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)

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1. 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

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

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 more[i].

69% of people over 85 live with multiple conditions[ii]. 35% of older people live with some form of frailty (15% moderate or severe[iii]), 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

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

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.

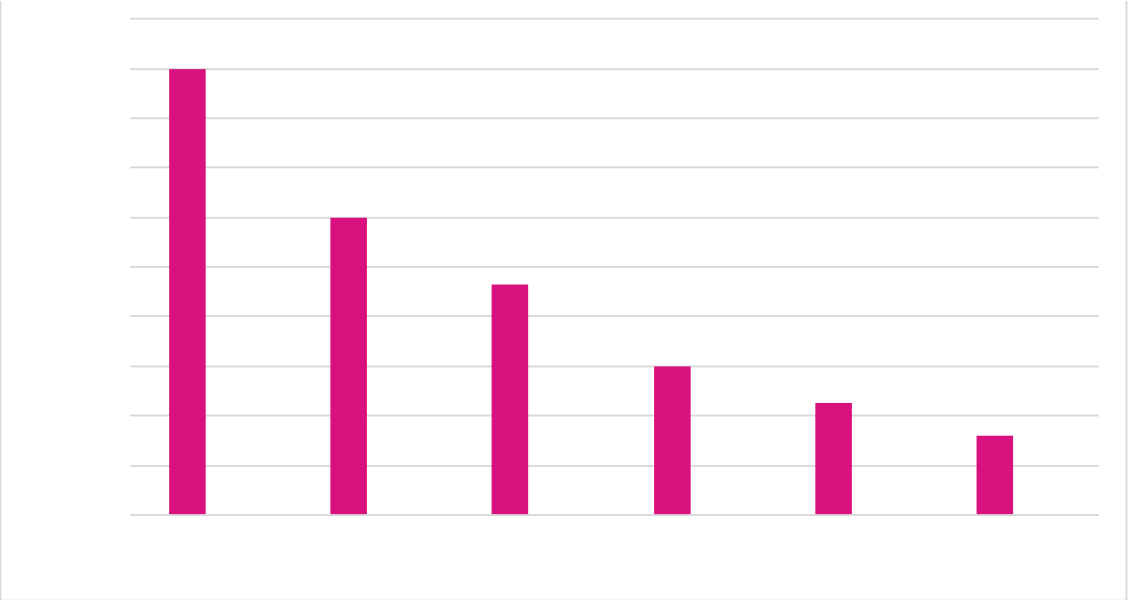
Figure 2

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

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



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

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

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Name	Sex	Age	Living arrangement	Care received/carer status	Conditions
Jean	Female	92			

4. Themes

Themes

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.

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, becausgk19Tw 0 (w f)1.9d.20.7 (e5 (l)8 (s t)9.1(t)20.7 (e)4 (n a)2..3(j)]TJ0)2.5 f)0.

6. 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.

Intermediate care/reablement can make a huge difference to someone leaving hospital.

The view from the front line

It is not unusual for hospital staff to find themselves caring for older people whose health

With the focus understandably on crisis care the risk is that people with less urgent needs,

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

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

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".

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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*

9. 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

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

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

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

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