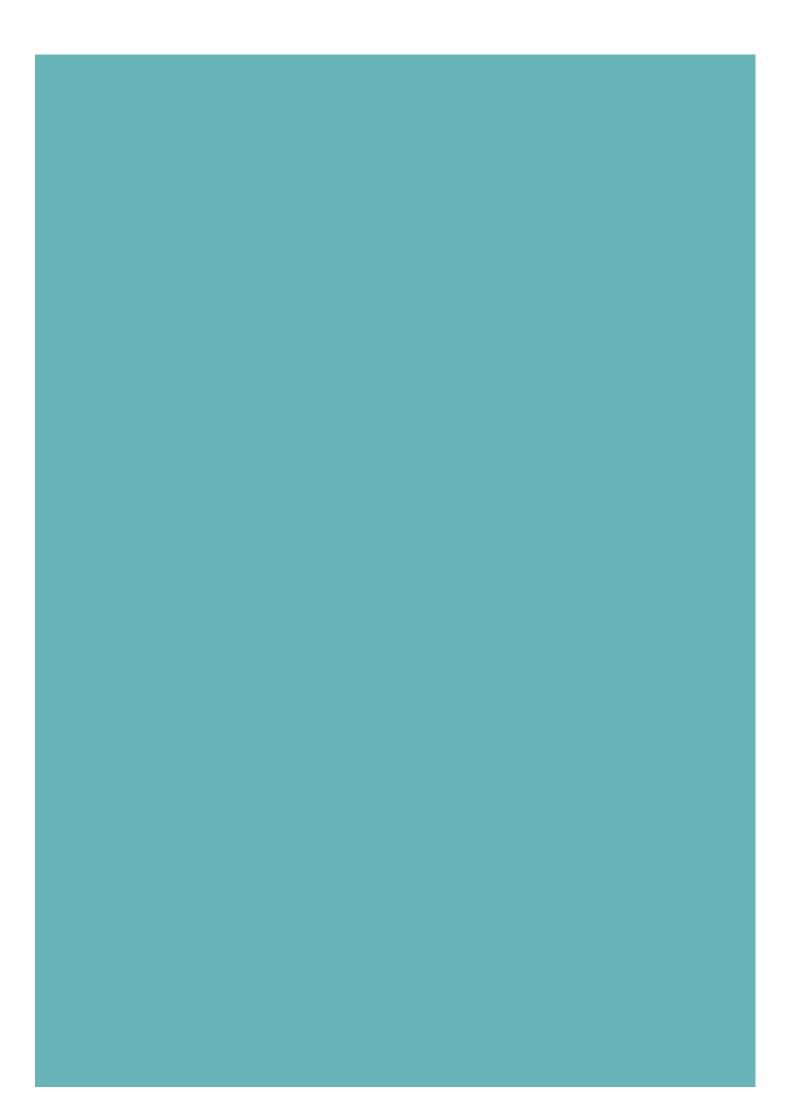
South East England Invaluable Report

Survey data from Shared Lives carers and Shared Lives schemes

2023





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

Contents

Contents	3
Executive summary	4
Introduction	6
How to use this report	8
Explainer: comparative averages	10
Scheme and carer response rates	11
About the commissioning organisations	13
Fee Uplifts	15
Lowest average fee rates for live-in arrangements	16
Highest average fee rates for live-in arrangements	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: Carer voices in the South East	32

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 are 22 Shared Lives schemes in the South East.
	According to data provided by Shared Lives schemes, care was commissioned by 16 commissioning organisations.
	Shared Lives schemes provided information about 19 different commissioning organisation fee rates
BANDINGS AND	Of the 19 commissioning organisation fee rates in the South East:
NON-BANDINGS	⇒ 16 are banded.
	⇒ 3 are not banded.
LOWEST FEE RATES	The <u>smallest</u> lowest fee rate was £155.40.
(LIVE-IN ARRANGEMENTS)	The greatest lowest fee rate was £509.03.
	9 out of the 19 (47%) commissioning organisation fee rates in the
	South East were below average in all comparative categories.
HIGHEST FEE RATES	The <u>smallest</u> highest fee rate was £240.04.
(LIVE-IN ARRANGEMENTS)	The greatest highest fee rate was £568.88.
	11 out of the 19 (58%) commissioning organisation fee rates in the
	South East were below in comparison to 2 or more averages for
	highest fee rates for live-in arrangements.
BOARD AND	Of the 13 commissioning organisation fee rates for whom data was provided, 10 (77%) above the English national average board and

LODGINGS	lodgings contributions.
	4 (31%) of these were below the regional average.
	Another 3 (23%) were below both regional and English average.
FEE INCREASES	⇒ 19 (86%) had provided a care fee uplift since April 2022
	⇒ 2 (9%) had provided uplifts within the last 1 to 2 years
CARER SURVEY STATISTICS	Of the 92 Shared Lives carers in South East who responded to the survey:
	⇒ 78% of carers who responded to the survey stated that they were affected by cost of living, just higher than the national average of 77%
	⇒ 39% of carers said that they have considered leaving Shared Lives due to the cost of living, which is more than the national average of 31%
	⇒ 29% of carers stated that they not very or not at all valued, which is slightly higher than the national average of 27%.
RECCOMENDATIONS	 Commissioning organisations ensure that they provide a lowest fee rate at or above the lowest non-banded fee for England, <u>£401.48</u>.
	 Commissioning organisations ensure that they provide a highest fee rate at or above the highest banding rate for England: <u>£495.12.</u>
	 Commissioning organisations ensure that they provide a board and lodgings contribution at or above the regional average: <u>£70.08.</u>

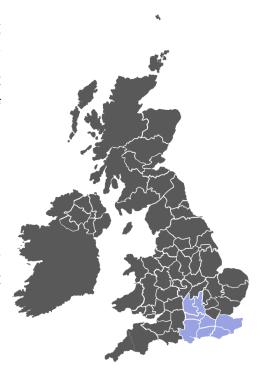
Introduction

"I love sharing my life and home with people I can offer support to; it helps me feel like I'm doing my part. I love the bond and relationship that is built with each individual person. I enjoy bringing my kids up to understand that not everyone is the same and with open minds. I also enjoy watching the [supported people] I care for grow in confidence and in their abilities. I would be absolutely torn if I couldn't afford to give care and support and a home in the way that we do.",

Shared Lives carer, South East England.

Shared Lives carers in the South East 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 and, we also 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 South East. 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,
- o A board and lodgings contribution,
- o 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., COSE001.

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

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

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 South East was £21,000 per annum or £351.97 per week.

The **average local authority senior care worker salary** in the South East was £28,900 per annum or **£455.28** 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 **22** Shared Lives schemes across the counties of Buckinghamshire, East Sussex, Hampshire, the Isle of Wight, Kent, Oxfordshire, Berkshire, Surrey, and West Sussex:

- Ategi Buckinghamshire
 Shared Lives
- Bournemouth & Poole
 Shared Lives Scheme
- Brighton & Hove Shared
 Lives Scheme
- Bromley Shared Lives
 Scheme
- East Sussex Shared Lives
 Scheme
- Futures for Shared LivesLtd
- Grace Eyre Shared LivesScheme
- Hampshire Shared Lives Scheme
 Adult Services
- Isle of Wight Shared Lives
- Kent Shared Lives Scheme
- Luton Council Respite & Shared Lives Scheme
- o Medway Shared Lives Scheme
- Milton Keynes Shared Lives
- Oxfordshire CC Shared Lives
 Scheme
- Portsmouth CC Shared Lives
 Scheme



- o Reading Shared Lives Scheme
- Southampton Shared Lives
 Scheme
- Surrey Choices Shared LivesScheme
- Surrey Shared Lives Scheme (Mencap)
- West Berkshire Shared Lives
 Scheme
- West Sussex Shared Lives Scheme
- Your Healthcare Kingston
 Shared Lives

19 out of 22 schemes in South East provided some form of data to the Invaluable survey. No Invaluable data was provided by the following:

- o Bournemouth & Poole Shared Lives Scheme
- o Luton Council Respite & Shared Lives Scheme
- Surrey Shared Lives Scheme (Mencap)

Shared Lives carers

When this survey was conducted, there were **1079** Shared Lives Plus carer members in South East. Of these, **92** Shared Lives carers responded to the carer survey.

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

About the commissioning organisations

There are **16 commissioning organisations** in South East who commission Shared Lives care according to data collected for the Invaluable survey in November 2022:

- ⇒ Bracknell Forest Borough Council
- ⇒ Brighton and Hove City Council (commissions care from 3 schemes)
- ⇒ Buckinghamshire Council (commissions care from 2 schemes)
- ⇒ East Sussex County Council
- ⇒ Hampshire County Council (commissions care from 2 schemes)
- ⇒ Isle of Wight Council
- ⇒ Kent County Council

- ⇒ Medway Council
- ⇒ Milton Keynes Council
- ⇒ Oxfordshire County Council
- ⇒ Portsmouth City Council
- ⇒ Reading Borough Council
- ⇒ Southampton City Council
- ⇒ Surrey County Council (commissions care from 2 schemes)
- ⇒ West Berkshire Council
- ⇒ West Sussex County Council (commissions care from 2 schemes)

Banded and non-banded commissioning organisations

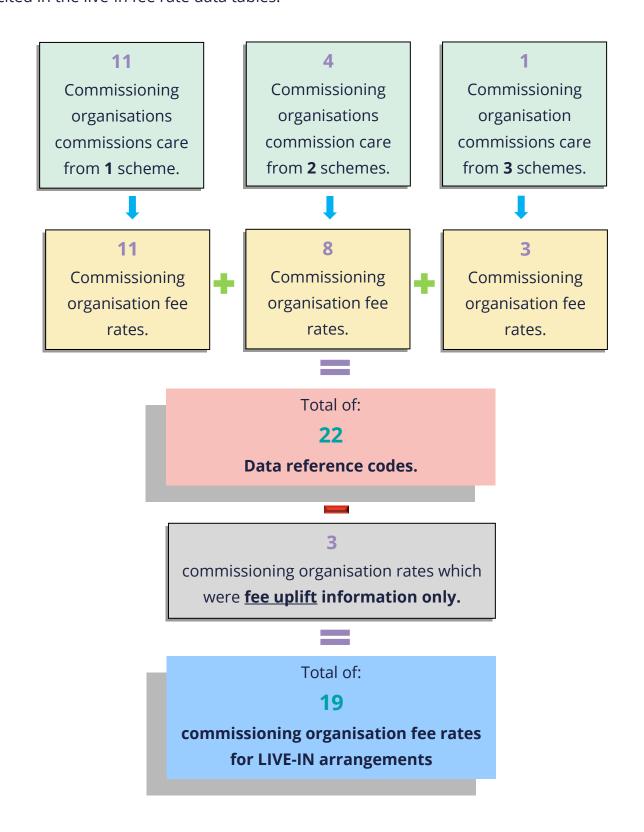
There are **19** commissioning organisation fee rates (or data reference codes) for the **16** commissioning organisations. See the flow chart on the following page for why this is the case.

Of the **19** commissioning organisation fee rates in the South East:

- \Rightarrow **16** are banded.
- \Rightarrow 3 are not banded.

Data reference codes for commissioning organisations

Whilst there are **16** commissioning organisations in the East of England, there are **22** data reference codes in total. There are **19** commissioning organisation fee rates are cited in the live-in fee rate data tables.



Fee Uplifts

These figures are accurate according to data collected in November 2022:2

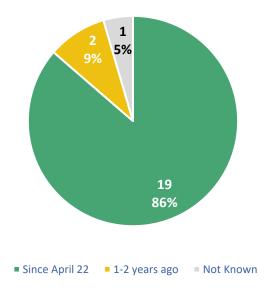
Of the **22** commissioning organisation fee rates in the South East:

⇒ 19 (86%) had provided a care fee uplift since April 2022:

- o COSE001
- o COSE002
- o COSE003
- o COSE004
- o COSE005
- o COSE007
- o COSE008

- o COSE011
- o COSE012
- o COEE013
- o COSE014
- o COSE015
- o COSE016
- o COSE017

- o COSE018
- o COSE019
- o COSE020
- o COSE021
- o COSE022
- ⇒ 2 (9%) had provided uplifts within the last 1 to 2 years:
 - o COSE006
 - o COSE01
- ⇒ There was **no data** on when 1 fee rate (5%) **COSE009** was last uplifted.



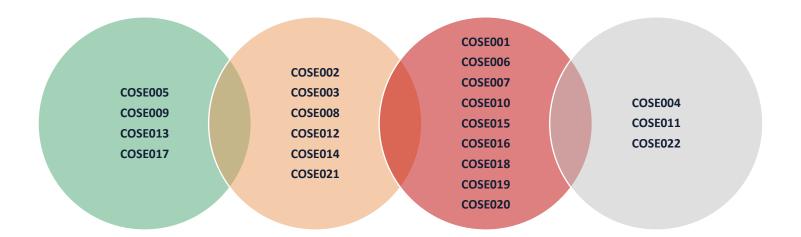
² This data is subject to change in the intervening period.

Lowest average fee rates for live-in arrangements

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

	COSE00 1	COSE00 2	COSE00 3	COSE00 5	COSE00 6	COSE00 7	COSE00 8	COSE00 9	COSE01 0	COSE01 2
Lowest Banding Rate	£250.96	£303.12	£292.50		£198.00	£211.26	£370.50	£406.93	£155.40	£379.27
Lowest Non-banded Fee				£509.03						-
Lowest SL Banding Rate (South East)		£284.95								
Difference	-£33.99	£18.17	£7.55	£224.08	-£86.95	-£73.69	£85.55	£121.98	-£129.55	£94.32
Lowest SL Banding Rate (England)					£324	4.57				
Difference	-£73.61	-£21.45	-£32.07	£184.46	-£126.57	-£113.31	£45.93	£82.36	-£169.17	£54.70
Lowest SL Non-banded Fee (SE)					£40	0.10				
Difference	-£149.14	-£96.98	-£107.60	£108.93	-£202.10	-£188.84	-£29.60	£6.83	-£244.70	-£20.83
Lowest Non-banded Fee (Eng)					£40	1.48				
Difference	-£150.52	-£98.36	-£108.98	£107.55	-£203.48	-£190.22	-£30.98	£5.45	-£246.08	-£22.21
Average Care Worker (South East)					£35	1.97				
Difference	-£101.01	-£48.85	-£59.47	£157.06	-£153.97	-£140.71	£18.53	£54.96	-£196.57	£27.30

	COSE013	COSE014	COSE015	COSE016	COSE017	COSE018	COSE019	COSE020	COSE021
Lowest Banding Rate	£449.39	£347.45	£173.18	£178.94		£210.00		£250.90	£381.35
Lowest Non-banded Fee	-				£451.22		£240.04		-
Lowest SL Banding Rate (South East)					£284.95				
Difference	£164.44	£62.50	-£111.77	-£106.01	£166.27	-£74.95	-£44.91	-£34.05	£96.40
Lowest SL Banding Rate (England)					£324.57				
Difference	£124.82	£22.88	-£151.39	-£145.63	£126.65	-£114.57	-£84.53	-£73.67	£56.78
Lowest SL Non-banded Fee (SE)					£400.10				
Difference	£49.29	-£52.65	-£226.92	-£221.16	£51.12	-£190.10	-£160.06	-£149.20	-£18.75
Lowest Non-banded Fee (Eng)					£401.48				
Difference	£47.91	-£54.03	-£228.30	-£222.54	£49.74	-£191.48	-£161.44	-£150.58	-£20.13
Average Care Worker (South East)					£351.97				
Difference	£97.42	-£4.52	-£178.79	-£173.03	£99.25	-£141.97	-£111.93	-£101.07	£29.38



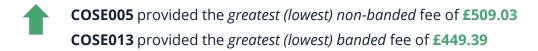
4 commissioning organisation fee rates were <u>above average</u> in all 5 regional and national categories for lowest fee rates.

6 commissioning organisations fee rates were <u>below average</u> in 2 or more categories.

9 commissioning organisations fee rates were <u>below average</u> in all 5 categories.

No data was provided for 3 commissioning organisation fee rates.

This means that **9** out of the **19 (47%)** commissioning organisation fee rates in the South East **were below average in all** comparative categories.



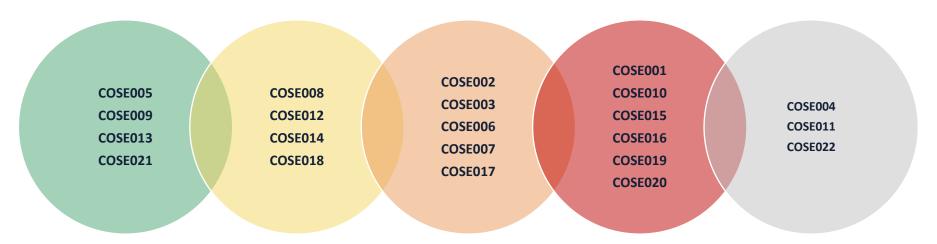
COSE019 provided the *smallest (lowest)* non-banded fee of £240.04 COSE010 provided the *smallest (lowest)* banded fees of £155.40

Highest average fee rates for live-in arrangements

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

	COSE00 1	COSE00 2	COSE00 3	COSE00 5	COSE00 6	COSE00 7	COSE00 8	COSE00 9	COSE01 0	COSE01 2
Highest Banding Rate	£312.78	£408.10	£406.21		£423.00	£422.38	£470.50	£568.88	£260.40	£494.76
Highest Non-banded Fee	-			£509.03						
Highest SL Banding Rate (South East)		£417.61								
Difference	-£104.83	-£9.51	-£11.40	£91.42	£5.39	£4.77	£52.89	£151.27	-£157.21	£77.15
Highest SL Banding Rate (England)		£495.12								
Difference	-£182.34	-£87.02	-£88.91	£13.91	-£72.12	-£72.74	-£24.62	£73.76	-£234.72	-£0.36
Highest SL Non-banded Fee (SE)					£40	0.10				
Difference	-£87.32	£8.00	£6.11	£108.93	£22.90	£22.28	£70.40	£168.78	-£139.70	£94.66
Highest SL Non-banded Fee (England)					£43	1.76				
Difference	-£118.98	-£23.66	-£25.55	£77.27	-£8.76	-£9.38	£38.74	£137.12	-£171.36	£63.00
Average Senior Care Worker (SE)					£45!	5.28				
Difference	-£142.50	-£47.18	-£49.07	£53.75	-£32.28	-£32.90	£15.22	£113.60	-£194.88	£39.48

	COSE013	COSE014	COSE015	COSE016	COSE017	COSE018	COSE019	COSE020	COSE021
Highest Banding Rate	£559.81	£473.80	£289.24	£299.67		£469.00		£312.78	£510.52
Highest Non-banded Fee	-				£451.22		£240.04		-
Highest SL Banding Rate (South East)					£417.61				
Difference	£142.20	£56.19	-£128.37	-£117.94	£33.61	£51.39	-£177.57	-£104.83	£92.91
Highest SL Banding Rate (England)					£495.12				
Difference	£64.69	-£21.32	-£205.88	-£195.45	-£43.90	-£26.12	-£255.08	-£182.34	£15.40
Highest SL Non-banded Fee (SE)					£400.10				
Difference	£159.71	£73.70	-£110.86	-£100.43	£51.12	£68.90	-£160.06	-£87.32	£110.42
Highest SL Non-banded Fee (England)					£431.76				
Difference	£128.05	£42.04	-£142.52	-£132.09	£19.46	£37.24	-£191.72	-£118.98	£78.76
Average Senior Care Worker (SE)					£455.28				
Difference	£104.53	£18.52	-£166.04	-£155.61	-£4.06	£13.72	-£215.24	-£142.50	£55.24



4 commissioning organisation fee rates were <u>above average</u> in all 5 average categories for highest fee rates.

4 commissioning organisation fee rates were above average in all but 1 category.

5 commissioning organisation fee rates were <u>below average</u> in 2 or more categories.

6 commissioning organisations fee rates were below average in all 5 categories.

No data was provided for 3 commissioning organisation fee rates.

This means that **11** out of the **19 (58%)** commissioning organisation fee rates in the South East **were below** in comparison to **2 or more averages** for highest fee rates for live-in arrangements.



COSE009 provided the *greatest* (*highest*) banded fee of £568.88 **COSE005** provided the *greatest* (*highest*) non-banded fee rate £509.03



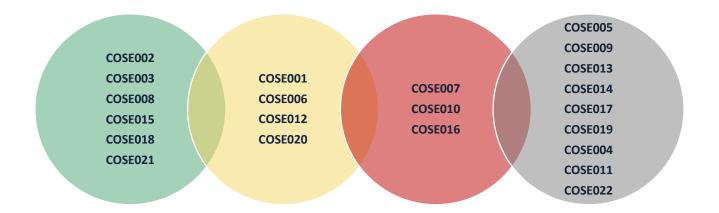
COSE019 provided the *smallest* (*highest*) non-banded fees of **£240.04 COSE010** provided the *smallest* (*highest*) banded fees of **£260.40**

Board and lodgings contributions

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

	COSE001	COSE002	COSE003	COSE005	COSE006	COSE007	COSE008	COSE009	COSE010	COSE012
Board & Lodgings	£65.00	£75.00	£88.30	-	£65.00	£55.20	£81.49	-	£55.85	£65.00
Board & lodgings (South East)		£70.08								
Difference	-£5.08	£4.92	£18.22	-	-£5.08	-£14.88	£11.41	-	-£14.23	-£5.08
Board & Lodgings (England)	£62.91									
Difference	£2.09	£12.09	£25.39	-	£2.09	-£7.71	£18.58	-	-£7.06	£2.09

	COSE013	COSE014	COSE015	COSE016	COSE017	COSE018	COSE019	COSE020	COSE021
Board & Lodgings	-	-	£77.56	£55.23	-	£76.40	-	£65.00	£86.00
Board & lodgings (South East)					£70.08				
Difference	-	-	£7.48	-£14.85	-	£6.32	-	-£5.08	£15.92
Board & Lodgings (England)					£62.91				
Difference	-	-	£14.65	-£7.68	-	£13.49	-	£2.09	£23.09



6 commissioning organisation fee rates were above national and regional averages for board and lodgings.

4 commissioning organisation fee rates were below the regional average.

3 commissioning organisation fee rates were below both national and regional averages.

No data was submitted for a further 9 commissioning organisation fee rates.

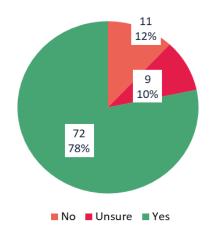
This means that of the **13** commissioning organisation fee rates for whom data was provided, **10** (**77%**) above the English national average board and lodgings contributions.

Regional live-in fees and contributions graph



Shared Lives carer survey data

Impact of the cost of living



78% of carers who responded to the survey stated that they were affected by cost of living, **just higher than the national average** of **77%**:

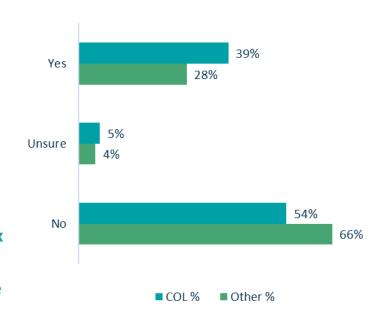
"The rising cost of food and utilities/petrol etc is higher than the amount I receive for my [supported person] and I cannot maintain the same standard of living for him from his money, so we are using more of our own money to keep his standard of living the same, including maintaining the same standard

of food, heating the house etc."

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

39% of carers said that they have considered leaving Shared Lives due to the cost of living, which is **more than the national average** of **31%**:

"It costs me far more to look after my
[supported person] now. I could work
back in a nursing agency for a higher
hourly rate, less hours, less
responsibility, 5 weeks annual leave, tax
and NI paid at source, every weekend,
Easter, Xmas, bank holiday off and have
a life."



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

How valued do Shared Lives carers feel?

41% of Shared Lives carers who responded to the survey said they felt somewhat or highly valued, as seen in the graphic below. This is just **less than the national average** of **47%**

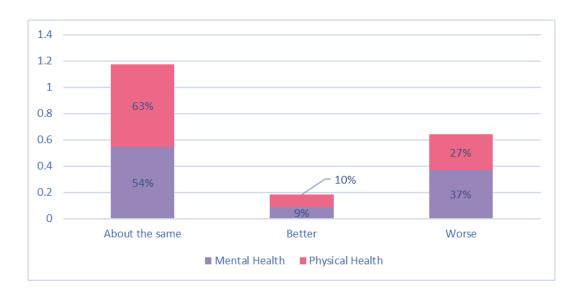


"Every is a new day but at the end of the day we are all human not machines, so we need all the support from the council to be able to do the job accordingly, which is obviously not the case."

29% of carers stated that they not very or not at all valued, which is slightly **higher** than the national average of **27%**.

"My scheme is superb! Absolute rock-solid support from my scheme manager. I think the absolute world of her. Hugely professional and caring. She always makes sure we have regular breaks and pay increases. She's the gold standard in scheme management."

Shared Lives carer physical and mental wellbeing



Physical health

- ⇒ **10%** of carers felt their physical health was **better**, which was **on par with** the national average of **10%**.
- ⇒ 63% felt their physical health was the same, which was slightly less than the national average of 67%.
- ⇒ **27%** 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 more than the national average of 7%.
- ⇒ **54%** felt their mental health was **the same**, which was less than the national average of **59%**.
- ⇒ **37%** felt their mental health was **worse**, which was **more than** the national average of **34%**. One carer said of their mental health:

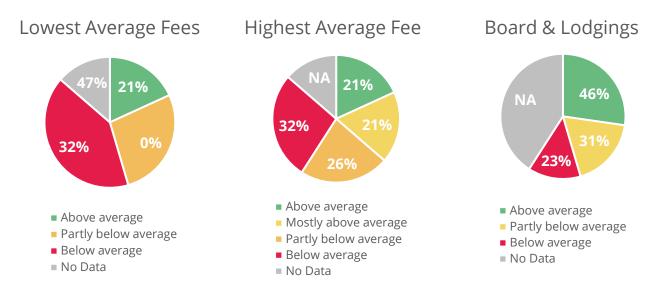
"I am currently signed off sick with burnout and work-related stress, I have had to resign from my role and am currently serving notice, I worked almost 18 months without any back up I am extremely worried about the long-term effects of this on my mental health currently my doctor thinks I may take up to six months to recover. This is a wonderful scheme, but the flaws are huge."

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

"I have anxiety and I lay awake at night worrying about how to protect these elderly people and keep them safe without getting myself in to debt."

Summary

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



"[I love] making a difference for the better for my [supported person by] giving him his right to freedom and finances and a working life. I enjoy knowing that I have provided him with a safe, clean, caring, family and home. I will advocate for him until I run out of breath. I love my job but hate all the fighting we have to go through to get anywhere".

Shared Lives carer, South East.

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 South East of England. This is reflected in the similar mix of Shared Lives carer feedback. Many Shared Lives carers expressed how much they enjoyed making a difference to the people they support. Many also told of how financial stress was impacting not only their work, but also their quality of life. See the appendix for more.

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

Areas of strength

→ Of the 13 commissioning organisation fee rates for whom data was provided, 10 (77%) above the English national average board and lodgings contributions.

Areas of improvement

- → Of the 11 commissioning organisation fee rates for whom data was provided, 7 (64%) above the regional average board and lodgings contributions.
- ⇒ 11 out of the 19 (58%) commissioning organisation fee rates in the South East were below in comparison to 2 or more averages for highest fee rates for livein arrangements.
- ⇒ 9 out of the 19 (47%) commissioning organisation fee rates in the South East were below average in all comparative categories.

Recommendations

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

Commissioning organisations ensure that they provide a lowest fee rate at or above the lowest non-banded fee for England, £401.48.

Commissioning organisations provide **15** lowest fee rates that **do not meet** the *lowest non-banded fee for England*, which is the highest of the regional and national averages:

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

15 commissioning organisations provide highest fees that **do not meet** the *average highest banding rate for England*, which is the highest of the regional and national averages.

Commissioning organisations ensure that they provide a board and lodgings contribution at or above the regional average: £70.08.

7 commissioning organisations' board and lodging rates fell **below** the English board and lodgings average:

⇒ COSE001

⇒ COSE006

⇒ COSE007

⇒ COSE010

⇒ COSE012

⇒ COSE016

⇒ COSE020

Appendix: Carer voices in the South East

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

What Shared Lives carers like the most about Shared Lives:

Making a difference

- We intervene in the basic of human life being close to a vulnerable and needy person that I find rewarding.
- ™ I enjoy enhancing the lives of the people I have looked after throughout the years. Nowadays, I have just one young male person living with me. We do water sports, outdoor activities, cinema etc. I'm helping him learn important lifestyle skills and doing my best to increase his own sense of worth:-) For the first time since starting this lifestyle choice I actually feel like the ""matching process" was a two-way thing.
- ∞ My [supported person] never fails to make me smile.
- ∞ I enjoy making a difference to the lives of the individuals I support. I enjoy the feedback they give about things they would not normally have done if I wasn't supporting them.
- ™ I absolutely love this role and think the scheme is wonderful but has huge flaws that no one wants to solve. I have had the honour of seeing the young man I cared for develop in himself and build new confidence, he is a joy to support I can safely say that after the almost 65 people I have supported privately over the last 20 years he is just the best. It's been the perfect match and though stressful a wonderful time to support him I feel lucky to have helped him.
- Making people happy and giving them the confidence to achieve anything they put
 their mind too whilst making them have a safe and happy home to come into, being
 able to be themselves and express their needs and supporting them as the people I
 support make me laugh every day and we have an excellent morale in our home.

- ∞ I love being a shared lives carer, I wish I had known about it years ago. I love that I get to make someone's life better and a better quality of life, I love to see their faces when we do something they love it brings a joy to my life as well as theirs.
- "Hearing my ladies laugh together. Being a 'family'. Knowing I do my best for my ladies and knowing that they are happy and well looked after, because they tell me. Seeing lives transformed by the stability they have living with me."
- Seeing my [supported person] development. Listening to him saying that it's the best place he's ever lived and although he understands we are not blood related he feels like we are family
- Being able to offer support and stability to someone. Knowing that I am giving my time to help someone live as independently and happily as possible and to reach their potential.
- ∞ To work in partnership with individuals who think you can make a difference in their lives. It's also very rewarding to see someone making a positive step towards living independently. It always a pleasure to someone settled and be part of the family.
- ∞ The feeling when [my supported person] says 'thank you' unprompted and unexpectedly.
- □ I enjoy the company of my [supported people] because I am single, they are my company and they are very easy to live with, because my [supported people] are very similar. Which makes for a happy house. I like taking them to their different events, they are like looking after my second set of children.
- ∞ I have cared for my lady since she was a child and see her as a member of the family. She has brought a lot of stress over the years but also so my fun and happiness.
- Sharing my house and family everyday with my [supported people], making a difference in their lives, actually caring. And seeing the difference I make.
- Helping to drive people's lives in the direction they choose. Helping them build a happy healthy life with choice! Love my job.
- ∞ Knowing that I am helping someone to make the best of their life. Or when doing respite, I am helping the original cater to take a break.
- Providing a normal home to those that because of their disability and own family structure would not be able to enjoy one.

- ™ The difference you make as a family when you welcome someone who need support
 in your home is a feeling one cannot describe. Caring for someone with special
 educational needs is very rewarding and seeing the progress that he is making is why
 we do what we do.
- Supporting people to have independence skills. Support for family carers have a respite break.
- ∞ "Helping people seeing them growing and gaining self-confidence and become your family member. The relationship you build".
- We get satisfaction from seeing how confident and independent they are becoming and seeing them happy.
- Transforming Lives, building confidence and helping [supported people] achieve a greater level of independence and satisfaction.
- ∞ I enjoy making a difference to my [supported person]. She really enjoys her days out with me, and she often rings me on the days I don't support her as well.
- I enjoy supporting my person and watching him grow in skills and confidence.
 Knowing that the young adult with us feels secure in life, knowing he is cared for. To enable him to grow and live life happily.
- ∞ Supporting people who are vulnerable, helping them to face this world full of discrimination and unfairness.
- ∞ I have very much enjoyed my shared lives work so far, I feel again I'm needed, as when my own children grew, I felt something was missing but I now feel that hole has been filled, I love my work.

Flexibility and home working

- Being a shared lives carer is very rewarding, knowing you make a difference in someone life, and flexible hours.
- ∞ The flexibility, I love not being 9 to 5.
- ∞ I work from home and I'm my own boss.
- working at home, the relationships develop with long term residents, being own boss to an extent.

- Freedom, also that I am being a useful member of society.
- ∞ Flexibility of working balances out with caring for elderly family members.
- We love working from home with our ladies and current lone gent and Have holidays and a social life together.
- ∞ Gives me the freedom to do other things. And helps someone.
- ∞ I love my job/life. It's very rewarding and has enabled me to raise a family whilst working from home.
- I enjoy working with my scheme and feel supported especially as my first child has additional needs and sometimes is ill or has holidays and I feel that my scheme works with me to work with my child and my lady so that everybody has a share of me.

Community and scheme support

- ∞ I love being part of the very lovely learning disabilities community.
- ∞ The ability to work hands on with our [supported people] whilst under the protective umbrella of a professional organisation. The fact that policies and guidelines are produced for us and with us.
- ∞ Meeting people and being involved, helping people achieve their potential.

What Shared Lives carers find most difficult:

Bureaucracy

- "The red tape and bureaucracy from the scheme. CQC isn't set up to support the concept of shared lives. Public sector workers overseeing self-employed people is a recipe for disaster.
- ∞ Not enough money and slow and antiquated system to claim money.
- ∞ The constant interference in my personal life from management. The red tape.

Fees

- At what point do you decide that it is no longer profitable to carry on doing the job you are doing? I provide round the clock support (as most shared lives carers) but one guy who I am receiving the minimum payment for, actually requires a lot more support than first thought.
- ∞ The cutbacks for [supported people], i.e., day services, day opportunities.
- Everyone is paid differently, if you know what to ask and how to go about it you get more. Banding for care grade is horrendous. Payslips are just the lump amount, not broken down to show you what you are earning and how.
- ∞ Currently the level of funding provided by the scheme is the most difficult issue.
- Although it would seem that we get reasonable support costs, when broken down in to hourly rates it's very poor sometimes less than £2 an hour for clients who have needed support around the clock, although this may only happen 3 or 4 times a year it's not recognised financially.
- 22 years ago, when it was called adult placemat. The wage was fantastic. There was a healthy profit to be made. Now there is no profit and I find myself subsidising my s/u to have a full and varied life.
- ∞ 15 years ago, this was a well-rewarded job financially. It has always sucked that we don't get respite, pensions, or day share payments. Now the [fees are] not in line with inflation and I'm afraid even those that love their jobs will be forced into making big decisions to maintain a decent standard of living.
- Shared lives carers live in unpredictable circumstances and often deal with stressful, turbulent situations. The amount we get paid should not be such a situation. It shouldn't depend on what council we are managed by, and the pay should realistically reflect the rise in cost of living as well as the value of what we do. We save the country millions in care that would be needed without shared lives carers!
- It is a difficult job to do and with the constant worry about money now being there it doesn't get any easier. It shouldn't be about money but if I can't afford to pay my mortgage when it goes up in February (end of fixed term) then I would have no choice but to stop being a shared lives carer. I want to be able to focus on the person I care for without worrying about paying the bills.

Cost of living

- ∞ Difficult to feed one [supported person] 21 nutritional meals 7 days a week!
- Managing increasing costs and nobody seems to realise. Saying we are all in the same boat is not acceptable. We are not all in the same boat as most people in this country are not paying for a non-family member utilities/food etc, which is what we are expected to do on a daily basis.
- Not being paid properly for the fantastic job we all do. I'm generally satisfied but am at boiling point regards the lack of extra payment for cost of living is pretty shameful and taking advantage of our good nature.
- Our utility bills have drastically increased, our clients receive the Government assistance with the Cost-of-Living Payments and Cold Weather Payments, but fortunately for them we pick up all of those costs. I have two clients with Mental Health Difficulties who rarely leave the house or spend money, our heating in in constantly but apart from the Rent contribution, which will be increasing by £22 on 16.01.23 they cannot contribute any more. From 16.01.23 the Rent eliminate will be approximately £155 a week for those that have not had a License Agreement Renewal in the past year, if they have, we have to wait for the year to end before they are allowed to pay the extra rent. Where can you find any good or even poor accommodation, 3 meals day, including specific dietary requirements and all utilities included for £155 a week?
- Utility cost have risen so much that we are forced to have heating and lighting to keep our supported people warm and safe and suffer the extra cost. I would not have the heating on during the day if I didn't have a supported person.
- Drastic change of day-to-day ways of living, with being careful in everything to save from buying the cheapest food, reducing the use of light, making the meals simpler avoiding using the oven, the toaster, or the kettle. Also, not using the car so often but also the heating is on the minimum bearable with many added layers of clothing to get a bit warmer.
- My increase in costs is increased disproportionately because the person I care for doesn't understand ""energy saving"", he is a teenage lad who eats for two.
- Our food bills have increased significantly. Our energy bills have soared astronomically. One of our guys spends most of his day at home so have to have the heating on far longer than if nobody was home.

- Having to cut back on food shopping that has more than doubled. Constantly prompting [supported people to turn lights, gadgets off when not in use. Meals and takeout are for special occasions only now.
- I have had to make cutbacks across the board to ensure that I can pay my mortgage, I now regularly use the community fridge/fare share scheme to top up my groceries, there is no spare money for home maintenance or holidays.
- We are living a significantly lower quality of life in every area. We are afraid to turn the heating on as outhouse is so big to facilitate us all. We have two teenagers living in the house so have no discount on our council tax anymore. We have doubled our electric usage; our food bill is 3 times what it was 3 years ago. We now have to plan here we are driving and when we are driving in an effort to reduce fuel cost on diesel.
- I have a 23-year-old, she showers (sometimes for half an hour) every day and changes all her clothes at least daily, and now it's winter I need to tumble dry most of it, she uses several gadgets at the same time all the time, she always leaves lights on even in the daytime.
- ∞ We live rurally and do the cost of transport and cars themselves have gone up. We also don't have any mains gas and the cost of oil and logs have doubled.
- I am constantly watching my smart meter. I have no heating on when my ladies that I care for are out for the day. I freeze and then I switch it on for them coming home but go to bed really early to save fuel.
- Both of my ladies are on benefits and have a rise every year. They also received over
 £600 each for the fuel costs yet neither of them pays for any of the things that have
 increased in price. Their day care is subsidised. Their bus fare is free. It's a hard pill to
 swallow.
- The person I support has a pc high powered gaming console, tv, internet, lights on, Alexa etc and is up all night from midnight to when I awake my meter has already had over 3 pounds spent on it... cost of food also increased - we get 2.88 per meal he's an adult - even a Mac Donald's (which at 22 he would like every now and then) this costs 6.76!
- ∞ My service users are all older and don't go to day services since pandemic, so the heating is approx. £200-250 per wk. I'm so worried about the oldest one who is frail and 84."

- ∞ COL money not being paid to carers isn't the schemes fault and should be addressed by the government and stop making excuses. All schemes should be the same.
- we have to keep the house heated all day to a reasonable level because our clients
 are not physically active because of their disabilities and our combined energy costs
 are regularly reaching £250 or more per week.

Issues with the scheme/social workers

- I find it difficult that most people especially professionals don't understand our role and assume we are just support workers. I find it difficult that we are looked over and taken for granted when I feel we offer the most quality care for people who need it.
- I hear of 'bed blockers' causing a problem for the NHS, I have a ground floor ensuite room that has been empty for a year and a half - maybe more people should be made aware that we can be a useful resource to help out.
- No face-to-face meetings to discuss or air problems. E mails ignored. When anything goes wrong you are totally on your own. People being treated totally different and being told not to tell other carers. When it fits being told it's my job to do it, everything is in my job description.
- ∑ob insecurity, one of our long-term residents left us in March to move to a care home and we have been managing on effectively a half wage since, have done some respite but, unbelievably, no referrals as yet.
- ∞ Shared Lives workers being so blinkered and set and not looking outside the box.
- The change in emphasis from being supported to being monitored and recorded is a disappointing change. When things go wrong which they can do from time to time the scheme distances itself from you rather than helps support the care provider.
- ∞ I find it difficult if my [supported person] is unhappy about something, and I flag the problem with main Carer or Shared Lives but nothing gets changed.
- Management can do a better job of not making it hard for us to rent etc as we are seemed to be classed as a care home.
- More thought about carers and what they deal with! And being fearful to speak out.
- ∞ Changes in managers and local policies. But that's the same whatever job or organisation you're in.

- ∞ Fed up with the whole political mess and lack of vision and support from the local authorities and government. We NEED to be recognised. Our job never stops. We don't leave work at 5pm go home put our feet up and pour a drink and just forget about it all and switch off. And we can't do that because we "CARE".
- We feel that the scheme supports the [supported people] more than the carers. I will give an example: we have 2 carers in our scheme that are forced to book & pay for a hotel near their home when they want respite because their [supported person] "refuses" to leave the house! This is totally unacceptable & the scheme should not allow this to happen. The scheme very much takes advantage of people's good nature & will let things happen to carers just because the carers don't want to cause a fuss or moan. There are different rules for different carers. Depending on who your officer is one carer will be told one rule & another carer will he told a completely different one. This causes discontent. We are told to follow advice from shared Lives plus, but the scheme does not. We feel that our manager does not support us, defend us, fights for us or represents us with regards to higher management.
- This job defeats you! We have no rights and no ability to challenge or make a difference to any part of our work. It's stressful advocating for our clients when you're told "just leave it alone "or "that's just the way it is" or "well you can always leave "absolutely every aspect of our work is a fight!
- Very frustrated and angry with the scheme & how we are treated. Communication is dreadful & one way. Management is ineffective. The scheme only takes advice from Shared Lives Plus when it suits them. Our expectations have increased but our wages have decreased. We are asked & expected to do things that we haven't before, for less money. The goalposts have totally changed. Shared Lives is not what it used to be at all.
- The pressure of dealing with Adult Social Care over deliberate withholding of payments and trying to agree an Adult Support Plan has taken its toll.
- Conflict of interest when SL officers work for the carer and the [supported person], carers have no one to advocate for them solely and life really does seem to be geared up more for the clients and schemes than the carer. We feel we are cheap care, free care almost, and that we truly don't matter to anyone.
- My scheme has been in disarray for quite a while now. But the new manager who started a few months ago is addressing the failures of the scheme, that give some signs of hope for improvement.

Respite issues and work/life balance

- ∞ Restriction of my own freedom, being on call 24/7 and unable to take a second job as no cover if supported person is unwell.
- ™ It can feel quite isolated. It would be lovely to have 1 evening a week to myself to go
 to a yoga class or a movie or for a drink with a friend. As a solo carer with a
 [supported person] who cannot be alone this is not possible and would use up all my
 respite.
- ∞ [Our supported person] can't be left alone, and this does restrict us, but she joins in everything we do.
- ∞ The lack of respite locally and the unhelpful attitude of Continuing Health Care in managing my lady's needs.
- Reducing lifestyle and no break. Being part of safeguarding training that is mandatory knowing we receive nothing like minimum wage, we don't get breaks and holidays.
- ∞ That you are totally on your own, no help with holidays told to sort it yourself even your own 21 days holidays.
- Hearing that others were either granted their missed holiday through covid years or paid for it, and I was told no... nothing.
- ∞ I could do with a bit more time off, but that's my own fault. I should care out more time and not feel guilty for doing that. I will get there.
- ∞ The lack of respite. Feeling guilty asking for holidays with my husband 1-1 or being able to lead a normal, healthy social life as a married couple.
- ∞ 24/7 for 3 people since 2018 am home full time is hard work.
- Not ever being "off duty". Not being able to be "spontaneous". It is not possible to ever just go away for a last-minute break. Having a strict rule about how long the clients can be left at home for whilst we are out. Having to take on the clients' families & all the issues, difficulties & problems that they cause. We have to act as social workers, nurses, financial experts, taxi drivers, advocates, job seekers, benefits advisors, instructors, relationships experts etc. People who work with our clients think they know them but cannot relate in any way to what it's like to live with them 24/7. People don't understand that just because someone is able to dress themselves &

catch a bus on their own doesn't mean they are easy to look after. It's things like being asked the same question a million times a day that makes that person difficult to live with. Levels of ability are not assessed properly at all.

- ∞ Caring for someone 24/7 it's not easy...It's not like I can go home after my shift and relax, they are living in my own house, I have to find the balance between my private life and working life...I support 3 people with special needs. I think that in my case I should awarded more respite days, 33 days is not enough. When I go on respite, I don't get my full payment, I have to pay the respite carer food and energy bills, I used to get my full payment before, but things changed last year, so in a way I'd 4% increase but in the other hand I now have to pay the respite carer when my service users go on respite. Not happy with that.
- Respite needs to be looked into for every scheme. We are not a cheap babysitting service, we work 24/7.
- ∞ I would like more breaks, luckily, I do have help from my daughter (unpaid).
- ∞ My respite has been cut from 4 weeks to 2 weeks, I had to take my client on a cruise with me (and pay for myself) or go without- was told it was a family holiday, but she takes all my attention all the time and it's hard to relax.

Lockdown legacy

- We have come out of lockdown without any respite or help and we are now facing financial difficulties.
- ∞ Lockdown was hard for me. A single person with 2 supported people to entertain every day for months on end. I now only have 1 supported person as a result.
- During covid, unable to leave supported person unsupported. 3 supported people have differing mobility / understanding. Unable to go outside for 6 months. Day services was reduced to 4-hour weeks. For many months. Personal mental health. Felt solely responsible for 3 adults with no external support. Burnt out and beyond.
- ∞ Lockdown was tricky, but now day centres are open things are better.
- ∞ After Covid, the energy crisis and the recession I feel mental health is declin8ng rapidly. I feel less able to cope with challenging situations and I'm feeling more anxious than before.
- Very poor support stressful after covid.

- ∞ Suffered during lockdown, coping alone with severely disabled client.
- Was told all holidays and respite. We're lost through covid didn't have one day break in nearly two years, and not paid for it either.
- We have found the 'post pandemic' period far more challenging than when restrictions were in place. probably because life has largely returned to normal for most, but we are still experiencing high levels of responsibility placed upon us. we feel strongly that had our 40 nights per year respite provision had not been restored we would most likely have resigned by now.
- We worked really hard to keep our clients safe throughout the Pandemic that now we feel fatigues both mentally and physically.

Challenges with supported people

- It seems that there is no progression in the support that I give to my [supported person] which is in contradiction with my own personal life that I base on my physical and mental development.
- I find it difficult when an individual doesn't like to take on board when we have meeting/conversations about shared spaces and the importance of keeping them clean and tidy.
- ∞ I had to tell on of the people we look after his younger brother had died from an epileptic fit. I knew his brother well. We just held each other and cried for some time.
- Unsafe choices but have to be done to learn by mistakes.
- ∞ Repeating myself 1000 times lol generally hard question as love my job. It can be extremely wearing and so I take time out sometimes but then feel really guilty.
- Not always knowing how to help them when it comes to the next goal you want them to achieve.
- ∞ Behaviours and really hard especially for my sensory children!
- ∞ The unpredictable nature of caring for someone with additional needs. Never being 'off the clock'.
- We do sacrifice some privacy and personal space which is par for the course and most of the time it's fine but on a difficult day can be a little overwhelming.

- ∞ Sleep deprivation caused by my lady waking in the night has impacted on me.
- ∞ Our long-term [supported person] becoming increasingly frail. We carry on as best we can.
- All three of our clients have high support needs, two are physically disabled, two have challenging behaviour traits, and all three have severe learning disabilities. we have been told that their level of support needs is far in excess of the level of support required for most SL clients.





Report by:

Dr Rebecca Viney-Wood, Support and Engagement Manager **Liz Collings,** Data and Support Officer

With support from:

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