

Fixing the foundations

Why it's time to rethink how we support older people with health problems to stay well at home

"I could see oceans of problems in the health and social care system, but it was like walking around outside the castle shouting at the guards on the battlements, trying to attract their attention but not getting anywhere....." (a carer)

1. Introduction

Introduction

In 2018, Age UK published a report called *The Failing Safety Net*. Using the stories of older people, the report outlined the challenges that older people face in negotiating a daily battle to meet complex health and care needs.

Theirs were not the stories of negligent or uncaring health and care staff, but rather of a system that was often fragmented, un-coordinated, and insufficiently focused on helping them to stay fit and well, so they can get the most from their later lives. We concluded:

“The bottom line is simply that far too many older people still do not receive the coordinated, wrap-around support at home that they need. And the problem is becoming more pressing by the day.”

The ‘failing safety net’ of the title referred to a series of missed opportunities whereby NHS and social care services were not there to catch someone when they needed it. The outcome was usually an admission to hospital, the final resort for many people who had simply deteriorated too far or who were put at frequent risk of a crisis.

However, by then the moment to work towards recovery, independence and long-term wellbeing had often passed. Older people like this typically returned home, or to a care home, with higher needs, worse mental health and, too often, the prospect of a shorter and less fulfilling life.

We said that the need to repair and reinforce this safety net was becoming more pressing by the day, so where are we now? In this report, we speak to a new set of older people and their carers, all with some level of health and care need, some more complex than others. We explore some of the same questions and examine to what extent older people are still being let down by a health and care system that is insufficiently integrated around their needs and that often kicks in too late.

Since we published *The Failing Safety Net* in 2018 some important things have changed. Above all we have lived through the acute phase of the COVID-19 pandemic, with older people disproportionately affected. Over 65s represent around 90% of all those who died as a direct result of the virus. In addition, many older people have experienced severe physical and mental health deterioration from the effects of lock downs. Some are effectively still locked down in their homes, anxious about the risks of mixing freely with others.

During the two years or more of the acute phase of the pandemic and since then too, as a result of enormous waiting lists, hundreds of thousands of older people who rely on support and care have gone without, further contributing to that deterioration and in some cases leaving them living with chronic pain, anxiety and unmanaged health conditions.

Part of the reason is that unfortunately, the Health and Care workforce has understandably also been badly affected by the experience of working through the pandemic. Now, in late Winter 2023, the shortfalls of staff in both the NHS and social care are huge and growing – considerably worse than they were before COVID-19 arrived. There is no doubt that this is impacting on the quantity and quality of help available to older people.

Introduction

However, we spoke to the participants during the Autumn and Winter of 2021/22 and some of the experiences they talk about pre-date the pandemic. The truth is that much in this report echoes what we have heard for a number of years and indeed, in our 2018 report.

The pandemic may have created some new challenges but the nature of what older people describe was often there all along: that is, a health and care system that is clunky and under-resourced, especially but not exclusively within its social care and community health service components. Care that can support and sustain older people to stay well at home can be the foundations of an effective and sustainable health and care system. At the moment, these foundations are often broken or simply not there at all.

The pandemic has certainly sharpened a lot of issues and increased the need for health and care support in the community; as a GP we spoke to put it: *“People [...] they’re living longer. They’re not living well for longer.”* For the sake of older people and their families, and to help our hospitals and the wider NHS to operate efficiently and effectively, this must change. What’s more, even in the current difficult circumstances, it can, if the political will exists to do it. Amidst the challenges there are some signs of hope and it is imperative that we build on them.

2. Background

Background

As we get older, we are much more likely to live with a long term condition and above a certain age, it is the norm to live with two or moreⁱ.

69% of people over 85 live with multiple conditionsⁱⁱ. 35% of older people live with some form of frailty (15% moderate or severeⁱⁱⁱ), a state in which you have lower physical reserves with which to recover from injury or illness. A very large proportion of older people have some level of care and support need such as help to get dressed or washed and we estimate that over 1.6 million do not get the help they need^{iv}.

This will typically mean that we need to access health and care support to live well, particularly in the final months and years of life. However, when care and support is delivered proactively, in the community and before our health worsens, we can avoid the need to go to hospital.

Why is this important? A stay in hospital can be essential for addressing an acute health need or to deliver specific treatment for a health condition or injury. However, a stay in hospital also exposes us to healthcare acquired infections, falls risk and deconditioning, i.e. the experience of losing muscle mass, mental wellbeing and general deterioration when you are stuck in a bed for long periods, potentially weeks. Too often, older people do not recover to previous levels of health or independence after such spells.

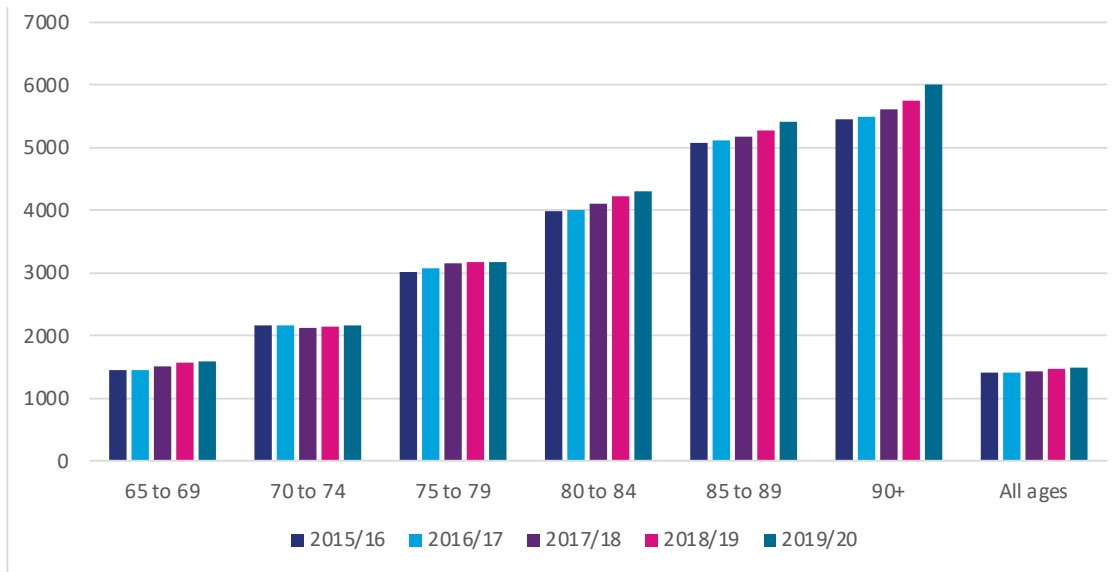
The stories in this report outline people's experience of having unmet health and care needs. At a national level, one way of demonstrating this challenge are the rates of avoidable hospitalisations for conditions that should be managed in the community. These are known as chronic ambulatory care sensitive conditions and include conditions such as diabetes, high blood pressure and heart failure.

Background

Figure 1, shows how much more frequent these hospitalisations are the older we get. It also shows that in the five years up to 2019/20 these admissions have become more frequent, particularly for the oldest old*.

Figure 1

Unplanned hospitalisations for chronic ambulatory care sensitive conditions, by age per 100,000 population



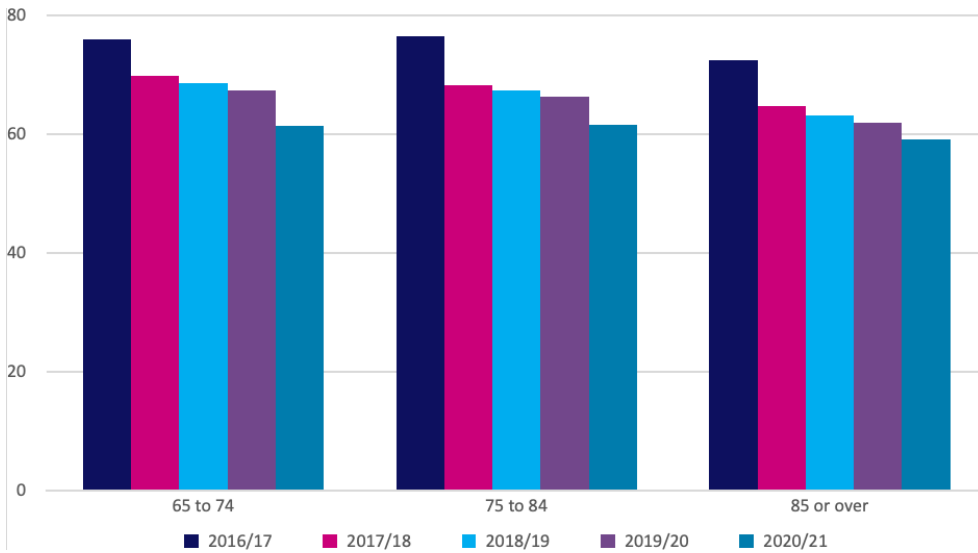
NHS Digital ^v

It is perhaps unsurprising that fewer older people feel supported to manage their long-term conditions. Figure 2 is taken from the NHS Outcomes Framework. In the five years to 2021/22 the proportion of older people feeling supported to manage their condition has been falling consistently, almost 20% in relative terms. In 2020/21, the pandemic will have had an additional impact, and across many of the measures cited in this report these impacts continue patterns of decline that stretch back years.

* To note, the graphs in this section describe total episodes/admissions, rather than individuals. This means that they will include people that will have gone in multiple times. Figures for 2020/21 are also available, showing a significant drop in total admissions due to practices linked to the pandemic.

Figure 2

Proportion of people feeling supported to manage their condition (%), 65 and over

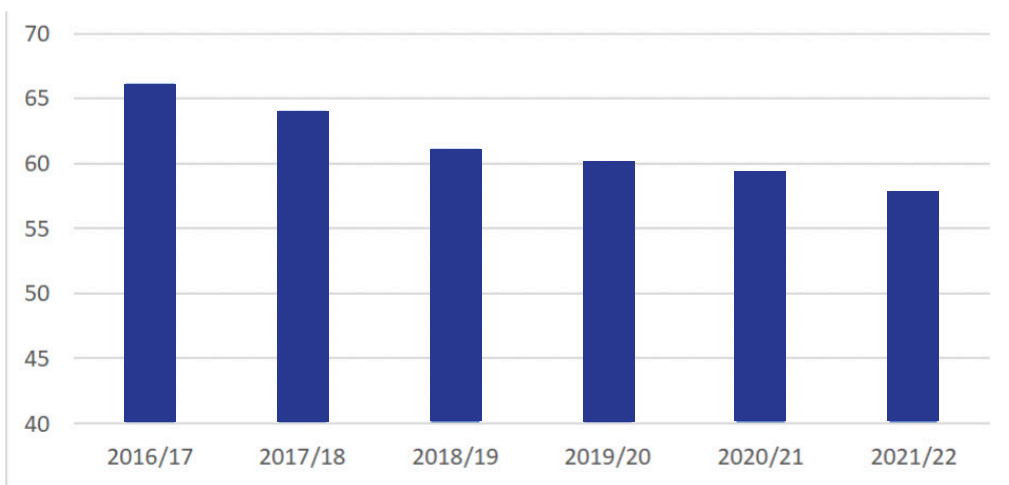


NHS Digital^{vi}

At the same time, access to long-term social care, which can prevent health deterioration and the need for NHS services, has been going down. Figure 3 shows the average number of older people, per 1,000 people over 65, that have received long term support from their local authority during the year since 2016/17.

Figure 3

Clients receiving long term support per 1,000 people over 65



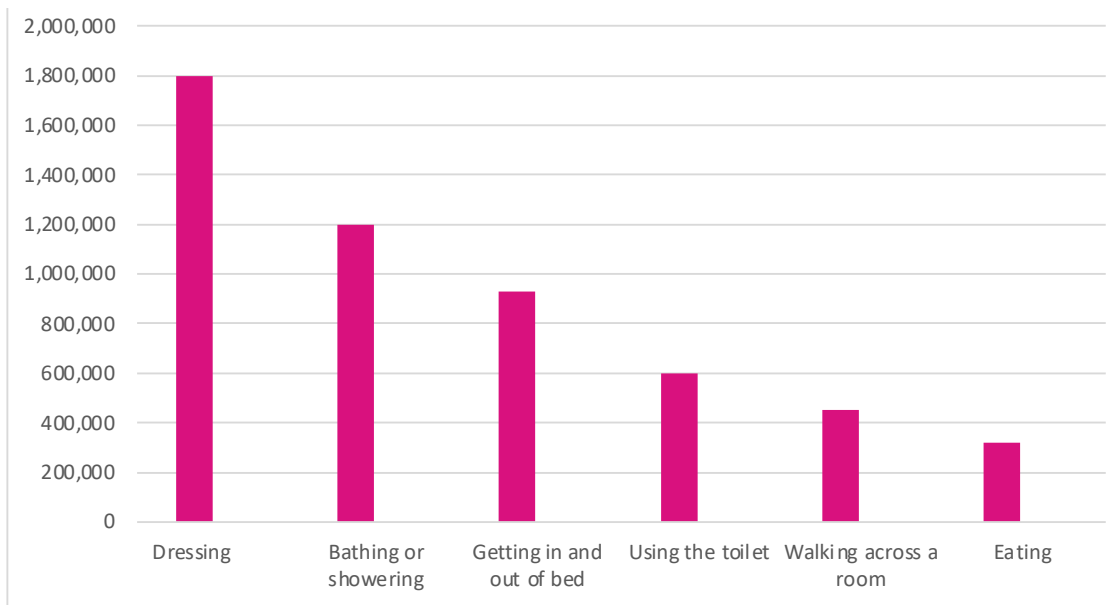
NHS Digital^{vii}

Background

Again, it will therefore come as no surprise that 2.6 million people over 50 have unmet social care needs^{viii}. This increases with age with 15% of people in their 70s and 21% of people in their 80s living with an unmet social care need. Figure 4 shows what areas of daily living are most badly affected.

Figure 4

People over 50 with unmet social care need



Age UK/Care and Support Alliance^{ix}

As we say in our introduction, much of the support people need to meet basic needs at home are being met by family and carers. They feature throughout our case studies in this report. However, the latest figures from 2019 estimate that 3.3 million older people live alone, up from 2.8 million just ten years earlier^x. Sadly, we would expect this figure to be even higher following the impact of the pandemic. Adult children, particularly daughters, also carry a significant load yet the number of older people ageing without children is increasing. In 2019, it was estimated that 1.5 million older people have either never had children or their children have died^{xi}.

3. Who we spoke to

Who we spoke to

We had in-depth discussions with 14 older people aged between 57 and 92. Many of them were carers but often themselves living with long-term health challenges, which they often had to de-prioritise for their caring responsibilities.

The following table provides more detail on each of the participants. We include the health conditions or health incidents they mentioned to us to demonstrate the complexity in their needs. In some cases, their name has been changed. The information below was accurate at the time of the interviews.

Name	Sex	Age	Living arrangement	Care received/carer status	Conditions
Alison	Female	67	Lives in sheltered housing	No care services	<ul style="list-style-type: none"> Mental health Fibromyalgia Joint pain
Carol	Female	57	Lives with adult children and cares for one of them	Receives community mental health services	<ul style="list-style-type: none"> Spine damage Wheelchair Heart attack Acute mental health
Colin	Male	68	Lives with wife	Cares for mother (living elsewhere); mother receives self-funded care services	Mother: <ul style="list-style-type: none"> Blind Hip fracture
David	Male	91	Lives alone	No care services	<ul style="list-style-type: none"> Overweight Poor mobility COPD Arthritis
Elaine	Female	72	Lives with husband who receives care services through a direct payment	Carer	Husband: <ul style="list-style-type: none"> Brain injury Prostate cancer Diabetes Vascular dementia Elaine: <ul style="list-style-type: none"> Asthma Diabetes Sarcoidosis
Eleanor	Female	71	Lives with husband	Carer	<ul style="list-style-type: none"> High blood pressure Cholesterol Takotsubo cardiomyopathy Chronic kidney disease Nephrotic syndrome Type 2 diabetes
Elizabeth	Female	84	Lives alone	Had intermediate care/reablement	<ul style="list-style-type: none"> Hip replacement Heart attack
Francette	Female	87	Lives alone	Had intermediate care/reablement	<ul style="list-style-type: none"> Chronic back pain (undiagnosed)

Who we spoke to

Name	Sex	Age	Living arrangement	Care received/carer status	Conditions
Jean	Female	92	Lives alone	Receives funded care services	<ul style="list-style-type: none"> Colostomy bag Back pain due to curvature of the spine Osteoarthritis COPD.
Jeremy	Male	76	Lives alone	Carer for wife (living in residential care)	Wife: <ul style="list-style-type: none"> Huntingtons; Jeremy: <ul style="list-style-type: none"> Heart attack + stent fitted Diabetes Spinal stenosis
Daniel	Male	65	Lives alone	Had intermediate care/reablement	<ul style="list-style-type: none"> COPD Atrial fibrillation Underactive thyroid Hypertension Registered disabled
Marie	Female	78	Lives with son, who has autism	Receives minimal care services funded by attendance allowance	<ul style="list-style-type: none"> Mental health Osteoporosis Pleurisy Severe back pain Fractured spine Fall (broken hip)
Noel	Male	69	Lives alone	Had intermediate care/reablement	<ul style="list-style-type: none"> Chronic COPD
Sheila	Female	71	Lives alone	No care services	<ul style="list-style-type: none"> Asthma Life-threatening allergies Sleep apnoea High blood pressure Type 2 diabetes Issues with eyes Osteoarthritis Awaiting treatment for a shoulder injury.

We also spoke to four health and care workers from different professions. These were:

- A geriatrician – a consultant physician that specialises in older people’s care
- An occupational therapist – an allied health professional that specialises in supporting people with health and care needs to find ways to undertake every-day tasks.
- A social worker and manager – someone who usually works for a local authority to assess individual support needs with daily activities and plan care to meet these needs. The social worker we spoke to also manages other social workers.
- A general practitioner (GP) – a senior primary care professional that is typically the first point of contact for health needs.

4. Themes

We break down the stories in this report across six key themes. These came up organically through the issues that our participants described:

- 1. Social care at home** Relating to the experience of receiving care with daily activities at home
- 2. Unmet need** Where older people have health and care needs for which they are not getting sufficient support
- 3. Continuity of care** Older people experiencing poorer outcomes because their care is not joined-up or coordinated around them
- 4. Being listened to** Where older people have a health and care need that is not acknowledged or for which the seriousness is not picked up
- 5. Personalisation in practice** Older people and carers who find that the system delivering care is too rigid and doesn't respond to their individual circumstances
- 6. Fixing the Foundations** How we can start to improve the health and care of older people

For each section we briefly describe what some of the key challenges are but give the space to the older people we spoke to describe the impact of their challenges. We use their own words wherever possible, but sometimes, we will summarise elements of our conversations to reflect what they told us. We also spoke to health and care professionals to better understand, as staff and local leaders, how they saw the problems and what might help resolve them. These are included in the second part of each section.

5. Social care at home

Social care at home

At some point in their lives, most often towards the end, many older people can come to rely on hands-on care to meet their daily needs. Activities which many of us take for granted such as being able to wash, dress or prepare food can become too difficult for older people living with serious long-term conditions and disability to undertake unaided.

More typically, it falls to informal carers, including spouses and partners, to help, but some will receive support from care workers. This could be paid for by the older people themselves but in some cases will be organised and funded by a local authority. In other cases, some older people leaving hospital will receive home care while they recover and often this is an essential step in enabling them to be safely discharged and avoiding a permanent admission to a care home.

The pandemic has had a significant impact on the availability and quality of home care but the challenges stretch back years. A combination of under-funding, over-reliance on independent providers (highly susceptible to market conditions and unevenly spread geographically), and pay and conditions. The latter making the sector increasingly uncompetitive vis a vis those in the hospitality and retail sectors, and in the NHS. These all help to explain the difficult position we are in now. Colin, caring for his mother reflected on the situation in his area:

“I think even within the private sector it’s hard to find the right people that provide the support that she wants... I know for a fact that they’re very, very short-staffed... I think that’s true whether it’s county council funded or whether you’re paying for it yourselves, it’s very difficult to get the right people. I just don’t believe there are enough people around anymore, trained or whatever, maybe because some of them have gone home after Brexit, but there just aren’t the people around”.

The total amount of home care delivered fell by 3 million hours between 2015 and 2018^{xii}, although the need for it did not. The effect has been to pile even more pressure on unpaid carers to fill the gap.

Elaine, caring for her husband and herself living with multiple conditions has no confidence that their needs can be met:

“I tried working... I couldn’t leave him with carers. They would leave him, and I would come home and find he’d had a seizure... So, I gave my career up and became a 24/7 carer”.

“My caring role is horrendous. It’s very, very difficult. There’s so many things I have to support Michael with, and my own health is not good. I’ve got asthma, and I’ve got sarcoidosis, and I’ve also got arthritis... It’s been six years since we last had a holiday.

Some of the older people we spoke to felt the care service they were getting did not really work for them, or meet their needs:

“I’m an early riser and I needed someone to come and help me get dressed because I was very feeble. I could barely stand. That never happened because they came at all odd times, and never the same time in the day.”

Social care at home

In the end, Elizabeth cancelled the service because it was too erratic and because of quality concerns too. She says she has “a very loving family who look after me and do whatever they can to help me”, but she wouldn't accept a care package again.

“[This] has happened to me more than once, so I would rather die on my own than have a care package. There are people who haven't got anyone, so if they're being treated the same way I am, then how on earth do they cope?”

Daniel was recovering from a very difficult spell in hospital and found that his home care was not coordinated around his needs

“I had a knee operation. I was very ill from it... I had to spend a few weeks in hospital”. When at home: “All they did was turn up when they wanted to turn up. They said eight o'clock in the morning; they could turn up at nine o'clock. Why not ring and inform me? When you ask them to do a bit of shopping for you, well it was like asking them to get blood from a stone”.

Low pay, an inadequate career structure and the pressures of not having enough time to complete daily tasks makes it incredibly difficult for care providers to retain staff. The effect is that there is a lot of churn and people delivering care do not always have the training or support to carry out their roles, especially as many of the older people they are working with have quite complex needs – certainly more so than a generation ago. Jean observed:

“Some of them are very good, but then you get an odd couple that aren't quite so good. And for me, it appears that some of them don't get enough training [...] And these [care workers], they only got a certain amount of time. They got three quarters of an hour in the morning, half hour at lunchtime, and to me it's not enough.

Noel said:

“Whenever I'm with a [care worker] I try to do things myself... they ain't got time. I haven't had a shave for about a month”.

The view from the front line

An occupational therapist we spoke to described home care availability in their area in the following terms:

“It’s dire. It’s the worst I’ve ever known it. It’s horrendous, and actually the staff quite often are in tears at the lack of help that we can provide them. We’ve got families ringing us in tears, and we’re pretty much in tears, because we’ve got nothing to offer them.

“In our particular area at the moment, we have no care. We have no care capacity whatsoever..... we’ve put an awful lot of burden on families, way more than we’ve ever had to”.

A geriatrician explained the impact of the problems with home care in deprived areas, and for older people for whom the State is responsible for their care, as opposed to those in a position to buy it themselves:

“[If] you go to someone who is state-funded the maximum they can have is four visits. They can’t have an overnight sitter – that has to be privately funded. So that means that as soon as that becomes an issue, unfortunately, that person probably has to be transferred to a care home. And then it does take time to set up their package of care, so if it’s not put in relatively quickly, again, that person might get into trouble and get into a hospital. There is a difference in those who fund their own care”.

And a social worker explained their concerns for older people living on their own, without any family or friends to support them:

“Anybody living alone clearly there is a vulnerability. Just little things like when we discharge somebody, somebody popping around, checking that there was food in the fridge and that the heating was on and that the water worked. I think that is a massively valuable and that just feels like a big gap. And obviously, that’s [less of a concern] where you’re discharging somebody back into a home that’s got a carer in it or another loved one. So, that really highlights the vulnerability of single people”.

6. Unmet needs

Unmet needs

One marker of unmet needs is emergency admissions for what are called ‘ambulatory care sensitive conditions’. These are conditions that can be managed in the community and that with the right support should not require an admission to hospital.

They include things like pneumonia, chronic obstructive pulmonary disease (COPD) and urinary tract infections. For the years leading up to the pandemic they were on the rise, particularly for the oldest old (85+), increasing by approximately 25% between 2010 and 2018^{xiii}.

Francette was struggling with chronic pain and found that little was done to work out why, so the underlying causes could be understood and treated. She had been told it could be ankylosing spondylitis, rheumatoid arthritis, and venous syndrome – different diagnoses by different doctors at different times.

“But every time there was no prognosis, no medication given”. “[My GP] said: ‘What do you expect? You’ve got some gel, you’ve got some painkillers, that’s all I can do for you”.

Previous experience had left others reluctant to seek help because they no longer had confidence that something would be done. Alison told us:

“I’m reluctant to say ‘my knee is bothering me at the moment’ or whatever. I don’t want to just have medication, drugs, chemicals thrown at me.”

“I have absolutely no treatment plan in place or support of any kind. I’ve had to find everything for myself. And I think that’s a big gap. [...] I should have something in place.”

For older people who were already receiving specialist care the pandemic had impacted their services, but, as Carol tells us:

“So even though the help weren’t that good when I started being unwell, now it’s really deteriorated quite a bit since... The waiting lists are so long now. I think it were going in that direction before the pandemic”.

When living with multiple long-term conditions the impact of unmet needs can accumulate. Eleanor described her experience:

“I get tired, not very quickly, but the heart condition brought on a necessity to apply for a blue badge, for when I drive my car, for parking. [...] The kidney condition has sometimes left my legs a bit tired, a bit shaky and hard to walk on. [...] Lucky, I live in a bungalow, but walking upstairs can sometimes be very difficult.”

Eleanor cares for her husband, adding further challenges. Some basic things that made life tolerable have stopped since the pandemic.

“Before the pandemic someone was coming in a couple of times a week and getting him to walk, and walk up and down, but then that all stopped.”

Unmet needs

Intermediate care/reablement can make a huge difference to someone leaving hospital. It is time-limited, non-means tested care that aims to aid someone's recovery. However, many older people can find that after that initial period the support stops abruptly and people have to start negotiating with the social care system for help to continue, and on what terms.

In May 2021, Marie fell and broke her hip and was in hospital for a month. After discharge she received 6 weeks of care at home, but she still had significant needs after that period.

“My balance isn't good and I'm still having to use a Zimmer frame to get about. So now I need someone to help me wash my hair, shower and that kind of thing.”

Marie was given a form to apply for further care after six weeks, but she did not fill it in as the questions left her concerned she would lose her independence. Instead Marie manages with twice weekly care visits which she pays for herself.

The impact of unmet needs, particularly on those living alone, can be devastating, making it impossible to go out and about and enjoy spending time with other people. Loneliness is also a serious risk factor for health complications. Noel spoke about his life at home:

“I've only got the telly for company. I'm missing company. I ain't got no friends. I've got no life. I've got nothing really. Nothing”.

Noel has had COVID-19 twice. He was hospitalised both times. It has made Noel's breathing worse, which has made it even harder for him to walk around and manage day-to-day activities. This has made his isolation and loneliness worse.

“I feel like a prisoner in here. My four walls. Loneliness is a horrible thing.”

The view from the front line

It is not unusual for hospital staff to find themselves caring for older people whose health problems could, in their opinion, have been tackled or avoided altogether if they had received better, more prompt care while at home. A geriatrician told us:

“When I’m in hospital you can see people coming into hospital and I’m like, oh this could have been sorted easily but for whatever reason, it didn’t happen. And there are many reasons why not. So yes, whatever the reasons are, people are still falling through the cracks”.

“A person will be transported to hospital because they’ve fallen, they’re lying on the floor, or someone has found them in a state of they’ve not been eating and drinking, and they’re dehydrated because they just couldn’t prepare things for themselves”.

A GP commented:

“You’re more likely to fall through the cracks if you haven’t got somebody who’s advocating for you. [...] I think if English isn’t your first language or if you haven’t got anyone acting on your behalf or if you’re living with dementia or if you’re not digitally engaged or if you have got sensory impairment, all of these things make people even less able to navigate the system.”

These issues have been painfully exposed by the pandemic, but they are not new. A geriatrician reflected on where things are now:

“This has been building up for many years. Already we knew that most care is informal care provided by older people, who are female, and tend to be related to the person. And as people get older and frailer, the same is happening with their unpaid carers.

“The pandemic I think just brought this to the fore. These things have been there and have been brewing for a long time. We have been burying our heads in the sand and the pandemic just exposed it all I think”.

This combination of deep-seated problems and a significant deterioration in health during the pandemic should be putting older people’s needs at the top of the agenda, but an occupational therapist talked about the challenges in the next phase of recovery from the pandemic:

“I think the pandemic has probably thrown a real spanner in the works there, because I think there’s been an awful lot of people that are missed, and that is continuing because services are only just starting to restart. And there is such a backlog, that really the only people that are being seen at the moment are the ones in absolute crisis and dire need.”

“People that are starting to become more unwell, and could probably do with some interventions now, are just not getting anywhere near the front of the queue.”

Unmet needs

With the focus understandably on crisis care the risk is that people with less urgent needs, who could be hugely helped if they receive timely care now, are missing out. A social worker said:

“There was a huge amount of work that went into looking at our population and the people who are the top 5% of need. That just sucked so much resource, it uses up everything and really we’re not doing a massively great thing for them. We’re just providing the services they need. But then when you start to go down, the next 20%, for very little input, could have a massively better benefit because you can keep them independent. That’s what they want to be, that’s what you want them to be. But you need to have something that just bridges the gap between the intensity of care in a hospital bed to being back on your own”.

“It’s the little lump underneath that [top 5%] that suffers most because they’re not quite bad enough to access services but there isn’t anything for them”.

Older people who are unable to leave hospital because care in the community is not available have significant knock-on effects on the flow of patients through hospital. If beds are occupied with older people who are otherwise well enough to leave, that means that new patients are not able to come in. The evidence for this is the extreme waits for ambulances and other emergency admissions to hospital. In August 2022, there were 19,000 patient handovers from ambulance to hospital delayed by two hours or more, more than double compared to August 2021^{xiv}. In the 12 months to July 2022, a total of 333,000 hours were lost to these delays, a staggering 1,787% increase compared to the same period in 2019-20^{xv}.

A social worker told us about the pressure to get older people out of hospital quickly and the consequences of this for everyone concerned:

“I think hospital discharge is a game of Russian roulette here. Looking at where we’re at today, our local hospital actually is at 105% capacity, with long waits outside, and not many people identified for discharge. That’s where we’re at.”

“I think in terms of hospital discharges, at the moment, the pressure is getting people out of hospital. And that’s what they’ll do, but it doesn’t mean that’s going to be a good discharge or a safe discharge, or actually those people are ready.”

An occupational therapist said:

“The complexity of people that we’re dealing with is massively more than I’ve ever known it in terms of discharge. But our actual cared for population has shrunk. And I don’t know how long that lasts. The issues are all around complexity.”

7. Continuity of care

Continuity of care

Large numbers of older people rely on a range of services and support to meet their daily needs. As our health needs become more complex with age we can be engaged with a number of different health and care professionals.

Even when an older person might need a single episode of care for an acute healthcare need, other conditions and needs may have to be considered in addressing that problem. Failing to take account of the medications you are on or the impact of your health conditions can mean you are not able to recover from a period of ill health. Equally, if your needs are not met in the round, you are more likely to deteriorate and be at risk of losing your independence.

Joining up care around the needs of older people and their carers is often critical in avoiding this. However, the people we spoke to felt this was not happening consistently. Alison reflected on her experience of using her GP service:

“I’ve spoken to so many doctors over the last 18 months, never the same one more than twice. There’s no continuity [...] and each time I speak to someone new, they ask me basic questions about who I am and what I am. And they, obviously, have not, either not had the time, I understand, but not taken the trouble to even find out something about me. I mean, if you look at recent stuff, the story’s there. I get asked basic questions and then, they talk about another pill.”

Carol had similar frustrations seeing her psychiatry team.

“I didn’t find I was getting anywhere with the psychiatrist because every time I went it was a different one and you have to start again”.

On one occasion, the psychiatry service told Carol it was changing its systems and she would see someone new next time. She was advised they would be in touch about what was happening. She didn’t hear anything, so her Community psychiatric nurse (CPN) contacted the unit and was told Carol had been discharged because she hadn’t shown up to appointments.

“And I heard this and I did get very upset with it... I said that’s a lie. I explained I was told to wait for them to be in touch and I have never missed an appointment”.

Daniel, who lives with multiple health conditions, found some services require persistent chasing, while others don’t work together at all. This has resulted in long waits, poorly joined-up care, and threats to his independence. In one case, Daniel had been referred for physiotherapy and finally got an appointment after he spent a long time chasing. Even then, when he started his treatment, the service had none of his records.

“The [hospital where the physiotherapy takes place] can’t access the notes from the [hospital where the surgery took place], which is pathetic, it’s stupid”.

Continuity of care

Jeremy, caring for his wife, also found that different parts of the service were not talking to each other, creating confusion and wasted journeys. Miscommunication between the GP, dentist and hospital teams led to three wasted visits to surgeries and hospitals, each requiring his wife to be specially transported with support from two care workers. Ultimately with Jeremy's advocacy his wife avoided having all of her teeth removed.

The emotional and practical pressure on carers in just managing the lack of joined-up care is considerable. Jeremy explained:

"I found being a carer very frustrating, because [...] I could see oceans of problems in the health and social care system, but it was like walking around outside the castle shouting at the guards on the battlements, trying to attract their attention but not getting anywhere and having to go home and start again. It was extremely frustrating for me to see organisational disconnects everywhere, and the whole system is fragmented."

The view from the front line

The people working for health and care services can experience similar frustrations. A social worker and local manager described some of these challenges.

“At the moment you could interact with a GP, an acute trust, a community provider, a social care provider, an in-house social care provider. There may genuinely be four to five organisations involved in that journey – possibly more if the agencies change. And it’s all those intersections that create barriers”.

Older people, living with multiple conditions and complex needs, are the most likely to encounter these barriers. A geriatrician we spoke to outlined the impact of an ageing and older population.

“I think we are getting older people who are more frail. People are living longer now, which is good, but as a consequence, they are more frail, they need more support but we are not able to get that in place as quickly as we’d like”.

They spoke about the divide between primary care (GPs) and hospitals where access to consultants is much more guarded and can cause delays in getting clinical support.

“Now it’s more single point of access, you follow some protocols, you wait a few hours to be seen, and are then passed on to the speciality even if you have informed them [from the outset]. So, they have all these layers of bureaucracy and things that have been put in”.

Most people experience care for single episodes and conditions, but older people with multiple and/or complex conditions need their care to be joined up. A GP described how the NHS can be too strictly organised along single conditions or issues.

“It’s great if you happen to be lucky enough to have just diabetes or just cancer or just heart disease or just epilepsy, but if you happen to have heart disease, epilepsy, cancer, and you’ve had a minor stroke, you’re caught in the middle of all these different people doing different things to you who aren’t necessarily talking to you.”

The GP spoke about their concerns for older people who don’t have someone to do the hard work of joining up a number of different health inputs for them.

“How do people cope if they don’t have a daughter or a son or a neighbour or a friend who does that for them?”

It becomes even more complicated when you also have a social care need. An occupational therapist told us:

“I think actually, the services between adult social care and health have been very difficult to navigate. So, unless really, you’ve got a relative that works in health and social care, you’re at a real disadvantage as an older person. It’s very difficult. The pathways are ridiculous”

8. Being listened to

Being listened to

During the pandemic, Age UK gathered feedback from thousands of older people and their carers about the impacts on their health.

For the majority, their health has worsened, but a familiar experience was an inability to see their GP. In some cases this was because they were unable to negotiate the online access portals or simply could not get through on the phone, or because a face to face appointment was not on offer.

Care in the community isn't only about GPs, but many older people rely first and foremost on the services provided out of GP practices, by doctors and practice nurses especially. Difficulties accessing these cause huge concern.

Francette talked about her experience of trying to get help for pain in her foot:

“For months long, they didn’t do anything. Eventually one nurse did come to my house and took some blood, and they found out that I had gout. And that’s what caused me all that pain. But all the time I was treated for water retention, it’s ridiculous... it had been all those months where I struggled”.

“Once you’re a certain age you are a nuisance. Very often it seems you are swept under the carpet. I’m very dissatisfied with the whole thing. I’ve always had a very active life, having brought up six children and working... And when you’re 87 and you live on your own... it is not a very good way to live”.

Jean talked about waiting several weeks to have her broken hip diagnosed, despite being in severe pain:

“I’d been walking around for five or six weeks with a broken hip, and nobody listened to me. Nobody.”

Marie started to experience severe back pain at the beginning of the pandemic. She tried to access support from her regular GP who she feels knows her family well, but struggled to navigate the new triage system.

She eventually saw a doctor who examined her in her garden and diagnosed a chest infection, but the pain intensified and an ambulance was called. In hospital an X-ray showed her spine was fractured in four places. However there was no in-person follow up once she returned home. She explains:

“The doctor phoned me up once a month to check me because of this morphine. I didn’t see anybody. So, got through best way I could.”

Sheila’s shoulder injury – which was not diagnosed for several weeks – continues to cause her pain. The waiting list for treatment is currently 24 weeks long, so she is hoping for a cancellation. She was recently offered an appointment with 20 minutes notice:

“Even where I live, I think with the bad knee as well as the shoulder, there’s no way I could have walked there in 20 minutes. And I didn’t have anyone around me that could have dropped me off in the car.”

“I think the pain affects me from the osteoarthritis more than anything. Some nights I don’t sleep very well because of the pain, and you max out on the painkillers.”

The view from the front line

A social worker said:

“Getting a face-to-face GP visit is nigh on impossible and I believe it does lead to... I don’t want to say ‘dismissive’ behaviours, I want to come up with another word. But it leads to this slightly... are you really sure? ‘Walk it off’ response”.

“I think they [older people] have a lower expectation than perhaps a generation or two to come. If the doctor says, “No just walk it off, you’ll be all right”, then there seems to be a bit of a temptation to say, “Oh, okay, well yes I can put up with it”. They’re more tolerant of what really shouldn’t be tolerated and it does mean they get a poorer service because of it. A bit of an old adage, isn’t it? ‘Shout loudest’ and all, but I think it’s true”.

9. Personalisation in practice

Personalisation in practice

Managing multiple health conditions can be complicated and difficult. For many older people, they find the health and care system can be insufficiently flexible, not really responding to their needs but instead working within its own rules.

This can lead to missed opportunities to keep someone well and also creates problems for their partner/carer if they have one. In addition, older couples are very rarely seen or treated in the round; instead they are viewed as individuals, which often makes less sense.

During the pandemic, Sheila found she had to make a number of trade-offs because the health and care system was not equipped to work around her multiple needs. This was made worse because her vulnerability to COVID-19 made her wary of seeking help. She had to postpone knee surgery due to cancer treatment, and more recently she has not been able to keep up her diabetes checks:

“I’ve got to admit, I have actually let the diabetes check go because I needed to go to the surgery for the blood tests, which [...] I’ve put off for two years. [...] The pharmacist at the surgery contacted me and really pushed me into it. But since April, that’s not really been due to the pandemic, it’s been due to the fact that I couldn’t drive to get there because of my shoulder”

David had a knee replacement 10 years ago, but at that time there was no suggestion of adapting his home. When he had to contact social services about his wife’s care he believes it would have made a big difference if he and his wife could have been considered as a unit. For example, a walk-in shower would have made a massive difference to both of them before their health got worse but was never considered.

“I was her carer but they didn’t look at the two [of us] together. They did not consider me as an 80-something-year-old person with a heart condition caring for another patient. In reality both patients were one problem. It would have assisted me and my wife if we’d been considered together.”

Elaine and Michael have had to pay for their own equipment and adaptations because statutory support has been slow to the point of being useless. The council agreed to provide a replacement bath lift for Michael but advised the process would take ten weeks and could only begin once the current bath lift had actually broken:

“Michael has brain injuries, which they’re fully aware of. He can’t have a shower. He won’t have water on his head. To leave him ten weeks is impossible. So, it’s easier for me to spend my money buying him another one”.

The view from the front line

An occupational therapist commented:

“I think the demand for services is the highest it’s probably ever been, and it has been going up year-on-year. And I think some of that is due to other services, so maybe housing, that they’re all starting to interpret their guidance and legislation absolutely to the letter.”

“Somebody who is starting to struggle with showering is going to be at the very bottom of that list. You’re potentially looking at months before those people get seen and assessed. And then, once the [occupational therapist] has done that assessment, they then send through a referral to the local authority, where they will potentially sit on another list, waiting to actually get that work done. You could be looking at two years, two and a half years from the minute that person is referred in, to actually getting anything on site”

10. Fixing the foundations

Fixing the foundations

Day in, day out, the staff working in health and care services make a huge difference to people's lives. Since the start of the pandemic, they have been under incredible strain to keep services going.

Now they have a significant up-hill battle to reduce the waiting lists of delayed or deferred treatment and to meet the needs that have accumulated across the last three years. This is all in the context of huge workforce shortages and sharing, with everyone else, the cost of living crisis. Morale is low and there is a risk that more people will leave the health and care sector to the detriment of all of us.

In this report, we have told some incredibly challenging stories about people's experience of care. Undoubtedly, the quality of care can be down to someone doing a bad job or behaving without compassion. However, we believe in most cases care is being delivered by people that want to do a good job but do not have the support or resources to do it. When staff are able to overcome these challenges, it makes a huge difference to people.

David told us about problems he has with his knees and arthritis in his shoulder, but he has a good relationship with GPs at the local practice:

One of the partners is more sympathetic and deals with me as a friend rather than a crusty old man with worries about his health.

Sheila had a similar experience with her GP surgery.

I was lucky enough to actually have a lovely female GP [...] who was really understanding, empathetic with my health problems, the sort of GP where we could sit and discuss things.

Sheila was equally positive about specialists at her local hospital and values medical professionals. They gave her information and an opportunity to discuss and make decisions about her treatment for herself.

For Daniel, he was able to witness what services working together can achieve. The hospital where he had his knee surgery made a referral to the council for an adaptation to his bathroom. This was well-coordinated, timely and has helped him stay safe and independent at home.

Stepping over into the bath was a killer... I couldn't get myself over the bath and I slipped.... Now I've got a wet room. And they did a great job. New toilet, they put in a higher toilet... new lights, grab rails. And honest to God it was unbelievably amazing.

For Colin, having a care agency that employed ex-registered nurses to support his mother, gave him extra peace of mind. Colin had to pay for this himself but it meant he did not have to wait for someone else to have routine checks done or wait for an issue to become more serious before his mother got help.

They can tell me quickly she needs to have a medical procedure and suchlike. And they do her blood pressure, which means you don't have to go to a doctor. So for instance she had to have a growth removed from her forehead... it was suspected cancer... and it was them that spotted that, and that's what helps me.

An older and ageing population

These are lovely examples of empathetic staff and joined-up working making a huge difference, so why aren't they the norm everywhere, for every older person, all of the time?

Nearly five years on from our *Failing Safety Net* report, it would probably have been over-optimistic to expect significant movement on the issues we described in 2018, given the enormous disruption caused by the pandemic. However, while our political leaders have been focused on a host of other pressing priorities, population ageing has been happening and at an accelerating rate. Around 19% of the population is currently over 65 and just over 3% is over 85^{vi}. By 2036, these figures are projected to be 26% and 5% respectively^{vii}. In some parts of the country, the numbers are appreciably higher. In West Somerset, for example, in the same time period it is projected that over 40% of the population will be over 65 and over 9% over 85^{viii}. For a significant number of local authority areas, their over 65 population will be a third or more of all their local citizens.

More of us living longer is a cause for real celebration. However, many of the stories in this report show that the health and care system is not yet equipped to deal with the challenges that an ageing population brings. And if that's how it is now it is all the more likely to be the case in a little over a decade, unless there are rapid changes to policies and practice. The problem it seems is that too often, the safety nets designed to catch us when we need help as we age either do not work very well or are not there at all, undermined by long term shortages of investment and staff.

Reform – two steps forward, one step back?

In the NHS, from 2019 the Ageing Well programme (later renamed Discharge and community services) aimed to roll out:

- better care in the community to prevent healthcare needs from emerging in the first place (Anticipatory Care or AC);
- a crisis response service to prevent avoidable admissions to hospital (Urgent Care and Response or UCR);
- and enhanced services in care homes (Enhanced Health in Care Homes or EHCH).

UCR and EHCH are both operating in some form, but AC remains in limbo. As of writing, some form of AC should be in place by April 2023, but ring-fenced funding to deliver it has been reduced or all but eliminated in the face of wider NHS pressures.

These approaches sit within a broader suite of changes underway in primary and community care. Among them are the push for 'virtual wards', which aims to deliver hospital-level care in people's own homes. There is good evidence that effective 'hospital at home' pathways, which inform this approach, can improve older people's outcomes from and experience of care. However, a great deal depends on how successfully the idea of a virtual ward is actually implemented and that's not easy in the current environment.

Some serious attempts were made to put in place the ground work to reform health and social care during 2021 and 2022. The most developed was the Health and Care Act 2022, which gave legislative shape to a range of new bodies designed by NHS England over recent years. In England, forty two 'integrated care systems' took over responsibility for running local NHS services from clinical commissioning groups (CCGs) in July 2022.

Designed to bring together a range of different services and commissioners across quite large sub-regional areas, they are charged with coordinating services alongside social care and public health bodies, with communities and the voluntary sector included too – though to date this seems to be happening quite patchily.

There was also the ‘Next steps for integrating primary care: Fuller stocktake report’, published in 2022. Led by Dr Claire Fuller, a GP and ICS chief executive, the report explores how the NHS could achieve a more fundamental change in how primary care is delivered. At its core are three calls that would see a more streamlined approach to those needing infrequent, though often urgent, support; a more multi-disciplinary and personalised service for those living with one or more long-term conditions; and a greater focus on prevention and staying well for longer.

This is a vision Age UK would support. However, to be successfully realised it not only requires speeding up front door access to the local surgery but also creating the conditions in which older people can be confident that their ongoing needs are assessed and planned for, joined up across multiple specialists where necessary, and that on those days where a call to the GP is required they can actually get through.

In furtherance of Prime Minister Boris Johnson’s pledge to ‘fix social care’, in autumn 2021 the Government set a date to implement a financial limit, or cap, on the amount people will spend on personal care in their lifetime (introduced in the Care Act 2014 but never triggered). As well as this cap, they also announced that they planned to increase the amount a person’s total assets must fall below before being eligible for financial support from their local authority, with the result that significantly greater numbers of older people would get at least a small amount of financial help with their care bills.

A new Health and Care Levy was to be put in place to fund this scheme into the long term, though in the early years the money raised by it was to be invested in the NHS.

During Mr Johnson’s premiership an Integration White Paper was also produced, setting out expectations for better joint working in local areas, speaking to many of the issues in this report. A Social Care White Paper was published too, the most notable features of which were funded proposals to strengthen the social care workforce, though not in terms of pay.

However, in Chancellor Kwarteng’s mini-budget in September 2022, the Health and Care Levy – introduced just 5 months earlier – was scrapped. The Integration White Paper was also essentially shelved by Liz Truss’s administration, as was a proposed one on health inequalities. And then, after several months of political and economic turmoil, and the fall of the Truss government, Jeremy Hunt, the new Chancellor, announced in his Autumn Statement in November 2022 that the cap scheme and all that went with it was to be delayed for two years, until 2025.

Many commentators now question whether it will ever see the light of day. At the time of writing it is also unclear how much of the money for the Social Care White Paper remains, and to what goals it may be directed.

The Autumn Statement did announce more funding for social care, partly as a result of redirecting the cap money. This was mainly focused on supporting services that either prevent hospital admission or speed up discharge, with less for other care services. In

Fixing the foundations

practice it is believed that much of the extra funding will go on paying for the increased National Living Wage which will benefit many care workers. This increase in pay is welcome but does not elevate the status of care work as against that of other low paid roles.

In addition, the Institute for Government has concluded that the Autumn Statement's funding for social care "will not be enough to return the service to pre-pandemic performance levels, to put the provider market on a sustainable long-term footing or to resolve the severe workforce problems facing the sector."^{xix}

Indeed, workforce shortages within health and care have been a growing concern in recent years and risk creating a downward spiral, in which remaining staff are placed under more and more pressure until they too feel unable to cope and leave. Amidst the cost of living crisis, within the NHS there is evident unhappiness among many clinical and non-clinical staff concerning pay and conditions, culminating in the Royal College of Nursing voting to strike for the first time in many years.

Within social care there is as yet no effective strategy to create a workforce environment in which social care providers are not having to compete with online retailers, supermarkets and the NHS for staff because sadly, and unfairly, it is often portrayed and treated as just another low-paid job. In October 2022 Skills for Care reported there were 165,000 vacant posts - an increase of 52% and the highest rate on record^{xx}. They also reported that 2022 was the first time that the total number of posts with someone working in them had fallen, down by 50,000 overall.

Shortages of home care staff are certainly having a devastating effect at the moment, with many older people stuck in hospital who could be at home with the right support. This applies both to those admitted for want of a care package, and those who cannot be discharged without that same support. This problem of home care staff shortages is viewed as the main, if not the only, cause of the delays of ambulance handovers and growing lengths of stay in hospital.

Policy and practice developments to help unpaid carers have mostly stalled in recent years too. The Johnson government agreed to introduce a right to unpaid carer's leave but the Employment Bill which was to contain it was lost during the transition to a new administration. There are hopes that it will pass through the mechanism of a Private Member's Bill, currently being taken through the House of Commons by Wendy Chamberlain MP. Meanwhile, support for unpaid carers has not returned to pre-pandemic levels, with many respite services having closed for good.

Looking to the future

As the preceding text shows, in recent months and years there has been ample cause for frustration when it comes to the reform of health and care services, so they better meet the needs of older people with significant health needs living at home and in care homes. However, there is some cause for optimism too. This principally lies in the greater acknowledgement among policymakers and leading professionals that part of the answer lies in getting practitioners working together more effectively within health, and more routinely between health and social care, to support these older people. The problem is actually doing it, despite workforce shortages and the differences in funding, culture, process and accountability between the organisations involved.

The ball is now in the ICSs' court, which face many challenges but which are positioned better than their predecessors to overcome these barriers and make integration come to life for individual older people. A lot depends on the quality of relationships and leadership, which is variable across the county. However, almost everywhere it seems that within ICSs the roles of the voluntary sector and of communities are under-recognised and under-played, to the detriment of older people, who need more than just a 'service', however important that may be, to make the most of their lives.

More profoundly, there are also questions over whether ICSs really constitute a new, much more joined up, place-based approach, or are just another layer of bureaucracy, with the big decisions about the allocation of resources in local areas still being skewed by engrained silo thinking and processes. Time will tell and it is important to give ICSs every chance to succeed, but we may also need to start thinking more boldly about how to enable older people to live happily, safe and well at home for as long as possible, drawing on their views and those of their families, paid and unpaid carers and clinicians, and on the experiences of other health and care systems around the world.

February 2023

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