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Foreword

It is a truth universally acknowledged that most people, even if they need a high level of care, want to stay at home, forever. With the Office of National Statistics predicting a 35 per cent growth in the number of over 80s in the next decade, up to 4.6 million people in the UK, the issue of how to find the best care for people is growing in importance.

At The United Kingdom Homecare Association, our mission is to promote high quality, sustainable care services so that people can continue to live at home and in their local community. To do that, we must enable people who need care to make informed choices.

Live-in care is one of a range of options available. People either don't know it exists, or do but believe that it is too expensive for them, so discount it.

This report, produced by a unique coalition of live-in care providers - The Live-in Care Hub - brings together data from the Competition and Markets Authority; research commissioned from the PSSRU (Personal Social Services Research Unit at the University of Kent and the LSE); a survey of people who have live-in care (following criteria set out by the University of Kent) and accident reports from Hub agencies. The report focuses on hip fractures and their consequences, as well as drawing on previous published and unpublished research from Hub members and the academic press.

The work shows that live-in care, in general, allows people to be happier, more independent and less likely to have a hip fracture than if they were in a care or nursing home.

It also looks at the costs of care and shows live-in care costs are on a par with a third of all nursing homes nationally, and with a higher proportion in London and the South East.

If you have to make decisions about care, I urge you to read this report first.

It will give you the information you need to make the most appropriate choices regarding care. The peace of mind that comes from knowing that you or your loved ones will live happily, safely and independently at home, until the end of life, is priceless.

Dr Jane Townson

Chief Executive Officer
United Kingdom Homecare Association (UKHCA)

January 2020



Care crisis

There are now 12 million people aged 65¹ or over in the UK, meaning later life care is something more and more families are having to consider.

BUT, the majority don't plan for it and when loved ones require full time care it's generally needed urgently and unexpectedly². Typically, it's where a parent or relative's declining health reaches a 'tipping point', or perhaps there's a family emergency, the illness of a family carer, a fall or a hospital visit.

Desperate families often have no idea who to turn to for help, or where to go for quality information about care choices. They are often suddenly at crisis point and have to drop everything to start researching full time care. It can be an emotive and stressful time for all concerned.

The default care option tends to be residential or nursing homes, although unsurprisingly 97 per cent of people³ DON'T want to move into institutional care if they become ill or less able to cope. It can be unsettling and deeply upsetting to move away from friends, a partner or pets.

However, there is a REAL alternative. Ageing in our own home - in a safe and therapeutic environment - is the oldest and most respected form of social care. Live-in care, still little known, but fast increasing in popularity can provide the perfect solution.

Most people are at crisis point when they start looking for full time care



No pets allowed: care home heartbreak

A survey commissioned by The Live-in Care Hub discovered that shockingly, over two million people in the UK⁴ know an elderly person who had to have their cat or dog put to sleep, or be given away, when they moved into a residential or nursing home. The study found that 20% of elderly people would put their health at risk by refusing to go into care without their pet and 17.4% would pretend they were fine so they didn't have to go into a home and leave them.

Parting from much loved animals is one of the most distressing consequences of moving into residential care. One enormous advantage of live-in care is that people can stay with the pet they adore; it is widely recognised they can help reduce isolation, loneliness and boredom in old age.

Poppy (shih tzu) has given mother much pleasure over the years and is great company for her. She is always by her side and now even sleeps in her room at night

What is 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.

Key benefits

Live-in care provides great peace of mind. To be in familiar surroundings, with treasured possessions, beloved pets, friends nearby, while receiving tailored, professional care enables elderly relatives to live well - and be as healthy and happy as they can be.

With no rigid timetables, each day is planned around the client and their own routines and preferences (this is especially beneficial for those with dementia). Carers can adapt quickly and easily to any changes in needs. Indeed, getting to know their charges well also helps a carer spot when someone might just be little off colour, enabling health issues to be picked up as early as possible. Live-in care is about caring for the whole person, not just an age or health issue.

Good carers possess a balance of dedication, reliability and compassion, combined with sociability, good humour and common sense. Hub care providers have developed proven in-depth carer-client matching procedures to Live-in carers help clients enjoy things in life that bring happiness: seeing friends, baking, gardening or reading a great book

ensure sensitive and compatible pairings. It's an essential part of making live-in care so successful.

Live-in fees can compare favourably with residential care homes, especially where couples are looked after together. Costs vary depending on requirements, for instance some people may need simple companionship and support with housekeeping, others may have complex medical needs.

Hub members are all transparent about their fees and fee structures. See pages 13 & 14 for more about planning and affording care.

Henry (golden retriever) has been such a comfort to Margaret over the years that I firmly believe he has been a fundamental influence on her wellbeing and recovery ##

It is little surprise that the Hub's survey found support for live-in care at home. Over 18% of respondents believe that those elderly people they knew would, if they were aware of live-in care, choose such care to remain with their pet.

Hub member care agencies say their carers help look after not just dogs and cats, but clients' pet chickens, donkeys and ponies, tortoises and even a llama in one case!

Real anguish

Up to 71 per cent⁵ of residential homes and sheltered housing schemes don't allow pets causing many elderly people real distress.

Being torn from a pet is hugely traumatic emotionally, but with live-in care pets can stay with their owners, avoiding the upset of rehoming, or worse, putting down their pet.

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 LSE⁶. 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 2017**⁷ 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 care⁷ reassures people in a world of hidden costs, lack of information and generally very limited time in which to research and organise everything.



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 districts⁷ 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 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...
- More than 50% of homes do not allow people to keep their pets⁶; whereas with live-in care pets are part of the family – and stay that way.
- More than a quarter of care homes don't let residents leave the grounds⁶; but with live-in, clients are free to go out and about wherever and whenever they want - their carer can always go with them, if desired.

Only 40% of care homes can guarantee residents won't have to move out if their condition deteriorates⁶; 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 residents⁸, 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 a day⁹. 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 live-in's much lower recorded rates of falls and hip fractures – 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 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/later-life-care, which is independent and informative.

Before choosing a care home, please read its section on what to do and what questions to ask: https://www.which.co.uk/later-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:



Hip fractures and shattered lives

There are about 66,000 hip fractures a year in England, Wales and Northern Ireland¹¹. According to the Royal College of Physicians: "hip fracture patients face a significant risk of dying or of losing their independence."

A month after suffering a hip fracture one in 12 people will have died¹² and only half will have returned home. The annual cost for all hip fractures in the UK¹³, including medical and social care, is about £2 billion.



HALF as many hip fractures:

Live-in care vs care from residential care and nursing homes²⁵.



Live-in care -

a **1.7%** chance of having a hip fracture 25 in any one year



Residential care & nursing homes -

a **3.2%** chance of having a hip fracture²⁵ in any one year





Preventing and avoiding hospital admissions

Clients with live-in care experience far fewer hip fractures and consequent long hospital stays. And, even if someone has been in hospital, they are able to be discharged quickly as they have care in place. Rehabilitation at home is far less traumatic and more comfortable in familiar surroundings. There's also less chance of contracting the ever-present risks of a beautiful acquired inforting.



Staying safe and well at home is the best solution for people, their families and communities.

Live-in care has an essential role working with the health service. It can make a real difference to avoiding hospital admission, which is traumatic for anyone, but particularly for people with dementia or advancing frailty

Bridget Warr CBE,

Former Chief Executive, United Kingdom Care Association Live-in care offers an effective solution to the issue of hospital bed blocking, which currently costs £900m a year for NHS England alone (BBC Feb '16). Early discharge from hospital is thought to save around £700 per bed per night. Live-in care means clients have an evolving personal care plan and ongoing bespoke, person-centred attention means they're far less likely to suffer from falls. This releases pressure on NHS A&E departments and significantly mitigates the risk of readmission.

Avoiding emergency hospital admissions is a major concern for the National Health Service (NHS), not only because of the high and rising unit costs of emergency admission compared with other forms of care, but also because of the disruption it causes to elective health care - most notably inpatient waiting lists - and to the individuals admitted.

The happiness survey

Anecdotally, it's recognised that the freedom of being able to ask for a favourite meal, see a football match, sit with a much-loved pet, listen to a story, or be taken to the seaside on a sunny day means quality of life is truly enhanced.

Live-in care honours dignity and independence. It offers the least restrictive environment for people as they age, with none of the rules associated with institutionalised care. Live in care is personalised, as no one person is the same as another. It can truly enrich quality of life.

The Live-In Care Hub's quality of life study¹⁵ backs this up. As people get older, weaker and less active, and especially where they have medical conditions, the simple things, such as food, drink and a sense of independence often become life's most important aspects. Having tasty, nutritious meals can become a highlight of the day, while conversely, meals that are unappealing or of low quality can make eating a tedious and unpleasant chore, risking a further decline in health.

- 39% of those in residential care and OVER HALF (53.5%) in nursing homes NEVER LEAVE THEIR HOME, Compared with just one in seven (14%) of people who choose live-in care
- 98% of live-in clients say the care and support they receive helps them have a better quality of life

Happiness is NOT a luxury – everyone needs it!

- 97% do at least some of the things they value and enjoy (despite many being sick, frail and close to the end of life)
- 5% of those in residential care and one in eight (11%) in nursing homes say they don't do ANYTHING they value or enjoy with their time



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 recollects 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 andcared 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 after all.

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 was also a tennis coach has managed, as far as possible (with the help of her 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 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.

Full time care: the costs

Most people only know about residential care or nursing homes, but The Live-in Care Hub is passionate about raising awareness of care at home as a real alternative. It generally offers a better quality of care and is often in a similar price bracket, or significantly lower where a couple stay together and are cared for together.

In The Live-in Care Hub's specially commissioned report: Price & Quality Across English Care Homes (published in partnership with the University of Kent and the LSE's joint Personal Social Services Research Unit⁶) undercover research was undertaken by 'secret shoppers'. They surveyed price and quality across 1,022 care and nursing homes for three different scenarios of the most common reasons people need full time care.

The report found that the average price for live-in care is £1,080 a week. When that's compared with nursing homes across the country (a large proportion of people with live-in care would otherwise be in nursing homes), a third of them charge £1,000 or more a week. Looking at London and the South East, live-in care is less than a quarter more expensive than the average cost of all residential care.

- Nationally, a third of nursing homes cost £1,000 a week or more and 10% of care homes cost over £1,000 a week⁶
- In the South East, the average price of residential care is £901 a week, with 64% of nursing homes costing £1,000 a week or more⁶
- In London, half of all nursing homes cost £1,000 a week or more, and a quarter of care homes cost this much
- In contrast, the average cost of fully managed 24/7 livein care for someone with dementia, who would otherwise need to be in a nursing home is £1,080 a week⁶

The investigation also confirmed that:

 Nursing homes are significantly more expensive than care homes, even though the conditions described in the

- secret shopper exercise are not necessarily more work for the care home. Live-in care fees are no higher for a 'nursing home' condition than a 'care' condition.
- A diagnosis of dementia leads to higher fees for both care homes and live-in care due to the increased support required
- There is great regional disparity in fees homes in London and the SE are much more expensive than in other parts of the country. Live-in fees are the same throughout the country

Some care homes are clearly excellent; they allow pets, or allow pets to visit, residents can pop out when they want (health permitting), they're friendly and engaging on the telephone and say the client wouldn't have to move elsewhere if their condition deteriorated. **However, they are relatively rare**: just 7% of the care home population. They cost an average of £893 a week (and 49% of them cost more than that), with 33% charging £1,000 or more a week.

All other things being equal, the study found that excellent live-in care agencies offer the same or more than residential care homes: they allow their clients to have pets, allow pets to visit, allow their clients to go for a walk when they want, are friendly and engaging on the telephone and their clients do not have to move if their condition worsens.

The cost of a medical appointment

A third of care homes charge extra⁶ for a carer to take their client to the doctor or hospital.

Live-in carers don't! In addition, carers often also look after their client if they need a hospital stay. This can be a massive relief for families, especially those who don't live nearby and for whom visiting regularly and getting to speak to medical staff is difficult.



Financing care

In recent years, the criteria for obtaining state funding for care has been tightened and far fewer people are now eligible. It's certainly worth exploring state funding - both with local authorities and with the NHS - but in most cases, it's likely that at least an element of care will need to be privately funded. Whatever type of care is required, making early saving plans is essential; costs will inevitably add up and it will be expensive.

A survey found that only 27% of the population⁷ had planned how they would fund potential care (something 75% of people are likely to need at some point), while 60% of women have planned their wedding before even meeting their potential groom.

The key considerations will be different for each person to ensure the desired balance of quality of life alongside financial constraints, as well as how long care is likely to be needed and whether full or part time is appropriate. Family members may also be available for additional support; if family can help one week out of four, that cuts the cost by a quarter - flexibility that's not possible in a care home.

It is certainly worth talking to a financial advisor who is SOLLA (Society of Later Life Advisors) qualified as well as checking fees upfront to clarify actual charges, rather than just percentages. The Live-in Care Hub is also a great source of impartial advice about arranging care for each individual circumstance.

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 Telephone hotline: 0330 311 2906 Email: hello@liveincarehub.co.uk Messenger: m.me/liveincarehub

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.

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.

Sources and references

- Office for National Statistics population estimates for the UK, England and Wales, Scotland and Northern Ireland: mid-2017
- ^{2.} CMA report p122-3; Live-in Care Hub anecdotal sources
- 3. Research conducted for One Poll, July 2014, for live-in care providers, Consultus Care
- ⁴ Nationally representative survey of adults commissioned by The Live-In Care Hub via market research specialist Censuswide during November 2014. Over 2 million Brits (2,081,878.60 - 4%) know someone who had to have their dog and/or cat put to sleep because of moving into a residential care or nursing home. 1,637 over 16 year olds were surveyed.
- ^{5.} Society for Companion Animal Studies (SCAS)
- ^{6.} 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
- ^{7.} Care homes market study 2017, Competition & Markets Authority.
- 8. http://digital.nhs.uk/pubs/adusoccaresurv1617
- 9. Anecdotal evidence from an ex-manager of a high-end care home
- $^{\mbox{\tiny 10.}}$ Care homes market study 2017 Competition & Markets Authority page 38
- ¹¹ NHFD 2019 annual report https://www.nhfd.co.uk/20/hipfractureR.nsf/docs/2019Report

- 13. NHS Choices website: http://www.nhs.uk/conditions/hip-fracture/pages/introduction.aspx
- ¹⁴ 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.
- A survey investigating the quality of Live-in Care Hub's clients using the ASCOT (Adult Social Care Outcomes Toolkit) Survey technique, developed by Personal Social Services Research Unit, University of Kent. 293 responses. Compared to Personal Social Services Adult Social Care Survey, England 2016-17



