



Scotland 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	7
How to use this report	9
Scheme and carer response rates	11
Benchmarking fee data	13
Lowest average fee rates for live-in arrangements	15
Highest average fee rates for live-in arrangements	17
Board and lodgings contributions	19
Scotland live-in fees and contributions graph	21
Shared Lives carer survey data	22
Summary	25
Recommendations	27
Appendix: Carer voices in Scotland	29

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 12 Shared Lives schemes in Scotland in November 2022. 9 Shared Lives schemes provided data on care fees and board and lodgings.
BANDINGS AND NON-BANDINGS	All 9 Shared Lives commissioning organisation fee rates were banded according to data provided by Shared Lives schemes.
LOWEST FEE RATES (LIVE-IN ARRANGEMENTS)	The smallest Scottish live-in fee of £178.21. The greatest Scottish live-in fee was £382.18. 5 out of the 9 (55.5%) rates for care commissioned through Scottish schemes were below all other UK comparative fee rates for lowest fee rates for live-in arrangements.
HIGHEST FEE RATES (LIVE-IN ARRANGEMENTS)	The smallest Scottish live-in fee of £269.44. The greatest Scottish live-in fee was £546.53. 6 out of the 9 (67%) rates for care commissioned through Scottish schemes were below all other UK comparative fee rates for highest fee rates for live-in arrangements.

BOARD AND LODGINGS	5 out of the 9 (55.5%) board and lodgings contributions to Shared Lives carers were below the Shared Lives Scottish and national average.
CARER SURVEY STATISTICS	Of the 36 Shared Lives carers in Scotland who responded to the survey: ⇒ 92% stated that they were affected by cost of living, significantly more than the national average of 77%. ⇒ 39% have considered leaving Shared Lives due to the cost of living, also more than the national average of 31%. ⇒ 34% of carers who responded to the survey said they felt not very or not at all valued, significantly more than the national average of 26% ⇒ 49% of carers stated that they felt highly valued or somewhat valued, 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 Scotland, £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 regional average: £76.70.

Introduction

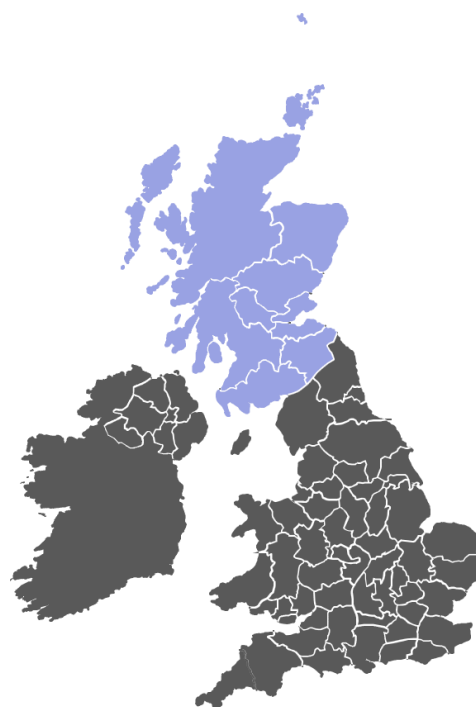
“As a Shared Lives carer, I am able to provide an environment that is safe and welcoming for the people in my care. It brings me joy to be able to help them achieve their goals and enjoy life. I value building relationships with those I support, getting to know them and what works for them as an individual is something that I find immensely rewarding. My role enables me to provide stability and comfort in times of distress, which makes a real difference in someone's life. All in all, it is immensely satisfying to be part of an amazing team that strives to make a real difference in people's lives.”

Shared Lives carer, Scotland

Shared Lives carers in Scotland 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 Shared Lives schemes set by commissioning organisations in Scotland. **Please note, in this report we have limited our scope to 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 a more detailed 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 Scotland Development Manager Ben Hall, 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 (namely local authorities, councils, and NHS health boards) 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.

Although commissioning organisations in Scotland all operate banding systems, a number of English commissioning organisations do not. To ensure a fair comparison with other figures across the UK, the data tables for lowest and highest fees contain the English average for non-banded fee rates.

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 only.

Data report codes

Each Shared Lives scheme has been assigned a data report code, e.g., SScheme1.

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

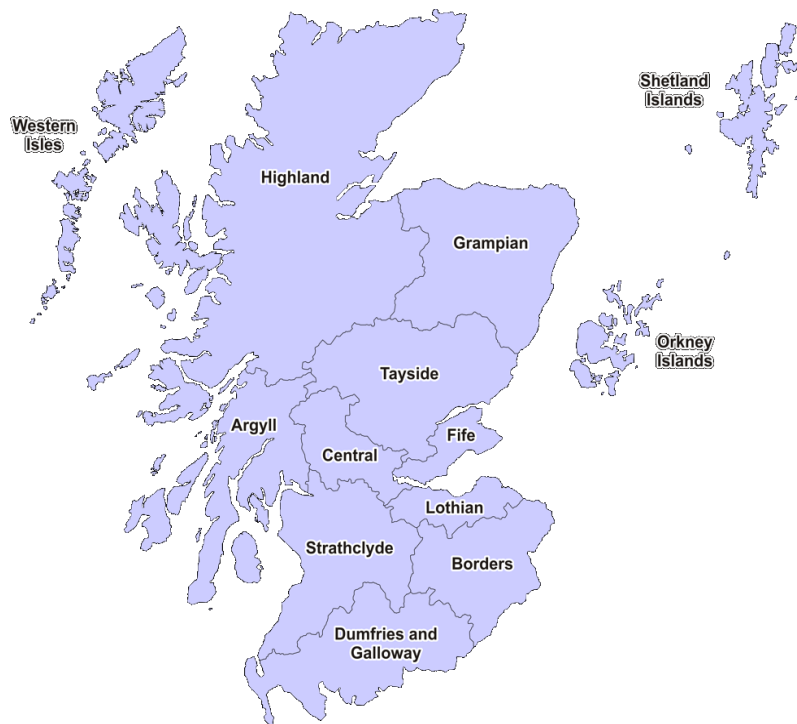
Shared Lives schemes will be provided with the data reporting code for their own data. If you are a Shared Lives scheme who does not have the code but would like one, you can contact us: membership@sharedlivesplus.org.uk

Scheme and carer response rates

Shared Lives schemes

There were **12** Shared Lives schemes in Scotland in November 2022 who were registered members of Shared Lives Plus*

- ⇒ Aberdeenshire
- ⇒ East Lothian
- ⇒ Edinburgh
- ⇒ Fife Community Living
- ⇒ Glasgow (Cornerstone)
- ⇒ Midlothian
- ⇒ Moray
- ⇒ North Ayrshire (Cornerstone)
- ⇒ Perth & Kinross
- ⇒ Quarriers Shared Lives Family Placement Service
- ⇒ Richmond Fellowship Dumfries and Galloway
- ⇒ Scottish Borders (Cornerstone)



9 (75%) of Scottish Shared Lives schemes provided data on fee rates and board and lodgings contributions. There was no data provided for Perth and Kinross.¹

¹ Perth and Kinross Shared Lives scheme has ceased operating since this data was collected. Shetland Shared Lives was established in May 2023.

*There is an organisation registered with the Care Inspectorate as Shared Lives in East Ayrshire, however they are not registered as members of Shared Lives Plus. We believe that this is a bespoke service for one family.

There is also an organisation in Glasgow 'supported carers service' whose carers are registered as members. However, it is not a registered Shared Lives scheme with membership of Shared Lives Plus.

Shared Lives carers

When this survey was conducted, there were **388** Shared Lives Plus carer members in Scotland. Of these, **36** Shared Lives carers responded to the carer survey.

This equates to 9% of the Shared Lives Plus carer members in Scotland.

Benchmarking fee data

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

See page 13 for lowest care fee data.

Shared Lives lowest banded fee rate (Scotland)

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

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**: Scotland, Wales, 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 minimum wage

The benchmark for the minimum care worker salary is taken from the **Scottish Adult social care workers minimum pay factsheet**. The figure below is based on full time equivalent (FTE) of 37 or more contracted hours a week.²

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

²See: <https://www.gov.scot/publications/adult-social-care-workers-minimum-pay/>

Highest care fee benchmarks

See page 15 for highest care fee data.

Shared Lives highest banded fee rate (Scotland)

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

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**: Scotland, Wales, 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**. To ensure a fair data comparison, the average of these figures for England have also been included in the data table below.

CCPS Scottish Social Care Living Wage

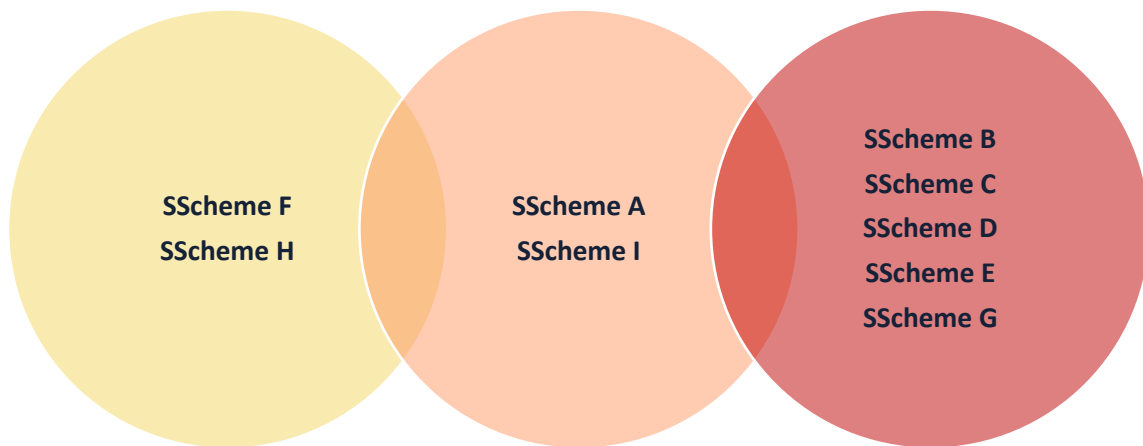
The **Coalition of Care & Support Providers in Scotland (CCPS) Scottish Social Care** has set a higher recommended **Living Wage**, which they said should be implemented in April 2023.

The recommended CCPS Scottish **Social Care Living Wage** is £23,400 gross annual income, or **£383.35** net income per week.

Lowest average fee rates for live-in arrangements

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

	SScheme A	SScheme B	SScheme C	SScheme D	SScheme E	SSchem e F	SSchem e G	SSchem e H	SSchem e I
Lowest Banding Rate	£345.20	£178.21	£213.15	£251.25	£238.00	£382.18	£183.75	£356.00	£336.91
Shared Lives lowest banded fee rate (Scotland)	£276.07								
Difference	£69.13	-£97.86	-£62.92	-£24.82	-£38.07	£106.11	-£92.32	£79.93	£60.84
Shared Lives lowest banded fee rate (UK)	£288.01								
Difference	£57.19	-£109.80	-£74.86	-£36.76	-£50.01	£94.17	-£104.26	£67.99	£48.90
Shared Lives lowest non-banded fee (England only)	£401.48								
Difference	-£56.28	-£223.27	-£188.33	-£150.23	-£163.48	-£19.30	-£217.73	-£45.48	-£64.57
Care worker minimum wage	£355.30								
Difference	-£10.10	-£177.09	-£142.15	-£104.05	-£117.30	£26.88	-£171.55	£0.70	-£18.39



2 schemes provided data about fee rates which were above all but 1 comparative average.

2 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 (55.5%)** rates for care commissioned through Scottish schemes were **below all other UK comparative fee rates** for lowest fee rates for live-in arrangements.



SScheme F were commissioned to provide the *greatest (lowest)* live-in fee of **£382.18**

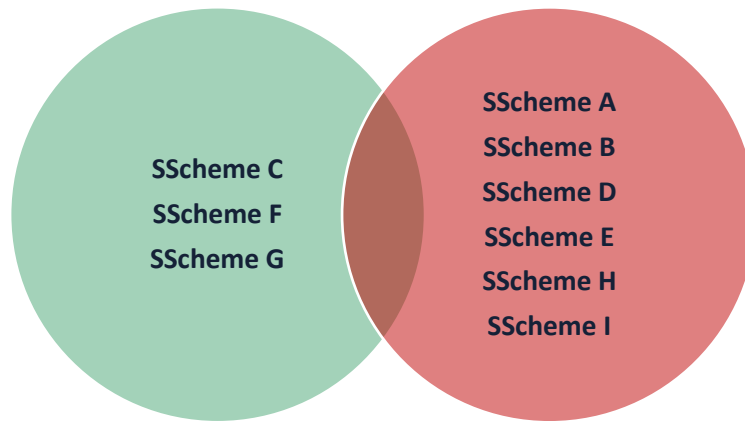


SScheme B were commissioned to provide the *smallest (lowest)* live-in fee of **£178.21**

Highest average fee rates for live-in arrangements

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

	SScheme A	SScheme B	SScheme C	SScheme D	SScheme E	SScheme F	SScheme G	SScheme H	SScheme I
Highest Fee	£379.65	£269.44	£546.53	£372.57	£350.00	£460.80	£441.00	£356.00	£336.91
Shared Lives highest banded fee rate (Scotland)	£390.32								
Difference	-£10.67	-£120.88	£156.21	-£17.75	-£40.32	£70.48	£50.68	-£34.32	-£53.41
Shared Lives highest banded fee rate (UK)	£432.66								
Difference	-£53.01	-£163.22	£113.87	-£60.09	-£82.66	£28.14	£8.34	-£76.66	-£95.75
Shared Lives highest <u>non-banded</u> fee (England only)	£431.76								
Difference	-£52.11	-£162.32	£114.77	-£59.19	-£81.76	£29.04	£9.24	-£75.76	-£94.85
CCPS Scottish Social Care Living Wage	£383.35								
Difference	-£3.70	-£113.91	£163.18	-£10.78	-£33.35	£77.45	£57.65	-£27.35	-£46.44



3 schemes provided data about fee rates which were above average in all 5 average categories for highest fee rates.

6 provided fee rates which were below average in all comparative categories.

This means that **6** out of the **9 (67%)** rates for care commissioned through Scottish schemes were **below all other comparative fee rates** for highest fee rates for live-in arrangements.



SScheme C were commissioned to provide the *greatest (highest)* live-in fee of **£546.53**.

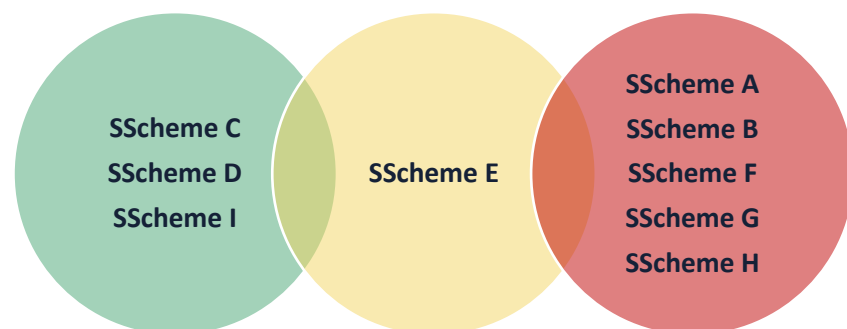


SScheme B were commissioned to provide the *smallest (lowest)* live-in fee of **£269.44**.

Board and lodgings contributions

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

	SScheme A	SScheme B	SScheme C	SScheme D	SScheme E	SScheme F	SScheme G	SScheme H	SScheme I
Board & Lodgings	£55.47	£55.30	£148.20	£90.00	£72.30	£62.00	£53.00	£69.00	£85.00
Board & Lodgings (Scotland)	£76.70								
Difference	-£21.23	-£21.40	£71.50	£13.30	-£4.40	-£14.70	-£23.70	-£7.70	£8.30
Board & Lodgings (UK)	£69.03								
Difference	-£13.56	-£13.73	£79.17	£20.97	£3.27	-£7.03	-£16.03	-£0.03	£15.97



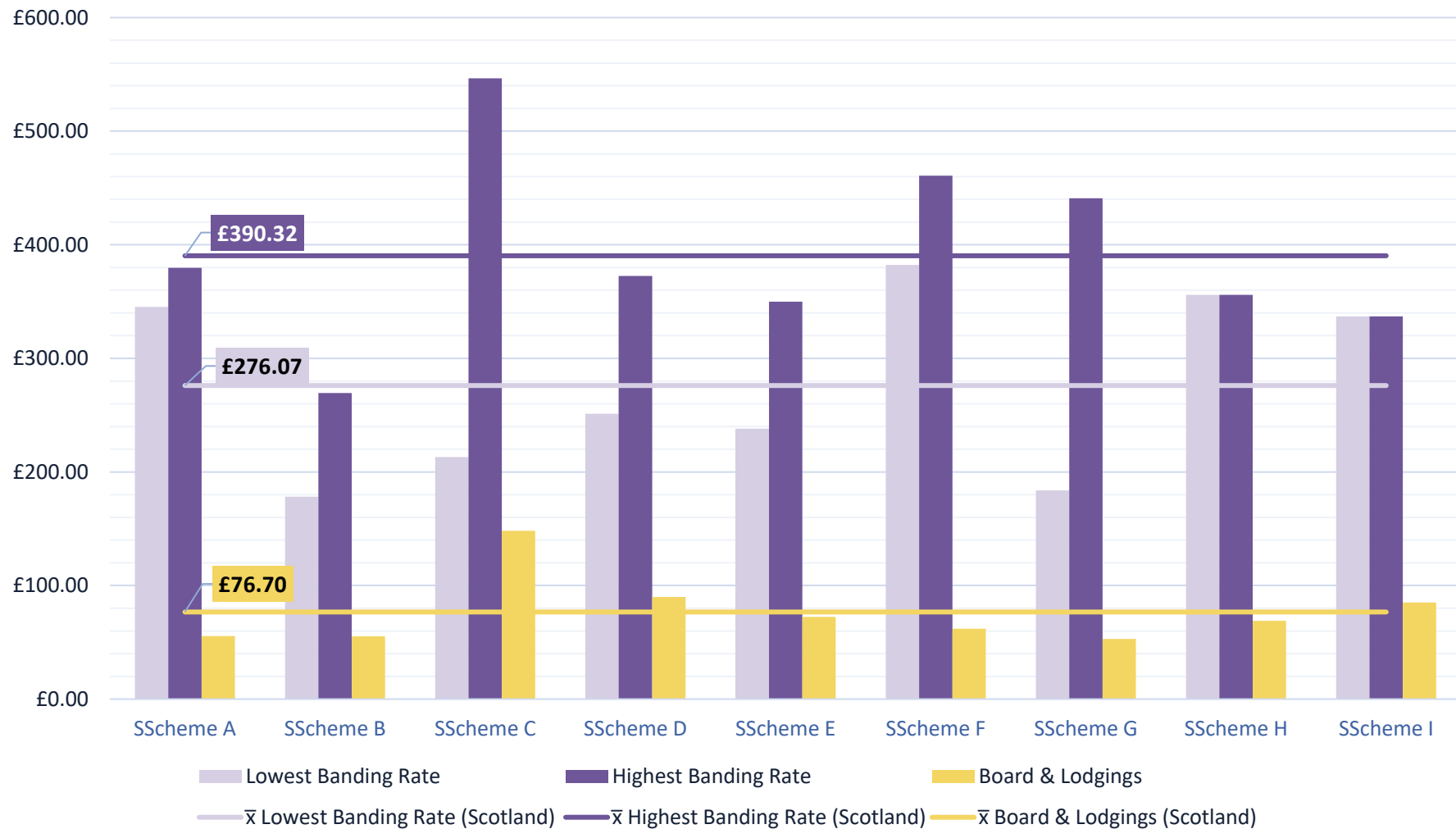
3 schemes provided data about board and lodgings contributions which were above national and regional averages.

1 provided data about a board and lodgings contribution that was below the regional average, but above the national average.

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

5 out of 9 (55.5%) board and lodgings contributions were **below** both national and regional average.

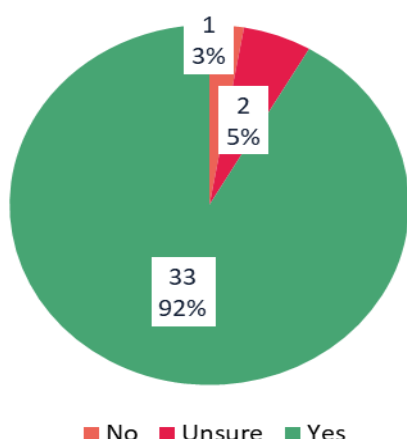
Scotland live-in fees and contributions graph



Shared Lives carer survey data

Impact of the cost of living

92% of carers who responded to the survey stated that they were affected by cost of living. This is significantly **more than the national average** of **77%**.



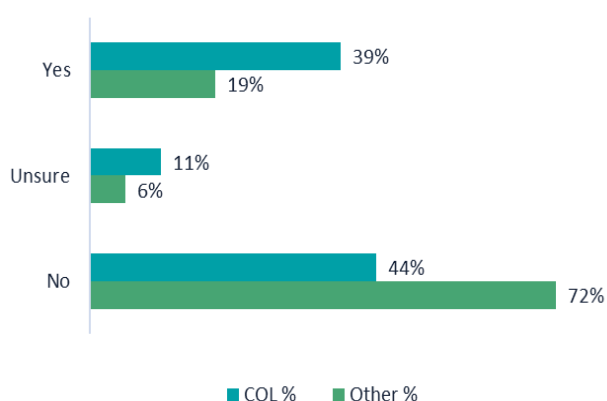
Have you been significantly impacted by cost of living (COL)?

"The crisis in the cost of living has had far-reaching impacts that have affected my life on a daily basis. Prices for basic necessities like food and clothing have skyrocketed, leaving me struggling to make ends meet each month. The situation is especially difficult when considering inflation or any unexpected expenses, as it can be nearly impossible to keep up with."

39% of carers said that they have considered leaving Shared Lives due to the cost of living. This is also **higher than the national average** of **31%**.

"[I've] had discussions with family but [don't like] the thought of letting down someone that been a part of our lives for so many years."

"If I was to stop working sell my home and move in with my retired mother. I would be better off as my mother would help pay the bills."

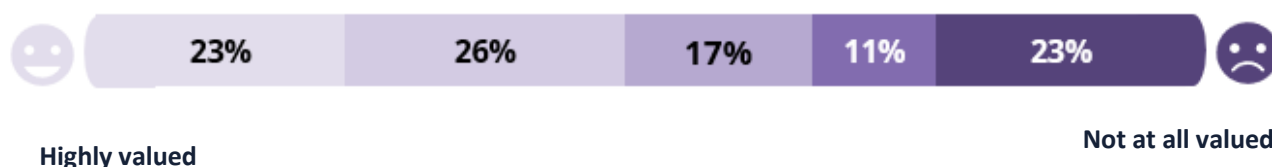


Have you considered stopping work as a Shared Lives carer due to COL or Other?

Scotland had the highest number of Shared Lives carers who said they had taken on additional work to make ends meet: **31%**. This is **9% more** than the next highest region.

How valued do Shared Lives carers feel?

34% of carers who responded to the survey said they felt not very or not at all valued, **significantly more** than the national average of 26%:



“[We need] more money for the mental and physical stress the job puts us under. If this was the private sector the financial reward would be a lot greater. At the end of the day, I am just looking to be treated fairly and with respect.”

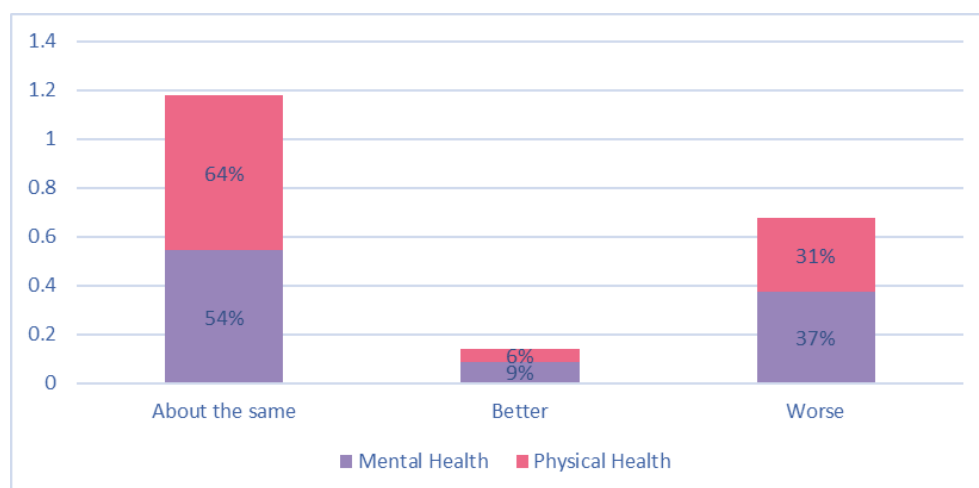
“[I feel] totally undervalued. No other carers work for such a low remuneration.”

More positively **49%** of carers stated that they felt **highly valued or somewhat valued**, **slightly higher** than the national average of **47%**.

“Knowing that you are in this person’s life caring and supporting them to the best of your ability. Building not just a clientship but a friendship. Fills my heart with satisfaction that I am making a difference in someone’s life.”

“[My scheme’s] support has been invaluable in helping me to build and maintain strong, lasting relationships with the people I care for.”

Shared Lives carer physical and mental wellbeing



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

Physical health

- ⇒ **6%** of carers felt their physical health was **better**, which was **less than** the national average of **10%**.
- ⇒ **64%** felt their physical health was **the same**, which was slightly less than with the national average of **67%**.
- ⇒ **31%** felt their physical health was **worse**, which was **more than** the national average of **22%**.

Mental health

- ⇒ **9%** of carers felt their mental health was **better**, which was **slightly above** the national average of **7%**.
- ⇒ **54%** felt their mental health was **the same**, which was slightly below the national average of **59%**.
- ⇒ **37%** felt their mental health was **worse**, which was slightly **more than** the national average of **34%**.

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

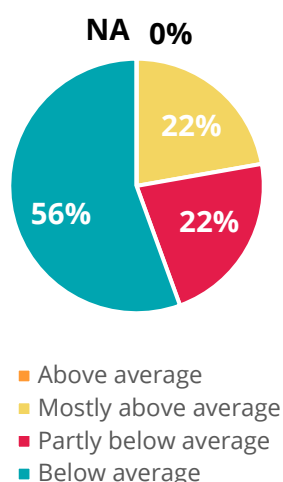
“I can no longer afford to heat my home! I am very worried that I may become ill due to this.”

“This job can be draining and with the cost of living it does put a strain on things.”

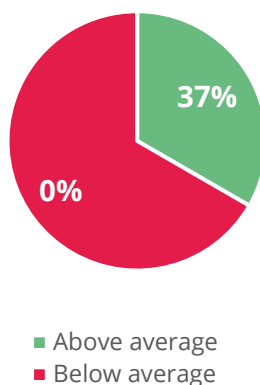
Summary

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

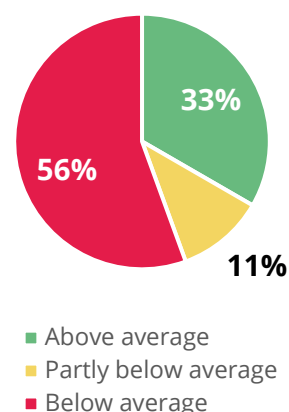
Lowest Average Fees



Highest Average Fees



Board & Lodgings



“[I love] working with my young person, and spending time with him doing the things he loves, however his is being scaled down due to the cost of fuel. My young person loves going for a drive in the car, but the cost of fuel doesn't allow for long journeys now.” Shared Lives carer, Scotland

The care fee and board and lodging rates for Shared lives in Scotland are below both regional and national comparative averages across the board. Importantly, care is commissioned from **7** schemes at lowest fee rates which fall **below the care worker minimum wage**. Care is also commissioned from **6** schemes at the ‘highest fee rate’, and yet still **does not meet the CCPS Scottish Social Care Living Wage**. The lack of financial parity with other regions and care models is reflected by Shared Lives carers in Scotland, who reported that they were significantly more impacted by the cost of living and felt significantly less valued than their counterparts in other parts of the UK.

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

Areas of strengths

3 commissioning organisation fee rates performed well in **all comparative average categories** for **highest fees**. These were:

⇒ SScheme C

⇒ SScheme F

⇒ SScheme G

Areas of development

There were several commissioning organisation rates cited by schemes in Scotland which **fell below** all comparative averages.

- ⇒ 5 out of the 9 **(55.5%) lowest fee** rates for care commissioned through Scottish schemes were **below all other** comparative fee rates for lowest fee rates for live-in arrangements.
 - No single lowest fee rate for care commissioned through Scottish schemes was above all other comparative fee rates.
- ⇒ 6 out of the 9 **(67%) highest fee** rates for care commissioned through Scottish schemes were **below all other** comparative fee rates for highest fee rates for live-in arrangements.
- ⇒ 5 out of the 9 **(55.5%)** board and lodgings contributions to Shared Lives carers were **below both** the Shared Lives Scottish and national average.

In terms of how Shared Lives carers in Scotland feel:

- ⇒ **92%** stated that they were **affected by cost of living**. This is significantly more than the national average of 77%.

Recommendations

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

Lowest live-in care fee rate

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

7 commissioning organisations provide lowest fee rates that **do not meet** the *care worker minimum wage for Scotland*:

- | | | |
|-------------|-------------|-------------|
| ⇒ SScheme A | ⇒ SScheme D | ⇒ SScheme I |
| ⇒ SScheme B | ⇒ SScheme E | |
| ⇒ SScheme C | ⇒ SScheme G | |

Whilst this is the **minimum recommendation**, we strongly urge commissioning organisations in Scotland 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 rate

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**.

6 commissioning organisations provide highest fees that **do not meet** the *UK Shared Lives highest banded fee rate*:

- | | | |
|-------------|-------------|-------------|
| ⇒ SScheme A | ⇒ SScheme B | ⇒ SScheme D |
|-------------|-------------|-------------|

⇒ SScheme E

⇒ SScheme H

⇒ SScheme I

Whilst this is the **minimum recommendation**, we strongly urge commissioning organisations in Scotland to meet the Shared Lives highest non-banded fee rate for England, which was the highest comparative average: **£431.76**.

Board and lodgings contributions

Commissioning organisations ensure that they provide a board and lodgings contribution at or above the regional average: **£76.70**.

6 commissioning organisation provided board and lodgings contributions that were **below** the *regional average*. These were:

⇒ SScheme A

⇒ SScheme E

⇒ SScheme G

⇒ SScheme B

⇒ SScheme F

⇒ SScheme H

Appendix: Carer voices in Scotland

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

What Shared Lives carers like the most about Shared Lives:

Making a difference

"I like to feel that we provide a family life for our boy. Giving him the best live and care that he deserves. He is our world and wouldn't want to be without him in ours."

- ∞ *"The variety of days. I love all my [supported people] and the smiles on their faces at being able to get out in the community."*
- ∞ *"Making a difference to the quality of life of the person I support."*
- ∞ *"Having developed a trusting relation so the person I support can feel comfortable disagreeing with me and making her own choices."*
- ∞ *"Making a difference to the people we support lives."*
- ∞ *"People oriented and care driven, flexibility and independence to tailor the care needs of individuals taking part."*
- ∞ *"Really love seeing our young adult lead a full and meaningful life."*
- ∞ *"The variety of [supported people] making friendships with clients and families."*
- ∞ *"We like the difference that caring makes to other people's lives."*
- ∞ *"Meeting up with other carers and chatting, I enjoy working with my young man."*
- ∞ *"We love spending time with our supported person. As it is family-based respite, we were already used to spending a lot of time together but the time we have one on one is invaluable."*
- ∞ *"The fact that I can provide a home to someone."*
- ∞ *"Watching someone grow in confidence and enjoy life."*

- ∞ *"Making a difference to the life to the person I care for."*
- ∞ *"Making a difference in the individual's life and supporting them.in their independence and choices."*
- ∞ *"Supporting the [person] who has become a valued member of our family."*
- ∞ *"You are giving the chance for someone to live a rewarding life and have the security and wellbeing that may have been limited previously. Being able to see happiness and enjoyment you bring to someone who deserves to be happy."*
- ∞ *"Supporting an amazing lady."*
- ∞ *"Continuing to provide care to [our supported person] to enable to have the family life he always wanted since the age of 14."*
- ∞ *"The appreciation from the family."*
- ∞ *"It's a calling to help people."*
- ∞ *"Looking after the person I support as I know this person is healthy and safe living with me."*
- ∞ *"I enjoy working one to one with many different supported people especially when you can see how much they appreciate what you do for them."*

Flexibility and home working

"Being able to organise my own days."

- ∞ *"The freedom to come and go as I please. Not having to go out when the weather is bad. Being able to go on vacation at any time."*
- ∞ *"Flexibility around my working week."*
- ∞ *"Actually, liking and enjoying my job as carer, I love the fact I don't have the stress of being working in a shop or factory or whatever other workplace.... been there and done it."*

Community and scheme support

"I feel they are very supportive and the fact that staff are long term and known to myself and the person I support is very positive."

- ∞ *"Nudging social workers and keeping regular monthly visits going. Help with discussing with myself and person I support any issues and how to deal with these."*

- ∞ *"If I need to talk, they listen."*
- ∞ *" [My scheme] understand that individual needs can change over time and have provided specialist advice and guidance when new challenges arise. They are always available to offer on-going reassurance and practical help, so I know that any issues will be addressed quickly and professionally. I'm grateful for the support that [my scheme] provide which allows me to continue my work with confidence, knowing that help is just a phone call away. [Our scheme] have provided extensive training opportunities which are tailored to my specific role as a shared life carer. From understanding safeguarding to learning about communication and behaviour, their training has enabled me to develop my knowledge and skills which helps me to provide the best possible support for those I care for."*
- ∞ *"They are always there to support us, whatever we need".*
- ∞ *"When issues may arise, they are quick to advise and help."*
- ∞ *"I know help is a phone call away."*
- ∞ *"Excellent council staff support - any issues, and there are few, get sorted."*

What Shared Lives carers find most difficult:

Fees

"[The scheme should] ensure that carers get similar remuneration as other schemes."

- ∞ *"Generally working for a less than minimum wage is demoralising."*
- ∞ *"Got to do loads of hours to pay my bills."*
- ∞ *"Increase [fees] - no process in place to increase on an annual basis. We have to fight for it and still get no increase."*
- ∞ *"The additional costs involved are not reflected in the [remuneration]. No [remuneration] for taking time off means that this is near impossible."*
- ∞ *"Not [getting remuneration] for sickness and holidays."*
- ∞ *"Finances could be better in the changing difficult times."*
- ∞ *"Working on basic income with no holiday or sick pay entitlement."*
- ∞ *"As many of my [supported people] are now 1:1, I only [receive] equivalent to min wages. I could work as a home carer for quite a bit more."*

- ∞ *"It is just not viable and gives me extra wear and tear to my cat and my home, my resources are used all the time in this job with no financial consideration financially. I have to bear the burden of providing quite a lot of resources."*

Cost of living

"Like most people the increase in general bills such as heating and electric along with food mean that times are tighter than ever, and it is difficult to make ends meet." "The cost of everything is so high that now we do less activities, go out in the car less and don't have takeaways."

- ∞ *"Increased gas and electric costs, rising fuel and food costs means I have to cut back. As a single parent - things are tough."*
- ∞ *"Increasing cost for groceries, fuel and gas and electricity. Also eating out and holiday costs."*
- ∞ *"Cost of living increase, utilities have risen by a huge amount."*
- ∞ *"Fuel costs, both at home and in the car, significantly increased. I am getting to the point where I'm worried that I won't be able to fuel up the car at the end of the month. This is exacerbated when the scheme pays my invoice later than usual, sometimes it can be 6 weeks between payments."*
- ∞ *"Impacting my income as more if it has to go into providing the service I give. Leaving less for me to cover my personal costs. No spare cash for holidays or illness breaks."*
- ∞ *"Bills higher, electric and Gas higher, fuel costs higher, Food and household bills higher so all round - a lot."*
- ∞ *"I find it hard to pay utilities and have to be very careful with my grocery bill, heating, and washing."*
- ∞ *"Cost of fuel, low pay, costs not being met and no longer viable."*
- ∞ *"Cost of gas and electricity has gone up everyday living expenses have significantly increased."*
- ∞ *"Higher food and utility, and higher gas and electricity charges."*
- ∞ *"More money going to mortgage utilities and food each week."*
- ∞ *"Mostly energy and the cost of food. Extra cost of keeping home warm for the individual we look after. This has impacted our finances."*
- ∞ *"Utility bills increase taking so much money from rest of budgets."*

- ∞ *"Nothing left at the end of the month, treats stopped. Using cheaper supermarket. Gas/electricity cost doubled. No increase in contribution from supported person. They've had cost of living payments despite having no responsibility for bills."*
- ∞ *"All living costs going up food electric etc and more time needed at home making all bills higher."*
- ∞ *"Extra food costs, fuel costs, and putting heating on more when young person has a short break."*
- ∞ *"The cost of living and the gas and electric prices are brutal."*
- ∞ *"Everything has gone up in price and it's costing me a fortune to heat my house."*
- ∞ *"Well, the price of petrol.... the respite money is back in the dark ages which no one seems to care about.... I could do 24-hour cover and be paid £1.50 an hour and that's been generous! I'm sick of complaining.... which seems to fall on deaf ears.... which makes me feel worthless!"*
- ∞ *"I am also very disappointed that Shared Lives won't allow me to use my supported persons Cost of Living payment from the DWP to help pay for the gas and electricity in our home. After all this is the reason, the government issued the payment."*
- ∞ *"Everything has gone up in price car costs utilities food etc."*
- ∞ *"The costs to maintain the home to a liveable standard."*
- ∞ *"Energy costs of heating home for the people I support."*
- ∞ *"Food costs up 25%. Fuel costs almost double - so less/none for other things."*
- ∞ *"Cutting back on heating - unable to provide choice of foods."*
- ∞ *"I am so worried about the cost of everything. I am constantly trying to find ways of spending less money and struggling to make ends meet."*
- ∞ *"Money worries. Not being able to take time off due to no income."*
- ∞ *"This job can be draining and with the cost of living it does put a strain on things."*
- ∞ *[I] tend to worry more about finances."*
- ∞ *"If prices continue to rise and I will seriously need to reconsider being a shared lives carer."*
- ∞ *"Being home more uses more electric. The cost of trips and outings increasing means sometimes I don't have that coffee when out."*

- ∞ *"I understand that the cost-of-living crisis is affecting everyone, and in my role as a Shared Lives carer I am not exempt from this. Despite this, I have chosen to stay in my role because of the commitment I have made to helping those in need of support with everyday living. The rewards I receive from doing this job are far greater than any financial rewards I could receive elsewhere, and I am passionate about providing care that is tailored to the individual's needs. I have found a way to balance my finances in order to continue doing what I love and will not be driven away by this crisis. I refuse to give up on my commitment to helping others and will continue in my role as a Shared Lives carer."*
- ∞ *"The amount we get is far too low, well below in comparison to other care providers."*
- ∞ *"Our fee has not increased sufficiently to match the cost of living, utility contribution from client is not realistic."*
- ∞ *"Had discussions with family but the thought of letting down someone that been a part of our lives for so many years."*
- ∞ *"If [there were] no disabled people in my home then don't need to keep heating and water on so can reduce fuel bills."*
- ∞ *"If I was to stop working sell my home and move in with my retired mother. I would be better off as my mother would help pay the bills."*

Issues with the scheme/social workers

Make us feel like we aren't being fobbed off all the time. Answer or questions and queries promptly.

- ∞ *Individually office staff are good to a point, but I feel they don't work for the benefit of the carers more for the provider of the scheme.*
- ∞ *Listen and act on grievances with a satisfactory outcome.*
- ∞ *Employ more support workers.*
- ∞ *Consistent support, turn over in field workers. Policy changes going back, and forward as new field worker has a 'bright idea' causing extra stress.*
- ∞ *Decision maker should be present at meetings, reply to queries.*
- ∞ *"The hoops you have to just through when getting started. Applying for a council tax rebate, rent, renewing a blue badge etc. This all comes from the council, but most departments don't know what Shares Lives is and I feel this should be allocated to*

you automatically once you start the job. I also wasn't made aware of this in the application process."

- ∞ *Some staff from other resources trying to tell you how to do your job, when you know the person you care, i.e., their capabilities and their needs. I don't like them coming into my home and trying to tell me my job, for me that's one of the draw backs that comes with caring in your own home.*
- ∞ *"Feeling like I have no control over allocation of sus. Although self-employed, having no say or control over payment level, contract, etc".*
- ∞ *Dealing with management demands and lack of concerns for us as carers.*
- ∞ *Having to keep track of all the receipts and note every single in a ledger when there is an activity and support from Support from Ordinary Living*
- ∞ *"I have to keep in touch with a support every 6/8 weeks to make sure that things are running fine but when I call [social worker] then it is just duty, and they can take up to 5 days to get back to me."*
- ∞ *"Prior to the previous social worker retiring communication was open and I felt supported in my role, however this is not the case now since being allocated a new social worker."*

Respite issues and work/life balance

Work/life balance

Individuals that stay with me need more day support to allow time away from each other and allow myself to do something for myself.

- ⇒ *Being let down and/or not having enough time away from individual.*
- ⇒ *[We should have] allocated [reneweration] for taking time off."*

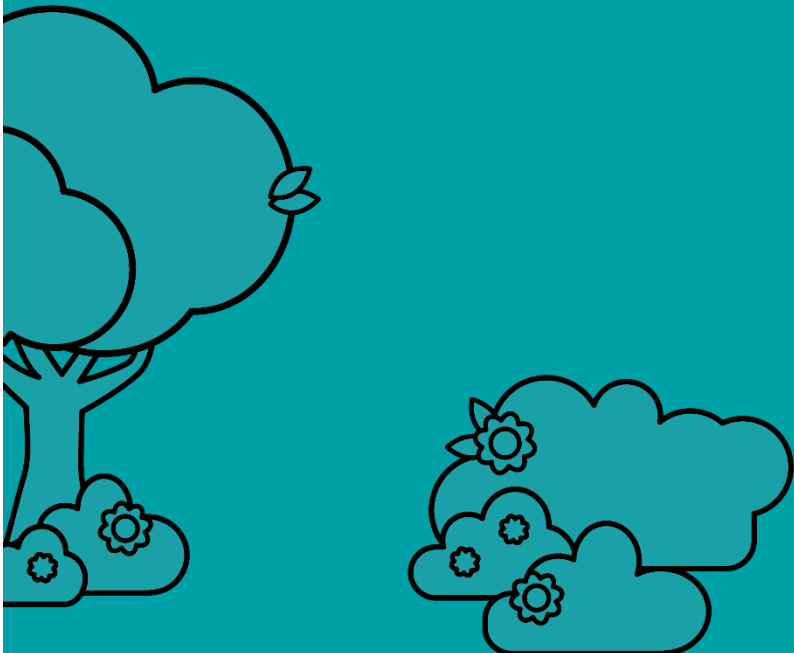
Feeling isolated

- ⇒ *Working in isolation. Very difficult to find other carers to meet up."*
- ⇒ *"I think the difficult part has been covid, as we have spent so much time together and that has been a bit stressful."*

Challenges with supported people

“It’s not an easy job and realising that I don’t have all the answers to every question asked.”

- ∞ *“Some testing moments due to learning difficulties and some sleepless nights. Trying to understand someone’s mood swings to identify what can be a trigger.*
- ∞ *“One of the most difficult aspects of being a shared lives carer is managing expectations between both the service user and my family. It can be challenging to ensure that all parties involved feel heard, respected, and valued, while also ensuring the safety and wellbeing of the service user. It is important to remain impartial while fostering positive relationships with all those concerned, which can be difficult to balance. Additionally, I often have to manage complex emotions and situations that arise from the role, such as cultural barriers between service users and family members, as well as other sensitive topics such as mental health. Keeping up with paperwork and providing comprehensive care plans for each service user is also an important part of the role yet can be time-consuming and difficult to manage. Ultimately, being a shared lives carer is rewarding and fulfilling but also comes with unique challenges that must be managed in order for the best outcomes to be achieved. Therefore, it is important to have access to quality training and support throughout the journey.”*
- ∞ *“Standing back and letting the person I support make her own decisions when I disagree with it. I have to remind myself it is her life and her choices not mine.”*
- ∞ *“Extra stresses involved due to day services still being unavailable,”*
- ∞ *“To see someone, struggle daily with their mental health.”*





Report by:

Rebecca Viney-Wood, Support and Engagement Manager

Liz Collings, Data and Support Officer

With support from:

Ben Hall, Scotland Development Manager

Nicola Watson, Scotland Development Officer

Lynne Harrison, Head of Membership

Lydia Bates, Digital Communications Officer

Shared Lives Plus

Eleanor Rathbone House

Connect Business Village

24 Derby Road

Liverpool

L5 9PR

0151 227 3499

Reg Charity number (England and Wales) 1095562

Company number 4511426

Reg Charity No (Scotland) SC)42743