HOUSE OF COMMONS

Communities and Local Government Committee

Oral evidence: Adult Social Care, HC 47

Wednesday 16 November 2016

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Watch the session

Members present: Mr Clive Betts (Chair); Rushanara Ali; Bob Blackman; Kevin Hollinrake; Julian Knight; David Mackintosh; Melanie Onn; Mary Robinson

Questions 159-196

Witnesses

I: Emily Holzhausen, Director of Policy and Public Affairs, Carers UK; Cllr Rory Palmer, Lead Member for Adult Social Care, Leicester City Council; Dr Linda Pickard, Associate Professorial Research Fellow, Personal Social Services Research Unit, London School of Economics

II: Peter Turner, Chief Executive, Carers First (Kent and Medway); Margaret Dangoor, carer and carer representative; Lana Harber, carer; Christine Euman, carer

Examination of Witnesses

Emily Holzhausen, Cllr Rory Palmer and Dr Linda Pickard.

Chair: Good morning and welcome. This is an evidence session of the Committee's inquiry into the financial sustainability of social care and the quality of care provided. This morning the Committee is going to look at care and carers, and the important role they play, so we welcome both our panels who have come to give evidence. Thank you very much for coming. At the beginning, members of the Committee may have some particular interests to

put on the record. I am a vice-president of the Local Government Association.

David Mackintosh: I am a Northamptonshire county councillor.

Melanie Onn: I am a former employee of Unison and representative of carers therefore.

Kevin Hollinrake: I employ a councillor in my office, Chair.

Q159 **Chair:** Those are our particular interests. Could you say who you are and the organisation you represent?

Dr Pickard: I am Dr Linda Pickard. I am from the Personal Social Services Research Unit at the London School of Economics.

Cllr Palmer: Good Morning. I am Rory Palmer, Deputy City Mayor and Lead Member for Adult Social Care at Leicester City Council.

Emily Holzhausen: Good morning. I am Emily Holzhausen. I am Director of Policy at Carers UK, an organisation of carers.

Q160 **Chair:** Thank you for joining us. Just to begin, Dr Pickard, we have heard quite a lot about the rising demand in general for social care and the problems of paid-for care not keeping pace. But in terms of unpaid care, is that keeping pace with the demand? Is it likely to keep pace with demand in the future?

Dr Pickard: I have carried out research on the future supply of unpaid care in England to the early 2030s, drawing on demographic trends in the provision of unpaid care and trends in the numbers of older people. The research shows that the supply of unpaid care is unlikely to keep pace with demand in future, and there is likely to be a growing care gap. Can I just provide a definition of unpaid care?

Chair: Yes, of course.

Dr Pickard: We mean care provided by family or friends to people with long-term ill health or disability or problems related to old age. It is not just any care provided to family and friends; it is specifically care provided to people with long-term conditions. The main group of carers where a care gap was identified are intergenerational carers who provide care to their older parents aged 65 and older. Our focus has been on provision of intense care—that is, care provided for 20 or more hours a week—because this type of care is more likely to be provided to disabled older people, who are more likely to need formal services.

The shortfall in intergenerational carers is projected to emerge in 2017—that is, next year—and will grow rapidly from then onwards. The shortfall will amount to approximately 15,000 care providers in 2017, 50,000 in 2022, 105,000 in 2027 and 160,000 in 2032. The shortfall will mainly affect intergenerational care provided by children to their older parents, and there is not likely to be a shortfall in numbers of carers looking after older spouses. Care by spouses or partners is likely to keep pace with demand, primarily because projected improvements in male mortality are likely to lead to a fall in the number of widows. However, it is important

to note that the shortfall in intergenerational care that we have identified takes into account this increase in spouse care.
Demand for care by older parents from their children will increase because of the rise in older old people, the majority of whom do not have a spouse or partner, and this is likely still to be the case in the early 2030s. A key underlying reason why supply will not keep pace with demand is demographic factors, especially the rise in the so-called parent support ratio. Numbers of older people aged 85 and over in the UK are rising much faster than numbers in the younger generation aged 50 to 64.

Q161 **Chair:** Thank you very much for that. That is very helpful information for the Committee. Do other members of the panel have anything to add to that in terms of your experience and what you are finding?

Emily Holzhausen: We do a lot of research, which backs up a lot of Linda's findings. Overall, the amount of care has not kept pace with demand. We have seen a rise in the number of carers very significantly outstripping the general population growth. In the mid-range of people providing 20 to 49 hours a week, that has risen by 43% in the last 10 years. That is not without consequences.
When we look at the amount of care that is provided, Age UK, for example, found that 1 million people are going without the care that they need. They do not get it from friends or family, because they cannot, so there is an enormous gap. I can cover the impacts on carers now or later, if you like.

Chair: We will probably come on to that in due course.

Emily Holzhausen: Yes, of course, because it has an important effect on employment of those family members.

Cllr Palmer: I guess, Chair, we may come on to this later on, but the most worrying point, from my point of view from the demographic structure of the carers' population at the moment, is that as a fairly typical local authority we have knowledge and understanding of and contact with such a small proportion of carers. We provide support to around 2,200 carers in Leicester city. The 2011 census told us that there are around 30,000 people in the city identifying themselves as having some form of caring responsibility.

Chair: We probably will come on to that particular issue in more detail in due course, if that is okay.

Cllr Palmer: The demographic structure of caring in Leicester is clearly a challenge, as it is in most other places.

Q162 **David Mackintosh:** Do you think we are seeing more people having to step in to provide unpaid care and, if so, why?

Emily Holzhausen: Yes, absolutely. We have seen that the number of carers has risen to about 6.5 million. There are not just more carers; they are also providing much more care as well. The number of people

providing round-the-clock care—so 50 hours plus—has gone up. The number of people providing between 20 and 49 hours has gone up, too. The types of care that people are doing has also increased. We find that people are doing much more intensive care. The co-ordination of care between different bodies and between different people, between health and social care, is increasing against a backdrop of shrinking health services and publicly funded social care services.

We would say that we are seeing increasing pressure on families. Although many want to care, and they do willingly, for loved ones, they do not want the negative consequences of poor health, poor wellbeing and poverty at times, because they have to give up work to care, or the funds do not stretch. There is a very important issue here for families.

Cllr Palmer: I cannot evidence that with hard data from my local authority's point of view, but I can and do hear anecdotal accounts from carers who tell me that their caring responsibilities are growing for the reasons that Emily has described. A key point is rising acuity and complexity of need across parts of the population is putting new pressures on carers. Some families have told us that changes in care packages provided have led to an increased level and scope of responsibility and pressure on unpaid carers and families. That presents a real challenge to local government.

We know the social care funding environment is extremely challenging. We are having to do more in terms of meeting need, and it is really important we recognise that that need is not just around an increasing need around age profile. Often people assume it is just an ageing population. Actually, it is that growing acuity of need. People with complex conditions are living longer, which is clearly a great thing for society, but it is presenting real challenges to the providers of formal care and unpaid carers as well.

We are seeing increasing levels of care and complexity of care being provided. The reasons are numerous. One of the reasons is local authorities are finding themselves in an extremely difficult situation, having to look at care packages and reviewing care packages. That means some people will be in receipt of a lower level of formal care by the local authority. That clearly presents an additional pressure to families. The caveat I would put on that is, clearly, as a local authority, we have an obligation to meet need. We do meet the needs of both the people in receipt of care and the carers themselves. If we identify need, we meet it, but that is clearly becoming a challenge as that demand increases and our budget becomes more and more stretched.

Dr Pickard: I just wanted to make a general comment about the increase in the levels and complexity of care, which we have just heard about, and the care gap, which I talked about initially. An increase in provision of care in recent years is consistent with an emerging care gap for two reasons. First, the increase in the number of carers that we have just

heard about refers to the past period, between 2001 and 2015, whereas the care gap refers to the future—the period leading up to the 2030s.
Secondly, an increase in the number of carers in future is consistent with the care gap. The care gap evidence relates to the difference between the supply of care and demand for care. Although the number of carers may be rising, need for care may be rising faster. In our projections, the number of carers providing care to older parents rises by 20% between 2007 and 2032, but the number of older people needing care from their children rises three times that amount—by 60%.

Q163 **David Mackintosh:** Thank you. I think you have answered some of this already. There has always been a need for unpaid carers. Do you think that has now shifted so that we are seeing not just low-level care but more intensive caregiving?

Emily Holzhausen: Absolutely. There has been a rise in the 50 hours plus, as I said, round-the-clock care. From about 1985, approximately 700,000 people were doing it—it is a slightly different data set—and now there are over 1.4 million, so that is a very significant increase. The concern, I think, is the level of care that people are providing without the kind of backup and support that they need in order to keep healthy and well. Some of the carers we asked to come today were not able to because they were just too stretched within their care packages. One person had their first break for a very long time. It demonstrates the difficulty that people have in attending. I just wanted to thank the clerks for trying to make it possible for them to contribute. We are seeing significantly increased challenges.
One really interesting impact in this, which Linda has also talked about, is that people of working age are taking on greater responsibilities for caring for parents as a backup. As families, we do not live as close together as we used to. We need a mobile and flexible workforce generally in the UK, so people are moving for jobs, but that means caring at a distance, which places enormous strains on families and is a growing phenomenon. We are also seeing among employers a rising concern about the stress and health and welfare of their employees who are trying to juggle work and care. About 2 million people have given up work to care for someone, and employers are also counting the costs in terms of the bottom line.
Taking on increased care has a range of effects, as I said before, and I do not have to spell out what giving up work does to your future financial welfare as a carer. If I might also make a link to John Cridland's review of the state pension age and the rise in the state pension age, he is very concerned about the number of carers who might have to pick up care in those later years of life. They might not be able to work and have to come out of the labour market and not be able to contribute to their pension.
When we are talking about funding social care, we are not just talking about allowing families to get the support they need, and for disabled and

older people to be independent. We are talking about people like you and me being able to stay in a job and keep working as long as possible, having financial security and being able to have time with family members and concentrate on relationships, and the things that people count as a quality of life.

Q164 **Kevin Hollinrake:** I will direct my question, if I can, to Emily Holzhausen. Other panel members, please, if you have any additional comments, feel free to make those. Could you comment on the impact on unpaid carers in terms of physical and mental health and how you see those people being affected?

Emily Holzhausen: Thank you for asking that question. When we ask carers a range of different questions, very consistent answers come back. Those providing a lot of care are twice as likely to be in bad health, according to the census.

Q165 **Kevin Hollinrake:** Is that as a result of caring?

Emily Holzhausen: That do not say "as a result of caring", but when we ask that of those providing a lot of care—over 50 hours a week—just over half have suffered a physical injury. Of the similar sort of cohort of between 20 hours and more, around 78%/80% suffer from stress and depression.

Q166 **Kevin Hollinrake:** Is that as a result again of caring?

Emily Holzhausen: That is as a result of caring. If anyone has any experience of that, it is not just a transaction; it is quite often an emotional issue as well. We are also impacting in many ways on people's long-term health and wellbeing, and additional costs for the health service in those areas.

Employers that look at the health and wellbeing of their staff do see raised and additional stress at work, which affects health and wellbeing at work, which is something that the Chartered Institute of Personnel and Development has also raised.

Q167 **Kevin Hollinrake:** Do you have anything to add?

Cllr Palmer: Our local understanding would chime very much with that.

Dr Pickard: I do not have anything to add.

Q168 **Kevin Hollinrake:** The next question is for Dr Pickard. I think you have done quite a lot of research into the economic impacts of unpaid carers leaving work to become a carer or reducing hours. Could you try to quantify that: the direct cost to the economy of unpaid carers as opposed to if we funded this through taxation or through formal social care?

Dr Pickard: Just to step back a bit, being a carer does not just affect physical and mental health. It also affects the ability to work, which I think Emily mentioned earlier. Caring can have a negative effect on carers' ability to work, especially when care is provided for long hours. Our recent research using new longitudinal data, collected over time,

shows that carers looking after someone who does not receive paid services, like home care or day care, are more likely to leave employment because of caring.

Coming more directly on to your question, we have carried out an estimate that the public expenditure costs of carers leaving employment in England are at least £1.3 billion a year. This estimate was carried out in 2012 and it relates to lost taxes on forgone incomes and the cost of carers' allowance for carers who leave work because of caring. It is an underestimate, because it does not include all the benefits that carers leaving work may claim, such as income support and housing benefit, and it does not include lost national insurance contributions.

We are currently looking at the question of whether the public expenditure costs of carers leaving work are greater than the costs of providing social care to people cared for by working carers. That work is still in progress. What I can say, though, is that if there were greater public investment in social care and fewer carers left the labour market, public spending on benefits would be lower and revenues from taxation would be higher. £1.3 billion represents a substantial sum of money in terms of social care expenditure. It constitutes nearly 10% of current public spending on adult social care in England, which is currently around £15 billion a year.

Q169 **Kevin Hollinrake:** Has your survey included looking at ways we could support carers to stay in work?

Dr Pickard: I expect Emily will want to comment on this but, yes, we have looked at evidence of the effectiveness of paid services as a way of supporting carers. There is evidence, based on a large-scale national survey of 35,000 carers, that paid services for the person cared for, sometimes called replacement care, are effective in supporting carers' employment. The evidence shows that carers are more likely to be in employment if the person they look after receives services, including home help, home care, help from a personal assistant, day care, meals and short-term breaks or respite. Our recent longitudinal study also suggests that providing more paid services to adults who are cared for would help carers to stay in employment.

Many disabled and older adults cannot afford to pay for care, so if an objective is to reduce the number of carers leaving employment because of caring, there needs to be greater access to publicly funded services for the disabled and older people who are looked after by unpaid carers.

Q170 **Kevin Hollinrake:** Did you want to comment on that?

Emily Holzhausen: Yes. When we have asked people who have left work, or those who are still juggling work and care, "What is it that makes the difference?", nearly four out of 10 said that the lack of care services and being unable to find appropriate care services for their relative was the cause of leaving work. That is really important.

The other important element, outside the remit of this, is care-friendly employers. Carers are in the sphere childcare was in 20 years ago. We need to move the understanding along. Some employers are supportive, flexible and understanding. They make adjustments for different staff, but at the end of the day the care needs to be there.

I remember one carer saying, "The care services are so unpredictable. If the care assistant does not turn up and my mum is left in bed in the morning, I am left all day worrying how she is. Has she eaten? Has she taken her medication?" For families not living with relatives, in particular, or even if you do live with relatives, it is extremely stressful to juggle all of that.

Q171 **Kevin Hollinrake:** Is that an indictment of the quality of care people are receiving rather than the fact there is care? In the instances you are talking about, the care must be there; you are just not confident it is going to be provided properly.

Emily Holzhausen: It is a good point. It is both. I am sure you have taken evidence on the quality of care and also the commissioning arrangements and the care market. The care has to be there; it has to be affordable. There is certainly an issue, as Rory, I am sure, will also say, in that if someone cannot afford to buy in the care—if it does not exist—they are really in the worst position. They have no choice at all. It is an important issue.

Cllr Palmer: This whole issue for me has to be set against the broader backdrop of the whole way social care is organised and structured financially. We all want to be able to support carers to play their full part in society, whether that is through employment or through other opportunities. Clearly, the way to do that is to ensure that good, reliable, good-quality options for paid and formal care are available. We all know how fragile the care market is, and we all know that local government, as we currently find it, cannot step up financially to make that happen unless we radically rethink how we fund the system. We are all talking about very laudable objectives, which we want to secure, but as the system is today it is just not feasible to expect local government to able to step in and do that at the moment.

Q172 **Chair:** Dr Pickard, you mentioned you were going to do some new calculations of the total cost of people giving up work and claiming benefits etc. When will that work be ready? Do you know?

Dr Pickard: I do not really know. I am awfully sorry. We are still working on it and these things can take quite a bit of time. I am not sure whether it will be available within the timescale of the inquiry.

Q173 **Chair:** Are we likely to have any of your further work available for us, do you think? Even some interim findings probably would be helpful to the Committee if you have any.

Dr Pickard: The research we have done already points to £1.3 billion, and that is publicly available. I can send you the document we have for that, if you would like.

Q174 **Chair:** Yes, that will be helpful for a start, with all the caveats you mentioned that there are extra costs you are still calculating.

Dr Pickard: Absolutely, yes.

Q175 **Julian Knight:** Councillor Palmer, what are the challenges in identifying and assessing carers?

Cllr Palmer: I will refer to the figures I talked about earlier. At Leicester City Council we are in contact with and providing support to around 2,200 carers. 30,000 people identified themselves in the 2011 census as having caring responsibilities. There are numerous challenges. One of them is that certain assumptions are sometimes made around certain parts of the population and cultural nuances around family units and what that means for carers. Sometimes people are apprehensive about coming forward because of what it might mean for the person they are caring for. Change is turbulent and difficult sometimes. A sudden change to arrangements can sometimes be a big challenge and a rather unsettling experience.

I think some carers are apprehensive about coming forward and seeking formal support because they might be nervous about the fact they might have to pay for services. They might not be eligible for a free service; they might have to pay and end up having to buy their own care. Clearly, if carers come forward, we assess their need and will meet their need if they are eligible. We are trying to understand why so many people who identify themselves as carers are not coming forward for support or to seek support. It is a question to which I do not think there is a straightforward answer, from my point of view.

Q176 **Julian Knight:** You say 30,000 people identified themselves. You obviously have a very good record in terms of identifying carers. Do you think the resulting costs that come from identifying a carer make it more likely that a council may not wish to identify that carer?

Cllr Palmer: No. Let me be absolutely clear. I absolutely want my local authority to meet the needs of every eligible carer. We have a statutory obligation to do that. We also have a moral obligation to do that. If half of those 20,000-odd carers, or people telling us through the census they have caring responsibilities, came forward, and two-thirds of them were eligible for support, let me put it in absolutely straightforward terms: that would essentially bankrupt my local authority. It is as black and white as that. That presents a real tension and quandary. We do go out there and seek carers to come forward, to support them. We have a very active carers' reference group and carers' forums, which we support. I meet carers through many different bodies and I am constantly talking to them

about how we can develop a better relationship with the carers' population in the city and how we can reach more carers.
I have a manifesto commitment from our local election last year to carry out a local carers' census to learn more about the carers' population and to understand some of these issues, as to why so many carers are not coming forward to seek formal support. Why is that? What can we do to reshape our services and assessment process to perhaps make it more accessible, perhaps easier for people to find us and contact us? We are looking at a more digital model of people initially coming forward, because we all know sometimes accessing public services in local government is not necessarily the easiest experience through contact centres and phone lines and whatever else. We have just launched a new initial screening portal that people can use online on their smartphone or on their iPad.

Q177 **Julian Knight:** Councillor Palmer, I am not disputing the fact you are very active in this area, and obviously you are seeking out and are willing to take on what you call this quandary between finding carers and then them coming forward and asking, effectively, for help, and the financial issues with that. I am asking whether, from your wider experience with other councils, they are less likely to take the steps you are taking because of that very quandary. If they do and they find lots of carers, they are obviously going to find their bottom lines really stretched.

Cllr Palmer: From my experience, and I cannot speak for every local authority in the country on this, I know that every local authority I am aware of and speak to wants to meet its obligations in supporting carers and meeting the needs of carers, but there is no getting away from the fact that there is a huge nervousness about the financial implications of more and more carers coming forward. That is an honest appraisal.
But, look, what local government tends to be good at is finding solutions to problems. If there are needs to be met, we will meet them by one means or another. We have sustained our adult social care budget and grown our adult social care budget for the last two years using reserves. Next year, those reserves will have been used. They are not there anymore.

Q178 **Julian Knight:** Dr Pickard, is there evidence of a lack of focus on assessing carers with the most intensive caring responsibilities?

Dr Pickard: Can I just say something about the point that Councillor Palmer has just made about whether councils are reluctant to identify carers? There is a lot of research literature on carers' assessments, which suggests that resource constraints may lead managers and practitioners in councils to ration access to carers' assessments. There is also evidence that I think this Committee has already heard that the implementation of the Care Act, with regard to carers, has been under-resourced. We did some research on this. I could give you some evidence about it, if you

want me to. If there is a continuing constraint in resource terms for councils, it may well be that they will be continuing to ration access to carers' assessments and to services, and that more resources are needed if councils are to meet their new duties under the Care Act.

Just looking at the more specific question you asked about whether councils focused on the most intensive carers, we carried out some research on what we called the visibility of carers to councils. We found that councils do tend to focus on assessing carers with the most intense caring responsibilities. We used data collected in 2009-10—this was the large-scale survey, the Personal Social Services Survey of Adult Carers in England, which is of carers who are in touch with councils. We found that councils appear to be focusing on full-time carers—carers providing care for 35 or more hours a week—the majority of whom cared for 100 hours or more a week and provided virtually round-the-clock caring. The study used data collected before the Care Act was implemented—the data was from 2009-10—but we concluded that councils' emphasis on the most intense carers was unlikely to be due solely to the wording of the legislation that preceded the Act, which emphasised "substantial and regular care".

Round-the-clock carers are targeted more than "substantial care", which is generally taken to mean 20 hours a week or more, not 100 hours a week. We concluded that dropping the "substantial and regular" clause, which the Care Act did, alone would not necessarily broaden access to carers' assessments and that, in order to achieve this, considerable new resources would be needed. However, as indicated earlier, sufficient resources do not seem to have been made available to implement the Care Act.

Q179 **Melanie Onn:** I want to pick up on the point that Mr Palmer made about it not being feasible for local government alone to meet the increased costs of social care. I wanted to turn to how you perceive the increased combined work of the NHS and local government, and how they are working together to ensure that carers known to them are better supported.

Cllr Palmer: To put it in fairly straightforward terms, as a local authority we can work on the information we have. If people in the hospital system, for example, are approaching the time of discharge from hospital and there may be a new care need or a continuing care need that a family member is meeting, we would want to know about that. We would want to know about it to make sure it was going to be a safe discharge and the appropriate care arrangements were in place. We would want to know about it so we could check if that carer was someone we were in contact with and supporting. We are entirely reliant, therefore, on the information the NHS can provide to us.

We have some really good examples of good integrated work between social care and the NHS, but ultimately the hospital discharge process is

something the hospital discharge team will look after. If they identify possible care needs, we need them to tell us and we would respond to it. I cannot have care management teams and social workers walking up and down hospital wards each and every day. Again, that is just not a realistic prospect, so we are reliant on the NHS.

It sounds as if we are talking about two separate systems. In many ways, we are still. The whole notion of integration is really effective in very precise and very specific projects, but let's be clear: this is not one integrated system yet, and it certainly is not from my point of view in terms of the links at the point of discharge and particularly doing something as important as identifying possible care need and possible carers in need of support. It is something the system more broadly and more generally needs to think very carefully about as we address some of the demographic challenges that have been described.

Emily Holzhausen: Can I say something about carers' experiences of how joined-up the system is? They do not feel it is joined-up at all, and that places a lot of stress and pressure on them. I just wanted to focus a little bit on hospital discharge, because that is a make or break area for people who are coming out of hospital. Our research has shown that, if we look at the over-65s for example, nearly two-thirds said the discharge was too early. That resulted in the family being overloaded at home and a proportion of readmissions as well as a result.

If I could just give an example here, speaking from one point of view, somebody said, "My husband informed me that he was being discharged, so I went in straight from work. The ward staff had informed Hospital at Home"—the local care provider—"on the morning that he would need support on discharge and sent them a request to come to the ward to discuss his needs. However, by teatime, they had not turned up, so they discharged him home without support." That is a working carer who has to then juggle work and care to care for her husband because the care support has not turned up.

I really hope with the greater integration of health and social care we will see more joined-upness. There is some good practice in some localities like Surrey, which is creating champions in local GP practices and in hospitals, and trying to find a digital solution to support people to make sure things are more joined-up. But from carers' perspectives, the very strong theme is that they fall down between health and social care. It is a really important goal that they work better together, but that in itself will not solve the shortfall in funding of social care. It will improve people's quality of experience and outcomes, but that in itself still will not solve the shortfall.

Q180 **Melanie Onn:** This has already been touched on, but specifically how has support provided to carers been affected by budget cuts, with regard to availability of respite care, which has been touched on already, grants to day-care centres and other local carer centres, and carer grants and personal budgets for carers?

Emily Holzhausen: Yes, it is very difficult reading carers' experiences. We have an advice line. We take around 21,000 or 22,000 queries from carers a year, so we quite often advise them on their rights and what to do. Quite often people feel at the end of the road. They do not feel confident enough to complain in case things are affected in the future, so I would not just take the number of complaints that you get from the local authority as an indicator.

There are a number of different areas. For example, a carer said, "The local social worker said that personal budgets were being cut; they came around and reassessed us and, without warning, the personal budget for my husband was cut by 30%." There are others where, on hospital discharge, no support was put in place or discussed: "I had to lift my six-foot husband around day and night. I am 70 years old and only 5 foot. No help was offered despite many visitors. I asked for help at the beginning of November and we got support from the beginning of January," and that was after a hospital discharge in October.

I have other examples of where somebody said that the respite care she desperately needed every two months had been cut because it simply was not available, and that meant less time with her husband. We also see relationship breakdown because people do not get the space and time to devote to other family members. It is affecting carers' health and wellbeing. What I have not said is that the people who do provide support—and it is there—are an absolute lifeline. All the care workers and health staff who support carers are fantastic. There is just an enormous shortage of it and there is a real concern for the future.

Cllr Palmer: I would say we believe that we continue to meet identified need at adequate levels. We will certainly do that in the current year and would expect to do that in the foreseeable future. But as the system gets more and more financially stretched, I would refer to earlier points: it will continue to be a very worrying issue from my point of view, as to whether we will continue to be able to provide support at current levels. We carry out reviews of people in receipt of care. Some of those reviews see people receive a decreased amount of care. Clearly that is within the framework of the Care Act and our obligations to meet need. I also have to say that when we review care packages at the moment, quite often it leads to an increased level of identified need and increased expenditure, so it goes both ways, if you like. Ultimately, it has to be seen in the broader financial context that we face.

We continue to provide a number of voluntary sector organisations in Leicester providing support to carers. There is a very active carers' centre that provides short break services and really effective advocacy for carers. One of the most important aspects of support that we support is peer-to-peer support for carers. It is another thing we expect some carers to do, but we do have carers who come forward to do that. It is fundamentally valuable work and it is something that I certainly want my

local authority to continue to support, and I hope local government more broadly can continue to be able to do that.

Emily Holzhausen: Can I just come back to some of the stats? We asked, through our State of Caring survey, whether people had seen a change in their support. About one-third of respondents—I think there were about 4,000 respondents from England—said that they had experienced a change. Around 13% had seen an increase, just as Rory is describing, on reassessment, because needs had gone up, but 59% said the amount of care and support they received had been reduced, either because of increased costs or the availability of services had reduced. 12% had cut down on the amount of care and support they got because the costs had increased.

A carer I spoke to last week said her costs had gone up from zero to £250 a month, which is very significant, and that is after all disability awards and expenditure. Many said that their personal budget no longer covered costs, because councils also hold the value of the personal budget even though there might be cost pressures in trying to buy it in. It is a net loss to the family. 13% said the care or support service was closed, and no replacement was offered. Those are quite significant proportions. We ask that question every year.

Q181 **Chair:** Do you have those figures and can we have them?

Emily Holzhausen: Yes, I have those figures and more examples. Each family is slightly different, which is why you do not get this overall picture. It is slightly different changes that overall affect the finances or the amount of care that somebody can have.

Dr Pickard: If I could just add to what Emily has said, with regard to whether support provided to carers has been affected by budget cuts, we have recently undertaken a study that has involved conducting qualitative interviews with carers who were in employment two years ago. Although in most cases we did not ask carers about the effects of cuts, they often spontaneously mentioned this themselves. For example, one carer had received money from the Independent Living Fund for her severely disabled daughter but the fund was closed in 2015. The carer was then told that home care for her daughter would be cut from 55 hours to eight hours a week. In this case, the carer challenged the cut but she still suffered a reduction of seven hours a week in the hours of care provided for her daughter.

The cuts have meant that some of the people who are cared for did not receive the services they needed, and this could lead carers to leave work. For example, one carer's mother had received home care but the service was withdrawn suddenly, leading the mother to deteriorate rapidly and the carer to leave work permanently. Other carers assumed that because of the cuts there would be no services for the person they cared for and they did not even attempt to obtain them, thereby depriving themselves of support, and in some cases leading them to leave work.

Q182 **Chair:** Thank you very much indeed. Is there anything else you would like to say? We have covered a fair range of issues this morning.

Emily Holzhausen: There is just one final point. On the point of carers' assessments under the Care Act, we warmly welcome the Care Act as a great piece of legislation and we thank all of you for your input into that. It is really an excellent piece of legislation. The issue is the funds behind it to implement it. Our work, as I said, looked at carers' assessments and how many they were getting. It is the largest study to date of carers' experiences of the Care Act. It is about 3,000 carers, and we found that 29% had waited six months or longer for an assessment. When you combine that with Linda's work, which shows that you only focus on those with pressing needs, it is a real concern.

Even more worryingly, three groups in particular fell behind. The first was those caring for people who were at the end of life. 39% were waiting six months or longer. Many people do not have six months at the end of life. Some people do, but you do not always. People with a mental illness are less likely to get a carer's assessment and more likely to wait for longer, and parents of disabled children are still not recognised as having very significant caring responsibilities and, again, have to wait longer. My apologies, I did not mention that earlier. As to local authorities—I do not want to take words out of Councillor Palmer's mouth—they are struggling to keep up with the pace of assessments—and they are needed.

Chair: That information is helpful. If we could have all that information to take on board, that would be really useful. Thank you all very much for coming to give evidence to us today. It has been very helpful to the Committee.

Examination of Witnesses

Peter Turner, Margaret Dangoor and Christine Euman.

Q183 **Chair:** Thank you very much for coming to give evidence to the Committee today. You are very welcome. Just to begin with, if you go round the table and say who you are, that would be very helpful.

Peter Turner: I am Peter and I am the Chief Executive of a carers' organisation called Carers First, based in Kent but currently operating in the counties of Lincolnshire and the London Borough of Waltham Forest.

Lana Harber: My name is Lana Harber. I am a carer for my best friend. I am also from Medway and a carers' champion for Carers First and a social work student in my second year.

Christine Euman: I am Christine Euman. I am a carer most weekends for my mother, who has dementia and mobility problems.

Margaret Dangoor: I am Margaret Dangoor and I care for my husband, who has advanced dementia.

Q184 **Chair:** Thank you all for coming. To begin with, tell the Committee a little bit about what you do as a carer: what it entails and what challenges and stresses are involved in it. Tell the Committee how you feel about it.

Lana Harber: Outside my studying roles, I care for my best friend, who is deaf without speech and has cerebral palsy, mental health and learning difficulties and autism. The caring can be everything from making appointments, making care meetings, personal care, budgeting, cooking—all kinds of care.

Chair: Please speak up a little bit, as that is helpful to the Committee. Thank you.

Lana Harber: Yes. It is all kinds of care for my friend. The deafness without speech means I have to do an awful lot of appointments and phone calls, arranging interpreters, and driving to appointments and social occasions. I have to do lots of different things, balancing that outside of my studying role.

Christine Euman: I look after my mother most weekends. She has dementia such that she cannot be left. She is quite delusional. She has mobility problems but is fast enough when she wants to get going on her trolley and disappear out of the door and things like that. I have to travel down to Bournemouth most weekends. We have paid carers the rest of the time. I am very lucky, I think, to get direct payments and higher level attendance allowance. But even with me giving free care, that still only covers about 50% of my mother's needs, so there is a big shortfall. Somebody else used the word "turbulent". It is not just turbulent in terms of the condition; it is turbulent in terms of trying to manage all aspects of my mother's care and co-ordinate it and things like that. It is quite tough on me. The other thing that does not get mentioned is she is 92 and I am 70 next year. I have got various health problems myself. When she has a fall, am I going to be able to get her up? I used to be able to. I do not know if I can now. There is that kind of ongoing and increasing level of uncertainty about the whole thing, but I am very lucky: I have two brothers who will help me and things like that.

Margaret Dangoor: I care for my husband, as I said. He has advanced dementia, and that means he is doubly incontinent. His mobility is now absent, more or less, so when he is at home all he can do is sit in a chair. I cannot move him without support so I have carers from an agency coming in three times a day. He is very fortunate because we have an absolutely excellent specialist dementia centre in our borough. He has been going there since 2008, and I have just now requested that he attend seven days a week, because if he is at home he has absolutely no

quality of life. He has quality of care but not quality of life, because of the lack of mobility etc.

Although he is away for about eight hours a day, I still have the rest of the time. For example, last night, I had a very bad night with him. I have to turn him during the night and change him etc. I only had about three hours' sleep and I never get more than about five: it is about four and a half normally. That is consistent. I am 77, and it is quite hard work physically moving and handling him in bed. I can do it when he is in bed. I can manage that, but when he is up I cannot move him at all.

He attends the intensive day centre. I will just give you an example, because I think it is important for you to know the changes. When he first started going there five days a week, the top charge was £40 a week. You did not pay any more than that. That was about £250 a month. For the same service, with meals, it is now costing me at least £1,500 a month. On top of that, I now pay for the home care.

I was coping on my own until he deteriorated and had a serious chest infection in March. From then onwards, I have had care in the home and that is costing me. It is the minimal care; they are coming in for two half hours, and three-quarters of an hour in the morning. They help me wash him and get him up then. That minimum care costs me over £1,000 a month. In fact, his care—and it is high quality and I feel very fortunate that he can have such a quality of life at such an advanced stage—is costing £3,000 a month. I think that is a very good illustration of the cost of caring for people with dementia in an advanced stage. It has kept him out of hospital.

We had support from reablement at one period and also the out-of-hospital care team, to prevent him going into hospital. There is an issue around that. I only received the out-of-hospital care because I remonstrated. There was a particular instance when he was receiving reablement and I suddenly got a phone call to tell me that reablement was not appropriate for him anymore—that was because he was very poorly and we actually thought he was not going to recover—and, "You will now have to self-fund your care."

I am a nurse and I am very involved with the local community in relation to representational work, and I said I really did not think it was appropriate that just before a bank holiday I was being informed that I would have to organise care. It was just impossible, because agencies need to come in and do an assessment. I mentioned the out-of-hospital care package. I said if I did not get support, my husband would land up in hospital as there was no way I could cope with him. That was true: there was no way I could cope with him at the time.

I had the out-of-hospital care package in, and the professionals were absolutely superb. But that was an indication to me, and I did bring it up with the commissioners and it should not have happened, that if you do not know your way around the system, you can be fobbed off. I could have been fobbed off just before a bank holiday as an elderly lady of 77.

All right, I am an ex-nurse, but many people find caring for their husbands and wives extremely difficult and they are not really up to the task.

I chair an expert carers' group at the local caring café, and many of us are pretty decrepit, and one or two have even died before the person they have been caring for, through cancer in two cases; they neglected themselves because they were so busy looking after the person with dementia. For many of us, yes, it is a jolly hard task. I do not know how very many, within my knowledge, cope with the day-to-day caring for somebody with dementia.

Q185 **Rushanara Ali:** Mrs Dangoor, your description of what you are doing is incredibly moving. Do you feel that this is a widespread pattern in the absence of more intensive support from family members and the absence of, or reduction in, services to local authorities? I would be grateful if others could contribute as well.

Margaret Dangoor: The whole direction of flow is care in the community, isn't it? I have spoken up at many meetings and have said that every time there is a movement towards more care in the community, the burden on families, whoever they are, increases. Yes, the funding is being reduced dramatically for people who receive personal budgets, but many older carers, like me, are self-funders because they are above the £23,250 capital limit. Many of us are spending significant sums of money. Some elderly people find it very hard to spend money. You know, they have saved all their lives and they are reluctant to spend, and then they take on too much care until they collapse. I have seen that happen, so that is an issue.

I have received, for a number of years, two hours' respite from a local charity. They know I do a lot of work. Every time I go to a meeting, it costs me money. For two years I was on a waiting list for respite care. I receive two hours a week of free care. That has just been discontinued as of 1 November. Our council is very strapped for cash. We are a wealthy borough in Richmond, but I think the social care budget has been reduced 70% in five years, and therefore they are strapped for cash. I understand that. They have just delivered a new leaflet and basically the money is going back to the local authority. They are going to assess people through the carers' assessment, but if you are above the limit for eligibility for financial support, you will not receive it.

Q186 **Rushanara Ali:** You have alluded to your own circumstances. How has it affected your own health?

Margaret Dangoor: A person of my age always has aches and pains. You are not as robust as you were. The moving and handling of my husband is pretty hard. I move my husband on sliding sheets provided by the Health Service. Perhaps it is not appropriate to say it, but with a particularly rigorous pull one night—it is quite complicated—I pulled the sheet out and I shot across the room with the effort. I was lucky not to

injure myself. That is the sort of risk we are taking all the time. Every time we move my husband—we do have a hoist but we try to do it without, just to keep something going—even from chair to bed or whatever, it is hard. Somebody with dementia is not able to co-operate at that stage. I have various aches and pains. I am basically pretty healthy but it does take its toll.

Rushanara Ali: Thank you. Mrs Euman?

Christine Euman: Has it taken its toll on me? I thought not, until Clive was really quite friendly towards us when we first got here and I burst into tears, and I thought, "This ain't me." Yes, it takes its toll overall on other things I would be doing. I would probably be involved in charitable works and things like that, because that is my nature, but everything is focused on my mother and what I do for my mother. Despite the fact that I am only there at weekends, I am probably fielding and managing lots of things during the week as well. It completely dominates my life despite the fact that, as I say, I am very lucky in these things.

I would like to say one other thing. Julian mentioned earlier that people were not coming forward as carers. There is still that residual feeling of, "They will be taken away from me." My uncle cares for his wife, who also has dementia, and he will not let any services near them. I think he fears she will be taken away, and that is still there, so he has no support whatsoever and is being completely run into the ground by the nature of the dementia. Let's not judge people's thinking by our own.

Q187 **Rushanara Ali:** Did you want to come in?

Lana Harber: I guess my situation is a little different as I am not caring for a family member; I am caring for my best friend and he lives next door. It has definitely taken its toll on my mental health. I found it affected my studies, certainly in my first year. I had to get support from my university and from Carers First as well. I am the sole carer for my best friend. There is no support package, no direct payments or budget. It is just me.

Of the resources I do have, initially I had a fantastic social worker over a year ago, but that person was made redundant and it has been a little sparse since. I think my last meeting was a year ago, and I have another one due quite soon. I have not been proactive in seeking a carers' assessment, because primarily I put the other person first—my best friend comes first—but I do get support with Carers First. I engage when I can but timing does not always allow that. A possible six hours' support may be offered at this meeting soon.

Q188 **Rushanara Ali:** Thank you. Mr Turner, could you say a bit more about the carers your organisation comes into contact with, and their experience.

Peter Turner: I can. I wonder if I could return maybe to Mr Knight's earlier point. I think he was trying to make the point that there is a

perverse incentive in terms of local authorities not identifying the carers, to paraphrase him. He is nodding. I would make the point that the three people sitting here and the almost 7 million people like them are at the forefront. You would not be sitting here today talking about the difficulties of health and social care if these people did not exist; you would be talking about the complete collapse of the health and social care system in this country. When you talk about prevention and you talk about keeping people out of hospital beds, residential care homes and GP surgeries—all of those things—these people are absolutely at the forefront.

In terms of Mr Knight's point, he is absolutely right; it is a completely perverse incentive not to identify carers. If I can use one example from Kent, if I may: over 40% of admissions to residential care homes in Kent are because of carer breakdown. It is well known that over 35% of those are completely unknown to any authorities before they present at that point. That is the point. In terms of prevention, we need to identify carers very early to make sure that we can support them in the best way possible through a variety of ways. That is about a range of identification methods of carers, for example identifying carers in GP surgeries and working in hospitals, where carers quite often present for the first time in dementia wards, stroke wards and A&E. We need to identify carers at that point. We should be working with pharmacists to identify carers, and with local employers and HR departments. Some of the largest employers in the areas we cover are health authorities and local authorities, and up to 10% or 15% of their staff are carers. We should be identifying them and also identifying them in terms of partnership working.

It is about proactively identifying carers, but Mr Knight's point is right: you need to be careful what you wish for in terms of that. The point of that is to develop services that are able to triage and ask the critical question: is this carer at risk of breaking down in their caring role? That is about organisations like Carers First developing a range of services that do a number of things. Firstly, we need to develop universal services, so all the things we do, such as benefit advice and other things Margaret talks about, such as peer group support. Carers want to have all of that, but we should also have the ability through systems to identify those carers who are at risk of breakdown. We can then use all the community assets that are available—not just us but all the health and social care assets, the leisure assets, the health assets, the employment assets, the housing assets—to work intensively with those carers, gathering data to target resources to the best extent possible to make sure that you deliver services that either stop or delay that carer breaking down and the cared-for person going into much more expensive interventions. That is the point I would like to make from your question in terms of what a carers' organisation could be like.

I would say that glass is half full. Carers First, as I say, in the recent past have moved from delivering in the South East of England on to

Lincolnshire and the London Borough of Waltham Forest. That is about being able to say that commissioners understand that the voluntary sector has a real role to play here.

Can I also make a point, if I may, Chair, about assessments? We heard in the early evidence about assessments, and I absolutely agree with the lady who spoke earlier about the quality of the legislation in terms of the Care Act. Many people who have much more experience than I do say that as well. But what you did not have was a number of people on College Green at the enactment of that legislation celebrating the fact that they were now eligible for a statutory assessment of 27 pages and more. Quite often, carers' assessments is becoming an industry in itself. The key is surely that an assessment should lead to something. That is the point here. It is about making sure the assessment is an assessment of need and whether that carer is particularly struggling, whether it be their health or their employment or having a life of their own, and developing services in the round to be able to target what that carer needs in terms of support. I would make those points.

Q189 **Melanie Onn:** Lana, how has your friendship been affected by the responsibilities you have taken on as a carer for your best friend?

Lana Harber: Fortunately, it is a really strong friendship. It has put more pressure on me than my friend would see, but it does mean that I am perhaps hiding more, so he does not see that, in a way. I will deal with that myself and put myself under more pressure as a result.

Coming away today, I need to know things are in place and he will be okay and plan in advance. That will affect me, but I can call on a handful of family members that might help me.

Q190 **Julian Knight:** I just wanted to ask the carers on the panel—maybe starting with you, Lana, if that is okay—casting your mind back to when you started on this journey, how did you find the information and advice you got on caring in your area? Was it easy to access? What was the quality of that information?

Lana Harber: I started caring five years ago. Certainly resources have declined, other than Carers First, which has increased for me, so there is a disparity in terms of the local authority and charitable support. I had a fantastic social worker. There was more of a team. There was more engagement, and more meetings and plans. That social worker has since gone. The team has changed, as have the numbers at the local authority. People have been off sick. It has varied quite a lot. I had more access, I think, to support at the beginning with the local authority, and that has now declined, whereas it has gone the other way with the Carers Trust and Carers First.

Christine Euman: I count myself as reasonably well educated and thought I cope with all this stuff, but there was the whole thing of trying to find information about lasting power of attorney and direct payments and differentiating between what was health care and what was social

care. The health care seemed to be well in place. The falls team and preventing mum going into hospital again all seemed to work fairly slickly, but then suddenly you are abandoned.
The social worker that I had contact with had to reapply for his job and got transferred to addiction, which he did not know anything about. The social work role seemed to be form-filling and very little else, and I suspect they did not have time for it. If only I had had somebody who could have taken me through this journey, that I could have gone to for the advice, but I did not have anything like that. It was such a struggle to make sense of it.
Now we have 24-hour care in place and I do not think it will change much. But those last two or three years, and probably well before—it took so long to accept what was really happening to mum—were very tough and, as you can probably tell, I am fairly articulate and will ring people up and all the rest of it. Yes, it was quite tough.
Margaret Dangoor: Our borough is considered good on information. I will give an illustration. We had a new member at our expert carers' group, who came in and sat down with a whole pile of paper and said "Can somebody help me? I have been to the access team and they sent me all this information but I do not know what to do with it." That is so true. If you are just provided with information but nobody helps you through the process or helps you go in the right direction, it is absolutely useless. It is really rather like being dumped off in a foreign country with a phrase book and a map and nothing much else; well, maybe a lot more—a guidebook and what have you. Even so, you are in a foreign country so it is not really very useful—and certainly not useful when you have to get into the care process pretty quickly.
This direction of flow, which is all about good information, is not much help if do not have the support behind it. Certainly, the charities and peer support group we have are considered very helpful in that way, but charities have their funding reduced and are finding it more and more difficult to do the job they want to do. Our caring cafe used to be held every Saturday. It is now every other week, and even then there are murmurings asking how they are going to keep it going, because of funding. These core services are really respite, because the person with dementia comes along with the carer, and then we have an opportunity to go into a little meeting on our own. That is respite. Many people say, "It is the best form of support we get, just coming here and sharing." All those opportunities when we can share and be supported personally are what you really need when you are a carer.

Q191 **Julian Knight:** Thank you, Margaret. Peter, briefly, perhaps, going over the ground that you just discussed a moment ago, what do you think are the challenges in identifying and assessing carers, and do you believe this process has been affected by any form of budgetary cuts?

Peter Turner: The main challenge is that carers quite often do not identify themselves as carers. Before the Care Act, as I am sure you are well aware, many a director of adult social services had sleepless nights around what that legislation might mean in terms of carers' assessments and the rest of it. That did not come to pass, because the reality is that many people just get on with their lives. They do not want support. They get on with it. They do not even think of themselves as a carer. Our point is that they need to know that that support is there for them, and that is about proactively identifying carers, as I spoke about earlier, in a variety of places, so that that support is there for them when they need it most, either at that point or maybe down the line. That would be the first point I would make.

In terms of budgetary cuts, I would say the word "transformation" is bandied about a great deal in a variety of places, and I think that is right. That applies to charities, particularly to charities like ours that spend public money. We have to be accountable for that. We have to show very clearly that how we are spending the money is making a difference in terms of what we do, and we are providing value for money through reducing back-office costs. We know criticisms have been made of charities in the past. It is about reducing those back-office costs to ensure that you put most of your money into frontline services, which is about supporting the people like the three people to the left of me. Those are the challenges, but with challenges come opportunities. We have an opportunity to think differently about what we have done in the past, and how we do it.

I make the point again. It is about organisations like ours. We have mentioned respite here. There is a real debate to be had around what we mean by "respite"; what do we mean by a "carers' break"? Yes, that is regulated care and all that goes with that, but it is much wider than that. I would make the point that health and social care services need to be as much involved with community services and empowering our communities and empowering our carers in those ways as they are in thinking that the state has to do everything. It is about empowering those communities as well in that and asking the question: "What is a break and how can you do that?" in a variety of ways. That is about using information: collecting intelligent data that commissioners and other organisations can use to target their resources most effectively. That was the point I would make.

Q192 **Melanie Onn:** I asked this of members of the previous panel, and I know, Margaret, you were definitely in the room; Peter, you were in the room as well. Do you think that your local authorities do support you, particularly around respite care, day care, access to carer centres and financial carer grants and personal budgets? Margaret, you touched on it. Perhaps you could start and illustrate that for us.

Margaret Dangoor: I sit on a carer strategy group for the borough. I have been on it for quite a few years now, and respite is a continual theme that comes up. Because respite is variable, it is very difficult to find an answer—and I can understand that. The local authority did offer two weeks of respite care to carers that were eligible; I am not sure they are going to do that anymore. Say, for example, they offer two weeks. It is very difficult for a carer who wants to go on holiday to find the services to provide the respite when they want it. It might be that the cared-for person needs to go into a nursing home. It is a nightmare finding an appropriate nursing home place.

Q193 **Melanie Onn:** Sorry to interrupt you, but is that about the level of care or the speciality and understanding the medical condition?

Margaret Dangoor: It is about no empty beds, because they are commercial organisations. It is very expensive. In our borough it is anything between £1,250 and £1,750 a week. Anyway, even if you try to find a place, the nursing homes do not have beds. If any do have beds, because one happens to become vacant, they well might not accept the individual if they cannot meet their level of needs. They are not always very willing to take on someone with advanced dementia in the short term. There are all sorts of issues.

If you want short breaks, the local authority has tried to offer, over the years, some form of respite, but it is a very difficult problem to give respite to an individual—it is all about personalisation— when they need it. It is a bit on a rota. The respite I had—two hours a week—was always the same day of the week at the same time, so it did not really fit around my needs. It was very welcome but it was limited, truly, in what I would have found most useful.

Christine Euman: I do not know whether respite is relevant in my mother's situation. She is at the stage where it would be extremely damaging for her not to be in her own home. I think it would be very disruptive to her. The respite that I would like is, with regard to the direct payments, to have some support. We employ people privately, not through an agency—just people we have met in my mother's local area who I do not know. Thank goodness my brother has taken on issues around formal employment, PAYE, insurance, paid holidays and things like that, because I really could not do that myself. You have to do that in order to access those direct payments, for which we are very grateful.

I do not know what the take-up rate is, but I would not be surprised if it is fairly low, given that you really need support to help access those. You need a one-stop shop in terms of support, I think. Quite how you get that I do not know. As I say, respite does not quite apply for my mother. She would be lost if she got moved anywhere. As I say, the people who look after her can cover those things; they are a family, in fact—it is a fairly crazy situation in some ways. We just throw a bit more money at it.

Lana Harber: I guess respite for me comes from just being able to pop out for a coffee, something that might be quite simple in many ways. If somebody is with my friend, I can pop out and do that. Respite is not identified via a statutory assessment, because I have not had one. I am not sure that a carers' assessment would provide any budget or respite for me, so that is just my own network. I received an award from Carers First a year ago. I went on an overnight break, which was lovely, but I took my friend with me, so, yes, that is my respite.

Q194 **Melanie Onn:** Thank you. Have any of you had any experience of dealing with post-hospital discharge situations and what was your experience of that? Christine, you mentioned that the health care package seemed to be there, and then when the social care package comes in, there is not a great deal. Can you just explain to us what support was provided and perhaps your own experiences of that?

Christine Euman: A team exists to prevent the elderly going back into hospital, and they made regular visits and were concerned about falls and swallowing and things like that. There was also the community mental health team. Even then, although I feel the support was good, we still had to go in different directions to try to get the kind of help that we needed. My mother's situation was deteriorating and yet the package you get is time-limited. I found it quite distressing to receive a letter to say my mother was no longer going to be supported by the community mental health team. You think, "Is she getting better? No, she is never going to get better." They said, "You can always get in touch again." But you did not have that ongoing support: it was gone. I can access help but nobody monitors my mother now, I think I can safely say. Yes—nobody.

Margaret Dangoor: My personal experience is a few years ago, and certainly there were issues then. But just to give an up-to-date experience, one of the members of the carers' group, where we get an awful lot of information exchange, had been asked at very short notice to take home the person she was caring for—I cannot remember whether it was the husband or wife—again just before a bank holiday without any support. I hear constant stories in my local work about unsatisfactory discharge arrangements because, as we all know, the hospitals are so pushed that the clinical staff are under pressure to find beds for patients.

I did have an experience that I suppose could have happened now, where a junior doctor rang me just before my husband had been discharged. It was an unfortunate situation. I found the clinical team had written in the notes that he was ready for discharge from their point of view, but nobody on the ward had read about it. The weekend was coming up and he needed incontinence supplies and I had not got them at the time—all the equipment. We agreed with the ward staff it would be better on Monday. Then I had a junior member of staff, I think, or a registrar, ring

me and say, "We hear you have refused to take your husband home." I was rather upset about it. I said, "No, it is not me; it is just that there was no discharge process in place and we agreed mutually it would be better for him to come home when the community team were involved." Again, you hear constant stories about procedures that really should be in place. Both my local hospitals have done a lot of work on raising standards for people with dementia, but in practice, because of the pressures on hospitals, there is a lot of sidestepping, and vulnerable carers do not know any better than to sort of cope with the situation, so there we are. Practical experience is not often as good as the intention at the top.

Q195 **Melanie Onn:** Would you think that things have improved over time, got worse over time or broadly stayed the same in terms of discharge?

Christine Euman: I was quite impressed with the health care side. Then, sorry, I am reminding myself that my brother would frequently ring the consultant and say, "This is Professor Orrell." That probably helped enormously to ensure that my mother got the best possible treatment, because he is a specialist in old-age psychiatry, so, yes, that was very lucky. He pulled strings, I am sorry to say.

Lana Harber: I think Margaret said you become very solution-focused because that is the best you can do. You need to just think, "What can I do? How can I do that? Who can help?" When my friend was hospitalised for two weeks just over a year ago, I took three or four weeks off college and nearly lost my place as a result of that. He could not mobilise for himself and I needed to take that time as there was no other support. He was discharged after two weeks. That then meant that I put in that care, and that was quite difficult. It was everything: injecting that person—I did not get to practise on an orange beforehand, which was scary—all personal care, all food. Trying to get somebody up and down stairs and then into a wheelchair on their bum was difficult, but that was what it was at the time; there was no other support. People would come and do physio for an hour. I managed to arrange a sign language interpreter for one hour a day whilst he was in the hospital. But his being there for an operation, with those communication needs and learning difficulties and being lost and not sure what was going on, meant that my care then ramped up even more. That was a particularly stressful time, and my support was really, again, family members. The discharge team discharged him to my care.

Peter Turner: There are probably two examples of hospital discharge from our point of view. There is the good example: those that think "carer", treat carers as the experts on the people who they care for, involve them in the process of hospital discharge, prepare them for them coming home, link them into community services, and make sure the

carer is well prepared for that person coming home from hospital discharge. That is the good example of hospital discharge.
The bad example of hospital discharge is those that do not do any of those things. They do not involve the carer in that discharge whatsoever. There is a huge amount of research that says that those are the people who bounce straight back into hospital within a week or two weeks because that carer is not prepared for that person coming home in terms of what it means to them as a carer.
That is the whole point, isn't it? It is the carer that matters. It is about carers as individuals, not carers who support somebody. Yes, they do support somebody, quite often very intensively, but it is about that individual and making sure that individual is ready to make that decision for the hospital discharge, and supporting them so that discharge can then work and that person can make sure they are well at home. They are the discharges that do not result in a bounce back into the hospital beds.

Q196 **Chair:** Thank you very much for coming to give evidence to us today. Have you all had a chance to tell us everything you wanted to tell us when you set off, do you think? Is there anything else?

Lana Harber: I think so. It was nice to have the opportunity to be here and do this, so thank you for that.

Chair: It has been really helpful to the Committee to have that first-hand information from you. That has been really useful. Thank you very much for coming in and sharing some often very personal experiences with the Committee. Thank you very much indeed