



Take Care

A VERBATIM TEXT FOCUSING ON
CARERS OF THE ELDERLY

AN ÉCOUTE THEATRE COMPANY LTD. PRODUCTION

ALL THE ACCOUNTS HERE ARE VERBATIM.

SOME NAMES HAVE BEEN ALTERED TO PROTECT THE IDENTITY OF THE INTERVIEWEES.

(A bedroom)

SHEILA

I used to have lots of lovely lovely people and they (slight pause) used to look forward to seeing ya cause we were such a jolly pair see me and my friend and er they did er they said you're the best you two Sheila and Sheila and Maureen we were the best pair everybody loved us but one particular tell you I must tell you this he was a very old man he was about eighty eight he couldn't walk. He could stand up but he couldn't walk we had a job of getting him into bed so we said can you dance? So we'd get him undressed my friend would take his trousers off and clothes off or put his pyjama trousers on with me holding him, we'd sit him down and get his pyjama top on and the only way to get him into bed was to dance so we walked er so we walked er we said come on come on we'll have a dance quick quick slow quick quick slow back I'd got backwards and It would get him into bed couldn't get him into bed if you asked him to walk he refuses to move but if you dance with him backwards go backwards and he's leading right and it'd get him into bed no problems at all.

Yeah and he was a lovely man, everybody adored him all the carers adored him he was lovely sort it was a lovely job I love it I did because you had so many different people ermm all types of people, ballet dancers, tightrope walkers and couldn't walk no more and you'd go in and put them in a chair or put em into bed.

There are a lot of nice carers, there are a lot of young ones who don't care so much as us older ones they just do the job, ya know? They don't do it as they're supposed to do it but like I said you've got to be that type of person who loves people, coz that's what I do I love people I'm not a clever person ya know doing a job like a manageress or any type of other job but because I was good with people and you have to be good with people and have to cheer people up when they're unhappy because you've got to have the gift of the gab. I'm a big softie you know (laughs) that's who I am, can't change. Another one I dunno whether I should tell this, this is what you have to put up with there was a jewish man and i came in and I said I'm here to do housework and caring and he said get on the bed and open your legs (whispers) that's what he said, get on the bed and open your legs and I came straight out of there I thought (ahhheeee weird sound) yeah and err I phoned the office and so she said did you go in and clean? I said no I bleedin didn't I said I ain't going in there (laughs).

Erm yeah let me think. . . Mr Butcher you know the one with the letter I showed you? I had a gentleman who was ninety eterm he was a lovely man and he said to me one

day he was a very tall man lots of white hair he says to me "Do you know? I love you, you know." I said do ya? He said "Your such a nice lady I do love you Shelia." and he wrote that to his daughter he told his daughter that he loved Shelia she's such a lovely lady he asked me when he was dying love him because er one particular time he had a kind of erm err I know what it was it was a cancer on his ear, scabs, scabs on his ear and I phoned the office up and I said I think he's got cancer I said cause he's got a growth on his ear and a growth on his neck a lump on his neck, I kept saying to him every time I was there is it hurting? No. Well it shudda hurt ya see? So I rang the office up and the office sent the doctor out the doctor was stupid and thought it a carbuncle it was no such thing as a carbuncle but Mr Butcher did tell me off for letting the office know, I shouldn't have notified the office, he was a bit cross about that but he got checked by another doctor and they took him into hospital and he had cancer. When you're a carer you pick up things, you're not a nurse your just a carer but you pick up things and you knew what it was.

After the operation he wanted to see me so I went up to see him he was so pleased to see me but, while I was in there I noticed that he had just that he was crackly only very slight his breathing very, very slightly and no one had noticed it, so I said he's got a chest infection so the nurse said how do you know? I can hear it! He'd got pneumonia hmmm yeah and he died. Love him; he had good old inns didn't he? He loved me he did, that's what carers do, you get involved because you like them and err you get to know them for years and when they pass away its very upsetting especially if you get two or three go at the near enough the same time it's very hard. Most of them are very sweet people though there are a few VERY WICKED EVIL old ladies they've got tongues like vipers they're spiteful and they're vindictive and they ring up and say "Sheila's just been in and hasn't done a BIT of work for me all she wanted was to sit down and have a cup of tea." Bloody liar (whispers) because I'd been and done all of her housework done everything for her, got her shopping, her pension showed her and made sure she'd got all of her change and make sure everything is all sorted and rings office. But that's only the bad side, you might get three out of ten that were nasty ladies and those ladies live a very old age all the young ones all the good ones go early see? (Laughs) But er it was a brilliant job, if I had my time over I'd do it again, oh yeah oh yeah oh yeah I loved it I did anything else?

(A sitting room)

THISSY

The big picture, I think a lot of people, erm (pause) view the caring industry with (pause) I think they see the news on the televisions, they see the bad carers working, because they make news, erm because they don't see- it's like any story you only see what they want you to see and there's a lot that's going on that no-body sees underneath that's good

I mean when I first started, they sent me out with no training what-so-ever, virtually *no* training. And they sent me to a lady, who was a double-hander so there was

supposed to be two of us, and I said to the other girl, I said, “I hope you know what you’re doing”, because I said “I haven’t got a clue”. And she said, “no, I don’t”.
(pause) Awfully. Because we didn’t really know what we were doing, (LIST) the client was non-weight bearing, I trod on her toe a couple of times, and it made me feel really awful, we were there about double the time we should have been because we didn’t know what we were doing and we didn’t know her routine, her husband was getting upset... So you can understand why, and this is, or one of the reasons why I think they’re (cough) trying to improve the system with training and the NVQ’S, and the training you’re offered now, with agencies is much better now than it was, yeah, it is much improved.

They do, **do** require (quiet) now that for a carer you do have some training, the NV, the NVQ, yeah. Which is a completely different issue that I won’t go into now. (Loud) No, no, the only thing I think about the NVQ is that-(high)erm (mouth together)
(pause) (soft mouth click) (high) I think part of caring is this, erm, abi—litayy to have empathy-ayyy nd understanding, with,(high) your clients, and it’s not something-it’s very difficult to teach somebody, those qualities, and I think it doesn’t matter what NVQ you’ve got, if you haven’t got that, innate ability to do that, then, it’s still, you’re still not going to be a very good carer.

0.28 (BREATH) I sthtarted caring about twelve-yearsth-agoO, after sthpendiing-the major-itay of my working life (pause, high) working in an offithce. And I decided I wanted to do something diff-erent, so something more a meaningful and useful, (laugh, smile) than (nose wrinkle) shaving bits of paper around all day
They don’t, a lot of them don’t, I think I signed onto one- I guess a couple of years ago, and the first thing the manager- the first thing she did was lie to me. About how much I could possibly earn a week, she started talking to me about another carer, although she didn’t mention the carers name, (pause) yes, in a negative way. She started talking about a client in a fairly negative way, and I think she did, she did mention her name, but only her Christian name, and to me, to me that was an instant turn off to start with, to me that was an unprofessional approach. And I was uncomfortable with it, but I went along with it, well not, go along with it, but I had to do a bit of work for them because I needed work, and then I thought this is no good, because you’re associated with them. I don’t like it. I really don’t like the attitude.

(A smoking shed)

GINA

(*breath*) ORH, I was-er fourteen-and-a-half. Yes. Mm. (*tut*) Errr because (*tut*) erm my father had - died and-that and errr my mum couldn’t afford pocket money and in those days you did work in shops-and-things from 14? (*high*) A girl came up to me, into the playground, and said, erm, I heard you’re – (*go up at the end of each*) Tina her name was, I remember it, I was sitting on the grass with my friends, and er she said (*very high*) ‘I here you’re looking for a job’, and, (*tut*) that was it!

I've seen a lot of things over the, yeah, couple of decades Mmm there was no regulationssss, as such, to follow, **no**. (bit shakey) I was left on my own, at fifteen, for an hour (*HIGH*) yeah, with a diseased body. People were locked in their rooms, that had dementia mrrr. (*matter of fact*) People were tied up with tights on comodes. They had to go to the toilet, and otherwise they'd, they'd, get off and walk about. So they were tied, yeah. (*Snort, shake head*). It was normal, normal because I didn't know any diffrent, and I didn't really tell my mother (pause) because I thought it wasss normal, at that age, and because I thought adults knew best (nod) mmm mmm. (Pause) I mean it still does in some, I mean there obviously, there obviously are legslation, legislations and that but- I mean, you've seen on television and panorama programs things happening, so unfortunately it probably still does. Before these legislations, the public was, well ignored, so there was no protocol, there was no.... If you had an older carer who erm did things wrong, that younger person, going into care, wouldn't have a good mentor at all, and they'd go onto...yeah. A bad apple all the way through.

They discourage relationships, you, you get erm, warnings and you get erm disciplinaries (breath) because you can't cross that line into friendship. You genuinely not allowed- if someone goes into hospital, you're-genuinely-not-allowed-to-visit-them-in-hospital. (slam) No, it's part of the contract with the agency, (dismiss) it's-a-business. Yeah. (high) But then - I suppose there has to be a line somewhere because, because there's bad things isn't there, li-erm if people diiiiie and (fast) wiws and things like that. But it's very difficult nnot to-cross, that line. (fast) But I don't have that now, I'm independent, I have my own- rules (laugh – a, huh huh).

If people have their (single clear throat) advocates, (breath) they have a voice if they haven't-got-a-voice-themselves. The people that haven't got family, or loved ones, or someone to look out for them, they are the vulnerable and they are the ones, they are ones open (high) for abuse.

No, I've had my moments, yeah, but it's, yeah. I was, ohhhh, I was about twenty-six, before I moved up here, I was twenty-six, I was in a rest home, I was really, aaaaahh, I always got taught, if you get annoyed, because not all clients are nice, is to leave the room. And I, and I left the room, and I – (quiet, show) and I stuck my tongue out. I felt soo, I felt sooo, I felt so, awful, yeah, it's upset me now, because what a thing for her to huh, sorry, she had to see me go (sticks tongue out with "eurrrgh") and (high) walkin away, do you know what I mean? (recovery) I should have just left the room, just left the room, but I had to have the last, (sniff) and that, that taught me. If you're not helping them, you just walk away.

(simple, high) I've also got a written warning as well, and I left a rest home when I was working here actually. Yeah. Horrible, horrible person. Shouted at this lady, she didn't put her hearin aids in, I could hear her from the, shoutin at her, I thought, how dare she shout at these, you know, little old ladies wakin up, just wantin a cup of tea? "What-do-ya-want? WHAT DO YA WANT?". "Why are you **shoutin** at her?" Awful, so she shut me out didn't she (laugh, apffff). She locked me out! And they kept *her* on! Yeah, she was agency, and they kept her on. I wrote a lovely long, letter, yeah. Oh it

was awful that bloody night, a mad woman! Maaaaaad woman! (simple, question)
Where did they get er from?!

See it's a very hard time to invite somebody into your home. Some people say that as you get older, you erm, retreat back into childhood (shake head) but erm, I think there should be another term for it. (Pause) Well I-just-feel-appreciated-for-my-knowledge, but then I suppose it might be different for a twenty year old or a thirty year old, I forget how old I am now. (False disgust) I'm forty-five now (laugh, high, forced) yeah!

(A cafe)

PATRICK HOLLAND

Um I mean, the system we have at the moment is founded on a piece of law called the national assistance act ...it's, it's very old piece of legislation, goes back to the 1940's and it, it, it really was a law that was written to, to make t-t-t to deal with bits that were left over when the NHS was created...and it was a pretty- it was a backwards looking piece of legislation even then erm, providing a minimal safety net, that it wasn't free, that you'd be means tested...and it, it retains sort of poor law notions that each locality was responsible for making the decisions about who was eligible and who was not. And what we've had in the last 60 years is just basically, bit by bit that's been tinkered with and changed but in its absolute essentials it's not changed...The system will eventually snap back to doing what the law requires in the end. And particularly when money is tight, like it is now, social care has been under the cosh financially for, for a lot longer than many parts of the public service.

So what the new legislation – the care bill - is trying to do, I think, fundamentally is say well we've got to change the mission. It's got to be about promoting people's wellbeing, the right to have a life not just be alive. Also for the first time wherever you are in the country there will be a minimum threshold that you have to cross that will be the same everywhere, that determines if you qualify for support. That is a really big change, it makes the whole system much more visible nationally umm and I think in the long run that's really important that the issue becomes a more nationally debated issue in politics just like the health service is.

(Sigh)...I think, I think local authorities are very conflicted, because on the one hand they can see that, that the changes in the law are one's that they, they want, they welcome, that goes with the grain of what they've been trying to do. Um but at the same time they are, financially very hard pressed. I would liken it...a bit like running a bath um but with the plug out um so, you know, government *has* objectively put in extra money, but it's also objectively taken out money um and the trouble is that you don't quite know which bit of the money is um the money that was given for one purpose or another. So the level is not staying the same and that, that has left local authorities, I think, with real difficulties.

So it's a, it's – a- the trouble with this particular piece is that it's a very, very mixed picture and, and um there are councils that have done remarkably well in straightened financial circumstances er and have mostly done that when they've actually involved the people who use the services themselves. So it's, it's about moving away from being paternalistic: 'we know what's right for you' To being er genuinely interested in the wellbeing of the individual and them being in control and often that means you can, you can deliver those things at a lower cost er but deliver a better result so there is some of that in all this as well.

I mean I- if we are boiling this down to, to those people that are receiving formal, personal care, ah whether it's in a care home or whether it's in their own home erm then the biggest cost of that care is the person that comes and delivers it and...the-the-there isn't really a saving to be had there other than on quality because in the end all you're doing is umm having a situation where you're paying people below the minimum and you're not training them because you're cutting those budgets as well. So, I- I agree with that proposition entirely, the point I'm making is, one of the biggest problems for, for our older population is actually social isolation and loneliness, it leads all sorts of health problems which have nothing to with health but are entirely socially driven, so there are things you can do differently, but when you get down to the basics of dignified care...then you know, then I think the only way you save money is by doing the wrong things.

Umm I mean I'm, I'm by nature optimistic um I don't overstate the impact the impact that the new legislation will have on its own but I think that what we probably have now more than ever is a national debate about care umm that is, is gaining momentum in a way that umm it historically hasn't so it's coming out of the shadows from the NHS, it's a separate debate and I think that's a good thing...

Well-slightly trite point but I mean in 1834 the houses of Parliament burnt down, there's a great story as to why it happened but anyway, and on the, on the opposite bank of the Thames the people of London gathered and cheered, err you know, the idea that politicians are somehow now uniquely ubiquitous, and unpopular um you know I-I think is not entirely true...you know the idea of the golden era when the politician was as well-regarded as the head teacher and the doctor, it never existed... um Other than in some sort of rather um sort of view of the world which was incredibly deferential, you know and there's a difference between deference and respect and yes I think maybe MPs enjoyed more deference in the past, I'm not certain they ever really enjoyed more respect. So that's the first thing um and I guess the, the other piece is- I mean I, I routinely when I'm talking about care and stuff I'll ask people err if they've heard anything in the news about the care bill- and people won't have done, um and most of the reason they haven't done is because mostly the legislation is going through non-contentiously, so you know we have an appetite for conflict, now is the media reflecting that appetite or stoking it? Um it's a bit of both, I think. And, as to what the answer to that is, all I can offer is by doing by talking about these issues more than most MPs...it is the thing I care about most as a politician.

(A meeting room in an office)

PAULINE AND ROBIN

Pauline: I'll just go get you some sugar.

[Exit] [Enter]

How many sugars? Dear oh dear, c'mon I think we can give you two. If this is too strong just tell me because I, I do make very strong tea. Umm, someone's just whispering in Robin's ear, he's in a meeting, that he's allowed to come out *(laugh)* *(Mobile call)* Hello. You sure? Oh. Okay, thank you. Bye. Shall we start and Robin will join us when he's ready? He knows you're in the building.

(Knock at the door) Enter Robin

Pauline: There he is! Come in Robin! *(laughter)*

Robin: So sorry! *(unclear)* hello, hello I'm Robin *(hand shake)* before we start can I be really cheeky and ask for a cup of tea?

Pauline: Yeah of course!

Robin: Oh err my work is over at the carer's centre *(upward inflection)* err because there's a, a need for carer's to be supported as well. yeah it's worked quite well.

Pauline: Very well.

(Is the service for carer workers as well?)

Robin: No it's, it's for unpaid carer's, but a lot of people don't know about it. It gives you certain things that you can access which you may not have known about. And some people would still say 'oh no, no I don't want any help I do it because I really, really care for the person' but what we say is well you can do both, you do care, they are still your husband, your father, your sister, whatever, but, you can also get this help and it's there so, you know, take it up. It doesn't mean your any less of a person in terms of the loyalty, because you're actually getting help because being a carer can be so emotionally demanding.

Pauline: The problem that we find *(ironically)*, is that people have got more issues with the caring service than they have with the person they're caring for and the irony of that is, *(laughter from both)* it just, it doesn't escape you does it really. Ummm And we try to work with those people about, how to manage that, and it's very difficult to *manage* a system, or to manage... agencies. A lot of times we've had

situations, haven't we? (yeah) where, the quality of care has been so poor, it's put, ironically, a person's life at risk. If you don't give them medication, you've overdosed on the medication, you haven't read the dosset box you've just give 'em a tablet, or you don't write in the book. You know all the things that are in the system that, that are what I'd call safeguards (yeah) they're not done, for a whole range of reasons.

Robin: And it's about knowing what those safeguard and things are, because if nobody's actually explained it to you (exactly) then you sometimes make an error, as a carer, and you think 'oh god I didn't know I was supposed to do that' so it leaves people with a lot of guilt and err yeah that's, that's massive actually.

Pauline: And I think whether that's agency staff, I know we all- I think the quality of agency staff basic- personally is really crap actually, errrm but there are always one or good- one or two good people ummm but they're holding up a whole system of other people and that's what the problem is. Or the people being cared for frightened to complain. We're in a difficult role because sometimes you really want to get hold of an agency and get hold of people and shake 'em, we get carer's in tears (absolutely) crying their eyes out, pulling their hair out cos they just don't know what to do next, they don't understand it, if your, you know.

(Do you think you need NVQ's etc. to be a good carer?)

Pauline: Any people think anybody can wash anybody, and you can't (no, of course you can't). No, you can't. And you're doing it with some dignity. I really struggle, when people talk about training people in dignity and respect, it's just a personal thing, you've either got that or you haven't. And I also think that courses- the best people to come and train on a course are the carer's themselves, why don't they ask people? Because once you get somebody standing in front of you telling their story the impact on that is much better than what you can read in a book. (Yeah, yeah). They could, they could run them courses standing on their head most of these people.

Robin: The thing is if you do caring for, in any caring role for like, two years or so, it may even be less than that, your motivation as carer, drops (mm, mmm) completely drops because you feel as if you're unsupported, it's not going anywhere, 95% of the time it's going to get worse rather than better and you get fatigue as a carer, you really do. A lot of people get very, very tired, they get depressed, they get exhausted, they don't feel as if they're having the support- in effect they feel forgotten about.

Pauline: I think abandonment, is a really good word, people feel abandoned don't they? (absolutely) or they get a quality of care that's so poor and they think 'Christ almighty'.

Robin: It's about being connected with people and having a sense of a network around you, that you're not on your own. And that's really important.

Pauline: And 'specially at peak times, you know like Christmas is eurg is iso is the worst time for

Robin: That's the other thing which it brings up for me, sorry, is that when I've been working with carers, or elderly, it's almost like there's a script in the family that this person's going to be the one that looks after – mum, this person's going to be the one who does this, now everybody else says 'Oh well she does it now so we can take a backseat, see they might start doing it when th...when thee erm older relative is like seventy-two, seventy-three but then fast-forward fifteen, sixteen years on that elderly person is now eighty-six, eighty-seven, eighty-eight and th...and the, the range of difficulties that people have is much more acute at that stage..

Pauline: There's a lot of resentment. So much resentment in some families. Yeah/

Robin: I'd been a carer for an aunt in London, and I felt a little bit, sort of, I dunno, embarrassed maybe sometimes saying 'Oh I'm a carer' for my auntie. I suppose on some level there was something not quite right about being a male, and doing all this, you know, if, if my auntie had had a daughter, if she'd had a niece then probably that daughter or that niece would have done it. Sometimes people fall into that role when it's not necessarily the right thing for them.

Pauline: But I think that's the same for women, I don't think women are any different, I think there's/

Robin: /Yeah, of course

Pauline: I think there's, when men are the carers, well, 'cos we've heard it/

Robin: /Yeah yeah

Pauline: Where people 'Oh isn't that....ohh haven't you got a great son'/

Robin: /Yeah

Pauline: 'Ohh, isn't that wonderful' (breath) I think, when men do the caring, I think there's a lot more erm credit given/

Robin: /Uhuh

Pauline: A, sorry about that/

Robin: /It's fine

Pauline: And I think we do sometimes get that don't we/

Robin: /Yeah

Pauline: And do people listen to men in services, more than women?/

Robin: /(faint) No

Pauline: I just think that, I was just wondering if that/

Robin: /I don't

Pauline: I don't know if that's the case, I'm just saying/

Robin: /No, no

Pauline: I think you were a great carer to aunty Rosemary.

Robin: No but that was, that, that that's was, that was just a bit of a one off

Pauline: I know, but you were still a great carer. 'Cos we all love auntie Rosemary

Robin: No, well but yes but I could have done better

Pauline: Noo, but it's nice that you done a good job/ Sorry, anyway, sorry I just, as I said, he was a great carer to auntie Rosemary... Mmm. The other thing I was just thinking of is about when somebody's a couple. And how we don't accommodate for people that are older to go into uh-homes together./

Robin: /Mmm

Pauline: The amount of time we've come across people where they've been split up

Robin: /Yes

Pauline: And most places have only got one place here, have only got one place there (breath) and, and I did a work, some work with a couple and they were split up! And I visited one, I was visiting the other and what they were saying, 'Oh where is (say her name's Susan), where's Susan?' And you thought, this is ridiculous, I'm a professional, you're asking me where Susan is, why don't *you* know? Why is no one taking you on a visit? And the daughter just said – 'I can't think anymore because I'm just so worn out, and then/

Robin: /Oh yeah

Pauline: I mean, unfortunately, it was really interesting because they didn't live four months apart and they died – and the daughter just said, 'My mum and dad died of heartache, of heartbreak, because they'd never been', you know they were a couple that had been married during the war and they'd never been separated. I mean, in theory you can't die of heartbreak, you know, in psychological theory – I think it's a load of nonsense (personally), 'course people die of heartache, how can they not? And I as a carer could do nothing about it, I asked social services, we've even had, I

even involved the Commissioners/couldn't happen, you think 'How can that not happen?'

Robin: /Yeah. That's a human right, for me.

Pauline: Yeah. And god forbid they should ever want to have sex. Gawd, they'd probably be sectioned wouldn't they, do you know what I mean,/ Well who's put an age limit on that then?

Robin: /Yeah, yeah

(How do you feel about the future of health and social care?)

(Silence)

Pauline: (laughing) Well the fact that we both said nothing says it all. I think our experience, at this moment in time, makes us very worried. For the elderly and for the carer, full stop. Unless we start to change our own attitudes (Breath) But the other thing just around the care, people caring, one of the things is, so if somebody has, I'm thinking about the bedroom tax, and if somebody has maybe their son and daughter need to stay over night to care for them or whoever/

Robin: Yeah.

Pauline: They need one bedroom

Robin: Yeah (cough) (cough)

Pauline: But that bedroom's not a permanent bedroom and they have to pay c-bedroom tax. And you just think that is/, how does that happen? I mean, you can fill a form in but it's a real fight. And they've not thought, that, that's actually used in in emergency care! Which then saves the government a huge amount of money it it you know, it doesn't take a lot of working out.

Robin: Yeah

Pauline: But everything has to be put in a way that's complex, that is complicated, 'Oh it's complicated'- well it isn't. Joe Public could do it, because they know. So when you say, 'What's the hope?' my hope is that they ask Joe Public,

(How did your professional relationship begin and develop?)

Robin: What, how I met Pauline?, how do I know you?

Pauline: I'm you're manager. (long laugh, loud) See you've just had that moment, he can't remember! (Laugh)

Robin: So she's my manager.

Pauline: We've been working together now erm... how long?

Robin: You've been my manager? (laugh) Since January 3rd 2007.

Pauline: There you are. (laugh) So that's how we know each other.

Robin: Yeah. She's very nice, you know. (Laugh)

Pauline: Well I hope we've been helpful.

(A kitchen)

STEPHANIE

As a newly qualified nurse ermm I've experienced a lot of elderly care and will do for the rest of my career erm I think its something like I don't know if this errr is correct but something like 85% of the patients that come into the nhs facilities or any nhs facility will be over 65.Erm Soooo I think you know the the biggest struggle is obviously two things is Time and finance erm and really its about patient choice when it comes to and elderly care with the way it is I think that the nhs needs to educate people.

Healthcare internationally has moved away from treating peoples illness and the theory is that you try and treat people holistically so you look at their social needs, their health needs, erm their emotional needs, their spiritual needs you you try and create a package for them that incorporates all of those things rather than trying to treat them as separate entities. you know at the end of the day it should be an individual choice erm but then the next problem (little laugh) is that when it comes to elderly care erm and vulnerable adults they might not be necessarily in the position to make those choices. Erm and really ultimately prevention is better than cure those decisions should have been made earlier on and I think that we live in a culture that doesn't like to talk about getting older that doesn't like to talk about what we might need and I think that we mention it in passing but we never organise it but I think that people need to be educated and people need to decide what it is they want before it gets to a crisis.

I don't know reading nursing theory and stuff like that and everything in relation to elderly care today erm I think there is a huge government interest in what nurses are doing and what carers are doing erm because of the Francis report because of because of all interests because you know (pause) I think this is political now I think the government would love a kind of scapegoat and I'm sure the public would agree with this as well they kind of scapegoat into nursing and caring being not caring enough which is true because i think that the the solution to that is that we educate nurses and carers more in basic nursing care, however the ultimate problem is there isn't enough carers and nurses (laughs) you know the ultimate thing that came out of

the Francis report, chronic understaffing you can come up with all the other things that were left out but that was it that was the main one *Chronic understaffing*. And we constantly say nurses and carers are understaffed and we say it in such a blasé way like, like its not gonna cause any problems anymore like it isn't even an issue the issue is that carers aren't caring enough and carers don't realise what it is the elderly want and the elderly need and I think that people do know.

I mean here's another contradictory, controversial thing to say. Have you ever been to great Ormond Street? Because they have everything there and they have enormous amounts of resources and enormous amounts of money from various things and that money is not pumped into elderly care that's a fact. you have to accept it and for various reasons we've made an ethical decision that children are more important and the health of children is more important. that decisions already been made that isn't an argument in this culture in this nation we have as a nation let elderly people down. I'm not just speaking as a student nurse, speaking as a young person or as a newly qualified nurse whose about to go into care for elderly people.

I think that the government are going to have to, this is for all healthcare be honest with the public and say it's a subsidized, it's a substandard level of care your receiving because your not paying private, that allows people to have choices is the best thing we can do, they can have, what they can't have. At the moment with the press and everything we're just having the same conversations over and over again and the focus is all lets educate the carers better, lets have more legislation, red tape for people caring blocking the view erm and I think that kind of, the focus on it is wrong and they're not dealing with the grass root of the problem which that decisions made under crisis you know its obvious there isn't enough financial help for the elderly. I think its heart wrenching because I think that carers and nurses don't have any are not the only people letting the elderly down but we as a nation are letting elderly people down and have been for generations and you know they do it in other countries they look after the elderly pretty well erm so we separate it too much.

I think that you know, the rule that was brought out in order to start your training as a nurse you have to have a a years healthcare experience and that rule was brought out that's why I was talking about scapegoating earlier because by bringing in that law erm I think that then makes the public think "Well so if they're bringing in that law they must be very concerned about nurses not having basic care skills" I just think that was a wonderful scapegoat, because most people who go into nursing now have been healthcare assistants. Most of them are carers or healthcare assistants who have then done an access course. At the end of the day you need to keep your patient alive, those basic nursing care needs you know you might not do as a nurse because Its more important that they're breathing that they're hydrated, that they're fed, if you don't have time, that's where personal hygiene is the bottom of the list. You know drugs and food are more important. And that's awful, that's that the most horrible thing you will ever have to do and will ever have to do as a nurse, say you're too busy to do that. No nurse should ever have to be put in that position but they are because we're short staffed in every single elderly care ward. Paediatrics are never

short staffed, that's what I'm saying it doesn't have the same issues, why? Because the funding isn't there.

If you go to the trust I'm working in if you go to any of the elderly care wards they're always in the old buildings of the hospital, they always have the poorest of equipment, they always have constant staffing issues. And then you go to see IT, you go to A&E you swear you were in fucking NASA, like honestly so there's a huge cultural change there and I don't think that healthcare providers and doctors want it that way I think that we have directed ourselves to those who are acutely ill and who are young. We as a nation made that decision; healthcare providers do not have the control you think they have.

(A kitchen table, cutting potatoes)

KATIE

(fact, fast-ish) (high, soft) Erm I started caring when erm III had left (smile) Falmouth University and I didn't-know-what-to-do-with-myself and my mum was having carers come in at the time (breath) but to be honest the care company weren't very good, erm..., they'd send one carer a lot when we needed two, and often when they came (I wouldn't expect them to know where everything is but you'd like to think that they'd been sort of briefed about the job beforehand) and sometimes they'd arrive and literally know nothing and that's not they're fault, but it gets a bit awkward and that's when it's not great for the patient.

I was sort of protective in a sense of – I suppose because of my mum's situation, I think sometimes people would talk to her like, maybe she didn't know what was going on and that was the most frustrating thing. Because once we had a lady who came to help my mother to bed, and my mum was just finishing watching a-something on the telly. And I was sitting with her in the sitting room and the carer sat down next to her and started, from her pocket, putting rubber gloves on. Which I thought was, she's got every right to do that, that's- that's good health and safety but she could have done it in another room or had her hands in her pockets so you didn't see that she had gloves on. Or she could have done it, you know, just before gloves are needed, if they were needed.

So that was sort of- we were just sat watching telly and gloves were on, and then she turned round to my mum and- I'm I'm sure she was only trying to make conversation but she said, 'so when do you normally go to bed?', and perfectly reasonable question, but my mum just kind of turned her head and went (eyebrows raised). And partly you just think- oh they, possible, possibly, they just want to help someone to bed and then go home- and part of me, I don't blame them but it's also a bit, you know, you don't want to rush anyone really.

Well (HIGH, CLEAR THROAT) they've changed the law now and apparently, apparently you you it's all about health and safety now, and it's – w – with care now you probably-couldn't-just-get-by-on – you know say, being-a-caring-person you actually-have-to-have-the - you know, relevant qualifications and now youyou have to have,

to-work-in-the-care industry (HIGH) or in anybody's home, you must have an NVQ2 in health and social care, which I do not have ...obviously because I'm not working for an agency (breath) erm, you know – (smile) it's, it's different. (sing) It's different

(OFFICIAL, CLEAN) I've said that actually, for an agency, the way- to be honest because I'm s- because I just work for your grandmother aand I I'm very – I feel I'm very attached to her, I do- I do know that by agency standards they probably would say to me (pause) erm, (HIGH) and no- not "back off" but they would say you have to be a bit more professional rather than sort of, c-'cos at the end of the day, I'm not part of the familyy (clear throat) but what I do- but what I do try and do is just be sort of as – Just make it as ho- I'm just trying to make to it as homely for her as I can rather than like a stranger coming in and (breath) and just sitting down with- just with the same-sort-of-old-routine maybe. I always let her know where Conny iiiis or where- you and Keir aare or who's in the house, that kind of thing, and I just hope that's nice for her because then she knows where everybody is - and knows what everybody's doing.

(HIGH) Erm, but no I-definitely-feel-valued, it's-really-nice, it's-that-feeling-when-you-go-away-and youuu've feel-like-you've-done (PAUSE) the best you can do. But no, I would definitely carry on with care work because it's the people that you meet and (PAUSE) jsssst – orhhh just just being part of some- well, loads-of-lovely-people's-lives really, and you've got those little stories that you / will keep forever. I can't imagine not doing it actually if I didn't do caring, I'd do, like voluntary work, something like that. I'd have to do- (fast, shake head, smile) something.

(Cafe at The National Theatre)

GEOFFREY

I do many things I, perform many roles, one of them as an artist but the other thing I do-do is I nurse umm did this fast-track masters two years ago umm that's not my career but it's, it's, part of me. umm over My life-*span* I've been involved in as a *buddy* within the lighthouse so I was there at the beginning when the Aids/ HIV crisis happened in the early 80s umm err the-the mortality rate was very high so I was dealing a lot with men that were coming in- and their partners and family- at end of life. At the same time I did dancing and then, and then I did theatre work, umm, I then progressed into caring for my aunt and that's still on going, my aunt is 92 and as the only family *member* umm it's this relationship where I'm I'm her advocate in a way umm I'm not- I don't do the caring part but um part of caring is to be that advocate.

I think the issue you're...I think there are two issues *one* the central issue is about compassion and empathy- that's one section (upward inflection)- and the other is um is the actual *system* and how it operates. The system operates um *badly* in my opinion but I don't see any other system that can actually deal with an ageing demographic population in the sense that it's happening, and with that (applause) is, is comes problems around who does the caring and wh- how it's done and where it's

done and how much we're being paid... So here's an issue, controversial here, so they charge £15 or £20 an hour and the carer gets paid 6.75 now work that one out, with the amount of people getting cared for in this country, at home, the care agencies are making a lot of money, what's happened to that money? I don't know, it's not been invested in education so, so there's an issue there and there's an issue *there*.

The issue of dignity and respect is a big, big issue um and that is the- and to address that I think it relies on good communication skills, knowing how to connect to the story of that person, not just going in and going I'm now going to wipe your bottom, goodbye- which is kind of what happens. Because you do have that number of clients, you've got to get round, you *don't* get paid for it, so you're meant to be there for an hour, the carer's are never there for an hour because they know they need to get to the next clients...yep... In my Aunt's situation she had 8 carer's a day, 8 different carers a day, now try to negotiate *that* relationship with a 92 year old woman that is, has partial dementia, um with 8 people coming into your *own* space to deal with a very physically intimate act of washing her after she's pooped her pants or pissed her pants- because she's doubly incontinent- umm err, no wonder she sort've wanted to give up...So there's- around that then there's the debate about quality of life umm...yep...and is the quality of life, is the quality of life acceptable that 8 people that you don't know come in and wipe you bottom, question mark...if that's your only interaction with the outside world.

When I did my training those questions were never asked, compassion and empathy were never mentioned in the two years that- I never once had lecture a on compassion and empathy or the concept- the philosophical concept of what we mean by that, no. At the same time I was...in a pragmatic way in the sixteen week introduction I was never shown how you washed someone, never shown. I never- in the two or three years- I never had a one to one tutorial with anyone in the university, no-one ever really asked me how, how, how am I doing, how is it?...umm...No! I didn't ever have that. SO it would require more people to be on the outside- it's not counselling- but for someone, this one to one where I would say to you, 'you've done 12 week stint on A & E, how did it affect your spirit?' It's an interesting question, when people are dying around you left right and centre, how has it affected you, how has it affected your spirit? How has it affected your thinking? What are you reading around this, not just the nursing bit, but how are you putting that into some kind of context, culturally and socially. Umm But that's kind of- it's not radical but people don't like that- people laugh when I say it because they...they don't know where you're coming from.

But I do have (laugh) kind of- I don't think I'm pretentious but I do have pretensions to think it can be better than this, it *can* be better than this and it should be better than this.

An- and it's, it's a controversial- and no one ever talks about it because it's a difficult area, izzue for the government to talk about, people aren't compassionate enough or empatheti- they don't know actually *what* they're saying , they don't know what the question is...

I think what the problem-the central problem is in the government- any government, that doesn't address it, is, is the fact that people don't really know what's happening out there in the field of caring work, people don't know, have no idea, they assume that, these very compassionate people are going in for £6.75 an hour to wipe someone's bottom and its being done in a holistic way that integrates the person into greater independence, blah blah blah blah...umm...no one really knows whether that is actually happening and I would say most of the time it's not happening, in that holistic let's make everyone independent, let's, let's celebrate the fact their living in the communit- all that jargon umm an-and, and it's good jargon, I mean it's not *bad*, it's just it's not happening. And people...ummm..s-so the clichés then sort of arrive at you know ummm, you hear all the horror stories in the paper erm as well, so the horror stories come out you know 'this is bad care' or blahblahbl or whatever, umm and then people focus on that and then they try and solve the problem through, through that, whereas the, the central problem of...of an ageing population and what that actually means isn't being addressed at all, not in any...real way, no. mmmm

I think you really have to question what care is, are you talking about the pragmatic skill of washing somebody, which is a skill, is that caring or is that just washing someone? Is caring about, is caring...could be seen to be just you know this...relationship, well I'm not caring for you but I- a relationship where I'm opening myself to you and I'm trying to get you to open to me, which is a- which could be seen to be caring, I mean I don't know, it's, it's, people sort of don't know what they mean by- well that's a bit like saying...compassion and empathy, people don't actually know what they're talking about or they're not asking the right questions.

(On the telephone)

CHRIS

Well what I found was that the actual professional people, were useless....but the um, supporting agencies, like age concern and the people that work for them, in this area they have some thing called...early intervention, and they were absolutely brilliant. They used to ring me up, and see how I was. Um they were very very good. all the professionals let my dad down in hospital and took just two weeks to kill him off.... sad to say its still happening with people. Uhm... well they while I was there virtually all the time and um quite able to speak up, they didn't take any notice.....so for example when he first got admitted to the ward.....with a broken hip um, I pointed out to the nurse the admissions nurse that um he had dementia, gave his tablets over and I said he doesn't know why he's in here, he's not aware, that he cant he cant walk uhm and he keeps tryina get out of bed to go to the toilet...uh so you know I stressed that, over and over again. And then...uh I learnt, not because they told me, they didn't tell me, or my brother, but I learnt the next day that well...he had tried to get out of bed and of course with a broken hip you cant walk on it, and uh they found him in the morning under the bed.....he'd been on the floor for hours under the bed. Even though I'd told them.

I was told that um this nurse said well he seems quite coherent, quite lucid to me, so they completely ignored the fact that I'd told them the fact that he'd got, uhm...they didn't take my word for it and that they came back with the fact that he seemed quite lucid. I mean what do they want people to be completely gaga before they say they've got dementia?

They didn't apologise to me. Not till I made a complaint....because actually, at the complaint meeting which took 13 months, at the complaint meeting I very sadly learnt that actually the same thing happened on the second night. And I learnt that 13 months later... and I know, even though they denied it, I know he fell out of bed twice more...and neither neither of those occasions did they tell, they said all cheerily uh you know, your father was found under the bed this morning. He, my brother, said what and you didn't ring us up, and they said no they didn't think it was important enough and this nurse said it happens all the time. It happens all the time with our dementia patients. It was a terrible terrible thing. It was like uh a living nightmare...the fact that they didn't care. He ended up having to have another operation on the hip on Christmas day...it was a terrible terrible thing

And I went in one day and this doctor..um said I wanna speak to you, and its gunna sound funny I know, but he cu well he knew that I had made a complaint by now, I made several after that, he said, I want to sp and he he took me into this linen cupboard, Samantha, and he said to me if you ask me outside I won't admit to it he said but I'm telling you he said, things have gotten terrible here. Terrible goings on, and this was the doctor...but why don't those people speak out? Wh he's telling me about that in a cupboard that I cant repeat cuz he'll deny it? Urm why don't they speak up? Yes it was a doctor, it wasn't a male nurse.... Maybe its uh like the police force you know, the managers higher up at the health service that don't experience it, they don't want anything bad said about whats under their uh...control because they think it reflects on them so its all ah ah a cover up. Well its criminal isn't it?

(A meeting with NHS workers. A stage and microphone)

JEREMY HUNT

Good afternoon uuhhhLadies and Gentlemen, thankyou for hanging on in the conference to the bitter end so you can hear the secretary of state...uhhm...I was (intake of breath) asked to take on this role in September and I said at the time it was the biggest, privilege of my life. A lot of people say isn't it the most terrifying thing you have to do, in your life and I can confirm that it isn't actually because I had an even more terrifying moment (intake of breath) uhm earlier in the year when I actually had to go into hospital for a minor operation on my head,, and I was

stretched out on the operating table, in the Chelsea and Westminster, and the errr, local anaesthetic had been administered, the surgeon had his scalpel out, and one of the nurses looked at me and said 'By the way Mr Hunt, what is it exactly that you do for a living?' (laugh) Uhhm but uh I discovered subsequently that uhh the uhhh, (intake of breath) asking people what they do for a living is something that nurses are trained to do to relax people before an ohoh(laughing whilst trying to say operation) peration, (intake of breath) but it didn't I'm afraid have that effect.

So umm, I, I didn't have very long to think about whether I wanted to be Health Secretary but I did, uhh, I did think that uhm one of the biggest challenges I have, as a politician, is that my shelf life in this job is likely to be considerable shorter than the brilliant men and women who have given their lives to the NHS and that the way to make a real difference, in, a couple of years is probably to pick, one or two priorities, and focus, relentlessly, on those priorities, for uh, my period in office.

So let me tell you what they are, the first one is dementia (iob) where we have a uhh we have an ageing population, represents a quarter of the people in hospitals, two thirds of the people in care homes *cough* and we are only diagnosing less than half of the people who have the condition, and uh, *cough* its as much a care issue, as it is a treatment issue, that we've got to do a lot of work on, so uhm, dementia's the first one. The second one is building a system, where, throughout every part of the huh health and social care system, uh quality of treatment and quality of care are as important as each other. Most people have a uhh an expectation they will get the best treatment in the NHS, but they are less confident in the consistency of the care that they receive, and that is something which is a, very difficult, uhh challenge, but I think its something that we have to recognise is important because that's what the public are, one of the things the public are most concerned with (iob).

Let me finish by, just saying I think we need to recognise... is that we have taken our time in the NHS, to give it proper operational independence. But this is not an abdication of responsibility by politicians. My head will be on the block for the next election, for delivering, the better NHS and the better health and social care system that the public has a right to expect. And, my belief is that it is by giving you, the operational independence at the front line that you have craved for so long that we will be more likely to get those objectives and to deliver that real change that people want, so please don't let me down. Thank you very much indeed.

(Front room, ironing)

RUTH

I started caring for my mother in two thousand and, two. She went in for a hip operation when she came out it became very apparent that she was never going to be able to look after herself, on her own again. And thats when it all started. It just started from there.

I would only want to ha send her to a care home if she was so physically ill that I couldn't cope with her any longer. Because my mother always had a fear of going into a care home when she was younger and never ever wanted to go into that sort of situation. And I feel that, yuh you know, we've had our ups and downs as mother and daughter but she's been a good mum and she's looked after us through some very difficult circumstances. Um so I didn't see the point of putting her in a home and paying an absolute fortune in fees when I could do the same job wi myself....Now also, this isn't the norm, the majority of the nurses and the nursing care's excellent, but just occasionally you would get a very unkind nurse, who would be incredibly cruel. Not physically but mentally they would be very unkind very cruel to these people. And I didn't wanna expose my mum who was so vulnerable to that sort of abuse because she wouldn't be able to tell anybody. And so we decided that as far as possible we would look after her. We had, we had a lovely lady-

(Jack enters)

Jack: MUUM, what's for dinner? I'm starving.

Ruth: Right just hold on, just pop a, just pop a thing on - right tell me another, ask me another question. Right one lady was exceptionally cruel, uhm in that we had a new lady in she didn't, she obviously needed to be reassured taken to her room introduced to the, people, that were gunna be caring for her, well what actually happened was she was put in her room, uhm, where she was quite comfortable, and the lady that was in there first, one of the nurses, realised that this poor lady'd had a stroke. And she couldn't swallow. And also because of that she couldn't speak. And so she knew exactly what was going on, all her intelligence was there, and she was obviously very frightened to be surrounded by a whole lot of people she couldn't communicate with. And um so this nurse, was, in the room and several of us were just ih inside the door, and we thought we were gunna get, the details on this lady. Who she was, what her name was, what had happened to her and everything. But instead of that this lady just looked at her and realised that she couldn't speak,, communicate and said what is IT..that we have here?....and what is IT?

Wuw, the money I receive from the state, is a very generous £55 a week. Which considering thats seven days a week, 24 seven, works out at very very good value. So I'm exceptionally good value at £55 a week. If I put my mother into a home, it would be a minimum of 740 pounds, , a week. Seven hundred a forty pounds, over a hundred pounds a day, which I'm doing for less that a fiver. Society doesn't value carers, because, they're, they are forgotten about. They just say well you love that person so you'll do it. You've married that person so you'll do it. And that isn't the answer, thats a copout. because there needs to be provision for everybody. And if I am looking after somebody else, I also have needs and desires and wants that I'm entitled to every bit as much as they are. The people that say wuw she's your mother, she's your husband, shes your child are wu uh are not doing it. Not in that positions. If they were they would change their mind instantly. They're the forgotten people who do it for the sheer love of doing it and for the fact of doing just doing it

for the right reasons you know?.... So no society doesn't value us, no not at all but that's society's loss, not mine.

END.