HOUSE OF LORDS

Adult Social Care Committee

Corrected oral evidence: Adult social care

Monday 28 March 2022

3.40 pm

Watch the meeting

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

Evidence Session No. 4 Virtual hearing Questions 35 - 45

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.

Q35 **The Chair:** Good afternoon to the committee, and a very warm welcome to our experts by experience joining us today. This is our fourth oral evidence session of the Adult Social Care Committee. It is, of course, live on our webcast. We will have a transcript later on for you to have at your disposal. We have some apologies for absence today. Lord Polak cannot be with us. Lady Jolly and Lady Campbell are joining us later.

A very warm welcome to our three witnesses, Norman Phillips, Helen Spalding and Katy Styles. You are all incredibly welcome and we are very grateful for your time. I am sure, given your family responsibilities, that it is not that easy for you to make time for us today, but it is invaluable for this committee to hear from people who are doing the work of caring for family members. I know that you are all in very different situations and I am sure you will tell us all about that. We long to hear about how you are managing your lives, as well as looking after and supporting the people you care for.

I hope it is all right if I call you by your first names. We really are a very informal committee. You will know, because you have spoken to our clerks and had conversations with them, that the committee is looking at some of the deep-rooted challenges in social care, from the point of view of the people who are either receiving care or, like you, are providing support and enabling that care.

It is relatively unusual for us to be able to conduct these sorts of conversations because adult social care is a very hyperactive field. There are many people looking at many different aspects of it. It is very important that we get it right for the future, but the important thing is that we get it right for the people who are at the centre of the service and the people who, like you, make it all possible.

We are asking fundamental questions about the purpose of social care. What does the best social care look like for the people you know and for yourselves? Why is it relatively invisible compared with the health service? It is a term that has been used many times already in the course of the inquiry. Why is it so hard and such a struggle sometimes for you to get the support and the help that you need, either to be part of the wider workforce or community, or to do the best for the people you care for?

We need your help today to help us to understand what it is really like at the sharp end, whether you are caring for younger people, as some of you are, or for older people. Essentially, we are here to learn and listen. We need to ask the right questions, and we want you to tell us whether they are the right questions, and to pursue whatever answers there are so that we can be effective as a committee. We want to know what works, what does not work and why. That is the context.

I will start with a very basic question. As I said, we are interested in identifying how the experiences of people like you—the unpaid carers in the picture—impact on the outcomes of care for people who draw on care

and support and rely on you. Could you describe your experiences to the committee, and the sort of challenges that you have faced in your life as a family member and a carer? We know that the definitions and descriptions are difficult. Tell us how you want to be known and identified, and how you identify yourself and what it means to you to be a carer.

Katy Styles: Thank you, Baroness Andrews. I think it is relevant that I mention that I have been a carer since the age of five, but I did not understand that I have been a carer for 46 years of my life. I only identified as a carer eight years ago because my husband had been diagnosed with a form of motor neurone disease. I was actually in a meeting with a councillor, advocating for patients with motor neurone disease, and he said to me, "But, Katy, you are a carer". I had one of those light-bulb moments that we always hear about. Until that point I had been a daughter, a wife, a granddaughter and a niece to all the other people I have cared for.

That is fundamental. It is not knowing that what you are doing necessarily as a family member is caring. In my family that is what we did, and I thought everybody did that. It was not until much later in my life that I realised that perhaps not.

Officially identifying as a carer unlocks support. I do not particularly like the term, but I know that if I do not use it I do not have access to that support. I have had to learn to embrace it and celebrate it. That is where I am with that. The other problems I have had are that, if you do not identify, you are not signposted to any support. You are not signposted to the support that is available. I missed out on benefits such as carer's allowance for some years. I have missed out on carer's assessments for years. If you do not do that, you miss out on the support.

Because I also care for my mother, my carer's assessment does not really look at the other part of my caring role. It looks squarely at the part I play for my husband, who has a progressive degenerative illness. The stuff that I am increasingly doing for my elderly mother, who has had a series of mini-strokes and has found it more difficult in the pandemic, seems to be very invisible. That caused me an awful lot of stress at the start of the pandemic because she was not on anybody's vulnerable list. Neither of us is on any list to be able to access online shopping, get drugs more easily, vaccinations, or anything. It was quite difficult, and it is because that part is invisible.

She lives in a different part of Kent from me. She is only 30 miles away, but a different carer's support organisation runs the carer's assessment. Here in east Kent there is one organisation that does it. If I wanted a carer's assessment for my mother's care, I would have to go to another one, and they never talk or meet up. The onus is then on the carer to find the support that is available, in my case for my mother in Maidstone. That is another stress on me, to find out.

I suffer from quite a lot of guilt, because I am not helping my mum as much as I would like to help her. I am not able to sit down and have a leisurely lunch with her or sit out in the garden with her, because I am basically doing all the nuts and bolts of changing the sheets, taking away the laundry, doing her cleaning, helping with the gardening and getting her to her appointments, bearing in mind that I have to get back for my husband and help him as well. That is another issue.

If you do not mind me mentioning breaks, I do not know any carer that has had a break. I have not had a break or one day off in eight years. Indeed, I had surgery 10 days ago for a major eye operation. I was in the theatre at 6.30 and back home caring at 9.30, because there is no support. I would not have known where to get the support. I have a phone number for social services, and that is it. I do not know what that is available for, so it is difficult.

It would be remiss of me not to mention carers' finances, because that makes you invisible and impacts on absolutely everything. I went from being a full-time teacher to being a part-time teacher to accommodate my caring role, and then from a part-time teacher to no time and having to give up my job because it was not flexible enough. You have to be there in core hours. You have to be there during term time. If your husband has an issue or needs a medical appointment that is out of that time, you cannot support them.

I am on £67.60 a week now, having had £150 a day. It is a very different thing. I am lucky, because I actually get carer's allowance. There are so many carers who are not supported with carer's allowance. That has to change. It needs reform. If there is anything I can urge you to do, that would be it.

Q36 **The Chair:** It rather takes one's breath away to hear that catalogue. I have a couple of very specific questions. When did you give up teaching?

Katy Styles: I gave up teaching 10 years ago.

The Chair: You have been an unpaid carer on £67.50 a week.

Katy Styles: Yes, for eight of those years. I did not identify for two of them, when my husband was poorly.

The Chair: How did you get to identify? Did somebody advise you? How did you find out that you could identify as a carer?

Katy Styles: It was literally in the meeting that I mentioned at the start. The director of adult social services in Kent sat across from me and said, "Katy, you are a carer". That is how that happened.

The Chair: That is for your husband, which makes a stark contrast to the care you are providing for your mother. As you say, you are not on anybody's list.

Katy Styles: Yes, absolutely.

The Chair: Katy, I am sure that colleagues will want to follow up many of the things you have said. Let us digest what you have said, because there is an awful lot that we want to think about there. Thank you so much.

Norman, what is your experience? Thank you for sharing, as you did earlier today, your news that your wife is in recovery.

Norman Phillips: If I get a bit choked, I am sorry.

The Chair: I think we are all quite emotional when we hear these stories.

Norman Phillips: A week ago, I thought I was losing her. Today, with a bit of wind, it will be all right.

I was a senior manager in an IT company, working 60 hours a week. One day the road came up to meet me and I ended up in a hospital. They did one of those lifestyle things. When they went through it they said to me, "No one can do what you are attempting to do". Bear in mind that this was back in 2008 or so.

We had gone to social services for help, but we were told that we earned too much and we had a big house. I said, "I'm not asking you to pay for it. I just want you to help me", but I was told no, I had to do it myself. I provided care for my wife, et cetera, but as the job became more challenging at 60 hours a week and her illness became worse, I was putting more and more care in. It ended up costing us half our income just to keep her safe.

I had that day when the ground came up to meet me. They thought I had had a heart attack, but what happened was that my thyroid had stopped working. I decided to take early retirement. That was quite penal. If I could have done four more years, I would have had a pension of £50,000 a year. I have ended up with a pension of about £18,000 a year, so it is quite a financial hit.

I started looking after Ros when her health deteriorated. I had intended to be a consultant somewhere, but then I had two very bad accidents and ended up completely incapacitated. What made me laugh was that because I was incapacitated the social care system kicked in and, from getting no help, suddenly I had two carers four times a day. This might make you smile. When they came to do my first assessment—as I say, things have changed—in 2008 this very fierce lady walked into our bedroom, saw me in bed and said, "I understand you're not willing to look after your wife". I said, "It is not a question of not willing". I rolled the bedclothes back. I was in a cast from my toes to my hip. I said, "I can't stand up". Her attitude changed.

I started looking after Ros full-time as her health degenerated. She has multiple sclerosis and other problems. Then my mum developed cancer and other problems, and dementia, so I moved her out to Stevenage. I was looking after her. My best friend had prostate cancer. He had no family, so I looked after him as well. Unfortunately, during 2021, I lost

mum in May and Eddie in August. As I said earlier, I thought I was going to lose three in 12 months.

My background is as a project manager and troubleshooter, so I turn those skills on to the health and social care system. I drive them nuts, because I write out root cause analysis. I am anally retentive. There is nothing that has happened to my wife, to me or my friends that I do not have detailed in a book. I fire it into the system, which frustrates them, but it is the way I cope.

I volunteer at a hospital. I go round finding people who are caring. The last thing I say to them is, "Are you a carer? Are you involved in helping this person?" We have a chat. The system's answer to, "Are you a carer?" is to give you a carrier bag with—I think at the local hospital—32 pamphlets in it. Who in their right mind goes home and reads 32 pamphlets? I belong to a carers' group called Carers in Herts, as well as Carers UK and Age UK. Basically, I reach out to anyone who might help. If I can help them, it works two ways. I reached out to Carers in Herts, and that is where I got a lot of my information.

This is a silly thing, but had I known the rules I would not have had to spend all the money I spent. Because I had a joint bank account, and Ros and I had always worked like that, when they did the assessment they charged me for everything. If I had separated the bank accounts, I would not have had to. We would have still paid something but, given that I was earning £4,000 a month take-home and spending £2,000 a month on care costs, it was a nightmare.

In all honesty, when I got sick, I did not go bankrupt but I had to get an IVA (Individual Voluntary Arrangement). There was a discipline there, because Ros and I learned that it is not what you want, it is what you need. If you reduce your life to what you need, you can cope.

The Chair: Is that what you say to carers who come to you for advice and help?

Norman Phillips: Yes.

The Chair: Is that the best advice that you would give them?

Norman Phillips: The advice I give them is, "You have to make a decision. Are you willing to do this?" That is interesting, because it is the first question you get asked on carer's assessment. If you want a laugh, tell them that, no, you are not willing to be a carer. A social worker always steps over the question and completely ignores it.

I would say to someone, "If you're going to take it on, it is not 'Don't do it' but understand what you're taking on. It is a full-time, high-stress, high-skilled job for which you are going to get little or nothing in financial reward".

The Chair: I have a couple of questions, Norman. When did Ros develop MS, and did you become a carer almost immediately or did it grow

gradually?

Norman Phillips: Well, sort of. Ros has been ill for most of our married life. Unfortunately, Ros's immune system is shot to hell. Over a number of years, various things happened. I was dipping in and out of caring, but the MS took grip when she was 39. We had 10 good years when she did not need a lot of help, but unfortunately she picked up a bad infection. If you get a bad infection and you have MS, it activates the MS. The only problem is that you do not know where it is going to attack. Ros went into hospital for a UTI/sepsis able to walk to a frame and left hospital not able to walk.

The Chair: Oh dear. From what you said, you had more support from your voluntary organisations than you have had from the official statutory services.

Norman Phillips: I will not talk about health, because they wind me up. With social care, once I got into the system and I understood the game, we now have a permanent social worker. I think that is to shut me up, because I keep writing my root cause analysis.

The Chair: That book you have must strike the fear of God into them.

Norman Phillips: Yes. I try not to go to the director straightaway. I try to follow the process, but if the process does not deliver what my wife needs, I step up, but I do not hang on long. I may wait a month or two months. If I do not have an answer by then, or even an idea when I might get an answer—

The Chair: Norman, I could spend another hour with you, but I had better move on to Helen. I know that my colleagues are deeply impatient to ask their questions as well. I will leave it there for now and ask Helen to share her experiences with us. Thank you so much, Norman.

Helen Spalding: Good afternoon. Thank you so much. It is such a privilege to be able to share my experiences here this afternoon.

I am not sure where to start. My daughter is 23. I am a parent carer for my daughter. She has severe learning disabilities, so although she is 23 it is often more like looking after a four year-old, give or take. A lot of her behaviour depends on the environment, the task and who is around her. Without going into too much detail, it became apparent that she was going to have some kind of lifelong problem at six months old. Suddenly she was referred to a geneticist, to cardiology, physiotherapy, occupational therapy and speech therapy. We were given a paediatrician. There was audiology as well, because she was not hearing.

I have been a carer now for 23 years. It has been battle after battle after battle, but I get so much joy from my daughter. She has taught me so much. She has an older brother; I have two children. He said, with no prompting from me at all, that he has learned an awful lot from his sister. That is lovely.

I do not really know what to say. Social services are next to useless. I have to go to social services, because every time we need something it has to be obtained through them. They are the gatekeepers. That is the process you have to go through. Now I am terrified. I get so anxious about it. I just do not want to talk to them. Usually, what I do now is research things. I know what I need, so I do as much research as I can myself. I talk to other parents. Whatever I am looking for, I go to the services or the organisations and get as much knowledge as I can, so that when I go to social services I can say to them, "Look, this is what we want. This is what we need".

The Chair: What are you terrified of? Is it whether they will cap the benefit or push you off in the wrong direction? Are they dismissive? Do they make you feel small?

Helen Spalding: All of the above, Baroness Andrews. You have pretty much hit the nail on the head. It is everything. I feel intimidated by them. I feel belittled by them. "Belittled" is a very good word. I feel that they do not listen if we have an assessment, and we have had lots of them, just to get some respite and a break.

The Chair: Have you been able to get respite? Sorry for interrupting you, but what you are saying is very important.

Helen Spalding: We were not able to get anything. I do not know whether it was available countrywide, but our authority for a number of years offered what they called a babysitting service. We had four hours a month. The problem with that was that they said, "If you don't use it, you'll lose it". It worked fine for a number of years while my daughter was little. Then the local authority gave it out to a private agency and that is when the problems started. I do not know if that service is still running.

I had to flee our domestic situation with my daughter and my son because of domestic abuse. We moved not a million miles away from where we had been living, but we moved into a different area of Wiltshire so I lost my social worker. I lost the support—the four hours a month—because we had moved into a city, we moved into Salisbury. There were far more opportunities for my daughter to plug into groups, clubs and things—it was a fair point—but I could still have done with the four hours a month and I could not get it back. It was impossible.

I always feel that I am lying. I always feel that they do not believe me, that I am making it up or that I am somehow exaggerating it. What tends to happen is that I have an assessment and I am completely honest. I never see the same face twice.

The Chair: You do not have a named social worker.

Helen Spalding: If and when we have a social worker, they are around for six months, maybe a year or two years, and then they move on. I think two years is the longest that we have ever had a social worker.

When I was having assessment after assessment trying to get a respite or some kind of a break, it was a different person every time. We did not have a social worker then, because they said that you could only have a social worker if you had a service. We did not have a service; I was trying to get a service, so we did not have a social worker.

What I would get is the paperwork after the assessment, and it would often look completely different from my memory of the conversations. In conversations, for example, I might say to a social worker, "Look, I'm incredibly tired. I'm sure my daughter is tired of me. We're at the point now where we're just shouting at each other. I can't do this any more without a break". The assessment would come back saying, "Helen said she was tired", and that would be the conversation. "Helen said she was at breaking point". For years and years they said that we were not eligible for any kind of a respite. I would say to them, "But that's nonsense. Of course we're eligible".

The Chair: Oh dear, I am awfully sorry, Helen, but I must stop. I have to offer you up to my colleagues, because I know they will want to follow up these questions. Thank you so much. My goodness me. Lord Laming, would you like to take on the questioning at this point to Katy, and other colleagues can chip in as well. Thank you so much, Helen.

Q37 **Lord Laming:** Thank you, Chair. Katy, I want to ask you a small number of questions that might seem self-evident but, as the Chair indicated, we do not want to make assumptions. We want to hear from the people who actually experience this, in your words.

One of the things that has struck us all is that unpaid caring is not something that one thinks of in one's lifetime plan. It is just thrust upon you because circumstances change. You have had wide experience of caring, and you were a teacher. Caring must have had a huge impact on your whole lifestyle.

Katy Styles: Absolutely. I do not think I have any choice. There is no choice for me in the hours that I provide in care, the shifts I do or the holiday I take. If you look at caring as a job, which I think it is because it takes up all my time as a job would do, and I am used to working long hours in teaching with preparation and things like that, nothing prepares you for the weariness, stress and frustrations, but obviously with some joy, that caring takes out of you.

As I said, I made a choice two weeks ago about whether I was sedated for a hospital appointment because I knew I had to get back. I very strongly feel that your choices are taken away: my choices to be promoted and have an occupational pension; my choice to enrich my life; and my choice to be warm, eat well and exercise as much as I would like. All those choices are taken away, as is my choice to sit where you are and to have a political career. It is very difficult. You need to change your mindset to be able to survive. You need to think about living in the moment and, as colleagues said, just looking at what you need and not what you want. That is very important for carers.

Lord Laming: There are two things, Katy, that come through from that. Am I right in thinking that, first of all, there is unremitting demand every day all the time and, secondly, there is a closing down of all the other opportunities in your life?

Katy Styles: Absolutely. That has hit the nail on the head. It is the relentlessness. I know that it is only going to get worse because my husband has a progressive degenerative disease, and he is showing signs that things are deteriorating for him. My mother is getting worse, and I know that I will need to step up and try to fit in more hours of care for her. There is that part of it.

Then there is the whole isolation of being a carer and feeling that you are on your own. It is lovely to meet other colleagues today, and there are ways of doing that digitally. It has been fantastic, but it is still pretty isolating when friends and family who are not doing caring do not understand what you are going through and do not understand why you cannot come for lunch or cannot come out and do things. Your whole world shrinks.

Lord Laming: You are clearly of absolutely central importance to your husband's life. You are of central importance to your mother's life. Are your views sought by the authorities? Do you feel that the importance you have in their lives is recognised by the authorities that you have to deal with?

Katy Styles: In terms of the NHS, I have to say, yes, on the whole for my husband's care because it is highly specialised, and they look to the carer to reiterate. You are treated more like the equal provider partner that you really are. In my mother's care, no. When I have taken her to appointments and things like that, I have said, "No, my mum has clearly had a stroke because she does not normally walk like this, she is articulate and she speaks and remembers things". It is having that battle and saying, "No, this is not normal behaviour for my mum", and trying to persuade her doctor as well. She can put on a really good show, as we all can, but that is not what is going on underneath.

There are degrees of it. In some aspects of my caring, yes, I am recognised, but in other bits, absolutely not. With my own care, I find it very annoying that you are given appointments at nine o'clock in the morning. People do not think about your caring role. I can manage at 10 or 11, but I cannot manage at nine because I have to get my husband ready and sorted and me out the door. There is a whole range of things that could be done by the NHS to actually consider carers whenever they see one.

Lord Laming: That leads me to my next question. You clearly have some needs in your own right. You are a human being in your own right. Does anybody ask you what your needs are, and how they might meet some of your needs?

Katy Styles: I get that once a year in my carer's assessment. I have to wait 12 months for that to happen.

Lord Laming: Does it result in your needs being met?

Katy Styles: No, but I feel like somebody has heard me. I think that is sometimes as important. Helen was saying that she did not think that people believed her. Having that point in my year, when I know that somebody is going to listen to me, much like today, to explain how my life has been impacted is important. But my needs are not met. The carer support organisation that we have where I live does things like cream teas and knitting. I would rather be on a paddleboard, surfing or doing something like that, or going away camping. Whatever it is, no one support system supports us all.

Lord Laming: My last question, because time is going on, is this. I imagine that being an unpaid carer can be a lonely business. Do you get all the information you need about forms of help and where to go for this, that or the other, or do you have to find out all these things for yourself?

Katy Styles: You have to mine that information yourself. It is through having networks with other carers and other organisations. I have to say that I am running my own carers' campaign, so I get to speak to an awful lot of carers, and we support each other and that is lovely. The onus is on me to find that. It is always down to you. The buck is passed, and it is passed back to me.

Lord Laming: It is wonderful that you have been so helpful. Thank you.

Q38 **Baroness Fraser of Craigmaddie:** Katy, you very clearly illustrated the difference in attitude between how people see you as a carer for your husband and how people see you as a carer for your mother, or not. Helen, did you notice any difference when Maja became an adult in how she was treated and what role you had in her life? I wonder if you could briefly speak about that.

Helen Spalding: Thank you. When my daughter was assessed as an adult at 18, that is when we got regular respite, because she needed it. That is great, but I sat there and said to the social worker, "This is brilliant and I am not ungrateful for it at all, but what has changed?" Nothing had changed. I had been battling for that respite for six years. I had had assessment after assessment after assessment. Nothing had changed, but she turned 18 and suddenly she needed it, so she got it. We got it, which was great. I think that often parent carers of children are just viewed as parents, and what is the big difference? Okay, so they need a bit of equipment and a bit more care. Often, they do not get understanding. People do not understand the gravity of a family's situation.

There will be other siblings as well, usually. My son missed out no end. I could not spend time with him, because I had to dedicate my time to my daughter. She needs 24-hour care. You cannot leave her on her own, even now. She cannot even cross a road. It is like having a toddler in the

house. But yes, you are right, things did change when she turned 18. The other side of that is that, when they turn 18, they suddenly have to pay for anything they are given as well.

Baroness Fraser of Craigmaddie: I am really interested that you have given us a positive story, which is great. Quite often, we hear that parents sometimes lose that consultative role. Maybe this goes back to identification and seeing yourself as a carer rather than as a parent of either a child or an adult.

The Chair: Thank you very much for the question. I think that is one of your transition issues.

Q39 **The Lord Bishop of Carlisle:** Helen, this question is for you. You have talked very powerfully about your relationship with your daughter and made it pretty clear that certainly up until the age of 18, and to some extent thereafter, as you were just saying, social services have not been able to provide you with very much help when it comes to caring for her. You said that you were terrified to talk to them, and you felt that they did not believe what you were saying.

Part of our task is to try to change some of this. What most needs to change? From your experience, what would make the biggest difference not only to you but to people in the same kind of position as you, so that things can be better?

Helen Spalding: Honestly, I am not entirely sure. All I can tell you about are my experiences now. What seems to happen is that I talk to a social worker, and I feel that they are listening to me, and I feel that there might be a chance of us getting whatever it is we are asking for. Usually, the answer comes back on a piece of paper saying no, with a brief description of what happened during our meeting that somehow seems completely different from my memory of that meeting and the conversation that took place. I am not sure how you can change that. It is about people.

The Lord Bishop of Carlisle: You think it is as much about attitude and being heard and understood as about the practical things that are provided.

Helen Spalding: I think so, yes.

The Lord Bishop of Carlisle: That is very helpful. Norman, is that something you would agree with?

Norman Phillips: I can tell in five minutes whether it is going to go well with social services or not. If they see me and my wife as a problem to be solved, they behave in that way and you can feel the defences go up because you are going to ask for something they do not have the budget to deliver or whatever.

I must admit that I have a very good social worker—a lady called Maurilyn —and she approaches us as part of a team. The system should

treat us as the bedrock of healthcare and social care, because that is what we are. Without us, the whole thing falls into a hole. A good social worker, a good nurse or a good doctor talks to you, asks what your problems are and asks what you need. A poor social worker or a poor doctor starts from the point of view, "This person is a pain in the backside, and they're going to ask us for stuff that we don't have the budget to deliver anyway, so go away".

If you get that sense, you can imagine how hostile it is. I do lectures for social workers and nurses at the University of Hertfordshire on the joys of being an unpaid carer. I try to say, "See the person, see the family and see what it is they are trying to do. Try walking in their shoes. All they are trying to do is their best".

There is another little chit-chat I do. I say to groups, "I would like you to thank me for the £870 a year I save you on your taxes. If my colleagues and I—all 6 million of us—were not delivering unpaid care, it would roughly work out to about £870 a year extra in income tax for the rest of you". It is a bit facetious and a bit numbery, but at the end of the day we are people trying to do the best we can.

The Lord Bishop of Carlisle: Thank you very much indeed. Is that change in attitude and a greater understanding of the needs of carers and those who are being cared for part of what you are campaigning for, Katy?

Katy Styles: Yes. It is about getting the voices of unpaid carers in front of decision-makers like you to tell their truths and to be treated equally. We are capable of strategic work, although we might need a bit of training, but we are never equal partners in that. There are always places for paid professional social workers and social care experts, but we are not at the same level, or not seen at the same level. I totally refute that. I have put carers in front of Ministers. They have been fantastic. We all know what we need; we just need to be listened to.

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

Q40 **Baroness Barker:** My question is specifically for Norman. I noted earlier your comments about the NHS as opposed to social care. We hear politicians talk about carers a lot. They talk about more money, breaks and all the kind of stuff you mentioned, but what do you think are the crucial things that would bring about a tangible change in your circumstances in having to cope as you do?

Norman Phillips: On the financial part, as a pensioner the minute I got to 65 they took away my carer's allowance because they said I was double-dipping the system. At the other end of caring, which is something I have come up to now because they thought my wife was going, is the cliff edge. For the person you love and have cared for, everything is taken away from you within a week.

Baroness Barker: When the person dies?

Norman Phillips: Yes. There is no transition. If we could get a transition period, not for ever—just two or three months—we could get back on our feet. Listening to my colleagues or fellow carers, particularly Helen, I know how rough it is for parent carers. I think that being an adult carer is tough, but when I see the horrors that parent carers go through, I do not know how they cope.

Having said that, there is no point in giving me extra breaks. I am lucky. I get two six-hour breaks a week. I was helped by the psychiatrist, because they wrote to the system to say, "With the stresses and strains Mr Phillips is under, he is near-suicidal, so you either help him or he isn't going to be around to help the person". I literally was at my wits' end. I did not know how to cope. Breaks are good, but I do not want to end up wandering the streets. I do lots of little bits and pieces. I do not want to end up wandering the streets for six hours just so that someone can sit with my wife. I want to be able to do something meaningful. It is not a lot of money.

Recognise the role of the carer. We are in a triangle of care. Treat us as team players; do not make us fight for everything. To give a little example, my wife was pressing the alarm all the time, so we were getting threatening letters from the local authority for inappropriate use. I said, "Well, let me move my bed back into my wife's room". It took two years of arguing, and eventually they allowed me to do that. Since then, my wife has not pressed the alarm once, because if she wakes up and is scared I am there instantly, whereas before she was pressing the alarm and I was being shaken awake by two wardens standing over me.

The other thing that could help is for the system truly to work together. I have had to ask health and social care professionals to leave my wife's bedroom, because they were arguing with each other about who would pay for a piece of equipment. They do not use bad language, but unfortunately they forget that the person they are talking about is lying in the bed. Then the person feels a burden; they feel guilty. They are the last people who should feel that.

A piece of equipment was needed. It took four years of fighting and there were two safeguarding issues. Because the carers had the wrong equipment, they dropped her; they smashed one ankle one year, which was pinned, and the following year they smashed the other ankle because of the same problem of inappropriate equipment. My wife ended up with a PE and, God bless her, lifelong anticoagulant treatment. It is crazy; it just does not make sense when you look at the cost of the equipment and the cost of the hospital treatment.

It became an argument about who paid. Is it social care? Is it the NHS? They argued. I said to the directors of both systems, "It would help if your people didn't hate each other". That starts from the top. If you listen to the healthcare system and the social care system at very senior levels, they talk very negatively about their colleagues and that permeates the system, and it is wrong.

Baroness Barker: Thank you.

The Chair: Thank you, Norman. We are listening very intently to all of this, as I am sure you understand.

Baroness Shephard of Northwold: I am tremendously moved by hearing everything our three experts have said today. What has struck me about their evidence is that they keep talking in quotations that we will have to use in our report. Absolutely key phrases have been used, with such illumination. For example, Norman has just said that social services and health people hate each other. That has been my experience. It is a question of budgets, and the patient or the person being cared for is the last thing that seems to matter in the duel.

I am not going to ask another question. I am so moved by what all of you have said. I am glad that this is a special day for Norman, and I pray that it will continue to be a special day. Thank you so much. When we come to the write-up of the things you have said and you see our report, I think you will find yourselves quoted throughout, with the actual sentences and phrases you have used. Thank you.

The Chair: Thank you, Lady Shephard, that was beautifully said. You spoke for all of us.

Q41 **Baroness Eaton:** I found hearing you distressing, Helen, and I can only imagine, because none of us has had that experience, all you must be going through daily in caring for your daughter.

I was going to ask you about how well you thought you were listened to. Clearly, from what you said, you are not listened to at all. How do you feel that situation affects your relationship with the person you care for, and how would you describe that relationship to someone who perhaps you have not met but are going to talk to about it? How would you describe the relationship you have? Does the system in any way answer the needs you have in caring for your daughter? Is there anything in particular where you feel that something would have made a big difference if they had listened to what you had to say?

Helen Spalding: I will try to answer all of that. Forgive me if—

Baroness Eaton: Sorry. It was rather a lot in one go.

Helen Spalding: That is okay. I think my relationship with my daughter is very instinctive. We are extremely close. My daughter has some communication problems. She can talk, she is verbal, although often when she is tired most people would not be able to understand her, but 99% of the time I understand her. I instinctively know what she needs and wants, often before she needs and wants it herself. Very early on, I started to realise that I was almost pre-empting in every situation what was going to happen next, as you would with a very small child. That is not what she is. She is a grown woman, but essentially we are dealing with an adult-size toddler, so that is what I do. I pre-empt: "Hang on. I

just have to move that chair out of the way". "What are you doing that for? Oh".

My relationship with Maja is instinctive. I am very close to her, as she is to me. I think that is partly what people find so difficult to understand, especially now that she is an adult. As an adult, even if she lacks capacity, which she does, she now has to be asked her opinion and what she wants and what she needs. That is great, and good, and I agree that she should have some input into discussions about her life, but it can also be a bit short-sighted, because she lacks capacity. For example, if Maja was here now and I said, "Maja, what do you want from your life?", she would probably beam from ear to ear, bless her, and tell you that she wants to learn to drive, she wants a big white van, she wants two dogs and she wants to live by the sea. Most of those things cannot happen. She cannot learn to drive. She cannot even cross a road. She lacks capacity.

She goes into meetings with social workers. They ask her things and she gives answers, and then I am the bad person because afterwards they come to me and say, "Well, Maja says—". For example, we have had a huge battle over something. Maja said that she wants to see her father. Of course she wants to see her father. She is essentially a little girl and she misses her dad, but she cannot see her father because her father is unsafe for her to be around, which was why we left him. That is another battle I had with social services. Then I was investigated by the safeguarding team here in Wiltshire because I was abusing her human rights by not allowing her to see her father. No, I was not; I was safeguarding her.

Baroness Eaton: It is a great dilemma, is it not, between the social worker's attitude to the person being cared for and the carer? I had a totally different experience. When my father was old they would not arrange his chiropody treatment through me because he was capable of arranging it himself, but then he could not remember when it was and could not pay the chiropodist. My situation is of absolutely no consequence, but it is the same sort of thing. They are listening to Maja without putting you and her together in context. I see that. Thank you.

Q42 **Baroness Warwick of Undercliffe:** Helen, and all of you, it is not only moving but rather horrifying to hear the way the whole of the social care system seems to have let you down in some form or another.

Helen, my question is addressed to you specifically. It comes out very much in the last thing you said. Clearly, you have had little or no support, particularly since your daughter was an adult, but they also do not seem to recognise your knowledge of how your daughter can best benefit from services. It seems extraordinary to me that they do not recognise that those with limited capacity who in effect have full-time carers will not be able to answer questions. If they think you want a positive response, they will give you a positive response. It seems to me to be totally lacking in any understanding of that relationship.

Perhaps I could slightly turn this around. Is there anywhere where you have had recognition and some help has been given? You said right at the start that your daughter had access to all sorts of assessments and professionals when she was little, and suddenly it was realised that she needed help. Was that sustained during her childhood, and was any of it carried over? For example, I wonder what on earth your GP is doing. Do you get help from your GP? If there is hospital care at all, is there a hospital consultant with whom you have any kind of relationship? I am trying to find some peg that we might be able to hang something on, because it all sounds so bleak that it is tremendously difficult to know how to navigate through it on your behalf, if I can put it this way, to get something more positive.

Helen Spalding: Norman and Katy have definitely spoken about the huge difference between our experiences with the NHS and our experiences with social care. My experiences of the NHS are largely very good. We were referred to all kinds of people—consultants—very early on, and that was great. We did not get a diagnosis, unfortunately, until Maja was about eight. We got the diagnosis then because there had been advancements in the techniques used for genetic and chromosome testing and all of that. That is fine.

When my daughter became an adult all that changed, and it is now more difficult to navigate. As a child, everything went through the paediatrician, which was great, because you had one point of contact. I know that this afternoon is about social care, but with the NHS everything went through a paediatrician. We had an appointment with the paediatrician once a year and he would project manage. Norman spoke earlier about being a project manager; the paediatrician was like a project manager. He would say, "What's going on with ENT? What's going on with the physiotherapy now? When did you last see the cardiologist?"

When Maja turned 18, in many ways it was like falling off the edge of a cliff and now everything goes to the GP, but our GP surgery is quite big. Every time we go there we see a different GP. I see a lot of people nodding their heads. I have now spoken to some people and I know of a GP in that surgery who is a bit of an expert on disabilities, including learning disabilities, so I will request to see her in the future, but, as was said earlier, all the time the onus is on us to find out. We make a mistake or something happens and we say, "Gee whizz. Where do we go now? What do we do now?" It was only by having a chance conversation with somebody that I realised there was somebody at our surgery who might not specialise in disabilities but who seems to know an awful lot, so that is the GP I am going to request in future. The onus is always on us.

I have a situation with social care at the moment. I will not go into details, but the upshot is that the local authority has not paid the day service for a number of months. The day service contacted me about a week ago. That was the first I knew of any problem at all. I said, "What do you want me to do? Do you want me to chase the authority for the money?", and they said, "Yes". I thought, "Hang on a minute. You are the service and you are not being paid, but you want me to do it".

I rang up the local authority and they looked into it. It seemed that there had been a small misunderstanding and I thought it was finished with. It seems that no, it is not. Apparently, it is my responsibility to ensure that the correct contracts and agreements are put in place between the local authority and day services, and because I have been remiss in that responsibility I am now liable for the unpaid invoices. I did not want to go into that, but it is a good example of everything coming back to us all the time. I often think, "I am actually my daughter's carer. That is my role. I'm not a contracts manager.

Baroness Warwick of Undercliffe: Helen, given that you were not even aware that you were supposed to be the contract manager, who actually set the contract? Was it the local authority or the GP? What was the thinking?

Helen Spalding: I cannot answer that question, but give me a week and I will have the answer.

Baroness Warwick of Undercliffe: I do not want to set you any more work.

Helen Spalding: In a week's time, I will be an expert on who needs to do what.

Baroness Warwick of Undercliffe: But in a sense what you are really saying is that the great benefit of Maja being under 18 was that there was one person who took an interest in your daughter and you. Now she is 18, there is nobody taking a continual or dedicated interest in either your daughter or you, and there is a great big gap. We have talked in the committee about transitions and so on, of very different kinds, and clearly this is something we need to try to focus on. Thank you very much indeed. That was a very powerful example because it shows the way in which huge gaps can suddenly open up in front of you and you have no route out.

The Chair: Thank you, Lady Warwick. You identified a point of process where we can put some attention. That was extremely helpful.

Q43 **Lord Bradley:** Can I first add my voice to the huge thanks to our three guests this afternoon for the experiences they have shared with us? What we have heard this afternoon has been absolutely extraordinary.

I want to pick up the question initiated by the Lord Bishop of Carlisle on campaigning and direct my question initially to Katy, but obviously if Helen and Norman want to comment I would be pleased to hear their views as well. Katy, this is about your activities in your We Care campaign. I was particularly struck by the comment you made to the committee clerks that, "It's always people speaking for us rather than us at the important tables".

Do you think it is possible that unpaid carers exist as a group that is able to come together to claim better rights for you all, recognising and hearing what has been said this afternoon about the massive limitations

on your time and opportunities to do that? If it is, how would the community of unpaid carers benefit from coming together in such a way? How do you think it would be possible to organise together to progress such an agenda more widely across the country?

Katy Styles: That is a fascinating question. Thank you very much for asking me, and for referencing We Care. I spend a lot of my free time sorting that out.

It is absolutely possible for carers to get together. I proved that with my own campaign. We are not massive; we are grass-roots and volunteer-led, but carers are absolutely desperate to get their voices across. We do not necessarily need carer charities. They provide amazing support as organisations, but they are not speaking for me and the carers I represent when they are campaigning. If you are a paid member of staff, your testimony will never be the same as the three of us today giving what we know and our lived experience.

All I have been trying to do is get that lived experience on the TV, in the media and in front of politicians. I think we have been a bit broken by inaction across the entire sector for many years. If you are on your knees, but you think there is a way out of it and you can articulate that, it gives you a bit of hope. From what you have heard, at the moment there is no hope that things are getting better. They are deteriorating. That is important.

On coalescing, I have seen a shift change in the last couple of years by big organisations that are really interested in what grass-roots organisations like ours have achieved, putting lived experience, co-production and co-design at the heart of their campaigning. We now have a grant from Oxfam to support us, which is great. We have been talking to the Joseph Rowntree Foundation, because it realises that it has power and the ability to help support us and lift us up. If it shares a bit of its power, it gives us a leg up. That is really important.

On the final part of the question—forgive me if I have forgotten what it is—there are so many of us. I am hoping that through the census I will get a figure. I say on my header that there are 9 million carers. It could be 13.6 million. I am hoping that it is even more. We could be that powerful force, but campaigning costs. If we were in a job, we would be in a union and that union would be campaigning with us, but there is only so much I can do without some sort of backing and support and trying to work out how to do that for carers. We do not charge for anything we do, and we think that is important, but we cannot necessarily go to a protest because we have to bring the person we care for. We have to think about campaigning in different, creative ways, but I know it is possible. I am living it. It is a real passion, and I am sure we could do it if we had a bit more help.

Lord Bradley: I would be really grateful for any further thoughts you may have on how that support could come through to you, to make your campaigning more robust and broadly spread, but time is short this

afternoon. Please send the committee any further thoughts you have on that. I would be pleased to see them.

The Chair: Can I echo what Lord Bradley said? In case I forget to say it at the end, if there is anything you want to say about how we can act on the obstacles, barriers and shortcomings, please tell us. We need to know how, and then maybe we can amplify your voices.

Baroness Goudie: Katy, I know a lot about campaigning. I think that grass-roots campaigning as you are doing it is absolutely vital, working not quite street from street, but carer from carer. The examples you have shown us today are tragic. We know that the system is not quite broken, but I feel that it is broken in many respects. It lacks respect, and that is what we want today for all of you and other carers like you. Perhaps you could send the committee details of how individually you have been trying to campaign for the people you are looking after, because that is important. We heard examples earlier from Helen that she was meant to collect bills and that kind of thing. Nobody knows that unless we get the evidence, and then it will be seen by many more people. That is what I ask all of you.

The Chair: Thank you. It is very important to reinforce that point. We come, sadly, to our last question, but I am sure you must be quite drained because you have given us so much already.

Q44 **Baroness Fraser of Craigmaddie:** This has been an incredibly powerful session. As colleagues have said, we are keen to focus on the "how" question. All of you, not just Norman, have told us about the difficulties of navigating the system and stories about arguing and fighting. If you had not told us and we could not put it in evidence, I do not think many people would even consider that this happens, or maybe not enough people.

Norman, how has this affected your experience? On the "how" question, are there any particular pressure points that we should be looking at? You mentioned discharge from hospital with your wife. People have mentioned changes in geographical circumstances. There might be differences because of age when you become a pensioner, or the person you are caring for becomes an adult, a pensioner or whatever it might be. Are there any particular pressure points? Can you think of anything that would make the care system less confusing and more accessible for you and colleagues?

Norman Phillips: If you will pardon me for making this quick point, today can sound bleak, but you have to recognise the fantastic people who are care workers, the wages they work for and the skills that they have, and the doctors and nurses who try to keep us going. The problem in my mind is the system.

I used to do systems behaviour. It is the system that is wrong. We were promised that they would put the patient front and centre. Everything would work for the patient and you would build support, et cetera, et cetera. It needs root and branch reform. It needs to start with the

patient. The next person is the carer, and then you work with the front-line workers and slowly build up a sustainable system. At the moment, nearly all change is top-down driven. I worked on the patient records system. That was a top-down change that went horribly wrong and cost £12 billion for nothing.

The other thing I would do is take PCs away from the professionals. Tell them to talk to each other. Too many times, emails are launched into the system. I will give you an example. My wife was discharged from hospital. I will not show you the picture, but I can send it if you want. I will not show it because it might make you ill. The message that went out into the system was that Mrs Phillips had a small blister on her bottom. That was then triaged by social care, community nursing, et cetera, and by the time we managed to get on top of it—fortunately, she was not in a life-threatening situation—she had a category four lesion on her back. It was crazy. If you want the picture I will send it to you, but that is the problem.

We have excellent workers out there. When I see the people who come in to work with my wife, there are days when I cry. They are good people, but they have their own lives to lead. Here we are so short of staff that these guys are working 16 hours a day, and they have their own families. It is wrong. The community nurses who come out are under pressure. I know this is a bit political, but the system just is not funded. They are not sensible about it.

I will not mention the politician, but once I was standing next to him. He gave me all these platitudes about what they were going to do. Then he got his picture taken with the Carers UK banner and he lost interest and left. Has he done anything since? No. I am so sick of getting the standard letter about how well everything is going and the fact they have invested billions and everything else. The reality is that social care has had a reduction in funding of maybe 60%. I liken my life to sitting on the Titanic. At the moment, I am sitting on top of a funnel and I see all these other poor souls drowning, having their services taken away because the system cannot afford it. Every day, I live in fear that the water will come up to my feet, and then what will I do for my wife? That is what is upsetting.

None of us as carers is asking for the earth but just for a little bit of help. With a little bit of help, I might not have lost our house. It is about getting in front of the problem and recognising that it is a problem, and the "how" is a system rethink. Start with the person and build from the bottom up. Stop coming at us from the top down. I worked on the passport system, on Horizon—fortunately not for too long—and on any number of other projects. If you do top-down change, it always fails. It needs a bottom-up change. Talk to the guys delivering the service, not just unpaid carers but the care workers. There is a bit of snottiness, because they are seen as low-skilled, low-paid women. I have said to my MP, "Come and work for a day with these guys and see what they deliver

all day, every day". It is amazing. If there was a George Cross for caring, you would give it to these guys.

Baroness Fraser of Craigmaddie: Thank you so much. Helen or Katy, do you want to come in at all? That was very powerful evidence from Norman. I think "Not top-down but bottom-up, please" is the message we hear loud and clear.

Katy Styles: Norman expressed very well the inequity in parity of esteem between the NHS and social care. They have to be seen as equal and that can come only with equivalent funding. That is absolutely loud and clear.

One thing we have been advocating on the how bit, if you are trying to get carers' voices heard and get them more involved in the system, is a national carers strategy. At the moment, we do not have that. It is absolutely appalling, because there are so many of us, that there is no overarching strategy. That does need to be top down, because unless you have the message from the top saying that it is cross-departmental and carers need this, this and this, we are on a hiding to nothing. I advocate a national carers strategy. It is absolutely vital. In the interim, we have a rash of local authorities doing their own care strategies. There is a postcode lottery of national strategies. My authority in Kent has not done a new one for 13 years. Caring has changed, and people's jobs and pressures have changed, in those years.

Baroness Fraser of Craigmaddie: You mentioned earlier that there is a difference between east Kent and other parts of Kent.

Katy Styles: Absolutely.

Baroness Fraser of Craigmaddie: It is not even that there is a Kent strategy.

Katy Styles: Absolutely, and you have to know which bit of Kent you are in. There are five different Kent carer support organisations. If you do not know which bit it is and who to contact, you will not get even basic signposting.

Baroness Fraser of Craigmaddie: Thank you.

The Chair: There may be a distinction between leadership and top-down. What you are showing us, Katy, Norman and Helen, is leadership, and I think we can use that as well.

The last, but by no means least, question is from Baroness Campbell.

Q45 **Baroness Campbell of Surbiton:** First, I apologise to Katy, Helen and Norman for not being here at the beginning, because what I have heard since coming in has been not only a great privilege but has made me think of so many things that I want to say to you immediately. You are absolutely right to feel the way you do, but I am angry on your behalf for some of the things that have happened to you.

I want to ask you a particular question. What value do you think there is in people who are receiving care and support from their families or unpaid carers, if that is what you want to call this group, and those who actually receive services? I can honestly say that everything you have said that annoys you, frustrates you and sends you into despair sounds exactly the same to me as a person who receives 24-hour support, so I agree. I identify with you. I have been a campaigner for 30 years on disability rights. Why the hell do carers and those who support us, and us, not get together and actually campaign together? There is a lot of power in numbers.

What has kept us apart is exactly what you said: professionals speak to us and then they speak to carers, but we rarely all sit down together and talk about our lives at home and what we need to support us so that my husband can be my husband, my mother can be my mother, my sister can be my sister, and I get support that allows me to be an independent woman who does not want to feel that she is a burden on all these individuals. Have any of you thought about this? Is it something you would want? I am quite interested for you to tell me why, because we have the same issues, we do not work together in these areas.

I am sorry if that was a bit of a ramble, but I am a bit angry on your behalf at the moment. Maybe Katy or Norman would like to say something about it, too.

Norman Phillips: One of the things I have learned as my wife's carer is that I am not her mind, and I have to give her independence. Even that does not sound right. She is independent and I have to respect that, but there is always a danger as an unpaid carer who is task-driven, with so many things to do, that, if you are not very careful, you take that person's world away from them. It took me a long time to learn that.

My job is to support my wife when she wants support, not to decide what support she wants and then give it to her. That takes a lot of learning. One of the problems you get as an unpaid carer is that there is no school for being an unpaid carer. We are all learning, but we are learning by mistakes. Sometimes that is to the detriment of the person we are trying to help. We make them dependent when we should be doing our damnedest to help them be independent.

Baroness Campbell of Surbiton: Katy, do you think quite a lot about campaigning? What do you think? I noticed that you were nodding a lot when I asked why we were not out on the streets together. What about us? We are so invisible to a lot of people.

Katy Styles: Absolutely. Why aren't we? It would be fantastic. I do not know whether it is because we have been reliant on organisations to get us mobilised before, and they have not had those conversations between themselves, or whether there are certain disability charities that do not talk to other disability charities. I am sure there are carers charities that do not do the same things either. If we are all interested in creating

change, I absolutely agree that if we could come together with our cared-for we could have a protest that would be fantastic.

Baroness Campbell of Surbiton: Most people who require this care are disabled people. There are a lot of disability organisations and a lot of carers' organisations, but never the two shall come together. I think that sometimes charities themselves prevent that natural dialogue. I think you would find that a lot more unites us than divides us. Something the committee could explore would be getting people together to have these conversations about what we want as a family, all of us, because we all have rights.

Norman Phillips: Can I throw something in? I have been a trustee in a charity. I resigned, because it became obvious that the charities defend their positions. They compete with each other, and sometimes, instead of telling truth to power, they tell the truth they think power wants to hear. That is why we as carers have to come together.

Baroness Campbell of Surbiton: Norman, I think you and I could have a very good conversation. I have a lot of thoughts about the charitable sector. Thank you. That has been so helpful. It has helped me, because it is one of my little bugbears that we are prevented from coming together. Maybe that is because we would be far too powerful if we did. We keep hearing you saying that again and again throughout the session and it warms my heart. Thank you all.

The Chair: We have come to the end of what must have been an extraordinarily powerful session. I think you have heard from every member of the committee just how effective you have been. You have heard the words of anger and shock, but it is a deep privilege that you have been able to share this with us.

We have opened a dialogue. It is wonderful for you to meet each other. It is a bonus for us to have been able to facilitate that, and it is wonderful to be able to meet you and hear you at first hand. Helen, Katy and Norman, your lives are extraordinary. I hesitate to use the word "inspiration", because it is so overdone, but it has been inspiring as well as anger-making. Katy spoke about being "broken by inaction". We have to look to people to reconstruct the system. I was so glad that Norman paid tribute to the excellent people who are in the system and who must equally be frustrated.

When we keep searching for the "how", we will have your words and experience in front of us. We will come back to you and we will do our best. What you have articulated is not just on your behalf; it is on behalf of everybody in your situation. We would like to assist you in what we do and say. What can I say except thank you and take care of yourselves? We will be in touch with you in the next few months.