Caring for Britain

Journeys through care

The stories

The stories in this report show that there is much more to be done to support older adults. They also show that there is some ground-breaking thinking, research and delivery happening right now. This report also contains the stories of real people, who have shown great courage to share how their lives have changed during their care journeys. The authors are grateful to Tony Watts, leader of EngAgeNet, for his work in writing the personal stories, based on interviews he conducted during the spring and summer of 2020 – for this reason, and decades of campaigning for older adults, the 'last word', of the report belongs to Tony.

Legal & General Thought Leadership Commitment

A vigorous national debate, about the issues that affect our customers, colleagues and shareholders, is an important part of national life.

We want to stimulate the big conversations and ideas that can contribute to the progress of our society and our economy.

Legal & General is delighted to support the work of Think Tanks and of academics and specialists in areas relevant to our business.

As part of our commitment to encourage debate and freedom of speech we exercise no editorial control over the conclusions or recommendations made by our contributing authors.

Foreword

Professor David Grayson, CBE

I hope after you have read "Caring for Britain," that you will share my sense of excitement and possibility. The possibility for good later lives; for extended healthy lifespans. The possibility that many more Britons can enjoy greater choice in later life. The possibility that digital technology and Artificial Intelligence offers for greater personal independence for longer and for more personalised health care. The possibility to build a preventive National Health Service rather than a reactive National Sickness Service.

At the heart of this timely paper is the aspiration that Tony Watts expresses: that all older people should be able to lead rich fulfilling lives connected to family and friends. The paper skilfully intersperses the stories of individual older Britons who have confronted the realities of today's care system, with the stories of individuals and organisations working for disruptive innovation and radical improvements in the quality and quantity of care available.

The stories told by Marguerite and Ken, by Phyllis and Peter, by Brenda, by Marion and Jack, and by Monica are powerful insights into both the good and the bad aspects of the care that older people use today.

Each of the organisations in this story of a journey through care come from different places. Some are entrepreneurial charities. Some are for-profit enterprises with purpose. What binds them is their purpose; what they all have in common is an absolute commitment to empowering the people who need care, their families, their carers, their medics and their advisers. All of these people, from consultants to care professionals to financial advisers work together to create an ecosystem that helps those who need care to meet their goals.

Telling the stories of the energy and innovation of start-ups, the research from our universities, the insight of charity leaders, the advice of financial experts and the experience of care professionals shows the power of what is happening around us all right now – people with vision are working for the people who matter far more than ownership distinctions, the users of care.

There are millions of people dedicated to caring, and even in today's circumstances, there are reasons to be hopeful about the future. This report is about what can be done, and is being done, today. The leaders, who have written about their lives and their organisations, are out there right now, contributing to the care of millions of people. It is right that we should all consider how to build a better, more integrated health and care system but it is also right to recognise that there are people with ideas, energy and compassion who are changing the system every day, right now.

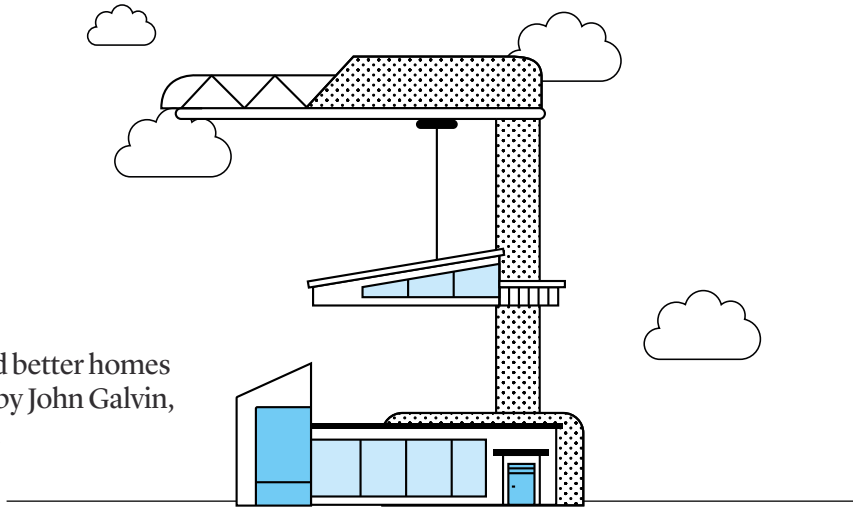
As a Legal & General customer, I am delighted that L&G has taken such a powerful, leadership role on making Later Life better for many more Britons. "Caring for Britain" is one more tangible example of this leadership. I hope that L&G will now use its convening role to generate an informed conversation around how the innovations described in the paper, can help to reinforce each other and spur further innovation from public, private, charity and social enterprise sectors. As Tom Lord reminds us in his essay, COVID19 has put added onus on healthy lifestyles. We should use this once in a generation moment, to create radical improvements in support for a good and healthy later life, where individuals and their families have genuine choices.

As a campaigner, I want this report to stimulate more positive collaboration and further innovation.

> **"When your loved one starts to change, that is a very disempowering moment. Being able to bring someone in, and being able to keep in touch with that carer, is a way of empowering a family when it feels like they're losing control."**
>
> **Rachael Crook, co-founder and CEO, Lifted**

Positive developments in UK care, happening right now

£5m
Newcastle post-COVID care home prototypes



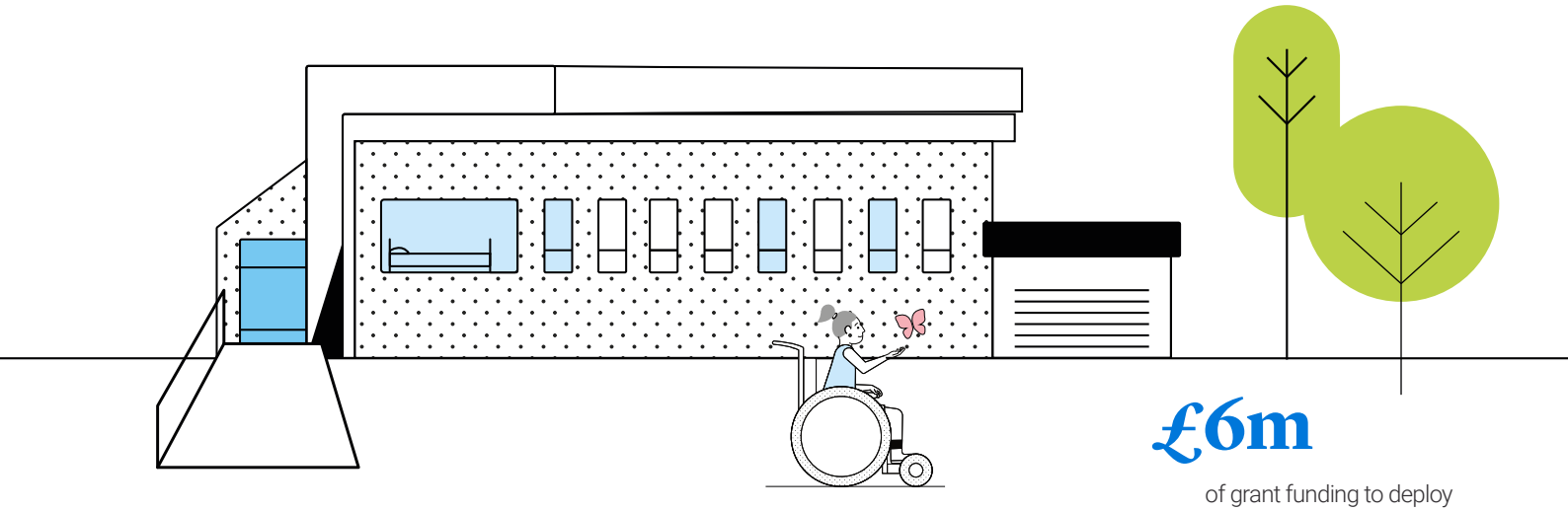
1 new kinds of leaders like Rachael, Max and Andrew

2 the development of new and better homes for older people, discussed by John Galvin, Adam Hillier and Tom Lord

3 high quality information enabling marketplace tools to empower care users – pioneered by Andrew at Care Sourcer

3,000
New homes being built for retired people

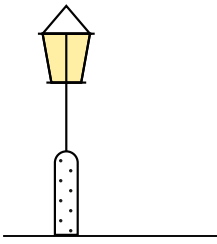
4 new roles for employers that Emily outlines



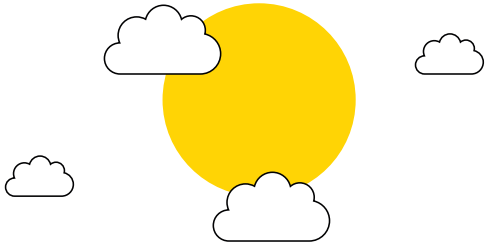
£6m
of grant funding to deploy to companies helping the healthy ageing market

5 new independence-at-home-technology from Chris at Current Health

6 new phone apps that empower families and friends from Rachael at Lifted



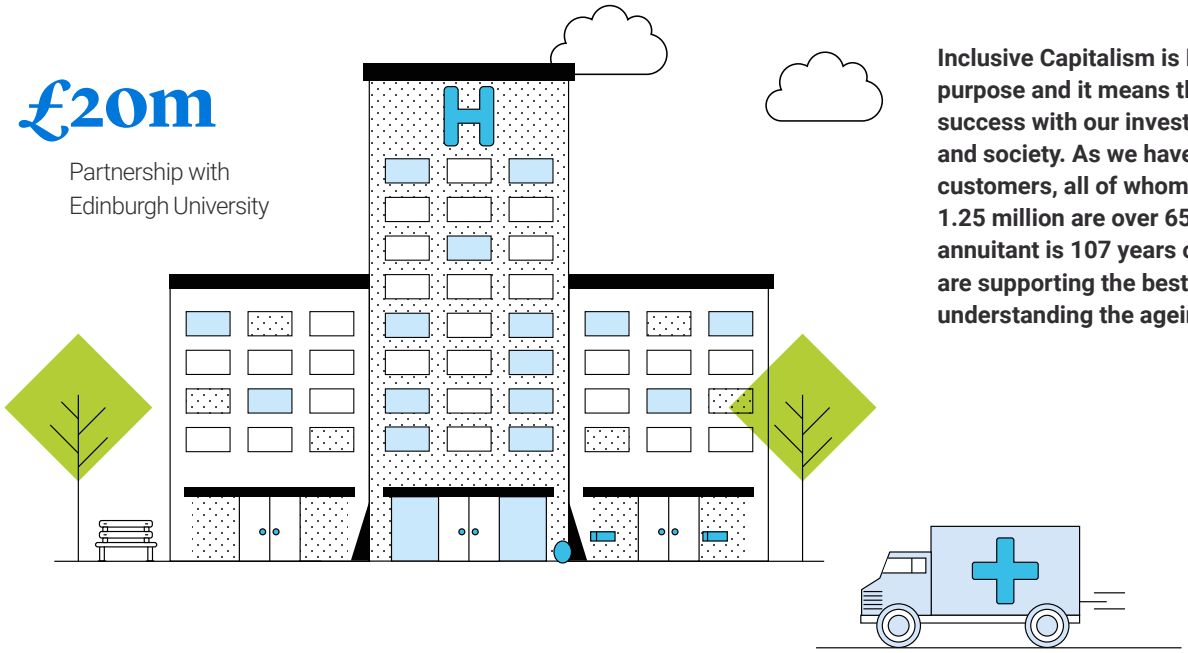
7 new cloud-data-processing, like Max at Birdie Care, that can spot early signs of health problems coming down the tracks



Building up the country's research about the ageing demographic

£20m

Partnership with
Edinburgh University



Inclusive Capitalism is Legal & General's purpose and it means that we share our success with our investors, customers and society. As we have 10 million customers, all of whom are ageing and 1.25 million are over 65 – our oldest annuitant is 107 years of age – we are supporting the best research into understanding the ageing society.

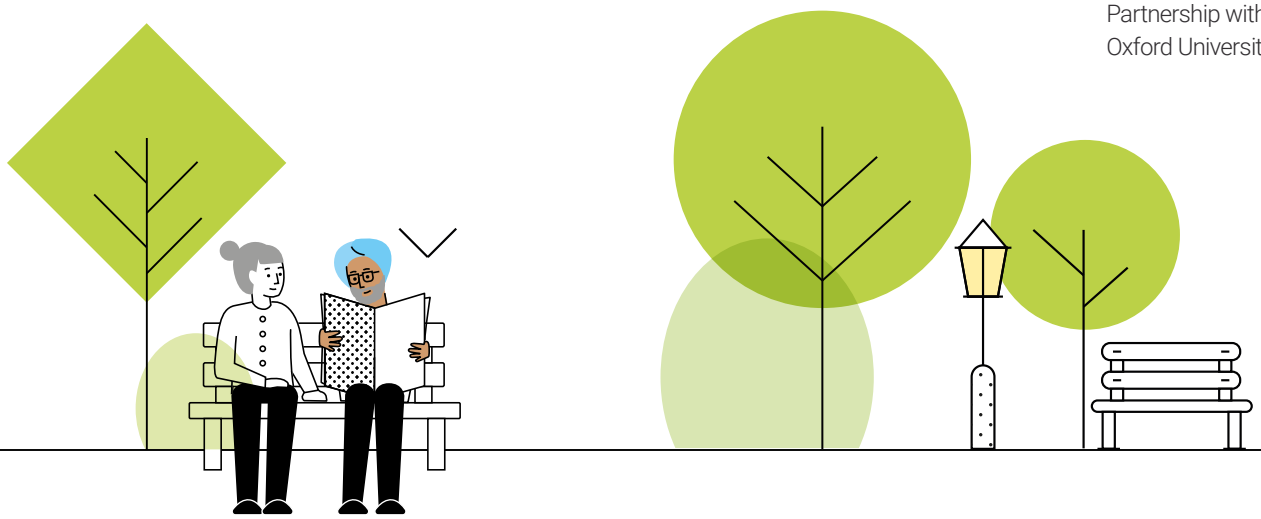
8 teamwork building technology to bring the people needing care, their family, their medics, their social workers and their care workers into one personal and tailored ecosystem

9 new ways of working for carers, created using the latest of behavioural science and medical research, to build new kinds of working cultures

10 new resources to plan for funding care like those Tony discusses

£4bn

Partnership with
Oxford University



Contents

“After her last fall, Marguerite was able to return to her own home from hospital because the couple had previously invested in some home adaptations such as a stair lift and grab rails throughout the house and into the garden.”

“The coronavirus pandemic has pushed awareness of the care system to the top of the public's priorities. For millions of people, lockdown has meant experiencing what it can be like to be an older person.

Andrew

Andrew Parfery
Co-founder and CEO of Edinburgh based Care Sourcer since January 2016.

Care Sourcer

caresourcer.com

“I'm still fit and healthy,” she says defiantly. “He's not going to go into a care home.

Phyllis

“This paper, written by real people experiencing the care system, and by a range of specialists, steps through the kind of questions and issues that people and providers face as they react to a need for care.”

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Giving up work to provide care

Emily Holzhausen OBE **Carers UK**

Emily describes how millions of people provide care for their friends and relatives, and looks at how this can impact on people’s jobs. Emily shows how important it is to have a plan and she looks at the way that employers can help to support existing and new carers.

“Half of all women will have provided unpaid care by the time they reach 46, and by 57 for men, which makes care a workplace issue.”

Emily

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Using your home to help with your care

Max Parmentier **Birdie Care**

Max describes the concept of ‘ideal care’, designed to support the physical independence of an older adult – the concept is at the heart of Birdie Care, the company he has been building since 2017. Max also explains how more structured data can help to understand what accelerates a person’s decline in health, identify infection flags and create a ‘very high resolution picture’ of the older adult.

“...older adults need a much more tailored, proactive and coordinated system of care at home, where the older adult is at the centre of the picture.

Max

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Case study: Sandy, David, & Sandy’s father

Sandy and David explain the difficulties involved with making, and getting, decisions to support Sandy’s father.

“You’re trying to make huge decisions on behalf of someone else that will affect their wellbeing and their quality of life in their last years. It’s also incredibly hard work, very tiring, and emotionally draining.

Sandy

Emily Holzhausen OBE is the Director of Policy and Public Affairs for Carers UK.

Carers UK

carersuk.org

Max Parmentier CEO of London based Birdie Care since July 2017.

Birdie Care

birdie.care

“Where advice is used, it is almost always received at a crisis point, quite often when family members understand that their older relatives can no longer safely live independently.”

Tony

Tony Müdd
Divisional Director, Development & Technical Consultancy at St. James's Place Wealth Management since 1993.

sjp.co.uk

“I am 66 and – until she passed away in 2018 aged 93 - was a long-distance carer for my Mum. As her only child it was down to me to organise her care: at the time I lived in London, she in Canterbury.”

Brenda

“When your loved one starts to change, that is a very disempowering moment. Being able to bring someone in and being able to keep in touch with that carer, is a way of empowering a family when it feels like they're losing control.”

Rachael

Rachael Crook
Co-founder and CEO of London based Lifted.

Lifted

liftedcare.com

“There are big challenges in how the country supports people who need care, as our case studies show. There are also great innovators who are right now changing the quality, coordination and delivery of care.”

“They do not want to move into a care home, so they are now trying to identify suitable supported living accommodation.”

Marion

“There must be greater focus on preventive, proactive health and care if we are to continue delivering high-quality, universally available and accessible healthcare.”

Chris

Chris McCann
CEO of Current Health since 2015.

Current Health

currenthealth.com

“I actually contracted Coronavirus quite early on and had to go into the local hospital, and they were very supportive of us both.”

Monica

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Finding and moving to new accommodation

John Galvin and Adam Hillier
Elderly Accommodation Counsel

John and Adam combine their experiences of supporting millions of older people at the Elderly Accommodation Counsel to explain the ups and downs of finding, and moving to, new accommodation. John and Adam look at the different events that can trigger a move and they also consider how people are adapting their homes to prolong their independence.

> Quite often, people who have a crisis moment make a decision based on finding that: "actually my home doesn't work, I need to move quite quickly, where can I go that is going to be suitable?"
>
> **John & Adam**

John Galvin
Chief Executive at Elderly Accommodation Counsel since 1995. Adam was John's Deputy until he joined Legal & General in summer 2020.

eac.org.uk

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Getting used to life in a new community

COO, Tom Lord
Inspired Villages

Tom runs retirement communities all over the United Kingdom and has spent the past few years creating villages. Tom explains how important it is to help people to get used to life in a new community. As well as looking at ExtraCare, Tom explains how his team have developed the role of 'wellbeing navigators' to support residents as they join a new community

> Buildings, services and facilities matter a great deal but community, belonging, support and friendships are the crucial pieces of social infrastructure that contribute to feeling safe and secure."
>
> **Tom**

Tom Lord
Chief Operating Officer at Inspired Villages, HQ in London.

Inspired Villages

inspiredvillages.co.uk

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Let's work together to design the future of care

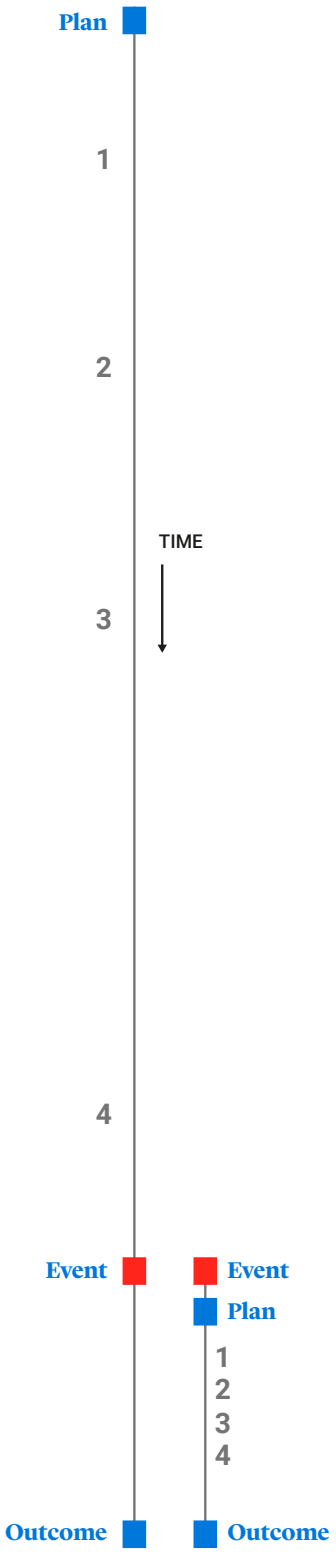
Tony Watts OBE
Chairman of the South West Forum on Ageing

Tony has spent much of the last 30 years of his career writing about and campaigning on behalf of those in later life, combining this with freelance writing on business and property. He helped establish and edited the UK's first national newspaper for older people, and now chairs the regional organisation representing older people in the South West as well as acting as Communications Director of EngAgeNet, which represents older people nationally. He received the OBE in 2014 for services to older people.

> We urgently need a readily-accessible choice of housing and care support resources enabling all of us to not simply eke out our last years... but to lead rich, fulfilling lives, connected to friends and family."
>
> **Tony**

Tony Watts
Campaigner on retirement issues and Chairman of the South West Forum on Ageing.

My Care journey planner



Big and sudden health or life changes often happen very quickly and it can be difficult to take everything in. Planning for this can make the whole process a lot less painful.

1 Understand

Understand the care landscape and your options within it.

= MY NEEDS AND MY GOALS

2 Find

Once you understand your needs and you goals, it is time to identify how you can find the right people and experts to support you.

= MY IDEAL CARE ECOSYSTEM

3 Fund

Work out the various costed options available to you.

= THE BEST ECOSYSTEM I CAN AFFORD

4 Action

Get all of your research together into one place. If you want to, write it into a plan or keep all the documents in one place.

Your Care Journey

Preparing for a life changing event

Planning your care ecosystem in the early years of your retirement, rather than having to create it in a few days after a health crisis, will focus your resources clearly on your goals, your independence and your quality of life.

Your checklists

These decisions will create your care ecosystem

Understand

Your health situation and needs

- GP planning
- Mental and physical health diagnostics
- Medication timetable
- Repeat prescriptions
- Understanding your capacity to complete Activities of Daily Living

Set your goals

- What can you achieve, now and in the future?
- Overcoming obstacles
- Adding value to every day

Examples
Walk 1 mile, go on holiday in 12 months, make dinner, read ten books, walk unaided, lose one stone in weight, leave a legacy to grandchildren

Figure out what you can do to achieve your goals

- Wellbeing
- Rehabilitation
- Exercise
- Socialise
- Hobbies
- Habits
- Volunteer

life changing event

Find

Health and care

- Medical care
- Hospital care
- Personal Care
- Pharmacy
- Dentist
- Optician
- Physiotherapist
- Podiatrist

Wellbeing

- Family time
- Social Care
- Network of friends
- Leisure
- Hobbies
- Charities

Employment

- Work
- Informal carers' work

Technology

- Cyber services
- Monitoring
- Smart phone
- Video with family

Safety

- Accommodation
- Transport

Law

- Lawyer
- Citizens Advice

Fund

Paying for health and care

- Calculate cost of 'care' , what the NHS will provide, and how much you are entitled to through the means-test.
- Find Financial advice
- Council liaison setup
- Monitoring
- Know your rights

Securing your income

- Review state benefits
- Bank accounts
- Insurance
- Annuities
- Private Pension
- State Pension
- Carers' benefits
- Equity release

Quality of Life

- Transport
- Hobbies
- Technology

Independence

- Power of Attorney
- Expressing your wishes about health decisions
- Identity
- Lawyer
- Advocacy

Action

Prepared plan in place

- Health professionals
- Finance package
- Informal care network
- Lifestyle choices
- Accommodation plan
- Advanced care options
- Employment changes
- Technology tools
- Workable range of goals

"Every one of us will have a journey through care and everyone of us will rely on a care ecosystem."

Introduction

John Godfrey
Corporate Affairs Director
Legal & General

Seventy two years ago the NHS was created to look after our health, while local councils assumed responsibility for Social Care. Today, in 2020, despite multiple reviews and much debate the basic framework of free health and means-tested care delivered by a range of providers remains intact. There are, though, changes planned for the 2020s. The NHS Five Year Forward View imagines a much more localised and patient-driven, preventative organisation and the government promises a white paper to reform social care. As these important changes are worked through into daily realities, though, there are today some real agents of change. This paper sets out the very best of public, private and charitable work in the care sector. The contributors each describe new kinds of thinking, new styles of leadership thinking, new technology, new kinds of housing and the clinical advances needed by our ageing population. This paper is neither sentimental nor judgmental – we seek only to add the unheard voices of older adults to the voices of leaders who are creating a new kind of care system right in front of our eyes.

The care challenge

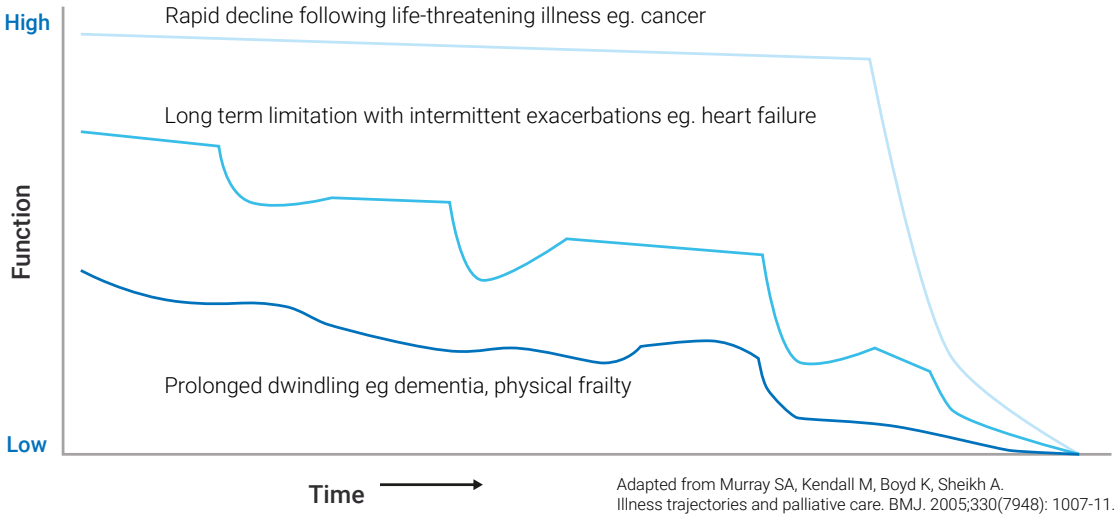
The reality of social care for older people across the UK is often problematic. 1.3 million older people request care each year while only c. 700,000 get it and the average cost of care is more than £30,000.[1] There is no national system of long-term care as there is a national system of free healthcare at the point of delivery. What we have is a patchwork quilt of services administered by local authorities whose budgets have shrunk over the last decade. The biggest contribution to care is made by informal carers whose value is estimated at £140 billion – about the same economic size as the NHS.[2] There are inequities built into the system such as the NHS paying for care after a heart attack or stroke but patients diagnosed with dementia have to pay for their own care. The boundary between health and care is hard to navigate and there are issues of variation between regions and between the UK jurisdictions, and of poor and disconnected data.

As a result, there is a poorly coordinated service that is not designed to put the patient at the centre of their own care ecosystem. As well as a sclerotic and confused supply of care, the next two decades will see more big rises in demand. A system struggling to service today's elderly population will worsen as the number of over 80s steadily rises; the growth in long-term conditions such as diabetes and heart disease increase the need for services. The average cost of health and social care for people who do not have a long-term condition is around £1,000 per year; this rises to around £8,000 per year for people who have 3 or more long-term conditions.[3] In short, our health spans are not growing at the same rate as our lifespans, leaving more older people trapped in poor and worsening health. Closing the gap between health span and lifespan is the work of a generation and will require effort from many different fields.

"If you organise care better – and that means coordination, personalisation, real time, proactive instead of reactive - you can support physical independence for a much longer period of time."

Max Parmentier,
co-founder and CEO of Birdie Care

1 Adult Social Care Activity and Finance Report, England - 2018-19 [PAS] and payingforcare.org
2 The Carers' Covenant, Ben Glover, Demos and Legal & General, 2018, p 6
3 Adult social care at a glance, National Audit Office, July 2018, p 22



Professor Bruce Guthrie, The Advanced Care Research Centre

Adapted from Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ. 2005;330(7948): 1007-11.

The Advanced Care Research Centre is a £20 million partnership between Legal & General and the University of Edinburgh to create high-quality data-driven, personalised and affordable care that supports the independence, dignity and quality-of-life of people both in their own homes and in supported care environments. Its work will be publicly available – anyone interested in delivering better care can access it. At the heart of the ACRC project led by Professor Bruce Guthrie is the recognition that care needs to be about serving the needs of people in later life, recognising the variation in how different people age and their ability to achieve what matters to them physically, mentally and socially.

Building a system that can improve outcomes for older people is the work of our whole society, including our businesses. The UK Grand Challenge on the Ageing Society seeks to: "Ensure that people can enjoy at least 5 extra healthy, independent years of life by 2035, while narrowing the gap between the experience of the richest and poorest." Earlier this year Legal & General was chosen by UK Research and Innovation (UKRI) to deploy £6 million of grant funding to early stage companies that are making a difference in healthy ageing. The UK Grand Challenge on Artificial Intelligence and Data is also particularly relevant to the future of care provision, particularly its role in preventative interventions and earlier diagnosis. As the report will show: unstructured data and fragmented systems thwart the insight and prediction that could drive better early interventions; tools to learn from the data will be an incredibly important part of the future of care, as Rachael, Max and Andrew all show.

Lastly, there is the issue of demand for retirement housing: as Adam and John, and Tom, show, the UK is only building 7,000 houses designed for older people – for a population of 12 million.[4] The future of housing and homes will be at the heart of how adult social care is provided, which is why Legal & General has donated £5m to Newcastle to pioneer new post-COVID approaches to elderly care. The partnership with Newcastle City Council will build a 20/25-bed 'new model residential care home' with built-in technology and specified to create a less institutional building that is designed for infection control. John Galvin and Adam Hillier's chapter looking at relocation explains the UK's struggle to create retirement housing, and Tom Lord shows how Inspired Villages, which is owned by Legal & General, is leading the creation of retirement communities in the UK.

Longer life is something to be celebrated – perhaps humanity's greatest achievement in the last hundred years. But longer lives also need to be better lives – hence the importance of better care for our most vulnerable older people. I hope this paper sets out some of the practical steps being taken.

The ACRC – why we should care for those in later life

Often have single or a few long-term conditions

Precision medicine targets treatment of single conditions underpinned by rich evidence, data and technology

Usually have multiple long-term conditions

Imprecision medicine overburdens people with interacting treatments of multiple conditions without good evidence, data or technology

We need a new approach which tailors care of the person to their individual circumstances, preferences and values

What happened when I first needed help?

Marguerite and Ken's story

Marguerite (75) and Ken (80) have been married for some 40 years, and while Marguerite has some mobility problems, the couple had been managing to live independently in their own home until Ken fell ill and had to go into hospital.

"While he had been showing signs of memory loss and forgetfulness before then, the doctors had not diagnosed dementia, says Marguerite, "even though I felt fairly sure that was what it was. But after the 'turn' that he had, it was obvious that this was now full-blown dementia, and while he was usually able to recognise me, it was plain that he was probably not going to get better. He was also suffering double incontinence."

"My own situation was also made worse by a series of falls, I think the result of stress, which put me in hospital at the same time. Until then we had pretty much looked after each other, but now some difficult decisions needed to be made."

While Marguerite had an LPA giving her control of the couple's finances, there was not one in place for Ken's health and welfare, so the decision on what happened next to Ken was not fully in her control.

"Ken was in hospital for two months before they felt able to discharge him, and as we don't have sufficient savings to be expected to pay for our own care, the choice of care homes was down to the Local Authority – although I did request they select one close to our home. I have to say that the one he is now in has been excellent, the staff are really caring and cheerful, and I have absolutely no complaints about the level of care they are providing.

"It's the one that my neighbour's husband went to, so I did know a little about it, and it has a good CQC rating - which is also very reassuring."

After her last fall, Marguerite was able to return to her own home from hospital because the couple had previously invested in some home adaptations such as a stair lift and grab rails throughout the house and into the garden.

"Being able to access the garden was one of the most important things for me," she says, "and I spend part of my Attendance Allowance on a gardener, with a cleaner also coming in to help with the housework."

While Marguerite wants to remain living independently for as long as possible in her own home, she is realistic enough to know that at some point she may need to move into a care setting. "One of the great things about the home Ken is in is that they offer accommodation for couples.

"It's been a very upsetting experience," concludes Marguerite, "as I really miss my husband being here with me. I never imagined we'd ever be apart. And if I could have cared for him myself I would have done – but in lots of ways the decision was taken out of my hands. I can see him regularly and I know he is happy there - and that means everything to me."

"...we had pretty much looked after each other, but now some difficult decisions needed to be made."

Setting up your own care ecosystem

Andrew Parfery, CEO Care Sourcer

In 2016 I ran my own care company and although the business was successfully delivering good care for older people, I could see that there were big gaps in the system. Older people were, at the time, frequently trapped in hospital beds while over-worked local authorities tried to organise a care package or a care home. I saw the damage this was doing; seven days waiting in hospital can cut a person's muscle strength by 10%.[5] I also saw the impact that this had on patients' families, who often tried to figure out care support but were confounded by a system that was confusing, disjointed, and over-worked.

Andrew Parfery
Co-founder and CEO of Edinburgh based Care Sourcer since January 2016

Care Sourcer

caresourcer.com

I teamed up with another Andrew, McGinley, who also ran a care company and saw the same issues I did. We were both under 40 and we were used to running our lives on our phones. It seemed incredible that the way we cared for our parents, older relatives, and friends was run on paper. Put simply, back in 2016 there was no way that a family seeking care for a relative could type their needs into some software that would match their needs with care that was available locally. If Rightmove could do it for houses, Amazon for almost anything, and the banks for our money, why wasn't there a website to help people organise care for their loved ones?

This is where Care Sourcer came from; it does what it says – anyone in the UK can register their details and then search for the care they need. The business has grown, we have added a care concierge service to help people, we've also hired experts to help our users when they need to have a conversation, and we've attracted investment to keep growing.

Seven days waiting in hospital can cut a person's muscle strength by 10%

What we have seen during the coronavirus lockdown is that people who have never needed to receive care have had to be isolated or supported by their family members through this crisis. The coronavirus pandemic has pushed awareness of the care system to the top of the public's priorities. For millions of people, lockdown has meant experiencing what it can be like to be an older person. The reality is that, for some people, when they reach a certain level of need, their lives can feel like lockdown. That is why some older people get lonely and can become isolated, because they don't physically have the ability to get out and about.

Take my mum for instance, she has asthma, she has some heart problems – she's only 65, she's perfectly mobile and healthy – but she's been shielding, she's probably 20 years away from needing care, but she's experienced being vulnerable and having to rely on other people – she doesn't like it, it's a loss of independence. As a consequence of COVID-19 people have become much more aware of the different stages that you move through in life, and they have seen that if you want to preserve your independence, and not be admitted to care, you need to be proactive in planning for that.

Before the coronavirus crisis, it seemed that people felt that they didn't want to talk to older generations about future care and about the future of the family home. It was almost a taboo subject, because people didn't want to talk about something that encroached on inheritance or power of attorney because it was an uncomfortable subject, and naturally as a human, why would you want to talk about a worse phase of your life that's going to come?

 National Audit of Intermediate Care Summary Report 2014, p 5

> **“For millions of people, lockdown has meant experiencing what it can be like to be an older person.”**

People are now talking, though. At Care Sourcer, we are seeing evidence that many more people are now considering their own future care needs and starting to figure out their own household-level care ecosystems.

As families move from the conversation about care and planning, to decisions and actions; this is where our vision for Care Sourcer fits. Without a system like Care Sourcer it is very difficult for families to create a care ecosystem for their relative; even if the right kind of care is available from a supplier two miles down the road, without the technology to join things up, you just wouldn't be able to find it.

A care ecosystem is a whole collection of different actions, often supplied by different people, that come together to achieve the person-in-need's objectives. For example, for a person in their early seventies who has a fall, their objective is more than likely to be recovery and back to independent life. This needs some temporary changes to daily life, maybe some help with getting up and dressed, maybe also some rehabilitation and some exercises. More than likely a family member, or more, will be able to help with travel and cooking. The point is that a choreographed set of activities and tasks needs to take place to help the person who fell – that's what we mean by an ecosystem.

Funding is also a key part of creating your own care ecosystem. In the future, we would like to see a government-backed savings scheme, like the auto-enrolment pension scheme, where people can save up a contribution to their care. If we all saved through our lives until it came to the decision point I think that people

> **“If Rightmove could do it for houses, Amazon for almost anything, and the banks for our money, why wasn't there a website to help people organise care for their loved ones?”**

would say – as happens with pensions – “no, no, it's my money, I'm going to decide what I spend it on – I'm going to spend it on this piece of technology that stops me going into a care home, or I'm going to spend it on this care home rather than the one you want me to take”. So, if consumers have choice and control through a marketplace, they will drive up the quality of care and pay what they deem is right.

People spending their own money, and making their own plan, will access services earlier. If they go and access the service via a local authority today, they will only be allowed to get that paid-for service when there is a really high level of need. It's too late by then – if they had been able to build their ecosystem the way they wanted to, and perhaps they would have accessed services earlier, that would have helped to maintain their independence more - it would delay the point at which they would need the local authority paid-for service. The current system doesn't allow people, or even tell people, that they can do that.

Back to my mum, and to the families I saw struggling with the system, I would say that there is a lot that can be done under the current system. I, and my whole team in Edinburgh, are proud of the power that Care Sourcer is putting into the hands of those people, and their friends and families, who need care to help preserve what they value. A system like ours is making it more possible for families to create their own ecosystem, tailored to what works for them.

Phyllis and Peter's story

Peter had a stroke back in 2016 and has suffered from quite poor health ever since. He now also has the early stages of dementia. After 61 years of marriage, he and his wife Phyllis are devoted to each other; and Phyllis, although now in her early 80s, cares for Peter almost singlehandedly.

Peter's story is fairly typical of many stroke victims – leading a very active life right up until the point that he abruptly lost the use of parts of his body. "I was doing marathons right up until 1991," he says, "and in under four hours. Then, one day, out of the blue, I tried to stand up and found it really difficult.

"We went to hospital, but never got to see a doctor. The nurse who saw me sent me home. I was soon back in again having taken a turn for the worse and a CT scan showed that a part of my brain had died. I lost the use of my legs."

From then on, their lives were focused on giving Peter some normality in his life, and despite the fact that Phyllis was then in her late 70s, she was resolved that her husband was staying with her. "I'm still fit and healthy," she says defiantly. "He's not going to go into a care home."

"Phyllis does almost everything," says Peter, "gets me out of bed, changes my catheters and clothes, and looks after the home too – all except when our son is about and he helps too."

"We did have a carer to begin with," says Phyllis. "But they could only come at certain times and only for a short time. If that didn't fit in with him needing to go to the loo, for instance, it wasn't any real help to be honest."

"The first thing we had to do was adapt the house," adds Peter. "We bought a stair lift to get me downstairs, and a chair lift which helps me into a sitting position - I spend my time mostly either in bed or in my chair in the front room. But I have a wheelchair and Phyllis also takes me out in that. We can even catch a bus to get us to a few other places too."

The couple also had a ramp installed to get into and out of their front garden, and all of these adaptations were paid for by the couple themselves. "The Council did help with installing grab rails," says Phyllis.

> **"Phyllis does almost everything," says Peter, "gets me out of bed, changes my catheters and clothes, and looks after the home too – all except when our son is about and he helps too."**

One of their important sources of help has been the Bristol After Stroke charity, which helps local people and their families as they try to get their lives back to normal after they have been affected by stroke. "We really enjoy going to the after-stroke café locally," says Peter, "because we can talk to other people who understand our situation and we can exchange ideas and information."

The charity also runs a befriending service, and after three months when they could only connect by telephone, their assigned contact now comes to chat to them in their garden.

> **"I've even learned to 'Zoom'!" says Phyllis proudly."**

Peter spent twelve years in the RAF as a flight simulator engineer before working in British Aerospace, and so he also receives calls and visits from volunteers in the Royal Air Forces Association. All of these contacts with the outside world are really important to the couple, especially as Peter now has early stage dementia.

Family visits are also an important part of their lives, and while this hasn't been possible during the crisis, things are starting to get back to normal. "I've even learned to 'Zoom'!" says Phyllis proudly.

If the situation for either of them changes, they may have to think again. But for now, Phyllis is determined to keep her husband where both of them are happiest: in their own home.

Giving up work to provide care

Emily Holzhausen MBE, Carers UK

Emily Holzhausen OBE is the Director of Policy and Public Affairs for Carers UK.

Carers UK

carersuk.org

UK care relies on millions of people who provide unpaid care to disabled, ill, or older relatives and friends. The numbers tell the story. Pre-COVID-19 our polling suggested that there were around 7.7 million carers across the UK, with around five million juggling work and care.[6] Our new estimates show that there could be as many as 13.6 million carers, including 4.5 million covid-carers - 2.8 million of whom work.[7] The value of their care, at £140 billion is about what we spend in a year on the NHS.[8]

Most of us (around 65% of all adults) will provide unpaid care at some point in our lives.[9] Half of all women will have provided unpaid care by the time they reach 46, and by 57 for men, which makes care a workplace issue.[10] For some, juggling caring and work becomes impossible; in the 2 years pre-COVID-19, almost 650 people a day gave up work early to provide unpaid care (totalling 468,000).[11] Some employers do see the impact of caring on employee wellbeing and are acting on it.[12] The business benefits of supporting employees who provide care are becoming ever stronger; UK companies could save up to £4.8 billion a year in unplanned absences, and a further £3.4 billion in improved employee retention by adopting flexible working policies to support those with caring responsibilities.[13] 'Employers for Carers', run by Carers UK, shares good practice and new learning.[14]

> **"Our new estimates show that there could be as many as 13.6 million carers."**

> **"Half of all women will have provided unpaid care by the time they reach 46."**

Whilst caring can be rewarding, it can also have negative impacts on carers' health and wellbeing. Carers are twice as likely to be in poor health if they are providing substantial care, and a majority of carers say it has impacted on their mental and physical ill health.[15]

Even though caring is part of millions of people's lives right now, many people do not recognise themselves as carers or feel that they know someone who is a carer. Half of carers took over a year to identify themselves as such,[16] and amongst the general public 51% of people say they do not have a family member or a friend who is providing care, even though one in seven people were likely to be caring at the time.[17]

At Carers UK, we would like planning-to-care to be as normal as planning a pension. Planning for future needs is difficult and can raise complex infra-family issues. Without a plan, most people are not prepared for caring.[18]

There are really important, but simple, things that people should do early, or if they become a carer, to help resilience and minimise the negative impacts of caring. There are financial considerations such as pension contributions and benefits. There are legal issues such as putting in place powers of attorney; doing this either for yourself or for your family is much less complex if done when there is a less acute need. The point at which people become carers can be a moment of extreme stress for a family; it could happen overnight if a relative has a stroke or more slowly over time for conditions like dementia. Having a plan already in place can actually help families to navigate these complicated and difficult circumstances.

> **"In the 2 years pre-COVID-19, almost 650 people a day gave up work early."**

Carers who have talked to their employer say that working flexibly has made a positive difference to their health and wellbeing, and for some, has meant they could continue working. Workplace support does not only have to start with your employer, it can be as simple as supporting your colleagues who are providing care. Several studies show that a supportive working environment makes a real difference to balancing work and care.

6 Carers Week 2019 research, Carers UK/YouGov polling February 2019
7 Carers Week 2019 research, Carers UK/YouGov polling February 2019
8 The Carers' Covenant, Ben Glover, Demos and Legal & General, 2018, p 6
9 Will I Care?, Carers UK, November 2019
10 Ibid
11 Juggling Work and Unpaid Care, Carers UK, January 2019
12 Employers for Carers, Carers UK, April 2020

As important as workplace help is, there are additional kinds of support that carers should consider. Technological support and connections have been show to make a difference for families and can offer peace of mind. It might be an off-the-shelf video doorbell, more specialist monitoring technology or an app that keeps everything in one place like Jointly. Finally, new carers should find out what care and support is available locally, including talking to your GP and the GP of the person you are caring for, and specifically asking to be identified as a carer. This can help link into different types of assistance including free flu jabs.

“Several studies show that a supportive working environment makes a real difference to balancing work and care.”

It’s important not to underestimate how emotionally challenging it is to worry about another person’s welfare and support needs. Some people find that talking and sharing helps. Most people, though, say that – despite there being millions of people caring everyday - they feel very alone on their caring journey. It is our responsibility to make sure that we all play our part in making sure that we are as prepared for caring as we can be.

Whatever we can do personally to plan for care, we also need Government to play its part. Clear and assured funding from Government for social care will help us all to prepare for and plan for care as well as helping millions to juggle work and care. Employers have said that good care for employees’ families is just as important as good health services in supporting staff wellbeing. Good quality care should be seen in exactly the same way that childcare is regarded as being central to people’s ability to work. With our ageing population there is increasing urgency for this to happen.

13 Estimate provided by Centrica, a founder member of ‘Employers for Carers’
14 www.employersforcarers.org/
15 Facts about Carers, 2019
16 www.carersuk.org/for-professionals/policy/policy-library/missing-out-the-identification-challenge, Carers UK, 2016
17 Prepared to Care, Carers Week, 2013
18 Making Connections, Getting Support, Carers UK on Carers Rights Day, 2017

Using your home to help with your care

Max Parmentier, CEO Birdie Care

The ideas behind Birdie Care have been with me for nearly twenty years. As a teenager, I saw first-hand the difficulty and sadness that came with making choices about the care needs of an older and much-loved family member. My grandfather was once a happy, playful, strong man; everything a grandfather should be to a teenager. However, he lived with Parkinson's disease and as his health became poorer my family was faced with the big question: how do we balance independence with the right kind of safety and care? It became clear that living in his own home was no longer possible and, so, he moved to a care home that was equipped to support residents with complex medical needs. However safe his new environment was, he was not happy there and I found seeing him like this to be increasingly distressing.

Max Parmentier
CEO of London based Birdie Care since July 2017.

Birdie Care

birdie.care

Setting up Birdie

It is with these memories that I am building a new way of delivering care, called Birdie. We launched in 2017 and Birdie is now a team of 58 brilliant social entrepreneurs with health, clinical, product, tech, and customer service background.

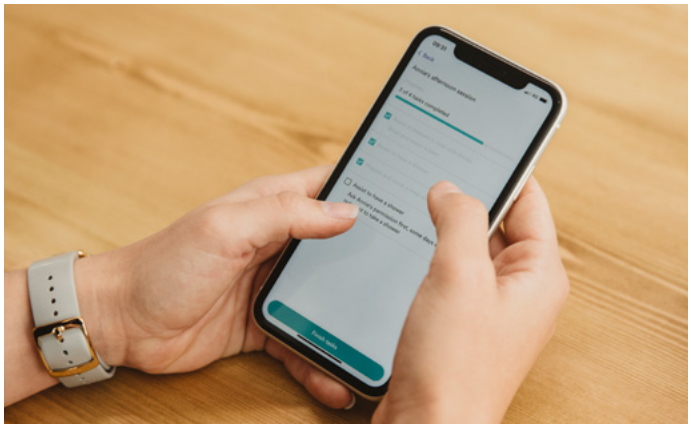
We want to see care that enables our older generations to live longer, in good health and happy in their own homes, surrounded by their families and friends. At Birdie, we focus on the quality of the care being delivered. Birdie Care operates in-home care and we provide a range of technologies, software, digital products and hardware, connecting devices in the homes of the elderly.

We think that delivering the best outcomes for older adults needs a much more tailored, proactive and coordinated system of care at home, where the older adult is at the centre of the picture. We want the whole care community to coordinate better; to anticipate the issues and flag them in real time.

Ideal Care

We use a concept of 'ideal care', designed to support the physical independence of an older adult for much longer. What we see frequently is a 'life curve', whereby an older adult experiences a sudden and rapid decline in their level of independence, leaving them unable to do as many Activities of Daily Living (ADL). The decline is interesting because it can happen really fast, and then it stabilises at a high level of dependency. There are a few reasons for that; it could be more chronic diseases, or more around acute medical issues. However, there is evidence to show that if you organise care better - and that means coordination, personalisation, real time, proactive instead of reactive - you can support physical independence for a much longer period.

> **"We have a team of GPs working on digitalisation of paperwork**



Understanding what accelerates a decline in health

At Birdie, we look at what factors could accelerate a person's decline, including: missed medication; falls; infections and, lastly, indications of depressive behaviour. What can make the situation more difficult is that, on top of the accelerating factors, the services designed to provide support are literally not coordinated. So, my team said "let's build technology to coordinate the care systems" and we now have apps and web apps that care professionals are using instead of paperwork, and we are trying to extend this to community nurses and GPs to help them access, plan, and deliver the care better.
We have a team of GPs working on digitalisation of paperwork and in the background we are building tools, which are clinically backed, to actually strengthen the quality of the overall assessment.

Instead of recording generic information, such as 'Mrs Smith likes tea or coffee and she has this kind of condition', we are working on building new ways of recording and processing data to ensure that older adults' progress and condition can be qualified with a health metric. Following the setup phase, the health scoring can be used to drive more integrated planning of care, so whether a social worker, a home care worker, or a family member is using our software, they can each contribute to planning what care is provided.

Adapting your home

It is crucial to say that care support means more than addressing just the medical and personal needs of an older adult, it's not only 'human being care', but can also be refurbishing the house, using some technology such as motion sensors, perhaps community services, and potentially some physio. Planning care much more realistically, and, using medically backed evidence, allows the whole care team to really focus on what interventions are most efficient at helping an older adult to remain as healthy and independent as possible.

Our aim, following the planning phase, is to keep our older adults safe, 24/7. At the delivery stage, our apps and web apps can intervene. For example, we also have motion sensors that we place in the house that connect to the system. The interesting piece then is the last bit we do, we use all that data from the carers, from the sensors, to really have a very high resolution picture of the older adult at all times.

We talk about Fitbit and so on, but for the care of older adults there are many quick ways to identify issues and tackle them early on. To be clear, we are not diagnosing anything, but we can use our system to inform carers and GPs of what could be going wrong.

> **"We use a concept of 'ideal care', designed to support the physical independence of an older adult for much longer.**

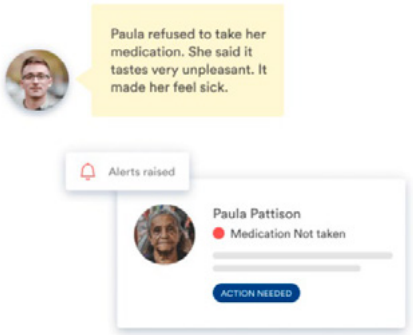
Identifying infection flags

Identifying infection flags is an example of how planned monitoring can alert carers to a potential issue. For example, if Birdie receives (through motion sensors) data showing that Mrs Smith is going up into the bathroom frequently, wandering at night and not sleeping very well, there's a very high likelihood that it's a urinary tract infection. Identifying the likelihood of an infection at an earlier stage means that Mrs Smith's team can, after a medical diagnosis, treat her within 24 hours instead of waiting 3 weeks and rushing to the hospital. Another common issue is mis-medication, which often results in hospital admission but could be better managed by using technology for delivery and monitoring

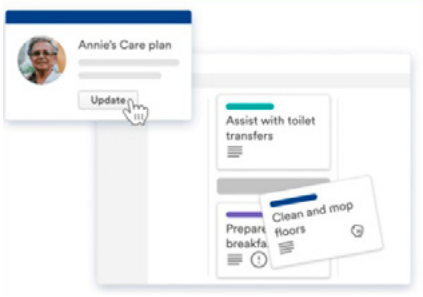
There are plenty of ways which could, eventually, lead to lower hospital admissions by 20 to 30%. When an older adult is admitted to hospital, she can lose a number of years of progress the moment she steps into that hospital because she's going to stay there too long and she's going to decline faster.

Informal and preventative care

The big potential in home care is in preventative care, so that Mrs Smith doesn't go to the hospital unless absolutely needed, and that is what we are working on. Informal carers (such as family and friends) are often the providers of preventative care, so it makes perfect sense that they are included in the comprehensive planning process. There is an unpaid work force of 5 million informal care givers and if they were to stop working, it is going to be care professionals stepping in.



Sample alerts and triggers from Birdie's software

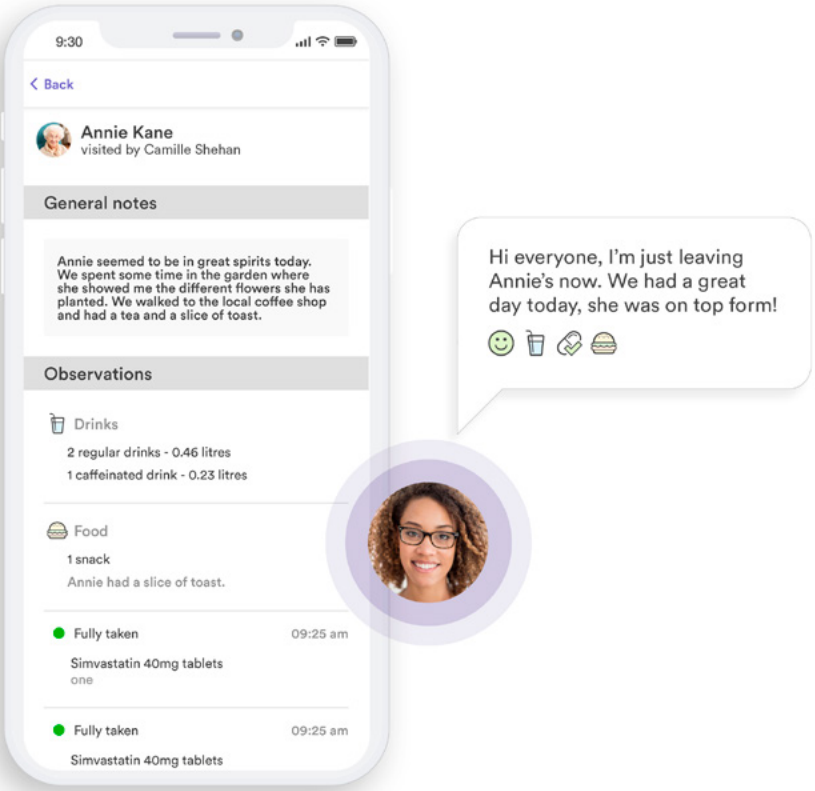


Sample alerts and triggers from Birdie's software

Integrated healthcare

At Birdie, we are aiming to create an integrated healthcare proposition. We have just hired a Chief Integrated Care Officer, who had worked at the Care Quality Commission, and has brought a wealth of strategy and knowledge with him. If we are to have a coordinated, preventative care approach, there must be a holistic view that integrates the budgets of health and care, and facilitates all of the stakeholders talking to each other.

I am convinced that technology can really help to deliver a new system of care that is focussed on the goals of older people. We will get to that ambition, of expanding lives and improving conditions for older adults, when a GP is talking to a care worker, and a community nurse, and a social worker, and community services – that is why we are building Birdie.



Sandy & David's story

Sandy and David are married and in their 70s: Sandy was a social worker and David a teacher prior to retirement. Sandy's father moved to the USA some years ago but always retained UK citizenship; so when he was diagnosed with Alzheimer's in 2017 and finding it increasingly difficult to cope with everyday life, the natural decision was to bring him back to their home in the UK and care for him there.

"He lived with us for about a year," says Sandy, "and that worked well until his dementia deteriorated and we were finding it more and more difficult to keep him safe. He would wander around in the night and really needed monitoring 24 hours a day. He was also suffering from restricted mobility because of arthritis, and it was impossible to make all the adaptations to our home to help him get around.

"My sister and I did a lot of research online about what to do next and the conclusion was for him to go into some form of residential care home locally that would be able to deal with his condition and we could make regular visits. We downloaded checklists from charities like Age UK and Dementia UK which gave us lots of really helpful pointers on what questions to ask when we visited potential care homes."

An initial care needs assessment organised though the local authority came up with two weeks' respite per year for the couple and several hours a week of care while they sorted out a care home; the financial means assessment which eventually followed determined that while Sandy's father had no real savings or assets, because he had a reasonable income from his pensions he would be a "self-funder" for future care.

Moreover, he was refused attendance allowance (despite our pursuing it to a legal appeal and contacting their MP) because he had not lived in the UK for two out of the last three years.

"In some ways that made our decision-making process easier as we didn't need to go through the local authority," says David. "We simply needed to find a suitable home within his budget. We relied heavily for recommendations from local friends and visited quite a few before deciding."

> **"Although they had established Powers of Attorney, the couple also found themselves occasionally not consulted about major decisions – such as whether he should or should not go into hospital after he had several falls."**

"The one we chose was close by, adds Sandy, "so we could easily make visits, and it was modern and perfectly nice. But when they said: 'This is your home now', it's only half true. Yes, you can personalise your room, but everything runs by rotas. There were some lovely carers, but - really - it's an institution. We also had a few problems like his clothes being lost or finding him wearing someone else's trousers. That's upsetting."

Although they had established Powers of Attorney, the couple also found themselves occasionally not consulted about major decisions – such as whether he should or should not go into hospital after he had several falls.

"While he was in hospital the last time, he contracted norovirus and was then moved from ward to ward and his physical condition continued to deteriorate," says David. "The residential home he was in could not provide the increased nursing care he now needed, so that meant finding somewhere else. Again, we relied on friends' recommendations. Because he was now entitled to Funded Nursing Care, that just about made the extra cost affordable."

"The matron of the nursing home was crucial in getting him out of hospital, says Sandy. "She went into the hospital and cut through all the red tape of getting him discharged – otherwise who knows how long it would have taken.

"Sadly, he wasn't in the nursing home for long – just six days – before he succumbed to a chest infection and passed away. But they did look after him well during that short time.

"The whole process of finding out what you need to know at such a stressful time is fraught," Sandy concludes. "You're trying to make huge decisions on behalf of someone else that will affect their wellbeing and their quality of life in their last years. It's also incredibly hard work, very tiring, and emotionally draining."

"And we were lucky… at least we had the financial ability to make choices in where Dad should go. Not everyone can do that."

What about our family finances?

Tony Müdd, St James's Place

Tony Müdd
Divisional Director, Development & Technical Consultancy at St. James's Place Wealth Management since 1993

sjp.co.uk

On May 13th, 1948, Clement Attlee's Labour government passed The National Assistance Act, introducing a comprehensive system of social security for **'the welfare of disabled, sick, aged and other persons'**. The NHS, also born in 1948, was **'free at the point of use'**, whereas much of the welfare state was means-tested, as Sir William Beveridge had envisaged.[19] The NAA placed a duty on Local Authorities to provide residential accommodation for persons **'who by reason of age, infirmity or any other circumstances are in need of care and attention which is not otherwise available to them'**. From the beginning of our modern social security system and NHS, care for older people has never been universal or free, but it has always been provided by Local Authorities and means-tested.

In the 75 years since, the basic framework has not changed and still, many people think that, like the NHS, care will be free to use and funded from taxes. It is often shocked and upset family members, supporting their loved on through a health emergency, who find themselves confronting a financial crisis as they discover the realities of the system.

> **"The vast majority of the two million people who ask for care every year will only discover their new needs during a rapid-onset health and family crisis."**

Since 1999, 330,000 older people have had to sell the place they call home to pay for help with things like washing, getting dressed and going to the toilet.[20] As care becomes more expensive and more people need it, costs will rise. For one in ten people, their care costs will exceed £100,000 – labelled as 'catastrophic costs', by the Dilnot Review.

The vast majority of the 1.3 million older people who ask for care every year will only discover their new needs during a rapid-onset health and family crisis. During this very difficult time, people can find themselves making big decisions about their home, their income and their future. The financial decisions made in these pressure-cooker moments can have long-term consequences for a family's finances and it is hard to make a good plan in the eye of a storm.

Because of the way the care system is configured, a good plan – a plan that creates an affordable care ecosystem – has to include savings, pensions, income and assets, most often houses. Nearly two million people ask for care over the course of a year and only a tiny fraction of them will seek financial advice. Even fewer families will have sat down together during the 'good years' and made a plan to use in a crisis.

Whatever the reformed care system looks like, people are going to have to make some form of contribution. Many ideas have been floated, the most recent of which is a kind of auto-enrolment style system where people older than 40 years of age could save towards a contribution to care, perhaps with insurers providing cover up to a certain level.[21] If this system, or one like it, emerges from the current decade-long process, then people will still need to integrate their care provision with their financial planning.

So what can be done to help today's generation of older people, whose care

19 The National Assistance Act, 1948
20 Independent Age, 2019
21 Over-40s in UK to pay more tax under plans to fix social care crisis, The Guardian, Denis Campbell, July 2020

£100,000+

For one in ten people, their care costs will exceed £100,000

Dilnot Review

“there are fewer than 500 advisers who deal with care specifically - that’s one adviser for every 2,600 people who request care.”

needs will be met by what is available today, to plan-ahead and build their own care ecosystems? First, we need to make sure that there are enough financial services professionals who can offer specialist advice on all matters relating to care. I have worked with the team at The Society for Later Life Advisers for many years and I am pleased to say that their work is bearing fruit. Although we still need many more advisers certified in the finances of care, the trend is upward.

As other contributors to this report have indicated, care in the twenty first century will be built by people themselves. It is clear that creating a care ecosystem of their own will be the route many people take to ensure their family, and themselves, have more choice and control. Resources will always be fundamental to any plan.

In an ideal world it would be clear that the state provides for those in the greatest need and have the least ability to pay, but that, for everybody else, they are responsible for making their own arrangements. We are likely to have a system that tries to achieve this, more or less.

“Financial decisions made in these pressure-cooker moments can have long-term consequences.”

Advice and Care

As things stand, the majority of people who start being cared for get no financial advice at all. If people run out of money (maybe because they didn’t get financial advice) while in private care, the transition to Local Authority provided care can be a significant shock in their life. They could be miles from their family in an unfamiliar and new environment at an exceptionally vulnerable point in their lives.

Where advice is used, it is almost always received at a crisis point, quite often when family members understand that their older relatives can no longer safely live independently. We, as a sector, need to find a way to have these conversations long before a family reaches a crisis. Part of the solution is to get more advisers who specialise in long-term care. As things stand, there are 1.3m new requests for care each year and we estimate that there are fewer than 500 advisers who deal with care specifically - that’s one adviser for every 2,600 people who request care. The situation is improving, and SOLLA is doing a great job in this area, but there is more that needs to done. The whole sector needs to consider whether the right kind and level of regulation is in place to encourage more advisers to enter the market while protecting the consumer? For instance, a clear definition of what a care client is, could help to support the growth of this part of the advice market. Although great work has been done on vulnerability by the regulator, it doesn’t deal specifically with care. We have taken our own path to support the upskilling of advisers in this area, so we now require our advisers to be members of SOLLA.

There is an important role for advised financing and from my customers’ points of view, a combination of innovation, regulation and advice could deliver better plans, ready to be put into motion when needed. And in the future, it may be that new blended products could be designed to offer a care financing package that takes into account real longevity risk, changes in people’s ability to carry out ‘Activities of Daily Life’, and provide a contribution to paying for care.

For real progress to be made, it is clear to me that there should be some form of government-backed education so that the general public understand that social care is means tested. A concerted effort to raise public awareness, just as was done in the early days of auto-enrolled workplace pensions, could help the public to understand that they are more likely (than they think they are) of needing care, as well as spelling out that any support from the government is means-tested.

Underpinned by a campaign to raise awareness of the reality of care, there is a real opportunity to show that people don’t need to struggle through the financial complexities of care on their own – for many people, professional advice about financial options should be an important part of the care planning process.

Brenda's story

Brenda's journey through care

I am 66 and – until she passed away in 2018 aged 93 - was a long-distance carer for my Mum. As her only child it was down to me to organise her care: at the time I lived in London, she in Canterbury.

Mum was diagnosed with dementia at 87, although her memory was getting poor before then. I'd see her at least once a week and in between she managed with the support of neighbours and friends: June was her "memory" and came to the house at least five times a week and got Mum's pills and shopping. We set up financial power of attorney and I sorted Mum's bills. Between us, we managed well.

In 2013 – when Mum had the diagnosis - I took over all her affairs and we agreed a living will.

Although Mum was coping I could see that she was not aware of the time of day and her memory was getting worse. Her mobility was limited and she needed a 'walker'. She'd forget to take her pills. I arranged a carer in the morning to ensure she took her pills with me reminding her at night. This worked for a while until she kept losing the phone. I increased the care to twice a day.

Mum then began falling, resulting in her going in and out of hospital. We brought her bed downstairs and arranged an OT assessment, so she had grab rails, toilet aids and a perching stool. Attendance Allowance helped pay for her care.

In April 2015 she fell again, and this time I knew in my heart that she could no longer go home. I researched all the options – fortunately I work in housing and care for older people - and asked for a care assessment. This was initially refused as Mum was a self-payer but I insisted as it is her right to get one undertaken by the local authority.

It was hard to get more home care with any companies I felt comfortable with because they had waiting lists. I looked at 'live in care' but it was costly; at extra care (there was none available locally); and residential care for people with dementia.

In the assessment, residential care was agreed as a trial for a month. I knew the home I'd chosen as Mum's friend had lived there, we had visited, and it seemed nice. It was run by a charity and had a reasonable CQC assessment - and a vacancy.

She settled well and thought she was in her own home. It was an older style place, but felt homely and the staff were good. We decided that she should be permanent and we set up a circle so she had visitors at different times.

"She settled well and thought she was in her own home. It was an older style place, but felt homely and the staff were good. We decided that she should be permanent and we set up a circle so she had visitors at different times."

The food was excellent, and as Mum loved her meals this was a real positive. The home had animals – two cats, a dog, a rabbit and a cockerel - activities arranged every day… and always tea with cake with hot chocolate at night! I would take her and June out for drives and into Canterbury so she could go to some shops and have tea and (of course) cakes.

Mum owned her home and had some capital, so I kept her house in order to stay over, and was lucky to have a deferred loan agreed by the council, so I did not have to sell until Mum died. Charges were about £700 per week, and the total at the end was over £100,000.

One night she fell and broke her wrist, and as she used her arms with her 'walker' I got her a wheelchair. She became more and more quiet and reached a stage where she would hardly speak at all… but you knew she was happy if she blew a kiss. The staff really made the home special and I am so grateful to them.

Mum died in her sleep on 25th November 2018. She had a bad chest every winter but this time she did not recover. I was sorry not to be with her in death, but so glad she died peacefully. I miss her a lot.

Photograph posed by models

Building the complete companion for anyone caring for a loved one

Rachael Crook, Lifted

I was 24 and studying in Oxford when my 56-year-old mum, a senior civil servant living in Edinburgh, was diagnosed with dementia. The doctor said to us at the time, "This is the diagnosis. She will probably die in 8-10 years. There's nothing we can do. I wouldn't seek support as you might meet people with more advanced dementia and that will be upsetting". As a family we tried to manage, but one day my mum left the cooker on and the fire brigade had to be called. It was clear that Mum was not going to be able to look after herself without any support. There was no one to help us, there was no guidance. We had a really difficult journey trying to find care. The Alzheimer's Society helped us a little but in the end we had to sort it all ourselves.

Paper files

When your loved one starts to change, that is a very disempowering moment. Being able to bring someone in, and keep in touch with that carer, is a way of empowering a family when it feels like they're losing control. I was really frustrated because soon my mum wasn't able to communicate that she was ok. I didn't know what was happening when I wasn't there because the carers would write their notes and then store them in a paper file. That paper file would sit on the table in Edinburgh and it would never get used. From a transparency (and an experience) point of view, it pushed us further away from her. The carers themselves were nice people, but they were under-trained and under-supported. The service cost four times my parents' mortgage payments, and from day one I could see it could be so much better.

So I quit my job and co-founded Lifted

Over the next few years, I thought a great deal about my experience, and that of my family, and how things could be improved. Could we use all those carefully written (and now filed away) notes to track and understand more about a person's health deterioration, and significantly, to learn more about effective interventions? Could we use technology to show families the value that Carers bring? Could new technology help to modernise the organisation of care? Could Carers get the respect they deserve? So, after a few years passed, I left my full-time job and set about building an organisation that could do the things I had been thinking about. I partnered with Zero 1, a Venture Builder, and my co-founder Sam Cohen, and we launched Lifted so that other people needing care, and their families, might not have to go through what my family experienced.

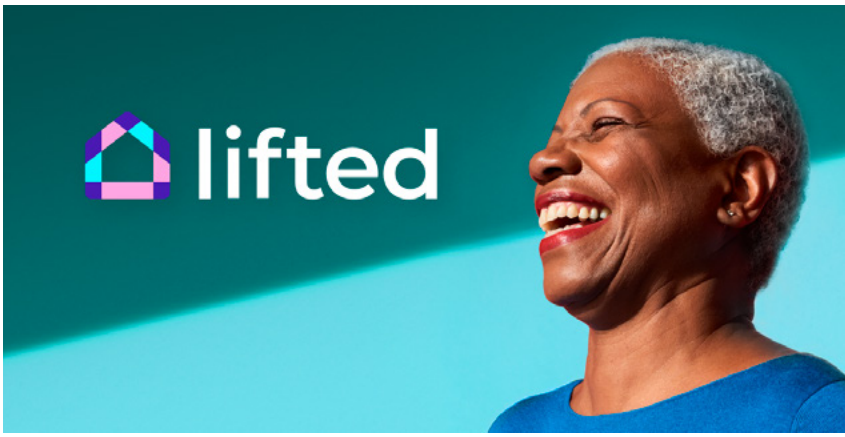
Rachael Crook
CEO of Lifted

Lifted

liftedcare.com

> **"My experience, and that of my family, caused me to start thinking about how things could be improved."**

“I go and speak to each of the carers when they start with us and I tell them about my mum. I ask them to imagine that everyone they’re looking after is like my family.”



The tech system

Our ambition at Lifted is to lift lives by building the complete companion for anyone looking after a loved one. From the moment of diagnosis to the end of life, we want to make sure that no one cares alone. Our strategy has three stages. First, we are delivering support, guidance and community to families before they need care. Second, we deliver care that lifts and empowers families and Carers and, thirdly, we create and maintain the working conditions that Carers deserve.

The need for our service is huge – the number of people that need home care will double in the next 15 years, while the number of care home places per person dropped 10% in 2018. Meanwhile, 1 in 12 people are dropping out of the workforce to look after loved ones. They deserve better.

To deliver the kind of care we can be proud of, we have built a ground-breaking ‘Care Management Platform’ that transforms the care experience for everyone involved. For families, we restore joy by keeping them up to date with care and by delivering around-the-clock support; and for Carers, we provide rapid insight into how their clients are feeling plus instant reward and recognition. Our platform centralises data from all parts of our care ecosystem to create and automate scheduling and alerts for our operational teams.

Building the Lifted culture

Last year the Care Quality Commission wrote a glowing review of Lifted. This is a big deal for an organisation like Lifted, particularly as the CQC highlighted both the service and culture of Lifted. The technology is great, and it is delivering improvements in care, but only when the tech is allied with strong culture do we realise the kind of strong, long lasting relationships between great carers and families – the kind of service I wanted to find, but couldn’t find, for my Mum.

Caring for Carers is as important to us as caring for families – this is the heart of our mission – so I go and speak to each of the carers when they start with us and I tell them about my Mum. I ask them to imagine that everyone they’re looking after is like my family. We directly employ our Carers and we will use our platform to recruit, train, support and manage them. We are proud to be among the less than 2% of care companies paying their hourly staff the real living wage. Caring for our Carers is as important to us as Caring for families and of course we pay for travel time. During lockdown we doubled sick pay so that no one had to choose between keeping people safe and supporting their family. We use the data and feedback from our platform to identify the strongest performing Carers and recognise them.

Rachael with her Mum

“Caring for Carers is as important to us as Caring for families.”

“So far, we have attracted ‘new’ people: we’ve got a couple of people with Masters in Public Health from University College London, including a fully-fledged doctor who came to work with us as a carer, another of our Carers is a jazz musician, she even composed a song for our clients.”

Talent matters

I want Lifted to be an outstanding innovator, so we have hired people who bring knowledge and talent from other sectors of the economy and combine their experiences with the best people in the care sector. That magic works together. For instance, Sam Cohen, our Chief Operating Officer, used to manage a staff of thousands of online estate agents so he knows what it’s like to work with lots of different people delivering a service, and I bring my experience from Government and the private sector. I used to be a Senior Advisor in the Prime Minister’s Implementation Unit and a consultant with McKinsey & Company.

It is disappointing that fewer than 30% of carers think that people respect them as professionals. We want this to change. To attract talent, we need to elevate the way people think of care; real change will not come unless we can get somebody who was not thinking about becoming a carer, to become one. During lockdown, over 50% of people looked after a loved one. There are millions of people who are passionate about care but are put off from becoming a carer because of the pay and conditions. This must change. We must build a culture that puts carers at the core by showing that they are the most important people in our business. So far, we have attracted ‘new’ people: we’ve got a couple of people with Masters in Public Health from University College London, including a fully-fledged doctor who came to work with us as a carer, another of our Carers is a jazz musician, she even composed a song for our clients. Ultimately, what drives us is focussing on what our families need.

What drives success?

As we have grown, it has become clear to me that there are some barriers to scaling up from start-up to mature organisation. For example, there is a mismatch between the needs of innovative and smaller companies and the existing institutional care infrastructure. For example, each Local Authority has its own tendering process, and this can place too large an administrative burden on smaller companies. There is also a case for the government to look at the infrastructure that already exists, like the CQC, or the Skills for Care, and consider how they can make those services more accessible for companies like ours. The other thing that holds us up is how long the Disclosure and Barring Service (DBS) process takes to vet new staff. It is a really important process but delays can hamper our agility.

There is also an important cost factor. Tight public sector budgets make it very difficult for providers to deliver state funded care. Extremely tight margins create a double whammy where the need for innovation is ever higher and the budget for delivering it is ever smaller. This must be addressed to deliver the care that people deserve and to drive the innovation the sector needs.

“By 2025, no one should care alone.”

Impact

We are 18 months into the Lifted journey and it is working; we have delivered a workforce churn rate that is below the industry average, and exclusively 5 stars Trustpilot reviews. We have raised over £3 million in investment most recently in a round led by Fuel Ventures and our revenue is growing rapidly. Our new community, for people caring for a loved one, has gained hundreds of members in a few weeks. We were crowned the UK’s Best Startup Home Care Service at the HomeCare Awards 2020.

In December, we opened up our app to offer families the first personalised care guide to help families through the care journey. Now anyone can download the Lifted app by searching "Lifted App" in the app store. We are developing our platform to digitally upskill and recognise care workers remotely and build out our AI capabilities to provide automated coaching and assisted decision-making. And we are putting together new tools to help employers support their workforce with caring responsibilities.

It’s not an easy set of problems to solve, but we are so proud to be building a team as passionate about this mission as we are. We would love to hear from anyone looking for care for a loved one or is interested in ways to support their staff with caring responsibilities.

In five years’ time, we aim to have lifted one million people, either through care directly, or through the support we provide through our platform. By 2025, no one will care alone.

My Thursday:
A day in Evelina's life

Working day, 06:00–19:30

This is the story of Evelina's Thursday. Evelina is 24 years old and works for Lifted (the company co-founded by Rachael Crook) and is full of professional enthusiasm following her recent promotion to a role with more managerial responsibilities. Evelina trained as a physiotherapist in Lithuania and came to the UK two years ago to be with her boyfriend. Alongside working as a professional carer, Evelina has been training in massage therapies that relate to her earlier physio studies – she is just about to start a new course in Sports Injury massage. She and her boyfriend share a flat in Hainault, at the eastern end of London Underground's Central Line.

Evalina in her Lifted uniform

"If you don't want to be late, you have to leave very early", explains Evelina. To reach her first client at 08:30 in North London, Evelina's day starts at 06:00. By 07:00, she is on a tube train towards London, she changes to the Piccadilly Line to head north, and then boards a bus, and at 08:30 Evelina arrives at her client's home. Evelina uses the Lifted app to see her journey details and plot her route easily.

It is the first time Evelina has worked with today's client; a lady with dementia who lives with her daughter. The client is new to Lifted, "but when you go there a few visits a day you get to know the person. She used to have carers before; we are not the first company to go there. I think we are the third or fourth company. Her daughter has been trying to find somebody who is better," as Evelina diplomatically puts it. Evelina logs into the Lifted app to read the notes from yesterday's visit to make sure she is up to date.

The client's daughter is trying to find the right care in place for her Mum, who lives with a form of dementia. There is a pre-arranged system for Evelina to access

> **"If you don't want to be late, you have to leave very early."**

the home of her client: "After putting on our personal protective equipment, we let ourselves in, we go upstairs and prepare everything for a full body wash, changing the pad and transferring her from the bed onto the chair". Evelina is clear that, because her new client has dementia, she has requirements that are very different from, say, her other clients who may have a physical disability.

"She is lovely, she recognises us and knows that we will come in the next morning… I think it is helping her daughter as much as helping her. We provide all the personal care for her Mum so she [the daughter] can go back to work. She wants to know that her Mum is being looked after – by someone she can trust every day – giving her food, personal care and generally everything she needs". Evelina is pleased at how the visit has gone; she always asks her client and their family what they thought about the care service she provides, and makes sure that she has explained the tasks she completed during the visit, otherwise "it would be a bit weird if you just came to assist on personal tasks". At the moment, Evelina and her colleagues are not preparing meals for the client but Evelina has talked with the client's daughter and believes that, "in the future she would like us to prepare the meals". She puts all the details into the Lifted app so the client's daughter can be up to date straight away even if she is not at home.

“She is lovely, she recognises us and knows that we will come in the next morning... I think it is helping her daughter as much as helping her.”

The appointment is a “double up”, which means that the client being cared for needs two carers. Evelina explains why this is needed: “This means the appointment is for someone who is confined to bed and requires a transfer from their bed to a chair, or vice versa”.

After her 08:30-09:30 appointment is finished, Evelina has a task that came with her recent promotion. Following a bus journey, Evelina begins a ‘spot check’ at 10:30 to assess how a Lifted colleague is delivering care for another client – whom Evelina knows very well. Evelina describes the purpose and outcome of that day’s spot check; “I spent an hour checking the tasks that he [Evelina’s Lifted colleague] was doing... I had to comment on how he was working, reinforcing our operating procedures and cheer him on a bit. He is doing everything right but, like everyone, he benefits from a bit of friendly support”.

After completing the spot-check, at 11.30 Evelina talked with the team preparing this research report and then took a call from Lifted HQ to ask her to return to her first client of the day for a lunchtime visit, between 13:00 and 14:00. She checks the Lifted app to find out where to go. Before hopping onto the bus, Evelina makes some time to eat a sandwich for lunch.

Returning to the home of her first client of the day, Evelina describes the different lunchtime routine: “The second visit [of the day] means another transfer for the client, from her bed to the chair, in order for the pad to be changed and the client can be washed”. Once the personal care is completed, Evelina and her colleague transfer their client to an armchair, have a bit of a chat, and get her comfortable for the afternoon, so she can watch TV and read her favourite magazines. The chat offers Evelina an opportunity to ask about her client’s morning, what she planned to eat for the day and how she is feeling. She completed the wellness data in the Lifted app so the whole team can see how the client is feeling.

At 14:00 it is time to head to another care client and the travel time allows Evelina to call her Mum in Lithuania and catch up.

The 15:00 appointment is with another new client. It is only Evelina’s second visit to her so she makes sure she has time to read the care plan and the client’s profile in the Lifted app. She is also careful to wear fresh personal protective equipment. The new client’s daughter has been staying with her Mum but only until the following day, so there was a lot of planning needed. The client has dementia “but it is not as advanced as other clients so you can have a great chat and talk about memories and everything. It was lovely. Then I had to administer medication for her, prepare some tea and then it was time to go”.

With this appointment over at 16:00, Evelina is back on the bus heading to visit the client she saw for breakfast and lunch. She puts on her personal protective equipment. This visit involves the same care delivered in the morning, again “doubling up” with Evelina’s Lifted colleague. Evelina describes the visit: “I did all the personal care that I did in the morning with my colleague. So it was transferring her back to bed, giving her a full body wash, changing her pad, making her comfortable, tidying up afterwards, preparing everything for the night”.

At 18:00, Evelina is finished working and heads for the bus, then the tube, to get home to the flat she shares with her partner in Hainault for about 19:30.

After a half hour for her dinner, Evelina gave this interview.

Marion and Jack's story

Until late 2019, Marion (82) and Jack (87) had enjoyed relatively good health and were perfectly able to live in their own homes without domiciliary support. This is despite Jack surviving cancer and being the country's oldest surviving kidney transplant recipient.

Marion being hit by a car sparked a chain of events which has changed everyone's lives, and shown some of the "gaps in the system" that can prevent people from living their lives as independently as possible for as long as possible.

Marion, the innocent party in the accident, was rushed to hospital where her left leg was amputated and her right hip pinned. During her stay, she contracted Covid-19, but still managed to make a sufficient recovery for her to be discharged into a smaller hospital nearby which provides specialist physiotherapy services.

From there she moved to a privately-run rehabilitation unit for a two-week stay, her bills paid for by the insurers. After that point, it was agreed that her physio costs were to be paid for by the State – except that no physio services were available for the next three months, and indeed this has never materialised because the lockdown subsequently prevented them from being provided.

Marion is still in the rehabilitation unit – together with Jack - and the couple are awaiting their next move. In an ideal world this would be back to her own home, but it would be unsuitable for anyone using a wheelchair to move about.

All of their five children and their partners have searched online to try and find suitable accommodation for them to move to longer term. Ideally, they would move to "independent living" style accommodation, but none that the family could identify locally would have allowed Marion full accessibility for facilities such as the shower using a wheelchair.

> **"Mark, who is Marion and Jack's son in law, has taken on the role of "Litigation friend". Setting up Lasting Power of Attorneys has also been set in motion."**

They do not want to move into a care home, so they are now trying to identify suitable supported living accommodation. The family have identified several options that would suit Marion and Jack, but it will be down to the insurers to decide how much they are prepared to pay.

Mark, who is Marion and Jack's son in law, has taken on the role of "Litigation friend" – liaising between the couple and the solicitors throughout the process. Setting up Lasting Power of Attorneys has also been set in motion to ensure that if their decision-making abilities become impaired, the family can make decisions on their behalf.

"Our experience has shown just how difficult the journey can be for anyone trying to move from hospital back to anything like a normal life," says Mark. "In lots of ways we've been lucky because we did at least have the insurers to cover many of the costs. Because Marion and Jack's savings are just above the Local Authority threshold, they were told in their assessment that they would have had to shoulder these themselves.

"They would certainly have had to pay for their later physio sessions had these been available.

"The fact that the much-needed physio for Marion wasn't available for three months after her discharge again shows up a flaw in the system: physio at an early stage is vital if someone is to make the fullest possible recovery.

"We were also dismayed to find that so many 'later-living developments' were totally unsuitable for anyone in a wheelchair – surely that should be a mandatory part of their design to enable people to carry on living there for as long as possible.

"And finally, it was an uphill struggle to identify suitable accommodation that would have met their needs. It's taken all of us a huge amount of time and effort to get this far - and Marion and Jack still aren't at the end of their care journey."

Safe and simple homecare tech

Christopher McCann, Current Health

Future healthcare

Current Health's mission is to predict illness and intervene so that every human has the chance of a longer, healthier life. As we all know, our population is ageing. As a result, we're experiencing more chronic disease. These diseases should be managed and treated differently to how we've delivered healthcare in the past. There must be greater focus on preventive, proactive health and care if we are to continue delivering high-quality, universally available and accessible healthcare.

Current Health delivers automated 24/7 monitoring of patient health in their own home and without confining them to a hospital, rehab or assisted living facility. We do this wirelessly and passively, invisibly fitting into the patients home, avoiding "clinicalizing" the patient's home.

Our focus is on using this stream of health data to predict illness onset and enable early, preventive treatment. We are developing a range of software-driven therapeutics, for diseases such as heart failure and COPD that enable innovative, new care models to be delivered, centered around early treatment in the home, improved patient quality of life and lifespan and prevention of acute hospitalizations and Emergency Department visits.

We have already seen these care models deliver greatly improved benefits, including a near-90% reduction in hospitalizations in one elderly population.

Monitoring and quality of life

Current Health provides the most sophisticated, continuous view of patient health at home available. This includes 24/7, passive monitoring of vital signs, like a tiny ICU monitor, including respiration rate, oxygen saturation, mobility and step counts, pulse rate and body temperature. This means that vital sign readings are taken throughout the day without any action from the patient required.

The solution also wirelessly integrates with top device partners, including Dexcom, and allows collection of symptoms and SDOH. These capabilities provide a complete holistic view of a patient's health, without disrupting their life.

Monitoring, itself, is not the solution to better health and care at home. Rather, monitoring allows the early identification of illness and the ability to pre-emptively treat. Thus, as we increase our ability to monitor health at home and as we increase the depth and span of that data, then we increase the opportunity to intervene and treat early – maximizing lifespan and quality of that life span. Our focus as a society should be on how we treat preventively, not reactively.

Over the coming months and years, we expect the importance of continuous and passive monitoring to grow. The number of parameters it is possible to monitor will grow. It will become ubiquitous and widely accepted that our health will be monitored 24/7/365.

> **These care models deliver greatly improved benefits, including a near-90% reduction in hospitalisations in one elderly population."**

Chris McCann
CEO of Current Health since 2015
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Current Health

currenthealth.com

Artificial Intelligence and machine learning

There are 67 million people in the UK. To monitor the health of every one of them would require a huge number of doctors, nurses and healthcare professionals. Instead, we can deploy machine learning to identify and predict the onset of disease. We can then focus the healthcare professionals we have on the much smaller number of patients who need their time, attention and skill.

The software-driven therapeutics we are developing, tailored to specific diseases, are focused on combining the massive bank of human health data we have captured, the stream of data from that specific patient and the world's existing clinical knowledge, to identify those who need treatment and help physicians, nurses and healthcare professionals deliver that treatment preventively and early.

> **Vital sign readings are taken throughout the day without any action from the patient required."**

Using wearable technology

As with anything, it is about understanding the personal motivations to engage with a service like Current Health. Life is the ultimate human right, but the quality of that life is just as important. No one wants to spend time in hospital. All of us want to live quality, long and healthy lives. Current Health is a part of the overall healthcare delivery circle, of which the patient and their healthcare professional is at the centre. It is critical that healthcare professionals adequately explain to the patient why they are receiving Current Health, the benefits it can bring to their health and that it is being used to keep them safe and well at home. When done correctly, this results in patient adherence above 90%.

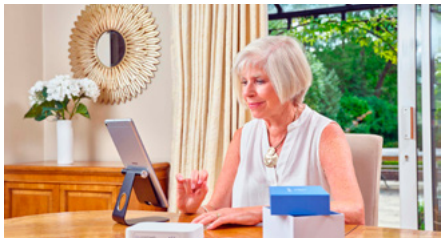
The second key part is simplicity. At Current Health, the very first metric we consider above all else is patient adherence. In every product improvement, we first consider patient adherence and how it will be impacted. Solutions in the home must be simple for the patient and they must be easy to use. We focus on making things work, right out of the box, with zero configuration and a setup that's less than a couple of minutes.

Collaboration with other technology

Interoperability is critical. Health and care is complicated. There are many different systems involved and many different teams of healthcare professionals across primary and secondary care. As such, its key that systems interoperate with other systems and are globally accessible. For preventive treatment to be successful, systems cannot be siloed to one group.

For example, Current Health already integrates with a number of electronic health records, as well as patient held electronic health records like Patients Know Best.

> **Life is the ultimate human right, but the quality of that life is just as important."**



Wider uptake of technology

A key barrier is that the patients who most need access are the hardest to reach. They don't have home internet, they don't have smart phones. This population has the poorest outcomes.

To manage this, Current Health have focused on the final mile into the patient's home. We provide the connectivity, we ensure the patient is set up successful, we provide everything the patient needs pre-configured and ready to go out of the box. We then focus on simplicity: simplicity of setup and simplicity of use. Solutions must be simple and easy to use, for all patient groups.

Where does wearables best

The US and some European countries, such as Sweden, are more mature than the UK in terms of care management and care coordination. These are the really critical aspects of developing remote healthcare pathways. Success is not about the monitoring itself, it's about using the monitoring to identify illness earlier and then using that insight to inform care. That means having the necessary infrastructure to actually do that. Current Health is unique in that we allow higher-acuity, higher-risk patients to be managed at home, but success means combining this with care management & coordination teams, community-based care of the elderly teams and pathways that allow for early intervention and treatment at home.

> **"Solutions must be simple and easy to use, for all patient groups."**

Driving early interventions

Current Health's solution is unique in that our continuous, 24/7 monitoring allows higher-risk, higher-acuity patients to be safely managed at home and moved out of the hospital earlier.

Case study

Historically, heart failure patients may have been given a weighing scale and asked to record daily weights. By instead continuously monitoring their oxygen saturations, respiration rate and other vital signs, Current Health can identify that the patient is becoming more hypoxic, that their respiration rate is elevating greater than normal when they are mobile and that they have reported feeling more breathless. This can allow an earlier appointment with their GP, earlier prescription of furosemide and thus has the potential to prevent a decompensation that may lead to a hospitalisation.

Rehabilitation

Firstly, remote healthcare allows earlier discharge from the hospital. Patients can get home faster, because there is greater clinical confidence in their safe management at home. That's great for the patient and good for the overall healthcare delivery system.

Secondly, having remote health monitoring at home helps patients feel safer and more secure knowing they have a continuous connection to their healthcare team. This helps them in the transitional period and can in itself prevent rehospitalizations and emergency visits.

Most importantly, solutions like Current Health allow objective tracking of response to treatment, or lack of response to treatment, as well as early identification of deterioration. This can allow earlier changes to treatment. It can also allow simple education and reassurance to the patient, which can sometimes be key in avoiding an unnecessary utilization event.

Prolonging independence

Healthcare should not just be about prolonging life, but about prolonging quality life. Systems like Current Health allow more patients to be managed and continue to be managed at home for longer while maximizing quality of life. More importantly, our focus is on early detection of illness and early provision of preventive treatment. This means keeping patients healthier for as long as possible and thus keeping them independent for as long as possible.

We must also consider how the solutions impact on daily life. There is no point in maximizing independence if the solution significantly impinges on that independence. At Current Health, we've worked to make our system as invisible as possible, fitting into daily life.

Social impact

There are two sides to this. The first is economic improvements, such as reduction in hosptialisations, Emergency Department visits and the cost of care. The second, and more important, is the patient outcome improvements. This includes satisfaction, but also improvements in health outcomes. Ultimately, the second is symbiotic with the first. The best way to reduce the cost of healthcare delivery is to create healthier communities.

Monica's story

After many years working and living in different countries around the world, we eventually returned to live in my home town in the West Country for our retirement years.

That worked well for quite some time – we have family locally, which was important as two of our children live abroad - and we love the area. My husband has always been keen on tennis and enjoyed good health right up until he was 80. And I too have enjoyed reasonable health.

A couple of years ago, my husband's health took a turn for the worse and we had to look again at our situation. We lived near the top of a steep hill, in a Victorian two-bedroom flat that required climbing steps. It took us a while to agree, but eventually we recognised that we would soon be needing support and it would be best to take action before it was forced upon us.

> "A couple of years ago, my husband's health took a turn for the worse and we had to look again at our situation."

Staying at home and buying in care would have been an option but getting out and about would still have been a problem. We decided to look at sheltered housing options locally.

The development we really liked would only allow you to buy an apartment, and that didn't seem the best route to us: we didn't know if we would need to move in the future if we needed more care than they could provide; having to sell would have added stress and expense.

We eventually decided upon a development a few miles away that provides warden-assisted, rented housing for independent living. While it is run by a religious charity, it welcomes people of any faith or none.

We have our own apartment, with our own front door, looking out onto very pleasant gardens… although if I'm honest it does feel small. Having staff on hand if there is ever a problem is really reassuring, and you can buy in extra care as needed. We have a three-course lunch in the dining room which saves us cooking – and as our own galley kitchen is small, that's probably a good thing!

The village is on the flat and has a couple of excellent shops and a pub; and while we still have our own car, we can also hop on a bus or coach in any direction for a day out. Another big plus from our perspective is that the rent is all inclusive: we pay a single amount each month which includes gas, electric, water and rates – making life that much simpler.

There's quite a lot going on here, such as trips and activities, although I have to admit that I'm not that sociable a person so we don't really join in that much. But if you wanted to have a busy social life here, you could do. Squeezing ourselves into a smaller apartment has not been easy for us… it's a shame that so many retirement developments seem to assume that older people don't need much room!

A big plus point has been the fact we have support on hand. And the staff are excellent. I actually contracted Coronavirus quite early on and had to go into the local hospital, and they were very supportive of us both.

Was it the right thing to do? For peace of mind, yes. But it's always nice to retain as much independence as you can in this life and I wish we could have delayed moving for just a short while longer!

> "Was it the right thing to do? For peace of mind, yes."

Finding and moving to new accommodation

John Galvin and Adam Hillier, Elderly Accommodation Counsel

When older people first reach out for help, it is often prompted by a local authority assessment, which has, in turn, been triggered by a crisis. In its thirty-six years, Elderly Accommodation Counsel (EAC) has helped millions of older people to make informed choices about meeting their housing and care needs. Managing a rapid home-move, triggered by a sudden life event, is taxing at any age. Frequently, the trigger for thinking about relocation is, sadly, the passing of a spouse. Losing a partner prompts big questions: "actually, this doesn't work for me anymore, what are my options? What can I explore?"

John Galvin
Chief Executive at Elderly Accommodation Counsel since 1995. Adam was John's Deputy until he joined Legal & General in summer 2020.

eac.org.uk

> **"A crisis-driven relocation often involves older people moving quickly."**

A change in health can also act as a spur to evaluate life-wide issues like housing. This could happen, for example, when an older adult sees that arthritis in the knee is making it more difficult to get in and out of the bath, or, at the other end of the scale, a diagnosis of Alzheimer's or dementia is often why a person starts to think seriously about how they can live safely in their own home for as long as possible. Quite often, people who have a crisis moment make a decision based on finding that: "actually my home doesn't work, I need to move quite quickly, where can I go that is going to be suitable?" A crisis-driven relocation often involves older people moving quickly.

Planning for a better life in the future

The second big reason for relocation is a plan. When people look ahead at their retirement lifestyle from an unhurried position of good health, they often choose to relocate to a property that can best support their goals. To preserve independence, it can work well to move somewhere with care and some support, and is already adapted to meet any future needs they may have.

As the range of housing for older people expands, many people choose to move for a better lifestyle: living with likeminded people in a new flat with nice views and a courtyard area, lounge area, and restaurants can be quite an attractive offer. Relocation happens not just because people are being practical and planning ahead; it is not just a pragmatic option, it is an attractive lifestyle offer.

The big issues around relocation

Finding somewhere that is right for you

Finding somewhere suitable is not always straight forward. If you are already in a property that can be adapted, there are things that can be done to make it work better for you. It can be a big decision to say: "I'm going to be better off there than if I just adapt and improve my current home", so, retirement housing options are developing and progressing, because they have tough competition from home-adaptation and technology. Taking retirement housing as an example, if a home owner is looking to move, they may want to buy a retirement property but there are plenty of parts of the UK where there is no stock.

> **"Many people choose to move for a better lifestyle."**

Selling your home and moving

In our experience advising people who contacted EAC's FirstStop service about moving home, at the age of 80 they were going through what is, at any point of life, one of the most stressful things that anyone can do. There's a physical and mental strain involved with selling your home, including trying to get it into a condition that is suitable to be sold, figuring out what to do with a lifetime of belongings and memories. The whole process of selling - estate agents, valuations, getting a buyer – and then finding the home that you want to move into and making sure it's attractive for you. It can also lead to difficult conversations with family members who might be upset by closing down what is still seen as 'the family home'. People can often conclude that "I'm better off where I am".

If people do decide to stay in their home, there is a great deal that can be done to make it work better.

The 'prevent, delay' focus of the Care Act 2014 can be an important driver of home care setups.[22] Tech, both assistive and smart, is still really in its fledgling period. There remains the challenge of people understanding what is possible with smart technology, trusting it, and having the money to pay for it. It's still at a period in its development where most things are quite costly, but small things like smart lighting can be reasonably cost effective. If later-life frailty is a risk, then lighting the path from bedroom to bathroom could reduce the risk of injury. It can be the very simple and effective uses of technology that can help older adults to live in their home and maintain their independence. There has been vast development of the traditional pull cord systems, or pendants, that can alert family or friends of a fall. There is also a move towards telehealth services, where people can have their blood pressure or blood glucose levels tracked and alert the relevant support service that a person is currently at a high risk of a fall. These systems can send a message out to a family member to get in touch with their loved one and, maybe, share a virtual cup of tea and a biscuit,

> **"The 'prevent, delay' focus of the Care Act 2014 can be an important driver of home care setups."**

and a sit down for a minute - all these little steps with technology are making a huge difference to those people who have it in their homes and lives.

What is going to be interesting over the next few years is how much the tech develops and how much more people feel comfortable with relying on that kind of technology. Smart hubs, such as Alexa or Google Home, are already having an impact: being able, as a son or daughter, to put into Alexa "these are the appointments that Mum has got" or "you've got so and so coming round on this day and a doctor's appointment on that day" and have the digital assistant remind your Mum in the morning so you don't have to be calling her while you're trying to do your job and look after your family.

If you do want to move, where is the retirement housing?

As things stand, retirement housing to buy is most easily found in the South of England. It does very well in the places that people see themselves retiring to. Seaside towns like Bournemouth, Brighton, or Eastbourne, or in the South West, places like Torquay or Weymouth tend to have good retirement housing stocks with popular retirement hotspots in Norfolk and Suffolk also well supported. Outside of those areas and major cities your options are likely to be pretty limited. There tends to be a reasonable number of retirement developments across the country that are owned and managed by registered social landlords, housing associations, and councils, but they are usually oversubscribed in the areas with fewer people in a position to buy a property. Homeowners are unlikely to be able to access council or housing association retirement housing schemes and they face a postcode lottery created by the geographic imbalance in the provision of retirement housing.

> **"Homeowners are unlikely to be able to access council or housing association retirement housing schemes and they face a postcode lottery created by the geographic imbalance in the provision of retirement housing."**

22 www.legislation.gov.uk/ukpga/2014/23/contents/enacted

23 Relocation at older age: results from the Cognitive Function and Ageing Study, 2015, Journal of Public Health Vol 37, No3, pp 480-497, Yu-Tzu Wu, A Matthew Prine, Linda E Barnes, Fiona E Matthews, Carol Baryne.

Home share?

There are good ideas that may still take off. Home Share could be a win-win solution for many. The idea of Home Share is that where there is an older person with a spare bedroom, they could have a younger person come and live with them. The younger person could live rent-free and for, perhaps, 10 hours a week, help with cleaning, shopping, resolving computer problems, setting up video calls with family, or just being company and being someone to share dinner with.

This could work well in big cities, and London, where accommodation is extremely expensive. For example, a student nurse could benefit from Home Share during their studies. If a student who has an interest in supporting and looking after people could be matched with an older adult, there could be a good fit. If that could be made to work, that could be an effective way of giving family members of the older person peace of mind, as well as forming a strong bond between this inter-generational pairing that helps drive out isolation and loneliness. Just knowing that somebody is there, somebody to say hello to in the morning, somebody to maybe share a meal with a couple of times a week makes a huge difference to a person's mental health.

What do retired people, who have moved, say about their relocation?

Every year EAC runs the National Housing for Older People Awards, which asks people living in retirement housing to say "I like living here and this is why". Some of the most frequent comments that we get are "why didn't I do this sooner? I've got this support around me, I've got good friends that I've made, good housing manager that listens to me and works with the residents to provide an environment that we're happy to live in. I wish I made this decision 5 or 10 years ago rather than waiting until something happened that triggered me to make that move". The feedback from people who have moved into housing designed for older people is, in our experience, overwhelmingly positive.

> **"Why didn't I do this sooner?"**

Where can people thinking about relocating go for help?

At EAC, our Housing Options for Older People tool (HOOP) is a sort of housing MOT. It asks about a person's current home and how they live in it. In a few areas of the country we have been able to work with local partners to produce bespoke versions of HOOP. It will ask you questions about your home, what works, and is it too big or too small? How is the garden, do you feel safe? How is the neighbourhood, how are the stairs? Do you feel isolated? Then, based on what the person has checked, it will produce answers at the end to say "if you're feeling isolated, here are the local befriending groups, this is how you get in touch with them" or "if you're worried about your stairs, this is the local improvement agency and they can look at getting in grab rails or putting in a stair lift". HOOP can also detail what funding might be available to help with the costs of that.

We are now also seeing more services that are set up to help older people with moving, taking the time to have a conversation to find out why are they looking at moving? Where are they looking at moving to? Can we help them with finding somewhere? Services will say "let's work together to declutter and think about the things that you can get rid of and the things that you want to keep, what is important to you. Why don't you leave it to us to deal with the energy companies and the water company? We will tell them all that you're moving". All those barriers to moving, mentioned earlier, are being addressed by organisations that are helping older people to navigate this, potentially difficult journey.

> **"A student nurse could benefit from Home Share during their studies."**

Getting used to life in a new community

Tom Lord, Inspired Villages

Tom Lord
Chief Operating Officer
at Inspired Villages,
HQ in London

Inspired Villages

inspiredvillages.co.uk

Between 30% and 50% of people aged over 50 relocate and, as other contributors have described, relocation can (broadly speaking) occur as a planned decision or because of a health crisis.[23] Planned moves to new communities have, however, been stifled by the lack of appropriate housing for older people to move to. Half of older people who had thought about moving, but did not go through with it, said their decision was because there were no suitable properties available. The UK builds 7,000 retirement dwellings each year for an over 65 population of 12 million and growing, and the UK only provides retirement communities for 75,000 people [24]. 0.6% of UK people over 65 belong to a retirement community, whereas the figure is 6.1% in the USA, 5.4% in New Zealand and 4.9% in Australia.[25]

30-50%

of people aged over 50 relocate

Inspired Villages, where I am the Chief Operating Officer, was founded in 2017 and from day one, it was a champion of creating retirement communities in the UK. Our mission is to create vibrant communities that help people live healthy, independent lives for longer, and to achieve this takes expertise, hard work, trust, research, and operational excellence. My background is in hospitality, running large international hotels where guests were with my team for a few days or a week. In our retirement villages, residents stay with us for years and I want to deliver the same high-quality standards seen in five star hotels day-in, day-out in our communities, using tried and tested methods from my hospitality days. I strongly believe companies should always focus on continuously improving performance, and the best driver of change for the better is understanding what our residents think of our services.

When we ask our residents about why they moved from their former home, they rated 'to feel safe and secure' highest.[26] Buildings, services and facilities matter a great deal but community, belonging, support and friendships are the crucial pieces of social infrastructure that contribute to feeling safe and secure.

That feeling of safety and security requires hard work from all of our professionals - community does not just happen. First impressions are always key so we focus resources and expertise on welcoming new residents to our communities. We work with professional research organisations to survey our new residents about their experiences. For example, we review the 'Introduction meeting with your village manager', 'the support offered to help you move into the village', and 'village activities prior to moving'. For 'move-in' day we look at seven key factors including connection

> **"The wellbeing navigator will be connected to and work with the local primary care network to ensure that village residents have access to the widest range of expertise whether services directly delivered by the village team or access to clinical specialties, and mental health services."**

24 Inspired Villages research
25 Inspired Villages research
26 Fuze Research Q3 2019

of broadband and phone services and the overall quality of the home on move-in day. To support older people with their relocation, we can provide moving-in services that help to declutter and assisted moving services to support the relocation process. I, and my team, are proud that our work is recognised and when asked 'to what extent do you feel you belong in the village', 100% of our surveyed residents agreed to some or to a great extent.[27]

Alongside the relocation journey and initial welcome, we have created a variety of programmes to support people as they navigate their new community. For instance, we can offer a buddy system whereby a current resident can team up

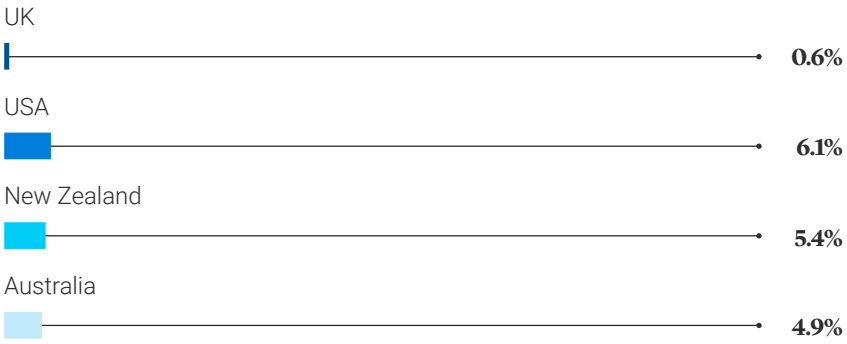
> **"These interventions add up and research suggests that they may create a National Health Service saving of £3,500 per resident, per year."**

with a new resident to help break down any social barriers and figure out the rhythm of the community.

The key innovation we have introduced is the role of the wellbeing navigator, who works with the residents in each village, and the local community. Their primary role is to connect with residents and bring people together through introductions and activities, so residents can naturally build networks, which often blossom into strong friendships across the village. Success for the wellbeing navigator programme involves outcomes that help residents to engage socially, access fitness and healthy activities, get out and about and, if required, be a point of support in the arrangement of more formal care services.

The wellbeing navigator will be connected to and work with the local primary care network to ensure that village residents have access to the widest range of expertise whether services directly delivered by the village team or access to clinical specialties, and mental health services.

People over 65 belonging to a retirement community



Technology also plays its part in the promotion of wellbeing. Working with partners, we are researching how best to use existing and emerging technological and digital solutions. This includes pinpoint alarms, fall prevention and detection systems, call systems and thermal control and lighting systems, algorithmic passive monitoring, and health and wellbeing monitoring.[28]

My team has worked hard to develop and deliver this model of support and we can see real results for our residents, our communities and the NHS.

> **"The UK builds 7,000 retirement dwellings each year for an over 65 population of 12 million."**

The UK government has stated that one of its 'grand challenges' is to ensure that people can enjoy at least five extra years of healthy, independent life, regardless of wealth and there is now strong evidence that retirement villages are supporting the achievement of this ambition. In a Longitudinal evaluation of the ExtraCare Approach, Aston University academics and researchers have found that living in a retirement village leads to a 46% decrease in the number of planned GP visits.[29] Beyond General Practice, retirement village residents experience a 31% decrease in planned hospital admissions and the duration of stays dropped from an average of 8-14 days to 1-2 days.[30] Retirement village

> **"Living in a retirement village leads to a 46% decrease in the number of planned GP visits."**

residents are also less likely to need to move into more costly institutional accommodation like care homes – research shows a 50% drop in need to do so amongst residents.[31]

These interventions add up and research suggests that they may create a National Health Service saving of around £3,500 per resident, per year.[32]

In a recent interview, Jamie Bunce (the CEO of Inspired Villages) cited a specific example of the benefits of the community building and wellbeing enablement model: "We also have inter-generational activities. We held an inaugural cricket match last year, for example, at our

27 Fuze Research Q3 2019
28 Inspired Villages Wellbeing & Care Strategy
29 www2.aston.ac.uk/migrated-assets/applicationpdf/lhs/245545-final%20report1.pdf
30 Ibid
31 ilcuk.org.uk/wp-content/uploads/2019/01/Establishing-the-extra-in-Extra-Care.pdf
32 Healthier and Happier, WPI Strategy, September 2019

village in Warwickshire. We convinced the local cricket team to play our group – comprising residents, residents' families, staff and our families – and we had an afternoon of cricket. At one point, we had a gentleman in his early 80s who admitted to not having been on a cricket pitch for 50 years. He was batting with a 14-year-old and I could see his biological age decreasing in front of my eyes, such was his joy at getting back in front of the wicket".

It is important to recognise that retirement communities are not care homes; care can be provided in our villages and we can facilitate this but the primary focus of a retirement community is peoples' health and wellbeing. We want to enable people to create their own ecosystem to meet their goals and adapt to manage or even overcome their challenges. Each residents' needs are different and no-two-people age in the same way: underlying levels of health, family and social relationships, personality and outlook mean that each

> **"I could see his biological age decreasing in front of my eyes."**

person's pathway will require different support and different tools at different times. One person living with dementia will not have the same experience, needs or wishes than another. To meet this need, a community must have access to the widest possible range of clinical and non-clinical expertise and interventions.

The communities we are building are well aligned with the NHS Forward Plan's goal to move from the current treatment model to a more proactive and preventative model of healthcare. As we move into our next phase of growth, in a world gripped by a global pandemic that has meant the onus on healthy lifestyles and safe environments for older generations has never been so strong, we will use the best research, technology and interventions to reflect this paradigm change in wellbeing and care. Our approach to dementia illustrates this pathway.

1 in 14 people over the age of 65 and 1 in 6 people over 80 have dementia.[33] Currently, 850,000 people are estimated to have dementia and this could reach two million people in thirty years. The increasing prevalence of dementia means that we will need to consider solutions to enabling those living with the condition to enjoy their lives within the village community for as long as it is safe to do so.

> **"Currently, 850,000 people are estimated to have dementia and this could reach two million people in thirty years."**

33 www2.aston.ac.uk/migrated-assets/applicationpdf/lhs/245545-final%20report1.pdf

Without becoming a specialist expert in dementia care, the demographic profile of our residents means we must deliver our model of community in such a way that residents living with dementia can be a part of village life, with appropriate care and support.

Our village staff are being trained to support residents with dementia and when we design our homes and communal venues, we will ensure that there is consideration of people living with dementia. The village will provide appropriate activities, therapies and events that are accessible to those living with dementia and support them and their families in staying put within the village community. The village team will seek advice support and expertise from the personal care team and with the Primary Care Network. The aim is to maximise the opportunity of someone remaining in the village if and until such time as there is agreement that this can no longer be safely achieved. An Inspired Village will be a 'Dementia friendly' environment but not a provider of specialist dementia care.

> **"The aim is to maximise the opportunity of someone remaining in the village if and until such time as there is agreement that this can no longer be safely achieved."**

Over the next few years, the retirement community movement is set to play a far larger role in how older people live in the UK. There is much work to be done to catch up with other countries like Australia and New Zealand. As larger organisations, like Legal & General, see the beneficial impact that retirement communities deliver, more investment will enter the sector to create many more new villages. I am looking forward to welcoming many more people to live in our retirement communities over the next decade, creating the opportunity for a fresh start, bringing in local investment and freeing up NHS resources.

Dementia in the UK

1:14
over the age of 65

1:6
people over 80 have dementia

Let's work together to design the future of care

By Tony Watts OBE
Director, EngAgeNet

Tony Watts
Campaigner on retirement issues and Chairman of the South West Forum on Ageing since June 2011

Quite rightly, another contributor draws attention to the significance of the 1948 National Assistance Act. As well as abolishing the Poor Law, put in place by Queen Elizabeth I, it laid the foundations of the care home and social support system we have today – ensuring that the last years of someone's life weren't spent in a workhouse or dependent upon charity.

That seismic shift in social provision followed a traumatic war that changed attitudes towards so many things, when we collectively decided that the old ways of doing things were no longer fit for purpose. Perhaps we need traumatic events to review established modus operandi. Perhaps one of those times is now.

The pandemic has thrown a harsh spotlight on how we care for people as they become less independent… and on how we keep them connected to the rest of society. The sight of grandchildren pressing their faces against their grandparents' windows has seared our hearts.

> **"Today's 80-year-olds are very different from those in 1948; tomorrow's 80-year-olds will also be different from today's."**

The 2014 Care Act, the NAA's long-awaited update, begins by describing the duty to promote "wellbeing". We have, the Act assumes, gone past meeting the first two of Maslow's hierarchy of needs, physiological and safety… now let's address belongingness, esteem and self-fulfilment.

That's what this paper addresses too. We urgently need a readily-accessible choice of housing and care support resources enabling all of us to not simply eke out our last years… but to lead rich, fulfilling lives, connected to friends and family.

Recent years have sadly seen a continuing squeeze on public resources diminishing many lifelines that connect those in later years to the rest of the society and threatening quality of care.

> **"We urgently need a readily-accessible choice of housing and care support resources enabling all of us to not simply eke out our last years… but to lead rich, fulfilling lives, connected to friends and family."**

The stories I recount in this paper highlight gaps in the system that only a major rethink of how we house and care for older generations will satisfy.

In particular, we need to focus on the ethics around how care can strip away people's freedom of choice and control - often unwittingly but often systemically. Today's 80-year-olds are very different from those in 1948; tomorrow's 80-year-olds will also be different from today's. We can't go on providing the same old care and housing.

Photograph posed by models

The good news is, there's plenty of evidence of "what works" to begin that process: housing models that promote intergenerational support; retirement villages where residents can smoothly transition to different levels of care provision; housing co-operatives where groups of older people support each other. There's no one-size-fits-all approach that will be to everyone's taste, but – critically – promising new models are emerging.

The challenge, of course, is finance. More certainty on funding future care will represent a major leap forward; until that long-awaited day arrives it's heartening to see institutions like L&G developing models that look long-term at societal needs, as well as harnessing capital for the public good.

> "no one has a better understanding of what will work for older people than older people themselves."

We need more examples of "what works" made available to our rapidly-ageing society; we need more choice locally allowing us to age in place; and we need more involvement of older users themselves in the design process. Because no one has a better understanding of what will work for older people than older people themselves.

Caring for Britain

Consultation questions

1 What are the barriers to innovation, start-up, and scale up, in the UK care sector?

2 What can be done to encourage families and individuals to set goals and create their own care ecosystem? How can they then be supported to make a plan to deliver it?

3 How can care-related benefits be more easily understood? How could the benefits system be reformed to integrate better with the way people make and plan their care ecosystems?

4 What more can be done to help people who want to stay in their own homes? How should the NHS and all kinds of care providers work together to deliver this?

5 What can be done to encourage greater choice and diversity in housing for older people, for example in retirement villages, multi-generational communities and both urban and country settings? market, to close the gap with the US and Australia?

Click here to complete the online consultation
To email your response, please send to john.power@landg.com
To post your response, our address is Legal & General PLC, One Coleman Street, London, EC2R 5AA

Directory of services

Voices of older people

www.engagenet.org.uk/

www.carersuk.org/

Academic research

davidgrayson.net/

www.ed.ac.uk/usher/advanced-care-research-centre

Finding the care in your area

www.caresourcer.com/

Home care and technology

www.birdie.care/

www.liftedcare.com/

currenthealth.com/

Finances

www.sjp.co.uk/

societyoflaterlifeadvisers.co.uk/

www.legalandgeneral.com/retirement/

Housing and accommodation

www.eac.org.uk/

www.firststopcareadvice.org.uk/

www.housingcare.org/

www.inspiredvillages.co.uk/

Contact us

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