

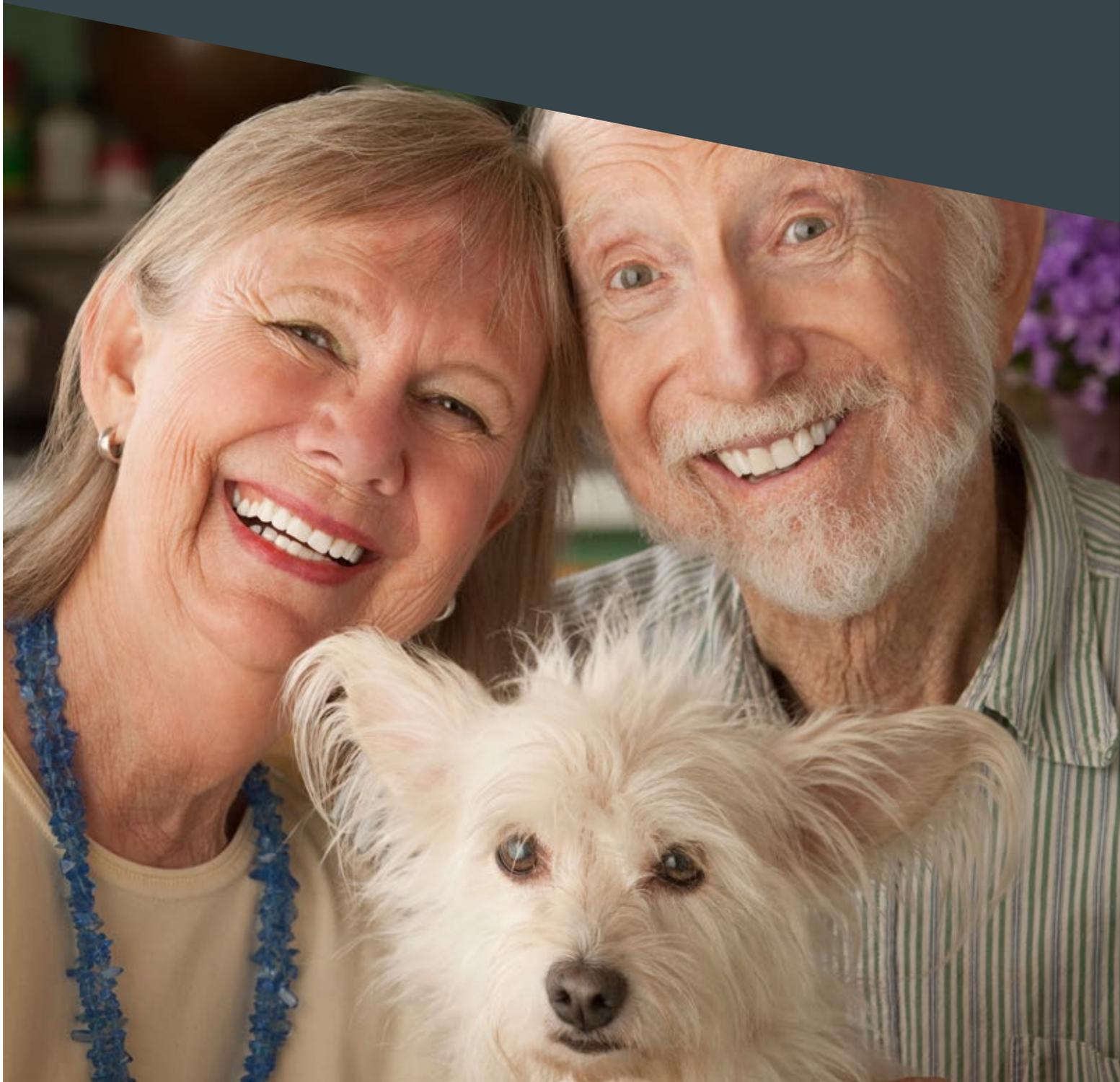


The Live-in
Care Hub

The home of expert advice

Better at Home

Why live-in care is a real alternative
to residential or nursing home care





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Foreword

The year 2020-21 has been a global catastrophe. In England alone, more than 127,000 people have died of Coronavirus, with many tens of thousands still suffering from long Covid.

The epidemic has shown the vulnerability of the oldest among us (mortality is highest amongst older people). It has highlighted the weakness in the way we treat our elderly, who deserve to live their years with dignity and happiness. Unfortunately for the hundreds of thousands of people in care homes, 2020-21 has been a year of isolation, loneliness, and vulnerability.

It doesn't have to be like this.

The last year has shown that, even if you need full-time care, you can stay in your own home, have a great quality of life, and see friends and relatives when you choose - while still being safe. A growing body of evidence shows that having a live-in carer gives a far better quality of life for the person who needs care. Live-in care is also within financial reach of almost anybody who owns their own home.

Looking forward: fix the system

The pandemic over the past year and this analysis lay bare the failings in the UK's current institutionalised approach to care. This analysis, commissioned by the Live in Care Hub, uses published data as well as proprietary research by the world renowned Personal Social Services Research Unit (PSSRU), a collaboration between University of Kent and the LSE. The analysis clearly demonstrates that not only do individuals want to remain in their own home should they need care, but it is also safer for them to do so.

In addition to the physical benefits of remaining in their own home, evidence shows the mental wellbeing benefits improve quality of life and can also help reduce the pressure on our wonderful, but over-stretched NHS.

With 'personalised care and a 'home-first' approach' identified as priorities by successive Governments, we are calling on them to stop paying lip-service to person-centred care and to ensure care in the home is prioritised by local government and for Live-in-Care to be given equal consideration when an individual reaches this level of need.

It is critical that we use the learnings from the Coronavirus pandemic to "build back better." The pandemic has shown us the shortcomings of a centralised, institutionalised and inflexible model of care. We need to give people the option to choose the care they want and need, in the place they want to receive it; care that is flexible, fits around the person being cared for (rather than the needs of the institution) yet is safe, effective, and excellent value for money.

This research report shows how live-in care, offers a real alternative to residential care and should be a major part of the future of care in the UK.

The Live-in Care Hub
April 2021



The Live-in Care Hub - the guiding light for live-in care

Founded in 2013, The Live-in Care Hub is a non-profit organisation committed to creating awareness of 24/7 care at home and therefore raising the quality of care in the UK.

As the expert in live-in care, The Hub guides families through all the options in an honest, impartial way. It's all about offering an enhanced life at home that challenges the traditional view that residential care homes are the only answer.

All the Hub's care providers are also members of the United Kingdom Care Association. Both organisations share a vision to guarantee the very highest standards of care.

Care Crisis. The system is broken

The care system is in crisis. The Coronavirus pandemic has shown that Care and Nursing Homes, despite the valiant efforts of their heroic staff, are not able to give their residents a safe, dignified and happy last few months or years of life.

During the pandemic, Care and Nursing Homes are the unwilling victims of government strategy, having been asked by government to accept people coming out of hospital, without a test, and without adequate PPE, early in the crisis. Their carers and teams have provided the best possible care they could, often at risk to their lives. However, despite doing their best, the residents in their care have had the most challenging year. It has shown that the system is broken.

The 19th and 20th Centuries were the centuries of institutionalisation. The hordes of commuters, all having to get to work at the same time: the centralised,

institutional solutions to problems; the creation of the concept of institutional care, arising from the workhouses of the 19th Century and evolving into the Care and Nursing Homes of the 20th.

This no longer works. We have seen the advantages of centralised, institutional life but there are also great disadvantages. New developments, from personalised medicine, to remote working, are going to make the way we live and work much more tailored to the needs of the individual, which will increase quality of life and happiness. The same is true with care.



Covid shows that institutions can't deliver safety, dignity, happiness, or value for money

Safety

Care and Nursing Homes are places which present a high risk of infection spreading quickly – however good their hygiene standards. The 2020-21 Covid crisis has shown this, with death rates of people in care homes at about 8,121 per 100,000¹. - three times the prevailing rate in the over-80s population of 2,376 per 100,000².

These figures would have been even worse if it were not for the unselfish and caring efforts of staff, who often put their own lives at risk to help their residents.

The great news is that the roll-out of the vaccine means that care homes are less likely to be hit by the devastating death rate we saw in 2020-21. However, the epidemic shows that there is a high risk of individuals in a care or nursing home being at risk of an infection spreading, whether Covid or something else.

Dignity and happiness

In order to control the spread of Coronavirus, the residents of care homes have had to live under more draconian rules than the rest of society.

All of us in the UK have had to endure months of lockdown but at least we have been able to go out for exercise, and at least we could see friends and relatives over the summer.

Residents of care homes have been (through nobody's fault) denied even basic freedoms. A trip to the shops or taking advantage of the "eat out to help out" scheme was not an option for them, even in the summer.

They have not been able to see their families and friends for months at a time. It was only on the 8th of March 2021, after eleven months of isolation, that care home residents were able to hold a family member's hand. Many people have faced a year of not being even able to hold hands with a husband or wife. The misery this has brought has been widely reported in the press and TV.

Basic freedoms

Even before Covid, those working in Care and Nursing Homes (by their nature) have not been able to give their residents the freedom and happiness that we all take for granted; which we all have at home.

The Live-in Care Hub worked with the Personal Social Services Research Unit (PSSRU London School of Economics/ University of Kent) and ran a large secret shopper survey of more than a thousand Care and Nursing Homes. It found that in many Care and Nursing Homes, freedom is significantly curtailed; for example:

- In a nation of animal lovers, in more than half of all the Care and Nursing Homes surveyed, pets are not allowed.
- And shockingly, in a quarter of the Care and Nursing Homes surveyed, residents were not allowed out of the grounds for a walk – a serious restriction of their basic right to liberty³.



Value for money

Most people are going to have to pay for at least a portion of their care. There is no way around this: local authorities' budgets are very tight and the hurdles before they will contribute have got higher over the last two decades.

The economics of Care and Nursing Homes are similar to any institution, whether a hotel, a hospital or a school. The only way they can survive is by being as efficient as possible with their costs, in particular with the variable cost associated with labour. In just the same way as hotels have introduced buffets to reduce the number of waiting staff, just as schools try to focus their efforts on the most needy people, so Care and Nursing Homes have to focus on being as efficient as possible with allocation of staff resources. Indeed, it's important to note that majority of care home fees will go towards providing the accommodation and food, and proportionally less going towards actual hands-on care or time with caring staff to do the things that care home residents love to do.

Even the most expensive care or nursing home carefully measures and rations staff time. The inevitable limit on staff time means that, by definition, residents can't have the spontaneity and freedom that we all value in our day-to-day lives. If someone wants to go for a walk but needs help, this will have to be planned. If someone wants to cook a boiled egg with soldiers for him or herself, at three in the afternoon, this needs to be planned.

What does this mean in terms of the amount of actual one-to-one care you get for your money? It means that although the average price of a nursing home in 2019-20 in the South of England is over £1,000 a week⁴ homes will typically allocate around three hours of one-to-one care a day, much of which is 'transactional' rather than quality time spent doing what the individual would like.

By their very design, Care and Nursing Homes can offer economies of scale. What is much harder for them, is to give their residents the one-to-one care, flexibility and freedom they deserve. Institutions can win on price but it is harder for them to win on a personalised approach to care.



What does give people the safety, dignity and the value for money that they want and need?

Live-in care.

Live-in care is just that. It allows an individual, or couple, to stay in the comfort and familiarity of their own home. They have one-to-one, high quality 24/7 support from a carefully matched carer who lives with them.

Depending on the provider and level of care agreed, core services typically include: help with mobility and safety, personal care, medication, night time support, shopping, cooking, housework, pet care, admin, trips out and appointments, plus companionship and emotional support.

Many carers are specially trained to cope with conditions such as dementia (75% of Live-in Care Hub clients live with dementia), stroke, MS, Parkinson's or palliative care.

Safety

In a pre, during and post Covid world, live-in care offers greater safety and improved wellbeing, than institutional care.

The members of the Live-in Care Hub together look after more than 2000 people and have been significantly less likely to be affected by Covid, despite being able to continue to enjoy their lives. The rate that people have died of Coronavirus in Care and Nursing Homes is about 7,136 per 100,000. The rate for over-80s in general was 2376 per 100,000. For live-in care, the rate was significantly lower at 1,482 per 100,000⁵.

Why is live-in care safer?

- The first and most obvious reason is that the person being looked after is in his or her own home, not in an institution. Whilst still being able to enjoy their lives, they are not mixing with others being discharged from hospital or enclosed with others who may have infectious illnesses. This personalised and intensive care also reduces the risk of injury.
- The second is that with live-in care, his/her carer is by definition living with him. Unlike in a care or nursing home, where carers are working with dozens of residents, a live-in carer is only working for one client, and is there just for that person or couple. With less travel and fewer chances to catch and pass on disease, the carer is unlikely to be an unwitting source of infection.

“ I live in my own house and have my own life and live how I want ”

MB aged 83

Safety for short-term care

Often, someone will need only short-term care. Perhaps giving the main carer (often a partner) a break or they may need help post-operatively and need a live-in carer for a few weeks until they are better. Family/friends are not always free to help and may not live nearby.

During the Covid pandemic, the people in the Live-in Care Hub supported dozens of people for short-term care. They too benefited from this safe and personalised support.

Safety in a post and pre-Covid world

Although Covid has dominated news for the past year, through the year 2020-21 as well as before and after, everyday accidents like trips and falls can and do end up catastrophically.

Previous research commissioned by The Live in Care Hub shows that with live-in care, you are less likely to have a catastrophic hip fracture than if you are in a care or nursing home. In fact, you are twice as likely to do so in a nursing home than when receiving care in your own home. In a normal year, there are about 66,000 hip fractures a year in England, Wales and Northern Ireland. According to the Royal College of Physicians, "hip fracture patients face a significant risk of dying or losing their independence."

Tragically, a month after suffering a hip fracture, one in 12 people will sadly pass away and only half will have returned home⁷.

HALF as many hip fractures: Live-in care vs care from residential Care and Nursing Homes¹³.



Live-in care - a 1.7% chance of having a hip fracture¹³ in any one year



Residential care & nursing homes - a 3.2% chance of having a hip fracture¹³ in any one year



Dignity and happiness

Everyone wants the dignity and happiness of being able to look after themselves and be as self-sufficient and independent as possible. Whilst many may need it, this does mean that people resist asking for help for as long as possible.

As a result, when you do need care, you want that care to allow you to have the freedom and dignity to live life as you want to, not as other people dictate. Live-in care enables this. The carer is only there to do the things you can't do any more and to help you to do the things you want to do.

During the pandemic and the repeated lockdowns of 2020-21, people with live-in care have been able to have just the same freedom as the rest of society, with the added benefit of not feeling lonely, as they have had the carer living with them and can continue to see the loved ones in their 'bubble'.

They have been able to have their daily exercise, just as the rest of us have; they have been able to enjoy the glorious hot weather of the summer of 2020, just as the rest of us have; they have been able to go out to restaurants and cafes, the moment we were all allowed to; they have been able to see friends and family, including for Christmas.

“My grandmother loves her dog and her garden, and claims to have gone for a walk every day of her life. She would be miserable without these. Our carers have let her live the life she loves”

Client's grandson

Real lives

Val Doonican's story

Household favourite Val Doonican, graced TVs and pop charts for over 25 years. A strong family man, his marriage to fellow entertainer, Lynette Rae, spanned 54 years. They had two daughters - Fiona and Sarah - who, in 2013 noticed their parents were becoming increasingly frail. Val was a carer for Lynn, who had Alzheimer's and arthritis, but he also suffered a series of illnesses. It was clear they needed extra support.

The family opted for live-in care. Fiona recalls that within a few days her parents were used to it: "They thought it was amazing. They were being cooked delicious meals, brought cups of tea and cared for, in their own home and to their own timescales."

In 2014 Val had a series of mini-strokes and went into a specialist nursing home to recover. Lynn remained at home with carers, who made sure she could visit Val regularly. Sadly, six months later in July 2015, Val passed away. After being married for 54 years, Lynn missed him terribly, but her carers remained at her side to provide much-needed consistency and care.



Rachel's care journey

When Rachel became increasingly frail, her family put her Devonshire house on the market and moved her to a care home near them in Luton, but, with demanding jobs and a large family it was difficult to visit as often as they wanted.

Rachel felt lonely and institutionalised and started going visibly downhill - until her son and daughter-in-law discovered live-in care. One of The Live-in Care Hub's member agencies quickly organised Lisa, an experienced carer, to move in so Rachel could return home.

Able to see her friends regularly, attend her local church and history society meetings again, the improvement in her happiness and wellbeing was rapid and sustained - and her family are reassured that she is in the best possible hands.

“One thing at the forefront of our minds was that we wanted to treasure their last years and have wonderful memories of our parents, helping them to maintain their dignity, together, in the home they loved. They both just adored their carers; I have recommended live-in care to so many people”

Fiona Doonican

Staying together

Margaret was diagnosed with Brown-Sequard Syndrome, a condition of the spinal cord, 20 years ago, tragically just as her husband passed away. Some 10 years later an operation to improve things went badly, leaving her with no feeling in her left leg and constant pain and sensitivity in the other one.

However, she is a brave lady who's been helped significantly by live-in care. The former specialist paediatric physio, who changed children's lives at Addenbrookes Hospital and also supported others as a tennis coach, has managed, as far as possible (with the help of her live-in-carer), to maintain her independence and a busy social life. Indeed, that's how she met Hugh, a wonderful man with whom she has lived for the past six years (plus his springer spaniel, Jack). They recently married and, because her husband is rather frail, sharing a live-in carer is the perfect solution for them; it has enabled them to build a happy life together.

The pair's respective sons and daughters live many miles away and have busy family lives, so live-in care means they can stay close to good friends and everyone is free from worry.

Value for money

Unlike a care or nursing home, the economics of live-in care are very simple. The majority of the cost goes to the wages of the carer, who deserves to be paid well for this responsible and hard work.

Most of the rest of the cost is back-office related, organising, training and recruiting carers. Because a live-in carer is there all the time, most live-in companies don't have any incentive to try and cut live-in carer working time. The incentives on cost saving are all to make the back-office support more efficient. This is the complete opposite of institutions, where the incentives are all to make savings on all costs including staffing.

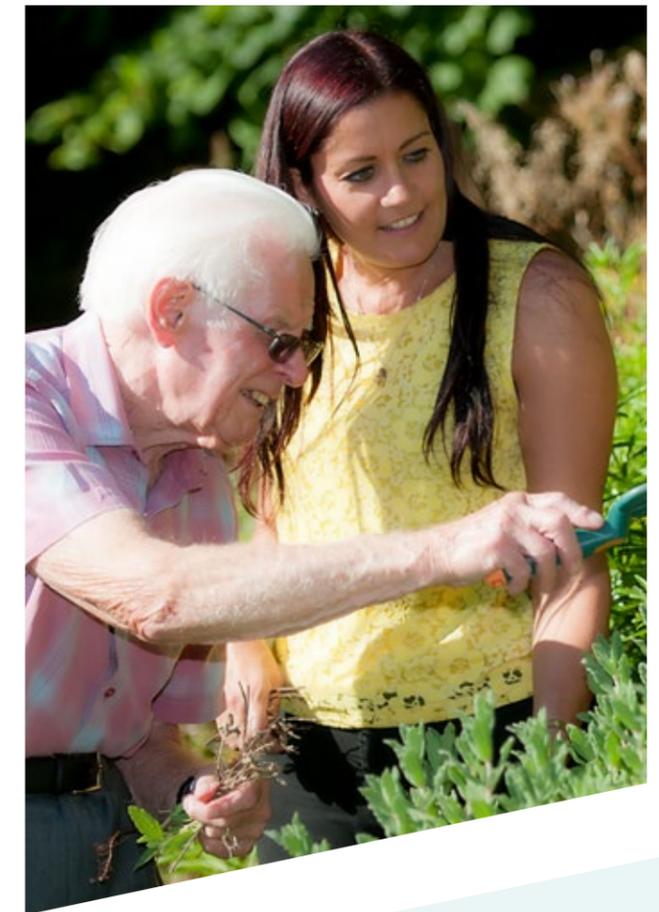
“ My mum spent the last years of her life at home, and I am eternally grateful for that **”**

SB client's daughter

Everybody who has live-in care has full-time one to one care from his or her carer. The carer is living with their client and is there to help that client do whatever he or she wants, whenever he or she wants. This means that if someone wants to go for a walk, he or she can, whenever they want. If someone wants boiled egg and soldiers at 3pm, they cook it. Someone with live-in care gets the flexibility to live life as they want, their way. It couldn't be any more person-centred.

With one-to-one care at home, the carer has all the time in the world to concentrate on her client. Instead of doing tasks by the clock, they have the time to be flexible. If someone is not hungry at lunchtime, the carer can give that person lunch a bit later. If someone doesn't feel like doing his or her physiotherapy exercises at 10 am, the carer can help do them earlier or later. If someone refuses their medication (very common, especially with people who have dementia), the carer has time to come back and try again in 20 minutes. And if, as happened with one of the Hub's clients, someone wants to teach their carer how to pack a parachute because that is what he did when he was in the SAS during the war, the carer has time to learn, again and again.

What does this mean for the amount of one to one care you actually get for your money? It means that although the price of live-in care ranges from between £800-£1,500 a week (broadly equivalent to the price of the top half of care homes in the south of England), you have a carer to offer personalised one-to-one support and care all of the time. In some cases a care or nursing home may beat this price but they certainly couldn't deliver the same value and the person living there would not be receiving one-to-one one to one care or anywhere near the number of hours of actual care time.



Paying for care

Most people will have to use their own money to pay for at least some of their care.

The Live-in Care Hub strongly recommends that before you make big financial decisions, you take advice, ideally from a SOLLA (Society of Later Life Advisors) accredited Independent Financial Advisor.

We also strongly recommend that you decide what care you want first, and then talk to the financial advisor about how to pay for it. Why? Because many, if not most, financial advisors do not know anything about care or the choices you might want to make. They tend to assume that their client will be moving to a care home and it is vital that you tell them what you want to do, rather than let their assumptions or prejudices influence your decision.

We know that as most people's main source of money to pay for care comes from their houses, equity release in one form or another is a very useful way of releasing money, yet allowing you to stay at home and still have the quality of life, happiness and dignity you deserve.

If you do talk to a financial advisor, the Citizen's Advice Bureau has good advice about how to choose one, questions to ask, as well as other websites to look at. See:

<https://www.citizensadvice.org.uk/debt-and-money/getting-financial-advice/>

Choosing full-time care

Knowing how to decide on care isn't easy, especially when it's needed urgently or when a loved one is in a vulnerable condition.

To give the latest insight on the care market and to reveal more about families' experience of finding full-time care, The Live-in Care Hub commissioned brand new research from the world renowned Personal Social Services Research Unit (PSSRU), a collaboration between

the University of Kent and the LSE³. Its 'secret shopper' research looks at price and quality across English care homes. The Hub has compared and contrasted the findings with its own vast knowledge of live-in as an option and lastly, combined these with intelligence from the authoritative **Care Homes Market Study 2017⁸** to identify the following key factors to consider.

Care considerations



1. Word of mouth: Asking trusted friends and family for advice on their own experience of choosing care reassures people in a world of hidden costs, lack of information and generally very limited time in which to research and organise everything. However it's also important to consider all of the options.



2. Distance from home: Naturally, people want to stay close to friends or family but when investigating care homes, most people look within just 20 minutes' drive from home. This significantly reduces choice given 19% of postcode districts⁸ have only two, or fewer, care or nursing homes within a 15-minute drive time. Obviously, with live-in care this isn't an issue.



3. Value for money: The research shows that the cost of live-in care is on a par with many care and nursing home fees, especially in the South East and London. More information about costs and financing can be found on pages 13 and 14.



4. Quality of care: Good care should enable people to maintain the best possible quality of life, for as long as possible, but...Only 40% of care homes can guarantee residents won't have to move out if their condition deteriorates³; in most cases live-in care clients enjoy packages that evolve to meet their needs until the end (in fact a large majority die at home or within 48 hours of going into hospital).



5. Cleanliness, friendliness and homeliness: Everyone wants to live somewhere that feels like home, rather than an institution. But while functional needs are easily achievable (more than two thirds of Care and Nursing Homes are clean and comfortable say residents⁹, with 70% saying all their needs are met), it's the feeling of being at home that's harder to capture. This is a key part of people's happiness.



6. Staffing: While in a care or nursing home there may be numerous staff (ratios range from three residents to one carer; to eight or more residents to one carer), one to one time is normally strictly allocated and it's rare to have three hours or more of it per day¹⁰. It's therefore harder for care home staff to give the level of care they might want to. Live-in carers however are there 24/7 to give individual, one to one, personalised care – a key reason behind the much lower recorded rates of falls and hip fractures for live-in care – a crucial safety and wellbeing factor with older people. Shockingly, "low expectations and pressure to make decisions quickly means people often accept the first home that is 'good enough'". The Live-in Care Hub recommends advance care planning to avoid the 'good enough' decision and achieve the 'perfect for me' scenario.

“Low expectations and pressure to make decisions quickly means people often accept the first home that is 'good enough'”

Questions to ask

Most people, until they or a loved one need care, don't know anything about it. So they don't know what questions to ask a care or nursing home, or a care agency before they start – to be sure of getting the best quality care.

Which, the consumer magazine, has a website:

<https://www.which.co.uk/older-life-care>, which is independent and informative.

Before choosing a care or nursing home, please read its section on what to do and what questions to ask:

<https://www.which.co.uk/older-life-care/housing-options/care-homes/choosing-a-care-home-azff15m2v43f>

Before choosing a care agency to stay at home, if you ask these questions, you will be in a much better position to make an informed decision:

<https://www.which.co.uk/older-life-care/home-care/organising-home-care/questions-to-ask-a-home-care-agency-axgud1t8rs28>



Live-in care - find out more

Live-in care options

There are two models of live-in care: full management and introductory. Some of The Live-in Care Hub's members offer the former and some the latter - and a few offer both.

With full management, the company providing the care employs and trains its carers and oversees all aspects of care. It suits families with significant other demands on their time, or those living some distance away.

An introductory care service is where agencies do not employ carers directly. They match clients with carers and provide training. Their carers are responsible for their own tax and NI contributions and are paid directly by clients or their families. This care option is appropriate for those families able and keen to be more closely involved.



Further information

If you would like to find out more about 24/7 care, The Live-in Care Hub is an invaluable information resource that shows how, with the right professional support, loved ones can stay in their own home, often right through until the end of life.

Website: www.liveincarehub.co.uk
Email: hello@liveincarehub.co.uk
Messenger: m.me/liveincarehub



Sources and references

1. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/numberofdeathsincarehomesnotifiedtothecarequalitycommissionengland> gives the number of deaths from Covid in care homes in England (April 2020-March 2021 = 28,543), and then multiplied down to give a rate per 100,000. Care / Nursing home population assumed to be 351,479 in England from CMA report (ref 8) which gives total beds in England as 382,042 and assuming a 92% occupancy rate.
2. <https://www.gov.uk/government/publications/covid-19-reported-sars-cov-2-deaths-in-england/covid-19-confirmed-deaths-in-england-report>
3. LSE - Allan, S. (2018) Price and quality across English care homes: Evidence from a secret shopper survey. Report commissioned by The Live-in Care Hub, PSSRU Discussion Paper 2945, PSSRU: Canterbury. <https://www.pssru.ac.uk/pub/5422.pdf>
4. <https://www.payingforcare.org/how-much-does-care-cost/>
5. Live-in care hub survey among 19 live-in care agencies, 12th March 2021
6. Falls and Fragility Fracture Adult Programme (FFFAP): National Hip Fracture Database (NHFD) extended report 2014. London: Royal College of Physicians. (National Hip Fracture Database National Report 2013)
7. NHS Choices website: <http://www.nhs.uk/conditions/hip-fracture/pages/introduction.aspx>
8. Care homes market study 2017, Competition & Markets Authority.
9. <http://digital.nhs.uk/pubs/adusoccaesurv1617>
10. Anecdotal evidence from an ex-manager of a high-end care home
11. Care homes market study 2017 - Competition & Markets Authority page 38
12. NHFD 2019 annual report <https://www.nhfd.co.uk/20/hipfractureR.nsf/docs/2019Report>
13. Johansen, A, Boulton, C., and Neuberger, J (2016). Diurnal and seasonal patterns in presentations with hip fracture—data from the national hip fracture database. Age and Ageing 2016; 45: 883–886. From this study we see that 12,141 hip fractures took place in 2014 in England, Wales and Northern Ireland. Competition commission research shows that there are 376,607 people in care homes in these countries. Therefore, there is a 12,141/376,607 = 3.22% chance that any one person will have a hip fracture. Using data collected by the Live-in Care Hub over 2018 and 2019, 47 people out of 2774 had a hip fracture = 1.7% chance of a hip fracture



www.liveincarehub.co.uk

Devised & created by The View: www.wearetheview.com

