

West Midlands 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	g
Explainer: comparative averages	11
Scheme and carer response rates	12
About the commissioning organisations	13
Fee uplifts	15
Lowest average fee rates	16
Highest average fee rates	19
Board and lodgings contributions	22
Regional live-in fees and contributions graph	24
Shared Lives carer survey data	25
Summary	28
Recommendations	30
Appendix: West Midlands Carer voices	31

Executive summary

Please note that the data in this report was collected in November 2022.

Fee rates are subject to change in the intervening period.

KEY DATA	There were 13 Shared Lives schemes in the West Midlands in November 2022.					
	According to data provided by Shared Lives schemes, care was commissioned by 11 commissioning organisations.					
	Shared Lives schemes provided information about 17 different commissioning organisation fee rates.					
BANDINGS AND NON-BANDINGS	Schemes told us that all 17 commissioning organisation fee rates in the West Midlands were all banded .					
	For more information about banding, see <u>"How to use this report."</u>					
LOWEST FEE RATES (LIVE-IN	The <u>smallest</u> lowest live-in fee rate was £254.89. The <u>greatest</u> lowest live-in fee rate was £425.88.					
ARRANGEMENTS)	9 out of the 17 (53%) commissioning organisation fee rates in the West Midlands were below all other comparative fee rates.					
HIGHEST FEE RATES (LIVE-IN ARRANGEMENTS)	The <u>smallest</u> highest live-in fee rate was £342.16 . The <u>greatest</u> highest live-in fee rate was £585 .					

	11 out of the 17 (65%) commissioning organisation fee rates in the West Midlands were above all comparative averages for highest fee rates for live-in arrangements.
BOARD AND LODGINGS	10 out of 17 (59%) commissioning organisation board and lodgings contributions were above the English national average .
FEE INCREASES	 ⇒ 15 (72%) commissioning organisation fee rates were uplifted after April 2022. ⇒ 3 (14%) commissioning organisation fee rates were uplifted in the last 1-2 years. ⇒ 3 (14%) commissioning organisation fee rates had not been uplifted for at least 6-10 years.
CARER SURVEY STATISTICS	Of the 66 Shared Lives carers in the West Midlands who responded to the survey: ⇒ 79% stated that they were affected by cost of living, slightly higher than the national average. ⇒ 33% have considered leaving Shared Lives due to the cost of living, also slightly higher than national average. ⇒ 36%, said they felt not very or not at all valued, more than the national average of 27% ⇒ 44% of carers stated that they felt highly valued, which is also slightly below the national average of 47%

	⇒ The percentage of carers reporting that their mental (11%) and physical (14%) were better than last year were above the national average.
RECOMMENDATIONS	 All commissioning organisations <u>increase</u> the board and lodgings contributions to at or above the English board and lodgings average of £62.91.
	2. Commissioning organisations ensure that they provide a lowest live-in fee rate at or above lowest non-banded fee rate for England: <u>£401.76.</u>
	3. Commissioning organisations ensure that they provide a highest live-in fee rate at or above the highest banding fee rate for England: £495.12.

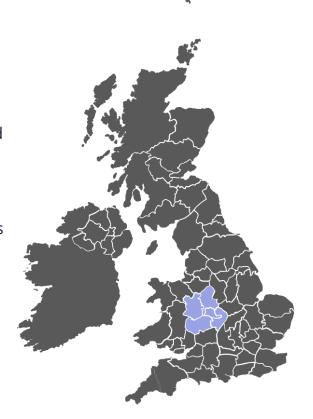
Introduction

"Like all health services, [Shared Lives is] going through difficult times. Support and investment need to happen: Promoting the care profession as a skilled work environment, bringing it up, losing the stigma of being 'just a carer'. Being paid for our skills. What service gives 24/7 cover by an individual/partner care team? We are caring skilled professional people. Let us have the support and true recognition we deserve. Failing that more people will leave the service."

Shared Lives carer, West Midlands.

Shared Lives carers in the West Midlands 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 cost effective, we know that many of our Shared Lives carers are struggling. We also 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 the West Midlands. Please note, for this survey we limited our scope to asking about <u>live-in</u> 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, using the data they provided in the carer and scheme Invaluable surveys. 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 <u>or</u> 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 live-in care fees reported in the scheme survey. It compares both banded and non-banded data, for a clearer overall picture of fees in this region. See 'Explainer: comparative averages' for more detail on the fee rates averages and benchmarks used in the data tables.

Data report codes

Each commissioning organisation (such as a local authority/council) has been assigned a data report code, e.g., COWM001.

This allows commissioning organisations to remain anonymous, whilst enabling 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

Explainer: comparative averages

Shared Lives banded rates for live-in fees

These are the average of commissioning organisation care fee rates which are part of a banding system. Banding systems provide set rates for care fees, based on the needs of the supported person. There are two Shared Lives banded rates in the data table, one for the region, and on for England.

Shared Lives non-banded rates for live-in fees

These are the average of commissioning organisation care fee rates which are not part of a banding system. There are many Shared Lives schemes across England who either do not operate a banding system of set rates, or who have non-banded exceptional rates, (for example where a new Shared Lives scheme has taken over an historic arrangement). There are two Shared Lives non-banded rates in the data table, one for the region, and on for England.

Regional care fee benchmarks

The regional benchmarks are taken from the *Skills for Care's Adult Social Care Workforce Data Set.*¹ These figures cover the period 2021-2022 and are full time equivalents (FTE) based on 37 or more contracted hours a week.

The **average local authority care worker salary** in the West Midlands was £21,100 per annum or £353.28 per week.

The **average local authority senior care worker salary** in the West Midlands was £27,300 per annum or **£434.35** per week.

¹ See: https://www.data.gov.uk/dataset/9cd42409-1a44-4e6c-9696-29d6a760e746/adult-social-care-workforce-data-set-asc-wds

Scheme and carer response rates

Shared Lives schemes

In November 2022, there were **13** Shared Lives schemes covering the counties of Herefordshire, Shropshire, Staffordshire, Warwickshire, West Midlands, and Worcestershire:

- Bethphage Shared Lives
- Birmingham Shared Lives
- Coventry Shared Lives
- Camphill Village Trust Shared
 Lives
- Herefordshire Shared Lives
- Positive Steps Shropshire Limited
- PSS Midlands Shared Lives

- Sandwell Shared Lives
- Stoke on Trent Shared Lives
- Stourbridge Ruskin Mill Shared Lives
- Telford & Wrekin Shared Lives
- Walsall Shared Lives
- Worcestershire County Council
 Shared Lives

100% of schemes in West Midlands provided some data to the Invaluable survey.



Shared Lives carers

When this survey was conducted, there were **682** Shared Lives Plus carer members in West Midlands. Of these, **66** Shared Lives carers responded to the carer survey.

This equates to 10% of the Shared Lives Plus carer members in West Midlands.

About the commissioning organisations

There are **11 commissioning organisations** in West Midlands according to data submitted by 13 schemes in November 2022. These are:

- ⇒ Birmingham City Council (commissions care from 3 schemes)
- ⇒ Coventry City Council
- ⇒ Dudley Borough Council (commissions care from 2 schemes)
- ⇒ Herefordshire Council
- ⇒ Shropshire Council (commissions care from 2 schemes at 3 rates)
- ⇒ Staffordshire County Council

- ⇒ Stoke-on-Trent City Council
- → Telford and Wrekin Borough Council (commissions care from 3 schemes)
- ⇒ Walsall Borough Council
- ⇒ Wolverhampton City Council (commissions care from 2 schemes)
- ⇒ Worcestershire County Council (commissions care from 2 schemes at 3 rates)

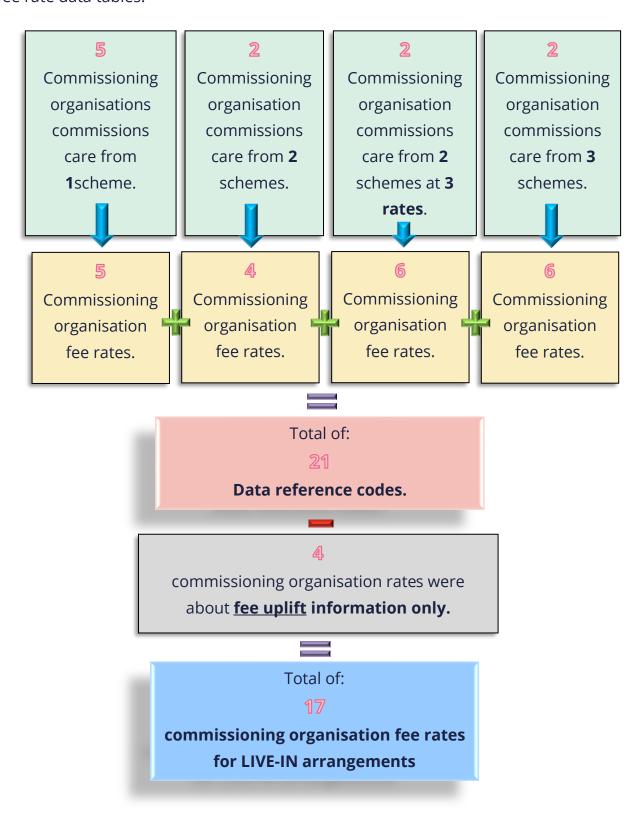
Banded and non-banded commissioning organisations

There are **17** commissioning organisation *live-in fee rates* (or data reference codes) in total for the **10** commissioning organisations. See the flow chart on the following page for why this is the case.

In terms of banding: Schemes told us that all **17** commissioning organisation fee rates in the West Midlands were banded.

Data reference codes for commissioning organisations

Whilst there are **11** commissioning organisations in the West Midlands, there are **21** data reference codes. **17** commissioning organisation fee rates are cited in the live-in fee rate data tables.

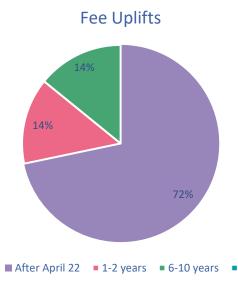


Fee uplifts

Of the 21 commissioning organisation fee rates in the West Midlands:

- ⇒ 15 (72%) commissioning organisation fee rates were uplifted after April 2022.
 - o COWM001
 - o COWM003
 - o COWM004
 - o COWM005
 - o COWM008
 - o COWM009
 - o COWM010
 - o COWM011

- o COWM013
- o COWM014
- o COWM015
- o COWM018
- o COWM019
- o COWM020
- o COWM021
- ⇒ 3 (14%) commissioning organisation fee rates were uplifted in the last 1-2 years.
 - COWM002
- COWM012
- COWM017
- ⇒ 3 (14%) commissioning organisation fee rates had not been uplifted for at least 6-10 years.
 - o COWM006
 - COWM007
 - o COWM016

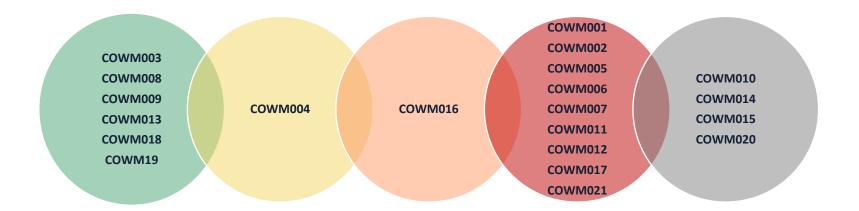


Lowest average fee rates

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

	COWM00 1	COWM00 2	COWM00 3	COWM00 4	COWM00 5	COWM00 6	COWM00 7	COWM00 8	COWM00 9	
Lowest Banding Rate	£269.00	£299.46	£425.00	£387.48	£299.46	£311.50	£305.61	£425.88	£425.00	
x Lowest Banding Rate (region)		£342.40								
Difference	-£73.40	-£42.94	£82.60	£45.08	-£42.94	-£30.90	-£36.79	£83.48	£82.60	
x Lowest Banding Rate (England)		£324.57								
Difference	-£55.57	-£25.11	£100.43	£62.91	-£25.11	-£13.07	-£18.96	£101.31	£100.43	
x Lowest No-banded Fee (Eng)					£401.48					
Difference	-£132.48	-£102.02	£23.52	-£14.00	-£102.02	-£89.98	-£95.87	£24.40	£23.52	
Average Care Worker		£353.28								
Difference	-£84.28	-£53.82	£71.72	£34.20	-£53.82	-£41.78	-£47.67	£72.60	£71.72	

	COWM011	COWM012	COWM013	COWM016	COWM017	COWM018	COWM019	COWM021			
Lowest Banding Rate	£260.29	£270.00	£425.00	£326.37	£254.80	£425.00	£425.00	£286.00			
x Lowest Banding Rate (region)		£342.40									
Difference	-£82.11	-£72.40	£82.60	-£16.03	-£87.60	£82.60	£82.60	-£56.40			
x Lowest Banding Rate (England)		£324.57									
Difference	-£64.28	-£54.57	£100.43	£1.80	-£69.77	£100.43	£100.43	-£38.57			
x Lowest No-banded Fee (Eng)				£40	1.48						
Difference	-£141.19	-£131.48	£23.52	-£75.11	-£146.68	£23.52	£23.52	-£115.48			
Average Care Worker		£353.28									
Difference	-£92.99	-£83.28	£71.72	-£26.91	-£98.48	£71.72	£71.72	-£67.28			



6 commissioning organisation fee rates were <u>above average</u> in all 4 regional and national categories for lowest fees.

1 was <u>above average</u> in comparison to all but 1 average.

1 was <u>below average</u> in comparison to all but 1 average.

9 were <u>below average</u> in all 4 categories.

No data was provided for 4 commissioning organisation fee rates.

9 out of the **17 (53%)** commissioning organisation fee rates in the West Midlands were **below all other comparative fee rates** for lowest fee rates for live-in arrangements.

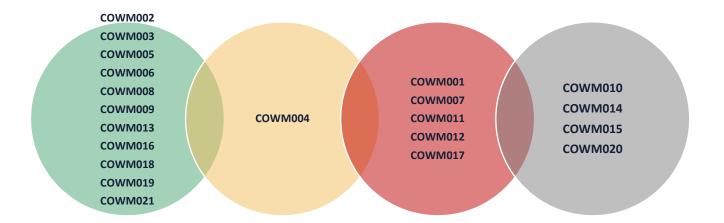
- **COWM008** provided the *greatest* fee of £425.88
 - **COWM017** provided the *lowest* fees of £254.80

Highest average fee rates

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

	COWM00 1	COWM00 2	COWM00	COWM00 4	COWM00 5	COWM00 6	COWM00 7	COWM00 8	COWM00 9
Highest Banding Fee	£359.00	£499.10	£585.00	£433.48	£499.10	£497.70	£364.39	£566.15	£585.00
x Highest Banding Rate (region)		£486.09							
Difference	-£127.09	£13.01	£98.91	-£52.61	£13.01	£11.61	-£121.70	£80.06	£98.91
x Highest Banding Rate (England)					£495.12				
Difference	-£136.12	£3.98	£89.88	-£61.64	£3.98	£2.58	-£130.73	£71.03	£89.88
x Highest No-Banded Fee (England)					£431.76				
Difference	-£72.76	£67.34	£153.24	£1.72	£67.34	£65.94	-£67.37	£134.39	£153.24
Average Senior Care Worker (region)	£434.35								
Difference	-£75.35	£64.75	£150.65	-£0.87	£64.75	£63.35	-£69.96	£131.80	£150.65

	COWM011	COWM012	COWM013	COWM016	COWM017	COWM018	COWM019	COWM021		
Highest Banding Fee	£349.53	£412.00	£585.00	£495.95	£342.16	£585.00	£585.00	£520.00		
x Highest Banding Rate (region)		£486.09								
Difference	-£136.56	-£74.09	£98.91	£9.86	-£143.93	£98.91	£98.91	£33.91		
x Highest Banding Rate (England)				£49	5.12					
Difference	-£145.59	-£83.12	£89.88	£0.83	-£152.96	£89.88	£89.88	£24.88		
x Highest No-Banded Fee (England)				£43	1.76					
Difference	-£82.23	-£19.76	£153.24	£64.19	-£89.60	£153.24	£153.24	£88.24		
Average Senior Care Worker (region)	£434.35									
Difference	-£84.82	-£22.35	£150.65	£61.60	-£92.19	£150.65	£150.65	£85.65		



11 commissioning organisation fee rates were above average in all 5 average categories for highest fee rates.

1 fee rate was below average in all but 1 category.

5 fee rates were below average in all 4 categories.

No data was provided for 4 commissioning organisation fee rates.

This means that **11** out of the **17 (65%)** commissioning organisation fee rates in the West Midlands **were above** all comparative averages for highest fee rates for live-in arrangements.



5 fee rates were the joint *greatest at* **£585.00**.



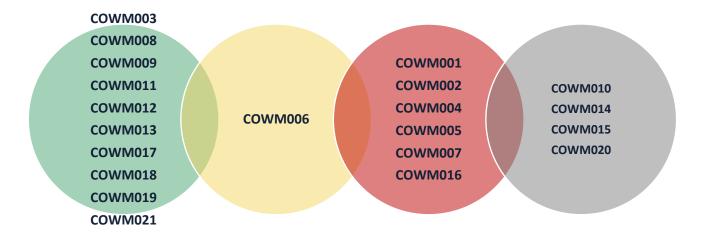
COWM017 provided the *smallest fees* of **£342.16**.

Board and lodgings contributions

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

		COWM001	COWM002	COWM003	COWM004	COWM005	COWM006	COWM007	COWM008	COWM009
Board & Lodgings	s	£51.55	£42.05	£63.00	£56.60	£42.05	£59.30	£29.00	£68.00	£63.00
x Board & Lodgings (region	on)					£57.80				
Difference		-£6.25	-£15.75	£5.20	-£1.20	-£15.75	£1.50	-£28.80	£10.20	£5.20
x Board & Lodgings (En	gland)					£62.91				
Difference		-£11.36	-£20.86	£0.09	-£6.31	-£20.86	-£3.61	-£33.91	£5.09	£0.09

	COWM011	COWM012	COWM013	COWM016	COWM017	COWM018	COWM019	COWM021			
Board & Lodgings	£67.65	£70.00	£63.00	£37.34	£67.65	£63.00	£63.00	£76.40			
x Board & Lodgings (region)		£57.80									
Difference	£9.85	£12.20	£5.20	-£20.46	£9.85	£5.20	£5.20	£18.60			
x Board & Lodgings (England)		£62.91									
Difference	£4.74	£7.09	£0.09	-£25.57	£4.74	£0.09	£0.09	£13.49			



10 commissioning organisation board and lodgings contributions were above national and regional averages.

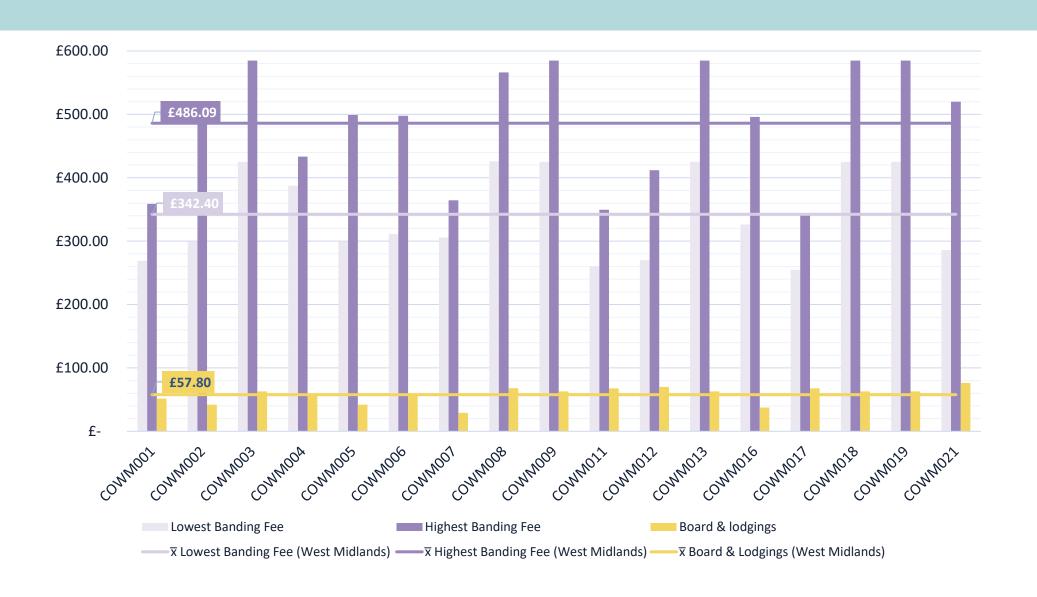
1 commissioning organisation fee board and lodgings contributions contribution was below the English average, but above the regional average.

6 commissioning organisation board and lodgings contributions were below both national and regional averages.

No data was provided for 4 commissioning organisation fee rates.

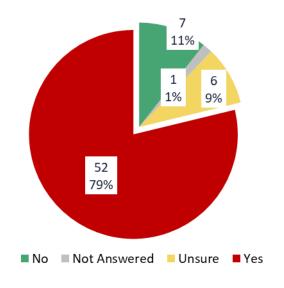
10 out of 17 (59%) commissioning organisation board and lodgings contributions were above the English national average.

Regional live-in fees and contributions graph



Shared Lives carer survey data

Impact of the cost of living



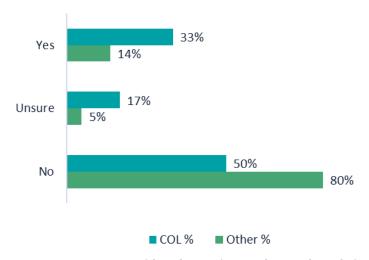
79% of carers who responded to the survey stated that they were affected by cost of living, **just slightly more than the national average** of **77%**:

"I have been looking around to see if I can earn more money. I might look at working as a checkout person to help the cost of living so I can feed the individuals. I feel it is now costing me to do the job."

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

33% of carers said that they have considered leaving Shared Lives due to the cost of living, which is also slightly **more than the national average** of **31%**:

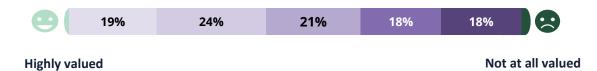
"I think a lot more carers will leave the Scheme if they don't receive the support they desperately need and it's really sad because the concept of Shared lives is very good, but it will not be sustainable if carers aren't happy."



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

How valued do Shared Lives carers feel?

36%, said they felt not very or not at all valued, as seen in the graphic below. This is **more than the national average** of **27%**:



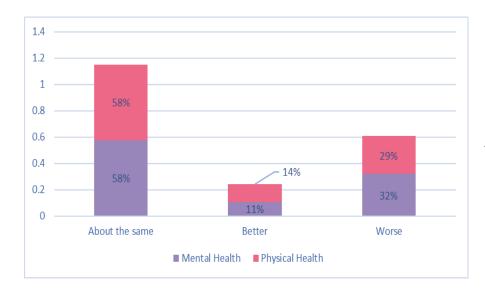
"We provide a fantastic service to our [supported people]. They all have thrived under our care. Would be nice to feel valued, supported and paid in reflection to what we give to the service."

44% of carers stated that they felt highly valued, which is **also slightly below the national average** of **47%**.

"I have enjoyed my shared life with my individual as I have supported her to enjoy a safe, non-threatening relationship with another human being -(me!). It is good to be able to make a positive difference in someone's life and to value the difference they have made in mine!"

"[Our scheme] keeps us regularly updated and trained and we are regularly visited by our SL workers. They take a deep interest in our individuals and also us as carers."

Shared Lives carer physical and mental wellbeing



Most Shared Lives carers surveyed in the West Midlands felt that their health was about the same as last year, as seen in the table to the left.

Physical health

- ⇒ 14% of carers felt their physical health was better, which was higher than the national average of 10%.
- ⇒ 58% felt their physical health was the same, which was lower than the national average of 67%.
- ⇒ 29% felt their physical health was worse, which was significantly higher than the national average of 22%.

Mental health

- ⇒ 11% of carers felt their mental health was better, which was higher than the national average of 7%.
- ⇒ **58%** felt their mental health was **the same**, which was more or less on par with the national average of **59%**.
- ⇒ 32% felt their mental health was worse, which was lower than the national average of 34%. One carer said of their mental health:

"Sometimes it can be mentally draining, and you just need to recharge your batteries."

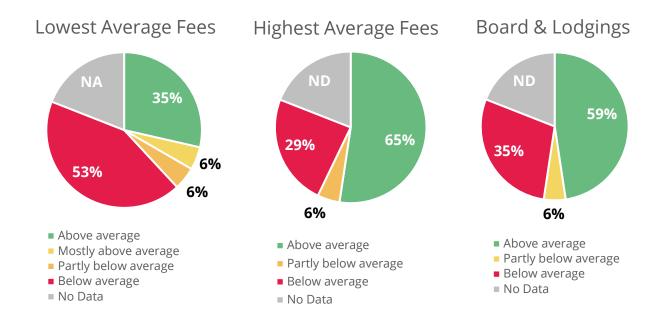
Several carers in the West Midlands identified **financial concerns** as a key cause of mental and physical ill health:

"[I have] financial worries about the increased cost of living, i.e., we paid 143pm prior to May. Now we pay 383 pm for Gas and Electric. This impacts on emotional issues and physical health."

"Financial stress has increased our anxiety"

Summary

Please note that this summary is based on figures from November 2022. and may not reflect current rates.



"We do this as a shared lives carer because we get so much out of it, we make a difference to their lives to keep them safe and give them a family. We don't do it for the money but the cost-of-living i.e., food gas/electric should be increased."

Shared Lives carer, West Midlands

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 the West Midlands. This is reflected in the similar mix of Shared Lives carer feedback. Shared Lives carers expressed how much they enjoyed making a difference to the people they support. Yet 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 the West Midlands to raise their fees and contributions to meet or exceed the comparative averages outlined in the recommendations section.

Areas of strength

- ⇒ 11 out of the 17 (65%) commissioning organisation fee rates in the West Midlands were above all comparative averages for highest fee rates for live-in arrangements.
- ⇒ 10 out of 17 (59%) commissioning organisation board and lodgings contributions were above the English national average.
- ⇒ 15 out of 21 (72%) commissioning organisation fee rates were uplifted after April 2022.

Areas of development

There were several commissioning organisations in the West Midlands whose rates <u>fell below</u> all comparative averages.

Most notably:

- ⇒ 9 out of the 17 (53%) commissioning organisation fee rates in the West Midlands were below all other comparative fee rates for lowest fee rates for live-in arrangements.
- ⇒ **79%** of Shared Lives carers stated that they were affected by cost of living, which is **slightly higher** than the national average.

Recommendations

All commissioning organisations <u>increase</u> the board and lodgings contributions to at or above the English board and lodgings average of £62.91.

6 commissioning organisation board and lodging rates fell **below** the English average:

 \Rightarrow COWM001 \Rightarrow COWM005 \Rightarrow COWM016

 \Rightarrow COWM002 \Rightarrow COWM006 \Rightarrow COWM007

Commissioning organisations ensure that they provide a lowest live-in fee rate at or above lowest non-banded fee rate for England: £401.76.

11 commissioning organisations provide lowest fees that **do not meet** the lowest non-banded fee rate for England, which is the highest of the averages. These are:

 \Rightarrow COWM001 \Rightarrow COWM006 \Rightarrow COWM016

 \Rightarrow COWM002 \Rightarrow COWM007 \Rightarrow COWM017

 \Rightarrow COWM004 \Rightarrow COWM011 \Rightarrow COWM021

 \Rightarrow COWM005 \Rightarrow COWM012

 \Rightarrow

Commissioning organisations ensure that they provide a highest live-in fee rate at or above the highest banding fee rate for England: £495.12.

6 commissioning organisations provide highest fees that **do not meet** the highest banding fee rate for England, which is the highest of the averages. These are:

 \Rightarrow COWM001 \Rightarrow COWM007 \Rightarrow COWM012

 \Rightarrow COWM004 \Rightarrow COWM011 \Rightarrow COWM017

Appendix: West Midlands Carer voices

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

What Shared Lives carers like the most about Shared Lives:

Making a difference

- ∞ I love it. I love to help people feel valued and part of the community.
- ∞ I came to shared lives as my foster child stayed with me after reaching 18yrs. Caring for this person for 42 years she has given us far more then we have given her we love her.
- Watching the transformation, the [supported people] make under our care. The little things they make for us in appreciation.
- My own experience is giving someone a safe and caring home and seeing them have a better and fuller life.
- ∞ Giving someone a family home with independence building skills, keeping people safe, including people in the community.
- ∞ Enjoying the young man, we care for especially when he has new experiences. Being able to continue to care for him as we fostered him previously.
- Enabling people to have an independent lifestyle in a family home setting, and seeing how people progress as the years go by.
- ✓ I've always been a person that cares for others because I'm good at it. I love the
 opportunities with regards learning through the courses. I have love being able to
 bring care quality of life and laughter to those that are vulnerable. I loved being able
 to work from home while my son was growing up.

- ∞ [My supported person] is an ex foster child who had nowhere to go and no family to look after him. Seeing the difference in the gentleman's life we support and with and how he is part of our family.
- ∞ Sharing my life with other people. Hopefully enriching their lives and enabling them to access as many things as they would like to in the community.
- We give someone a home a family environment where they feel safe and part of a family, to see them shine and enjoy life.
- ∞ To carry on supporting from transition from fostering to give stability through continuous support in the development of the person that is being supported.
- ∞ I love my job just to make someone smile and live as independent as possible to overcome any fears they have.
- ∞ Love how rewarding it is daily! From the start of everyday, it impacts you! Wouldn't do anything else, but care now!
- Promoting independence as much as possible, promoting self-esteem, promoting good health & wellbeing, providing the right care on an individual basis. Being able to access resources from Shared Lives plus and [the scheme].
- ∞ Sharing time with vulnerable people. Seeing them blossom. Seeing them increase their confidence. Keeping in touch afterwards.
- Helping to enrich someone's life. Giving 1-1 personalised care. Helping somebody realise and achieve their potential. Giving somebody opportunities that they might not get otherwise.
- I enjoy helping and looking after my [supported person] knowing that I am making a difference to her life by supporting her and making her feel like a member of my family and also my extended family.
- ∞ I enjoy the company of my [supported person], feel like I am giving back a little. A job that means I am not out of the house or doing regular hours. A chance to improve someone's life and introduce them to new experiences.

- ∞ Providing to support to enable people to have a more fulfilling life than they would achieve alone makes the job truly worthwhile. It's actually the main reason most carers do it. We are carers by nature, do-gooders, we want to help.
- ∞ "Supporting someone to get the opportunities in life they should be able to access. To see someone getting more confident and more independent and enjoy life!"
- ∞ Love my job enjoy seeing our [supported people] thrive in what they do.
- The care and development of the [supported person], Supporting in the community and encouraging life skills and friendships. To see over time how a person improves their quality of life. Satisfaction in knowing you can help!
- I love how the guys we support have grown make their own judgment s about things. Sometimes they make the wrong choices but that's how they learn and everything they choose you are behind them to support them and guide them through but most of all just to have a happy fun life.
- ∞ It has been a pleasure looking after as we call her out daughter.
- ∞ If the young person was not with us, he would be in an institution and not be living as part of a family.
- □ I really enjoy being a shared lives carer and have seen firsthand the difference it
 makes to someone who needs support I think it a 5-star service and is very valuable
 to people who can't live independently it's just ashamed it not paid very well.
- ✓ Just to say it's a way of life not a job .and every individual you support is different you
 can't treat them all the same, they all come from different walks of life, you can't be
 judgmental. We are all different and have to be treated that way, as I said I love what
 we do.

Flexibility and home working

Working with people with disabilities in my own home as part of the family, to promote their rights and independence, enabling and empowering the supported person to fulfil their potential.

- ∞ I love being flexible, working when I want, having fun with the people I support, caring.
- Like [working from home] and seeing the positive impact we have on the [supported people] we care for.
- "Not having to go out to work and knowing that my lady is happy & well."

Community and scheme support

- I'm happy with how the scheme are supporting me so, at the moment I do not think there is anything they could do to support me better.
- ∞ The [supported people]. And the carer friends I have made whilst being a carer. We meet us regularly and we all go on holidays.
- ∞ We thoroughly enjoyed the Christmas party disco for shared Lives families.
- [The scheme] keep me on top of my paperwork which I hate doing because to me it is more important to look after the people than paperwork, but paperwork can help you if you have a complaint against you, so it is so important to keep it up to date.
- ∞ The [scheme] are always very easily contactable and very approachable. But there is only so much they can do. They don't decide the payments.
- We are very lucky to have a fantastic support worker who we feel we can reach out to at any time.
- ∞ I know they're only a call away but aren't always at me.
- ∞ Just knowing that they are there if I should need any help, is a big support for me.

What Shared Lives carers find most difficult:

Bureaucracy

- Being time and money poor. Feeling under pressure to meet the ongoing paperwork, training, and audits.
- ∞ Lack of wrap around care difficulty in using it because of red tape.

- ∞ [It would helpful if the scheme would] try and lean down the paperwork, processes, and tick box training rather than add to it.
- Some of the paperwork could be revised to reflect shared lives respite care as, in most cases, it assumes that carers are operating on a full-time basis.

Fees

- Nork as well as doing Shared Lives. The money from Shared Lives isn't enough and
 the recommended amount my [supported person] pays towards food and utilities
 hasn't kept up with real costs so I'm subsidising him out of my fee. I only have one
 [supported person] as his needs are complex.
- Essentially, I do not agree with how the banding (tooling) works to indicate which carer goes on for pay scale. i.e., a [supported person] with emotionally complex needs may be put on the middle band because the tools are not in place for higher banding because this appears to only accommodate physical needs for higher-this must change because in fostering emotional and challenging behaviour is significant and is rewarding with pay that reflects this. Physically demanding [supported people] are time-consuming, and the pay reflects this and rightly so but let's not forget our mental/emotional [supported people] that require a different specialist therapeutic support which in my view does not get the recondition because the banding has a ceiling (middle) and this needs to be looked at with urgency.
- ∞ Am happy with the support I receive [for the scheme]. My payment issues are not down to them. I feel as though the council takes us for granted and we are the cheaper option for care services.
- ∞ If I was financially in a better position, I would retire. As we seem to do more and
 more but get paid less and less. The money we receive does not cover the cost for the
 people in our care. We do not even receive anything for damages or added wear and
 tear to the property. I feel that carers are being taken advantage of.
- There has been a huge delay in receiving funds from the provider which is now up to date but was very difficult in the beginning as we had to pay out for insurance, boiler checks etc. A carer with no other income would not have been able to pay out or wait.

- Due to the pitiful offering of £75 which was insulting. We have been fighting for 2
 years for our fee to be upped after our [supported persons] needs have changed, and
 he now requires 2-1 support. We would earn more in an unskilled role.
- ∞ Just feel after everything we did through the pandemic now been forgotten and we are not getting [an increase contribution]. We are losing money.
- ™ There is no time out when your supported people are at home all day every day. As
 their needs change you adapt to their needs. To provide them with the best care you
 can give them. There is no [increased contribution] to reflect that ever.
- ∞ Last winter I was car parking to get extra money and my health suffered because of the cold. I have chosen not to do this year because of my health.
- ∞ I believe for the work we do and the money we save local authorities we should be held in higher regard and [renumerated] substantially more.
- The way things are going it's just not sustainable for us. All the support and help go to the [supported people] and when you think about how much carers save the council, it makes us very angry. We feel unappreciated and let down.
- Sometimes 24/7 can be a strain. When you analyse the hours spent with the supported person, the financial rewards are extremely low.
- My SL support worker is a truly wonderful lady but the 'system' itself is insufficient in
 its support i.e. I am awaiting a first pay rise in SEVEN years for one [supported
 person] who originated from out of county still no response of his original LA.

Cost of living

- I'm worried about the cost of food and utilities. I have had to cut back on the food I buy, and we have the heating on in short bursts. I'm constantly turning off lights. We are having less baths and showers.
- [I have] less money and more things to buy to eat, petrol in car, mortgages going up and bills 480 a month for gas and electric. That has doubles for us. No [contribution] rise. [It feels like] carers are the bottom of the pile shared lives carers and foster carers are deeply affected loads of them have said they will leave if nothing is done,

- how can you look after people with additional needs on nothing, it is not fair we have been ignored for years and it needs to change rapidly.
- Outgoings are higher but income remains the same. Although [supported people] are getting Cost of Living payments because they are claiming benefits, they are not allowed to pass any more money on to us to help with the higher food/energy bills. The [supported people] have the extra money accumulating in their accounts while the shared Lives carers are having to pay the higher bill's.
- ▼ I lost my husband to cancer in November 2020, and it's been a struggle to make ends meet and with everything going up I can't save for other things such as repairs to car and any other unexpected bills.
- Prices have increased on every aspect of day to day living without any significant increase to help offset additional costs.
- ™ literally living month to month on my wage and have not a penny to my name at
 the end of the month. With my husbands and my wages going on rent, council tax,
 food which is rising in price dramatically, horrendous energy costs, fuel for the cars
 and everything else it's a real struggle and we have no savings and can't afford to
 save a penny to be honest.
- Our young man needs his heating on through the night which has a big impact on our energy bill. He also has a number of electrical items that need to be on charge constantly. These are items such as feed pump, hoist tracking, bed, monitor, change bed, chair power pack.
- ™ The bills have increased so much it is worrying. we only get £29 per week for any food drink for an individual, we have to provide healthy breakfast, lunch, dinner as many drinks, tea coffee hot choc, orange blackcurrant fresh fruit in the bowl and snacks. TBH this is not possible, and we use our own money to subside to ensure there is enough food.
- Price of fuel LPG and electricity so we have to heat the main house for Shared Lives Caring otherwise we are in the annexe. The cost of food has risen exponentially, and we have to consider the quality of snacks and food provided. The costs of petrol - our trips out have to be considered as we do not charge mileage.

- Both my gentlemen are at home all day every day. Both have their tellies on all day every day. The kettles constantly on. Along with all their other equipment. This has a big impact on the cost of living for me now. One gentleman needs a lot of extra care (hygiene) which means more washing and drying. With the way things are going it is becoming harder to sustain my care. Then money we get does not cover what is needed. And I am careful and not wasteful.
- ∞ Food, utility bills, fuel, and clothing have all increased and fees have more or less stayed the same. There has been a small increase in fees/housing benefits but very small, no way near in line with inflation.
- My partner is retired due to cancer treatment so is home, the gentleman who we look after is home on a number of days in the week and with the price of fuel increase i.e., Electric and gas our bills have gone up quite a large amount,
- ∞ Cost of washing and drying up to 5 washes a day but at least 2 loads just on young person.
- Having to cut down on extra treats, lower priced goods, being careful on how long the heating is on, wearing extra layers.
- Heating costs and good costs has significantly reduced the opportunities to take our [supported person] places. Lack of increase in payments or client contribution has meant it is becoming more and more difficult to justify carrying on. I am now using my own money to feed the individuals and cover the cost of fuel.
- Money doesn't cover all you have to pay out activities are getting less because you can't afford to do them things are only going up, but income stays the same.
- We spend four times as much on food, utility bills. I have raised my concerns to Management but not yet received any response. Every day things are going up and the small amount we receive from the supported persons is not enough to cover the cost. We a good hard worker carer and we need more support.
- Have heating in where I wouldn't previously. More washing and drying. More cooking all this leading to extra use of gas and electricity
- ∞ The cost of shopping has increased but the supported person's contribution remains the same. Therefore, to continue our current standard of living I am having to

subsidise my supported persons' food or reduce the standard that they are used to. The same with the energy price increase. The costs have increased but payments have stopped. Do I carry on as normal and subsidise from my income? Or do I reduce the amount of time the heating is on?

- ∞ I could earn more if I gave up Shared Lives and my current part time job and went back to my old career full time.
- □ I feel the system is unfair. It's weighted against the carer. We have all the costs and no extra financial support meanwhile those we care for have been given significant money to help with crisis which they have not had to use for any increases in the costs associated with running the home.
- ™ The Gentleman who we look after likes to spend a lot of time in his room which
 means tv PlayStation and lights are on most of the time in his room, plus the kettle is
 on a lot, plus heating to keep everyone warm.
- ∞ To be honest the whole country is depressed. First covid and now horrendous rises in living costs. It gets you down having to worry about paying for everything and doing this job you have a duty to provide good food and a warm house etc for our clients.
- It is very daring being a carer, our young man has high care needs, 24 hours a day. It's very frustrating when you are being told the cost-of-living money he was given cannot be used towards his heating/electricity.
- ∞ In the past few months my wife and I have considered downsizing and doing some part time care work. Although we have now stepped up a gear and are increasing our workload, by taking on more respite or another [supported person] fulltime. We feel that a third person would not increase the overall costs and we could continue to be a value to our [supported people] and the Shared Lives Service.
- ∞ The cost of living is inescapable and impacts on everyday life. It is foremost in most people's minds. I have always lived carefully so adjusting save energy aren't easy to find.
- ∞ The cost-of-living crisis is very bad at the moment and we're all working just to live at the moment. Many activities have been put on the back burner due to cost. Days out

etc and Christmas won't be the same this year. More important to keep warm and well fed than Christmas gifts and trinkets.

Issues with the scheme/wider social care system

- Shared Lives is a valued and needed service. It is personalised and person centred, it gives people (the client) the confidence and wellbeing, security to live an active life in the community and have a true home environment. Like a great machine to run it has to have all parts working well together. From building it, servicing, and maintaining it
- ∞ It can be very rewarding but very demanding and sometimes it feels like you are not appreciated.
- ∞ Our voices are not heard, and we are always being fobbed off. Not told the truth about what is happening. It's them and us. Carers are not valued as members of staff and therefore not included as a team member.
- ∞ The lack of support from [the scheme] since February 2020. They hid behind lockdown as an excuse not to be able to perform their role.
- NHS system and increasingly social care... I worry that if I struggle as person who is lucky enough to have good contacts and experience of trying to get things sorted... how difficult is it for people who have additional needs or are not used dealing with processes etc.
- About time we are recognised for the hard work we do 7 days week without being belittled by social workers who 'know best'.
- Have felt very unsupported during pandemic and it's not much better now as they are having staffing issues. There is no consistency with staff and management. Lost faith
- The management and development workers are changing a lot. Don't know whether we are coming or going and due to the inconsistency of the staffing issues it's hard to have faith in the scheme to support us.

- We have been part of shared lives for 7 years and until recently only one of our development workers had ever met our young man and we are on worker number 6.
 We get the odd email and the odd visit.
- There are regular meetings but seem to be more about what we need to do as carers.
 As a new carer I feel that most of the support and information I have received has come informally from other carers.
- They have huge turnover of staff.

Respite issues and work/life balance

- ∞ There is a lot of pressure on us, and we are sacrificing our own quality of life.
- We just do the job looking after the Gentleman because we enjoy it, He is part of our family we have known him for 10 years and having him for 3 years living with us it has been hard at times due to feeling that sometimes the [scheme] are not there for you, especially for respite. We took the Gentleman on holiday with us in March and were off for xmas it's easier to take him with us rather than stress about respite.
- ∞ The rare lie ins, time for us as a couple, just being able to be spontaneous.
- The not being able to switch off now both men are at home all day every day. The few breaks provided. Knowing if I'm sick or ill that still have to work or use my limited holiday.
- Not having your own space sometimes, we have been involved in a lot of hospital and assessments lately and it's been about this gentleman a very lot and sometimes my own relationship is put on hold, and I've been a carer more than me as a person.

Covid legacy

- ∞ Last year I really mentally struggled 'getting back' after covid lockdowns.
- ∞ Covid took its toll on me and people I support.
- → Pressure of Covid and cost of living has upset the routine and lifestyle of the

 [supported person and me as the] carer. More work and time put into [supported persons] welfare. Less time spent with family.

∞ Up to the pandemic we enjoyed it but now it is getting harder.

Challenges with supported people

- ∞ I am very tired of having to fight and push for support in my role with three difficult [supported people].
- ∞ I feel society is not very good with young people with additional needs. Security guards in supermarkets are very suspicious about young man with OCD and Tourette's syndrome and accuse them of stealing but because this has happened, he is more nervous to go into a shop without being jumped on, how sad is that. I also have a young lady who thinks nothing of sticking her fingers up at anyone who looks at her, which causes problems in the community needs 24-hour care 7 days a week.
- We go through difficult periods of challenging behaviour i.e., aggression/verbal abuse.
- Living with people and dealing with their family members and the [supported persons] challenging behaviours.





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