The
Richmond
Group
of Charities

No time to lose

Changing the trajectory for people living with long-term health conditions

November 2022

The Richmond Group of Charities

The Richmond Group is a coalition of health and care charities working together to help people living with long-term, multiple or complex health needs to live well and thrive.

This report draws together data, insight and patient stories from The Richmond Group's 12 member charities, with wider evidence, about the impact of the pandemic on people living with long-term, chronic or complex illnesses, who were amongst the hardest hit and still now find themselves lagging far behind in terms of recovering their health and well-being. Our analysis highlights the issues for this group of people before the pandemic, the impact of the pandemic and cost-of-living crisis, and the ongoing and long-term effects.

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VERSUS ARTHRITIS

Foreword

Duleep Allirajah, CEO

The Richmond Group of Charities

We are facing one of the most challenging periods in health and social care in living memory. NHS and social care services are working harder than ever before. At the same time, demand is rising fast, and faster than we might have reasonably expected back in 2019.

Against this backdrop there are immense workforce challenges across both health and social care, that have escalated in the past few years at an alarming rate. We are witnessing in real time the impact of a decade or more of capital underinvestment in estates and infrastructure.

Public and patient frustration is at a high-water mark perhaps last seen in the 1990s. Professional morale is at the lowest point anyone can recall.

The impact of the last few years has been profound. While many of the trends we explore in this report are not new, they have been exposed, exacerbated and accelerated by the pandemic, putting us on a fundamentally different trajectory.

The number of people now sitting on an NHS waiting list for care – a staggering 1 in 8 of the total population at the time of writing – is just the tip of the iceberg, however. What has been less well documented, and the subject of this report, is the deep and enduring impact of the pandemic on the group of people living with long-term, chronic or complex illnesses who were amongst the hardest hit and still now find themselves lagging far behind in terms of recovering their health and wellbeing. This group includes, but is not limited to, those identified as clinically vulnerable and advised to shield.

There is a much wider group of people living with chronic ill health that have experienced similar challenges, losing contact with social networks, frightened to leave their homes or receive care within them. People who have lost routine contact with the services, support groups and social activities across health, social care and the voluntary sector that they rely on to keep well and manage their conditions.

For some people, the impact of the pandemic means they will not recover their previous state of health. Others are facing a much worse prognosis than would otherwise have been the case. As always, the burden is falling hardest on those in the least advantaged circumstances.

Chronic illness and multi-morbidity were (and remain) the main challenge for the NHS and social care, as for systems across the economically developed world. The overwhelming strain, particularly across primary care, has put care continuity at risk. At a time of crisis, it is easy to forget those people who benefit most from relationship-based care. And people living with chronic, complex illness and disability are not rare. About 26 million people in England alone have at least one long-term condition.

On top of all of that, we are now plunging headfirst into a cost-of-living crisis. This will of course bring its own problems for people managing long-term health conditions, adding to the challenges staff and patients face as they are still reeling from the pandemic. Let’s not forget that many of these people are themselves working in the NHS and social care and not coping. Workforce wellbeing must be a priority. These challenges are interconnected and cannot be solved by focus on urgent and emergency care or elective care backlogs alone. Short-termism cannot pay down the debt we are accruing against the nation’s future health. To avert this downwards spiral, so we need to get on top of what is driving demand.

Government and national system leaders will need to take immediate action to relieve the pressures on the health and care system and see us through the next 12 months. At the same time, in order to put care on a sustainable footing, the very real underlying challenges outlined in this report – workforce, social care, health disparities – must be tackled. Doing nothing is not an option. Indeed, failure to act will lead to adverse social and economic consequences in the future. We hope the evidence in this report can help system leaders to take stock and rethink the design of health and care services over the next few years, informed by a more realistic understanding of what the population needs will be.

So many people have lost so much time already. There is no more time to lose.

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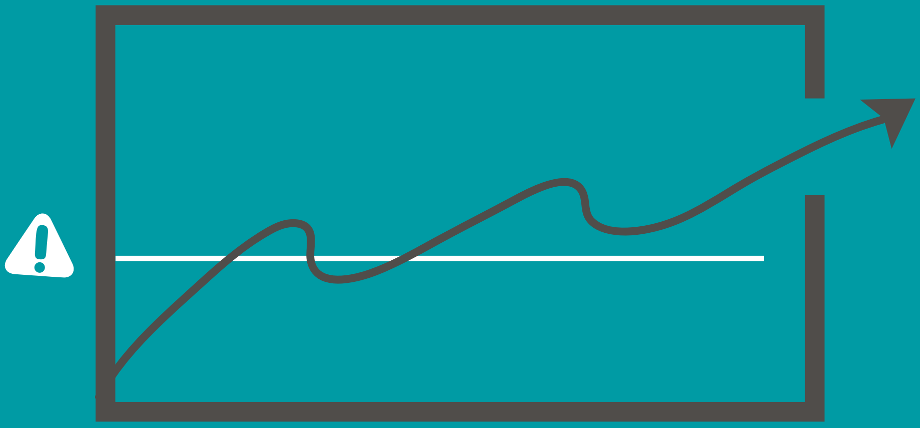


1. Before the pandemic

The first chapter of this report explores demographic and systems trends across health and social care in the years leading up to the COVID-19 pandemic.

It is clear that levels of umet need were already rising in the decade leading up to 2020. Primary care and community services were increasingly stretched, leaving a growing number of people struggling to access routine or urgent care. Social care had been in a more or less perpetual state of crisis as successive governments failed to grasp the nettle on sustainable funding or reform. As a result, levels of unmet need amongst older and disabled people had been rising steadily. Waiting lists for elective and diagnostic care were also growing and patients were waiting longer to be seen.

In part, this is due to demographic changes. A population growing older, coupled with rising numbers of people of all ages living with long-term or complex health conditions, means demand for health and care services had, and will continue to, increase. Meanwhile, efforts by the NHS and local authorities to respond to these changes - most recently in the form of the 2018 NHS Long-term Plan and implementation of Integrated Care Systems - have been hamstrung by a lack of investment in long-term workforce planning and capital investment. At the same time, there have been a number of ‘false dawns’ for social care, as reforms were promised and then failed to be delivered.

All of this had real world consequences for people’s health and wellbeing.

Rising real world demand

Our population is ageing. It always bears repeating that when the NHS was founded and the origins of our adult social care system established more than seven decades ago, one-in-two people died before they reached 65. In 2019, as we headed into the pandemic, there were around 12.4 million people aged over 65 in England (or 1 in 5 of the total population).[1] The prevalence of nearly all long-term conditions increases with age.[2]

Life expectancy and healthy life expectancy gains have stalled. From the beginning of the 20th century, England experienced continuous improvements in life expectancy. But from 2011 onwards improvement slowed, almost grinding to a halt for much of the population and even falling for the poorest 10% of women. At the same, there has been no significant improvement in healthy life expectancy, while measures of disability-free life expectancy indicate people are in fact spending more time living with disabilities and poor health over the course of their life.[3]

More people are living alone and ageing without children. A growing number of people – especially older men – are living alone, with single person households increasing 6% between 2008 and 2018 alone. Nearly half of those living alone were aged 65 years and over, and more than one out of every four were aged 75 years and over.[4] Meanwhile, an estimated 25% of women born in the 1970s will not have children, compared with just 1 in 10 of those born in the 1940s.[5]

More people are providing more unpaid care for family and friends. The 2011 Census found there were 6.5 million carers in the UK. By 2019, this had increased to an estimated 8.8 million adults.[6] There is also strong evidence that people are caring more intensively, with the reported numbers of hours of care provided per week increasing particularly amongst those providing ‘round the clock’ care.[7]

8.8 million carers

in the UK in 2019

Societal factors changing how we live and work are often detrimental to our health. The start of the 21st century saw the first generations that needed to make a conscious decision to build physical activity into daily life. Societal changes, including fewer manual jobs, longer commutes, and growing dominance of technology at home and at work, meant physical activity was increasingly designed out of our lives. At the same time we have seen major changes in food manufacturing and provision.

As a result, the number of people living with long-term conditions has increased. In England, 43% of the population has at least one long-term health condition[8], while over one in four – or 14.2 million – adults in England live with multiple long-term conditions.[9]

In 2016,

people in the UK were an estimated

20%

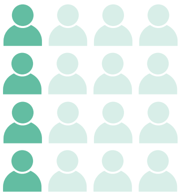
less active than in the 1960s[10]

The percentage of adults who are overweight or obese rose from

53% in 1993 to 64% in 2019[11]

1 in 4

adults in England



(14.2 million people)

live with **multiple** long-term conditions

Many people's health needs have become more complex too. Living with multiple conditions, frailty and/or disability typically leads to greater challenges managing long-term health. Physical health and mental health are also reflexive, with those living with physical health conditions more likely to develop a mental health condition and vice versa.[12]

People with diabetes are twice as likely to have depression[13]

●●●●●●●●●○

9 in 10 people with dementia have more than one other long-term condition.[14]

Almost half of people with a heart, lung or mental health condition also have a musculoskeletal condition by the age of 65.[15]

Together, these trends translate into greater demand for all types of health and care services. Pre-pandemic, people living with multiple long-term conditions accounted for an estimated two thirds of outpatient appointments and inpatient bed days, 70% of all health and care spending and half of GP appointments.[16]

Without careful management, multiple or complex health needs are also associated with more intensive use of healthcare, particularly urgent and emergency care. Research has found that people who frequently attend A&E make up less than one per cent of England's population but account for more than 16% of A&E attendances, 29% per cent of ambulance journeys, and 26% of emergency hospital admissions.[17]

5x

People with musculoskeletal conditions consult their GP five times more often than those without.[18]

The hardest hit

Although numbers of people living with health conditions has been rising across the board, some communities still carry a far heavier burden of poor health than others.

- People living in the least advantaged areas can expect to have two or more conditions by the age of 61, while those living in the most advantaged typically reach this milestone a decade later at an average age of 71.[19]
- Not only are people in the least advantaged circumstances more likely to develop long-term conditions at an earlier age, their conditions and the impact on their health is likely to be more severe than their more advantaged counterparts.[20]

There are clear ethnic and regional patterns that emerge from this picture as well.

- People from Pakistani, Bangladeshi and black Caribbean backgrounds have higher levels of diagnosed illness than people from white ethnic backgrounds.[21]
- There is a north-south health divide, with people living in the north of England experiencing a greater burden of poor health. Chronic pain, COPD and cardiovascular disease account for much of the difference.

Living with long-term conditions

> **"Deep down it is as if I can't be myself. I am half my health and half me".** [22]

The challenges of living with long-term conditions are common but far reaching. Despite living with a wide variety of different health conditions and in different circumstances, there are a number of common experiences for people grappling with long-term health conditions, including:[23]

- Loss of mobility and chronic pain
- Greater social isolation and a higher risk of loneliness
- Low mood and poor mental wellbeing
- Greater challenges maintaining paid employment or volunteering

> **"I have fought all my life to be independent. But when the pain started, I couldn't. It felt in that dark period like I'd never be independent again."** [24]

The impact of poor health can become a vicious cycle as one problem leads to another. For example, living with a long-term condition increases the risk of loneliness. In turn the impact of loneliness on health and wellbeing is widely documented. It increases the risk of mortality and disability, including dementia, and the likelihood of accessing the NHS in an emergency.[25]

Managing multiple health needs is a much trickier balancing act. For instance, the more health conditions someone has, the more medications they are likely to take. However, taking multiple medications – known as polypharmacy – increases the risk of a range of problems including adverse side effects, drug interactions and mismanagement.[26]

People can fall through the gaps in services. People with multiple conditions have poorer health outcomes and are more likely to report poorer experiences of care and care coordination. As you acquire additional health conditions, the challenges associated with managing them stack up. Organising services around a single disease or need can fragment care and result in a high 'treatment burden' as people have to juggle appointments and treatments for many different conditions. People can fall through the gaps in services because of the lack of clear accountability between those services. Health and care professionals may not communicate effectively with each other, leading to disorganised care, and even medical error. While these problems are not unique to patients living with multiple conditions, the overall burden is often greater than for those living with one condition.

> **"Different parts of the system do not seem to talk to each other. The memory clinic tells you to contact your GP and then the GP tells you to contact the memory clinic. Social workers say that your relative should be entitled to a review, but then you can't get a referral, and so on. It is like banging your head against a brick wall."** [27]

Caring responsibilities can also take their toll on families and friends. Many unpaid carers are older people or have a health condition themselves,[28] something which the pressure of caring without support can exacerbate. Before the pandemic hit, in 2018 research found that 6 out of 10 people said their physical health had got worse as a result of caring, while 7 out of 10 said it had impacted their mental health.[29]

Caring can have a significant impact on people's social life, ability to work and financial security. In 2019, 2.6 million people reported they had stopped work to care. A further 2.1 million reported they had reduced their hours in order to juggle their responsibilities.[30] 8 in 10 carers have described themselves as lonely or isolated as a result of their caring responsibilities.[31]

> **"It's hard work, it's exhausting, I don't think there's a day gone by in the last three years where I've not sat there and cried my eyes out."** [32]

A struggling health and care system

Spending on social care stagnated over the last decade, failing to keep pace with growing demand. In real terms, spending on social care decreased sharply between 2010 and 2015 before recovering towards the end of the decade. By 2020, we were spending approximately £20bn a year – broadly the same as we were in 2010.

Between 2016 and 2019, the proportion of older people living with unmet care needs

increased from **1 in 8** to **1 in 7**[33]

...that equates to

1.5 million older people[34]

However, that still amounted to a 7% decrease in spending per head of the adult population at a time of rising demand.[35] The total real terms cut in local authority budgets between 2010/11 and the end of 2018/19 was £9.5 billion, at an average of £1.19 billion per year.[36] Data from local authority returns shows that in the period 1 April 2019 to 31 March 2020, nearly 720,000 people aged over 65 and nearly 385,000 people aged 18-65 requested but did not receive statutory support to meet their social care needs.[37]

Although NHS funding continued to increase over the last decade, the pace of growth fell and fell short of demand. NHS funding grew by 1.1% over the period 2009-2015, rising to 1.6% over 2014-2019. This is down from the 75-year average of 3.6%.[38] As a result, the NHS was already showing signs of being under pressure.

- **Waiting times for elective surgery were rising.** The target to see 92% of patients within 18 weeks of referral had not been met since March 2016, and performance continued to decline in 2019. At the end of February 2020, only 83.2% of patients were seen within 18 weeks, and there were 4.4 million patients on the waiting list to start treatment.[39]

- **Urgent and emergency care was under increasing pressure.** The number of emergency admissions grew 42% between 2006 and 2018, from 4.25 million in 2006/07 to 6.02 million in 2017/18. The impact on acute hospitals was compounded by the increasingly complex needs of patients requiring an admission. In 2015/16, one in three emergency patients admitted for an overnight stay had five or more health conditions, up from one in ten in 2006/07.[40]

- **Delays to discharge were impacting system flow.** In 2015/16, patients spent more than 1.8 million extra days in hospital because of delays in their discharge.[41]

- **Access to mental health services was a growing issue.** Despite greater awareness of the importance of mental health care, research in 2018 found that people severely affected by mental illness waited 14 weeks for an assessment alone, and a further 19 weeks to begin treatment.[42]

- **Primary care and community services were under growing pressure,** which was having a significant impact on timely diagnosis, routine care and rehabilitation after an episode of ill health.

In 2016, almost half of stroke survivors reported feeling abandoned after leaving hospital, with the care and support they received seen as a 'postcode lottery'[43]

The pre-pandemic diagnosis rate for dementia was only 67%

Without a diagnosis, people are left unable to access commissioned support and services for dementia.[44]

Workforce gaps were significant and growing. Primary care, which provides most long-term chronic condition care, has been under sustained pressure for many years. In 2015, there were 0.52 full-time equivalent (FTE) GPs per 1,000 patients, but this had fallen to 0.46 by early 2020. On average, each practice had 7,456 patients in 2015, which had risen to 8,922 by early 2020.[45] The NHS was reporting significant shortages of clinical staff, with the biggest shortfall in nurses, paramedics and some medical specialists. In the first three months of 2017 over 86,000 NHS posts were unfilled.[46]

Recruitment and retention across social care services became increasingly challenging over the course of the decade leading up to the pandemic. Vacancy rates rose from an average of 4.4% in 2012/13 to 7.2% in 2019/20 – a shortfall of around 100,000 staff.[47] Amongst key staff, including registered managers and nurses, vacancy rates ran at closer to 10%.

The maintenance backlog in NHS trusts has been rising, from £4.4bn in 2013/14 to over £6bn by 2017/18. This is around double the amount of annual capital spending in NHS trusts. Many trusts were seeing capital-funding constraints have a direct, negative impact on their ability to deliver optimal care.[48]

Making the change

A package of legislative reform was agreed to address these challenges, including most recently the NHS Long-term Plan, published in January 2019, setting out a 10-year practical programme of phased improvements to NHS services and outcomes, including a number of specific commitments to invest the agreed NHS five-year revenue settlement.

The shift to personalised care was also starting to have an impact. Policy reforms and implementation of universal personalised care were starting to improve care and support for some people with long-term conditions. For example, pre-pandemic diabetes care was generally showing positive improvement. The proportion of people with diabetes receiving all eight diabetes care processes increased in the three-year period before the pandemic [49]

Reforms to social care were promised but the funding reforms were a long way off ‘fixing social care’ with workforce and funding challenges limiting factors.

What does this mean?

By the start of 2020, NHS social care staff were working harder than ever but, despite their best efforts, capacity could not keep pace with demand.

Older people, people living with chronic and complex illness, mental ill-health, frailty and disability faced growing challenges accessing services, treatments and care to the detriment of their long-term health outcomes, with the hardest hit being those with the highest needs and in the least advantaged circumstances.

Efforts were being made to address these challenges, with a package of legislative reforms widely supported by system leaders agreed, but still in the early phases of implementation.

Enter COVID-19, an unprecedented global public health emergency, at a time when the whole system was running hotter than perhaps ever before.

2. The pandemic

Since 2020, our organisations have worked hard to understand the impact of the pandemic on the people we represent. We are in no doubt that the experiences of the last few years have fundamentally altered the trajectory of many people's lives and, with it, the overall health of our population. This chapter explores what we know about people's experiences during the pandemic, and how it has impacted people's ability to stay well and access timely treatment and care.

Our collective evidence is clear. The pandemic has tipped more people into a poorer state of mental and physical health than would have otherwise been the case. And as always, the burden is falling hardest on those in the least advantaged circumstances to start with.

Lack of access to day-to-day health services made it much more difficult to manage pre-existing health conditions or diagnose new ones. Some avoided or delayed seeking medical attention, including a third of those who had a stroke during the pandemic, often presenting with much more advanced or severe symptoms as a result.

At the same time, the sudden and dramatic changes in our everyday lives left millions of people reeling – particularly those advised they were at exceptionally high risk from the virus. Overnight, many of the daily routines, social networks, facilities and services that people relied on simply disappeared, sapping their resilience, and cutting off their usual coping strategies. The material impact this had on people's health, and that of their carers and loved ones, is perhaps one of the most underappreciated aspects of the pandemic.

It's still unclear to what extent many can or will recover. For millions of people this simply represents a new and more challenging phase in their health and wellbeing, one that they will have to live with and manage long-term. Some of this 'need' is sitting on a waiting list for treatment, but much of it isn't. A hidden 'backlog' is emerging, as is evident from the extreme pressure on primary care, mental health and community services as well as across social care.

We are storing up problems for the future as well. For many individuals, the true impact on their long-term outcomes may not become apparent for a number of years. For instance, missed opportunities to diagnose and treat conditions like hypertension may have implications for rates of heart attack and stroke. While the evidence on the effect of Covid-19 infections on people's long-term health is still emerging, it seems clear it has created an additional burden on the nation's health, alongside changes in lifestyle that mean we are seeing rates of obesity, physical inactivity and harmful alcohol consumption on the rise once more.

The impact of the pandemic on people's health

> **"He has Parkinson's and dementia and this (the pandemic) has left him more vulnerable and weak, his legs are a lot worse. His mental health has got worse and not having a normal routine has really affected his health in a bad way."** [1]

In bringing together the research and our collective insight, a consistent pattern emerges. **People who went into the pandemic with pre-existing conditions and care needs are overwhelmingly reporting that it has had a profound - and they fear long-lasting - effect on their physical and mental health.**

As well as the disruption to their ongoing treatment and care, people living with health and care needs, their families and carers often felt there was no option but to adopt and sustain the most restrictive measures to protect themselves and their loved ones. More than four million people living with health conditions were identified as 'extremely clinically vulnerable' and advised to shield. Many millions more were told they were high risk and should take great care to protect themselves, including anyone over the age of 70 and those with common conditions such as diabetes, dementia, COPD, asthma and heart problems. Unfortunately for some – particularly those living with conditions that suppress their immune system – social distancing is still a feature of daily life.

> **"The announcements kept saying it was a problem for people suffering from diabetes, asthma, heart conditions and the over-70s. I tick all these boxes so I started thinking there's not much hope for me. It was a bit scary."** [2]

One of the most striking findings of our work is the major impact the pandemic has had on the common challenges faced by those living with long-term conditions – pain, fatigue, loss of mobility and independence, loneliness and social isolation. Some report that their health has improved as we have emerged from pandemic restrictions and they have been able to get back to 'normal life' but this is far from a universal experience.

Hardest hit

People living in the least advantaged communities were dealt a triple blow. Already overrepresented in the numbers living with long-term, multiple or complex health condition at the outset of the pandemic, our evidence shows they were amongst the hardest hit by pandemic restrictions and the impact on their health was even more profound. Last but not least, they were at greatest risk of contracting Covid-19 and becoming severely unwell if they did.

Ethnic minority communities have been among those most at risk of being exposed to and dying from Covid-19. Public Health England has reported some of these differences are due to racial discrimination, and that the associated stress has a negative effect on people's long-term mental and physical health, as well as affecting Covid-19 exposure risk and outcomes.[3]

Nearly 1 in 3 older people in less advantaged circumstances reported increased pain, compared to 1 in 5 in more advantaged.[4]

Pain

> **“My pain has got a lot worse. I am in my chair 24/7. Some days I don’t eat as I’m in too much pain to be able to get up and make a meal. I virtually only get up when I need to go to the toilet.” [5]**

Living in pain is debilitating and has a huge effect on someone’s mental health, activity levels and ability to work or participate in activities they enjoy. Whether due to deteriorating health, delayed or cancelled treatments or disruption to ‘self-care’ routines, **many people living with long-term conditions reported increased levels of pain.**

Pre-pandemic, an estimated 5.5 million were living with chronic pain.[6] In 2020, 46% of people aged over 60 living with a long-term condition reported being in more pain than before the pandemic.[7] Alarmingly, by Spring 2022 this figure had not improved, suggesting the impact is long-lasting.

Living with increased levels of pain has taken a major personal and financial toll. In 2021, nearly two thirds of people with arthritis or a musculoskeletal condition, whose surgery had been delayed or cancelled due to Covid-19, said they were living in pain because they could not afford the treatments they need. Worse still, those on the lowest incomes were more likely to be forced to live in pain because they were unable to cover the financial burden of the condition. 1 in 5 whose surgery had been delayed or cancelled due to Covid-19 said they often go without essentials, including food or heating, to pay for treatments needed to manage their pain.

Brenda’s story[8]

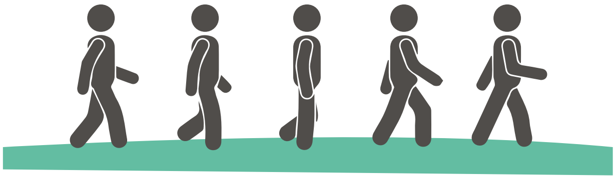
Brenda is waiting for a double hip replacement after developing severe osteoarthritis at the end of 2019, which has left her housebound, unable to walk and out-of-work.

“I haven’t left my house for a year now, apart from going to my hospital appointments. It’s like standing on jagged glass. I used to enjoy swimming, running and walking my dog, but in less than six months I became immobile because of the pain in my hips. With the pain and the pain medication comes incredible fatigue, which is way beyond just feeling a bit tired. Then with the lack of mobility comes a significant loss of muscle mass and overall health and wellbeing. My knees have also now started to deteriorate. Before arthritis I worked a busy job in a London law firm, but now I can’t work, walk or drive.[12] I’ve had to sell my house so I could move into a ground floor flat without stairs. I would love to go back to my career, not just because of the financial pressures, but to regain my normal life. This is simply impossible while I’m waiting for surgery.

“It’s not just medical bills, arthritis adds a cost to your daily life. I initially thought this was a temporary situation, as did my daughter, so she was initially able to help me with normal day to day activities like cooking, shopping, cleaning and dog walking. But because I’ve been waiting for so long, I can’t rely on my daughter anymore. So along with my loss of income comes the expense of a cleaner, a dog walker, someone to paint my fence, put pictures up on my wall… the list goes on.

I feel so helpless. Last summer I woke up crying every morning. I would get so depressed about the pain. Without a surgery date, you’re just left hanging, thinking, ‘What am I going to do with my life?’”

Brenda received both of her hip operations by early 2022, after waiting over two years. Following an appearance on national television, a private donor offered to pay for her first hip operation, while the NHS provided the second. The operations transformed Brenda’s life and restored her independence. However, the wait for surgery has left her with long-term damage, including back problems and issues with her knees. Brenda has said she found the health system incredibly difficult to navigate, despite her high level of education and the fact that she speaks English as a first language, and worries about how much more difficult it must be for people who don’t have those advantages.



Mobility and independence

Physical deconditioning is a major risk older people and people living with long-term health conditions face, with it leading to increased frailty, reduced mobility and risk of falls. This in turn compromises people's ability to work, socialise and independently manage everyday tasks. For older people in particular, 'use it or lose it' is a good rule of thumb. Once someone has lost muscle mass, cardiovascular fitness, strength and balance, it is very difficult to recover.

> **"My mobility had deteriorated badly. I can walk to my gate but that's all. Even a small amount of effort leaves me breathless."** [9]

Older people experienced a considerable reduction in strength and balance activity from March to May 2020. This disproportionately affected older people in the least advantaged circumstances who were more likely to be inactive than those amongst the most advantaged.[10]

Research tracking the impact of the pandemic on people aged 60+ between August 2020 and March 2022 showed a sudden and alarming deterioration in people's mobility and independence in the first 6 months of the pandemic.[11] Unfortunately, subsequent waves showed few signs of recovery as time went on. Predictably, older people living with long-term conditions were most likely to be struggling:

- **1 in 10 older people** were finding it harder to manage essential everyday activities such as getting in and out of bed, getting dressed or washed and preparing meals. This increased to 1 in 5 amongst older people with a long-term health condition.
- **1 in 5 older people** lost mobility, saying they found it harder to get up and down the stairs or walk short distances outside. This increased to 40% of older people with a long-term health condition.

Mental wellbeing

> **"Although I have a husband and family I am so alone. I sit and cry for no reason. My mood is so low as I feel so isolated. I am now taking pills for pain and low mood."** [12]

It is no surprise that the pandemic and its legacy has had a huge impact on our population's mental health and wellbeing driven by deep uncertainty, sudden and dramatic changes in our everyday lives, social isolation, loss of financial security, a huge increase in health anxiety and, sadly, many traumatic bereavements. A consistent picture emerges from the research:[13] rapidly rising levels of psychological distress, particularly depression and anxiety, at the onset of each wave of the pandemic and implementation of restrictions, followed by some degree of recovery but not for everyone.

People with pre-existing physical and mental health conditions were amongst the most likely to see their mental health deteriorate over this period. A large majority (79%) of people with pre-existing mental illness reported their mental health was worse or much worse as a result of the pandemic.[14] Before the Covid-19 pandemic, one-third of people with a long-term condition also had a mental health problem.[15] It is highly likely that this increased further during the Covid-19 pandemic.

Unfortunately, the impact on people living with long-term conditions may prove long lasting. There is a well-established relationship between mental and physical health. However, not only does having a physical health condition put you at great risk of developing a mental health one, and vice versa, it can also impact on your ability to effectively manage your health.

Throughout the pandemic our organisations heard repeatedly from the people we represent about how **they were battling low mood, depression and anxiety, and struggling to keep going and manage their conditions risking a long-term, possibly irreversible, decline in their health.** Nearly a quarter of people said that not having sufficient access to emotional and psychological support was a reason for having difficulties with managing their diabetes, rising to one in three people in more deprived areas.[16]

"I've eaten more and have lost some control over my diabetes. I was on a low carb diet and checked sugar levels but now I eat anything and don't monitor levels" [17]

The physical health consequences for those living with pre-existing mental health conditions are also clear. People with pre-existing mental illness reported significant impacts on their lifestyle.

"The support groups that I normally attend are no longer running. These groups provide a structure to my week. Having no structure means that I struggle to impose order on my life. Without something to do I struggle to get up, eat at reasonable times, avoid snacking and looking after myself and my home." [18]

During lockdowns...[19]

54%	of people with pre-existing mental illness reported exercising less
51%	eating less healthily
16%	smoking more
23%	drinking more alcohol

Social isolation and loneliness

As relationships and connections became harder to maintain, loneliness and social isolation increased dramatically during the pandemic. Pre-pandemic, 1 in 5 people reported feeling 'often or always lonely'. By May 2020 research found double that number (41%) saying they were feeling lonelier since the start of the pandemic, with 1 in 3 saying they felt like they had no one to turn to and the same proportion saying they hadn't had a meaningful conversation in the last week.[20]

"I'm feeling even more isolated than I did before, and I'm just trying to hold everything together. I'm on quite a bit of medication anyway. Feeling totally lonely and totally vulnerable, and worried about how long I can cope. All the support I've had for anxiety, panic attacks and agoraphobia has been put on hold." [21]

Some groups were more vulnerable to loneliness over this period, particularly those living with pre-existing risk factors. In common with pre-pandemic patterns, people from ethnic minority communities, those living alone, people with long-term conditions and those who were digitally excluded were all more likely to experience increased loneliness.[22] Unsurprisingly, people who were shielding or managing a condition that made them more clinically vulnerable were particularly likely to have become severely isolated.

There is a major risk that patterns of loneliness have become entrenched for some groups. Some people have found themselves increasingly 'left behind' as restrictions eased and 'normal life' resumed.[23] The reasons are varied. For some – particularly those deemed 'extremely clinically vulnerable' to Covid-19 – an ongoing fear of catching the virus means they have continued to limit their social activities. For others, the pandemic triggered long-term changes in their lives such as bereavement, relationship breakdown, job losses or changes in the way they work. This is compounded for many people by the fact that many forums for fostering social connections, including social clubs and community groups, have struggled to get going again.

> **"As a reasonably active senior citizen I have become a lonely, introverted recluse"** [24]

> **"I'm getting used to being on my own/withdrawn and dread the thought of company"** [25]

Rob's story[26]

Rob lives alone in a tower block and has been shielding during the pandemic due to having severe asthma. Prior to the pandemic, he would socialise most nights after work with colleagues from his office, usually going to the cinema or out for drinks. Whereas he used to feel 'lucky to have a day alone in the flat' by himself, during this time he has really struggled with working from home due to the lack of face-to-face contact with his colleagues and opportunities for socialising after work. This has resulted in regular feelings of loneliness which he feels he rarely experienced before. He says his situation is making him feel depressed, and that he knows his current routine of staying at home alone all day is bad for his wellbeing. He says he has 'always been a worrier' and the extra time alone to ruminate has worsened his feelings of anxiety. He doesn't know when he will be able to go back to his office, and has found even as restrictions have eased, his colleagues are not keen on things like going to the pub with him due to fears of the virus.

Social connection is not just important for mental wellbeing. It also plays an important role in sustaining cognitive capacity, particularly as we age.[27] **Loss of social connections and routines during the pandemic appears to have had a significant impact on older people's thinking skills.** In August 2020, 1 in 5 people aged over 60 reported they were finding it harder to remember things than pre-pandemic, rising to 1 in 3 older people with a long-term condition.[28] Concerningly, although perhaps unsurprisingly, in subsequent waves of research this figure has not shown any improvement.

In August 2020, 1 in 3 people aged over 60 with a long-term condition reported finding it harder to remember things than pre-pandemic.

> **"My memory has got worse. I think this is because I can't meet up with people and have a chat so I am forgetting words."** [29]

The impact on people living with neurological conditions such as dementia has been particularly profound. Many people living with dementia and their loved ones reported that their symptoms got worse over lockdown and their condition progressed further and faster than they might have expected.[30]

> **"Mum has vascular dementia, so the loss of routine and socialising has meant she is a lot slower mentally than this time last year."** [31]

Challenges managing long-term conditions and keeping well

Managing long-term conditions became much harder for many people during the pandemic and in its aftermath. A number of common themes have emerged from our collective research and insight, including the lack of access to routine or urgent health care, loss of care and support services, closure of community facilities and groups, as well as practical problems such as getting hold of the right food and medication.

Day to day services and support

"Once lockdown came into play, everything got worse. Firstly, getting food supplies was impossible in the early days... This impacted further on my ability to eat the correct foods to control my blood glucose levels"[32]

Difficulties accessing food, medication and other essentials was a widespread problem in the early days of the pandemic. However, for people managing health conditions who relied on specific diets or specialist foods, regular medication or medical products (such as incontinence pads or infection control products), problems getting timely access had a material impact on their health.

Even after supply and distribution settled down for the majority of the population, the challenges persisted for many people living with long-term conditions. In particular, millions of people advised to shield or take extra precautions felt they had no choice but to continue to avoid basic activities such as shopping for food or picking up prescriptions long after the wider population.

"I used to swim every day which helps dramatically with arthritis. I'm now crippled and need two new knees. I don't know how this helps the NHS. It certainly doesn't help me."[33]

Perhaps the most underestimated impact of the pandemic on people living with long-term conditions was the closure of universal services and community groups. Living with long-term conditions can be a difficult balancing act and over time most people come to rely on a range of coping strategies that work for them. Activity classes and clubs, peer support, community facilities such as libraries and leisure centres, faith groups and access to green spaces all play an important role in helping people manage their pain, maintain mobility and stay connected. The sudden and unexpected shut down on the things people relied on to stay well left many struggling to keep their health on track. Unfortunately, even as we have emerged from the pandemic, loss of funding, volunteers or facilities means many support groups have permanently disappeared.

While any support groups and services rapidly adapted and moved online, digital exclusion means this did not work for everyone.[34] This shift online was a particular problem for older people and those on low incomes, (who were most likely to be digitally excluded),[35] those living with conditions and disabilities that make it harder to engage online, and groups who typically relied on places with access to free Wi-Fi (such as voluntary organisations and libraries).[36]

"Telephone and video appointments are ok if you can hear and cope with IT. If you're not, then you are cut off from what you have known all your life."[37]

But even amongst those who are digitally enabled, many people with pre-existing conditions are simply not comfortable with remote support, or feel it fails to deliver the same benefits.

"I have been unable to continue with cognitive behavioural therapy (CBT) because they cannot - understandably - offer face to face consultations and I do not feel comfortable with remote delivery"[38]

Changing lifestyles

With gyms and pools closed, a fear of catching Covid-19, low motivation or low mood induced by the crisis, many people turned to increasingly unhealthy behaviours as coping strategies or to alleviate boredom. **These changes in lifestyle – whether temporary or not – have put people at greater risk of poor health, now and in the future.**

There were already increased alcohol-related hospital admissions and deaths before the pandemic, but between March 2020 and March 2021, there was a 58.6% increase in the proportion of survey respondents drinking at increasing risk and higher risk levels. This was accompanied by an upwards trend in alcohol-related hospital admissions and deaths.[39]

> **"I'm drinking too much and not looking after myself because my husband died of Covid-19. We had been together for 40 years and it was just gone in an instance."[40]**

Carers at breaking point

An estimated 13.6 million people were providing unpaid care for a loved one during the pandemic, with 4.5 million tipped into caring responsibilities overnight. This amounts to 1 in 4 of all adults across the UK. As before, many carers are older people or have their own health issues to contend with.

> **"I was scared to let anyone into my home in case they were infected."[41]**

Not only did the pandemic dramatically increase the numbers of carers, it made a challenging role that much harder. As with other services, much of the support carers may have relied on suddenly disappeared. Many carers – often caring for people who were shielding or clinically vulnerable – felt they had no choice but to stop receiving help at home, particularly in the early days of the pandemic when masks and other infection control products were hard to buy, even for professional care services. At the same time, carers were trying to manage deteriorating health and escalating needs of the person they cared for with limited, if any, access to health services.

> **"It was a hard job before but now it's becoming unbearable. There is a lot of talk about mental health of people during lockdowns. For a regular person they only lasted a few weeks at the time. The majority of people caring for the severely disabled have been on full lockdown for nearly two years. No one seems to care or understand the damage it is doing to families of disabled people."[42]**

During the pandemic:

81%	**of carers said they were providing more care than before**
78%	**of carers said the needs of the person they care for had increased**
64%	**had not been able to take a break in the last 6 months.[43]**

This has taken a major toll on carers' own health and wellbeing. **6 in 10 carers said it had had an impact on their physical and mental health.[44]**

Research amongst people aged over 60 found carers were significantly more likely to report changes for the worse in their health or ability to manage everyday activities.[45]

1 in 5 older carers reported greater difficulty getting in and out of bed, getting dressed and washed than pre-pandemic.

1 in 4 were finding it harder to walk short distances outside or get up and down stairs.

1 in 3 were in more physical pain than before and felt their health had deteriorated.

> **"I feel forgotten. I have given up everything to care for my relative and there is such little support"** [46]

Unfortunately, the picture has not improved much for many carers since. Many face ongoing challenges getting access to services and support they and their loved one need. A combination of permanent reduction in or closure of services, poor quality, unreliable or unsuitable care, or continued concerns about infection means **many are still struggling on alone.** In 2021, just 14% of carers said they had full access to their usual day services, while 35% reported reduced or severely reduced access and 20% said the service had closed.[47]

Unpaid carers are reaching breaking point. Almost three-quarters of Directors of Adult Social Services report seeing more cases of breakdown of unpaid carer arrangements in their area.[48]

What happened to treatment and care?

> **"I have liver and kidney disease which I was getting treatment for, but it has now stopped. I now find it difficult to eat, walk, breathe or sleep."** [49]

Overall, the risks to people's health caused by the pandemic go beyond the direct harm caused by the virus. As NHS capacity was reprioritised to manage the demands of Covid-19, many people saw access to their routine or planned services reduced, cancelled or postponed.[50]

There is also evidence that some individuals were reluctant to access healthcare services, even in an emergency, either through fear of infection or out of concern about pressure on overstretched services.

However, the failure to access timely routine or urgent care can have significant consequences for an individual's long-term health outcomes.

Accessing planned treatment and care

> **"I have been waiting for consultant appointments which have all been cancelled and the focus has been completely lost in respect of long-term health problems."** [51]

Evidence showed that outpatient visits, GP appointments and medication reviews were all lower than would usually have been the case to manage multiple or complex conditions. While those in the general population also experienced delays for treatment, research suggests there remained a particularly high level of unmet health need concentrated within the extremely vulnerable population.[52]

This is largely a reflection of the extent to which **routine care for long-term conditions was significantly reduced over the pandemic period**, with many health, care and wellbeing services stopped altogether, particularly those that operated face-to-face. Services highlighted as particularly difficult to access included blood tests, rehabilitation and physiotherapy, mental health, drug and alcohol services, and rheumatology.

Access to mental health care also suffered as a result of the pandemic. 42% of people living with a pre-existing mental health condition reported a deterioration in their health owing to less support from mental health services. Access to medication was also an issue for some, with 8% reporting that being unable to access medication had made their mental health worse.[53]

> **"Because my cancer and diabetes check-ups have been cancelled, and I have been unable to see a GP in person, I am worried that my conditions have worsened."** [54]

> **"I've been put in touch with a pain specialist and offered physio but when the pandemic hit it put everything on hold. I think if I'd had more regimented physio and face-to-face support, I would have progressed more with my recovery."** [55]

More people are waiting and waiting for longer.

As of September 2022, there were a record 6.84 million people on a waiting list for NHS treatment in England.[56] This is equivalent to 1 in 8 people in the population. And the number is rising.

For many, this means living with symptoms that are impossible to ignore and that have a devastating impact on their quality of life. These include chronic pain, fatigue and insomnia, all of which impact people's psychological wellbeing, ability to move, work and keep active. For example, people with arthritis waiting longer than ever for joint replacement surgery are reporting a major impact on their health.

A delay in receiving timely care can also have an adverse impact on people's health outcomes. In June 2022, official data shows nearly 4,000 people diagnosed with cancer were still waiting to start treatment more than two months after their urgent referral, the second-highest number on record after January 2022. Only three in five people are now starting treatment within two months of an urgent referral, compared with the target of 85%.[57]

People on waiting lists for treatment

79%
report physical health has got worse

89%
report that pain levels increased

79%
are now less independent

72%
report deterioration in mental health[58]

Accessing social care

> **"Sometimes there is no carer due to staffing levels at the care company, I assume due to sickness, the cleaner and the person doing his shopping stopped coming altogether for the 3 months of lockdown. He has spent nights in his chair with dirty incontinence pads, so he now has open sores. The house is filthy and his clothes aren't being washed."** [59]

The impact on access to social care services is harder to quantify, however alongside the closure of day services and wrap around support **our organisations have heard repeatedly from individuals and carers struggling to access paid care at home.** In July 2020, 41% of people living with dementia and 48% of people living with Parkinson's who had a paid package at home reported receiving less care since lockdown began.[60]

Since then, it is clear that unmet needs have increased as services have struggled to return to full capacity, let alone expand to meet new demand. By October 2021, less than half of carers reported a full return of their loved one's home care package, with 27% still reporting a reduced or severely reduced service.[61] In 2022, a survey of Directors of Adult Social Services found more than half a million people waiting for either a social care assessment, care services, a personal budget to commence or a review. They also reported that during the first three months of 2022 alone, almost 170,000 hours of home care a week could not be delivered because of a shortage of carers.[62] One in eight older people now say they are concerned about their ability to access home care or find a carer.[63]

Urgent care and new diagnoses

> **"This active and independent lady has sunk into deep depression and has been unable to access help from her GP other than telephone appointments, which have resulted in inappropriate medication being prescribed twice…. She has ended up being admitted to hospital via urgent care."** [64]

Across the course of the pandemic, fewer people accessed treatment. In 2020 alone, analysis shows that 6 million 'missing patients' did not seek treatment (compared to 2019).[65] Missed diagnosis or delayed treatment mean that not only are there more people living with ill health for longer, their conditions and symptoms are more severe when they do obtain treatment and risk poor long-term outcomes. We must expect the legacy of the pandemic to continue to emerge for many years to come.

Diagnoses were missed, at least in part due to the cessation of health checks and screening. For instance, in diabetes alone in the first year of the pandemic, type 2 diagnosis dropped by two-thirds and there were are an estimated 5.2 million fewer HbA1c tests carried out. Reduced rates of diagnosis were particularly evident in older people, men and in deprived areas.[66]

The number of people under 80 who had their blood pressure checked and treated dropped by almost a third in the first year of the pandemic.[67]

Early diagnosis matters. If left untreated, both diabetes and high blood pressure increase the risk of serious health problems, including stroke and heart attack.

Meanwhile, we know some people delayed seeking emergency medical attention due to Covid-19, including 30% of those who had a stroke during the pandemic.[68] In England and Wales, the number of stroke admissions fell by around 13% in April 2020, with fewer people experiencing milder stroke presenting at hospital. Stroke deaths in private homes were 52% higher than usual during the Covid-19 surge.[69]

The pandemic has also had a very direct impact on the health of many people. By May 2021, an estimated 1 million people self-reported being affected by Long Covid-19 (equivalent to 1 in 5 people who tested positive for Covid-19).[70] For some people this means acquiring a long-term condition for the first time, for many it will have tipped them (further) into living with multiple conditions.

Beca's story[71]

Beca lives with her parents, sister and fiancée in Rhyl, and has experienced various health problems over the last few years, meaning she has often been in and out of hospital. Her hospital appointments continued during the pandemic, and she found that the combination of being isolated while in hospital and having to shield while at home had a huge impact on her emotionally. While completing the diary task [for this research], she had just started to resume some elements of her social life (as guidance on shielding was relaxed) including visiting her nan and having a makeover session with a friend. Shortly after this, she fell unwell again and had to return to hospital, where she was advised she had to continue shielding. She describes this as "completely devastating" as it feels like she has taken a big step back.

What does this mean?

Despite the superb efforts of staff and volunteers across health, social care and the voluntary sector, it is clear that the health of much of our population is in a worse place than we might otherwise have reasonably expected. And within that population there are a group of people, predominantly people already living with long-term, multiple or complex needs and their carers, who are now in a much worse state of health. The consequences of this will be with us for a long time to come.

There are now higher than ever levels of unmet need manifesting across primary and community care, in social care and mental health. As we explore in the final chapter of this report, the capacity of NHS and care services to recover and respond to this new reality is far from assured.

3. Where are we now?

This chapter explores where we are now, the emerging challenges and the extent to which the health and care system is equipped for the future.

With much of our population still grappling with the impact of the pandemic, we have plunged straight into a once in a generation cost-of-living crisis. The relationship between personal insecurity, financial hardship and health is well established. An impoverished population is not a healthy one. We face the alarming prospect that, rather than the period of recovery we sorely need, the next few years drive a deeper and more firmly entrenched decline in the nation’s health, and over the long-term, the prospect of an unhealthier nation becoming a less prosperous and productive one.

More immediately, rising costs are having a pernicious impact on people living with long-term, multiple or complex needs. Our organisations are already seeing the direct consequences on those we represent, with more and more reporting they are unable to heat their homes, pay for prescriptions or care costs, run their medical devices, refrigerate their medication or maintain their diet. The struggle to afford day to day essentials has a direct impact on people’s mental and physical health and, ultimately, overall demand for services as a social and financial crisis too often quickly turns into a medical crisis.

Meanwhile, it is fair to say the NHS and social care system are in their most perilous position in memory. Pressure has been building for a number of years as the impact of long-term, structural problems becomes increasingly apparent in delivery of day-to-day services. The pandemic bombshell has turned cracks in the system into gaping chasms. With little time to regroup and recover, services are now grappling with spiralling costs and further pressure on workforce recruitment and retention.

These system shocks have occurred at a time when the NHS and social care services had hoped to be focused on addressing their underlying challenges, and putting in place the reforms required to adapt to a growing older population and rising number of people living with long-term, multiple or complex conditions. Instead it is now a longer, harder road to recover lost ground and achieve those ambitions.

The NHS and social care

As we set out in Chapter One, a series of major challenges had already emerged across the health and care system pre-pandemic. Rising demand, lack of capital investment, workforce shortages and funding constraints were long standing concerns for policy makers and service providers alike. We are now three years further down the track and, left unresolved, these issues have continued to ferment. The pandemic then not only exacerbated these problems in many cases, but also exhausted the time, energy and resources that might otherwise have been directed towards improvement and reform. Rapidly rising costs driven by high inflation and an exodus from the workforce now threaten to engulf services in yet another crisis.

Workforce

The pandemic itself had a profound human impact on the workforce, and now the added pressure of a cost-of-living crisis (impacting staff as well as patients) combined with historic low levels of unemployment means problems have hit an historic high.

Some NHS trusts have opened food banks for their staff. Other measures taken by trusts include discounted public transport and school uniforms provided to children [1]

The impact of Covid-19 on health and social care staff has been significant, leading to stress and exhaustion. In August 2021 alone, the NHS lost two million full-time equivalent days to sickness, including more than 560,000 days to anxiety, stress, depression, or another psychiatric illness. The result is that many in an exhausted workforce are considering leaving.[2]

> **"I pride myself on the level of care I provide to my patients. However, at times I leave work feeling deflated knowing that if I had one less patient or there was one more nurse on shift, those patients would have had an even better experience that day. There is only so much overwork, stress and heartache we can endure before we reach breaking point."** [3]

The pandemic and cost-of-living crisis has added fuel to the fire of long-standing workforce challenges. Around a third of the NHS workforce are aged 50 and over [4] and many workers of all ages are increasingly looking for greater flexible working, including opportunities to work part time.[5] We cannot dismiss the risk that older workers, those struggling to navigate a suitable work-life balance or seeking better renumerated opportunities will vote with their feet. Indeed, in April 2022 we saw a significant increase in the number of NHS staff retiring, with a 28% increase in the number of pension awards compared to April 2021.[6] By the year to June 2022 over 40,000 nurses had left active service.[7] And now two thirds of NHS trust leaders say the cost-of-living is having a major impact on their ability to recruit and retain staff, with staff leaving to take better paid jobs in retail and hospitality.[8]

1 in 9

nurses left active service in the last year

The picture in social care is quite possibly worse. It has long been a sector characterised by low pay and poor conditions that struggles to recruit and retain sufficient staff. [9] However, these long-standing difficulties have been severely exacerbated by a combination of the pandemic, cost-of-living and the fact that in a competitive labour market pay, terms and conditions are increasingly falling behind other sectors – including hospitality, retail and healthcare.[10] Adult social care workforce vacancy rates are now the highest they've been since the pandemic began.

71% of care workers are paid below the real living wage[11]

1 in 3 workers on a zero-hours contract

34% annual turnover of all care staff [12]

The cost-of-living crisis is having a direct impact on recruitment and retention of adult social care staff. Directors of Adult Social Services across England now say an average starting wage of £12.77 an hour would be required to minimise – let alone reverse – local recruitment and retention challenges. This is £3.27 more than the current national living wage rate of £9.50 and is comparable to the mid-point of NHS Band 3 for Healthcare Assistants.[13]

As of June 2022, the NHS reported 132,000 FTE vacancies, while social care had an estimated 165,000 unfilled posts.[14] This is in the context of recognition that the workforce will need to grow in order to meet increasing demand - with an extra 475,000 jobs projected to be needed in health and 490,000 jobs in social care by the early part of the next decade.[15]

Pressure on social care services

The impact of the pandemic on adult social care has been profound, and is far from over. More people are waiting for assessments, care and reviews. People have been faced with support being rationed and continuity of care being severely compromised.[16]

The overall number of adults waiting for assessments, reviews and packages of care exceeded 540,000 in April 2022 - a 37% increase since November 2021. There are around 600 adults a day continuing to join waiting lists to be assessed for care and support. At this rate, Directors of Adult Social Services anticipate the number of adults waiting for an assessment to double over the course of the year (between November 2021 and November 2022).[17]

> **"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."** [18]

While demand is rising fast post-pandemic, the number of providers who are closing or handing back local authority contracts is also increasing rapidly. In the past six months, 67% of Directors of Adult Social Services reported providers in their area had closed, ceased trading or handed back council contracts.[19] For the six months prior to the onset of Covid-19, this figure was 25%.

Overheads are of particular concern for care homes, with many struggling to remain viable in the face of the spiralling costs of energy, fuel, insurance and food. Across the sector the lack of available staff means many providers simply cannot meet demand for their services, leaving older and disabled people with nowhere to turn even when funding is available.

Both services users and Directors of Adult Social Services are increasingly concerned about the quality of what is still available. Two thirds of Directors report that quality and choice of services in their area have reduced compared to the pre-pandemic period.[20] As we set out in the first chapter, unmet need has been rising steadily over the last decade. Now – as we emerge from the pandemic – there are an estimated 2.6 million people aged 50+ living with some level of unmet need with one or more activity of daily living. This equates to 1 in 8 people across that population.[21] This has a profound impact on the health, wellbeing and independence of individuals with care needs and puts carers under unsustainable pressure. In the last year, three quarters of Directors of Adult Social Services have reported rising numbers of referrals and requests because of breakdown of unpaid carer arrangements.[22]

2.6 million people aged 50+

7% of people in their 50s have an unmet need for care, 12% in their 60s, 15% in their 70s, and 21% in their 80s and older.[23]

Of those with an unmet need for care and support:

1.8 million	have difficulty dressing
1.2 million	have difficulty bathing or showering
320,000	have difficulty eating
600,000	have difficulty using the toilet [24]

The challenges in the NHS impact on adult social care, and vice-versa.[25] Nine in ten Directors of Adult Social Services reported an increase in the average size of care packages of people being discharged from hospital, pointing to increased complexity of need with people being discharged earlier and/or with higher levels of acuity than in the past as hospitals struggle with capacity. Around half also reported increased activity because of a lack of community-based support or because someone could not be *admitted* to hospital.[26]

Pressure on NHS services

> **“I’ve been told I’m definitely still on the waiting list for surgery, but they can’t give me any indication of a timeline. They just leave you hanging, thinking what am I going to do with my life?” [27]**

The NHS has long been a lean service, with a low bed base, low length of hospital stay and a high occupancy rate compared with other similar countries. This means it uses resources intensively and with little spare capacity. **At a time of crisis, the healthcare infrastructure is stretched to breaking point as there is simply no slack in the system to meet the surge in demand alongside other essential care needs.**

Even pre-pandemic, the ‘winter crisis’ was a regular calendar event as services struggled to accommodate the normal seasonal surges in demand. But the NHS now faces the prospect of the worst winter storm on record as the mismatch between demand and capacity reaches new proportions. ‘Winter’ levels of demand and subsequent capacity challenges are now normal across the year.

> **Workforce challenges have a particular impact on the ability to discharge patients to other settings, including the availability of social workers to co-ordinate those packages of care.[28]**

Pressures are a complex mix of increasing demand, reduced supply, workforce shortages and challenges in other parts of the health and care ecosystem, all impacting on the flow of people through NHS services.

> **In the summer of 2022, many areas were already experiencing the equivalent adult social care pressures that they would normally see in winter.[29]**

While the numbers of people contacting NHS 111 and phoning for an ambulance have been above pre-pandemic levels, other measures of NHS activity have remained at or below those seen in 2019 as services continue to grapple with the long-term effects of the pandemic.

> **Ongoing cases of COVID-19, increased complexity of patients and significant backlogs of care needs across services all have disruptive knock-on effects that are cumulative and can lead to a downward performance spiral.[30]**

Recent analysis found that to deliver pre-pandemic rates of care, the NHS would require a far larger increase in bed supply than we would expect under the current hospital plan. Even if the NHS makes progress on reducing the time patients spend in hospital, the NHS would still need an additional 23,000 to 39,000 general and acute hospital beds by 2030/31.[31]

Taken together, this picture suggests that the Richmond Group analysis from 2018 holds true: that for better or worse, the NHS, social care and public health are fundamentally interconnected and destined to 'sink or swim' together.[32] Pressures in social care, public health and other parts of the system have real and immediate consequences for NHS services, driving up demand and leading to postponements or cancelled appointments, delayed handovers, admissions and discharges to and from hospital. This all ultimately impacts negatively on people's healthcare experiences, access and outcomes.

Although during the peak of the pandemic the NHS was able to pull out the stops and perform exceptionally well, this came at a heavy cost for both staff and patients and is not sustainable. As we look to the future, demand for NHS services over the next decade is only anticipated to grow.[33] To lessen the impact of future shocks to the NHS, the question for policymakers must be how to plan a more resilient service.

Added to this, NHS England's chief financial officer recently warned that increases in inflation will force the NHS to drastically scale back services unless the government provides extra funding. Savings required could add up to 10 per cent of the NHS's cost base, threatening further crisis.[34]

People living with long-term, multiple or complex health conditions

> **"Food prices have been rising for a couple of years. Not just recently. Electric and home heating oil prices have rocketed. It means that we can only afford the basics. Heating is a luxury. My wife sits with blankets over her as she feels the cold really badly and it affects her fibromyalgia and pain levels. The price of bread has rocketed which is what I mainly eat so I've had to change to the cheapest bread. I feel trapped in the house and in unbearable pain, and worried if and when I can get treated."** [35]

The UK is experiencing a cost-of-living crisis with real incomes falling as wages and benefits fail to keep pace with rising prices. Those on the lowest incomes are hit hardest as essential costs such as food and energy already take up a larger proportion of their income.[36]

The 'disability premium'

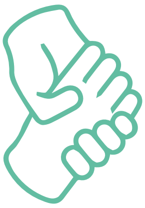
£583

a month

In 2019 the disability 'premium' was already an estimated £583 a month. Some of the additional costs people face include: prescription charges, care costs, running medical equipment at home, extra heating and washing costs, specialist food and transport.[37]

As we have set out in previous chapters, financial disadvantage and poor health often go hand in hand. **People living in disadvantaged circumstances are more likely to develop long-term, multiple or complex health conditions earlier on in their lives.** Acquiring a health condition or disability, or taking on a caring role for someone who does, can in itself have a serious impact on personal finances. At the same time, people managing health conditions and disabilities often face additional costs.[38]

Carers providing more than 20 hours a week of care are 22% less likely to be in work. And those in work earn less than their counterparts.[39]



Taken together, people living with and caring for those in poor health are more likely to have entered the cost-of-living crisis in a much more precarious financial position and are twice as likely to report that they are now seriously struggling as a result.

In a 2022 survey of NHS trust leaders,

over half

reported an increase in safeguarding concerns as a result of people's living conditions.[40]

People living with long-term conditions or disabilities are already struggling with the increased cost-of-living.

- People living with a long-term condition or disability are twice as likely to say they are already ‘going under’ financially (22% in this category compared to 9% without).
- They are more likely to have already reduced essential spending, with close to half (45%) saying they have reduced spending on things they need (compared to 35% without).
- 1 in 5 (20%) say they are already skipping meals (compared to 10% without). [41]

Rising prices do not just make life more difficult however, they can severely compromise people’s ability to manage their health and wellbeing – particularly increasing food and energy cost.

> **“I try not to put the heating on now unless absolutely necessary and I have Reynaud’s disease. I know when the winter comes it will be awful and I am worried about this.”** [42]

Affording prescriptions and medical equipment

Most long-term conditions require regular prescription medications and/or access to medical kit at home to manage day to day. Even pre-pandemic, people living on a low income regularly reported either going without or rationing their medications because they could not afford the prescription charges. Lack of adherence to medication is associated with increased risk of an unplanned hospital admission. Some conditions also depend upon people using electrical equipment at home, such as CPAP machines for obstructive sleep apnoea, home dialysis treatment for people with kidney disease, refrigerators for insulin and nebulisers for lung conditions. This equipment is essential for people to manage their health conditions but is often costly to run.

> **“Like many people, we are very worried about fuel prices. My wife and I both have breathing problems. We are going to have cut down on our gas usage. This won’t help us at all.”** [43]

Before this year’s energy prices rises, home dialysis machines already added between £593 and £1,454 a year to utility bills.[44]

Staying warm

Every year tens of thousands of people across the UK are admitted to hospital or die from conditions that can be linked to exposure to the cold – with the highest risk amongst older people and those with pre-existing health conditions.[45] It is linked to an increased risk of falls, exacerbation of respiratory conditions and – as it puts more pressure on our hearts and circulatory systems – a rise in the number of heart attacks and strokes. Alarmingly, the effects are apparent once indoor temperatures drop below 18°C.[46]

> **“Mentally, we are extremely worried about how we will manage financially. We have done everything we can to reduce our outgoings, including selling my car. We worry about keeping warm and fed - not just the cost of food but the cost of cooking it.”** [47]

Maintaining an adequate diet

Being unable to maintain good nutritional intake has an adverse impact on people with long-term conditions. For example, poor nutritional intake can contribute to the development and severity of delirium - a particular risk for people living with dementia - which in turn can lead to a rapid decline in mental state and behaviour. Poor diet can make the symptoms of conditions including asthma worse. People with conditions like diabetes need to maintain specific diets to manage their symptoms, and people taking some medications must manage their diet to mitigate adverse interactions.

Mental health

Unsurprisingly, the rising cost-of-living is driving anxiety, with 1 in 2 UK adults already reporting feeling anxious as a result of the higher prices.[48] Nearly three quarters of NHS trust leaders say they have seen more people coming to mental health services due to stress, debt and poverty.[49]

> **"All this (the cost-of-living crisis) has an impact on both my mental and physical health. I find it difficult to not worry about my future. I can't sleep and feel weary with the stress of it all." [50]**

Carers

> **"I am anxious & scared of what our living costs will be in the coming months. I'm unable to sleep and worried about surviving" [51]**

Even before the current cost-of-living crisis, almost two thirds of carers were spending their own money on care and support services or products for the person they care for. Carers also reported having to spend a larger proportion of their income on energy costs to keep the person they care for warm and manage their condition. This as well as potentially washing clothing and bedding more frequently, having higher food bills due to the nutritional requirements to support the person they are caring for, and having higher transport costs because the person they care for needs support to travel or the carer has to travel to provide care. As day-to-day costs have increased, carers report that they are having to cut back on essentials and are increasingly running down savings or getting into debt to make ends meet.

In March 2022 - when inflation was at 9.2% - 58% of carers reported cutting back on heating to manage their finances, with 14% having already fallen into arrears with their utility bills. 45% of carers reported relying on their savings and 26% were using credit cards to get by. [52]

> **"I'm worried about heating the house as my husband doesn't go out, plus the cost of diesel means I won't be able to get out as much to see friends to give me a break." [53]**

Growing financial pressure on carers is likely to have a negative impact on their own health and wellbeing and ability to cope with their caring responsibilities. Over three quarters of Directors of Adult Social Services say they are concerned about unpaid carers being unable to cope with rising costs and believe this will result in increased need for state-funded social care.[54]

What does this mean?

The gap between people's needs and the capacity of health and social care services to meet them is wide and getting wider. We fear this winter will prove to be the pivotal point where the weight of that contradiction becomes painfully apparent.

Clearly, we will need urgent action to shore up people's health and wellbeing, make absolute best use of the workforce we do have and be as creative as possible in how we deploy resources to maximum effect. We are in no doubt of the collective commitment of the NHS, social care and our own voluntary and community sector to do all we can. But it is equally clear this position is unsustainable and as we look to the future, it is essential we fix the foundations and build a more resilient health and care system.

4. Looking to the future

Multiple, long-term and complex illnesses are the 'new normal', but our health and care system has not caught up to the challenge.

There are more people living with health conditions, more people presenting with advanced or severe symptoms, and those already living with conditions have seen their health deteriorate into multimorbidity.

This has led to heightened demand on community-based treatment, care and support (including primary care where much of the need washes up).

When coupled with the pandemic and now the cost-of-living crisis, those with greatest needs are not being supported, reinforcing a vicious cycle of ill-health, chronic stress and financial hardship. If the government is serious about levelling up as a moral, social and economic imperative, then it must respond to this challenge.

Our current care models, skills-mix and values must change to reflect the realities that those we serve are likely to be increasingly older and with more complex care needs. We need a plan to get back on top of long-term condition care and routine management. This includes rebuilding community services and joining up multidisciplinary teams, whilst boosting mental health support, access to specialist recovery, rehabilitation, community pharmacy and social prescribing services.

All of this will reduce downstream demand on health and care services.

As well as being socially unjust, ill health is economically destructive. Poor health and widening inequalities leave large sections of the population vulnerable to both the long-term impacts of Covid-19 and to future health and economic shocks. The reluctance of successive governments to address the root causes of these problems is counterproductive. Failing to manage our collective population health and wellbeing will mean the demand on elective and emergency services rises even faster.

With the right services and support, we know people living with long-term, multiple or complex health needs can live well and thrive. We need to see clear and focused political leadership to make that happen.

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