



Why can't I get care?

Older people's experiences of care and support

Why can't I get care?

At Age UK “why can't I get care?” is a question we get asked a lot. This short report aims to explain the answer, drawing on older people's experiences, as well as on what we know about how the social care system is supposed to work, and how it actually works in cash-strapped 2022.

As we look forward to our older age we see ourselves enjoying retirement – spending more time with family, travelling perhaps, having the time to focus on our hobbies. Everyone wants to be able to live their life to the full.

But a broken care system means that a shocking 12% of people aged 50+ in England (2.6 million) have an unmet need for care and the older you are the more likely it is that you will have needs that are not being met.¹ People are struggling to even go the toilet, eat, get dressed or washed, because they can't do these things unaided and the support isn't there for them.

There is something deeply wrong with a care system when even people's critical needs aren't being met. And it's getting worse.

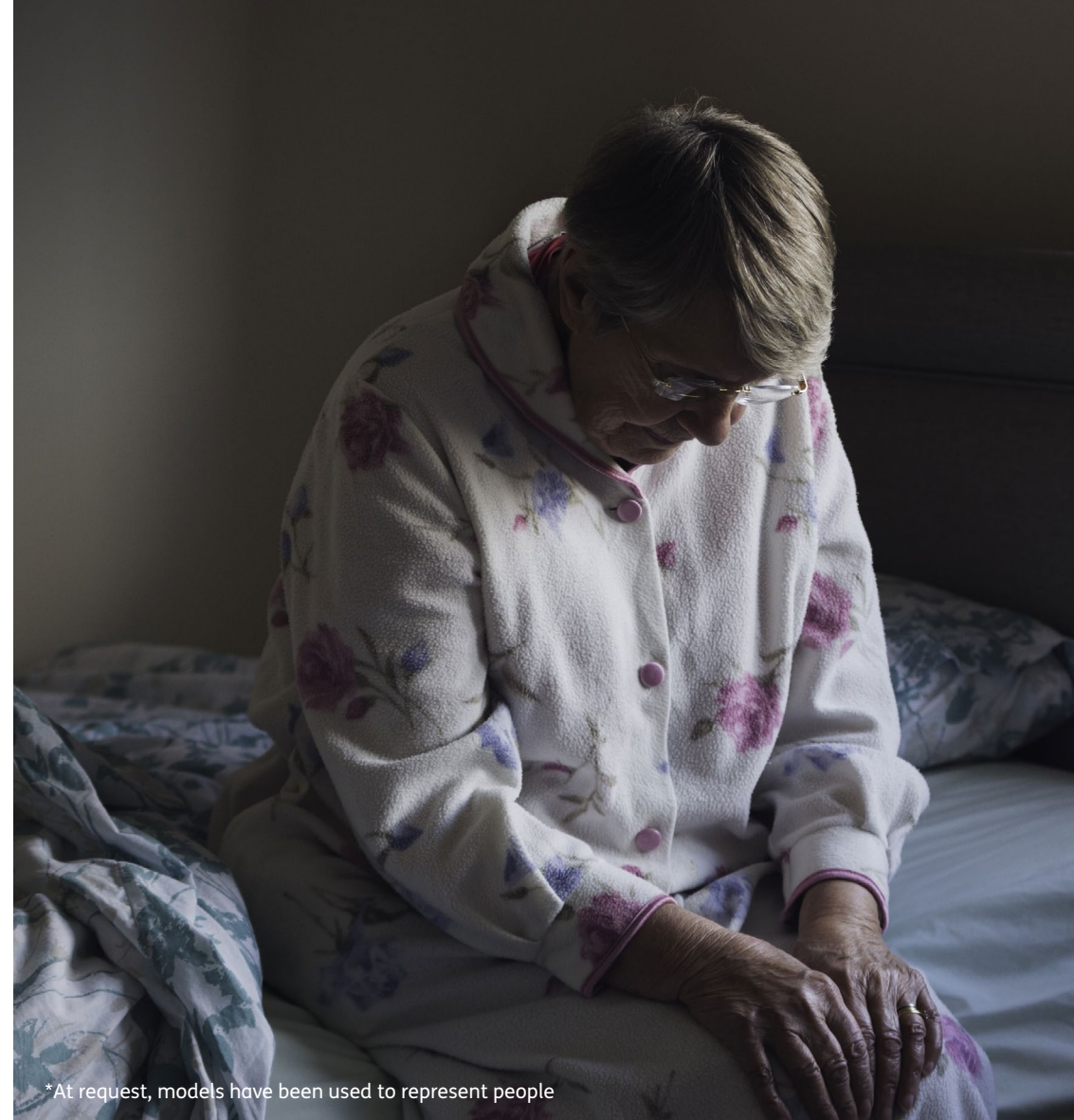
Older people and unpaid carers often

tell us they feel forgotten and left to fend for themselves with little or no support. From the start of the process of trying to get a local authority assessment of the care they need, all the way through to securing end of life support, too many older people are failing to get all or sometimes any of the help they need.

No wonder 40% of adults think social care in England is working poorly or not at all.²

We all want our parents and grandparents to live with dignity, and we want that for ourselves too.

While it's welcome that the Government has set out some reforms, including a cap on costs, we are still waiting for those reforms to be implemented, and it's clear that much more must be done to support older people now.



*At request, models have been used to represent people

In our representative poll 83% of the public said the Government should prioritise improving social care. And the same number agreed the Government should allocate more money to improving the social care system.³

Everyone should grow older confident they can get the support they need to live well.

We can't stop until there is high quality, reliable and affordable care available to all, when they need it.

Asking for care and getting assessed

Higher prices have resulted in older households on the lowest incomes often being unable to cover essential day-to-day costs, with an increasing number turning to Age UK's national Advice Line for support.

It can take a lot to admit to yourself and others that you need some assistance with activities you've done without thinking throughout your life, like washing and getting in and out of bed. But getting help is now much harder than it should be, and the process of getting an assessment of your social care needs isn't working well. Many older people are waiting an intolerable amount of time just to have an initial conversation with their council about the care that they need.

If you are very well off you might be able to bypass the State system and go straight to a home or live-in care agency, or a residential care home, and buy some support – if there are staff to provide it and services available. However, self-funded care doesn't come cheap: it is not unusual to pay £25 an hour for home care and £1200 or more for live-in care or a care home, a week. These amounts add up

very quickly and the reality is that most older people and their families have no choice but to rely on the State system, and the starting point is having your needs assessed.

Applying for State funded care is complex, long winded and the barriers to getting an assessment, and means tested help with your care needs, can make it feel like a battle. Even those with previous experience of the care system, or who have received support from our Advice Line, find it difficult to navigate. It's no wonder people often feel the process is designed more to fob them off, than to truly meet their needs.

Once you have jumped through all the hoops and got an assessment you can then wait for months for someone to come back with the outcome. This is leaving those with an urgent need for help to wash, eat, or even get out of bed, feeling hopeless and abandoned.

It's easy to blame local authorities, who administer the social care system, for such a parlous state of affairs. However, in truth, older people are paying the price for overloaded, underfunded councils, that have far fewer staff than they need to carry out assessments quickly, and when they identify that a person has a social care need, often struggle to find a provider with capacity to deliver that care.

Shockingly, 28,890 older people died in 2020/21 before receiving the care that they had requested.⁴ Think how much better and more comfortable their last weeks and days would often have been had they been given the help they needed.

And the situation appears to be worsening - ADASS recently reported that almost two thirds (61%) of Directors of Adult Social Services were only able to assess people with serious safeguarding needs or when they are going home from hospital or a care home, as they struggle to manage the post pandemic increases in requests for care and support that they face.

Older people waiting for an assessment at home, not because they are coming out of hospital, are a long way down the queue. In such a pressurised NHS and social care system there's a logic to this, but it leaves many older people living in intolerable situations at home that

28%
increase in the number of people awaiting assessment, care or direct payment, or review between November 2021 and February 2022.⁵

28,890
older people died in 2020/21, without receiving the care they were waiting for.⁶

14,000
people each week are having their request for care turned down.⁷

More than 6 in 10
councils say they are having to prioritise assessments and are only able to respond to people where abuse or neglect is highlighted, or for hospital or rehabilitation discharge.⁸

may also put their health at risk. It can also mean that by the time someone does arrive to assess their needs, their condition has deteriorated significantly.

Even if you get a long-awaited assessment, the strain on the system

can mean you miss out on the care you expect, because it seems that as resources tighten the threshold for getting support rises – a rationing response in effect. Last year, Age UK estimated that every week, the requests for care of around 14,000 people were turned down. We doubt that all these outcomes were fair.

Age UK and many others fear that this

situation will get even worse when the Government's new social care cap and Fair Cost of Care measures start to be introduced in 2023. Although we welcomed these reforms, not enough has been done to increase the capacity of councils to deliver them, and the problem is that they are bound to lead to more people asking for assessments, thereby adding to an already lengthy queue.



*At request, models have been used to represent people

“Care is too hard to access - every conversation we have with admin is like talking to the wall.”

“[I] was on a waiting list for an assessment for a care plan but had no update as to when this might happen.”

“[I've had] great difficulty in accessing companies who provide the required care package due to staffing pressures.”

“I've found the system very confusing and have only very recently gone through an initial assessment which will, hopefully, lead to another assessment which might, in turn, lead to some form of support.”

“I have not had a carer's assessment since the start of the pandemic. I understand that this is the case for all unpaid carers in Cornwall.”

“Trying to get mother-in-law into sheltered housing but waiting list for assessment is very long (12-14 weeks).”

“I have tried to get help for my parents, had an assessment for them but no follow up despite it being promised. Empty promises are made by those supposedly helping, as the help never materialised.”

“Tried accessing relative care reassessment regarding care equipment needs. Took from August 2021 until January 2022 to get assessment even though had gone through the GP.”

“She has become increasingly frail, has fallen several times recently, suffers from low blood pressure & is regularly dehydrated (forgets to eat & drink). We are in the process of arranging a care package, which is proving very difficult.”

Getting good care at home

Many older people wish to be able to stay in their own homes, where they have built their lives, for as long as possible. With a timely, accurate assessment, help with home adaptations, and a good package of care in place, this ought to be possible for many older people. It's a choice which successive governments have agreed is important.

But the serious care workforce shortage is now making care at home unreliable and inadequate for many. This is especially so within the State funded system, but even older people who can afford to buy their own care tell us that securing a reliable home care service has become awfully hard. This leaves older people scared about whether anyone will come to help them each day.

Older people repeatedly tell us that what matters most to them is that they get enough support from a small number of the same kind and skilled people who they can get to know and feel confident will come when they are supposed to. Surely, this shouldn't be too much to ask, but at the moment it frequently seems to be.

The problem is that vacancies, rapid staff turnover and reliance on agency workers results in a task-focused,

depersonalised service that older people don't particularly like and cannot trust to be there when they need it. Some older people also say they feel infantilised by care worker schedules that mean they are put to bed at 5, or left to eat a sandwich as no-one is available to cook for them at meal times.

Sadly, some are being denied the choice to stay at home at all when, until quite recently, this would probably have been available to them. It is not unusual at the moment to hear of older people who feel forced into care homes as they are told the care they need is unavailable at their home in the quantity required, due usually to shortages of staff.

Consistent high-quality care should not be an unreasonable expectation. It should be possible for older people to have some choice about how

and when they receive care so they can maintain their dignity and receive the personal care they need and that suits them. No-one wants to be cared for by over-stretched and stressed staff who are effectively strangers, albeit well-meaning ones, working under impossible conditions.

A recent report by Skills for Care has revealed that for the first time, the number of care workers in England has fallen, with vacancy rates rising by 52% in just a year. We urgently need bold thinking on workforce to address this unprecedented crisis. Not merely to fill the growing number of vacancies but to tackle the high turnover rate by making care work a desirable career. This means higher pay and better conditions to go alongside the professionalisation and long-term workforce planning that is so badly required. And because so many older people who need care have serious health conditions it also means we need to look right across the NHS and social care workforce and develop strategies that work for both. This might well include formal arrangements to share staff and resources between health and care settings, homecare providers and community services.

170,000
hours a week of home care could not be delivered because of a shortage of care workers during the first three months of 2022. Seven times more than Spring 2021.⁹

1 in 8
older people are concerned about their ability to access home care or find a carer.¹⁰

1 in 6
older people are concerned about their ability to access local authority services.¹¹

165,000
care staff vacancies on average in 2021/22, a 52% increase on last year.¹²

29%
staff turnover rate over 12 months in 2020/21.¹³



“With so many carers being ill the agency was very stretched. Times of visits were ridiculous. Carers and times were changed without warning.”

“When she first came home after her stroke, she was eventually offered NHS carers which came 4 times a day, for about 20 minutes. She never knew what time they were coming, even had a male come at 10 pm to put her to bed, which terrified her as she lives alone.”

“Very difficult to get carers for my partner who lives with me even though he has to self fund.”

“I have been in need of carers for the last 3 years and found them hard to get a rapport and the irregularity was a big issue, since the Covid there is insufficient staff, for 3 weeks I was left in bed for between 15 to 17 hours a night, which has contributed to me losing a vast amount of muscle therefore making it more difficult for me to walk.”

“Unreliable, never come when they should. Sometimes don't turn up at all. Some carers are lovely, but some just come in, check in ok and leave in less than 5 mins even though they are paid to be here for 30 mins. I did have carers come twice a day but the tea time ones only turned up at 10.30 to 11pm so it was far too late for me to eat so I cancelled them and just get on the settee early instead.”

Getting a place in a good care or nursing home

Unfortunately, the situation in care homes and nursing homes is often no better than in home care.

Many older people and their loved ones find the decision to move into a residential setting a very difficult one, but sometimes it is without doubt the right place for them to be, particularly if they are living with advanced dementia or other serious health conditions and it has become impossible to continue living in their own home.

The social care workforce crisis is putting a huge strain on care homes and nursing homes and reducing the level of care they can offer. Where specialist care is needed it can be difficult to find it close to home, leaving families struggling with long journeys to see their loved ones, and residents isolated with fewer visits or vulnerable older people deteriorating in hospital beds for want of a specialist care home placement.

During the pandemic there was a virtual halt in new people being admitted into care homes, plus a widespread loss of public confidence in this form of provision, given the problems with visiting when COVID-19

was rife. Confidence is gradually returning, admissions have resumed and more people are seeking a care home place again as a result, but care homes' finances took a big hit from which smaller homes that are not part of a large chain have found it especially hard to recover. Residential care providers now face spiralling energy and food costs - the last thing they need - the near-term future for them looks pretty grim. There is serious concern about how many will be able to continue to survive without more funding, threatening to leave older people who need a care home place with even fewer options than they have now.

It's essential that the Government continues to provide support with energy costs to care homes after the current Energy Bill Relief Scheme comes to an end.

Even if you can find a care home it may not provide all the care you need. Some are struggling with the basics.

Finally, those who manage to find



*At request, models have been used to represent people

a suitable bed in a home near their loved ones often then live in fear that once their money runs out they will be forced to leave, as the costs are higher than the small budget their local authority can afford to allocate for their care.

Caring for frail older people in a care home, many of them with advanced dementia, is highly skilled, intensive and demanding work. It is impossible to provide really good care unless you have enough staff, with enough time to give each resident the individual attention they truly need. Too many care homes are falling short at the moment as a result and unless the Government provides more help for them it is hard to see the situation getting better any time soon.

Meanwhile, regrettably, in nursing

homes the situation is often worse still. There is a worrying shortage of nurses in nursing homes, a particular concern because the availability of nursing care is what differentiates these establishments from ordinary care homes. When nursing homes struggle to recruit the health professionals that they need, it is not unusual for the provider to deregister the nursing home and re-register as a care home. Older people who live in nursing homes are, by definition, usually profoundly unwell. We fear that too many are failing to get the excellent, integrated health and care support they need.

The kinds of measures we recommend to improve home care - above all, a concerted effort to strengthen the workforce - would assist care homes and nursing homes too.

22%
of older people with
a long-term condition
were concerned about
their ability to access
local authority services.¹⁴

70%
of care home residents
have dementia or severe
memory problems.¹⁵

21%
But the average proportion
of care home beds
dedicated to dementia in
each region is only 21%
- a 4.2% decline from 2019.¹⁶

50,000
fewer care worker posts are
filled now than in 20/21.¹⁷

36%
decrease in registered nurse
filled posts since 2012/13.¹⁸

“The experience I have had in placing my brother in a care home has been very stressful because of the lack of availability in his preferred area. Eventually he had to be moved 30 miles away from his friends and family which has affected his mental health.”

“Oh my God, I don't know where to start. The staff are kind but the home is understaffed, mum doesn't like agency staff, no dignity, one shower a week, wearing other people's clothes, covered in unexplained bruises.”

“Communication with social care is very difficult and extremely slow because of pressure on the service. Mother-in-law spent two months in hospital because there was no space in care homes or community hospitals.”

“Left in room in care home for 6 weeks - 4 stone weight loss.”

“It was agreed in December she needed 24 hour care, we asked for care home as she didn't know who or where she was and needed help from carers it took so long to arrange she passed on 25 March this year.”



*At request, models have been used to represent people

Support for unpaid carers

Unpaid carers are propping up the care system – providing hours of care for their loved ones, often at the expense of their own health and wellbeing. The pressure on carers is only increasing. In fact, 30% more unpaid carers are now providing over 50 hours of care per week than in October 2020.¹⁹

2 million over 65s are unpaid carers and over half of them have a long-term condition themselves. These dedicated, strong and resilient people are being pushed to the brink with no breaks and little support to look after their loved ones, as they pick up the slack created by a lack of formal care support.²⁰

Just 30% of carers reported in a recent survey that their loved ones had received home care in the previous 12 months – continuing a steady decline over time.²¹

Older carers are telling us they are worried about their health, their finances, and that they will no longer be able to look after their loved ones. Those pressures have increased immensely in recent weeks, and we know that some carers will face impossible choices as we head into winter and they try to meet the rapidly rising cost of energy, food and essential

supplies without receiving a rise in their benefits to match.

We frequently hear heart-breaking stories from carers who are too exhausted to keep going, but who also feel they can never stop as there is no one to help or replace them. Three in five (59%, 1.1 million) older people caring for loved ones felt tired because of the care or support they provide.²²

The Government's plans for social care don't address the serious needs of unpaid carers. It is essential proposals are brought forward to help carers get back on their feet and support them to do what they want to do – look after their loved ones well.

This plan must ensure carers can get adequate breaks, improved financial support, and more help for those still in work, a right to flexible working and more help overall to manage their caring responsibilities.



4.87 million unpaid carers are worrying about the impact of caring on their physical and mental health.²³

84% of the general public agree that the Government should provide additional support for unpaid carers.²⁴

3 in 10 older unpaid carers had felt overwhelmed because of the care or support they provide.²⁵

1 in 6 older unpaid carers had felt lonely because of the care or support they provide.²⁶

18% of older unpaid carers were finding it harder getting into and out of bed than before the pandemic. Compared to non-carers (9%).²⁷

“ I am exhausted..... I rarely get one day off a week. My physical health is awful to the point where I suffer daily pain and go bed by 8pm.....I feel that I have lost my life choices.”

“ Services almost impossible to access. No respite as nobody to care in my place. Unpaid carers were and still are treated badly, we're invisible to authorities and get very little help.”

“ [Help for her terminally ill mother was] ‘non existent, and no-one listened that she needed help or gave me help.’”

“ I was unable to access paid carers to help and had to put my mother in a care home for temporary respite when I had surgery and COVID. This was expensive and stressful for my mother.”

“ The last 6 months as a carer have been horrendous. So much so that I have run myself into the ground and am trying to get permanent care for my husband. I have needed respite care for months but nursing/care homes have had problems with Covid testing and have put me off until I couldn't cope. Social services are now looking for a place for my husband but I need a real assessment of our needs and what funding I can have. Been waiting three weeks for that.”



Conclusion

In most cases, the answer to the question this report poses – ‘why can’t I get care?’ - is that there simply isn’t the care to get. The severe shortages in staff and the lack of funding to pay for more or better services to provide care or respite provision have left a gaping hole in support, and often services just aren’t available.

Older people and their carers are paying the price and suffering without their basic needs being met.

Care is far from fixed and we fear that, in the context of rising costs and falling staff numbers, the reforms that have been announced, may not be deliverable without more funds and certainly won’t work without a robust workforce plan. We must not lose the urgency to fix the care system so that older people can get the care they need, when they need it.

Cutting the wait for millions needing social care, addressing the shortage of care workers and providing enough help for unpaid carers will help us all. It will save the NHS money, ease waiting list pressures and help older people to stay well and independent for longer.

Most importantly it will allow older people to live; not struggle, often in pain, their dignity taken away.

High quality care that is available when and where you need it – it’s what we all deserve. Some of us are still fortunate enough to receive it, but tragically it’s becoming increasingly rare.

Good care is possible and it makes all the difference:

“After her health went downhill following a catastrophic fall my Mum was given only weeks or short months to live, but in the end she survived for more than three years. I’ve no doubt that’s because she received really good social care, delivered by committed staff who came to know and love her. Good care saves lives.”



*At request, models have been used to represent people

These are challenging financial times, but that’s all the more reason for Government to invest in social care and in the people who provide it. Good social care is much cheaper than hospital care, which is usually the only alternative when it’s unavailable, and it helps unpaid carers to remain economically active too. Above all though it gives older people dignity and comfort - surely not too much to ask.

References

- 1 Age UK analysis of data from wave 9 of the English Longitudinal Study of Ageing, scaled up to the population of England using data from the 2021 Census.
- 2 1724 people aged 18 in England were polled by Britain Thinks for Age UK. They were asked Based on what you know, how well, if at all, do you think the Social Care system is working in England? Response options were on a scale from 0 (not working at all) to 10 (working very well). We defined those who responded with scores 0, 1, 2 or 3 as thinking that the social care system in England is working badly or not at all.
- 3 1724 people aged 18 in England were polled by Britain Thinks for Age UK.
- 4 Adult Social Care Activity and Finance Report, England 2020-21, accessed here: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2020-21>
- 5 Adult Social Care Activity and Finance Report, England 2021-22, accessed here: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22>
- 6 Adult Social Care Activity and Finance Report, England 2021-22, accessed here: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2021-22>
- 7 Age UK analysis of NHS Digital (2020), Adult Social Care Activity and Finance Report, England – 2019-20, accessed here: <https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2019-20> We have used the most recent data for 2019/20. We have assumed that the number of people who had their request for formal care denied each day has remained the same as the average for 2019/20.
- 8 ADASS Waiting for Care Report May 2022
- 9 ADASS Waiting for Care Report May 2022
- 10 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.
- 11 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.
- 12 Skills for Care workforce estimates and ASC-WDS data 2021/22
- 13 The state of the adult social care sector and workforce in England - Skills for Care October 2022
- 14 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.
- 15 A focus on elderly dedicated dementia bed in the UK, Carterwood and Alzheimer's society, May 2022
- 16 Average regional allocation of dedicated dementia beds - A focus on elderly dedicated dementia bed in the UK, Carterwood and Alzheimer's society, May 2022
- 17 Skills For Care - The state of the adult social care sector and workforce in England - October 2022
- 18 Skills For Care - The state of the adult social care sector and workforce in England - October 2022
- 19 Make Caring Visible, Valued and Supported: Carers Week 2022 report
- 20 Age UK analysis of data drawn from wave 11 of Understanding Society (the UK Household Longitudinal Study), scaled up to the UK population using ONS mid year population estimates for 2020.
- 21 Survey of Adult Carers in England, NHS Digital, 2021/22 – 40% of carers said their loved ones received home care in the previous 12 months in 2014/15
- 22 Make Caring Visible, Valued and Supported: Carers Week 2022 report
- 23 Make Caring Visible, Valued and Supported: Carers Week 2022 report
- 24 Make Caring Visible, Valued and Supported: Carers Week 2022 report
- 25 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.
- 26 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.
- 27 Age UK polling undertaken by Kantar, March 2022 - Representative polling of the older population, aged 60+, into the impact of Covid-19 on older people's health and care across the four nations.

Age UK

7th Floor

One America Square

17 Crosswall

London EC3N 2LB

www.ageuk.org.uk/carecrisis

Email us: campaigns@ageuk.org.uk

Age UK is a charitable company limited by guarantee and registered in England and Wales (registered charity number 1128267 and registered company number 6825798. Registered address: 7th Floor, One America Square, 17 Crosswall, London, EC3N 2LB.