HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Monday 27 June 2022

3.45 pm

Watch the meeting

Members present: Baroness Andrews (The Chair); Baroness Barker; Lord Bradley; The Lord Bishop of Carlisle; Baroness Eaton; Baroness Goudie; Baroness Jolly; Lord Laming; Baroness Shephard of Northwold; Baroness Warwick of Undercliffe.

Evidence Session No. 18 Heard in Public Questions 135 - 141

Witnesses

I: Norman Phillips, expert by experience; Helen Spalding, expert by experience; Katy Styles, expert by experience.

Examination of Witnesses

Norman Phillips, Helen Spalding and Katy Styles.

Q135 **The Chair:** Good afternoon, everyone, and welcome to the Select Committee on Adult Social Care. This afternoon, we have a few apologies for absence, from Lady Campbell, Lady Fraser and Lord Polak, and Lady Warwick is leaving early.

I am delighted to say that we have a return match with five witnesses who were immensely helpful to us in the early stages of our inquiry, and who have returned this afternoon to give us advice on whether the way we are thinking about it on the basis of the evidence we have received so far makes sense to them. It is an opportunity to sense-check with experts by experience, and it will be extremely valuable to have their frank comments this afternoon on our progress and understanding so far.

I am delighted to say that we have Norman Phillips, Helen Spalding and Katy Styles with us. Our first session will focus on their experience as unpaid carers and the sort of things we have heard, which we would like their comments and reflections on. In the second part of the afternoon, we shall talk to two other people we have had the pleasure of meeting before, Andy McCabe and Tricia Nicoll. They are experts by experience, by virtue of the care they receive. We will again ask both Andy and Tricia whether we are on the right lines and whether the things we are hearing are the things they would expect people to be telling us. They will know, of course, that we are being broadcast and that a transcript will be taken and made public for them to comment on.

Since we saw our five friends some weeks ago, we have heard a great deal of evidence about how the present system and the way it works impact on both unpaid carers and the people they are caring for. We have heard from more experts by experience. We have heard from some of the campaign and advocacy groups. We have heard from people who are expert in knowing about housing, information systems and technologies and so on.

It is very obvious to us that there is a consistency of experience and a consistent frustration with the way, for example, the Care Act has not been implemented, and aspects of the way that the local authority systems do not work. We have also had some very optimistic and inspirational examples of good practice, at the level of local authorities and local agencies in the community, and lots of ideas that should work, not just in the areas in which they are operating but elsewhere.

Our questions today will range over whether this is what you would expect people to be telling us, but also whether you think these ideas and good practice examples could work across the country or in other local authorities. We have quite a rich agenda this afternoon. I shall start with a question to Helen Spalding. When you spoke to us, Helen, the language you used was very striking because you talked about battling the system, trying to navigate the system, trying to find out what was there for you and for your daughter and the difficulties you had with that.

One of the questions we are trying hard to pin down—it is eluding us so far—is what a good system of information and advice would look like. What would it have to do for you? Who would be the best person or what would be the best agency to take responsibility for that? If there was a central point of contact, who would hold that responsibility and why do you think it would work?

The second part of that question is, essentially, about advocacy. Who do you think could be the best advocate you would hope to have on your behalf and on your daughter's behalf? It is a big question, I am afraid, Helen, but I know you are up to it.

Helen Spalding: Thank you very much for your confidence. It is lovely to be here again. I feel very honoured to be a part of this. That is a really good question and it comes up again and again whenever I meet parent carers in particular. I am a parent carer myself, so I largely meet up with other parent carers. One of the big bugbears is this issue of not being able to access information and I do not really know what the answer is.

I live in Salisbury and the interesting thing is that in the next week or so I am going to meet up with a lady called Jo Broom, who used to be the mayor of Salisbury a few years back. We are going to be discussing this very thing, just to chew it over and see whether we can come up with an answer for Salisbury about having a central point of information, because that does seem a really good idea.

The frustration that I hear and that I have experienced among parent carers is that, for example, when a child is diagnosed, you are given the diagnosis, you are perhaps given medication and prescriptions, and you are perhaps referred to other services, professionals, consultants or agencies, but you are still left with this diagnosis, which you do not know what to do with. It is really hard sometimes. Even if you are given an information leaflet, it is an information leaflet and it is very clinical. Let us face it: even with more common things—Down syndrome or autism for example—there is a whole range of different symptoms and difficulties that your child may or may not have, so it is really hard.

From that point of a professional being involved, the next professional would be social care, but again social care is not, in my experience, that great at giving out information, which is largely because it has a huge job as it is. It is a bit like a GP. They cannot be specialists in everything.

On top of that, a lot of information goes out of date really quickly. Sometimes, in my experience, a consultant at the hospital or a social worker will give me information and I will later find out that it is not the case any more. It is already out of date, because things move quickly. It can be frustrating, but it is nobody's fault.

The idea of a central point of information is a really good one. My only concern would be that it is just another appointment, another place, another agency or another organisation for the carer to have to deal with, to worry about or to go along to for a meeting or an appointment.

When it was first recognised that my daughter had difficulties, she was only six months old and we were referred to a paediatrician. From that paediatrician, we were then referred to ENT, audiology, genetics, physiotherapy and, within a couple of months, cardiology, speech and language, and a learning disabilities nurse. That is eight different professionals doing different things.

The fortunate thing with a child is that a paediatrician pulls all that together, which is great, and serves as an advocate to an extent—you used the word "advocate"—but they are certainly a bit of a central point. They pull all those professionals together, which is handy.

If we were to throw in another place or another agency, my concern is that it would just be another one, which would take it up to nine, going back 23 years, but it is a good idea and it is needed.

The Chair: It is interesting when you say that the paediatrician was the person at the beginning. I can see that, for children—especially a child with all those very complex, different aspects—you really need a paediatrician.

This is a question that Norman and Katy might want to reflect on as well. As the child grows older, could the GP or somebody attached to the GP surgery do the liaison for you and keep the record or act as the point of single conversation? Would that be easier as the child grows older or for adults?

Helen Spalding: All these people have far too much to do as it is. If you are going to have a single point, that has to be specialists themselves, because carers could be caring for children, for somebody elderly, for an adult with mental health issues, or for an adult or a young person with addiction issues. They are still carers. That person would need to be not a consultant but a specialist.

The Chair: It would be a dedicated person.

Helen Spalding: Yes.

The Chair: Their job would be to make sure that the conversation was directed to you and to act on your behalf, perhaps. I do not want to put words in your mouth.

Helen Spalding: It might be, but it is a good idea to have somewhere to go to as a central point of information, even if all they do is signpost you to somebody with knowledge of support groups, for example. That will be different in different towns and cities.

The Chair: I am going to ask Norman to comment on that, because I can see that he is anxious to do that.

Norman Phillips: In Hertfordshire, they started to introduce what they call the care navigator, who is a person you can go to for some help. It applies mainly to social care at the moment. I had a long discussion with

a safeguarding panel last week, because the Lister Hospital was found responsible for organisational abuse of my wife.

Again, what was missing was the fact that no one in the hospital owned the problem of liaising with the family carer. There needs to be a function within primary care, the NHS and social care that recognises that you have unpaid carers out there who are a valuable part of the system and part of the team. In my opinion, what we need is a function within each of those entities that we can go to and say, "This has happened. Where do we go?" It has to be up to date, because one of the biggest problems in dealing with the system is that so much information goes out of date so quickly.

The Chair: Norman, you have given us some really important information here. How do we get hold of more information about the care navigator in Hertfordshire?

Norman Phillips: The best organisation in Hertfordshire to talk to would be Carers in Herts and a lady called Roma Mills.

The Chair: Terrific—it is precisely that sort of example that we want, to see how effective it is.

Norman Phillips: There is a chap in Herts Valleys CCG (Clinical Commissioning Group) whose name I can pronounce but cannot spell—Tim Anfilogoff. He has been a great leader. We burn up a lot of resource in the system asking questions, and you are passed from pillar to post. The problem is that someone will tell you something to get you off the telephone line, when you need something solid. That is what I would go for.

The Chair: Katy, I need to ask you to be brief, because I was supposed to put this question only to Helen, but that would never have worked. What do you think, Katy? Do you have positive advice on this?

Katy Styles: Care navigation is vital. In our particular circumstance, we have specialist nurses for MND (Motor Neurone Disease), but they rarely look at carers. Perhaps in the next question that I am going to answer, we will go on to say more about that.

The Chair: If, after we have finished, things come to you and you say, "I wish I'd said that. I wish I'd remembered that", just drop us an email. That would be perfect. Thank you so much. That is a really good start.

Q136 **Baroness Shephard of Northwold:** My question is for Katy and it carries on from the excellent discussion that we have had so far. Katy, one of the first barriers to carers getting greater support is the failure to identify them in the first place. This is because, at least partly, family members and close friends very often do not see themselves as carers quickly enough.

We have looked at and worked around this problem all the way through our discussions so far. Can you tell us why it does not happen within the

process at the moment? Is it partly because people do not see themselves as carers? What would be a key change? Could the key points of contact that you as a carer have with public services, for example in primary care, constitute a route towards identification? What would the route be like if you agree with that proposition?

Katy Styles: Fundamentally, we have the issue of identification and people not seeing themselves as carers. We have all given expert evidence that that has happened to every single one of us, so that is a given. Why it does not happen at the moment is that we are not seen as a true workforce, if you like, or partner providers for the NHS and social care. It is inexplicable to me why we have duties on the social care side and none on the NHS as carers, so I would squarely lay the responsibility for this within the NHS.

It also has a far greater budget at the moment and, if we are going to be brutally frank, it has the money to be able to do this without too much upheaval. It is always great to know who has the money for things.

You could also place a duty of care on the NHS for welfare of carers, and for identification and support, which Norman and Helen have mentioned. We have so many points of contact. We have a specialist nurse, but the specialist nurse is not there for me. They are there for the person they are caring for—for my husband—but it would not take much to tack on a question to me: "Do you know that there is this within your area?", "Do you know that you are a carer?" or whatever it is. That is quite easy.

We also have a higher allostatic load as carers, which means that we have a greater health burden from being carers, so anything that prevents stress, anxiety and ill health has to be of benefit. Where the NHS can pick us up earlier, it prevents us using its services further down the line. There are all of those really good reasons.

There are previous Private Members' Bills sitting in your archives that tell you exactly how to do this and were just not picked up. I really think that the work is there.

It has to go beyond primary care. If it is just within primary care, it has to be across the whole of it. If you cannot get past the GP receptionist, you will never get any further, so it is really important. It is not just the GP or the pharmacist, but everybody within the surgery or within acute care. It might be that it is the person running the restaurant who picks up that you are there at different hours or whatever.

We have given the committee written evidence that we collected as a campaign, mainly from parent carers, about how, once your cared-for is in hospital and you are there to support them, maybe because they have a learning disability—Norman, whose wife has dementia, will go in to help her—you have no rights. You do not have the right to somewhere to sleep while you are helping and supporting the NHS to look after your loved one. You do not even have the right to get something to eat 24

hours a day, to go to the toilet or to get a drink. That is pretty appalling and, again, easily sorted.

Baroness Shephard of Northwold: That is extremely interesting and very practical. If you, therefore, wanted them to change, you said that you could add a routine question to the questions that they put to people accompanying those who need care. Another way might be to add it to NHS training, but right across the board. Indeed, doctors' receptionists are enormously important in this.

In other words, it is getting recognition, first of all, for the role of carer, and getting the carer to know that he or she is a carer. There needs to be recognition of the role by the person as well, at the same time as just putting it into routine training, rather as there is similar training for when patients do not have capacity. This is up on a screen in opticians' consulting rooms. The idea of capacity is at the forefront of their mind because it is there on the wall.

You think that, in a sense, a very simple thing could be a reminder that this sort of question should be asked: "Do you see yourself as the carer? Are you the carer?" Something like that is very neutral. If you begin by asking, "Do you see yourself as a carer?" somebody might well say, "No, not really". Then you need to take it from there. Is that the sort of thing you have in mind?

Katy Styles: Yes, absolutely. You can rock up to A&E with the person you are caring for, for your own appointment, because there is nobody else to look after the person you are caring for, and be asked, as in my case, whether you are pregnant, but not whether you are a carer. That has an impact on when my appointments need to be or what makes it easier for me and supports me, as it would support others. It is fairly simple.

Baroness Shephard of Northwold: Yes, I quite see that. In a very unlikely way, I have recently, when getting vaccinated, been asked frequently whether I am pregnant. I am a bit past that but, of course, they feel that they have to ask it. So you think the question, if we could get the right one, and it is really very simple, could be fed in across the board. It is already being done with capacity and, indeed, one might well say, with pregnancy.

There was a supplementary question, but you have answered it. What language would encourage identification? We need pretty direct, descriptive language. I am so grateful. That has been very clear. Thank you so much.

Q137 **The Lord Bishop of Carlisle:** Helen, this is another question for you. We have just heard from Katy that, very often, the work you do as carers is simply not recognised or properly understood. This committee has heard a number of times about a possible triangle of care. This is really about attitudes, whereby you and, in your case, your daughter and care professionals are regarded as a triangle of expertise, all of whom are

involved in the care of your daughter. I wondered whether, if that were the case, that would improve your whole experience as a carer and make things a bit better. If it would, how can we change things? What would bring that about?

Helen Spalding: Can we just be clear, who would be in the triangle, please?

The Lord Bishop of Carlisle: Yes—you, your daughter and care professionals.

Helen Spalding: The first problem that jumps into my head is that my daughter lacks capacity. She is 23 years old and, so often, what happens is that professionals come in or meet her at her day service to carry out an assessment. They have to ask her and involve her. A lot of the time—I do not mean to be rude or sound awful—it is a waste of time, because she lacks capacity.

Often, when people lack capacity, instead of trying to tick their boxes, professionals might be better off exercising a bit of common sense and saying, "We accept the situation here." I almost want to say "leaving her out". It sounds awful to put it like that but, if she lacks capacity to take part, it is really a waste of time trying to get her to take part.

The reason they try to get my daughter to take part is because of her human rights, but it seems a bit foolish, really, since all she will offer is something that does not mean anything. It might be something she saw on "Postman Pat" the day before, or she might go off on a complete tangent and start talking about a horse she has just groomed. It is completely irrelevant and it just wastes time.

I understand, by the way, that we all need to be mindful of human rights in these situations. I am not dissing a person's human rights, but sometimes professionals and care professionals get so wrapped up in the issue of human rights that, when my daughter says something quite ridiculous—I will have explained why it is ridiculous; I will have already had those conversations—they have to investigate that further and try to make it work.

The Lord Bishop of Carlisle: There needs to be a sensitivity to the circumstances and the situation.

Helen Spalding: There really does. A triangle of care is brilliant from the point of view of carers being recognised and involved, as Katy was pointing out earlier, but we need to be sensitive and mindful that, sometimes, the person being cared for cannot contribute that much. We need to be careful with what they contribute, because it might not be in their best interests.

The Lord Bishop of Carlisle: That is a very helpful corrective. Thank you very much.

Helen Spalding: I hope that is helpful.

The Lord Bishop of Carlisle: Yes, very.

The Chair: Yes, we need to know the reality, Helen, so what you say strikes a very important chord with us about balancing ideal situations and circumstances with real ones. It is important for us to hear that.

Q138 **Lord Laming:** Norman, it will not be a surprise to you that we want to talk about hospital discharge arrangements. It is very timely so far as your experience is concerned. Much of the evidence that we have had is that it is an anxiety-provoking time for many carers, because the decisions are made without consulting them, and they are presented with a decision with which they have not been involved in any way.

We have heard some good examples of hospital advisers; I know you have experience of something similar in Hertfordshire. If we were going to make the discharge arrangements a much better experience for carers, what would be the essential steps to achieve that?

Norman Phillips: They start the planning from the minute the person is admitted, and they engage with the unpaid carer immediately to get the background and everything else. There are pre-Covid and Covid times. In Covid times, the whole thing has just collapsed in a nasty heap, so let us forget about Covid, although we cannot.

When the person is coming out, they need to talk to us about what is going to be done and what changes we can expect, including to medication. They wanted to discharge my wife last Friday to home and I said to them, "Her leg is straight out in front of her. We can't get her in the door, let alone anywhere else", so they then decided to send her to rehab. Had I not said anything, we would have ended up with an ambulance and a patient here who could not have got into the bungalow. She could have got into a bit of the bungalow but she could not have moved around in the bungalow.

It is about that communication up front. Pre Covid, in my experience, a nurse would sit down and go through things with you, with Ros present, so you understood exactly what you were going to do, what you were being asked to do and where you could go to get advice if it started to come unglued.

Sometimes they mess about with medication. I was once told by a Dutch doctor that they call it "huisarts" in Holland because medicine is an art, not a science. You get that feeling, because every doctor you talk to has a different opinion about the medication and so on. We are not medically qualified, but that communication with us is to make sure that what we are being asked to do is safe for the person being discharged and we are not creating a revolving door so that the person ends up going back into hospital, as my wife did 14 times last year, within a few days. It was not because of what I was told but because she was given the wrong treatment. They were treating the wrong thing and it took them the best part of 12 months to get to a point where they were treating her.

The problem I then had was that they thought I was being fussy. I was treated like that because she kept ending up going back into hospital. They said, "You're not trying", and I said, "What do you mean, I'm not trying? She's sick. She's unconscious." It is that toing and froing that goes on. Give us the information and listen to what we say.

Lord Laming: We have had information about, in some parts of the country, the health service appointing hospital advisers who talk to the carer and the patient about planning the discharge, which seems to work well. Have you any experience of that yourself in the number of times your wife has been discharged from hospital? Have you been engaged in that process?

Norman Phillips: Pre Covid, yes. During Covid, as I said, our local hospital has fallen in a heap, because it just has too many people to deal with. That is the problem. It is under such pressure to clear the beds.

Lord Laming: But pre Covid and now, are you satisfied that you get all the information that you need and that your circumstances will be considered?

Norman Phillips: I would say, pre Covid, yes. Following the safeguarding review, in that discussion, we went through all those issues, and Lister Hospital has promised that it will reinstate that interaction with unpaid carers. It is going to be a resourcing issue, because it means that you are going to take a nurse offline for 45 minutes to an hour to talk to an unpaid carer. In my mind, that one hour is a good investment if the person does not bounce back into hospital for another five days within five days.

Q139 **Baroness Eaton:** We have heard quite a lot already this afternoon about the relationship that carers have with the professionals, but I would like to ask you a bit more about the relationship with peer groups. I wonder whether Katy could let us know how effective peer support is in helping carers deal with the issues you have, such as loneliness, self-identification or navigation. Are there other roles that peer support can play for carers? How can organisations provide peer support? How can they help it grow and become more widely available to carers?

Katy Styles: We have already heard from Helen that the information she gets as a parent carer, together with other parent carers, is of the most value. It is when carers are supporting other carers that we find we are not alone, which is quite a revelation in itself, and we no longer feel isolated.

Especially at the moment, there is a case for both online and offline peer support. We have to be mindful that there are still people shielding, and we do not often hear their voices or those of their carers. It is very important that we also look at rural communities, which I know you have mentioned in previous sessions, and the fact that there is a great digital divide. We need to look at that when we look at peer support.

We should not be looking only for carer-to-carer support. It might be that you pick up your best support from your swimming group, your choir, your church or whatever it is, because carers do not necessarily want to be talking about care 100% of the time. That is something to put in the mix. There is definitely a place for social prescribing, but it has to be sensitive.

In terms of volume and increasing peer support, there are companies such as Mobilise; I do not know whether you have come across it. It runs an entirely digital offer for carers, with one-to-one calls, so carers can talk to other carers, and online support. The organisation I set up, which is a form of peer support, is more to do with advocacy and then helping carers who have not spoken to their MP before. Building their confidence and allowing them to believe that they have something of value to say, like us today, is vital.

How can we build things? Organisations such as mine need money and it is really hard to get funding for these things, so we have to be more flexible in the amounts of grants and the ability to get grants, but people are so strapped for cash at the moment. It is really hard. I am chasing money, grants and things like that all the time. We need to be a bit more flexible, because I may not be providing peer-to-peer support, but what I am doing is vital for carers to get them a bigger voice, get them heard and get them in front of committees such as this.

The Chair: Katy, before we leave that, may I just ask you where you are looking for money from? Are you looking for it from charitable sources or are there local and community grants?

Katy Styles: It is really hard when you are a campaigning organisation, as you will be aware. We are apolitical but, as a campaigning organisation, it precludes you an awful lot of the time. I feel very lucky that we have had a grant from Oxfam, which has realised the value of what we are doing; it has something for poverty and for unpaid and paid care. That grant is running out. We do not charge carers for anything we do, knowing how much money they have, so I am always looking to the next thing. It is not easy to find local support because we are national.

The Chair: That is something for us to think about. There is something in the White Paper about enabling the voluntary sector, as I remember, so we need to ask questions about how we create resources that you can draw on to expand what you do and save the state and the rest of the community money. That is a personal reflection.

Q140 **Baroness Barker:** Norman, last time you impressed on us the financial difficulties that come with being a carer. Do you think that redesigning Carer's Allowance is sufficient to keep carers from falling into poverty? If it is not, what other changes to the benefits system do there need to be to enable carers to survive?

Norman Phillips: That is a challenge and a half. Pensioners lose carer's allowance the minute we get the state pension, but we are still denied the

right to work. If I go out to work, who looks after Ros? I cannot go out to work. That is just a basic unfairness. Is £160, or whatever it is these days, enough? Clearly it is not, because I went from earning £100,000 a year—and I could not finance Ros's care even back then—to £23,000 a year after my early retirement, so it is a bit of a shock.

As for redesigning it, it is about value. If the money spent on unpaid carers was seen as an investment because of the protection we put into the system, maybe people would think about it differently, but people see Carer's Allowance and the support of carers as a cost, because the mindset is not a prevention strategy but a crisis strategy. We have gone back to managing crises, rather than thinking about how we prevent all these people ending up in hospital and enable them to have a reasonable life. Someone has to do the work, but we are not seen as workers; we are seen as carers.

Redesigning it is fine, but it is simply a question of money at the end of the day. Someone—the state or whoever—has to say to people, "Please look after your family and we will help you to do that." I am not asking for glory life, but just being able to do some of the things that we did before would be handy.

I get more in Attendance Allowance than I do in carer's allowance, because Attendance Allowance is not taxed. The fact that I can get Attendance Allowance shows you the impact of being a carer. Your health is shot. In the cost of living crisis, one social worker told me, "You could always earn more money", so I said, "Great, I'll earn more money and you can pay £1,500 a week to take my wife into care", because she cannot stay on her own.

The system just does not join up; it does not think. It needs a root-and-branch rethink. We want to keep these people, my wife and everyone else, at home. We are not asking for everything but, if you think about it, if we really deliver £132 billion to the economy through the work we do, that saves every UK taxpayer about £900 a year in tax. Are you just going to abandon those people?

Baroness Barker: Thank you very much, Norman.

The Chair: Thank you very much indeed. That was a wonderful answer.

Q141 **Baroness Jolly:** The committee has put to you questions related to possible solutions to a number of challenges that have consistently come up during the inquiry. Are there any other key issues that the committee should acknowledge when it comes to improving the lives of unpaid carers?

I just want to throw something else in. About 10 years ago, BT had a really good reputation for looking after its employees who were carers. I have just had a quick look online and it appears that it no longer does that. I would be quite interested to know whether this committee could find out why.

Katy Styles: Keeping carers in employment is the best option, because they then have support from their employers, but it is just not possible for carers such as me, Helen or Norman to do that, because we are all doing full-time care. I do feel that there are stages of caring and a journey. If you are doing 20 hours a week, that is very different from doing the whole 24/7. I had to give up my career as a teacher, because it just was not flexible enough. No support that they could have thrown in would have allowed me to carry on with my career, because you have to be there in core hours, so there is that bit.

As for what else, there are probably two things. I will try to be as brief as I can. We have to, as Norman says, really value caring. Changing our mindset to one where we have a caring economy that values our care input is vital. It is that whole infrastructure argument that is going on in the United States at the moment, and I would really value a push towards that. It is about not just paid or unpaid care, but all of us together, because both parts have an impact.

The other thing that would improve carers' lives is some leadership, responsibility and ownership. By leadership, I talked about the Carers' Strategy and the fact that we do not have one, which still really grates with me. As for ownership, there is not one entity or one person looking after carers. A Carers' Champion would be brilliant, to hold other people to account. They could hold the Government, Ministers and everybody else to account and say, "You're not doing this for carers, and you should be."

We also need all that research, evaluation and monitoring that I spoke about in my previous session; otherwise you have things such as the Care Act that, while very well intentioned, do not work.

Norman Phillips: The only thing I would say—I have used this anecdote several times—is that, at the end of the day, we as carers need hope that something will change. My father was in III Corps, trying to get to Arnhem Bridge. I liken unpaid carers to 2 PARA. We have been on this bridge for a lot of years and we keep being told III Corps is coming to help us. All I would ask you to do is to tell us when III Corps will get here.

We are fighting the fight. We are fighting the battle. We are stopping NHS and social care being overwhelmed, but when is the help coming? We have been promised so much, from Dilnot to other things. If you could deliver one thing for carers, it would be hope that things are going to get better and that the system is going to value us. If you could give us that, I would come down there and I would buy you all a lovely bottle of champagne.

Helen Spalding: I do not think I have much to add, apart from to just add my voice to what has been said. We need to value unpaid carers in the UK. They are not valued. I was talking to a friend the other day and described unpaid carers as an unsung, largely unseen army. It is interesting that one of the questions I answered earlier was about the

fact that previously I had used the word "battle" in an answer, and Norman has just likened us to 2 PARA.

It really feels like that. When I talk to professionals, I am often made to feel that I am somehow dramatising or exaggerating the way that I feel when or if they ask me, "How are you feeling today, Helen?" I am beyond knackered, but what is the point of them asking me and of me answering if there is nothing that can be done about that?

We are lucky. We have respite, but I know families—there are many I could name straight off the top of my head—and friends of mine who care for young people and children. Some are single mums. They have not had a wink of sleep for 15 years. They have not had a full night's sleep, because the young person or child who they care for does not sleep throughout the night.

Those children are getting older. One lady has a son who is now 17. He has never had a full night's sleep. He sleeps for about two hours, but that is all he needs and he functions on that. That is all she gets, unless she can get one or two hours during the day, but she cannot get any support, any respite or a direct payment. She cannot get anything, because she is told that she does not meet the criteria. That is not unusual; it is normal. Families cannot qualify for the support. It is just complete madness.

All these things need to happen if anything is to change. We need to look at Carer's Allowance. We need to look at the attitudes up and down the country towards unpaid carers. Katy's idea of a Carers' Champion is a really good one. I have nothing new to add, sorry.

The Chair: You do not have to have anything new to add, Helen. We just learn from you all the time. We are drawing this part of the session to a conclusion. I just want to say what a privilege it is to have got to know you in the context of this inquiry and to have you share with us what your lives are like. Norman, I hope we can do something along the lines that you suggest. Certainly, we will do our very best to represent you, to amplify your experiences and to value what you and the people you speak for do.

We will certainly keep in touch with you, because all of us on the committee have been changed by the experience of what we have heard as well, so this is not something that we are going to just do and suddenly drop. There have been lots of wonderful ideas, but also lots of tremendously important experiences that you have shared this afternoon, as you did before. Thank you for your time. I know that, in your tiring lives, this is not an easy thing for you to find space to do, so I hope that things go well for you and your families. Believe me, we will stay in touch. Thank you so much.