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# East of England Invaluable Report

## Survey data from Shared Lives carers and Shared Lives schemes

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2023





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# 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	<p>There are <b>9</b> Shared Lives schemes in the East of England.</p> <p>There are <b>12</b> commissioning organisations according to data supplied by Shared Lives schemes in November 2022.</p> <p>Shared Lives schemes provided more detailed information about <b>11 commissioning organisation fee rates</b>, which are cited in the data tables for live-in rates.</p>
BANDINGS AND NON-BANDINGS	<p>Of the <b>11</b> commissioning organisation <u>fee rates</u>:</p> <p>⇒ <b>8</b> are banded.</p> <p>⇒ <b>3</b> are not banded.</p>
LOWEST FEE RATES (LIVE-IN ARRANGEMENTS)	<p>The <u>smallest</u> lowest fee rate was <b>£198</b>.</p> <p>The <u>greatest</u> lowest fee rate was <b>£445.63</b>.</p> <p><b>8</b> out of the <b>12 (67%)</b> commissioning organisation fee rates in the East of England <b>were below</b> either regional or national averages for lowest fee rates.</p>
HIGHEST FEE RATES (LIVE-IN ARRANGEMENTS)	<p>The <u>smallest</u> highest fee rate was <b>£245.30</b>.</p> <p>The <u>greatest</u> highest fee rate was <b>£585.00</b>.</p>

	<p><b>7</b> out of the <b>12 (58%)</b> commissioning organisation fee rates in the East of England <b>were below</b> either regional or national averages for highest fee rates.</p>
<b>BOARD AND LODGINGS</b>	<p>Of the <b>10</b> commissioning organisations for whom data was provided, <b>7 (78%)</b> were <b>above the national average</b> for board and lodgings.</p>
<b>FEE INCREASES (ALL ARRANGEMENTS)</b>	<p><b>3 (25%)</b> commissioning organisations provided a fee uplift after April 2022</p> <p><b>6 (50%)</b> had provided a fee uplift in the last 1-2 years</p> <p>A further <b>3 (25%)</b>, had not provided an uplift for between 6-10 years</p>
<b>CARER SURVEY STATISTICS</b>	<p>Of the <b>42</b> Shared Lives carers in the East of England who responded to the survey:</p> <ul style="list-style-type: none"> <li>● <b>74%</b> were affected by cost of living, slightly <b>lower than</b> the UK average of 77%</li> <li>● <b>17%</b> have considered leaving Shared Lives due to the cost of living, <b>lower than</b> the UK average of 31%.</li> <li>● <b>31%</b> were neutral about feeling valued in their role.</li> </ul>
<b>RECOMMENDATIONS</b>	<ol style="list-style-type: none"> <li>1. Commissioning organisations ensure that they provide a <b>lowest fee rate</b> at or above lowest non-banded fee rate for England: <b>£401.76</b>.</li> <li>2. Commissioning organisations ensure that they provide a <b>highest fee rate</b> at or above the highest banding rate for England: <b>£495.12</b>.</li> <li>3. All commissioning organisations increase the <b>board and lodgings</b> contributions to at or above the English board and lodgings average of <b>£62.91</b>.</li> </ol>

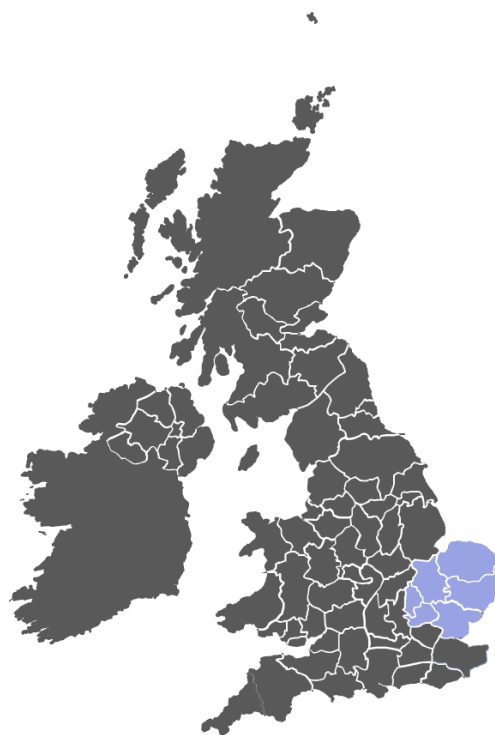
# Introduction

**"I have enjoyed looking after the young person in my care. She came as a foster child and this arrangement has helped us continue to live together. I feel happy that she didn't have to have any major disruption in this last part of her life, considering her childhood was one of neglect. I feel happy to be part of a workforce that offers compassionate family-based care to persons who would otherwise not receive it."**

## **Shared Lives carer, East of England**

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

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



# How to use this report

*This report has been primarily written for Shared Lives carers and Shared Lives schemes, 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 or have arrangements which are not within their banding system.**

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



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

## Lowest and highest fees

To compare data efficiently, this report compares only the highest and lowest 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., COEE001.

**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](mailto: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 one 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 one for England.

## Regional care fee benchmarks

The regional benchmarks are taken from the *Skills for Care's Adult Social Care Workforce Data Set*.<sup>1</sup> 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 East of England was £21,000 per annum or **£351.97** per week.

The average local authority **senior care worker salary** in the East of England was £24,300 per annum or **£395.12** per week.

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<sup>1</sup> 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

In November 2022 there were **9** Shared Lives schemes covering the 6 counties of Bedfordshire, Cambridgeshire, Essex, Hertfordshire, Norfolk, and Suffolk in the East of England:

- Bedford Shared Lives
- Essex Shared Lives
- Hertfordshire Shared Lives
- Luton Shared Lives scheme
- MacIntyre Shared Lives Central Bedfordshire
- PSS Norfolk & Suffolk (East)
- Southend Shared Lives
- Sunbeam Shared Lives (Bedfordshire)
- Cambridgeshire Shared Lives



**7 out of 9 (78%) schemes in the East of England provided some data to the Invaluable survey. No data was provided by Luton or Sunbeam Shared Lives.**

## Shared Lives carers

When this survey was conducted, there were **327** Shared Lives Plus carer members in the East of England. Of these, **42** Shared Lives carers responded to the carer survey.

**This equates to 13% of the Shared Lives Plus carer members in the East of England.**

# About the commissioning organisations

There are **10 commissioning organisations** in the East of England who commission either live-in care or day support according to data collected for the Invaluable survey in **November 2022**:

- Basildon and Brentwood CCG (Clinical Commissioning Group)
- Bedford Borough Council (commissions care from 3 schemes)
- Cambridgeshire County Council
- Central Bedfordshire Council
- Essex County Council
- Hertfordshire County Council
- Norfolk County Council
- Southend-on-Sea Borough Council
- Suffolk and North East Essex ICB (Integrated Care Board)
- Thurrock Council

## Banded and non-banded commissioning organisations

There are 11 commissioning organisation fee rates (or data reference codes) for the 10 commissioning organisations. See the flow chart on the following page for why this is the case.

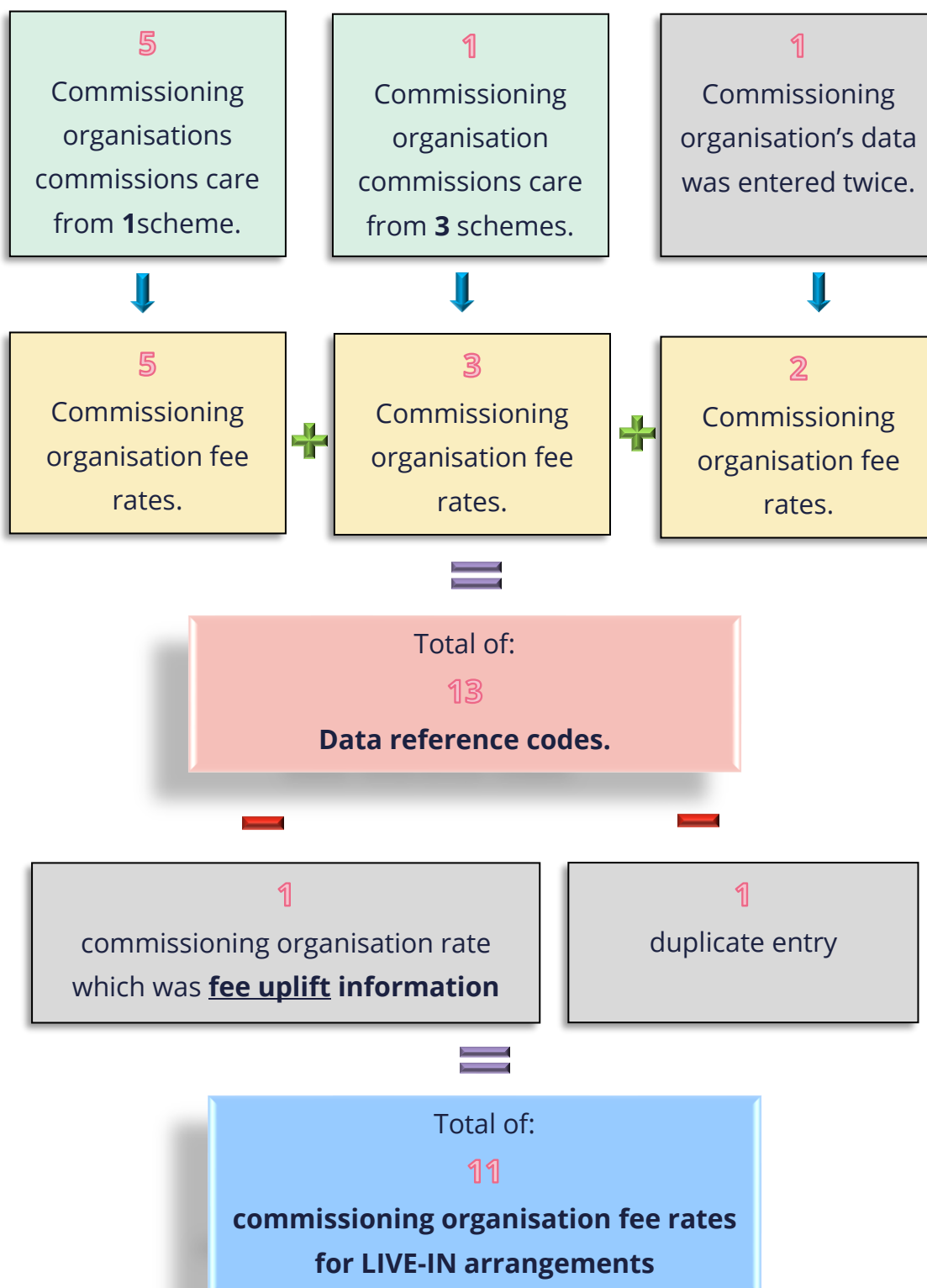
In terms of banding: Of the **11** commissioning organisation fee rates for live-in care in the East of England:

⇒ **8** are banded.

⇒ **3** are not banded.

## Data reference codes for commissioning organisations

Whilst there are **10** commissioning organisations in the East of England, there are **13** data reference codes. **11** 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:*

Of the **12** commissioning organisations in the East of England:

⇒ **3 (25%)** provided a fee uplift after **April 2022**. These were:

- COEE003
- COEE006
- COEE013

⇒ **6 (50%)** had provided a fee uplift in the **last 1-2 years**. These were:

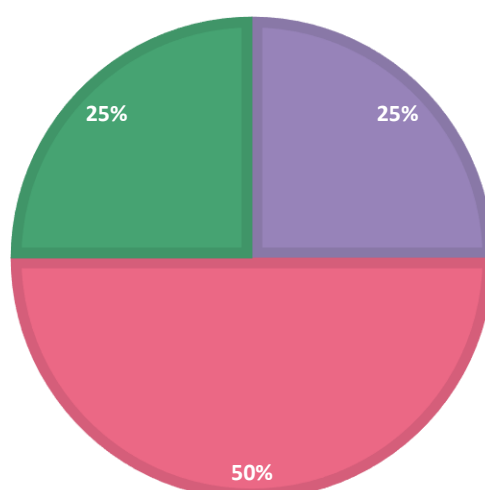
- COEE002
- COEE007
- COEE010
- COEE005
- COEE009
- COEE011

⇒ A further **3, (25%)**, had not provided an uplift for between **6-10 years**. These were:

- COEE001
- COEE004
- COEE012

## FEE UPLIFTS EAST OF ENGLAND

■ After April 2022 ■ Within 1-2 years ■ Between 6-10 years ■

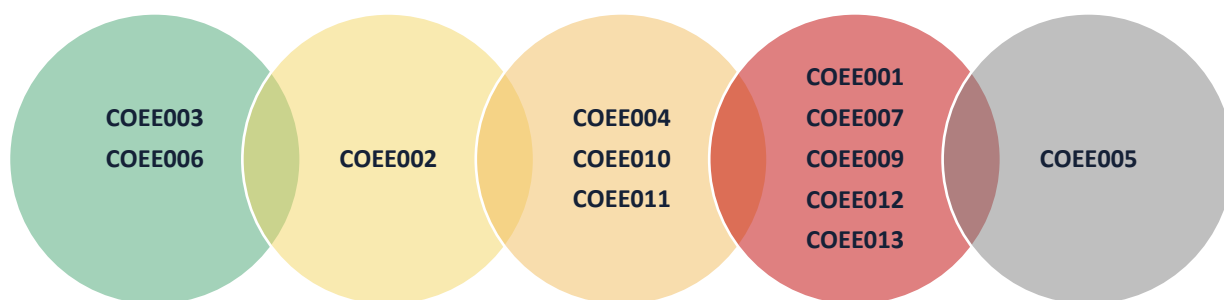


# Lowest average fee rates for live-in arrangements

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

	COEE00 1	COEE00 2	COEE00 3	COEE00 4	COEE00 6	COEE00 7	COEE00 9	COEE01 0	COEE01 1	COEE01 2	COEE0 13
<b>Individual CO Lowest Banding Fee</b>	£280.00	-	£425.00	£311.50	-	£280.00	£198.00	£326.53	£331.87	£280.00	-
<b>Individual CO Lowest No-banded Fee</b>	-	£364.00	-	-	£445.63	-	-	-	-	-	£245.30
<b>Lowest Shared Lives Banding Fee (East of Eng)</b>	£304.11										
<b>Difference</b>	-£24.11	£59.89	£120.89	£7.39	£141.52	-£24.11	- £106.11	£22.42	£27.76	-£24.11	-£58.81
<b>Lowest SL Banding Fee (England)</b>	£324.57										
<b>Difference</b>	-£44.57	£39.43	£100.43	-£13.07	£121.06	-£44.57	- £126.57	£1.96	£7.30	-£44.57	-£79.27
<b>Lowest SL Non-banded Fee (East of England)</b>	£351.64										
<b>Difference</b>	-£71.64	£12.36	£73.36	-£40.14	£93.99	-£71.64	- £153.64	-£25.11	-£19.77	-£71.64	- £106.34
<b>Lowest SL Non-banded Fee (England)</b>	£401.48										
<b>Difference</b>	-£121.48	-£37.48	£23.52	-£89.98	£44.15	- £121.48	- £203.48	-£74.95	-£69.61	- £121.48	- £156.18
<b>Average Care Worker salary East of England</b>	£351.97										
<b>Difference</b>	-£71.97	£12.03	£73.03	-£40.47	£93.66	-£71.97	- £153.97	-£25.44	-£20.10	-£71.97	- £106.67





2 commissioning organisation fee rates were above average in all 5 regional and national average categories for lowest fee rates (as shown in the table above.)

1 commissioning organisation fee rate was above average in 4 out of 5 categories.

3 commissioning organisation fee rates were below average in 3 or more categories.

5 commissioning organisation fee rates were below average in all 5 categories.

There was no lowest live-in fee data for COEE005.

This means that **8** out of the **12** commissioning organisation fee rates in the East of England **were below** either regional or national averages for lowest fee rates.



**COEE006** provided the *greatest (lowest) non-banded* fee of **£445.63**

**COEE003** provided the *greatest (lowest) banded* fee of **£425.00**



**COEE009** provided the *smallest (lowest) banded fees* of **£198.00**

**COEE013** provided the *smallest (lowest) non-banded fees* of **£245.30**

# Highest average fee rates for live-in arrangements

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

	COEE00 1	COEE00 2	COEE00 3	COEE00 4	COEE00 6	COEE00 7	COEE00 9	COEE01 0	COEE01 1	COEE01 2	COEE01 3
<b>Individual CO Highest Banding Fee</b>	£427.00	-	£585.00	£497.70	-	£427.00	£423.00	£474.54	£533.19	£427.00	-
<b>Individual CO Highest Non-banded Fee</b>		£364.00			£445.63						£245.30
Highest Shared Lives Banding Fee (East of England)	<b>£474.30</b>										
Difference	-£47.30	- £110.30	£110.70	£23.40	-£28.67	-£47.30	-£51.30	£0.24	£58.89	-£47.30	- £229.00
Highest SL Banding Fee (Eng)	<b>£495.12</b>										
Difference	-£68.12	- £131.12	£89.88	£2.58	-£49.49	-£68.12	-£72.12	-£20.58	£38.07	-£68.12	- £249.82
Highest SL Non-banded Fee (East of England)	<b>£351.64</b>										
Difference	£75.36	£12.36	£233.36	£146.06	£93.99	£75.36	£71.36	£122.90	£181.55	£75.36	- £106.34
Highest SL Non-banded Fee (Eng)	<b>£431.76</b>										
Difference	-£4.76	-£67.76	£153.24	£65.94	£13.87	-£4.76	-£8.76	£42.78	£101.43	-£4.76	- £186.46
<b>Average Senior Care Worker salary East of England</b>	<b>£395.12</b>										
Difference	£31.88	-£31.12	£189.88	£102.58	£50.51	£31.88	£27.88	£79.42	£138.07	£31.88	- £149.82



3 commissioning organisation fee rates were above average in all 5 regional and national average categories for highest fee rates (as shown in the table above.)

1 commissioning organisation fee rate was above average in 4 out of 5 categories.

6 commissioning organisations fee rates were below average in 3 or more categories.

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

There was no lowest live-in fee data for COEE005.

This means that **7** out of the **12** commissioning organisation fee rates in the East of England **were below** either regional or national averages for highest fee rates.



**COEE003** provided the *greatest (highest) banded fee* of **£585.00**

**COEE006** provided the non-banded *greatest (highest) banded fee* of **£445.63**



**COEE013** provided the *smallest (highest) non-banded fees* of **£245.30**

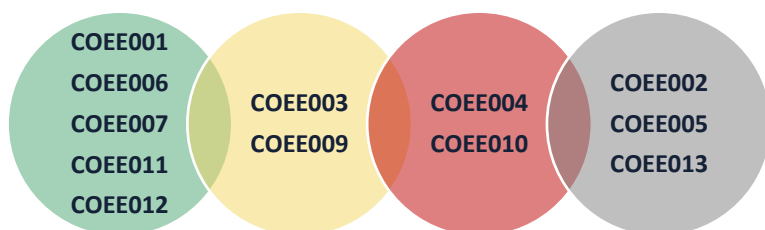
**COEE009** provided the *smallest (highest) banded fees* of **£423.00**

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# Board and lodgings contributions

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

	COEE00 1	COEE00 2	COEE00 3	COEE00 4	COEE00 6	COEE00 7	COEE00 9	COEE01 0	COEE01 1	COEE01 2	COEE01 3
<b>Board &amp; Lodgings</b>	£70.00	-	£63.00	£59.30	£76.40	£70.00	£65.00	£55.31	£74.10	£70.00	-
Board & Lodgings (East of Eng)	<b>£67.01</b>										
Difference	£2.99	-	-£4.01	-£7.71	£9.39	£2.99	-£2.01	-£11.70	£7.09	£2.99	-
B&L Rate (Eng)	<b>£62.91</b>										
Difference	£7.09	-	£0.09	-£3.61	£13.49	£7.09	£2.09	-£7.60	£11.19	£7.09	-



**5 commissioning organisation contributions were above national and regional averages for board and lodgings.**

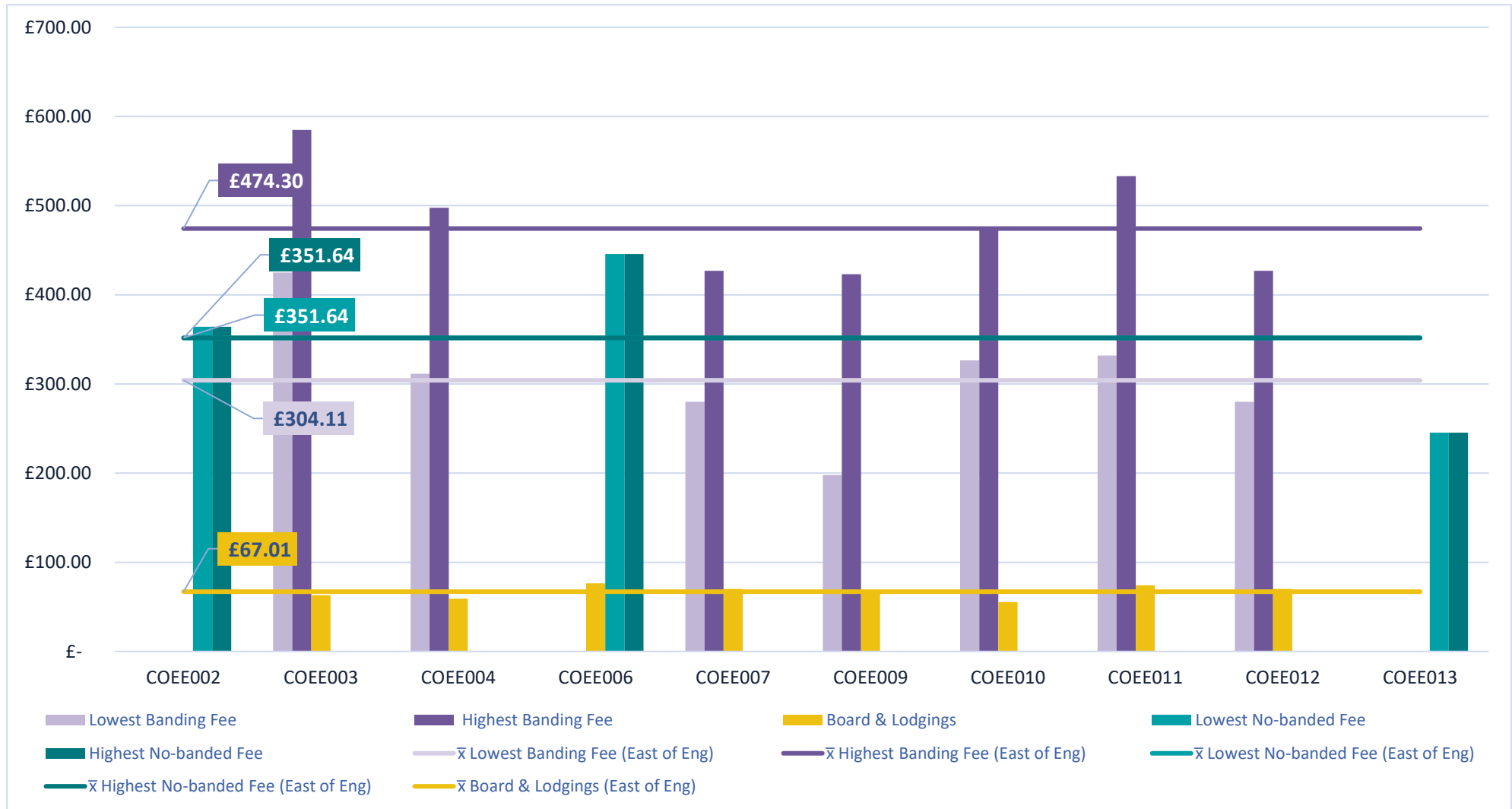
**2 commissioning organisation contributions were above national but not regional averages.**

**2 commissioning organisation contributions were below both national and regional averages.**

No data was submitted for a further 3 commissioning organisations.

Of the 9 commissioning organisation contributions, **7 (78%)** were **above the national average** for board and lodgings.

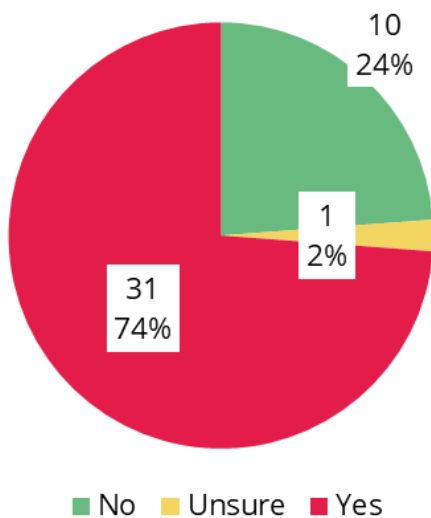
# Regional live-in fees and contributions graph



# Shared Lives carer survey data

## Impact of the cost of living

**74%** of carers who responded to the survey stated that they were affected by cost of living, slightly **lower than** the UK average of **77%**.



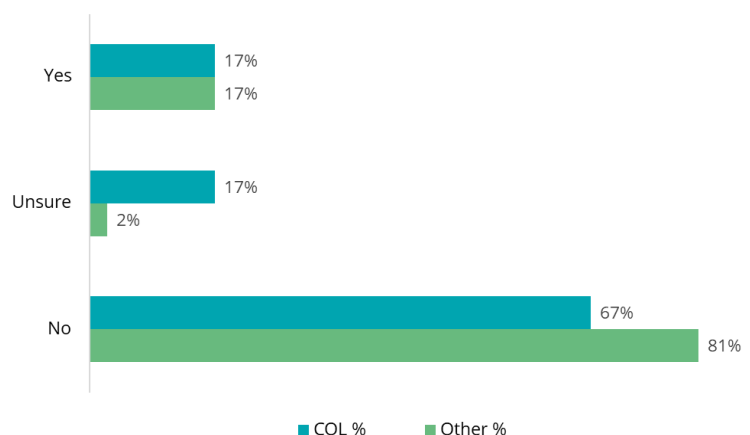
Have you been impacted by the Cost of Living?

One carer stated that:

**"We are not using our heating because I'm afraid of not being able to pay the bills. When it's cold we put on extra clothing and the young person I care for has two Oodles which she wears over her clothes. The hot water is only on for two hours each day so we can shower, and we wash up just in the evening. The outside lights are turned off and food has gone up so much that I've been using my saved tax money to pay for it".**

**17%** of carers said that they have considered leaving Shared Lives due to the cost of living, **less than** the UK average of **31%**.

**"Everything costs more and it's getting harder and harder to make ends meet!"**



Have you considered stopping work as a Shared Lives carer due to the cost of living (COL) or Other?

## How valued do Shared Lives carers feel?

The greatest number of carers who responded to the survey, **31%**, were neutral about feeling valued in their role, as seen in the graphic below:



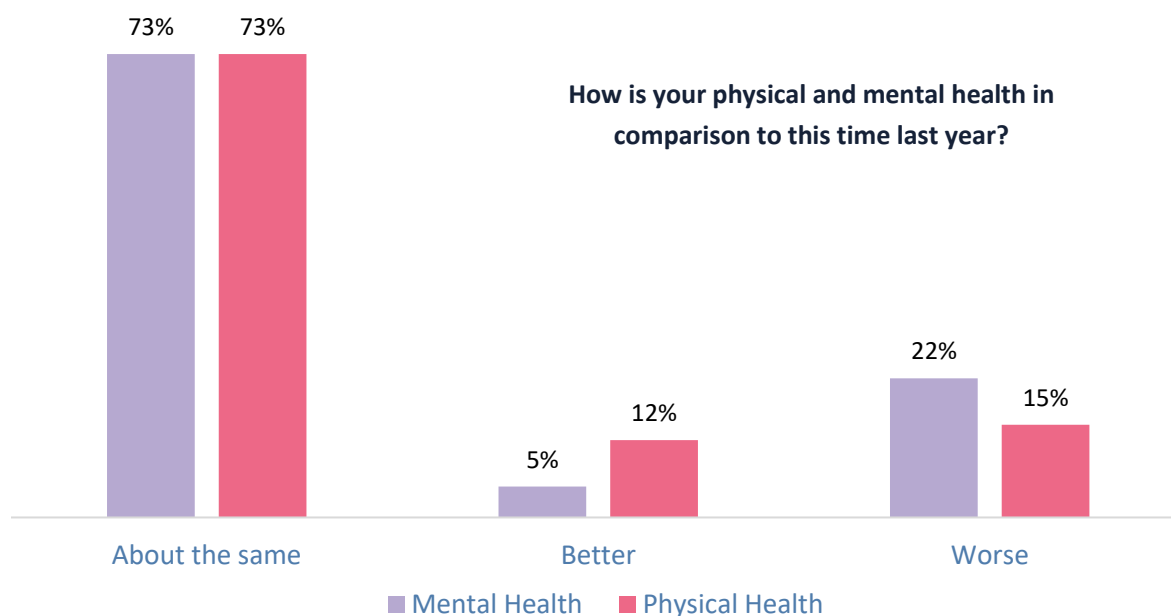
A close second, **24%**, felt that they are **not very or not at all valued**. This is **slightly lower** than the UK average of **26%**. One carer noted that they were:

**“Feeling like I’m just a number! The anxiety that comes with lack of confidence in what you’re doing as I feel I haven’t been provided with all the information we might need. It’s almost like we’re just “winging” it some days. This is really disappointing as we don’t want to fail our lady.”**

More positively, **46%** of carers stated that they **felt highly or somewhat valued**. This **on par** with the national average. In one scheme, 100% Shared Lives carers said they feel highly valued in their role. One carer stated that:

**“The opportunity to be able to provide care and support that makes us feel valuable and doing something worthwhile”.**

## Shared Lives carer wellbeing





## Physical health

- ⇒ **12%** of carers felt their physical health was **better**, which was **more than** the national average of **10%**.
- ⇒ **73%** felt their physical health was **the same**, which was more than the national average of **67%**.
- ⇒ **15%** felt their physical health was **worse**, which was **less than** the national average of **22%**.

## Mental health

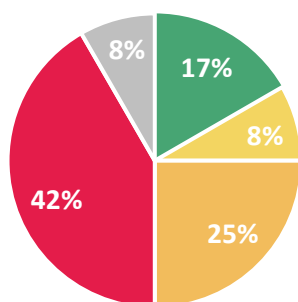
- ⇒ **5%** of carers felt their mental health was **better**, which was **less than** the national average of **7%**.
- ⇒ **73%** felt their mental health was **the same**, which was more than the national average of **59%**.
- ⇒ **22%** felt their mental health was **worse**, which was **less than** the national average of **34%**. One carer said of their mental health:

**“Winter was a struggle last year, but we are really worried about switching on the heating for more than a bare minimum this year which isn't helping.”**

# Summary and recommendations

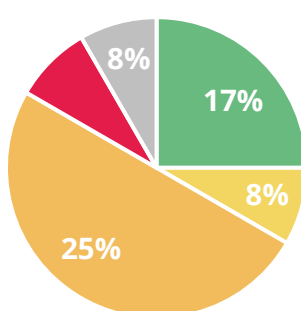
*Please note that these figures were accurate as of November 2022.*

Lowest Average Fees



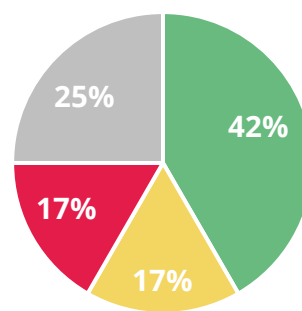
■ Above average  
■ Mostly above average  
■ Partly below average  
■ Below average

Highest Average Fees



■ Above average  
■ Mostly above average  
■ Partly below average

Board & Lodgings



■ Above average  
■ Partly below average  
■ Below average  
■ No Data

**“As the cost-of-living crisis bites harder, we, as I am sure many other carers, would most welcome some extra financial help, we are managing ok on all other levels. Moving forward it is impacting on our ability to support our [supported person] socially - we have less spare cash to pay to support her ourselves.”**

**Shared Lives carer, East of England.**

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 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 East of England raise their fees and contributions to meet or exceed the comparative averages outlined in the recommendations section.**

## Areas of strength

- Of the **9** commissioning organisation fee rates for whom data was provided, **78%** were **above the national average for board and lodgings** (see figure above).

## Areas of development

As a region, the East of England has significant room for improvement in both its lowest and highest fee rates.

- **8 out of the 12 (67%)** commissioning organisation fee rates in the East of England **were below** either regional or national averages for lowest fee rates.
- **7 out of the 12 (58%)** commissioning organisation fee rates in the East of England **were below** either regional or national averages for highest fee rates.
- No single commissioning organisation fee rate was above average in all three areas: lowest fees, highest fees, or board and lodgings contributions.

# 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 lowest non-banded fee rate for England: £401.76**

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

- |           |           |           |
|-----------|-----------|-----------|
| ⇒ COEE001 | ⇒ COEE007 | ⇒ COEE011 |
| ⇒ COEE002 | ⇒ COEE009 | ⇒ COEE012 |
| ⇒ COEE004 | ⇒ COEE010 | ⇒ COEE013 |

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

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

- |           |           |           |
|-----------|-----------|-----------|
| ⇒ COEE001 | ⇒ COEE007 | ⇒ COEE012 |
| ⇒ COEE002 | ⇒ COEE009 | ⇒ COEE013 |
| ⇒ COEE006 | ⇒ COEE010 |           |

**All commissioning organisations increase the board and lodgings contributions to at or above the English board and lodgings average of £62.91.**

**2** commissioning organisations were below both national and regional averages. These were:

- |           |           |
|-----------|-----------|
| ⇒ COEE004 | ⇒ COEE010 |
|-----------|-----------|

# Appendix: Carer voices in the East of England

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

## *What Shared Lives carers enjoy the most about Shared Lives:*

- ∞ "That we have been able to continue caring for our placement into adulthood, she is very much a part of our family and lives and gives us a lot of satisfaction that we are doing something worthwhile and making a difference to someone's life."
- ∞ "Providing a caring home, helping to develop increased independence, and sharing my life with my 2 ladies, one who has been with me for 15 years. I also have continued contact with one lady who I helped become independent, and is now married and has a baby, she considers me to be 'mum' and 'grandma'".
- ∞ "We have been carers in some capacity for over 25 years. Knowing we can make a difference to people's lives is priceless".
- ∞ "Supporting different clients with their needs and introducing them into a family environment."
- ∞ "When family and staff at day centre say they have seen positive significant changes with the individual using the scheme when they move in. Supporting someone to learn new skills and living as one big family."
- ∞ "The fact that it is more relaxed than under fostering. The friendliness of the staff who look after us."
- ∞ "Working with someone with special needs and supporting them to achieve the best they can in their lives."
- ∞ "Watching our girl grow up. She came to us aged 10 as a foster child."
- ∞ "Providing support to our lady who lives with us. She's lovely and has settled in really well with us. She's the only reason we are still happy to be carers as she has been doing really well."

- ∞ "Sharing our lives and our knowledge with others, taking people on holiday".
- ∞ "We enjoy being able to support and help with living in a family environment knowing that they are happy, safe, and as independent as possible."
- ∞ "Being able to offer people with complex needs and significant learning difficulties the opportunity to live in a family home."
- ∞ "Enabling people who have been fostered by ourselves an opportunity to stay with us rather than go into residential care."
- ∞ "Supporting people to access opportunities which help them to experience things which give a better quality of life."
- ∞ "The opportunity to work from home which allows flexibility to do other things that we want to do."
- ∞ "Sharing our home and lifestyle with others, not just the people who we support but also the wide range of others who we come in contact with whilst doing it."
- ∞ "Being introduced to different perspectives that the people who we support have."
- ∞ "The opportunity to be able to provide care and support that makes us feel valuable and doing something worthwhile".
- ∞ "Helping shape someone's life to the way they want it."
- ∞ "Being able to continue to support our young people who were formerly fostered by us and have a higher level of needs/would not be able to live independently."
- ∞ "The people we support, being able to make a difference. We have seen two young men move on to independent living and move their lives forward and offered respite to people who needed a helping hand."
- ∞ "The flexibility within the work, supporting someone to become more independent."
- ∞ "Enabling a person to live as independently as possible."
- ∞ "Supporting the clients to lead a normal life as possible according to their disabilities."
- ∞ "In our case working with the young lady who lives with us and watch her progress."

- ∞ "Helping my person to access everything she wants in life and seeing her blossom!"
- ∞ "Sharing my life with someone who I have looked after for 17 years is like having an extra special family. Knowing we make his life happy."
- ∞ "Enjoy every minute of caring for who I look after."
- ∞ "The satisfaction of sharing my house with someone and living as a family."
- ∞ "Making a difference to the lives of the people we support".
- ∞ "It's a wonderful alternative to traditional residential accommodation for adults with additional needs.
- ∞ "It allows me to be at home for my children when they get home from school. It's flexible"
- ∞ "The feedback from people I know telling me what a difference I have made to my carers life how much she has blossomed and gave her confidence to challenge a situation she does not agree with".
- ∞ "I love the lady I have she responds likewise, it's all about the match. She is very endearing it is extremely rewarding more than I thought it would be".
- ∞ "The role of helping a young person to grow and find themselves. It is such a rewarding role."
- ∞ "Seeing the [person's] progress. I have been a carer for three years and to see [the] difference in behaviour is what makes this job so satisfying."
- ∞ "Making a difference to someone's life and being able to work from home."
- ∞ "We have a fantastic relationship with our young person."



## *What Shared Lives carers find most difficult about Shared Lives:*

- ∞ We do not find it difficult as we have been carers for over 25 years, and it works for us. We are however having to juggle our finances more than ever.
- ∞ "Constant red tape issues for benefits /different schemes have different ways of working."
- ∞ "Rising costs are not always addressed".
- ∞ "Lack of communication from social workers and development workers. The wages aren't increasing, and mileage has been 45p a mile for the past 10 years."
- ∞ "Not having any time for myself."
- ∞ "Not really knowing where or who to turn to. Feeling like I'm just a number! The anxiety that comes with lack of confidence in what you're doing as I feel I haven't been provided with all the information we might need. It's almost like we're just "winging" it some days. This is really disappointing as we don't want to fail our lady."
- ∞ "Clock watching and feeling restricted to personal time."
- ∞ "The only thing really is the online courses; I know the importance of training, but all the courses are for care/residential/nursing homes. The courses could perhaps be tailored for the single service user home carer environment."
- ∞ "The lack of respite care, we have been shared lives carers for 2 years and are yet to have any respite."
- ∞ "We have been carers (foster and shared lives) for over 20 years now and not much seems difficult. As we get older, we may become more physically challenged due to the nature of young people who we support, and I get frustrated by the increasing bureaucracy that is creeping into shared lives caring."
- ∞ "Feeling isolated. No local carer group and SL staff themselves cannot really understand what we do without lived experience. We understand that there are more foster carers coming through and feel it would be useful for them and us to make a connection."
- ∞ "Lack of support, very little understanding of what SL is within the community and across professional services".
- ∞ "Organisational issues, different schemes have different rules and rates."

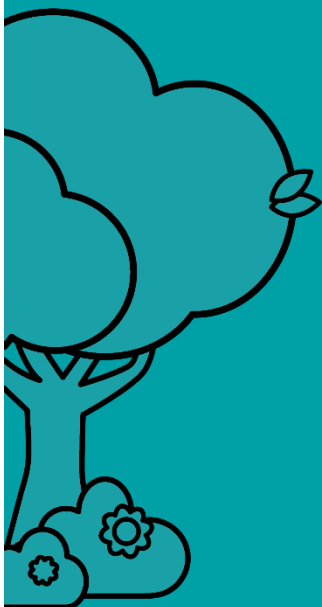
- ∞ "Now I'm getting older and not so mobile I worry how long I can keep her going and meet her needs!"
- ∞ "Limited resources for activities and having to fulfil someone's life experience when this isn't recognised as part of his care package."
- ∞ "If you have no support from development workers or they don't seem to know what they're doing."
- ∞ "Being on call 24/7."
- ∞ "My young person finished college and does not have day care. She also does not have respite care. This was part of our package originally. however, the respite carer felt unable to continue. Neither Shared lives nor the LA funder have found any solution to this. So, what is difficult is not having a break at all in any 24-hour period."
- ∞ "Our young person has been turned down by all the care agencies that the LA have approached. This is because she has complex needs and can hit out at carers amongst other things. She has high care needs. So, we are stuck."
- ∞ "There are many things as a family that it's harder for us to do and we cannot have spontaneous trips out for meals etc as husband and wife."
- ∞ "Lack of privacy. Keeping our house clean and tidy."
- ∞ "Working with Universal Credit and Social workers."
- ∞ "Getting respite sorted when I want it. Then worrying that the Carer will be ill when I've booked a holiday which has happened before. So never having that certainty that the respite is def going ahead so can't really plan anything."
- ∞ "My husband also became a shared lives carer and after one very difficult placement we never heard of another placement and so we had to start fostering again as there were no placements."

### *What Shared Lives carers would like schemes to do better:*

- ∞ "Accept that we also need to work outside the scheme: either regular jobs or other businesses."
- ∞ "Look at individual young people as our YP is so complex he doesn't really fit their service as he is 2-1"
- ∞ "I do feel though that I get most of my information from being a member of shared lives plus."

- ∞ "Be honest, inducted their new recruits better, more supportive leadership for the SL workers and the careers."
- ∞ "Being more realistic with how much housekeeping is paid, there is no way you could feed anyone healthily on the food allowance."
- ∞ "Campaign more to get us a pay rise."
- ∞ "Help find suitable clients. Give face to face encouragement and support - this used to happen."
- ∞ "I actually cannot think of any improvements although it is becoming very difficult financially."
- ∞ "I need them to look at cost of living and review their wages."
- ∞ "Look more at the needs of the service user and consider paying me for the significant time and effort I put into providing learning, positive experiences, days out and new opportunities for the service user rather than just the basic care needs."
- ∞ "Make it clear how the scheme works, provide every important contact in one place/booklet. Development workers should be more involved at the beginning of the scheme in providing support."
- ∞ "More action and pay conditions."
- ∞ "More calls or check ins to chat and support."
- ∞ "Not sure how much better they can do but supporting with some considerable force the need to gain all carers a significant increase in funding."
- ∞ "Organise coffee mornings or meet ups that we haven't got to organise ourselves. When we have a dinner and get together, we have to pay."
- ∞ "It would be nice if we were more valued."
- ∞ "Perhaps have someone as an empathetic listener who we can offload to when things are tough, without judgement."
- ∞ "Better links with other departments so that they know who to go to for answers."
- ∞ "Provide financial support in line with inflation. Have less last-minute cancelled meetings. Be pro-active and have better communication."
- ∞ "Push for more payments, reduce red tape."

- ∞ "Regular contact."
- ∞ "They should revise the wages, mileage payments and housekeeping as the cost of living has gone up."
- ∞ "This training that we have to do online."
- ∞ "When I needed respite, they were unable to help me, and I ended up having to get someone for myself."





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