Cenedlaethol) recommended conducting a search of senior care worker salary statistics on the demographic site, 'Indeed'. The average figure was also approximately £12 per hour.

The CCPS Scotland/Indeed Wales joint average is £23,400 gross annual income, or **£383.35** net income per week.

Average Senior Care Worker salary (English border regions)

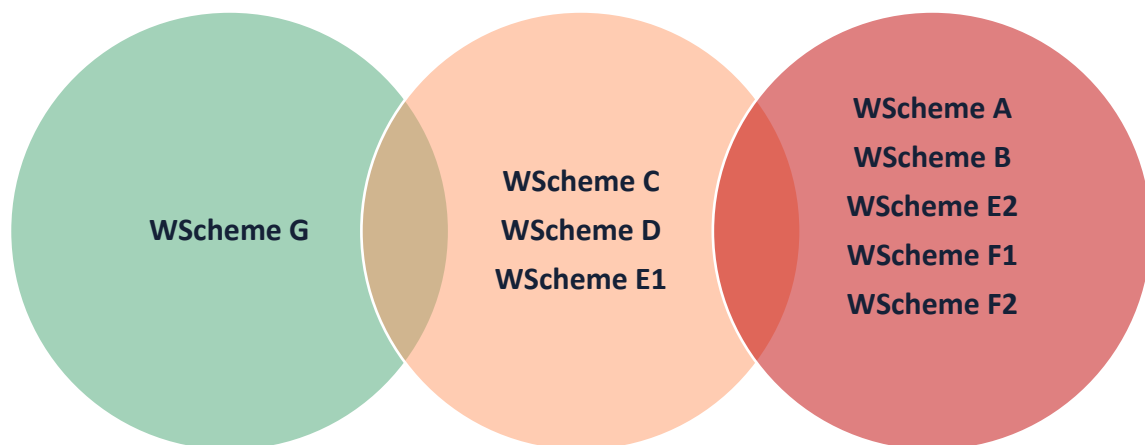
Skills for Care collected data on the salaries of care workers, broken down by region and profession in England. As an additional benchmark for senior care worker roles in Wales, this report has created an average of salary rates from three English regions that border Wales: The North West, the West Midlands, and the South West.

The average senior care worker salary in the English border regions is £26,200 gross annual income, or **£419.97** net income per week.

Lowest average fee rates for live-in arrangements

Please note that these figures were accurate as of November 2022.

	WScheme A	WScheme B	WScheme C	WScheme D	WSchemeE 1	WSchemeE 2	WSchemeF 1	WSchemeF 2	WScheme G
Lowest Banding Rate	£175.12	£161.00	£283.25	£322.00	£280.00	£260.00	£221.26	£243.50	£424.31
Lowest Shared Lives Banding Rate (Wales)	£263.38								
Difference	-£88.26	-£102.38	£19.87	£58.62	£16.62	-£3.38	-£42.12	-£19.88	£160.93
Lowest SL Banding Rate (UK)	£288.01								
Difference	-£112.89	-£127.01	-£4.76	£33.99	-£8.01	-£28.01	-£66.75	-£44.51	£136.30
Lowest SL non-banded Fee (England only)	£401.48								
Difference	-£226.36	-£149.48	-£118.23	-£79.48	-£121.48	-£141.48	-£180.22	-£157.98	£22.83
Real living wage	£355.30								
Difference	-£180.18	-£103.30	-£72.05	-£33.30	-£75.30	-£95.30	-£134.04	-£111.80	£69.01



1 scheme provided data about a fee rate which was **above all comparative averages**.

3 provided rates which were **below average** in 2 or more comparative averages.

5 provided rates which were **below average** in all comparative categories.

This means that 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were **below** all other comparative fee rates for lowest fee rates for live-in arrangements.



WScheme G were commissioned to provide the *greatest (lowest)* live-in fee of **£424.31**.

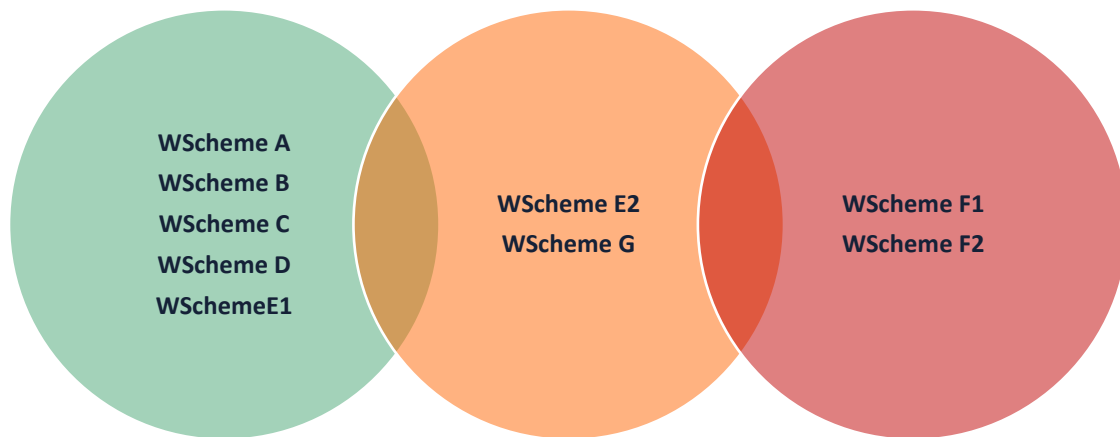


WScheme B were commissioned to provide the *smallest (lowest)* live-in fee of **£161**.

Highest average fee rates for live-in arrangements

Please note that these figures were accurate as of November 2022.

	WScheme A	WScheme B	WScheme C	WScheme D	WSchemeE 1	WSchemeE 2	WSchemeF 1	WSchemeF 2	WScheme G
Highest Banding Fee	£443.19	£532.00	£463.50	£515.00	£445.00	£425.00	£221.26	£243.50	£424.31
Highest Shared Lives Banding Rate (Wales)	£412.53								
Difference	£30.66	£119.47	£50.97	£102.47	£32.47	£12.47	-£191.27	-£169.03	£11.78
Highest SL Banding Rate (UK)	£432.86								
Difference	£10.53	£99.34	£30.84	£82.34	£12.34	-£7.66	-£211.40	-£189.16	-£8.35
Highest SL Non-Banded Fee (England only)	£431.76								
Difference	£11.43	£113.24	£31.74	£83.24	£13.24	-£6.76	-£210.50	-£188.26	-£7.45
Scotland/Indeed Wales average	£383.35								
Difference	£59.84	£161.65	£80.15	£131.65	£61.65	£431.76	-£162.09	-£139.85	£40.96
Senior Care Worker (English border regions)	£419.97								
Difference	£23.22	£125.03	£43.53	£95.03	£25.03	£5.03	-£198.71	-£176.47	£4.34



5 schemes provided data about fee rates which was **above all comparative averages**.

2 provided rates which were **below average** in 2 or more comparative averages.

2 provided rates which were **below average** in all comparative categories.

This means that 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were **above** all other comparative fee rates for lowest fee rates for live-in arrangements.



WScheme B were commissioned to provide the *greatest* live-in fee of **£532.00**.

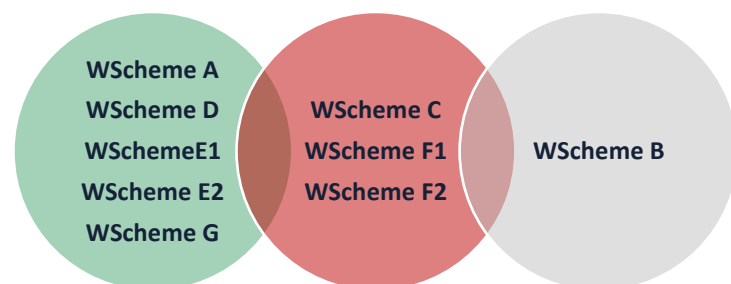


WScheme F1 were commissioned to provide the *smallest* live-in fee of **£221.26**.

Board and lodgings contributions

Please note that these figures were accurate as of November 2022.

	WScheme A	WScheme B	WScheme C	WScheme D	WSchemeE1	WSchemeE2	WSchemeF1	WSchemeF2	WSchemeG
Board & Lodgings	£93.79	£0.00	£25.00	£76.40	£76.40	£76.40	£56.00	£56.00	£79.95
Board & Lodgings (Wales)	£67.49								
Difference	£26.30	-	-£42.49	£8.91	£8.91	£8.91	-£11.49	-£11.49	£12.46
Board & Lodgings (UK)	£69.03								
Difference	£24.76	-	-£44.03	£7.37	£7.37	£7.37	-£13.03	-£13.03	£10.92



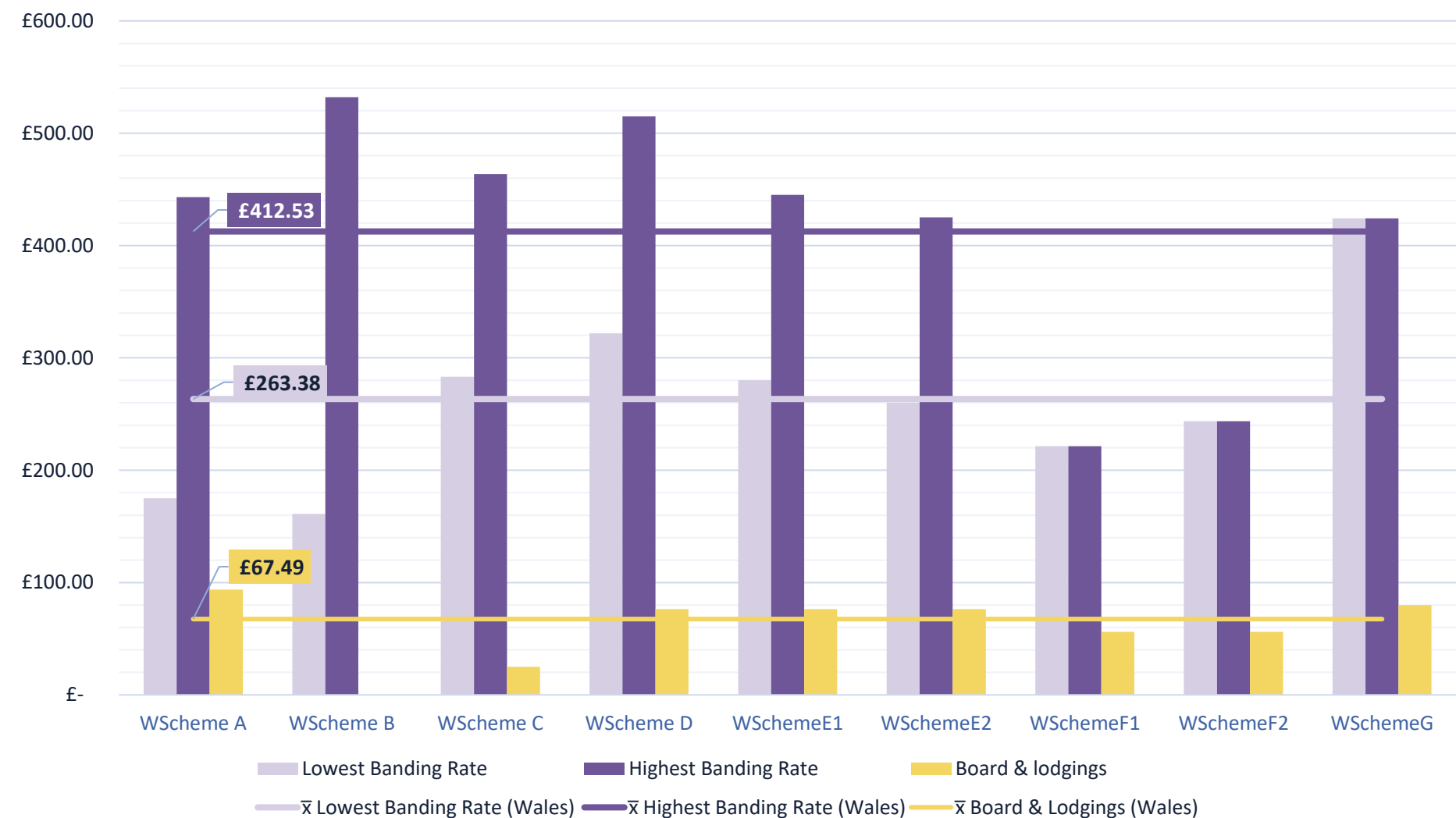
5 schemes provided data about board and lodgings contributions which were **above national and regional averages**.

3 provided data about board and lodgings contributions were **below both national and regional averages**.

1 incorporated the board and lodgings payment into the housing (rent) contribution: WScheme B.

5 out of 8 (63%) board and lodgings contributions were **above** both national and regional average for Shared Lives.

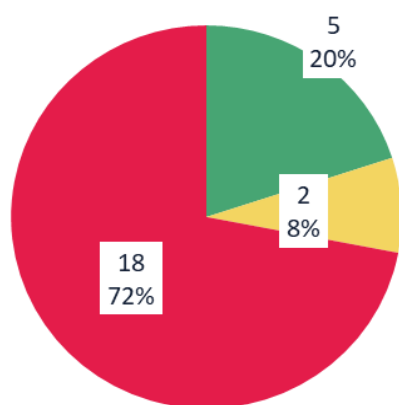
Wales live-in fees and contributions graph



Shared Lives carer survey data

Impact of the cost of living

72% of carers who responded to the survey stated that they were affected by cost of living. This is **slightly less** than the national average of 77%.



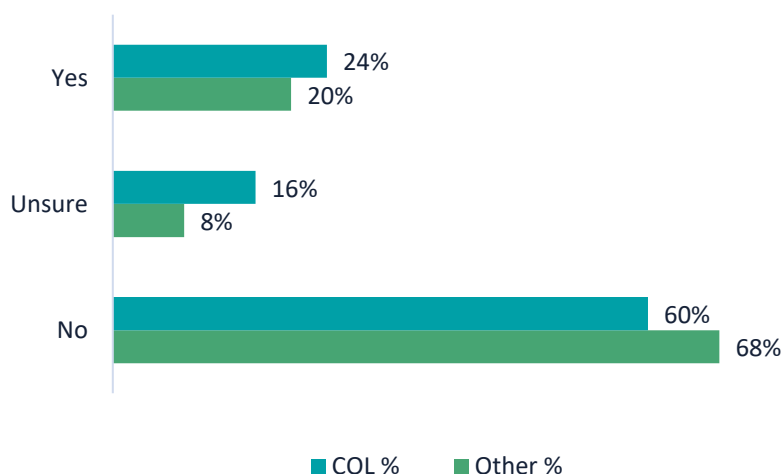
■ No ■ Unsure ■ Yes

Have you been significantly impacted by cost of living (COL)?

“Maintaining support safely and without detriment to the wellbeing of my [supported people] means I cannot cutback on energy very well. Massive financial increases without equal pay rises means I personally bear the brunt of worry, suffer personal financial hardships, and have to increase my workload to ensure our family unit remains stable, safe, and happy and also to keep progressing towards their goals.”

24% of carers said that they have considered leaving Shared Lives due to the cost of living. This is **slightly less** than the national average of 31%.

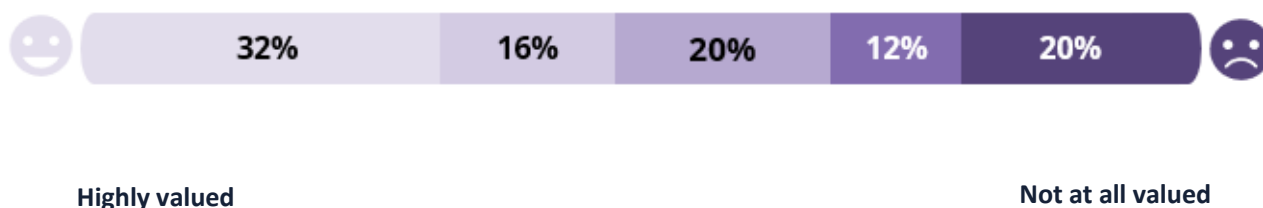
“I [am considering] quitting shared lives as it costs me a whole weekend and pays almost nothing when the additional expenses of having a second person in the house are considered. My time would be better used elsewhere to fill in the financial gap.”



Have you considered stopping work as a Shared Lives carer due to COL or Other?

How valued do Shared Lives carers feel?

32% of carers who responded to the survey said they felt not very or not at all valued, **higher than** the national average of 26%:

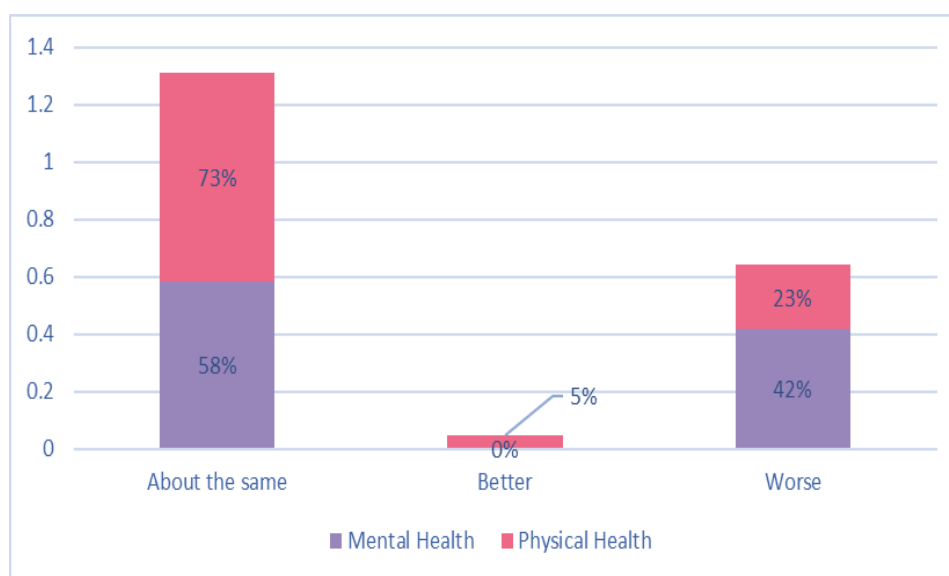


“At the end of the day it is us the shared lives carers who bear the brunt of pressures to do with increasingly limited access to services and increased living costs.”

48% of carers stated that they felt highly valued or somewhat valued, although this was **slightly higher** than the national average of 47%.

“With the regular support I receive from Shared lives - we never feel alone or isolated. The support management are like a comfort blanket around us as a family. They make regular phone calls, teams’ meetings, and home visits sometimes text messages or emails. Like I said before they are like a comfort blanket as and when I need it and the bits in between.”

Shared Lives carer physical and mental wellbeing



Most Shared Lives carers surveyed in Wales felt that their health was **about the same as this time last year.**

Physical health

⇒ 5% of carers felt their physical health was **better**, which was **less than** the national average of 10%.

“Maintaining physical fitness is very important to me and is at the forefront of my day to enable me to continue being able and active within my caring role.”

“We as a family keep active best we can. Also living in the rural setting as we do we feel privileged and make good use of our surroundings.”

⇒ 73% felt their physical health was **the same**, which was slightly more than with the national average of 67%.

⇒ 23% felt their physical health was **worse**, which was **more than** the national average of 22%.

Mental health

⇒ 58% felt their mental health was **the same**, which just about on par with the national average of 59%.

⇒ 42% felt their mental health was **worse**, which was **more than** the national average of 34%.

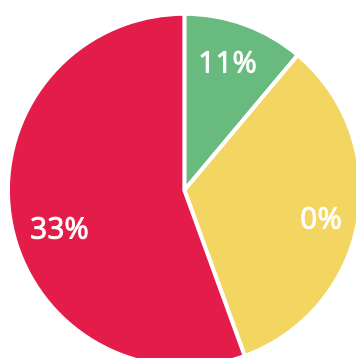
Several carers in Wales identified financial concerns as a key cause of mental and physical ill health:

The stress of cost of living, the stress of ensuring service user is safe and content at home.

Summary

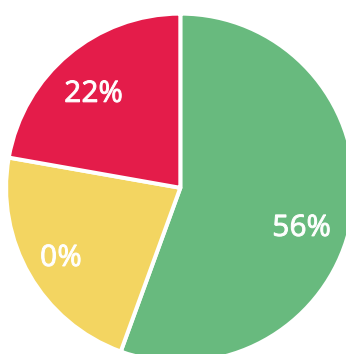
Please note that these figures were accurate as of November 2022.

Lowest Average Fees



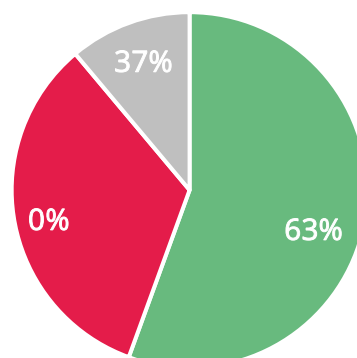
■ Above average
■ Partly below average
■ Below average

Highest Average Fees



■ Above average
■ Partly below average
■ Below average

Board & Lodgings



■ Above average
■ Below average
■ No Data

"Carers are never valued, and this has to change. [Other care workers] are getting a fair wage. Shared Lives carers should be too [or] we will end up with no one to care."

Shared Lives carer, Wales

The picture is mixed when it comes to commissioning organisations' provision of live-in fees, and board and lodgings contributions to Shared Lives arrangements in Wales. This is reflected in the similar mix of Shared Lives carer feedback. Many Shared Lives carers expressed how much they enjoyed making a difference to the people they support. Many also told of how financial stress was impacting not only their work, but also their quality of life. See the appendix for more.

We strongly urge commissioning organisations in Wales raise their fees and contributions to meet or exceed the comparative averages outlined in the recommendations section.

Areas of strength

- ⇒ 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were **above** all other comparative fee rates for lowest fee rates for live-in arrangements.
- ⇒ 5 out of 9 (56%) board and lodgings contributions were **above** both national and regional average for Shared Lives.

Areas of development

- ⇒ 5 out of the 9 (56%) rates for care commissioned through Welsh schemes were **below all other comparative fee rates** for lowest fee rates for live-in arrangements.
- ⇒ 48%, said they felt not very or not at all valued, **significantly higher** than the national average of 26%

Recommendations

Please note that these recommendations are based on data collected in November 2022.

Lowest live-in care fee

Commissioning organisations ensure that at a minimum they provide a lowest fee rate at or above the care worker minimum wage for Wales, **£355.30.**

8 commissioning organisations provide lowest fee rates that **do not meet** this:

- | | | |
|-------------|--------------|--------------|
| ⇒ WScheme A | ⇒ WScheme D | ⇒ WScheme F1 |
| ⇒ WScheme B | ⇒ WScheme E | ⇒ WScheme F2 |
| ⇒ WScheme C | ⇒ WScheme E2 | |

Whilst this is the **minimum recommendation**, we strongly urge commissioning organisations in Wales to meet the Shared Lives lowest non-banded fee rate for England, which was the highest comparative average: **£401.48.**

Highest live-in care fee

Commissioning organisations ensure that at a minimum they provide a highest fee rate for live-in arrangements at or above the UK Shared Lives highest banded fee rate **£432.66.**

4 commissioning organisations provide highest fees that **do not meet** this:

- | | |
|--------------|--------------|
| ⇒ WScheme E2 | ⇒ WScheme F2 |
| ⇒ WScheme F1 | ⇒ WScheme G |

Board and lodgings contribution

Commissioning organisations ensure that they provide a board and lodgings contribution at or above the UK national average **£69.03**.

3 commissioning organisation provided board and lodgings contributions were **below** the *UK national average*:

⇒ WScheme C

⇒ WScheme F1

⇒ WScheme F2

Appendix: Carer voices in Wales

Below are anonymised quotes from Shared Lives carers in Wales who responded to the Invaluable survey.

What Shared Lives carers like the most about Shared Lives:

Making a difference

- ∞ *"I love the happiness, opportunities, and achievement our citizens experience by being an integral and important part of if their chosen family. With Trio the joy the sessions bring and the respite for the family are wonderful and could not be attained so successfully by any other means."*
- ∞ *Caring is the most fulfilling job I've ever had.*
- ∞ *Helping others achieve things they thought they couldn't.*
- ∞ *Being part of a genuine caring company that truly understands and listens to us as Carers. What it is really like to be a 24/7 Carer in our own home.*
- ∞ *I like the fact I have flexibility in my role which can give me the chance to see my family more. I like making a real difference to the people I look after and to know I am doing a worthwhile job.*
- ∞ *Caring for my young man he's a character so is fun.*
- ∞ *I enjoy the company of my cared for person and value her young insight to life in general.*
- ∞ *That the young person could continue on with his wishes, stay with us as a part of our family.*
- ∞ *We absolutely love what we do, we get a great deal of pleasure, so rewarding and we feel the guy's we support benefit from it as well.*
- ∞ *We have had our 'son' for 21 years. Shared Lives enabled us to keep him when he became an adult.*
- ∞ *Seeing the change and development of [the supported person], seeing him smile and knowing we are making an impact in his life.*

- ∞ *Offering support to enable people with a need to have potentially reach their goals and aspirations to live an independent life style.*
- ∞ *Being able to offer individuals with opportunities and to be a part of an ordinary family setting.*
- ∞ *Being able to support our young lady as she's transitioned from a child to adulthood.*
- ∞ *I enjoy seeing the people I support enjoying life and progressing.*

Flexibility and home working

- ∞ *My wife and I are a good team. We are very grateful that the day centres are running again, this allows us to spend time together and do jobs around the house.*

Community and scheme support

- ∞ *Meeting the variety of the people we work with, to see the benefit to all our lives, to see the benefit to families and long-term carers when providing respite placements.*
- ∞ *Friendly, approachable, considerate and listens.*
- ∞ *They are always there for us if we need them.*
- ∞ *If we were to need help our support worker would be there for us.*
- ∞ *"Monthly home visits or team meetings. Always available by telephone. Gives good support with any issues and always available for any advice."*
- ∞ *[Our scheme] is singularly the most fabulous charity that enables so many vulnerable people to not only live in a family environment but to prosper whilst doing so.*
- ∞ *Keep in touch and always there when needed.*
- ∞ *Constant care and support*
- ∞ *Always available, trust me, do not interfere.*
- ∞ *Our support worker is always on hand whenever we need her, she's amazing.*
- ∞ *Keep up the good work you are ALL doing. Project Shared Lives best as you can Nationally - I do on a local level to anyone who listens - doctors, police, shop*

keepers - neighbours - friends - family. Speak out and about Shared Lives - BE VERY PROUD OF THE SERVICE> I am.

What Shared Lives carers find most difficult:

Bureaucracy

- ∞ *Nothing has really changed since we stayed with money and it's becoming more like running a care home.*

Fees

- ∞ *In real terms my wages have gone down 26%.*
- ∞ *"Pay more, fight for us more. Are they not ashamed to tell prospective carers that pay is £35 a day? And out of that £35 you have to run that person around to activities or college, if you are respite carer then you have to collect them from their home and drop them off again. Take them to the beach, days out, showers and electric blankets washing and drying. It's just not do-able. Carers are expected to operate as a charity. This option of caring even at the living wage must be massively cheaper than supported living or residential respite. Why are the wages so low - it doesn't make sense. And while we are talking about a living wage - remember you have to keep two people on that wage not one so it should be higher than the living wage. The median wage (most commonly paid) in Wales is around £30,000 And remember Shared Lives carers work 7 days a week and not 5 and they don't work 7.5 hours either. At £9.90 assuming 7.5-hour days (which is nowhere near the truth) and 7 days a week the income would be around £27,000. That's a truer reflection of the responsibility and difficulty of the role - and that's still not anywhere near the average salary in Wales of £33.9K".*

Cost of living

- ∞ *As our home is large, energy bills are magnified. Supporting people and keeping good comfort levels are very costly here. Maintaining support safely and without detriment to the wellbeing of my [supported people] means I cannot cutback on energy very well. Massive financial increases without equal pay rises means I personally bear the brunt of worry, suffer personal financial hardships, and have*

to increase my workload to ensure our family unit remains stable, safe, and happy and also to keep progressing towards their goals.

- ∞ *"Outgoings now > than income. Cut down and cut out certain leisure activities. Increased cost of supporting service users in terms of food price increases, heating and electricity, insurances etc."*
- ∞ *"Diesel. Coal. Electricity. Food. All gone up. Days out have gone up, by at least 30%. I am using my wages now to supplement my lady's life. It's very difficult."*
- ∞ *The cost of fuel. It is difficult to expect [supported people] to be mindful of energy cost. They don't remember to switch off light's close doors, limit their behaviours when it's cold outside. One of my service users likes to go in and out of the house into the front garden. Food prices have gone up but the contribution to food and utilities haven't.*
- ∞ *"The rising cost of household fuels and petrol has meant we are having to forgo traveling in the car unless essential, leisure activities, and using the heating as much as we usually would. Husband stays in hotel during the week whilst at work as it's cheaper than driving."*
- ∞ *"The rise of cost of living. Only using essential heating in the morning and evening and not through the day. Basic food and no luxury items for carers. Buying fewer and cheaper Christmas presents. Stressful."*
- ∞ *"I can't heat my house to a reasonable standard because I can't pay for it. My wages will pay the basics, but this doesn't include clothes, haircuts, car maintenance, vets' fees, home repairs extra heating costs etc. Visiting my children and grandchildren is difficult as additional fuel has to be paid for. My car is 18 years old, and I can't afford to replace it. The list is endless. I have 3 jobs to try to maintain normal things like house repairs and MOT. It's no way to live."*
- ∞ *Providing long term support and the individual is at home 24/7 this has an impact on energy bills.*
- ∞ *I took on a PA role 5 hours per week to help with the cost of living. It impacts my precious free time.*
- ∞ *Both me and my wife have had to take on part time jobs to cover the cost of living.*
- ∞ *I would like to be a full-time Shared Lives carer but can't afford to take a pay cut. My existing job is paid below the average wage for the area, I couldn't take even less and keep 2 people on it. So, I work as a respite carer, and I feel I am doing*

some good. However financially it isn't worth it. I use more fuel taking the person out and making sure they enjoy their respite; I spend money while I'm out that I wouldn't have spent otherwise. And what do you say when the person says to you 'you do a lovely roast dinner, could we have that tomorrow?' They then ask to have their washing done and dried, so they are not taking home dirty washing. It seems to me this is part of the respite - to help their full-time carer so they don't take a bag full of washing home with them.

- ∞ *Looking for another source of income if we can't find something that fits in, we may have to give up.*
- ∞ *I just feel that the work life balance and my ability to pay my mortgage has been impacted severely by the cost-of-living crisis which seems unfair when we absorbed the extra work and costs during the pandemic as well.*
- ∞ *We have been thinking of both getting employed work and downsizing.*
- ∞ *Daily stresses around the economy and money worries are very mentally draining while striving to remain upbeat and positive to those around me and ensuring family motivation continues.*

Issues with the scheme/social care system

- ∞ *[I would like] more personal contact. [The scheme could] be prompter and more proactive with arising issues. All could be addressed with higher staffing levels as spread a little thinly. I think their caseloads need reducing by extra hands on the deck.*
- ∞ *It's difficult to know how they can support us other than be there in case of an emergency. Having contact is reassuring. Sometimes I feel they could do more to raise awareness about what we do as shared lives carers, but they are only interested in raising awareness of exceptional good news stories.*
- ∞ *Only just started face to face meetings. This could have been done much earlier.*
- ∞ *Take some of the pressure off when dealing with social workers, court deputy and issues arising with a UC application that lasts a month. Rather than siding with the local authority saying other arrangements are experiencing similar like it's acceptable.*
- ∞ *We struggled with the benefit side of things during change over to shared lives carers and our old social worker wasn't very proactive, so maybe more help with that would have been beneficial and less stressful.*

- ∞ *[It has been difficult] changing from the ways things were done in fostering to how things are in adult care even though the young person hasn't changed at all.*
- ∞ *"Having to chase up social services and day services. Keeping [supported person] occupied to stimulate and reduce anxiety. Trying to organise around [supported person] and other employment to keep everyone happy."*
- ∞ *More input required from social services to enable the individual to have choices and decisions.*

Respite issues and work/life balance

- ∞ *I feel worried about my ability to provide good quality care. I feel a bit burnt out.*
- ∞ *"It's hard to have more than one job let alone 3, keeping up with garden maintenance and general home maintenance even that which doesn't cost is hard because there is not enough time. I feel like slave labour at times. And much as I love working with shared lives, there is no time for me in this life."*
- ∞ *Our young lady has lived with us for 12 years we became shared lives carers when she turned 18, we haven't had had anything respite since she turned 18 whereas before she had at least 3 night's a month, that's a long time without a day off, it can become very stressful at times.*
- ∞ *Lack of respite, our young lady needs 24-hour supervision and that's extremely hard without a break.*
- ∞ *We miss out on so many immediate family occasions due to not having enough breaks.*
- ∞ *[I have] no time off without a huge effort on my behalf.*
- ∞ *[The scheme] help when I ask apart from respite always seems to be an issue.*
- ∞ *"The restriction at certain times due to decreased day service and lack of independence of [the supported person] for myself to access activities I may want to choose [is difficult]."*
- ∞ *Finding private times with my husband to discuss things that is just for our own ears, i.e. bank statements - our own medical issues if we have any. HOWEVER, I have mastered the art of creating our own space if required - without excluding our service users and making them feel uneasy. i.e. Code words lots of ways to distract our service users from eaves dropping on private conversations.*

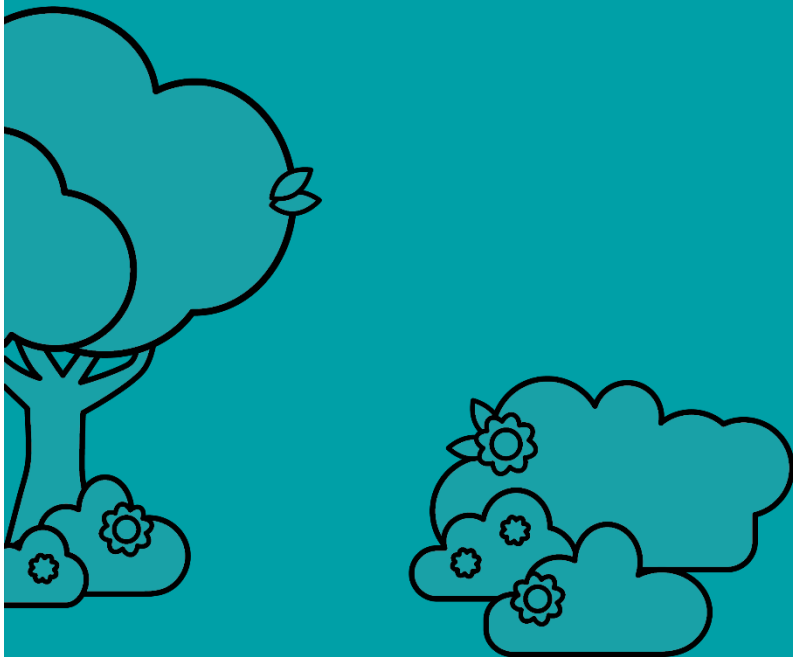
- ∞ *Being limited to 28 days respite as I don't think it is enough when you consider we are on duty 24 / 7. Sometimes the impact on my ability to be 'present' with my own family can be difficult.*

Covid legacy

- ∞ *I got very down especially after getting covid and feeling abandoned.*
- ∞ *Covid/flu is still around and impacts on our lives due to the lingering symptoms.*

Challenges with supported people

- ∞ *Day provision closed short notice. Seriously affected my young person with his mental health and his diabetes.*
- ∞ *As I have had my lad from aged 10 to now he is 21. Nobody has ever helped us with his severe autism.*
- ∞ *A person with learning disabilities very often has narrow boundaries in life and are very reticent to try new things. This is a constant frustration. Parents control finances when you are a respite carer, so money is not always available for new experiences.*
- ∞ *[I find it difficult when] my [supported people] become disheartened by anything out of my control. The disappointment when their own families do not step up to the mark.*
- ∞ *[It can be difficult] getting other people to understand about adults / children with additional needs.*





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