



Arthur's Story

“The last week of her life we got somebody”



Arthur's Story

Interviewer: Addison

Addison: Hi. So, it sounds you've quite a story to tell.

Arthur: Yes, okay. Well, there are two issues here. I'm talking about the problems that I've had with Social Services. Health is probably of less interest to you but they are intertwined as I'll explain later. I've been paying for carers for my parents for many years. The two problems I've had recently is, one, that I haven't had the payment which was due towards my mother's care after a financial assessment that was carried out. The other is about continual care.

The way the Social Services are involved in continual care is because the social worker has to contact health services. We had problems because the district nurse had signed my mother off while I was on holiday. I was horrified. They used to come and visit and they said they're no longer visiting because she's got no bedsores, but she's still an old lady with Alzheimer's! How do they know I've got the same carer that's going to do the same job? And, we haven't seen them until about a week ago or two ago. My mother died a week ago, so two weeks ago.

I'm so annoyed about what's happened I felt that I needed to get it clear in my head about different events that have taken place. So, I actually went on my computer and I spent all Sunday night listing the problems I've had with continual care. I thought, knowing you were coming, I ought to do that. I've got one paper that's three pages long all about continual care right up to past my mother's death which was just over a week ago. This is the one I've done for Social Services and how I started paying for care.

We'd applied for two things. We'd applied for a reassessment of my mother's care because obviously when my father died my mother's financial situation changed. He had to pay for all his care. We started paying for care a long time ago when my mother got diagnosed with Alzheimer's and then followed it with a broken leg. When she came out of hospital my father was incapable, 'cos he was blind, registered blind and had dizzy spells and everything. He was not capable of looking after her and she needed looking after. She went into a care home for a little while, came out and she got care in her home. We started care which was three visits a day.

And, that's how it started. As her Alzheimer's and their health got worse the more care we needed. It eventually became clear that she needed a lot more care. A 24/7 carer was employed privately to help mother and my blind father to a lesser extent. So, it was more for my mother's care but a little bit for my

father. They were living in a flat and my parents had separate rooms. When you've got a 24/7 carer you've gotta have a room for them, so the difficulty was providing that.

The bungalow next door but one to me came up for sale at that same time. My father, who had all his marbles right to the end even though he had other health issues, suggested "Why don't we buy that?" The idea was to buy it and basically, we had to gut it cos that how we'd get the two bedrooms. You can't change a flat but you can get planning permission to build out and that's what we did. We built a lounge, a new room for the carer, we moved the bathroom from one part of the bungalow to the other, widened all the corridors so that a zimmer frame... um the doors were all narrow when these houses were built, they were too narrow for wheelchairs and things to get through with ease, so they were all widened. So that had to be done. In the meantime, my father had to move out of his bedroom to give the carer her bedroom.

Now I've always understood that Social Services do not fund 24/7 care and my father, because he had savings was not eligible for any funding but my mother was assessed separately. I don't think that's always the case in every authority but it certainly is in Cambridgeshire, I knew that. My mother had very few savings, she'd never worked apart from during the war and she was always, you know, at home for me. That's what housewives did in the fifties and sixties, they were at home, they weren't working. It was quite a complicated issue. So that's where the care started. We had to pay for all or most of the care at that time until she had an assessment. I got somebody privately and although it was a lot of money each week, it was a lot cheaper than going to an agency which wanted about £1,000 plus a week.

Addison: How did you find approaching people privately?

Arthur: I did that by ringing people through The Lady magazine. The back of The Lady magazine advertises for jobs for some very rich houses who want a housemaid, a cook, a gardener, whatever but also carers, people who care. I used to get The Lady, I'd go through it and ring them up. Of course, some people were in some parts of the country and were willing to travel, others weren't willing to travel. It was always a long conversation. You would have to explain what care was needed and what your parents were like. Then you'd have to start getting on to money and for some people it wasn't enough and I didn't want to pay it. People had their own absolute minimum but on the other hand I was trying to keep the costs down.

That's how we started. So, we got a private carer. We had a contribution and um... A lot has happened, trying to get all the facts and be accurate with everything is not always easy, which is why I've written most of these points down. I'm trying to think when we got involved with Penderels. I think it was after speaking to my mother's social worker, very nice lady and a helpful lady

she was too. She suggested using Penderels because otherwise I would be having to do all the tax and all those things. I had enough to do dealing with all my father's finances and paperwork is not my greatest gift, so I decided to do that.

That's right, because our first carer we had, we didn't get any contribution for because she was not willing to sign up to Penderels. I asked her to sign up to Penderels but she kept putting me off. I got a bit suspicious and then she told me the story about what happened. Her parents were in Zimbabwe and this, that and the other. She said she'd sent her passport back for renewal to the embassy and when she got it back she'd sign up and you know, all that. I had all of that story. In fact, I remember drafting a letter. I said I'd help her, I said "We'll send a letter to our member of parliament. You're living here, I don't mind sending this. It is terrible that you're waiting so long for your passport, da di da, something ought to be done." Then she was in tears and I didn't feel that I was getting the whole story but basically, she was frightened because you make waves in Zimbabwe and there could've been repercussions on her parents. So, I backed off, but I explained to her, "Look," I said, "If you're not willing to sign up to Penderels I've got to find a carer who is."

So that was the beginning of the story. So, this first carer stayed with us when we moved. She was marvellous, she helped us move, she was a brilliant carer, very loving, she loved my parents very much and I was sad to see her go. Then we had two carers who both signed up to Penderels. So that was our first experience with continual care and that was that was reasonably successful. They weren't with an agency. I got them privately, but they were willing to pay their taxes and give their national insurance number and everything else like that.

I did have a bit of problems with one of the carers, well both of them actually. One was taking liberties. She was a lovely girl. She used to go off for her breaks and that was fine. She was allowed two hour breaks and then she'd take three hours and I'd get a bit cross and father would start asking her where she'd been and I said "You can't do that, it's none of your business where she's been." He kinda looked on her like a daughter, he was very protective towards her and she was lovely. She used to sit and ask him questions about the war and they got on really well but she was taking liberties. In the end she did have to go because she was, as I say, she'd take three-hour breaks when she's told me she was going for two and always an excuse. She would arrive late when she was supposed to be taking over. She was in rotation in with another carer so when it was her slot she'd say, "Oh, oh there was traffic." And I used to say, "Well leave early, you know what the traffic's gonna be like, so leave early." It didn't make any difference she was always late. So anyway, she eventually left, and we had the other carer who stayed for a while. She got on very well with my mum, but she didn't get on terribly well with my father.

Um, now where do we go, what happened then? I was getting very worried and I did persuade my father that we would join up with an agency, so we did, which was our first real experience with an agency. That was okay, we had no problems with Direct Payments then. When we joined Penderels they came here, sat in the chair, they gave me all the paperwork, all the advice, it was totally different to Purple. I haven't had hardly any paperwork from Purple. Penderels gave me all sorts of advice. How to employ a carer and everything else. They were always on the end of the phone. I would have time sheets and I would fill them in and send them in. I'd have to have a certain day to do them because if they didn't get sent in the carer wouldn't get paid. I always made sure because I had a calendar Penderels gave me that I put on the wall which had the dates on. That was very clear. Totally different to Purple. I wished I hadn't moved to Purple because I haven't had anything like that. So, everything when we were with the agency and when we were with Penderels was fine. It was an efficient company and it seemed to run very well. I had no problems.

The problem came because my father was worried about money. Even though we were getting a contribution from Social Services, the majority of the money was being provided by my father. So, he saw his savings going down and down. Sometimes I was paying the carer, in the old days before we went through Penderels; sometimes I was paying the carer in cash and when he saw me counting, well I mean, I couldn't do it in front of him because he'd just see these twenty-pound notes counting out a weeks' wages. It's his money and he was very careful with his money, he was from that generation. He saved all his life and he was seeing all his savings being spent on this care and he was worried what was going to happen when he died. The reason why he worried, and he sat in his chair worrying what was going to happen when his money ran out; what was going to happen if he died was because we'd lose his pension but the carer would cost the same, 24-hour carers cost the same. We'd lose his pension, lose his Attendance Allowance and we'd still have the upkeep of the bungalow because it was his greatest wish to keep my mum out of a care home. He got very upset when she was in one temporarily. I mean he just came away in tears all the time. He was very old fashioned. "I'd promised to take care of her, she's my girl." He called her my girl. "She's my girl, I promised to take care of her and I will, you know."

So, then he sadly passed away and that is another awful story. Then of course it all needed a new financial agreement. Many years ago, he had a lot in his savings account because he saved and he had shares and everything. It sounds an awful lot of money and I know to some people it is a fortune but it isn't when you think what a lot of people have. If they sold houses and things they could have many hundreds of thousands but it doesn't matter. What he did, many years ago, he signed in his will that when he died, the money would be put into a Trust for my mother so that if she needed care it would be there.

She wouldn't be able to use that money but the interest would pay her a wage that could be used towards her care. That was the idea and he felt that that would be the best use of the money. Unfortunately, in hindsight it wasn't a good idea because when my father died, I couldn't use that money, couldn't touch it. It put her over the limit for care. You don't get help if you've got X amount in savings, so it put her over her limit and yet the only thing we could get was the interest. The trouble was it wasn't X now. We'd spent Y up to his death, on care. That was our contribution, not what Social Services contributed. My father paid, while he was alive. I had to do all the paperwork because he was blind so that's how I knew, I was able to count it all up. We've now spent a large portion of his saving. So, if Mrs. May hadn't stopped what Cameron was trying to do to put a lid on how much you spent, I would have had a lot more help with my mother's care.

So, I was in this predicament and when she had her financial assessment after my father passed away, we had this difficulty. The money that was left was put into a Trust, I couldn't touch it, I couldn't use it to pay for care. Prior to my father's death I was employing a carer on behalf of my parents from a care agency. Cambridgeshire had used Penderels Trust as a manager. This is where it comes into what I've written down here. When my father died I had the same care bills but I lost my father's pension and his Attendance Allowance towards the cost of care. Cambridgeshire now carried out a new assessment of my mother's funding for care. While this happened, I gave notice to the agency because I couldn't afford to keep the agency. I was thinking "Well actually, I could save such and such by employing someone privately," while all this was going on and if I was gonna lose the contribution towards what Social Services was giving because it puts my mother over. So, I've not only lost my father's pension and his Attendance Allowance, I'm probably going to lose some of the contribution they were contributing. They were contributing about X a week and my father was paying the rest. I was in a situation where I might not even get that. Trying to find X a week and more every month for the upkeep of the bungalow, well, it's a lot of money.

Addison: Yeah, that's a lot of money every month.

Arthur: You could say. Yeah, and I couldn't put my hands on this much 'cos it was all wrapped up in this blimmin' Trust. My father thought he was doing the right thing but this is why he was worrying in his chair before he died, he knew the problem. I told him off. "Stop worrying," I said, "You don't know you're gonna die first!" Which he didn't. Life can be, you know. I remember saying to him "Look you can't make any more money. I will manage as best I can. I mean, I will do the best I can," which is what I'm trying to do.

Addison: Did you speak to the people he set up the Trust with and try and sort things out?

Arthur: Oh yes, all through the solicitors but there was nothing we could do. You know what really frustrated me, and this is another story, is that they hang on to that. And, of course apart from there being much less in the Trust now, interest rates when he took it out were a lot better. So, he could see, “Oh she’d get so much a month for my something and something thousand and at this interest rate she’d get a nice bit of money coming in on top of her old-age pension, which would have probably have paid for the care.” It would have probably been enough to pay for all the care but now with much less in the Trust and the interest rates being so low...

So, I had to meet with a solicitor and I suggested an investment I’d seen on the internet and they said “Oh no, no, no, no, no! We can’t just use anybody, we’ve got to use somebody that we’re happy with.” So, a meeting had to be set up. I had to wait months for that to happen. I had to sit down with this man, I can’t remember the name of the company; to invest this money. And, do you know, it took nearly a year, so somebody was hanging on to that money all that time. Even though the interests were very little, it could have been making something. I could never work out if the solicitors where dealing with it or whether solicitors had handed over the money to this money company but either way, I thought it was all set up. Then I had a letter from them saying, oh, can we have your father’s, oh I don’t know, national health insurance or something? I said, “I haven’t got it and I thought it had all been sorted?” “Oh well,” they said, “They’ve just asked for this and they’ve just asked for that.” I was thinking, “My goodness.” I said, “He’s been dead a year. What are you doing? You pay all these solicitors all this money and they...” and anyway. So, that’s another story.

So, it’s difficult isn’t it? Anyway, they started to do this other assessment so I had to get all her bank accounts and stuff sorted out. I had a mammoth amount of paperwork. I’m trying to think of the events. Um, basically we came into the new year and I had a phone call from the financial team who started it. I can’t remember if they started the assessment at the end of the of the year or in the New Year but I was just going away on a planned holiday. The day before I was due to go on holiday I received a phone call from the manager doing the financial assessment. She told me she was the manager, I wish I’d got her name. She accused me of hiding thousands of pounds of my father’s money as they found out my parents had owned a flat in Stukeley Park and therefore where’s the money for that gone? Now I was absolutely exasperated trying to explain, “Well, where do you think it’s gone?” And, of course this is the day before my holiday and they’re asking me for proof. I’m thinking, “Oh God, we’re waiting for money and help and it’s all gonna be delayed. I’m going off on holiday but I’ve got to get all this paperwork and proof.” Well, it was impossible, I couldn’t do it. So, I wasn’t very happy. As I say, I was exasperated knowing I was going away and did not have the time to prove to them where my father’s money had gone.

I explained we had to buy a bungalow while he still lived in Stukeley Park and we had to gut the place in order to change it from a 2 bedroom to a 3 bedroom. This would enable him to provide a bedroom for the 24/7 carer. He was sleeping in a bed the lounge in the flat so the carer could have his bedroom. It was not good. He couldn't get a mortgage because he was too old. I had to get a mortgage for the place. I had to apply, so all that took time. I explained that the extensions cost a lot of money and we had paid the lion's share of the wages for 3 years. That is where the money had gone. You know, they wanted to know where all his money had gone. On my return from holiday in early March, I had another telephone call from the financial assessment team telling me they were not going to fund any care for my mother as the team had discovered my mother owned 2 properties. I mean, do they make these things up? I bought this house; my mother has never had her name on any part of this house. They were in Portugal when I bought this place in the 80's. Where do they make these things up?

Addison: How did they come to that conclusion?

Arthur: Oh, God knows! I mean you know, this is where I've got exasperated with it, their total incompetence. My mother never paid towards her care, whereas my father had to pay for all his care because as I say, he had his savings. His name was on both properties at one time because obviously if you're doing something, they couldn't move from one to the other and they couldn't sell the old one until they had the other one ready. They couldn't, as elderly people, move into a place while the builders are gutting it. So, his name was on it but my mother's name was not on there because she had paid nothing towards it. And, I said to father, "You wait until mother's half of the flat is released and that can help pay the mortgage off," which I had been paying, "And, she can pay in towards some of the costs." So, she never owned two properties, ever. We put her name on the old one, we had to pay to put it on once we sold the flat. Although it was all my father's money, she never paid for the flat, but because it's in both their names obviously they get a cheque for half the amount when they sold the flat, half each. Her name was put on the flat when she moved there and her money was used to pay in towards some of the costs and pay off the mortgage which I'd taken. So that's what happened, she had never owned properties, she only ever owned one property at one time.

So that, again, was a completely false accusation and she had never ever had anything to do with my home. I said that, "Now that I was back from holiday, I would look at all the carers' bills, building costs of the bungalow as well as statements of my mother's bank accounts."

I was worried about how was going to photocopy everything, there was so much. I mean, I've got a whole file on just the bungalow. All the receipts, for all the invoices, for all the builder's work. So, later I had a call from the team

and I explained I had files of paper to show them and could not possibly photocopy them and neither could I post it all. Now, I spoke to another woman and she was very different to this vicious woman that kept ringing up and accusing my mother of owning 2 properties and accusing me of hoarding my father's money away. She offered to come round for the meeting and I said, "Oh yes because I can have it all here and show it to you." And that's how it worked. So I thought, "Well how am I gonna do all this?" I've kept receipts for every single thing that we paid for. I'd got a book from when our first carer came and I wrote in each week how much I paid her. If I paid her transport or I'd paid for her food. I kept records of all the carer's wages, kept a tally of everything I'd paid out. It had nothing to do with what Social Services had contributed, just what we had paid out to the carer for. That's why I was able to say, up to when my father died, he had paid X amount of his savings. And I was able to show this person that and she was satisfied. I was able to show all the receipts for the care and the building work.

I took her to the bungalow and showed her what it was. "This used to be part of the kitchen and this was there. That bathroom's over there now and we've built out. The lounge is there and there's a separate bedroom there." I was able to show her everything we did, show her all the receipts and show her what we'd paid on altering that bungalow and where his money's gone. So, she was satisfied and eventually they came to a conclusion and an assessment was done.

Addison: Sounds like a lot of back and forth.

Arthur: Oh it was, it was awful, it was very stressful the whole thing. So here we are, the actual financial assessment. I mean, disappointing because I was getting X and now I'm getting quite a bit less with Y but Y better than nothing. Another annoying thing which is nothing to do with how much care my mother needed was just the financial side. I was also having a battle with Social Service care side needing more hours because I thought "Actually, I need more hours of care for my mother." When they were paying X, that was for 16.5 hours of care a week. My argument was "My mother was much worse than when she was assessed for that and she deserved far more hours than that," but we never got it. And, that's another story.

So, the annual financial reassessment of care contributions for was posted to me. When my father was alive the full cost of 16.5 hours a week was paid by Social Services. My father then paid the difference for the 24/7 carer because we understood Social Services don't pay for 24/7 care; unless they were in a care home then they would have to. Now I had to find another big chunk of money towards the 16.5 hours and Social Services would pay me Y pounds a week. I could not receive Y pounds while I employed a carer who wanted to be self-employed.

So, I had to employ, after the leaving the agency, a carer because I needed to get somebody quickly. It's very difficult sometimes to find an independent carer who will sign up to this because most of them are probably all signed up to agencies and those that who are not, who don't want to for whatever reason they have, want to stay in self-employed or whatever. So all those people I'd phone up from The Lady magazine, when I actually got on talking about signing up to Penderels, oh the phone went very quiet. Very, very difficult.

One thing that I was not happy about at Penderels is that they said, "Oh, they have a department that helps to employ carers for you. You fill out a form and we'll see if we can get somebody for you." I spent ages filling out this form, saying exactly what care was needed da dee da dee da. I had one phone call from the entire time I was with Penderels. That girl then rang me and said, "Sorry I've found a job, I won't be coming to the interview." And, that's that for you. All that effort. So, that didn't work.

Addison: Yeah, I think generally carers and individual Personal Assistants are quite difficult to find. That's a big problem for a lot of people.

Arthur: Yeah, they are, yeah. So I had to search, so that I could get this contribution and I had to find a carer that would sign up and I did. I knew that I wouldn't get any money from Social Services while I had a carer that wasn't willing to sign up. The carer that we had was costing me less so there wasn't an awful lot of difference but I wanted to do things by the book. I knew this carer she wasn't an illegal immigrant or anything. I saw her passport, she had permission to be here but she hadn't got a National Insurance number. So, she didn't want to sign up for whatever reason she had, maybe it was just because she wanted to be self-employed. I had another English lady who once came and cared for us but she didn't want to sign up because she liked being self-employed and she wanted to be free to do that. So eventually I find somebody.

In the meantime, I rang Purple who told me they had not received any money from Social Services so could not pay my carer. Oh, that's right! Sorry, I've jumped a bit. My new carer sent her details to Purple and she completed her timesheets and they said, "Well you send me your timesheets, either do them weekly or monthly and then we'll pay you." It sounded so easy, so simple and then it wasn't. I rang Purple who told me they had not received any money from Social Services so they obviously couldn't pay her. If I wanted to keep the carer and my mother was in desperate need of a carer in the last few months of her life, I had to find the full cost of her care for one month thinking it would be sorted by the next. So, I paid the carer the whole lot because otherwise, I mean, as much as she loved mum and enjoyed working and caring for mum, it's her job and if she doesn't get paid, you know, she's not a charity. So I made sure I paid for her. I rang Purple they said, "Well as long as

you keep the receipt.” So, I said, “I’ve got a record. I’ve paid the money into her bank account. I’ve printed it off on my printing machine so I’ve got a record that I paid her for that money.”

Addison: And did you go back to Social Services about this?

Arthur: Oh yes, yes. In the meantime, I was contacting Social Services also asking to review my mother’s care. I wanted more than the 16.5 hours and I thought that if I got more hours I might get a little bit more contribution. Her health had declined considerably and much more care was needed. Just one example, when they assessed her for 16.5 hours... My mother never had a big appetite but if you provided her a meal of food that she liked, like salmon and some broccoli, just small portions, she never liked big; you could put it on a tray, ‘cos she was basically in bed. I mean, it wasn’t that she had to be bed bound but after her leg broke and everything, she spent a lot of time in bed. She always said, “Oh, I’m not well enough to get up,” but it was a psychological thing and due to her dementia rather than she physically couldn’t get out. She could get out of bed but she always wanted to go back to bed as soon as she got out. She didn’t want to sit in the lounge or anything. But anyway, you could put the food on a tray and she would eat it with a knife and fork. When I sat with her a year ago, we were having to feed her, we were having to actually cut it up and feed it a little at a time. Now, that takes a carer a lot longer to do. They’re not just putting it there saying, “There you are.” You’d have to keep reminding her, my mother, to “Drink your coffee, don’t forget your coffee,” and she’d take a sip, put it down and you’d have to say it again in a few minutes time, “Don’t forget your coffee.” If a carer just puts her drink down and goes off to do something else, that drink will still be there the next time somebody turns up. That’s even more important than the food because of dehydration.

When my mum was given 16.5 hours if she needed the loo she would get up, get out of bed with her zimmer frame. She was very careful with her zimmer frame unlike my dad who rushed about on it. I never feared she was gonna fall over, she was very good. She went into the bathroom, the carer would have to go in and check she’d cleaned herself and said, “Now go to the sink and wash your hands,” do all that. She was able to turn the taps on and do all that for herself.

But, eventually we had a situation where you have a lady where her brain’s not even telling her she’s going to the toilet. And they can’t give me more hours? They’re still saying to me, “I don’t think you’ll get any more hours.” I said, “But look at the amount. How can somebody, the best carer in the world, come in in about half an hour, even three quarters of an hour and cook a meal and feed it to her. That’s gonna take three quarters of an hour just the feeding. Make her sit there and drink and you’ve got to keep reminding her. They’ve got to take her to the bathroom and they’re gonna have to clean her

up. They've may have to change her nightie, they may have to change bedding. They've got to write their notes. They've got to put the bedding in the laundry. How can you do all that in one session?" I know what would have happened, they'd have come in and said, "Oh, we didn't give her anything because said she wasn't hungry today," because that's what my mother would have said. You had to encourage her like a child. You'd say, "Come on." "No, no, I don't want to." "Oh come on, just one more spoon." "No, no, no. Oh, all right." Then she'd eat a little and you'd do that and you'd have to it again. That's how she got, towards the end.

When I was asking for more time my mother had gone further down that line. She wasn't even able to get to the bathroom. She had to be changed in the bed, the carer couldn't manage my mother on her own. All her food had to be liquidized and they're not giving me any more hours. It's disgraceful, it's a scandal. I am so angry.

The only help they gave, the new social worker sat in that room in the bungalow and she did say, "I'll try and get a carer to come in three times a day but it won't be this week." "So, what am I supposed to do this week?" "It'll be next week." The last week of her life we got somebody. Last week of her life. The week before I had to help the carer or find and paid somebody privately. So, I was paying two carers, paying two carers on my own, no help from Social Services. Paying two carers, one 24 and one to come three times a day. So that was the situation. I was contacting Social Services to review my mother's care and still no money towards it.

I talked to Purple and they knew I was getting exasperated about the whole payment thing. They said, "We've not had any money from Social Services, we can't pay until we've got some money from Social Services. Then we've gotta tell you what you have to pay us and then they can pay the carer," 'cos that's how they work. Social Services pay their bit, they then work out the rest of the wages, what I have to pay to make that bit up and then they can work out the carer's tax, national insurance, etc. and send them a cheque for the rest of the money or pay it into their bank. That's how the whole thing works but they can't do anything until they've got any money from Social Services.

So someone said, "Let's get a meeting together, we'll thrash it out and sort it." I thought "Thank goodness for that, somebody who's sensible." Then we couldn't get a meeting together for a month. So, we waited and waiting, and I said to the carer, "Look I'll have to pay this all. I'll have to pay last month and I'll have to pay you this month 'cos we're not getting anything from Social Services or Purple so you're not going to get paid in from them." She was sending in her invoices for her hours but nothing was coming back.

So, it comes to the day before the meeting and somebody from Social Services rings and says, "Oh, sorry I can't make the meeting." I blew my top. I

said, "Do you realise how long I've been waiting for this, do you realise this? I had an invitation the day before to go out and I said no because this is an important meeting. I hoped that Social Services would think it's important about my mother's care because it has not been sorted. Purple have given up their time to come tomorrow and left their diary free to come and now you're telling me you can't." "Oh, oh dear," the woman on the phone said. "Can you hang on a minute? I'll need to speak to somebody." So, she came back and she said, "Yeah, a lady, it isn't the same person, but a lady will be there tomorrow." I said, "Thank you very much. You don't realise how happy I am to hear that news because I was just so angry. Finally, I thought we were gonna get things sorted out tomorrow and you rang me to say somebody wasn't coming I was angry." And, I said, "I know it's not your fault but that's why I was angry." So, anyway I was pleased.

Come to the meeting. We were in the bungalow and Purple were there. I have the carer there because I want to carer and me to explain to the social worker the needs my mother has. By this time, the doctor had been in the morning and told us, "Your mother is dying. I'm gonna stop all her medication. There's no point in her having this medication it's not doing her any good. I'm afraid this is the natural course of this awful disease." Although we knew it inside, it was still upsetting to hear it. You know you're in the last... we didn't know how long and you can't get a doctor to say that. They're not gonna say, oh well it's a few days or six weeks or six months. It didn't necessarily mean that she's gonna die the next day; it could have been Christmas or the New Year. But this is the thing... So, after that we told the social worker.

Now we got two things from the social worker. One, she said she would get a carer in to help the carer change my mum. They couldn't do that week but could do the following week. And, then she rang to say they couldn't get anyone in the morning, they could only get somebody at lunchtime and in the evening. However, I'm around in the morning so I was able to, luckily. But, I mean you know, what would happen to somebody who doesn't have a son or daughter living nearby?

Anyway, as for the money, I said to her, "I need, you know, this is the situation. We should, be getting more than 16.5 hours." I went through all the things that were happening and what the carer's were having to do with my mother. I said to her, "We haven't had any money." To be fair on the social worker at the meeting she had not been my mother's social worker. So, this poor woman, because of my exasperation, they'd got her to come to the meeting. She knew very little about my mother, so a lot of the time was spent explaining the situation. I'm not blaming her for what had gone on in the past because we had to explain the situation that my mother was in. She met my mother and she went and saw her and everything. I explained how I'd been trying to get more hours and had been told by the previous social worker that it was very unlikely that I would get more hours. Obviously this is to do with

these cuts. Somebody's obviously said, "Look you don't start giving out more hours and we can't afford it or whatever." But, this is an old lady dying from Alzheimer's. I think it is disgusting the way that she was treated. And, so we never did get anyone to say you will get more hours.

To be fair the social worker at the meeting, I think it was her, she helped us get a hospital bed put into the bungalow. So we had a hospital bed in there for the last days of her life. That made it easier because I had help to change my mum. When you've got an elderly person and they need changing, they wear a pad. It's not something that you as a son or daughter, but particularly a son, want to be involved in, the personal hygiene of your mother. I mean, they do it for you when you're a baby and you do it because you love them but it feels the wrong way round somehow but you just have to get on with it, you have to get on with it.

But, it isn't just as easy as that because if you start lifting her, she slides down the bed. If you start trying to drag a lady up the bed... her skin was so thin, she'd have ended up with bruises and the carer could have been accused of abuse, understandably. So, we used to have to get my mother to roll over to me to one side and a mat was put underneath her. Then we'd roll her back the other side and the mat was then pulled up. Then we could move the mat and slide her up the bed. That's how we move her. Now, you might say, "Well why can't you leave the mat there?" Because, she had a special mattress so she doesn't get bedsores 'cos she's lying in bed all the time. You can't leave the mat there because that will stop the good that the mattress does.

That's just one thing. If you've gotta change her, you've gotta get her nightie off. You've gotta do all the changing, you've gotta take her knickers off and the pad off and then when you start bending my mum's legs she's going, "Ow, ow, ow!" And, you know you're not really hurting her and she always kind of exaggerated it but it was very hard. That's bad enough but if she was cross because she doesn't wanna be touched even though the bed is wet you've got an added problem. You've got somebody when you say, "Please roll over," she wasn't helping you and that made it very difficult. She never thrashed out or was aggressive but when she didn't help you to change her, it made it very difficult. And, we're given an hour in the morning? You know, the carer could go and she could mess herself and she'd be like that until the next carer turned up. And, how would the carer manage to change my mum on her own? It's impossible. We were never given any more than 16.5 hours a week right up to the end.

Money-wise, I said to Purple "We still haven't had any money," and they sat in the chair in the bungalow and said, "Well we haven't had any money from Social Services," and the social worker turned to them and said, "You haven't asked us for any yet." I'm just thinking, "What the hell is going on with your two organisations? I mean, this is terrible." And, that was the situation. You

know, they both promised me faithfully they were going to go off and sort this out. My mother's died in the meantime. It's terrible, it's absolutely disgraceful. So, that's the story really.

I telephoned Purple and asked them where the money was. They told me they knew what was holding it up now. Apparently, Penderels owed us some money from before we switched to Purple and that was holding it. Why would that hold everything up? Because, they were waiting for that to be sorted out first. I said, "I'm so angry I'm going to get in touch with the MP about this." I tried to, the whole matter is disgraceful. If they owed me this money why should I have to wait for the money that is due now? I've had to pay the carer full wages. She's off on a planned holiday but then she's coming back and helping me sort out the bungalow so I'm paying her right up to the end of the month 'cos I thought she's gotta be given time. It'd be really ruthless for me the day she died to say, "Right, well pack your bags sorry we don't need you tomorrow." So, I'm employing her right up to the end of the month and if I could afford it I'd employ her further but as I'm not getting any money at all. I've had to pay the carer full wages otherwise my mother would not have had the care that she desperately so needed at the end of her life.

Is this the way they treat people? If this happens to someone with dementia who has a son chasing things up as I've done, goodness knows what happens to poor people who have nobody to fight their corner. I told all this to Purple and Purple said they would get straight onto Social Services. Later that afternoon he rang to tell me it was her day off so he would try again on Monday. That was yesterday, haven't heard a word. No message, not a penny of money owed by Social Services.

I've written it down as honestly as I can recall, remembering the facts and the phone calls and the people it involved. There were some I wished I had asked their name and written it down, like the team manager at the Financial Assessment team who was so snotty and accusing me or my mother of owning two places and accusing me of hoarding my father's money. I didn't but I should have done.

Addison: It sounds like an incredibly stressful process.

Arthur: This other file is all about continual care and the battle I've had with that. I'll tell you something else, just as a point of interest. This is irony; I've been fighting this battle for continual care for a while. So I've had this battle with social service and I've had every excuse-delaying tactic under the sun from Health services. Direct National Health have been saying, "Oh we've had a new system put in, our computers aren't communicating with Social Services' computers so we can't read the social worker's signatures on the form, they have to be redone." They were all redone and they left it another month. The next one was, "The social worker signed in the wrong place." The

next one was, “Your mother hasn’t signed the form.” “Hello! If you read the form, she’s not capable. If you read the details that you’ve been given, she’s ill with Alzheimer’s and is incapable of signing and if she could sign it she wouldn’t know what she was signing.” What the matter with these people?

The next excuse was, “Oh, you’re down as next of kin and you have no right.” I said, “No, I’ve given the social worker my enduring power of attorney,” and they said “Oh, well for financial purposes only.” I said “No, it is enduring power of attorney.” I shouldn’t be having to tell her, her job. As much as one of the social workers had been very supportive to mum and I know her hands are tied because somebody’s obviously told her, “Don’t give any more hours or whatever.” She has tried, I believe, her best. But, I mean, I had to tell her that this enduring power of attorney was taken out before they changed the law. I don’t know whether you’re aware? In about, I think it was 2007 they changed the law so you had to have two power of attorneys. One was purely for assessment, which is what I had for my dad so I could deal with all his finances because he was blind. I didn’t have one for his care. So, if something had happened I couldn’t have had any more rights than a next of kin over what the doctors or hospital decide to do with him. I had enduring power of attorney for my mother because we took it out due to her illness a long time ago before they changed the law and that covers both.

So for a year, backwards and forwards, phoning Social Services, phoning health. The social worker got absolutely frustrated with this health people who were saying they couldn’t read her signature and we were saying, “The bank reads it, it’s good enough for the bank, it should be good enough for you.” That’s how we ended up losing her as a social worker. She got so exasperated with the health, the way Direct Health were dealing with it and she handed it over to a colleague. I wish I could’ve handed it over a colleague and got somebody else to fight my battles but I couldn’t. But then, finally I had, “Yes we’ve got the form, we’ve got your signature. We can act on it.” “Good, when will you be coming to assess her properly?” “Oh, well we’ve got a backlog. It might be a month.” We’d not seen the district nurse all year. Suddenly, when the doctor tells them she’s dying we see them twice in the week before she died. I had a letter the other day saying, “Your mother has been granted continual care.” It was dated the day she died.

Addison: That’s ridiculous.

Arthur: It’s scandalous, it is absolutely scandalous. Every delaying tactic you can give and it’s awful because I know this isn’t the only case. There was, I think, one of these documentary programs. It was, not Look East, what’s the one that was on last night after the news? Oh, I can’t I can’t remember. It’s like a news programme; they do some issues after the local news. It was about a man having the same problem that I’ve had but he was the husband and he was in his 80s fighting for his wife’s continual care who had severe

Alzheimer's, like my mother. And, he was having the same battle. Poor man. I mean, it wore me out and they're having the same thing. Apparently it came out of that program that sometimes when district nurses were assessing, the work they were doing was not carried forward because the Direct Health were trying to avoid payments. They were falsifying what the nurses were putting on the forms so they didn't have to pay out. It is expensive continual care and because it's National Health, they pay the whole lot so they don't like doing it obviously. And, its 'cos of budgets again, you know people at the top saying, "Oh don't give any more of this out." I don't know what goes on but you have to surmise.

That's me surmising of course. All I know is the facts of how they used every delay tactics they could. And then, as I say, we had a district nurse. I walked in one day and the first time the district nurse had been near my mother during the year, said, "Oh yes, we're doing an assessment." I said, "Oh, have you met my mother?" "Yes," she said. She said "We're fast tracking it." Well they didn't fast track it enough, did they?

So that's the story! I feel exhausted telling you. I mean it's not even half as exhausting as actually having to go through all those phone calls and the frustration of dealing with all these people. Because, it's two very different things you know? There's the whole social work, social workers and the Direct Payment, which is the bit you're interested in and the big battle I've had with continual care; although they are interlinked because of social workers.

Addison: Yeah, well they would be.

Arthur: Yeah. It's too late for my mother but I'm happy to do this because I feel for other people that are in a similar position to me or in a similar position to my mother. And, it also frightens me because of what's ahead for me. I haven't got anybody to fight my battles and I've been fighting mother's battle and little good it's done. I just think you know, is this the way they treat people? I just think it's disgusting. I've always been brought up for most of my life in the belief that I felt I was lucky to be born in this country. I've always believed that, my father always brought me up to believe that. But, you know when I've gone through these recent experiences and I think, "There must be other countries that do this a hell of a lot better than this, it can't be much worse."

Addison: That sounds very sad.

Arthur: It is. Well it's too late for my mum now but there are other people that this could all be ahead for them. If doing talking to you can help in any way to get things sorted. But, you see, it worried me a little bit because I remember speaking to you and correct me if I'm wrong... I can't remember when this phone call was, it was after or the day before my mum died and you said

you'd been speaking about it to the head of Social Services and she wanted to know about it. Well nothing's happened as far as I'm aware. I still haven't been paid any money.

Addison: I didn't speak to her directly.

Arthur: Oh right, but somebody you know?

Addison: Yeah, my colleague. He facilitates something called the Adult Social Care Forum.

Arthur: Right, yeah

Addison: And the head of social worker for Cambridgeshire, she sits on that. So, I fed your information back to him and he fed it to her.

Arthur: Right I see that makes sense. Thank you.

Addison: And then, what he came back and told me was that if I passed on your details, they would look into your case specifically. This is all I can do because I don't know what happened.

Arthur: Oh, of course you don't, no, no.

Addison: I can go back and tell them what you've told me, that still nothing has happened.

Arthur: Nothing's happened so far, yeah.

Addison: Which is terrible.

Arthur: Well as somebody said to me when I told them the story, they said "It's actually robbery really." I mean okay, I was disappointed with the amount that my mother was assessed as getting but I understand why. The reason for that is because of the money tied up with my father. If that hadn't been there or it had been spent then, obviously, she would have been eligible for more contribution. But I mean, to think that I haven't even any contribution.

Addison: Yeah, a big mistake tied up with Penderels.

Arthur: Yeah, I still don't understand that business with Penderels. Why, if they owed money did that delay everything for so long? I mean, I left Penderels a while ago, they've had plenty of time to sort it out you know. I don't know why that even has anything do with this but it obviously has.

Addison: No, at a time as well when you're endured a lot of stress.

Arthur: Well that's right, it does put on extra stress which you could do without. You know, I mean apart from now, when I'm mourning my mother's death. All this was when my mother was seriously ill and I was worried about her. So, there we are. I don't think there's any more to tell.

Addison: Do you perhaps have any other advice for people in a similar situation to you?

Arthur: Cor dear. I don't know because I don't what else I could've done. I'm trying to think what, in hindsight, what I could've done. I mean, I did try, I kicked up, I rang up, I followed up. I mean, the only thing I could've done I suppose was get the solicitors involved earlier on but that costs money and I'm spending all the money on care.

I've no regrets on spending all my mother's and father's money on care. I know my father was sad because he thought he was going to leave it to me one day or my sister. But, it's their money, they worked hard for it and I have no regrets. In one way, I mean, one good thing that comes out of all of it is that it was my father's wish. It was his money basically. My mother never earned any money so it was basically my father's money but shared obviously because they were married. And, they were married more than 70 years which is quite a record. I managed the money and it lasted long enough for me to keep my mum out of a care home. There are some good care homes about but when you hear on the television that 25% are not fit for purpose, you realise you've done the best thing by keeping her out of one. She was in her own home and I was able to keep her there, so that was one thing I was able to do. Some people wouldn't be able to cope with that or they don't have relatives nearby to do what I've done for my parents and they would have to go into a care home. I won't have any relatives to do that for me and this is what frightens me that I'll end up in one of these care homes.

And, I'll tell you what, I think what other people don't realise, and this is another frightening aspect, is that if you think that you haven't got X amount of money the state will care for you. They will give you the care they think you need, not the care that actually need. They were still telling me that my mother only deserves 16.5 hours of care a week. That is frightening when you saw the state she was in. That's not care, that's negligence. That's frightening for everybody because people who think, "Oh well, I haven't got a lot of money so the state will have to look after me." Well... if the state look after you as well as that it is very worrying because my mother deserved far more than that.

As an example, the other week I stood in for the carer while the carer had some time off, which she deserved. She went off to see her family, so I stayed and cared. And, she said, "Look, don't worry about changing her I'll do it." But,

I did it, I was able to manage to change my mum. If I hadn't I'd have had to wait until the carer came back that night. I had a pot of tiramisu. She refused all the food I cooked for her, she refused it all. She liked sweet things. So, I had a pot of tiramisu. It took me all afternoon to feed her that tiramisu. You'd give her a spoonful; she'd take the first half off and then turn away. "No more, no more." I said, "You've got to," you know and you'd do everything, "Come on you've got to eat, keep you strong, keep you well." Da da da da da. "I'm not hungry, not hungry." Then you see she'd forget and then you'd give her another one, she'd forgot she'd had one and so on. It took me all afternoon. How can you do that in 2.5 hours a day? It's terrible. So I'm disgusted with that. I'm disgusted that nothing was done about that because that is very, very worrying for all of us.

Addison: Yeah. That's very true.

Arthur: I don't know what the answer is. I suppose the answer is that all the politicians have got to get their acts together and sort this. The aging population is going to get bigger, this is only gonna get worse. I can't see how this can be improved unless there's a big shake up and that needs everybody. The trouble with politicians is they're just interested in the next five years. They don't wanna touch this because they know this is such a huge task. To give people the care they need in the last part of their life it's gonna cost and they don't wanna find the money for that. They find the money for things they want to, don't they? The politicians have got to do something, it's gotta come from them, I believe, to make any serious changes. While these cuts are in place it's terrible how people are being treated. And, my mother is just one case, goodness knows what's happening in the rest of Cambridgeshire and presumably the rest of the country. I suppose each authority is slightly different and they have different priorities. Obviously this isn't their priority.

Addison: I'm sad to say your case isn't atypical.

Arthur: No, I bet it isn't. That's not a surprise to me. I've never taken any of this personally. I mean, I know when they're making all these decisions it's not because somebody dislikes me or my mother. I know that and I know it's not personal. It's just that somebody's told them, "Do what you can so that we don't have to pay out any money." That's what too many people are being told I believe. Otherwise, why would this have gone on? And, as I say, it's not just Social Services it's health as well.

Addison: That's not good.

Arthur: No, no.

Addison: It's very sad story.

Arthur: Yeah, it is.

Addison: I mean, when you're already going through a lot of stressful circumstances, the Direct Payments should have been there to make things easier. It sounds like it made things harder.

Arthur: Well it has, yeah, it has. It's worn me down, it's worn me down. It's funny you know, a good question, "What advice would I give?" I really don't know because I don't know how you fight this thing.

It's just so unjust. You think there's a system there, that there's a safety net for people, the elderly and the dying you know, but it just obviously isn't there. I'm sure there are some that have been very fortunate and have been in wonderful hospices. I suppose if mother had gone into a hospice that may have happened but I didn't want to move her, that would have just stressed her out even more. But yeah, you do hear stories of wonderful hospices doing wonderful work but then that's all charity isn't it? It's not Social Services. There we are, well.

Addison: So, we'll get it all typed up, make sure everything anonymous, dates, place, etc. and we will be feeding this back to the Country Council.

Arthur: Yeah. Well I hope it does some good because if you're telling me that this is not a unique situation, that they've already heard about situations like this in the past then why is it going on? That's what I would question. If this was a unique situation and that I slipped through the net or whatever that would be one thing but when you're saying to me, "Well this is not unique," and I'm not surprised it's not unique; then why hasn't something been shaken up already? Why is it still going on?

Addison: It shouldn't be. I think unfortunately like you said, funding's getting tighter, so things are going down rather than up.

Arthur: Yeah, shocking, shocking. I've even thought about, you know, the Prime Minister should know what's going on in our country. You know, what these cuts mean. Somebody like that has no idea what somebody like my mum and I were going through in our sort of situation.