

# Health and Social Care Committee

## Oral evidence: Adult social care reform: the cost of inaction, HC 368

Wednesday 19 March 2025

Ordered by the House of Commons to be published on 19 March 2025.

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Members present: Layla Moran (Chair); Danny Beales; Dr Beccy Cooper; Jen Craft; Josh Fenton-Glynn; Andrew George; Paulette Hamilton; Alex McIntyre; Joe Robertson; Gregory Stafford.

Questions 215 – 296

### Witnesses

[I](#): Holly, expert by experience; Keyaan, expert by experience; Jayne Simpson, expert by experience.

[II](#): Dr Maria Petrillo, Research Associate, Centre for Care, University of Sheffield.

[III](#): Tom Gentry, Head of Health Influencing, Age UK; Caroline Abrahams, Charity Director, Age UK.

Written evidence from witnesses:

– [Add names of witnesses and hyperlink to submissions]



## Examination of witnesses

Witnesses: Holly, Keyaan and Jayne Simpson.

**Chair:** Welcome to the last session of the Health and Social Care Select Committee inquiry into adult social care reform and the cost of inaction. It is our delight to start our last session with three amazing people who are unpaid carers, two of whom are young carers. We will start with questions from Jen Craft.

Q215 **Jen Craft:** Good morning. We are very pleased to have you with us. I have a nice easy question to start with: would you tell us a bit about yourselves and your experiences as carers and as young carers?

**Holly:** I am Holly. I am 22. I grew up as a young carer; I grew up with my mum and my sister. I supported my sister, who has a range of conditions including epilepsy, cerebral palsy and hydrocephalus. When she was born, the doctor said that she would never walk or talk, but she ended up doing really well and went to a mainstream school with a full EHCP. Although I was not the primary carer, I was often involved with helping her do her physiotherapy exercises, sometimes helping her have a shower or dry her hair, and sight-guiding her out in public.

When she was about 17, she lost even more sight and became severely sight-impaired, so that was quite an adjustment. She had a lot of hospital stays. The number of surgeries that she has had, including many on the brain, is in the double digits, so I would often be providing quite a lot of emotional support.

It is probably also slightly the single-parent family dynamic: my mum sometimes just needed an extra person to talk things through, for example about my sister's EHCP, what to do if she was not getting the full support at school, whether we should ring 999 or 111 right now—all of those kinds of things.

Although I am not the primary carer, I have still played a role. I consider myself quite lucky compared to other young carers my age, but caring is quite a fluid, flexible thing. I am away at university right now, which has meant that my role has decreased, but as I get older I am probably going to have to take on more of a role as my mum becomes less and less able to care for her.

**Keyaan:** My name is Keyaan. I am 14. I look after my mum and my brothers. My mum has epilepsy and some other muscle diseases, which does not help for housework, so she will often need extra help with carrying stuff or looking after the babies. My brother, who is 10, has ADHD and often needs help with behaviour management and stuff like that.

**Jayne Simpson:** I am Jayne Simpson. I will not give my age, but I am much older than Keyaan and Holly. I care for my adult daughter, who is autistic and has complex mental health issues as well. As a result of her



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autism and her mental health issues and the inequalities that those bring, she is now starting to develop physical health needs as well.

She lives with us in the family home. She requires support to be available 24 hours a day. Her needs are very complex. She has a lot of needs around being kept safe. Without support, she would have a very diminished life and really would not be able to function. We get 14 hours of support from our local authority, but in reality it is much less than 14 hours, because there are difficulties in the care provider providing all of those hours with adequate and well-trained staff.

Alongside caring for her, I am in paid employment. I can only work part-time, and I have to work from home. It is barely possible for me to leave the house. Something like today is quite a rare event in terms of being able to leave and have adequate care for her.

Alongside that, as a result of being a carer, I do a lot of lived experience work. I am a parent carer representative on the West Sussex autism partnership board. I am an expert by experience with Sussex Partnership NHS foundation trust, which is our local mental health provider. I am also involved with Carers Support West Sussex, on its carers voice network.

**Q216 Jen Craft:** You are a very busy woman, basically. How does your work react to your caring responsibilities? How does it tie in?

**Jayne Simpson:** As I said, I can only work part-time and have only been able to take a zero-hours contract now. When I began in the job that I have been in for 21 years now, I had a substantive contract; I had fixed hours, like my colleagues. I was able to play a full part in the team, but I have had to very much reduce that as a result of being a carer.

That has brought a lot of difficulties financially, being on zero hours with much lower pay than my colleagues. It has affected my pension. I do not have a substantial pension to make any choices about retirement in the near future, which perhaps I would have been doing. I am very concerned: as it stands I will not be getting a full state pension, because I have lost national insurance contributions as a result of being part-time and zero-hours. I do not always know what hours I am going to get each week. It can work both ways for my flexibility, but equally my employer does not have to give me a fixed number of hours. It has brought a lot of difficulties with my employment, and my career has stalled as a result of being a carer.

**Q217 Chair:** Did you ever add up how much you lost over the years?

**Jayne Simpson:** I have not. For me, the very tangible one is the pension in terms of knowing what I might be getting, and knowing about the gender divide, in that my husband is also very involved in supporting our daughter, but he has been able to keep full-time employment. Because of the tradition that caring tends to fall to women, it was much easier for me to be part-time than it was in his role. It was not seen as a possibility for him to go part-time. I am seeing now that he has that choice of



retirement, and he has an adequate pension that he will be able to live off. I do not. I am afraid that I cannot give any figures. I have not sat down and worked it out, but I just know that I am not in a great financial position. I lack financial independence.

**Q218 Josh Fenton-Glynn:** Thank you all for coming today. One of the things that we are trying to think about is the cost of the fact that the social care system does not do everything that it needs to. I want to just ask you all a bit about how it has impacted you personally, in terms of what you are able to do and how it gets in the way of other things in your life. That is what this question is about. Do not feel that you have to answer all of these.

Does being a carer limit your ability to be involved at school? Does it limit your ability to socialise with your friends or take part in sports, or anything like that? Does it have that kind of impact on you?

**Keyaan:** I am not sure.

**Josh Fenton-Glynn:** Holly, looking back at your school experience, has it had an impact on that social side as well as your ability to participate more generally?

**Holly:** I have been very lucky compared with a lot of other carers. We know that, on average, young carers are missing a month's worth of school every year, and half of young carers are missing one day of school every fortnight. Compared with that, I have been very lucky.

As I mentioned, my sister was in school with me on a full EHCP, but I know that there is also a SEND crisis and it is really difficult. I do not blame the school for this, but there were times when she lacked a TA. Most break times in key stage 4, towards GCSE years, I would make sure that she had something to eat and drink, and occasionally help her get changed for PE. In between every lesson, I would go to her lesson, sight-guide her and walk her to the next lesson, and then go to mine.

At the time, that felt fine, until things went wrong. She has anxiety. She sometimes had moments where she got really overwhelmed and I would have to deal with that and try to get her to eat something. I remember once then running to a speaking exam. It was quite intense in that I did not really have that break, and my mind was always wandering.

I have been lucky. I have been able to go to university, but a lot of young carers who I know in youth groups either have not gone, in order to be eligible to still claim carer's allowance, or have gone and dropped out, or have stayed very local. I would say that that is much more of a common picture.

**Q219 Josh Fenton-Glynn:** Jayne, you talked a bit about how it impacts your ability to work. I assume that there is a bit of a read-across to the impact on the rest of your life.



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**Jayne Simpson:** Yes, very much so. Before I go on to say a bit more about how it impacts me, I do want to say that it was a difficult decision to come here and talk about the impact on me, because that also then impacts on my daughter. She already has a sense, as a person with a disability, of perhaps being a burden and being unequal to others in life, and it is very difficult to talk about the impact on me without passing on guilt to her. It is a really difficult thing as a carer to have to talk about that impact on your life and the effect that that has on your family.

I would say that it has wide-ranging effects. In terms of health, I would say that caring has got much harder in the last few years, with much less support out there. Services are just broken, which is having a major impact.

Mentally, it is not just the strain of caring for the person and the worry of keeping them safe and well and keeping that going; it is also the mental strain of doing battle every day to get the help you need from whatever service it might be. That has a real psychological impact. Life can feel extremely negative, given that so many conversations every day are about difficult things, not getting what you need and perhaps feeling that you are being too demanding. That is quite hard.

I have already talked about work and finance, which have a massive impact. It has an effect on relationships with other family members. We have two other daughters. It is about trying to find time, so that you give equal time, which can be really hard when you have someone in the family who has quite high needs.

You find that friendships drop off when you cannot leave the house or when you cannot be reliable about making arrangements. You cannot go along and feel free to just talk about the things that you have been doing; you feel that people do not want to keep hearing about your caring role. That has a real impact on maintaining friendships and relationships generally.

**Q220 Josh Fenton-Glynn:** I hear what you say about not wanting your daughter to see the negative side. I am sure that you would, conversely, say that spending time with and supporting people who you love is a privilege. We should understand that, but the job of society is to balance that and to make it easier and possible, which is one of the things that we are looking at today.

You talked about the mental strain. Do you find it easy to look after yourself and your own health? One of the things that came up when we had Skills for Care and a few other organisations here was that they said that carers at home will often miss their medical appointments and not look after their own health and wellbeing. Do you find that you sometimes fall into that?

**Jayne Simpson:** Yes, absolutely. I would say that my health comes very much at the bottom of the list. When you are a carer, your focus is



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absolutely on that person you care for, particularly if they have high needs. There is not time. If you have spent hours trying to get through to a GP surgery, trying to arrange a hospital appointment or trying to arrange social care, you do not have time to then do that for yourself, so you tend to leave that at the bottom of the list and think, "I will be okay for another day. I will leave that," but of course that accumulates and you are going to end up with a problem. I would absolutely say that it has affected my health and my ability to look after my health and plan for good health for the future. You cannot do that.

**Q221 Chair:** Holly and Keyaan, do you have anything to add on the impact side? Keyaan, you are the lead student young carer at the Swan school. Tell me a bit about that.

**Keyaan:** I help to organise events and trips. At the moment, we are looking at getting Anneliese Dodds down to the Swan so that we can talk and see what she can do to help young carers in schools. I help make young carers' lives at school much more fun within the time that we get. We get 40 minutes on a Tuesday and a Thursday. On a Tuesday, we have a homework club, where we do 40 minutes of homework. Amir Steve Ali, who is a politician from Oxfordshire, came and spoke to us about what he does and what he could do to help young carers. On a Thursday, we get free play and stuff, basically.

**Q222 Chair:** Holly, when you were at school, what was your experience of support for young carers?

**Holly:** I was really lucky. I grew up in Cambridgeshire. Centre 33 supports young carers in Cambridgeshire and Peterborough, and they ran a group in the school. I was identified through them doing an assembly in my school. Again, it is probably important to stress that my experience of having so much support—I was offered a transition assessment and everything like that—is very rare. On average, young carers are waiting for three years to access support. You even hear of some waiting for more than 10 years, and that is presuming that they know that they are a young carer in the first place.

I have been very lucky, and that support made a real difference to me, especially when I was considering and applying to university. I felt a lot of guilt, and it coincided with a period when my sister's health was very unstable. Having that one-to-one support and someone outside the family setting who I was able to talk to, to express these quite complex feelings of guilt and feeling very selfish for wanting to go away, was ultimately what propelled me on to university. I just wanted to stress that my support and having so much is not common across young carers.

**Q223 Paulette Hamilton:** Thank you all for coming today. My first question is for Holly and Keyaan. Jayne mentioned that her daughter receives 14 hours of local authority care each week. Holly, do you know how much local authority care your sister receives each week?



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**Holly:** She currently receives 10 hours. In future years, that might change. My mum is in the same position as Jayne as a parent carer and is filling in a lot more hours than the 10 that are provided. My sister wants to be as independent as possible, so it is about doing it in a very respectful way, where she does not feel that she is being cared for as such. She currently receives 10 hours, but my mum also does a lot.

Q224 **Paulette Hamilton:** Keyaan, both your mum and a sibling live with additional needs. Do they receive any local authority support?

**Keyaan:** I am not sure.

Q225 **Paulette Hamilton:** My next question follows on quite easily. I was a cabinet member for adult social care for seven years. How difficult was it, Jayne, to receive the care that you have received? If you want to access additional care because you want to go away or do anything, how difficult or easy is it?

**Jayne Simpson:** It is extremely difficult. In our case, the funding has not been the issue. We have been funded for a lot of care over recent years. Our daughter was previously in a residential home and then in supported living, both of which broke down because of the poor service that both provided, again through recruitment and retention issues. We had so many staff coming and going with our daughter that it caused her huge anxiety and made things worse rather than better, hence her now being back at home with us, because it was felt that that would be better for her than the care that was originally being provided.

The difficulty is that I feel like I am managing that package of care. It is provided and paid for by the local authority, but there is no accountability. No one is checking if people turn up, or the quality of that care. I feel that, when it goes wrong, it is on my shoulders to sort that out and then take the consequences when my daughter is further damaged by poor care.

Q226 **Paulette Hamilton:** What care does your daughter receive? What does she actually get?

**Jayne Simpson:** Her support is really to help her go out into the community and have, if you like, a meaningful life. She does not need personal care, but she needs care to access the world. Her autism means that communication is a difficult area for her. She has severe social anxiety, so she is very isolated at home. The support is to provide that link with the world and to just give her some purpose in her life, but it is hard to get it right. I do not think that we have yet. We keep trying. We have some brilliant staff who come, but they then leave because they do not feel able to stay in social care.

Q227 **Paulette Hamilton:** Keyaan, you may not be able to answer this. I know that you do not know how many hours the family gets, but what sort of support do you get at home from the external services that come in?



**Keyaan:** I don't know.

Q228 **Paulette Hamilton:** Holly, what about you?

**Holly:** It is mainly the 10 hours. Ironically, my mum, as a parent carer, is too busy to access support for herself, which is probably quite common.

Q229 **Paulette Hamilton:** This question is more for Jayne, so I hope that you guys do not mind. Following on from yesterday's announcements and the reforms coming through to PIP payments, what do you understand it to mean? How are you feeling at the moment, as a mum who is looking after a young person with additional needs? How do you feel about the reforms?

**Jayne Simpson:** I feel very scared about the reforms. I do not feel positive about them. I found it quite distressing to hear the news yesterday and to wake up to it this morning, and to feel that it is just another layer added on to all the stresses of caring and all the worries about my daughter's future.

I am particularly concerned. My daughter gets PIP; I get carer's allowance. As we know, they are linked. If my daughter does not get PIP, will I stop getting carer's allowance? Does that mean that I have to go and get more work? How do I then care for her? I am really very uncomfortable. I would have liked to hear some more positive news about how we would support people not to need those benefits first, before I heard that those benefits were possibly going to be cut.

I do not know which category my daughter will fit into. Will she be seen as someone with a very long-term disability who may not have to keep reapplying, or as an autistic person who has the potential to do more in life? I feel that she does have the potential, but the support that we get at the moment does not allow for that potential to be utilised. I am really very anxious about it. It is just something else that is leaving my mental health affected.

Q230 **Paulette Hamilton:** Holly, would you like to say anything regarding what is going on with the reforms at the moment, especially around PIP?

**Holly:** I really echo everything that Jayne said. I had a conversation with my mum over the phone last night about it, and what this might mean five or 10 years down the line when my sister is a fully-fledged adult. It really worried me as well. It is just a lot of unknowns. I worry that, as Jayne said, instead of people being supported not to need those benefits in the first place, they are just being reduced before step one has happened, but it is too early to say.

Q231 **Paulette Hamilton:** My last question is to Keyaan and Holly. Although you offer a lot of support to your family, where do you get your support from? Where are your support mechanisms?





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**Holly:** Like I said, Centre 33 supported me a lot growing up. I will let Keyaan talk about Be Free Young Carers, who are great. They offered me one-to-one support. I had free counselling through them. I went on trips, activities and things like that; I learned to ice skate with them. It was really positive.

Now, I am supported a lot by Carers Trust and I do youth groups and things like that. It is such a postcode lottery, though. Be Free Young Carers, for example, does not receive any local authority support. It really does vary from place to place. I was on a youth group with young carers yesterday, and there were some in Blackpool who were telling me that they wait years to get support in the first place. When they get it it is great, but it is really hard to access.

Q232 **Paulette Hamilton:** Should local authorities be offering more support than they are?

**Holly:** Yes, 100%. They have a duty to offer young carers' assessments and transition assessments, but the reality is that that does not always happen. Young carers do not know that they have the right to ask for that. Even if the assessment happens, it does not necessarily then lead to support. It is not a guarantee. That is something that I would really like to see change.

Q233 **Chair:** Keyaan, tell us a bit more about Be Free Young Carers. How often do you go to them? When did you meet them?

**Paulette Hamilton:** Also, why did you start going?

**Keyaan:** I heard about them last year through my school and the young carers' group, when Lorraine came over to the Swan. She has been coming quite regularly on a Thursday for our hangouts. She told us about Be Free Young Carers, so I and one of our counsellors at school signed up for it. She then came visiting to my house and, from there, I have been involved with trips and meeting new friends. I have gone ice skating, to Thorpe Park and stuff like that.

Q234 **Jen Craft:** I just wanted to pick up on something that you said, Jayne, which is that you are concerned that every day feels very negative and that you never want your daughter to feel like she is a burden. I would just like to offer you all the opportunity to tell us something about the people who you care for before the Chair wraps this session up. What do you like about them? Why are they a fantastic person?

**Jayne Simpson:** My daughter is really brave. She has been through an awful lot as a result of her autism and a lack of really good understanding and good care. She has had some dreadful hospital admissions in places that she really should not be, but that she went to because there was a lack of support in the community. She keeps going. Life is really tough for her. She is anxious about everything. The outside world is really scary to her, but she keeps going and she keeps having hope that she will one day have the life that she wants to have.



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She really cares about us as a family as well—she really does, although with autism it can be difficult. We think that people do not empathise. Sometimes, they over-empathise, and she really cares about us as a family and will do whatever she can to make things better for us. She has lots of talents, and I just wish that we had the support in order for those talents to be used and for her to be a full part of the community and society.

**Holly:** My sister has a wicked sense of humour. Sometimes, when I am sight-guiding her, I pay so much attention to her that I end up being the one who steps in all the dog poo and stuff, and she does like to remind me about that on a regular basis.

**Keyaan:** My brother is very humorous and a very funny person. He likes to make everyone laugh and have a good time.

Q235 **Chair:** That was a lovely question—thank you, Jen. Keyaan, what do you want to be when you grow up?

**Keyaan:** A politician.

**Chair:** You clearly have the bravery. You should do it, absolutely. Why do you want to be a politician?

**Keyaan:** During covid, the news was on all the time. Boris Johnson was the Prime Minister then, and when I was listening to it, I heard a lot about covid and about staying home and staying safe. From there, I got really into politics and listening to all of it, and then the general elections and the council polls and stuff. I got really into it.

Q236 **Chair:** That is fantastic. Holly, what are you studying at university?

**Holly:** French and linguistics.

**Chair:** What do you want to do with that?

**Holly:** I don't know. It could be something to do with charity sector policy. We'll see what the job market looks like next year.

Q237 **Chair:** Holly, you mentioned that you think that caring will feature continually in your life, but it is not stopping you from doing stuff either. Do you think about how you are going to fit everything in as you get older?

**Holly:** Yes. I do worry about it a bit. I had work experience in your office, and then had to pull out early due to a caring situation. I just do not know, because it is so unpredictable. I really hope that everything will be fine, but you just do not know. Things could take a turn for the worse. We will have to see, but yes, fingers crossed.

Q238 **Chair:** Keyaan, do you think about how family and your ambitions are going to fit together?

**Keyaan:** Yes, sometimes.



**Chair:** What do you think about it?

**Keyaan:** If I am being honest, I am not too sure.

Q239 **Chair:** Keep dreaming and keep going. Jayne, in terms of the prospects for the future, is there a version of the world where your daughter gets more independence, or do you just see it as this being your role? Tell me about your future.

**Jayne Simpson:** I stay hopeful. We have a really good opportunity to create a brilliant social care service. I would like to see it have parity with the NHS. I would like to see it and the staff valued in the same way that we perhaps value those who work in the NHS. We value them for saving lives; we value social care less for giving people lives that they want to live, but that is just as important.

Yes, I do have hope, but this is the moment when we really have to do something about this. As I said earlier, we have some brilliant staff who come and support our daughter, and I want those people to really want to stay in social care, not to have to say, "But I can't afford to, so I am going to have to go and get a job at the local supermarket." People feel that they have to move on in order to get a profession that is not available in social care. We do not see it as a profession; we see it as unskilled.

We really need to look at reframing social care and how people feel about it. It is a lifelong service, from the very young who need it all through their lives, up to much older people. We just need to up that image of it and its value, and then my daughter might stand the chance of having the life that she wants to live.

Q240 **Chair:** You pre-empted my question in terms of recommendations. What needs to change? What needs to be better in the system? Holly, if you could wave a magic wand, which I do not have, what would be helpful to you?

**Holly:** I will try to be brief. There are two things. First of all, transitions need to be a lot better supported. So many young carers drop out of university or are not able to work. In the youth group yesterday, there was a young carer, Eloise, who said something really good that I scribbled down: "When you are a young adult carer, you don't really get to enjoy being a kid, but you can't really get to be an adult either. You are left in this grey area." That really rang true. You cannot really access university and employment in the same way.

Transitions are one area where a lot more support is needed, as well as the responsibility of adult social care services in general to identify young carers. Inevitably, they are going to be interacting with young carers, whether that is through hospital appointments or anything, really.

Q241 **Chair:** How and where would we best do that—in schools?



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**Holly:** It already happens in schools, although in the last school census, 72% of schools said that they had no carers, which is definitely not true. In hospital and GP settings, if a young person is accompanying a parent who has a lifelong condition to an appointment, for example, they probably are going to be carrying out some sort of caring responsibility. In those sorts of settings where external support is being provided to a family, it is just about looking at the wider picture and thinking, “Who else is providing support here too?”

Q242 **Chair:** Keyaan, is there anything about the system that you would change if you had a magic wand?

**Keyaan:** I am not sure.

Q243 **Chair:** I will just offer one last word from you. You have a room full of cross-party politicians wanting to help. Is there anything that any of you feel you did not manage to get across today that you would like to make sure that we know, before we move on to the next panel? Jayne, do you have any last words?

**Jayne Simpson:** Yes. I just want to get across that I want a service that I can really trust, so that I can have a life too, and have choices, without guilt, but be able to trust that that service really does give my daughter the best, not a service that I feel unsafe with or one that just seems to be a bit of a mess. I do not want to keep hearing carers saying, “But what is going to happen when we are not here? Nobody else can care for my loved one like I can.” We do not want to keep hearing that. We want to have people all having lives that thrive, and normal relationships, not relationships that struggle because of that whole caring dynamic.

**Chair:** Keyaan, do you have any last words?

**Keyaan:** No.

**Chair:** What about you, Holly?

**Holly:** I am really grateful for the opportunity. I would also really like to see changes to the carer’s allowance at some point.

Q244 **Chair:** What changes do you want?

**Holly:** Specifically, there is a 21-hour rule. If you are in full-time education, you cannot claim carer’s allowance. There are a lot of people I know in youth groups who are the primary carer and are certainly providing 40 or 50 hours of care and completing university at the same time, and yet they are not eligible for it. That is something that I would really love to see change.

**Chair:** We are very grateful to all three of you for coming and sharing your stories, and to your loved ones for allowing their stories to be told too. Thank you so much for doing that. It is very brave of you. It was really very much our pleasure that you were with us today—thank you so much. We are now going to move on to the second panel, and you are



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very welcome to stay and watch.



## Examination of witness

Witness: Dr Maria Petrillo.

Q245 **Chair:** May I welcome Dr Maria Petrillo? You are going to be presenting to us “Estimating the Cost of Informal Care with a Novel Two-Stage Approach to Individual Synthetic Control”. Maria, over to you.

**Dr Petrillo:** Thank you so much for having me today. I have been asked to present this paper, which is a joint effort with colleagues at the ESRC Centre for Care based in the universities of Sheffield, Oxford and Birmingham.

The aims of this paper are as follows. The first is to understand and give an estimate of the income caregiving penalty in the UK, where we define the caregiving income penalty as the reduction in income as a result of the uptake of unpaid care responsibilities.

The second is to investigate the relationship between the magnitude of this income penalty and the intensity of care provided, which is measured in terms of hours of care provided every week.

The third is to understand a bit about the diversity of this caregiving income penalty. In particular, we want to understand how it varies by age, sex, ethnicity and so on.

To do so, this might sound scary, but we developed this methodological approach, which is a new approach to the individual synthetic control that improves the accuracy in the estimation, and which I am going to explain in simple words in a few slides.

You already know this, but according to the latest census, millions of people in the UK provide unpaid care every single day. The care that they provide is worth an estimated £184 billion, which, to contextualise, is equivalent to the combined NHS budget across the four nations. The literature has been uncovering the triple penalty that they face to financial, relationship, and physical and mental health wellbeing. In this presentation, we will focus on the financial wellbeing aspect.

Balancing paid work with caring responsibilities often leads to reduced productivity and declining work performance. Because the nature of unpaid care is so unpredictable, it cannot really be combined with fixed work schedules. Flexible work schedules are very hard to secure, so unpaid carers need to decide between a decrease in their working hours and leaving work entirely.

If this is not enough of a motivation to care about this reality that is affecting millions of people, we can look at it from the macro perspective. There are a few recent estimates from the ONS showing that the population aged 85-plus is predicted to double by 2045, while the working-age population will increase by only 5% and then flatline until 2035.



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This raises two main concerns. The first is that there will be increased pressure on the social care system and on unpaid carers. The second can be looked at from the point of view of labour supply. We will see an increase in people aged 85-plus, meaning that demand for care is going to increase and that many people will face a choice between remaining in paid work or leaving to provide unpaid care. Hence, we will have a shrink in our labour supply at a macro level.

This individual synthetic control is a new approach. Let me explain methodologically the main issue when we want to estimate this penalty. The main challenge is that in order to estimate the penalty, we want to know what would have happened to unpaid carers had they not taken on unpaid care responsibilities. This alternate universe is impossible to observe. We know only that unpaid carers provide unpaid care. If we compare unpaid carers with those who do not provide unpaid care, we are comparing apples and bananas: it is completely different.

What we can do is synthetically construct this universe. We call them doppelgängers. Doppelgängers exactly mimic unpaid carers; the only difference is that they never take up unpaid care responsibility, hence we can track them over time and follow the income trajectories. If there is a change, we know that this is due to unpaid care responsibilities. We can see the doppelgänger as a customised control group allowing for a more accurate comparison and a better estimate of the caregiving income penalty.

To do this analysis, we relied on this dataset, which is called the UK household longitudinal study. This is a national representative survey that follows individuals and households over time in the UK. We are able to track them down, follow their income stream and try to understand what happens over time. Most importantly, these data have two precious pieces of information: the first enables us to investigate their care status, and the second the intensity of care provided.

We are able to identify our treatment group, which is unpaid carers, and we divide this treatment group into four sub-samples: high intensity, those carers providing more than 50 hours of care per week; medium-high intensity, between 20 and 49 hours per week; medium-low intensity, between five and 19 hours per week; and low intensity, up to five hours per week. We then have a control group of those who do not provide unpaid care responsibility for the entire span of our data.

We want to measure the caregiving income penalty. Income can have different definitions. A caregiving income penalty can be defined in lots of ways. We focus on individual and household monthly income, and income share—how much I contribute with my individual income versus the household income. In order to compare like for like, we adjust the model for some control variables. We control for background characteristics, education level and ethnicity.



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This is just a graph showing the data as they are. Before we do any adjustment and run our model, this is what we call raw data. On the horizontal axis, we have age; on the vertical axis, we have individual monthly income. We then have different shapes that describe what we call the age-income relationship. Those shapes have different colours according to the intensity of care provided. The control group is the shape in black.

We want to compare this with what happens for unpaid carers. For example, let us do the comparison with the red line, which is 50-plus hours. You can see that those people earn less for every single age considered. The incomes are lower than our black control line, for every single age, and especially for those of working age.

This is just a table to provide a bit of a flavour of how different those categories of people are. We have low intensity, medium-low intensity, medium-high intensity, high intensity and then control. Let us focus, for example, on employment. You can see that the higher the intensity of care provided, the lower the likelihood is of being employed. The likelihood of being employed for a low-intensity carer is 56%, but that goes down to 23% for high-intensity carers.

Let us look at income share. Low-intensity carers, who care for up to five hours, contribute 26% to the household income. This goes down to not even 9% for high-intensity. Let us look at males, for example: the high-intensity subgroup is characterised by only 36% being males, while 64% are women.

Let me give you straightaway the headlines from our findings. High-intensity carers lose almost £200 a month in the fourth year after taking on unpaid care responsibilities. I am going to show you how, and how to read this graph.

On the horizontal line, we have the treatment time; on the vertical line, we have the individual monthly income. The red dashed line that goes to year zero signals the onset of unpaid care responsibilities. In that very moment, in year zero, unpaid carers start to provide care for the very first time.

On the left side you can see blue bars and blue markers, which let us know the difference between individual income for unpaid carers and for their doppelgängers—those people who look similar and do not provide care. As you can see, those bars always touch zero. This means that there is no statistically significant difference between the income of unpaid carers and of their doppelgängers—the ones not providing care—prior to the uptake of unpaid care responsibilities.

Now, you can appreciate how much the situation changes after year zero. There is a sharp decline in income for unpaid carers compared with their doppelgänger: two years after taking on unpaid care responsibilities, they are already losing £166 per month. You can see the marker on the line.





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In year four, it is £192 per month, which is an incredible amount of money for an individual income.

The graph before was about high-intensity carers providing care for more than 50 hours, but we investigated what happens when we consider different caring intensities. We have high intensity in the top left of the graph; medium-high intensity in the top right; medium-low intensity in the bottom left; and then low-intensity. The intensity of care does not matter. Prior to year zero, there is no difference in income between unpaid carers and their doppelgängers. Once they take up unpaid care responsibilities, they all face a caregiving income penalty. I will summarise the percentage in just a few slides.

I want to show you now what happens to the income share and how much individual incomes contribute to household incomes. For the sake of time, let us focus only on the high intensity, which is the first graph on the left. What you can see is that the percentage contributed to household income declines by 4.8% in the second year and by 4.9% in year four.

This has an impact on household income as well. Let us focus on the first graph. You can see that the first three red bars touch zero. Why? We can speculate about that, but we think that when a person in a household becomes an unpaid carer, they start to activate a compensating mechanism in which they redistribute financial responsibilities. They adjust their expenditure and try to modify their approach—but then, as you can see, after a few years this compensating mechanism does not work any more. Households face a penalty in year five of £400 per month, which is an extraordinary amount of money.

You can see, on the individual income column, a percentage for the penalty. This penalty is 45% for high-intensity carers, going down to 22% for medium-high intensity, 13% for medium-low intensity, and 4% for low intensity. We have a penalty in any scenario, but the magnitude of the penalty depends on the intensity of care provided—in this case, on the weekly hours of care provided.

As I said, we tried to explore the diversity of unpaid carers by sex, for example. This is another headline feature. The financial impact of caring is higher for women than men.

Due to data limitations, we are not able to slice the data, as we did before, into the four categories of high, medium-high, medium-low and low-intensity care. We can only divide the data in this case while investigating sex in high intensity and low intensity. In this very case, high intensity is 20 or more hours, and low intensity fewer than 20 hours. I would be very happy to come back to this graph, but I will go directly to the table on the next slide.

Here you will see that women face a penalty for high-intensity care—in this context, 20-plus hours—of 30%, compared with 25% for men. This is



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the most significant result that, at least while doing research, I was really impacted by: young carers face the most substantial income reduction, with the penalty reaching £502 per month when compared to their doppelgänger.

Again, I am not going to focus on this graph. You can read it in the same way as we did before. I would be very happy to go over it afterwards. We divided the sample that we have into three main groups: young carers, aged 25 and below; working-age carers, aged 25 to 64; and carers aged over 65.

To summarise, the financial penalty for young carers is 181%. This goes to 70% for those aged 25 to 64. Let us not consider those aged over 65, because, unfortunately, the income variable that we use depends mainly on labour market incomes, so what we have there is really an approximation.

We had three research questions. First, is there a caregiving intensity? There is. We can see a shift occurring after taking on unpaid care responsibilities.

Secondly, is there a relationship between hours of care provided and the magnitude of the caregiving income penalty? Yes, there is. High-intensity carers are the most impacted by providing unpaid care.

Thirdly, does the magnitude of the caregiving income penalty vary by sex, age or ethnicity? I did not have the time to show ethnicity, but I would be very happy to share that with you later. Yes, there is a difference. Women face the hardest penalty compared with men, and young carers face the most substantial income reduction, at 181%.

**Chair:** Thank you. To summarise all of that in the time that you had was genuinely impressive.

Q246 **Dr Cooper:** Thank you so much. That was really interesting. I have just a couple of areas of clarification. The result that you said you found the most surprising related to young carers' substantial income reduction. When you were running your models, did you have cause to look at why that might be? I realise that you were modelling, but was there additional information that gave you an understanding of why that is coming out as it is?

**Dr Petrillo:** What shocked me was the £502. I knew that they were facing a penalty, but not to this extent. If I had to speculate on the result, we can really understand why, because they face the highest opportunity cost. Those are the people who, instead of dedicating their time to education and training and to building up work experience, provide unpaid care. This affects them not only in the short term but in the long run, so they will always have less education and less work experience than young people who can invest in education instead.

Q247 **Dr Cooper:** Just for my understanding, when you say "substantial



income reduction”, are you calculating their future earnings potential or are you looking at it in terms of education? How are you calculating that?

**Dr Petrillo:** The percentage that you see is the ratio between the average loss in the five or six years that we follow and the pre-treatment income. We can contextualise in terms of how much they were earning even before, and have a relative penalty. If you do not want to see the relative penalty, you can check the numbers directly and see that in year three or four they face a loss of £500. That is the average. I am referring just to opportunity cost, because I am speculating about what can happen. What can happen is that they are not investing in anything other than unpaid care. We are considering 20 more hours of care. How can they combine education, training and work experience, as the doppelgänger does?

**Dr Cooper:** So it is opportunity costs that you are looking at.

**Dr Petrillo:** Yes.

Q248 **Dr Cooper:** That is clearer—thank you. When you are looking at the substantial reduction for women, are you also controlling for things like previous maternity leave, or leave taken for other reasons, and other issues that impact women’s lives more?

**Dr Petrillo:** No, we are not controlling for that, because unfortunately we have limitations due to data. We try our best and try to find the closest doppelgänger. For example, we control for family size, which gives us a hint as to whether there is a child and previous maternity leave. We always compare the individual to the closest doppelgänger. We are comparing two people who are as close to each other as statistically possible. We are not comparing different people.

Q249 **Dr Cooper:** You are looking for averages and then statistically comparing them. I appreciate that you have looked at this data, and I am not expecting you to design policy here and now, but based on the conclusions that you have come to, what should the Government learn from this research in relation to the reforms that they should be looking at?

**Dr Petrillo:** I am not a policy expert, but I will try my best.

The main result here is that there is a caregiving income penalty. We are investigating further, with our next paper, to understand what the driving force is. If you think about it, when we take into consideration the caregiving income penalty, our variable income takes into consideration labour market incomes. We can speculate and say that the driving force is a reduction in working hours, a change in occupation or leaving the labour market.

The most straightforward thing to say is that we need policies that help unpaid carers to combine paid work with caregiving responsibilities. For example, flexible work arrangements, working from home, paid care



leave, which you already know about, a robust support system or targeted financial measures. The lady here before mentioned the criteria for the carer's allowance. It is unbelievable that there is a limit for people who are in education. This affects young carers so much.

Another conclusion is that because it is so diverse, we really need a targeted policy. We need to take into consideration the fact that people face these penalties differently and think about, for example, policies that can help identify young carers immediately, support them into education and employment and try to limit the short-run problems that they face.

**Q250 Dr Cooper:** That sounds completely sensible to me. As you say, in terms of the data back-up, we might say that it is obvious, but these data make it incredibly clear.

In your appendix, as you mentioned, there is the ethnicity comparator. I know that you did not go into detail in your presentation, but is there anything significant that you want to highlight about the ethnicity comparator?

**Dr Petrillo:** What is significant here is that we need to investigate more, because I am a bit ashamed of the classification that we were able to do because of the data. We divide only into whites and non-whites, and we are losing out so much variability here in what is not a good distinction, but we wanted to give a bit of a flavour of what could happen.

What we see here is that whites face the biggest penalty, but the explanation is that those we categorise as white have higher income prior to treatment, which is quite expected. That is why I did not show it, but this is something that we are investigating further, 100%.

**Q251 Dr Cooper:** That is really useful. It sounds like there is a whole lot more research to it.

**Dr Petrillo:** On ethnicity, yes, absolutely.

**Q252 Danny Beales:** You have made my head hurt slightly with the amount of data and graphics. I very much hated SPSS and statistics at university. It is giving me flashbacks to my university degree; trying to interpret data gives me nightmares.

It is really interesting data, as my colleague said. Just looking at the gender-based differences on slide 19, my reading is that you are saying that relatively, compared to the relative level of income, the percentage is greater for women, but because men's average incomes are higher, the real-terms impact is still higher on men. You are projecting that the relative value of income loss is greater. Is that right?

**Dr Petrillo:** I did not mention the value itself. We can check it out on the graph. If we look at this slide, female high-intensity carers are on graph A and male high-intensity carers are on graph B. They are on the left and right. For example, in year two, women face a £100 penalty. The highest penalty they face is £180 in year six. For men, the penalty in year three



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is £100. The greatest penalty they face is £200. It is more or less the same, but it hits women harder.

Q253 **Danny Beales:** It hits harder as a relative percentage because of the total level of income. On your previous slide, you have average loss as £121 versus £137 on the high-intensity group. The post-treatment average loss is £121 versus £137.

**Dr Petrillo:** Yes.

Q254 **Danny Beales:** Relatively, there is a higher level of loss. Relative to income, it is a greater percentage. That is what your data is suggesting. It is about the relative levels compared with previous income.

**Dr Petrillo:** Yes. What you see post treatment is the average of all the numbers in that line.

Q255 **Danny Beales:** Building on my colleague's question, I appreciate that you cannot make policy recommendations, but it seems to me that there is a case being made that, as you said, care work does not affect everyone equally. You could make the case that there is slightly higher income loss for men than women, although the relative impact on women is a higher percentage of their income. Carer's allowance is a flat benefit. You could argue, from your data, that it would be better to target higher levels of intervention on certain groups that face a relatively higher level of payment.

**Dr Petrillo:** Just to be clear, the relative penalty is already computed. It is as it is. It is not hitting men harder.

Q256 **Danny Beales:** Maybe I am interpreting the data wrong, but I read that the post-treatment average loss is £137 in the high group for men and £121 for women, and £137 is a higher loss than £121.

**Dr Petrillo:** Yes, but that is in absolute terms. You want to see the penalty.

Q257 **Danny Beales:** My point was that in income terms it is a greater loss, but as a percentage of the starting income, which is lower for women, it is greater.

**Dr Petrillo:** Yes. There is a lot of literature explaining why this is also happening. We did not investigate it in this paper, but many previous papers acknowledge that pre-treatment income is lower for women for a reason. It is because of social norms and—

Q258 **Danny Beales:** Yes, that is the nature of the gender pay difference. I am trying to get to a different point. At the moment we have a carer's allowance system, which is at a flat level. From your data about gender—and potentially ethnicity, but more work is needed on that—there might be a basis for targeting higher support at certain groups that face relatively higher penalties. Is that fair to say?



**Dr Petrillo:** Yes, it is fair to say, but what women will really benefit from is help to remain in employment. It is not really about the flat rate. I cannot really speculate on that; it is not in my experience. What I can see from the literature and the data is that this happens especially because women are those who have to combine more unpaid care.

If you think about it, yes, the penalty is 30% against 25%, but 64% of women are providing high-intensity care. We need to target women a little bit just because they are already receiving more of this high penalty than anyone else.

Q259 **Danny Beales:** Yes, that is very helpful. Similarly, you point to a five-year cliff-edge point or five-year penalty. Initially there is household adaptation, which potentially causes a relatively less loss, but at that five-year point there is a cliff edge where there is suddenly a significant increase.

**Dr Petrillo:** Can we go back to the household income slide so we can contextualise a little bit better? I did not say that there is a change in year five; I only read the highest penalty that happens in year five, which is £400. I cannot speculate on when this happens and when there is this threshold effect.

What we can see from our data is that in the first few years people try to compensate, but then something happens. They cannot handle the situation financially any more, and there is a drop. I only read out the highest penalty they face in year five. I cannot say, "This is the point at which something happens."

Q260 **Danny Beales:** That is helpful. You have controlled for a doppelgänger. Have you done any international comparisons?

**Dr Petrillo:** That is our plan for the future.

Q261 **Danny Beales:** It would be very helpful to understand international comparisons. Would you also be able to do a doppelgänger analysis for other forms of unpaid work? In particular, would you be able to control for childcare, which is significantly unpaid, and the relative impact on someone providing unpaid childcare?

**Dr Petrillo:** Yes. I am working on a paper on childcare, which does exactly the same estimation. In terms of international comparison, my colleague and I are putting forward a bid to win a grant on this. We want to compare the policies that have been adopted in other countries to see what works, what does not, where the UK positions itself in terms of its economy and care regime, and what can be adopted in the UK. We want to do a cost-benefit analysis of those policies. This is in our plans.

**Danny Beales:** That is exactly the thing that we were hoping to glean from this session, but that sounds very helpful. I hope your bid will be successful.



**Dr Petrillo:** Me too.

Q262 **Danny Beales:** It sounds very useful. Just to clarify something that my colleague mentioned, this is purely projected income loss; you are not taking into account the impact on pensions or the impact on broader benefits and welfare, both positively and negatively, for these individuals.

**Dr Petrillo:** I am laughing because you are basically reading my bid at the moment. This is what we are trying to write.

There are three things that my colleague and I want to focus on next. First, we want to understand the driving force behind this, whether it is working hours, level of employment or change in occupation by age, job type, category and everything else. Secondly, we want to do an international comparison and try to see which policies work and which do not. Thirdly, we want to understand the long-run effect. As you mentioned, we want to understand the pension problem and the assets problem. The long-run problems are known to be very gendered.

Q263 **Danny Beales:** As a Committee, we have been conscious that the potential audience for our report would be the Treasury rather than the Department of Health. It is making cost-benefit analyses of a series of interventions for a series of population groups. We know what the relative income loss is for people, but we do not necessarily know what the impact on the Treasury is from lost taxation from that lost income versus the potential benefits from the cost of paid care or other financial support, if that intervention were needed. It sounds like your bid would be very helpful.

**Dr Petrillo:** Yes, it will be a cost-benefit analysis to see who benefits, who does not and how we could implement this.

Q264 **Danny Beales:** I am sure my colleagues want to come in, but lastly, in terms of the spread of intensity, is it fair to say there is a sweet spot around the zero-to-20-hours level of care that mitigates—

**Dr Petrillo:** Do you want to refer to some graphs?

**Danny Beales:** It probably is helpful for my understanding to see a picture, to be honest, if there is a relevant graph. From what I was reading in your presentation, no loss is acceptable for a person, but in terms of the significance of the loss, is it fair to say that that zero-to-20-hours level of intensive care is a more manageable level?

**Dr Petrillo:** Yes. I do not know what is manageable or not for people, of course. People are characterised by different income streams. The literature knows that there is a threshold effect at 20 hours of care; many papers have confirmed that already. From 20 hours, people really start to struggle financially. We have confirmed that. Even in the shape of the graph that I presented before, you can see that. Yes, this is raw data—this data has not been cleaned. You can see that the big change is in the green and red lines, and a little bit in the yellow line. In the green and



red lines, you can see a sharp decrease in the curvature. Yes, what you are saying and claiming is right.

**Danny Beales:** Thank you very much. That is really helpful work. Good luck with your bid. I am happy to write a letter of support, personally.

Q265 **Chair:** Can we go back to that last slide? Can I just ask about the uncertainties in the data? I am quite struck. For medium-high intensity, if you take the uncertainties into account, one might argue that there is no change.

**Dr Petrillo:** We justify this in the paper. It is not that there is no change; it is that there is a lot of noise in the data.

Q266 **Chair:** Why is there more noise in that group than in other groups?

**Dr Petrillo:** I will explain that. Low intensity is zero to five hours. Then we have five to 19; then we have 20 to 49. That is a big portion of people. Unfortunately, the way in which the data was collected does not help us to disentangle and stratify this category more, hence the problem. We think too many individuals are providing a wide range of hours of care, hence the noise.

Q267 **Joe Robertson:** Without us somehow explaining some of this—I appreciate this was not the purpose of your paper—it is going to be hard to make arguments to Treasury or Government as to the reasons for some of these things. A lot of your answers seem to be unexpected: I was sitting there thinking, “Really?”

Young people aged 25 and below have the biggest financial penalty from a caring role. Have you taken into account the household situation in which those people exist? I do not know—I am speculating—but it could be that if you are aged under 25, other earners in the household may be earning significantly more money than you could. If you take on a caring role at that age, you might simply not enter the workplace at all, but you can only do that because you are living with your parents. That could be an explanation of why that penalty is so high at a younger age. It could be that too many people simply do not enter the workforce at that age because of a caring role.

**Dr Petrillo:** Yes, this is exactly the explanation as well. They cannot enter the workforce. This is a big problem.

In our estimation, we try to compare these unpaid carers with their doppelgängers. We try to account for all possible characteristics that are available in the data. We control for household size, as I said, which should somewhat take into consideration this aspect of how many adults are in the household. For example, if the unpaid carer is in a two-person household with another adult, we compare that with a doppelgänger in a household of only two people. We average out the effect for every single combination and every single treatment, untreated and treated with the doppelgänger. We average that out, and this is the total effect.





I did not investigate what happens next; that is going to be for a future paper. We can only speculate. As I said, if they are losing out so much compared with a person who is completely the same in terms of household size, gender, education and everything else, the only thing missing is that they are losing an opportunity. The other person, the doppelgänger, can build up work experience, undertake training or invest in education. This person cannot, hence we see a decrease in the possible income he could have earned if he had not been providing care.

**Q268 Joe Robertson:** It is not necessarily age per se. It is that people under 25 are more likely—only more likely—to be living in a household where there is another higher earner, and possibly two more higher earners. Compared to their doppelgänger under 25, most people probably have more freedom to decide whether or not to work or go into education because they are more likely to be living with their parents than someone in their 50s. That is why you have the difference. It is about the household environment in which under-25-year-olds are more likely to exist, rather than their age per se.

**Dr Petrillo:** I would not be able to answer this question. We did not investigate any further. I am just providing speculation, really.

**Q269 Joe Robertson:** Can I ask about the difference in gender or sex as well? I thought that was quite interesting. A woman who is providing high-intensity care will have a greater financial penalty than a male who is providing high-intensity care. That is correct, is it not? That is what your data shows.

**Dr Petrillo:** The relative penalty for women is greater than the relative penalty for men.

**Q270 Joe Robertson:** That runs against the anecdotal evidence that we heard earlier. There is this idea that, because it is harder to adjust in traditionally male breadwinner jobs, the man often simply does not. The woman is more likely to give up her job or go flexible. Your data runs against that. You are comparing women who are providing high-intensity care and men who are providing high-intensity care. You are forgetting this idea that the responsibility shifts to the woman. The financial penalty for the woman providing high-intensity care will be greater, which suggests that the man has more job flexibility to do the intense work and retain an income. I do not understand how that happens.

**Dr Petrillo:** Again, it is speculation. We did not investigate this further. Women can be hit hard. There is literature out there by my colleagues explaining that women expect to care, and so they self-select occupations that allow them to have a little bit more flexibility. This is an even bigger problem. They are constrained to select some occupations just because they know that they are going to care.

**Q271 Joe Robertson:** Surely the doppelgänger is doing that already. I take it that there could be that sort of gender gap unfairness, where women are almost preparing to be flexible in life, but your doppelgänger is already



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doing that. Your comparison is with a doppelgänger.

**Dr Petrillo:** The doppelgänger is a woman as well, who could think that at some point in the future she will care.

Q272 **Joe Robertson:** Yes, if there is structural unfairness in that—I guess there probably is—your doppelgänger is already doing that.

**Dr Petrillo:** That is all I am saying. There is structural unfairness. That is my whole conclusion.

Q273 **Joe Robertson:** I still do not quite understand why the man who provides high-intensity care is less hit financially, because you would think he is not in a job that says, “Yes, we will keep paying you, and you can do that for 50 hours as well.”

**Dr Petrillo:** The next step is to understand why—whether men have more flexibility in work and whether they can reduce.

Q274 **Joe Robertson:** They still get paid. It would suggest men should be doing a lot more because they seem to be able to retain their income and do high-intensity care. That is what the data is saying. It runs contrary to what we think or see around us.

**Dr Petrillo:** I am not able to answer. I am sorry.

**Joe Robertson:** No, I take that.

**Dr Petrillo:** I can only say what I see here. That is extra speculation, which we want to address. We finalised this paper three months ago. We really did not have the time to investigate this further. I understand your concern and your questions. It is definitely something that we have to look into. I am sorry; I wish I could say more.

Q275 **Josh Fenton-Glynn:** I just want to draw you back to this young carer who is down 181% or £502 a month. That is the starkest statistic. I am perhaps asking you to speculate again, but one of the biggest indicators of having a higher-percentile income in your later life is having it in your early career.

Looking at the data that you have produced, what impact does having caring responsibilities have on a young person’s ability to work, to contribute to the economy and to contribute to the tax base, going back to Danny’s point, throughout their career? I wonder if you think that will in fact become an even greater gap because of their caring responsibilities.

**Dr Petrillo:** Yes, it could be. Again, I am not sure I can answer this question directly, but it is something that is worth investigating. Yes, I wish I had all the answers.

Q276 **Josh Fenton-Glynn:** I appreciate I am asking you to speculate wildly, but I was just caught by the starkness of that. A case that one could make to the Treasury is that supporting young carers is even more vital,



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because otherwise you are setting them up for a career whereby they massively underperform against their earning potential, as it were.

**Dr Petrillo:** I will write down all your concerns and curiosities. I will be the first one to let you know as soon as I discover more.

**Chair:** We will be very interested in all your future work.

**Dr Petrillo:** Thank you.

Q277 **Alex McIntyre:** Just to follow up on one of the questions that my colleague Dr Cooper asked about opportunity cost, we heard from Jayne in the previous session that, as your caring responsibilities intensify, there is naturally a drop-off in your capability to work more hours. That seems to be the logical conclusion from the graphs that you have shown: the high-intensity group are perhaps physically less capable of working. The assumption is that the doppelgängers continue in full-time work for the most part, as the average person would. Have you done any extrapolation to see whether there is a reduction in the wage earned per hour that carers are able to work?

There could be a bias coming in that compounds the opportunity cost. Because you are caring over a period of time, you might not be able to progress into other roles because you are not able to continue with your career. I wonder whether that has an additional cost on top of the impact of not being able to work additional hours.

**Dr Petrillo:** We did not see that. We developed this method in two or three years. We are now ready to apply it to all sorts of research questions. Understanding the impact that we see here is our main objective now. That is what we want to do. We want to understand why there is this decrease. It can be for a million possible reasons. We are going to focus on the employed population. We are going to try to understand the before and after in terms of wages, working hours, shifts in occupation and participation in the labour market. Those are the next steps that we want to consider, but we did not see that.

The doppelgänger exactly mimics the unpaid carers prior to the event. It just shows what would have happened. They are different.

**Chair:** Dr Petrillo, thank you so much for your time. I hope that was not as scary as any viva.



## Examination of witnesses

Witnesses: Caroline Abrahams and Tom Gentry.

Q278 **Chair:** We will now move to our second presentation. Thank you so much, Tom Gentry and Caroline Abrahams, who are going to present to us “The State of Health and Care of Older People in England 2024”, which was commissioned by Age UK. I will hand over to you, Tom.

**Tom Gentry:** Thank you very much for the invitation. Just to briefly introduce myself, I am the joint head of health influencing at Age UK. I oversee a lot of the health and care policy work that we do.

I am one of the co-authors of this report, which is an annual report that we have been doing since around 2015. We look at some of the key metrics around populations and ageing, what the access to social care looks like in the previous year, the levels of unmet need, the impact on NHS services and some of the funding decisions that sit around that. We just take some of the publicly available data and put some of our own analysis and commentary on it.

We always start at the top, to remind people that we are in a very rapidly ageing population at the moment. As you will see from this graph, we project that there will be 4.3 million more people over 50 by 2044. As you will see quite clearly, the groups that are growing the fastest are the oldest groups. The 80-plus group is accelerating at a faster rate than others.

We also know that healthy life expectancy is in decline. This, on one side, is the number of years that you can expect to live in reasonably good health; this is the disability-free life expectancy, which is the number of years you can expect to live without a disability. This graph, going from 2016 to 2022, shows that if you are age 50 you have about 20 years, whether you are male or female, of healthy life expectancy left. On average, you will live for about another 30 to 34 years at 50. Although there has been some covid effect on disability-free life expectancy, there has been a pattern of decline across both those measures for the last 10 years.

The effects are not evenly spread, which again will probably not come as a surprise to people in this room. If you are living in the north-east, you can expect to live far fewer years of healthy disability-free life than those in the south and south-west in particular. Behind this is the fact that people have higher levels of need and poorer outcomes at the end of their life.

Again, this may not really come as a big shock, but as we get older we have more difficulties with the activities of daily living—things like washing, dressing and going to the toilet. The difficulties with these basics of daily life, as you can see from this graph, really accelerate in that 80-plus age group. One in 10 people who are 80-plus have three or



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more difficulties with the activities of daily living. They have self-reported that. A very large proportion overall have at least one.

How is this playing out on systems? This graph is showing the number of new requests for support going back to 2018-19. The thin line at the top is the total number of requests. The blocks at the bottom are the numbers of formal support delivered in response to those requests. The thin lines in those blocks at the bottom are the long-term support ones; the larger ones are generally short-term support.

As you can see, there is a very large gap between those who have requested it and those who receive something after that request. Within that gap, there are a lot of people who get signposted. They are passed on to other services, notably places like local Age UKs, which can provide some extra support services that are not formal. There is certainly a gap between those who need support and those who get it.

We also noted in the report that the waits for those assessments are getting longer. This is using last year's data, because it is from last year's report. One in three of those who have requested a care assessment are waiting six months or more for a response. Again, almost two thirds of councils are having to prioritise the higher-risk ones, such as those where abuse is highlighted, those around hospital discharge in particular and some of those temporary periods of residential care. There are a couple of quotes from people who have said what impact that has had on them.

This plays out in the numbers of people who are receiving formal long-term support from their local authority. This has been in decline since 2017-18. We know that the amount spent on long-term care has been creeping up slightly, but the number of people who are receiving it has been going down, which suggests that there is much more complexity in the system. Fewer people are getting more intense care. That is part of the picture. On the basic equation there, 25,000 fewer people are receiving long-term support. In that same period, the number of people who are over 75 has grown a significant amount: there are 18% more people who are over 75 over that same period. As you can see from those earlier slides, they are the ones who are most likely to need that support, but fewer people are getting it.

This slide is quite a difficult one to read, but it demonstrates some of the variation in capacity in care homes. On one side is total care homes by region, which in itself shows that there is quite a lot of variation between the capacity of care homes across different regions. Both bed capacity and total care homes have been declining similarly over the last five to seven years in every region across the country. Even within that, there is big variation in capacity between regions.

Some of this plays out in how many staff are available to do these things. We know staff vacancy rates have been steadily climbing for the last 10 years. They jumped significantly during the pandemic and have come down slightly since then. Some of that is being filled by workers coming



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from abroad. Across all major social care service providers, there is a very high vacancy rate. Above 10% of all roles in domiciliary care are currently vacant. That is also played out in the turnover rate, which is made up of the people who do not stay in these jobs for a significantly long period. Those turnover rates, again, have been climbing much quicker than the total vacancy rate.

Some of that is played out in that stat on the side around salaries. A senior care worker, on average, is paid between £11 and £14 an hour, which is roughly similar to some retail jobs. Junior care workers are paid even less, but that statistic demonstrates that the pay progression for those workers is remarkably slow. Even if you are in a senior role, your salary is going up by quite nominal amounts.

Some of this plays out in the comparison between the number of staff and the money spent on health and social care respectively. On the left side, the total number of staff is relatively comparable. The number of people working in these sectors is the same, but the spending on health absolutely dwarfs the amount spent on social care, by a very large amount.

Of course, this is all having an impact on older people. One of the major stats that we put out with this report is the level of unmet need. Our estimate is that last year 2 million people over 65 had an unmet need for social care. That is someone who described having difficulty with an activity of daily living and does not get enough support to meet those needs. This is how that plays out across different categories. Dressing is the main one, which they are least likely to get support with, but others are getting out of bed and eating. These are things that are not being delivered to people.

We cannot directly compare them, but in the first report that I mentioned this figure was around about 800,000. The last comparable figure that we have for that was 1.6 million from last year. We have had to calculate it slightly differently in this version. In a comparable period, that unmet need figure doubled over the course of about eight years, according to our analysis.

You have already heard about the impact on carers. This is how the number of hours that people care in an average week is spread out across the age groups. The largest block is in that 55-to-64 group. That is when you are most likely to be a carer. More typically, it is the daughters and daughters-in-law of fathers and grandparents. As you get older, the proportion of your time spent caring increases. That purple block at the top is those people who are caring 50-plus hours a week. That is mostly going to be co-caring couples and people who are caring for partners. That brings complications. They are having their health needs compromised by that caring relationship. There is a huge burden placed on older carers in that period as well.



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That also reflects how easy it is for people to step away from caring roles. This is the proportion of people who report being able to take a break at short notice or in an emergency. Over 85% just cannot take a break, if they need to, at short notice or where something has come up. Again, that is a number that has been increasing over the last 10 years. More people are in that position compared to 10 years ago.

How that impacts the hospital sector is another big one. This is the number of people who are having long stays in hospital. The three sections there are those who have been there for seven days or more, those who have been there for 14 days or more and those who have been there for 15 days or more. These are the long stayers in hospital.

The point behind this is that we are seeing a level of deconditioning that is happening at home. Without some of that care and support, people are declining at home. They are under-eating and not hydrating enough. They are at risk of falls. There are lots of things going on, and it gets to the point where they need an admission to hospital. When they are in hospital, that can accelerate that deconditioning process. You get muscle wastage and delirium. There is a fall risk within hospital itself; there are hospital-acquired infections; and there are big mental health impacts from being stuck there for a long time.

That number did jump during the pandemic, but it remains very high for those who are staying in hospital for long periods. Part of that is explained by those who are delayed in hospital. This is a very small graph to read, but these are people who have been in hospital for 14 days or more and who are at the stage where they are ready to be discharged but who are unable to leave hospital. Those three long lines at the bottom are effectively the main social care indicators for that. If you are waiting for an assessment to get care at home or a bed in a care home, that represents around 20% to 25% for each of those. People cannot get out of hospital because they cannot get that social care provision put in place quickly enough.

That has knock-on effects. That is a big reason why A&Es are so overheated. There are long waits for those who want to get into a bed but cannot have one. Just as a brief comparison, they count this slightly differently now, but they used to count this under delayed transfers of care. Usually, on an average day about 4,200 people were delayed in this fashion in that 2016-17 period. In the most recent figures—that is from 2022-23, but this is virtually unchanged today—about 12,000 to 13,000 people are delayed in hospital for those reasons on a typical day. The further effect of that is that one in six people over 75 who are admitted in an emergency have been in hospital in the last 30 days. Even if they get home, they are coming back in again.

To summarise, we have an older and ageing population. We are seeing an increase in complexity, partly because there are more older people and they are more likely to have these needs. There is also complexity



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because of some of the systemic issues around how health and care is delivered more generally. The level of unmet need is continuing to grow. That has very real impacts on people, but it also puts additional strain on the NHS when a crisis comes.

Carer strain is going up. As we saw from that graph, it is much more difficult to care today than in the last few years. That increases the pressure on hospitals. This is a big explanation for why a lot of the funding ends up gravitating towards hospitals, because they have to meet that need when it arises. There has also been a big loss of intermediate care, reablement and rehab support, which is the sort of thing that, when you get home, can help you to recover well and stay at home afterwards.

In more recent years, some of the cost of living challenges have added even further pressure. People who may have picked up the bill themselves when they could are feeling less able to pay for those things in the current climate. Even more unmet need is coming from there.

I will leave it there. Thank you for listening.

**Chair:** Thank you very much. That was a lot of work summarised in a very short time—well done.

Q279 **Andrew George:** It is a very depressing picture. Just to get some clarity on the figures on those who have a significant unmet need, you are saying that there are a number of people who are simply not eating because they are not getting the care they need.

**Tom Gentry:** The way we capture it is that we ask people, "Do you have difficulties with these activities?" and then we list things like eating, dressing and going to the toilet. We ask, "Do you have support to have those needs met?" Those people who say "No" or "Not enough" are captured within that. That will capture people who are not eating at all, people who are not eating enough and people who are not eating correctly.

Q280 **Andrew George:** We are talking about millions who are not getting dressed.

**Caroline Abrahams:** It does not quite mean that, actually. It means, "I am going to struggle to do this on my own. If there is no one to help me, it is going to take me a long time. I might not fully manage it. I might be at risk of falling over while I am trying to get dressed." It is more that.

**Andrew George:** Yes, there are gradations.

**Caroline Abrahams:** Yes.

Q281 **Andrew George:** You also gave figures on the reduction in care home beds and so on. Were you able to disaggregate between nursing care and residential care? Which one is experiencing the greatest decline?





**Tom Gentry:** We have done that; it was not in last year's report, but we have done it. We know that the number of registered nurses working in the social care sector has declined significantly. We included that in the predecessor report. We estimate that there are around 40,000 fewer nurses working in social care. That will reflect on both nursing homes and nursing capacity in other residential homes. Nursing capacity is under strain.

We saw that differential in the figure being spent. Working in the NHS can be a lot more attractive for people who have that qualification. There is better pay, progression and all those sorts of things. You find that, especially through periods of general financial hardship, people move over to the NHS because they have a better chance of a career there.

Q282 **Andrew George:** Is it workforce shortages causing the reduction, not the proprietors deciding to get out of the sector?

**Tom Gentry:** It will be both. There will be some where it is not affordable to deliver those services any more. We are going to hit a hard wall of that next month.

Q283 **Andrew George:** You say that there has been an 18.2% increase in the proportion of people living over the age of 75 since 2017.

**Tom Gentry:** Yes.

**Andrew George:** That is a very dramatic increase.

**Tom Gentry:** We are in the baby boom period now. That 70-to-80 category has been growing exponentially for the last 10 years because of the bulge that came out of the post-war baby boom.

Q284 **Andrew George:** The previous presentation was saying that there will be a doubling of those over the age of 85 by 2045. All of this is building up a very significant increase in care needs going forward.

One aspect that concerns us—it is an issue that we are going to have to get our heads around in our report on the cost of inaction—is delayed discharge, the delay in discharging those who are medically fit to be discharged. Again, you have provided a lot of very helpful figures on that, but many of the packages, particularly in pathways two and three, will require a joint package of primary care and social care. The whole idea of having integrated care boards was to break down those barriers and encourage joint working. Over the last 10 years that you have been doing this since 2015, have you seen any improvement in terms of integration?

**Caroline Abrahams:** It is patchy. There are some places that have moved ahead and have done quite well with integrating their services.

Q285 **Andrew George:** Such as where?

**Caroline Abrahams:** I would not want to name them offhand.

**Andrew George:** Can you supply that to us? It would be really useful to



us, if you did have exemplars.

**Caroline Abrahams:** Yes, absolutely. The problem is that if you do not have enough social care staff or much of a social care service locally, it is really hard to integrate that care.

Secondly, although this is not the focus of your inquiry, there is a huge shortage of district nurses and community health services. Typically, older people discharged from hospital are likely to need a bit of support from primary healthcare, as you say, but even more so they will need community health services—they need district nurses to come in and change dressings and that kind of stuff—and social care. You need all those people and you have to be able to join it all up for individuals. There are dire shortages across all of those.

The point is that we have an ageing population. You would expect the system to have kept pace with that and to have expanded, if we were being logical. Instead, it has either stayed the same or gone backwards. That is why we are seeing these big gaps.

Q286 **Andrew George:** Are you seeing a push to reduce the requirements in packages of care in residential care home or nursing care home settings? For financial reasons, are people seeing whether they can get away with not providing that care?

**Caroline Abrahams:** I would not put it like that, to be honest.

**Andrew George:** No, I have probably used pejorative terms.

**Caroline Abrahams:** No, it is fine. There is a strong consensus that it is absolutely right for most people, if they can, to stay in their own home. It is what older people want; it is better value for money for the taxpayer as well. There is a definite shift.

If you are going to do that, you need to be able to brigade those services around an older person. The Government are going to be bringing forward proposals in the 10-year NHS plan, and also the neighbourhood health service, soon. That is all about joining up primary care with those community health services, but we are still going to face the problem of historically not having enough staff and needing to scale up really quickly.

Q287 **Andrew George:** With regard to discharging, there is some anecdotal evidence that there is spare capacity in nursing and residential care homes that is not being taken up. To save money and move the system forward, discharge to assess in a care home until a final decision is made is one option that is surely worth pursuing.

**Caroline Abrahams:** It may be. The downside of that is that once an older person goes into a care home, they may get stuck there. Not very many people go to a care home and come out again. The risk is that somebody goes into a care home to be assessed, is less mobile, does not



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retain their independence, does not get the rehab that Tom was saying is so necessary, and then they are stuck. Then it is down to the family and the older person to pick up the bill, which may be enormous.

The other thing is that all care homes are not the same, as I am sure you have heard in your inquiry. It may be that some of the ones where there are spaces are either in the wrong place or are very expensive and are charging more than commissioners are able to pay. That is what happens when you have such a mixed market.

**Q288 Josh Fenton-Glynn:** I want to go back to the point about partners caring for each other and those circumstances, because this plays into the broader cost of not doing care properly. You talked about there being a significant impact on the health of the partner with the caring responsibility. In my experience as a cabinet member for social care, I saw that particularly with men who would refuse to get help, yet did get quite a lot from their wives.

First, is that impact borne out by the data? Also, how many of the hospitalisations are because people are reluctant to get care packages and therefore much more reliant on their partners?

**Caroline Abrahams:** We do not hear a lot about that, it would be fair to say. We do not hear a lot about men refusing to accept care and only wanting it from their partners. It is more that, in lots and lots of people's lives, couples expect that they are going to look after each other if something goes wrong. They do not even view themselves as carers; it is just what you do.

That is fine and we do not want to discourage it, but it is a really hard thing to do all on your own. Part of the problem is the lack of back-up for people. It is one thing to be a primary carer for someone with a really good suite of services coming in to support you; it is another thing if it really is literally you. If you are supporting a partner with dementia, they might be uncomfortable if you even walk out of the room. People in those sorts of situations are under the most immense pressure. Those people need a package of care around them to support the whole household.

**Q289 Josh Fenton-Glynn:** Yes, respite is something I have definitely seen a lot. Does that have a longer-term health impact on the caring partner?

**Caroline Abrahams:** Absolutely, yes. Speaking as an ex-carer—I am sure there are lots in the room—you are just focused on the person who you are looking after. It is very easy not to think about yourself at all. Two or three years on, you find that something that you did not quite deal with suddenly gets a lot worse. You might not even have the time, as Tom's slide shows, to go away and make an appointment to see your GP. That is the trouble. I do not want to discourage people from caring—it is what people want to do; it is the right thing to do—but we need to support them better.

**Q290 Josh Fenton-Glynn:** Has the level of support always been bad? Has it



got worse as council budgets have become more stretched?

**Caroline Abrahams:** It is probably a bit of both. It has never been great. These days, even if you are entitled to a carer's assessment, how long you will have to wait to get one and whether anything will emerge off the back of it is quite debatable. It has got harder. As Tom's slide shows, the pressure on council budgets has led to them having to ration a lot of their support, frankly. As a councillor, you will have seen that. It is not that anyone wants to do that, but it has put councils in an almost impossible position. Carers tend to get squeezed out at that point, understandably. That is really tough.

**Tom Gentry:** It is about raising the thresholds. You do not have to go back that far to think about this idea of moderate care need, where someone has the early stages of needing something. That can be a fork in the road for many people. We observe that with things like frailty. That is a big issue that we talk about, where someone has low physical reserves to respond to things. They talk about this tipping point when they first needed help and did not get it. The acceleration to dependence is much quicker from that point onwards. That chance to intervene early just does not exist in the social care world as perhaps it once did.

Q291 **Josh Fenton-Glynn:** In my council, one thing we found was that if you got in early, the rate at which people declined was much slower. There are also some things you can do early, such as assistive technology, with tracking watches and things like that. People would get used to them, even in the early stages of dementia, and then they would be able to continue to use them. If you do not get in early, you miss that saving later down the line.

**Tom Gentry:** Thinking about the example of refusing care, people are much more ready to accept lower-level care and smaller adaptations rather than what can feel like invasive care, which comes further down the line. You have a much better chance of getting a response from them as well.

Q292 **Paulette Hamilton:** Good morning to you both. I am going to go back to the title of today's session: social care reform and the cost of inaction. Like Josh, I led social care in Birmingham, which is ethnically very diverse as a community. In Birmingham, we found that people from large numbers of our ethnic minority groups, including parts of the Irish community, the Gypsy and Roma communities, the black community and the Asian community especially, did not access social care at all. They did the caring within their communities.

Going back to the cost of inaction, if we are truly saying that at the moment everything you have said is correct, what would happen if, say, 50% of the people who currently do not even access the care they deservedly need came on to the market? Remember, the kids are working away. In the Asian community, for example, they may be working in local corner shops—I am just giving you the context. What



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would happen if these people tried to access care? What would be the cost to what we are trying to offer at the moment?

**Caroline Abrahams:** I think you know the answer to your question.

**Paulette Hamilton:** I do, but we are on film and I want the answer from the experts.

**Caroline Abrahams:** The system is buckling now. The system is finding it really difficult. Birmingham city council, in that example, would suddenly have thousands more people wanting an assessment and appearing to have an absolutely valid need for care, which you would have absolutely no opportunity to fulfil. Even if you were one of the councils that has tried really hard to sustain a local level of support and infrastructure, as Leeds city council has, that would not be enough. You would see a complete system collapse.

Part of the problem with social care is that it never completely collapses, so it is easy for people to think it is not really in crisis. Something like that would definitely precipitate it.

Q293 **Paulette Hamilton:** As experts on elderly and care needs, what are the two things you would like to see? Do you have a vision for the future or something you would like to see in our report? What would you like to happen around social care and inaction? What could we do next?

**Caroline Abrahams:** The Casey commission is about to start. I hope that can happen quite quickly. Most advanced countries reformed their systems 30 years ago, in the late 1990s or the early 2000s. We are really late to this party. The one good thing to be said is that there is lots to learn from other countries. I hope we will look outwards and not just internally in the UK. We need to try to learn from countries such as Germany and Japan. They have recognised that social care needs to be part of our infrastructure, so we probably all need to contribute a bit through our life so that if and when we need social care as older people, there is a minimum standard for everybody that we might be able to choose to top up in various ways. At the moment, there is nothing like that for people who are absolutely on their own: as we have seen, more and more of them are not able to get care at all.

Q294 **Paulette Hamilton:** Caroline, you have highlighted one thing that you have seen in Japan about people making more of a contribution. What about you, Tom? I always say two because that is my favourite number, but you could give me one.

**Tom Gentry:** The relationship with the NHS is a really big one. Part of the picture around delayed discharges is because in a lot of areas there is complete dysfunction across that divide. Some of it is funding because the funding does not go quite where it needs to go. Some of it is about relationships or just co-locating staff so that social care staff are working alongside NHS staff rather than working in silos.



From my perspective, this is partly about delivering on the promise of ICSs. They were designed to bring together health and social care in a more systematic way. I know this is all up in the air a bit, because of the demands being put on them to cut staff and other things, but we really need a sea change in how that relationship works. That has to be acknowledged in the 10-year plan, as that comes out, but it also needs to be captured in the Casey commission. Older people are the ones who are most likely to rely on both for very long periods in their final years. They have the most at stake in getting that right.

Q295 **Andrew George:** There has been passing reference to respite care throughout the evidence session today. It is often seen as the icing on the cake of what fundamentally needs to be provided. I just wonder how the picture has changed over time, over the last 10 years or even further. It seems to me that all those providing care need breathing space and a chance to recharge their batteries and look after their own health and wellbeing.

**Tom Gentry:** It is not something that we have captured in the data, but every year we do a polling and survey exercise with older people and carers to ask how they are doing, what they are missing out on and those sorts of things. From the responses that we have got, there has been a huge decline. There was a steep decline during covid because everyone was in the same house. A lot of pressure was put on people for those periods.

Very frequently, they will come back and say, "That thing I used to use is not there any more." We have a network of local Age UKs, which deliver all these services. They are really struggling at the moment. They will struggle more going into next year with the national insurance rises. The availability of those things was one of the big things that came out of the survey at the end of last year. Those low-level services are just not there for people. That has definitely jumped up the list of responses.

Q296 **Andrew George:** You are in a more advantageous position than me, but certainly over the last 20 or even 30 years, references to the availability of respite support have declined and it has almost fallen off the radar in many locations. I just wanted your impression of whether there is any quantitative data that supports the anecdotal evidence I am picking up.

**Tom Gentry:** There is plenty of anecdotal evidence. Some things might not be formally recognised as respite services, but that is exactly what they are for a lot of people. Again, that is what a lot of local Age UKs will be providing: social clubs or spaces that people can go to. It is the chipping away at those that has had a cumulative effect.

**Chair:** Tom and Caroline, thank you so much for your time. Thank you to my panel, and thank you to everyone who gave evidence today.