HOUSE OF COMMONS

Health and Social Care Committee

Oral evidence: Supporting those with dementia and their carers, HC 96

Tuesday 18 May 2021

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Watch the meeting

Members present: Jeremy Hunt (Chair); Paul Bristow; Rosie Cooper; Dr James Davies; Dr Luke Evans; Neale Hanvey; Taiwo Owatemi; Sarah Owen; Dean Russell; Laura Trott.

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Witnesses

I: Jonathan, an individual with lived experience; and John, an individual with lived experience.

II: Fiona Carragher, Director of Research and Influencing, Alzheimer's Society; Caroline Abrahams, Charity Director, Age UK; and Sarah Pickup, Deputy Chief Executive, Local Government Association.

Examination of witnesses

Witnesses: Jonathan and John.

Chair: Good morning and welcome to the House of Commons Health and Social Care Select Committee. My name is Jeremy Hunt. I am the Chair. This is Dementia Action Week, so welcome to our special evidence session for a short inquiry looking at the way we support people and families living with dementia.

We have already done a report into the social care system, which was published in October last year. It recommended some big changes. Since then, we have had some important commitments from the Prime Minister for a 10-year plan, although there were no further details in the Queen's Speech.

This morning, we want to look particularly at the social care system through the prism of the 885,000 people who are living with dementia, and their carers. What we conclude will be fed into our recommendations for the 10-year plan for social care that we have been told by Ministers is on the way. This week, we have representatives from organisations involved in the care of people with dementia. Next week, we will hear from the Minister for Social Care, Helen Whately MP.

In our first panel this morning, we are going to hear about the difficulties and challenges of dealing with dementia first hand. My colleague Paul Bristow is going to speak to someone called Jonathan, whose mother Gillian had dementia and sadly passed away in January this year after having to sell her home to pay for her care.

Jonathan, I am very sorry for your loss, and thank you very much for being with us here today to share your experiences.

Q1 **Paul Bristow:** Thank you very much indeed, Chair. Jonathan, I really appreciate you coming in and speaking to us today on what is likely to be a very distressing experience. Like the Chair, I want to say how sorry I am for your loss.

Could you talk us through your experience of caring for your mother Gillian?

Jonathan: Good morning. First, thank you both very much for your condolences, which are greatly appreciated. If I may, in the interests of transparency, I should let the Committee know that I am a former senior civil servant but now run a charity in the care sector. I am a trustee of another charity in the care sector and am also vice-chair of a cross-sector organisation called Championing Social Care. I speak today in a personal capacity.

My mother was head of modern languages in a state school. My father was a head teacher. Dad died in 2007. Indeed, at the end he had vascular dementia. In around 2011 or 2012, it became pretty clear to me and members of my family that things were not right with mum. Her fine brain was not operating as it always had done. To cut a very long story short, it took us two years of really quite difficult discussions with the GP, who indeed was using data protection as a reason not to talk to us, to persuade her that there was a serious problem with mum, and that it was more than just grief for my father or a bit of old age, and there was something badly wrong.

By the time we finally got a sensible diagnosis and got her in front of the experts she needed to see, and to have the scans that she needed, it was very clear that not only did mum have mixed dementia—Alzheimer's and vascular dementia—but that it was pretty far advanced. We had some care, with experts coming in to see her, and four months later I got a call, out of the blue, from the ambulance service saying that they had found mum wandering over a mile away from home, in a rural village in Wiltshire. She did not know where she was or why she was where she was. By the end of that day, I had driven over and we had found a care home. She was in a care home at the end of that day. The point I would make from that is that there was a real battle for diagnosis leading to having to really accelerate the opportunity to get mum into a care home, without being able to prepare her properly for that.

Without dwelling on the details, things did not work out with that care home. Frankly, they made some pretty bad mistakes. It was not the right place for mum. She was not getting the support she needed. Less than six months later, I moved her to a care home near me. It was a nursing and care home because it was quite clear that she was going to need more than just some caring. I do not wish to denigrate that at all, but she was going to need medical support as well.

It was a big upheaval for someone who had lost all her communication skills. As I said, she was a languages teacher. Dementia is so cruel. She could not communicate in any meaningful way, or verbally with me. She knew she could not, and that was incredibly painful for her.

The new care home was fantastic. The carers there were brilliant. One young carer realised, in a way that I had not, that he could communicate with mum in French because foreign language is stored in a different part of the brain. It was absolutely miraculous; that is incredible care.

Sadly, because mum had mixed dementia, it was not nice—it is never nice—and it was not a gradual decline. It was a jumping around. Although medically she had always been quite fit and healthy, life became really quite difficult for mum. She needed a lot of support. Part of the reason for moving into a nursing and care home was so that she could get nursing support. The care home professionals around her said, "Look, she does need that extra support. You should now be applying for funded nursing care, so let's do that assessment."

Despite being modest schoolteachers, my parents had saved up to make sure that they could look after themselves and their family moving forward. I could see that by renting her house out, one month of rent would cover less than one week of care home fees. If you had the equivalent of a village thermometer for the new church steeple, you could see the thermometer working its way down through her savings quite rapidly.

I could see where we were going, so we applied for funded nursing care and continuing healthcare. You would not believe how much nagging and delays we had. Finally, the nurse assessor came. We all sat round the room. We did an assessment at the end of which, probably wrongly, she said, "Yes, you're right, she should get funded nursing care. We are really sorry for all the delays. I'll recommend that it be backdated."

I thought, "Great." That meant that she would still be contributing. Her pensions and other income would still contribute to her care costs, but that extra bit of pretty modest support would mean that her house and any savings would be protected from that point moving forward. That seemed to me like a pretty reasonable deal. I should say that my brother, who lives abroad, when mum first went into a care home, said, "Ah well, of course, that will be paid for by the state." I just laughed. I was pretty aware of the broader situation. It was a very hollow laugh. There has never been an argument that there should not be some support that we should pay for, and that mum should pay for from her money.

Six months later I said, "Is the benefit coming through? I haven't seen it yet." The care home was still charging the same amount. I had been warned that it could take a long time. It turned out that the assessor had never filed the paperwork. She had registered it on the computer system but had never filed the paperwork. They said, "Don't worry, we will get that in." What they neglected to say was that they had then decided to do a peer review, and took a decision—having never met my mum and having never been part of the assessment—that actually she did not qualify and, terribly sorry, there were no funds coming.

The way in which they handled that was appalling. They would not tell me the reasons. They did not even tell me there was that panel, so when I appealed because I thought it was an admin mistake, it transpired that it was not. It was an utter catalogue of errors. We were back in the same position, with my mum's hard-won savings being used to fund her care.

Life progresses. Her illness progressed. I did not want to have to go through the process of arguing with that awful bureaucracy. As I said, I was a senior civil servant. I understand bureaucracies, but this was Kafkaesque. That is the only way I can describe it.

We waited until mum got markedly worse. By this point, there was no communication. She had fallen over in the care home and broken her leg in two places. She lost the ability to walk after that. She was doubly incontinent. She could not eat without support. There were some real, serious risks around that. Even so, I still thought I would not go through that process again until I was really sure. It had been such a bruising one, with that bureaucracy. We engaged a private elder care consultant to do an independent review for us to see whether we should, indeed, be going through the process of applying for financial support again. It was quite clear: "Yes, absolutely, your mother needs medical support around her, and that should be supported financially by the authorities."

We applied. Again, there were delays. I think we were one of the last assessments to happen pre-Covid in the care home. We all sat around and everyone agreed with all of the assessments apart from one, which was mobility. The local authority representative said, "Yes, absolutely, of course there are severe mobility needs," whereas the clinical assessor said, "Oh no, the care home tried to use a standing hoist rather than a normal hoist; therefore she cannot be a falls risk," despite the fact that there was a falls risk assessment making it clear that she was a high falls risk. I remember saying, "You are going to use that to wriggle out of this again." She said, "No, no, of course we are not." Of course, they did. We appealed it, but it was again refused.

The whole process is utterly outrageous. No support whatsoever was provided for mum. I had no choice but to sell her home to make sure that we could continue to pay the fees. Two months before they rejected the appeal, in January, mum died, quite clearly needing funded support.

It was a harrowing experience. As I have said, I wanted to be there to support my mum. I did not want to have to spend my time worrying about her finances and arguing with bureaucracies for what I think should be a basic right. Forgive me, that was a very long answer.

Q2 **Paul Bristow:** It is incredibly powerful testimony. I purposely wanted to hear your full story. Thank you very much for telling us that. Again, I am sorry for all the delays and the bureaucracy you encountered.

Do you feel that during your battle with the authorities, and the diagnosis delays—from the start it was the delay in diagnosis and then it was a delay in application for funding and support—that the system was geared not towards granting your mother the support she needed but to finding excuses not to give that support?

Jonathan: I am glad you said that because I would be accused of being a conspiracy theorist and I am not one. I do not believe in conspiracies. It was very, very clear to me that any possible excuse not to provide mum with the financial support that was her right was taken. Even the way in which the CCG handled this matter—I will make a separate point on that, if I may—struck me as a very obvious tactic. You refuse as many as you can, and then you make it as difficult as you can to appeal, on the basis that most people are not as stupidly determined as me to pursue it and will just give up.

In the end, I had to force them—because they would not tell me without an FOI request—to tell me whether they actually monitor their performance in meeting the statutory guidelines for dealing with appeals.

They do not even monitor it, which tells you everything. They do everything they can to kick it into the long grass. With the diagnosis and the delays, I do not think it was quite the same situation, but I think there is a disparity in the way the system treats dementia compared to other conditions. It does not appear to be rated as significant an issue and as comparable. I had a heart issue 18 months to two years ago, concurrent with this. There was never any question but that I was going to get support and that the system was going to go into action quickly in a way that I never encountered with that system.

As a brief aside, I know you are focusing on dementia and social care, but it is very often about the interface with the health service and the health sector. That lack of integration was certainly what I witnessed. It was quite clear that the local authority person thought that mum should have the money, but they would not have to pay for it. Therefore, it was the CCG who were doing everything they could to avoid it. You get caught in the gap in the middle.

Q3 **Paul Bristow:** Thank you for that. I have one final question. What do you think would have improved your experience of caring for your mother and trying to ensure that your mother received the support she so obviously needed?

Jonathan: A much more understanding and accessible system and for it to be much more transparent about what support is available. I had to find out so much of this. I know other friends and relatives who were not even aware that there were these sorts of allowances available, let alone trying to get them.

I talked about some of the amazing care my mum received, but it is often very much on the basis of the personal contribution that care workers put in. In even the very best of homes you can see how they are stretched. You can see how the staff are not supported. I brushed over some of the mistakes in the first care home, but it is overworked and under-recognised staff who make mistakes like putting the wrong "Do not resuscitate" order on the wrong file, which is what happened in my situation.

What would have made a difference? People treating dementia with the respect it deserves, and on the same level as you would any other condition; being much more open and welcoming of those around people with dementia about the support available; and then making damn sure that the people you entrust your loved ones to have respect. We have seen in the pandemic, finally, just how important social care is.

Forgive me, Chair. You described the lack of reforms in the Queen's Speech as a glaring omission, and you were quite right. It is frankly amazing.

Paul Bristow: Thank you very much indeed, Jonathan.

Q4 **Chair:** Jonathan, let me ask you one question. You came to tell your story, but you have a background as a civil servant. What is the policy answer that would stop other people going through what you had to go through with your mum?

Jonathan: Thankfully, there is probably a reason why I have moved on from the senior civil service. I do not come here with all of the answers. I think what is really clear—you have said as much—is that on a policy level we need to understand that social care is incredibly important. We just need to up the number of people engaged in it and dealing with it.

There is absolutely no way we can escape the funding, but it has to be with really significant system-wide reform, investment and recognition. We need real leadership and talent brought into the sector. We want the brightest and best of graduates and career switchers thinking that social care is the place for them.

We have to try to give carers the time to care rather than fill in bits of paper. I have seen files as thick as my leg, but the care has not been there because carers have to fill in forms and tick stuff, when they should just be doing their job better.

I do not come with all the answers. Lots of eminent people have come in with lots of answers, but you cannot escape the fact that we need to pay more, as a country, for this. This Government are in the unusually lucky position of having a majority that could deliver change in a way that we have not seen for a little while. I really hope that they honour the promises that they have made from the start of their Administration.

Chair: Thank you for joining us. We really appreciate it.

Jonathan: Thank you very much for the opportunity.

Chair: It is a sad time, but it is really important that we hear this kind of testimony. Thank you for joining us.

We are going to move on to our second witness in this first panel. John O'Doherty was diagnosed with vascular dementia five years ago. He lives at home with his wife. John, we are so grateful to you for joining us this morning. We really appreciate it. My colleague, Sarah Owen, is going to ask you a few questions.

Q5 **Sarah Owen:** Thank you so much, John, for joining us. We had a problem with the mic earlier, and if it happens again I will ask you to move forward to your computer screen. Are you happy to talk us through your experience of being diagnosed with dementia, probably starting with some of the symptoms you experienced at the beginning and the impact on your job and everyday life?

John: Yes. Good morning. I used to work for a local authority. I worked in the finance department where, annually, I would be dealing with hundreds and thousands of pounds. Obviously, I had a huge responsibility there. I had to be on the ball because, if I did not get my job right, it would affect the local authority and could influence how much council tax people would have to pay.

I was promoted twice. I was considered to be the person to go to, and I was considered to have a good sense of humour. I was considered to be somebody who could be relied on, but this started to change.

Like I said, I had responsibility for administering hundreds of thousands of pounds annually. I would go into a shop and, if something was 84p, I would have to put my hand out with the money and ask the assistant to count the money for me. With dementia, it is simply developing strategies. What I started to do was to go into pound shops, where I knew I just had to hand over a pound.

In the workplace, my work was deteriorating. I was making huge mistakes. One day I was asked to issue a cheque, and I issued the cheque from 7 January. Had that cheque gone out, it would have caused huge implications for the local authority. My work was slowing down. I could no longer meet my performance. Personality-wise, I was different. It got to the stage where I changed from the person to go to, to the person to avoid. It came to the stage where I might be advised to send an email to such-and-such a person, but just remembering the name I found very difficult. I had worked with them for years and years, but I could no longer remember their names.

I used to be very social. I used to enjoy talking to people. It got to the stage where, if I was walking through the office and somebody came towards me and spoke to me and said, “Hello,” all I would say was, “Hello,” back. I would not make conversation. The reason I would not engage in conversation was that, invariably, if you are speaking to somebody, you have to remember their name. I could not remember names at all.

It got to the stage where I could not meet my responsibilities. I could not be trusted by people with the advice that I was given to be conveyed to people. I was changing, and I found it very difficult to speak to people on the phone. I was getting muddled, and it was not conducive to have that kind of personality in my role. As a result, I was reduced to a lesser role, where I had lesser responsibilities. I was dealing with areas of work that were completely different from the area of work I had had.

It got to the stage where I could no longer even do that job. I was reduced again in responsibility. I had gone from a person dealing with hundreds of thousands of pounds a year to making appointments for people to come in. I was even getting that wrong. I sent a letter to somebody one day for an appointment, and the letter that I sent out to that person was for a Sunday. Of course, the building was not open; it was closed for the weekend.

To cut a long story short, I eventually received my diagnosis of dementia, and because of what was happening at the time I was given an opportunity to seek early retirement, which I did.

Q6 **Sarah Owen:** Thank you, John. Can I ask a few questions about your diagnosis because you have come on to that? Was there a delay before your diagnosis? What was your experience of the post-diagnostic services?

John: I had been going to my GP for a number of years because I knew my personality was changing and there were other factors involved. I explained about my memory and the fact that my personality was changing. I continued to go to see my GP, but nothing was happening. It got to the stage where I went to see the doctor with my wife, and I had a complete and utter meltdown in the surgery.

As a result of that, I was referred to a psychiatrist, who did a memory test. He said that he was a bit concerned about the memory test. I had a brain scan, and I went back to see the psychiatrist. He referred me on to another consultant. I went to see him and had a meeting with him. I was there with my wife, and I was told that I had mixed cortical and subcortical vascular dementia.

My wife took the news quite badly. To me, the actual diagnosis was vindication. I knew I had dementia. All the signals were there. I knew people who had dementia, and I felt that I was not being listened to at all. Being given that diagnosis was giving me a chance. I could move on with my life. I could make decisions.

As for my support, to call it poor would be complimenting it. For example, I went for an appointment to go to a post-diagnostic support group with my wife. I agreed to do it because I wanted to learn as much as I could, to develop strategy and friendships. Like I say, I could go to the post-diagnostic support group. I waited and waited, and my wife booked time off work to come with me, but I heard nothing. After a number of weeks, we eventually contacted the memory clinic where the decision was made that I would go to the post-diagnostic support group, and I faced the irony that they put me through for this post-diagnostic support group.

Obviously, I lost complete faith in the system, to be let down so much like that. Since then, my care and support has been through organisations like the Alzheimer’s Society. I do a lot of work through them which occupies my time. It keeps my brain stimulated. It is a question of trust. As I said previously, I completely lost faith and trust in what is considered the conventional care system.

Sarah Owen: Thank you so much, John, for sharing your experience with us today. Hopefully, it will go on to help people have a better experience than the one you have had. Thank you.

Chair: John, thanks from me too. I am not sure whether anyone living with dementia has actually given evidence live to a Select Committee in the House of Commons before. It was an incredibly brave thing to do. It was not the best of lines, but we heard some very powerful things. The thing that stuck with me was your description, right in the early stages, of how you moved from being the person to go to at work to the person to avoid. That came across very powerfully.

Thank you very much indeed for joining us this morning, and best of luck with your continuing work with the Alzheimer's Society and continuing treatment. Thank you, Sarah, for asking those questions.

We now move on to our second panel, but, Jonathan and John, you are welcome to stay on the Zoom link to see the rest of the session. I am sure people will have comments on some of the things that you have said.

Examination of witnesses

Witnesses: Fiona Carragher, Caroline Abrahams and Sarah Pickup.

Q7 **Chair:** For this panel, we are joined by Fiona Carragher, director of research and influencing at the Alzheimer's Society; Caroline Abrahams, the charity director at Age UK; and Sarah Pickup, the deputy chief executive of the Local Government Association. Thank you all, and welcome back. I know that you are regular attendees at our Select Committee.

I want to start with Fiona, if I may. This is a session where we are focusing on people with dementia. You work for the Alzheimer's Society. There are so many places you could start. You could look at the financial pressures created on individuals by the social care system, as we heard from Jonathan; the speed of diagnosis that John talked about; and the post-diagnostic care where John said he felt let down. Let me ask you very bluntly, if you were Secretary of State for a day, what would be top of your list of things to change if we are to improve the care of people with dementia?

Fiona Carragher: Good morning, everybody. First, the stories told by Jonathan and John are so powerful, and something that we hear at Alzheimer's Society day in, day out. It is absolutely heartbreaking, particularly through this pandemic. It has been the toughest year for people affected by dementia.

You are right that there is a multiplicity of things that we need to tackle in what is, without doubt, the biggest challenge that we face in health and social care. If we put infectious diseases to one side, this is the biggest non-communicable challenge that we face. There are issues and things that we can tackle around prevention and risk reduction. We know through the Lancet commission work that 40% of dementia in the future could be reduced in terms of risk by taking steps, particularly in mid-life.

There is a huge amount that we need to do in research and in understanding that most complex organ—the brain. We need to understand the pathologies that underpin the diseases that cause dementia, such as Alzheimer’s, or others such as frontal temporal dementia. There is a huge amount to do in understanding what really good care looks like. I completely agree that we have significant issues with diagnosis. The diagnosis rate dropped from only 67.4%, which is not great, to 61% in the last year. There is a huge amount to do around diagnosis and post-diagnostic support.

All of that is really important, but the most important and the most urgent and pressing need is for social care reform. While the diseases that cause dementia are not curable yet, we know that there are things that can be done by the Government to ensure that the stories we are hearing from Jonathan and John are not everyday occurrences. Top of my list—top of our list—is social care reform.

Q8 **Chair:** Thank you. That could not be clearer. Not all the care that people with dementia get is bad. There are some wonderful examples across the system. Indeed, even the 61% diagnosis rate is higher than in many other countries.

There are about 900,000 people living with dementia, or just under. What proportion of those are getting the care they need, even if it is a broad-brush estimate? I am trying to get some sense of the scale of the issue.

Fiona Carragher: You are right; there are about 850,000 people with dementia in the UK. The number is set to rise to about 1.4 million by 2040. This is a challenge not just for now but for the future.

The MODEM study, which is funded by Alzheimer’s Society and led by leading academics at the London School of Economics, estimates that about 200,000 people with moderate and severe dementia in England do not get any kind of funded or professional support. They get most of their support from informal carers and family and friends around them. There are many who get access to social care support, but we know that access is an issue. We know that the quality when we get there is an issue, as Jonathan described. It is variable across the country. Obviously, we also know that there are significant issues of funding that Jonathan most eloquently described earlier.

Q9 **Chair:** Thank you. Lots of people want to ask you questions, but I want to bring in Caroline and Sarah briefly first.

Caroline from Age UK, lots of people were disappointed that there was not more detail on social care reform in the Queen’s Speech. If you were writing the 10-year plan for social care, particularly thinking about it through the lens of people and families living with dementia, what are the most important things that that plan needs to include?

Caroline Abrahams: Thank you. Good morning, everybody. We were not altogether surprised that there was not more detail in the Queen’s Speech because we had not been led to think that there would be. We were glad to see it mentioned. As I think Jonathan said, we think it is incredibly important that the Prime Minister fulfils his promise to bring forward proposals.

If you talk to most people who work in the social care sector, or in organisations like mine or Fiona's, they do not usually start with funding reform. What we hear from people we work with is that, yes, it is very difficult and it can be very expensive, but there are many other issues to fix as well. The problems in social care are so many that a 10-year plan is a very good idea, because we are not going to fix them overnight; Rome was not built in a day. That would mean two or three Parliaments. It would mean a sustained push, and that is probably what we need.

What we are thinking at the moment in Age UK and other like-minded organisations is that the Government have said they will bring forward funding reform and are committed to doing a cap. Our view is that a cap, while obviously important because of the sorts of issues Jonathan was raising, would not be enough on its own.

Our other two absolutely top priorities for reform right now are, first, more money in the means-tested system so that, whether you are a homeowner or not, you get some help, and council budgets start to get topped up after all the money that has come out of them over recent years. That would help everybody in social care.

Secondly, we should take action quickly on the workforce. Again, as Jonathan explained with the wonderful example of the person who communicated through French, this is a people job. There are things you can do with technology, but in the end the people are absolutely crucial. We have some great people in social care, but we do not have enough of them. The vacancies are huge. We have learnt through the pandemic what all those shortages have meant and how they have exposed care homes and the people living in them to risk. We need more great people, and if we want that we are going to have to pay for it.

Q10 **Chair:** What would you do to make that happen? We all understand the pressures on the workforce, but what would you do?

Caroline Abrahams: We need a proper workforce strategy for social care. Our view is that the Government should set an ambition of achieving parity with the NHS, with the same terms and conditions for people doing the same job, whether in social care or in the NHS.

Q11 **Chair:** Sarah Pickup, presumably you would agree with that.

Sarah Pickup: I would agree with that. I think this Committee commissioned a citizens assembly back in 2018 to look at this issue. One of the things they called for in their recommendations was greater levels of investment alongside reform. When I went to that panel, I explained to them the different ways that different conditions were funded if you had a stroke, heart disease or dementia. They said to me, "Well, don't the Government care about people with dementia?"

Clearly, the things that that assembly said are still pertinent today. For me, we need reform and funding. For people with dementia and their carers, that is really crucial. We need to shift prevention, support and enablement in social care, and in the NHS. It is part of the NHS long-term plan as well. We also need to give people greater choice in how their long-term care needs are met.

In the case of dementia, there is probably a post-diagnostic gap. Having heard from the two speakers earlier, there is obviously still a big problem with diagnosis, which has had a big focus through various Governments and Prime Ministers' challenges over the years. It has improved, but when you have the diagnosis, sometimes there is no treatment the health service can offer you, and you do not yet cross the eligibility threshold for social care. We have to move away from a post-diagnostic gap, and enable people to have information and advice, as well as a go-to person to support and advise them. That is in place in some parts of the country. Alzheimer's Society has dementia advisers and dementia navigators. We need to have that for everybody.

Q12 **Chair:** If the Chancellor was here, he would say that the Select Committee's own report said this was going to cost a minimum of an extra £7 billion a year in the adult social care budget by the end of the Parliament, but potentially £10 billion to £12 billion a year more. Briefly, where is that money going to come from? We cannot have an intelligent debate about this unless we are honest about the fact that the money has to come from somewhere. Let me ask all of you where you think that money should come from.

Fiona Carragher: At Alzheimer's Society, we are clear that we would look for universal care. This is what we believe would be the best approach to meet the needs of those with dementia. As we have described, similar to the NHS, it would be free at the point of contact, but—

Q13 **Chair:** But that would cost even more, Fiona. Is that through a tax rise?

Fiona Carragher: Through a tax rise, but in terms of risk pooling I am thinking about to whom the tax would apply. It might not be a universal tax. To Caroline's point about the—

Q14 **Chair:** But would it be a tax paid for by older people? Just tell me what you think that tax should be.

Fiona Carragher: We believe that any solution has to have people with dementia at the heart of it. We know that the complex care—

Q15 **Chair:** That is who benefits from it. I am just wondering how we are going to fund it. Do you want to have a think about that? Let me ask Caroline, and I will come back to you. Caroline, how do you think we should fund it?

Caroline Abrahams: You asked who should pay, and I think the answer is us. It is all of us. We are all going to have to pay more if we are to have a decent social care system. I think that is okay. It is something for everybody. This is often just viewed as an older people's issue, but it is not. Obviously, there are younger people with disabilities. You can fall down the stairs tomorrow and have a serious brain injury at 30 and need long-term care. This is something that we should have in our society, and we all need to pay.

That must include older people too. Older people may not have large incomes to be able to pay more from, but perhaps they have assets. They might be homeowners. When we have talked to older people about this, they have no objection, once the arguments are explained, to paying a small amount, maybe at the time of their death.

This is politically very difficult and I completely understand that, but it is a matter of looking at where people are best placed to contribute. People are in different situations. Not everyone can pay more out of their income, but maybe they could pay from their assets. The point is that we all need to pay because it is something from which our whole society would benefit.

Q16 **Chair:** Sarah, what is your answer to that question? Also, where does the social care precept come in and what is the balance of funding that can come from council tax?

Sarah Pickup: The LGA's approach to this is that the Government should consider increases in national taxation, or a social care premium. As Caroline said, the social care premium could be paid for in a number of ways. You might pay as you go in traditional insurance premium style. You might be able to pay, if you were lucky enough to have a pension lump sum, at that point, or you could have a deferred premium that you might pay at the time of your death. What that would do is pool the risk. Rather than Jonathan's mum spending the whole value of her house on her care, we would all perhaps use a bit of the value of our house to do that. It would be a deferred premium, like the deferred payments that are already in place for care homes.

As to where the funding comes from for the social care premium, there is a question looking forward as to whether you change the way the entire system for social care is funded or whether you focus on the additional funding that is needed to improve it and change it going forward, to meet the rising demand. At the moment, more than 60% of the funding for adult social care comes from local taxation and 40% of it is from council tax. That raises variable amounts in different parts of the country; it is capped and it has an historical base, which means that there is very little room for manoeuvre. Business rates fund about 20%, and people themselves fund around 13% to 15% of the care through the means-tested system. The amount coming from direct Government grant is only 11%. It does not add up. Someone is doing the sums in the background. There is 15% under the category "Other", which is probably things like funding through the NHS and the Better Care Fund. There is 11% Government grant funding.

What we have is a system, set up through the Care Act, with national eligibility criteria, a duty to prevent, a duty to support carers and all the things that we would very much like to be doing effectively in councils, funded by a system that relies on local taxation, which does not grow in line with the needs of older and working-age adults going forward, never mind in line with the needs of people with dementia. You would probably need to keep what you have, and look for new sources of funding to match the demand and the aspirations going forward.

Q17 **Chair:** Fiona, do you want to come back?

Fiona Carragher: I think the piece about the complexity of care is really important. We know that the numbers with dementia are set to rise. Whatever happens, and whatever solution is put forward, we have to recognise that there is an additional 10% to 30% that families or individuals with dementia have to pay. We have to remember that dementia is not only complex but progressive. Care needs change over that period of time.

We are clear that, whatever funding solution is put forward, people with dementia—because they are the biggest users of social care—need to be at the heart of it. We need to recognise the complexity and the progressive changes through the life course as well.

Chair: Thank you. I am going to bring in my colleagues, starting with Dean Russell.

Q18 **Dean Russell:** I have several questions. My first builds on the very powerful testimony earlier, and in particular a comment by Jonathan when he mentioned the sheer amount of paperwork required when trying to get support. I am interested in all of your views on how we cut through some of the red tape. Is there a role for technology in having a better way of tracking and monitoring how people are asking for help, and making sure they get it quicker?

Fiona Carragher: Jonathan's testimony is what we hear day in, day out at Alzheimer's Society. It is so hard to navigate such a complex system and to get any support, information or guidance.

The other bit to mention is that this goes across the NHS and social care, and there are gaps between them. If you are worried about your memory, you will go to your GP practice, as John described. It may take a long while to get your diagnosis, but you are referred from primary care, probably to a mental health trust, to see an old-age psychiatrist to have your memory assessment clinic. At that point, you may be discharged without any post-diagnostic support because it is incredibly patchy through the country.

The other point is that the majority of care, as we have heard today, is through the social care system. At the moment, there are no treatments that will slow or stop the progression of the diseases that cause dementia. Again, you have to navigate the social care system. Many are telling their stories more than once. There are huge amounts of bureaucracy and no clear guidance on where to go.

Technology is important, but there is a role for dementia navigators, people who really understand your story and understand the needs of the individual. They put what matters to the person with dementia at the heart. That person will help and enable navigation through this really complex system. That is one of the things that Alzheimer's Society, through our Dementia Connect model, had in the long-term plan as an example of navigating the complexity. It is telling your story once, with technology enabling it to be then shared with multiple agencies. That is a very simple step forward in the first instance.

Q19 **Dean Russell:** Improved integration across the systems, and perhaps technology and people to support that. Thank you. I will come to you, Caroline. Would you agree with Fiona? I have a few questions, so please be brief.

Caroline Abrahams: I would agree, but thinking about the bureaucracy that Jonathan was talking about, a lot of that is defensive on the part of health and social care. They are trying, frankly, to bat away demand, reduce demand and reduce the cost. It is not the case everywhere, but it is a very common experience. If people did not feel the need to safeguard their resource in quite such a vigorous way because they are so broke, I think we would find that behaviour would change. We would need to incentivise that as well, and part of it might be by giving people more rights than they have at the moment.

Q20 **Dean Russell:** Thank you. If I may, Sarah, I will ask you the same question.

Sarah Pickup: I agree; the social care system is set up to ration. First of all, you cross the care eligibility threshold. Then you cross the means-tested eligibility threshold. Then, if your needs really rise, you end up in the continuing healthcare system. We know that areas set budget targets to reduce their spend on CHC when they have tight budgets. If that is the case, it will not be easy to achieve it.

There are criteria, but all criteria are open to interpretation, and there can be a real battle. Integrated and electronic care records could help. We have been talking recently about the Bill that is coming forward on integration and innovation, and around earlier intervention and putting in support before you cross the eligibility threshold. We have to find a way to fund the system adequately so that you can meet the needs of people who have really high needs, and also invest in preparing people, and helping people set themselves up for the future. It does not have to be bureaucratic. The bureaucracy is all about managing the system as it is established in law.

Q21 **Dean Russell:** Fiona, my second question is related to unpaid carers. Of course, we have thousands upon thousands of unpaid carers helping their families every day. Obviously, funding is one aspect that is often discussed, but are there any better mechanisms for supporting unpaid carers in your view?

Fiona Carragher: You are right; there are 700,000 unpaid carers for people with dementia in the UK. We know particularly that what has happened in the pandemic is that they have been picking up the pieces. We did an evidence-based report in October that showed that 92 million extra hours had been picked up by family carers during the first lockdown. They are absolutely on their knees and exhausted coming out of this pandemic.

One of the things that can be done for family carers is that, in the context of the reform and the long-term vision, they are seen to play a key role. Really importantly, it is the relationship. As Jonathan described, it is being the daughter or the son, the husband or wife, not in the context of being the carer or the person who is having to fill in all of the bureaucracy. Going back to the long-term vision, what really matters for people with dementia are those relationships. That is an important part. It is their relationships with their loved ones and with the community. It is giving carers the support that they need, cutting down the bureaucracy and helping with the navigation through the system, so that they can do the thing they want to do, which is to have a loving relationship with someone with dementia.

Q22 **Dean Russell:** Caroline first, and then Sarah on the same question.

Caroline Abrahams: With unpaid carers—I was one myself until very recently—there is, first, an issue about money. If you give up work to care, as many people do, you are consigning yourself to be poor later in life. We must do something about carer's allowance. We ought to be trying to support carers to keep working, if they can, alongside caring. To do that, we need a different approach to flexible working, which may have been accelerated, helpfully, by the pandemic.

Above all, if you talk to most carers, they really want to do what they are doing. They are doing it because it is what they want to do, but they want some back-up and support. The more reliable the formal care system is, the easier it is for a carer to work alongside it.

Q23 **Dean Russell:** Sarah, the same question again please about unpaid carers.

Sarah Pickup: I agree. A well-funded and reformed social care system will help carers. We need to make sure that any reforms have carers in there and that they are not to one side. Coming out of the Covid crisis, as a shorter-term thing, there may be a case for some direct support for carers. They have not been able to access some of the support. They may have had more caring responsibilities because some of the day services have been closed. People have not been able to access them. Perhaps there is a place for the Government to consider what they could do for informal carers, coming out of the crisis, who have probably had an additional burden and are quite tired and worn out. It is not that they do not want to do what they are doing, but that they have had to do more of it than ever over the last year or more.

Q24 **Dean Russell:** What would that look like, if you don't mind me asking, Sarah? What would that extra support be for unpaid carers?

Sarah Pickup: The thing that people often need is a break. It does not have to be a respite care-type break. There are lots of good examples up and down the country. Everybody does not get what they need, but there are good examples where people provide a direct payment for a carer to do what they want with, to help them have a break in a way that suits them. There could be a carers' hub, where you could drop in and access things. There are examples of good practice. You do not need to invent anything new to provide extra support. You just offer a bit more of what you sometimes struggle to deliver.

Q25 **Dean Russell:** I will direct my final question just to you, Fiona, as it is directly related to what you do in the charity and the organisation. One of the really disheartening comments I have had from people when speaking about this topic has been a misunderstanding in the community around people who have dementia. In particular, I had one story told to me about their very elderly relative being in a shop acting in a way that caused some questions, and the police came along and dealt with them in a very bad way. They did not understand that they had dementia. They did not understand what processes to go through.

Many police I have spoken to have been brilliant in that way, but do you think it would make sense on the training side of things to make it a requirement for all people working in the medical profession or in the police to have some dementia-friendly training?

Fiona Carragher: Awareness of dementia is an incredibly important thing. It is linked to the piece around stigma. One of the reasons that we still do not have very high diagnosis rates is the stigma surrounding dementia. Initiatives such as Dementia Friends and dementia-friendly communities, of which we are incredibly proud at the Alzheimer's Society, are one way to do that.

Specific training for medical and other public sector workers is a really good solution. We run a programme called Time for Dementia. This is a wonderful programme where undergraduate medical and other health professionals, such as nurses, pharmacists and physiotherapists, in their undergraduate training, are buddied with the family of somebody who has dementia. Right at the heart of their training they understand the complexities of dementia and what it means to the individual who has that disease, so that as they become more generalist in later life and in their career they will understand a little bit more about that.

There are some great initiatives that are already funded by Health Education England that we could look to roll out to other parts of the country, and to other professions.

Dean Russell: Thank you for all your evidence.

Q26 **Laura Trott:** I want to follow up the Chair's questions around quality of care. We heard very clearly from Jonathan's evidence about the difference in quality across various care homes and, indeed, in the community as well. We spoke a little bit earlier about the need for greater numbers in the workforce. What else should be contained in the 10-year plan in order to drive up quality? Should we be thinking about extra regulation, a means of complaining and greater training? What do you think can help us push up the quality bar, in addition to extra numbers?

Caroline Abrahams: I think it is all the things that you mention. There needs to be a proper strategy to improve quality. It starts with the money, though. You cannot do it unless people have more money. Above all else, it needs to be focused on training and on recruiting people, making sure that people come into social care because they want to and that they will get properly recognised for it.

As Jonathan was pointing out, there are some great care workers, but there are also some people who are only there because that is all they can get. One has to be absolutely honest about that. As soon as Aldi opens up down the road, some people are off because they will be paid more there. We cannot go on like that. In fact, we get better quality of care than we deserve as a society, given how we treat the people who provide it.

In the context of dementia particularly, it is a really hard job. It requires intelligence, insight, staying power and huge commitment. It is not something that everybody can do. It takes real skill. It is not for everybody, but we want people to want to do it and to be really recognised for it when they do.

Q27 **Laura Trott:** In terms of how it is monitored, Caroline, have you seen that being done really well? Is there something you would do to change the current regime? It strikes me that there are so many regulations already in place. If you look at the principles of the Care Act, for example, it is incredible. If everyone could meet those principles, it would be transformed across the country, but we are not quite there in how it is actually working. Is there anything you would do on the actual regulation or reporting around that side of things?

Caroline Abrahams: The Care Act is wonderful, but it is breached every moment of every day. We are miles away from fulfilling the Care Act. It was a piece of legislation that came about as a great vision and a great process and which was never resourced. Again, part of it absolutely comes back to money.

There may be questions about the role of the CQC, certainly. I know that the CQC have lost a lot of their own resource. They have had to put up with huge cuts over the last few years. We have to be clear too about what we want them to do. Yes, we want them to inspect, but where is the improvement function in social care? Are we resourcing that properly?

We have Skills for Care at the moment. It is a very small organisation that does a great job. We have peer reviews and peer support through LGA and local government, but is that enough? It still feels, quite often to me, that we treat social care like a cottage industry and not like the fundamental public service that it needs to be, because so many people absolutely depend on it every day.

Q28 **Laura Trott:** Thank you, that is incredibly helpful. The same question to Fiona.

Fiona Carragher: I agree with everything Caroline said. We set out our vision for really good dementia care in our recent policy report, "A Future for Personalised Care". The central principles are giving people choice and control; supporting the individual to choose and set their own goals—what matters to them; and recognising the importance of relationships, which I discussed earlier.

The final bit is building the care and the improvement piece on the evidence that we have. Really good evidence has come out of academic centres such as the Centre of Excellence at the University of Exeter. We have things like cognitive rehabilitation in the NICE guidance for dementia care. There is huge patchy uptake of this across the country. There are some things that we know can be done, and should be done, but they are not there across the country.

Q29 **Laura Trott:** Why do you think that is the case, Fiona? How can we make the uptake not patchy in terms of the quality improvements? That is my key question.

Fiona Carragher: It comes back to Caroline's point. It is about the funding. Funding is at the heart of it. Equally, it is about the training that we could give to the workforce to say that, once you have a diagnosis of dementia, there may not be a pharmaceutical or medical treatment that will stop or slow the progression but there are things that can be done. That is why early and accurate diagnosis is important. These things can be put in place early. For me, workforce training is the second big piece. It is recognising that there are things that can be done and that there are evidence-based interventions. We should be doing them as a matter of course across the country.

Q30 **Laura Trott:** Finally, to Sarah.

Sarah Pickup: I agree that the workforce is at the heart of this. It is about training, but it is also about career progression and recognising someone's skills, particularly if you think about the dementia pathway. Understanding how you might try different tactics to communicate with someone as their dementia advances is a really skilled job. You cannot expect someone to be a minimum wage care worker, develop those skills and not be rewarded, yet we do.

Any workforce strategy has to pick up the pay levels, but also the training and the specialist strands of work that people can do without necessarily having to become a nurse or a social worker. There is a specialism, which is about supporting people to live their life, and we need to recognise that.

How you assure it is really difficult. How do you assess how good dementia care is in your area? The NHS tried through its CCG monitoring. It counted the diagnosis rate and how many reviews were done, not what the reviews did or delivered and whether the service was good, but, "Did you do a review?" It seems to me that that is not sufficient. That is on the health side.

On the social care side, we tend to count the nature of support. What we need to do is work out how we can ask people whether they have what helps them to live their life. If we are to have more assurance, it needs to be based on delivering what is needed for people and the outcomes, not on counting inputs. There can be real unintended consequences and perverse incentives if you do that.

We have to think about quality. We accept that more assurance is needed. The witnesses here today want assurance that things are going to improve. Any new assurance has to be based on improvement and a model that is about support and improvement. Certainly, the LGA is working with the CQC and DHSC on how sector-led improvement can be built on to ensure that there is improvement in the social care sector generally.

Of course, with my colleagues, I refer back to the funding. This is all well and good, and there are good things that you can do, but you have to be able to fund them.

Laura Trott: Thank you.

Q31 **Chair:** I have a couple of follow-ups from what Laura has just said. The CQC system was modelled on the Ofsted system for schools. When a school gets a bad Ofsted rating, they get an enormous amount of support to help improve their rating. Are you saying, Caroline, that that support is not there for social care providers who get unsatisfactory ratings?

Caroline Abrahams: I honestly do not know. I think the answer is that there is some support, but there is not a proper system of support that helps with social care more generally. It is all very ad hoc and fly by night, and very patchy across the country. If we are serious about wanting to improve the quality of care, which I am sure we all are, there needs to be a proper system of properly funded bodies, working with Government but also with local government and the regulator, to achieve that.

Q32 **Chair:** Sarah?

Sarah Pickup: I referred to the work on adult social care assurance, but of course it is a system-wide issue. Jonathan's experience in particular when applying for continuing healthcare, and the fact that the diagnosis starts in the health system and then things cross over backwards and forwards throughout, means that the discussions that this Committee has referred to around the assurance of integrated care systems and the systemic work, and not the organisation, should not be about reviews of organisations, but reviews of how things work for people who need the support. In this case, it is people with dementia and their carers.

Chair: Thank you.

Q33 **Neale Hanvey:** I would like to thank Jonathan and John for their testimony. It was very powerful and is really valuable for the work that the Committee is pursuing. My personal reflection is that it is quite extraordinary that such a distressing and devastating condition is excluded in the way that it is. It really underscores the need for social care reform. I reflect on my aunt, who was caring for her husband in England, while I was caring for my dad, both of whom had different types of dementia. Our access to respite nursing care and care home costs was vastly different. I say that not to say that it is perfect in Scotland because it certainly is not.

I am interested in the research and the development of treatment for these diseases. One theme coming up in many different places is that conditions such as ME and heart and lung disease, which are generally regarded as idiopathic in nature, are perhaps caused by chronic inflammation. I wondered if there had been any research into that particular area and on Alzheimer's in particular. Vascular is a slightly different issue. Has there been any consideration of the vitamin therapy that is beginning to rise in prominence to deal with some of these chronic inflammatory processes?

Fiona Carragher: We are a long way from a breakthrough treatment that will have a single cure for Alzheimer's disease. What we have recognised over the last few years in particular, with more funding going into dementia research, is that the diseases that cause dementia and Alzheimer's are complex. There are probably multiple underlying pieces, inflammation being one of them, as well as genetics, sleep and looking at different protein folding. There will be a whole range of things that come together.

In the UK, we have had significant investment in the UK Dementia Research Institute, which is a global-leading centre. Seven of our best academic universities are coming together to start to tackle this. We recognise that it is not just one thing.

Globally, there are now hundreds of clinical trials looking at various aspects of the biochemistry and underlying disease pathologies, including inflammation. As yet, we do not have the answers. Linked to that, though, is that we still need to increase the funding for dementia research. We were really pleased to see the Government committing to doubling dementia research. We want that to come through as soon as possible, looking at both the underpinning pathologies and looking for new drug targets and discoveries in treatments, and also, exactly as we have discussed today, how we can have good understanding of good care both on the clinical and the social care side.

Q34 **Neale Hanvey:** This is probably more appropriate generally. How has the charitable funding that many organisations rely on been impacted by Covid, and how are you being supported to continue with your work?

Fiona Carragher: Alzheimer's Society is a major funder of dementia research and has been for its entire time, through the last 40 years. The Covid pandemic has hit all charities hard, ourselves included, in the amount of fundraising we have been able to do. Last year, we were only able to fund a small amount of new research, to the sum of £2.6 million, which is significantly down on where we would wish to be.

What we are looking for is for the Government to recognise that the charities have played a big role in funding dementia research over a long time, and this is a very difficult time for us coming out of the pandemic, so now, more than ever, we need the doubling of dementia research to get the breakthroughs, both in drug discovery and in the care and clinical space.

Q35 **Neale Hanvey:** I want to move on to the interdependency of social care and the NHS, particularly thinking about the integrated care systems, as they are described. What are your thoughts on them? Without additional funding, how effective do you think the change will be?

Fiona Carragher: Alzheimer's Society welcomes integrated care. If ever there was a group of people who cross between the NHS and the social care system to get the support and care they need, it is people with dementia.

We did a very recent investigation that went out to nearly 200 NHS trusts to ask them about emergency admissions for dementia of people over the age of 65. In a four-year period, between 2015 and 2019, we found a 27% increase. In the final year, in 2019, before we went into the pandemic, two thirds of those emergency admissions were avoidable. They were things such as urinary tract infections, dehydration or falls, which, with really good care, could have been prevented.

The benefits that we could get from a really good integrated care system will not be delivered unless we have, exactly as we have described, the investment and long-term vision, and all of the issues that we know need to be addressed for social care.

Q36 **Neale Hanvey:** To wrap up my questions, Sarah, has the allocation of funding for end-to-end pathways within an ICS across a range of services been sufficiently explained to you? Do you understand how that is going to work and how funding will stream to different providers in an end-to-end pathway?

Sarah Pickup: The integrated care system arrangements are quite complex. We have an NHS body being established at system level, but also a health and care partnership. The funding that flows through the NHS body will be NHS funding to fund NHS services. Any integration will happen through the health and care partnerships, but, actually, more likely, at place level through health and wellbeing boards or other integrated arrangements with councils.

What you need to deliver those kinds of support, without the passing backwards and forwards, according to who is responsible for funding, is pooled budgets. You need pooled budgets focused on need. Pooled budgets exist in some places. There is a big history of running pooled budgets for mental health and learning disability services, and increasingly for services for older people.

The new NHS bodies need to be willing to partner their funding at local level with councils to create pooled budgets. Of course, the pooled budget contributions are based on what each set of organisations has. The core funding that councils have for social care is acknowledged to be insufficient to do the joint job that needs to be done. Yes, it is about pooling of teams, funding and services, and focusing on what people need and not on whose responsibility it is today to fund a particular piece of the jigsaw.

Q37 **Neale Hanvey:** Do you have a feedback mechanism that would allow you to explain that it is impossible to deliver the service without additional funding? Do you have a clear avenue to make that point?

Sarah Pickup: We are engaged with DHSC on work on the "Integration and innovation" White Paper. We are also engaged with them on the beginnings of the refreshed work on social care reform. Obviously, we seek to make the connections between the two all the time.

The connection to wider local government is also important. We have not talked today about housing for people with dementia. The APPG on older people's housing recently did an inquiry. That is a really important aspect. There is a wider role for local government. It is not just about integration of health and social care. It is about people living their lives in communities.

Neale Hanvey: Absolutely. Thank you.

Q38 **Dr Davies:** I am interested in the bricks and mortar of care homes—in other words, the suitability of the housing stock as regards care for those with dementia. To what extent do we think that the existing stock is fit for purpose?

Caroline Abrahams: I think we know that care homes are very variable. Given the horrible experience of this pandemic, it is clear that if you have a very large site that is not easy to compartmentalise, it is quite hard to do infection control. Infection control has to go on being a really important attribute for care homes going into the future. We can never again tolerate the high level of deaths from flu, for example, in care homes that we have seen year after year. I think we are moving into a different phase for care homes. The capacity to do good infection control will be really important.

On the whole, I think smaller tends to be better in quality of care. In the end, it is probably as much about culture as it is about sheer bricks and mortar.

Q39 **Dr Davies:** I was aware that during the pandemic there were multiple care homes, often converted Victorian homes, that did not have en suite facilities and isolation facilities. Yes, they were small, but they did not have perhaps what we would expect in this day and age. Does there need to be more attention in that respect, Fiona?

Fiona Carragher: We know that one of the major crisis points, as Jonathan described so well earlier, is when you need to find residential care. We need to think about it across the whole journey. That is why the diagnosis is really important, so that you get it at a time when you can make future plans.

Another point is that we now have a moment, with the Government considering their new dementia strategy. This is very much led by DHSC, but we would seek at Alzheimer's Society for it to be a cross-Government initiative, thinking not only about housing, but about transport and about how it links to BEIS, so that we have the breakthrough innovations and research that we need. There is a clear moment now to think about the transformation not only of the health and social care piece but of wider Government initiatives around dementia.

Q40 **Dr Davies:** Sarah, when it comes to upgrading the standard of care homes, is there a disincentive for local authorities, because if there is better accommodation it costs more?

Sarah Pickup: I don't think so. When I was a director in a local authority, we worked with an industrial and providence society to recommission a whole series of replacement homes to upgrade them, and make sure that en suite facilities and all the right things were available for everybody, and that they were delivering good-quality care to people with dementia.

Local authorities want good care. Obviously, there is an affordability issue. There is a role for nursing homes and a role for care homes, but there is also a role for specialist extra care housing. I know of an excellent, relatively small, extra care housing unit, focused on people with dementia. It settled people who had been in secure accommodation before. It is a different approach and a different way of working.

When we think about bricks and mortar, we need to think not just about care homes, which of course must be suitable, appropriate and what we would expect in this day and age, but also about housing and about people's own homes. Two thirds of people with dementia live in their own home. Their own home could be an extra care housing unit, because that is your own home. A lot of what we learnt on the APPG inquiry into housing people with dementia is that there are things you can do in your own home to adapt. If you know early enough, you can learn.

There was a great contribution from a lady called Wendy Mitchell, who has written a book about it. She has dementia. She explained how she had adapted her own home, learning by doing, and working out tactics and strategies, as John said. You can help people with that if you get it right.

Q41 **Dr Davies:** I had a great tour of an extra care housing development in my constituency just days ago, so you are quite right.

On a different topic, how is the Dementia Friends agenda going, Fiona? Has it reached its conclusion or is there more to do?

Fiona Carragher: I think there is more to do, not only on awareness but on inclusion. It comes down to what really matters for people with dementia, and that is about relationships and being connected to their loved ones and the communities in which they live. There is a lot more to do around that. At Alzheimer's Society we are very proud to run flagship initiatives around it, but we need to do more to be aware and to have inclusive mixed housing stock. There are great examples in parts of Europe, where young and old are living together so that there is a link to the community. For us, it is about moving it towards an inclusivity agenda, as well as just an awareness piece.

Q42 **Dr Davies:** It was very much pushed by David Cameron when he was Prime Minister. Do the Government need to do more to push the dementia agenda, and dementia-friendly communities and so forth?

Fiona Carragher: It goes back to my earlier comments about having a cross-Government strategy that really puts dementia at the heart of all of the Government's thinking in different areas. It will not just be DHSC or the health and social care system that addresses this. We want to see it being right at the heart of the Government agenda.

I go back to my initial point. This is the biggest health and social care challenge that we face, outside infectious diseases. Dementia is still in the top ten, if not the first, for people dying. There are huge amounts to do.

Dr Davies: Thank you.

Q43 **Sarah Owen:** We heard earlier from Jonathan that staff need time to care, but they also need skills. What do you think are the key skills for those caring for people with dementia? Do you think that those skills are matched in pay and sick pay and in terms and conditions?

Fiona Carragher: We know that dementia care can be complex. The training that the workforce need is incredibly important, and we should recognise that, both in pay and in the remuneration they have in their broader development piece. It comes down to building a relationship with the person with dementia, so that the carer can really understand what matters to that individual and has an individual care plan put in place. They need a feedback loop so that, as things progress, they can adapt the care plan to it.

One of the major issues we have is not only vacancy rates, but high turnover of staff, which means that that relationship is hard to build. If you are only going in for a short period of time in a domiciliary care setting, it is hard to build a relationship and understand what the individual with dementia needs.

It is time, yes, and the skills to understand the complexity of dementia care. As I say, there are some great evidence-based initiatives that could be put in place. We also need recognition and remuneration of the workforce.

Q44 **Sarah Owen:** Thank you. Caroline, do you have anything to add?

Caroline Abrahams: I agree with everything that Fiona said, of course. As we have heard, dementia is a progressive condition. You need different skills when you are working with people at different stages of their journey through dementia.

Focusing a bit more on those with advanced dementia, by that point of course people may not be able to communicate. Typically, they are older people who have other long-term health conditions. They are not able to say whether they are in pain. You have to have the skill, which can be taught, to identify when someone is in pain but they are not able to say so. They may have big problems swallowing. You may need to understand how you can help somebody to eat. You need resilience and the patience to maybe sit with them for an hour while they eat. It is all sorts of things like that. Because these are people who, as I say, very often have other health conditions too, if you are a live-in carer or a domiciliary carer, you need the insight and experience to be able to know when Mabel is not as well as she should be and when to call for medical support.

Very often, carers are the only people in those people’s lives. It is up to them to decide, perhaps with an informal carer, when things are going awry and they need more support. Of course, that partly lies behind the issue around people having to end up in A&E because the more preventive medical support is not there for them.

The other feature of the way the care workforce works, of course, is that if you are really good at it there is very little place for you to go, except to become a supervisor in a domiciliary care company. That means you go around and help other people. As in other professions, if you are really good at it we want to keep you doing frontline, public-facing work where you can display your skills to help many people. I think it was the Chair who mentioned the career structure earlier. That is why there needs to be a proper career structure for people, so that people who are really good at this stuff are enabled, supported and properly remunerated for staying on the frontline.

Q45 **Sarah Owen:** Thank you, Caroline. I completely agree with you about the complex skills that carers would need. Do you think that the minimum wage is enough to retain those people and attract the right people to care work?

Caroline Abrahams: Sorry, I did not answer that. A rhetorical question, to which the obvious answer is no, not remotely. It is amazing that we still have some great people doing it, given that we absolutely do not recognise the proper skills that they have.

Q46 **Sarah Owen:** I have one final question. We have talked about some good examples, but is there any country—whether international or a local example—where you have seen dementia care done right?

Fiona Carragher: Internationally, Germany and Japan have good examples of dementia care. There are parts of Scandinavia that have really thought well about the housing stock question that James raised.

I think there are wonderful pockets of really good and amazing dementia care across our own country. One of the things in Dementia Action Week that is wonderful to see is the celebration of the amazing, great care that happens day in, day out. While we have focused on what needs to improve, great care, given by wonderful individuals, happens day in, day out in this country. We just need to see that everywhere for everybody.

Q47 **Sarah Owen:** Sarah, do you have anything to follow up with on either of those questions?

Sarah Pickup: No, I think my colleagues have covered it. I once went to Sweden and was shown a dementia facility that was great. I came back and thought, actually we have great things here, and what would I show people who came from Sweden? There is great care here. The extra care facility I talked about is one example. There is the effort that people in the voluntary sector and frontline care workers put in to understand and think about people as the person they have been through their life, not just the person they are now with dementia. That is the key to personalised care. "I am not just this person with dementia; I am a modern languages teacher," or whatever you are.

Q48 **Chair:** Thank you. It has been a really good session. If I may, I would like to give the last word to Jonathan, who told us very movingly about the battles he was having trying to get good care for his mother. He has been following the whole session. Jonathan, do you have any thoughts as we conclude the panel?

Jonathan: Chair and Members, first, thank you very much for taking the time to listen and for giving me one last chance. I will not detain you long. This has been an incredibly useful session with lots to learn.

There are two key things running through this around workforce and funding, and they are linked. We spend countless hundreds of thousands of pounds trying to recruit more care workers into the sector, only to see an appalling number of them very quickly leaving. It struck me that one issue that has not really come to the fore—I briefly mentioned it—is that we should be investing in leadership and talent development in our workforce in a way that we are not, across the whole sector, be that private, local authority or voluntary, to make sure that the amazing young carer who looked after my mum is supported by the best possible leadership and talent around them. Whatever change we embark on to bring this fairly mad system, which Caroline rightly described as a cottage industry, into a modern age, we will need to invest in leadership. That will save a lot of money, which goes back to your point about where the money is going to come from. We are wasting money day after day.

I would make the point on funding that we have to remember that this is a very moral issue. Why on earth does an individual's suffering get supported if there is one diagnosis as opposed to a different diagnosis? That makes no moral sense to me. I do not understand how we have managed to get ourselves into that position.

Going back to my mum, which is the reason I have done this and why I have her looking over my shoulder today, dementia is incredibly cruel at its worst. It is morally inexcusable that we compound that suffering by people and their families having to worry about their finances and getting the care they need.

Thank you all very much for this opportunity to air some of the issues. I hope that, with your support, it can lead to some really powerful change. In my experience, the care sector wants to change, but it wants to do that hand in hand with a Government who accept, as I think everyone does, in every party, that more funding will be needed to fuel reform, so that people like my mum get the support they need quickly and, frankly, so that I and other carers do not have to spend wasted years arguing with a bureaucracy that is trying to dodge the bullet.

Chair: Thank you. It is good that you finished on the topic of leadership. This time next week, we have the leader herself, the Care Minister Helen Whately, and we can put some of these points to her. Thank you very much for your very powerful testimony. Thank you, too, Fiona, Sarah and Caroline for the light that you have shed on the issues. We really appreciate your time.

That concludes this panel and this morning’s session.