# Carer01 interview 03/11/2023 call time was 1 hour 8 minutes.

# Transcript

*00:00:05 Interviewer - CB*

Hello. Oh, good afternoon. Is that [Carer01]?

00:00:08 Carer01

Yes, hi Catherine.

*00:00:09 Interviewer - CB*

Oh hello. Yes, it's me. The first thing I just want to double check something before we begin anything. Are you OK for me to record this telephone call?

00:00:20 Carer01

Yeah, that's fine. As long as I don’t swear!

*00:00:21 Interviewer - CB*

Thank you. And can I also doublecheck, can you hear me OK?

00:00:27 Carer01

Yes, not too bad, my headphone isn't...

*00:00:29 Interviewer - CB*

OK.

00:00:31 Carer01

My phone isn't always brilliant, OK, but it's OK now. Yeah, that's fine.

*00:00:36 Interviewer - CB*

All right. I'll just make sure I keep my face close and I can hear you nice and clearly. So that's a good sign as well. Alright. Brilliant. OK, just bear with me one second. I'm just going to shut the door, OK.

00:00:47 Carer01

I'll be slurping my tea.

*00:00:48 Interviewer - CB*

No problem. You do whatever you need to to feel comfortable. OK, right. So, the first thing I want to say before we start anything is just thank you so much for agreeing to speak with me today, and I do really appreciate your time. And just a few things I want to check with you before we actually start the interview. I know that you - thank you for returning the consent form and I just want to check is there anything that on the consent form that you would like clarification about or anything that you're not sure of?

00:01:20 Carer01

I don't think so. I think I saw it signed it and I'm OK.

*00:01:25 Interviewer - CB*

Lovely. And you had an opportunity to read through the information sheet?

00:01:31 Carer01

I'm pretty sure I did it. I sort of had a busy morning with a dentist and all sorts. OK. Yeah. So yeah, I'm. I'm. I'm. I'm happy. I'm really keen that people’s – patients’ experiences are used to benefit other patients. That's my complete impulse.

*Interviewer – CB*

Yes. So OK, that makes sense. Well, thank you. That's helpful to know. So just to just to be clear then, well, any questions I ask you, you know, I'm truly interested in your perspective, so there's no right or wrong answers to anything I'm going to ask you and all the questions are completely voluntary. So, you don't have to answer anything you don't want to. And if if you do need to take a break or you decide you want to stop at any time, just say. That's absolutely fine. And for the purpose of confidentiality, I'll just encourage you to try and avoid saying names of people or places. But don't worry if you do forget because when I do the transcription so when everything's written out.

00:02:26 Carer01

OK.

*00:02:31 Interviewer - CB*

I'll remove any anything like that from the transcript to make sure it's anonymous.

00:02:37 Carer01

OK, so do you anonymise the hospital and for example, the GP surgery?

*00:02:42 Interviewer - CB*

Correct. Yeah. Correct. I do. So, you know if, yeah, so you don't, you can say things like the hospital or the clinic if you forget, if you forget I, I won't put any names of people or places in. So yeah, it is all anonymised. Brilliant.

00:02:42 Carer01

Ok. That's fine. How big is your your size of survey? What - how many patients?

*00:03:01 Interviewer - CB*

Yes. Yeah. OK. So the at this point because of the nature of the kind of research that I'm doing, I don't know exactly how many people will be included, but what I've said for getting my ethics approval is that it would be a maximum of 20 people who've got liver disease, a maximum of 20 people who are carers and a maximum of 20 healthcare professionals. So, it might be less than that.

00:03:25 Carer01

OK.

*00:03:26 Interviewer - CB*

It depends, and I mean potentially it could be more. It depends. It's the type of research that I'm doing where, as you go along, it sort of dictates to you how many people you actually need. But it would, but that's how it stands as things are at the moment.

00:03:40 Carer01

That's that's lovely. Just give me. OK. Well, don't let me slow you down.

*00:03:42 Interviewer - CB*

Yeah, sure.

*00:03:45 Interviewer - CB*

No worries. OK, well, let me do a quick time check here. It's OK. Right. So also, just before we start, can you confirm what type of liver disease the person that you were caring for had?

00:03:58 Carer01

He had cirrhosis. Decompensated.

*00:03:59 Interviewer - CB*

Yeah, yeah. OK. Thank you. And what, I'm just some details about yourself. Again, it's all voluntary information, but would you be happy to tell me your age and what your ethnicity are?

00:04:16 Carer01

Oh, yes, yes, yes, I'm a white. Well, actually, English. Irish. So yeah, you want to put that? 65,

OK.

And I was, hold on. Sorry it was., I'm trying to work out my age when he he.

**Interview questions start here**

*00:04:38 Interviewer - CB*

That's OK that that's alright. That's that's fine. OK. Right. But I think that's everything I need to to check with you before we actually start the the questions, but I'll. I'll start now if that's OK then. Yeah. So to to begin with, could you just tell me a bit about the person that you've got experience of of caring for?

00:05:00 Carer01

He was my stepfather.

00:05:07 Carer01 [trying not to cry]

Oh, I get all upset, sorry it's been 18 months. It’s my stepdad. He lived on his own. In sheltered accommodation, but it's not, it wasn't sheltered, it I mean in a little flat, bedsit-flat thing. He he was a working-class chap that had just been in the building trade all his life. And he uh, I mean obviously this is related to his liver disease, you know, he was a chap that went to the British Legion every night without fail because he was lonely and because he'd been, he'd been part of his life for literally ever so. And he what else can I say? He lived in a village quite a large village,

Yes.

00:06:03 Carer01

So the population probably 4000.

Yeah.

Carer01

And what? What else about him? He was just a small chap. White.

And how long did you care for him in that role?

00:06:13 Carer01

It wasn't very long. It was. I live 15 miles away and I've had health problems, so I've had like chronic fatigue from an infection, Lyme disease infection. Then I had cancer treatment.

*Yeah.*

And the whole thing knocked me for six. So, I didn't see really much of him that I used to, but I used to phone him every night. Yeah, because we had COVID.

*Yes.*

So there's the COVID issue, so I couldn't see him. So sorry, I'm waffling a bit.

*That's OK.*

So really I, he he kept, he kept losing weight and I was just thinking well, you know, I knew elderly people that had done that, so I didn't think much of it, but I thought something's wrong. I can't put my finger on it. But, then I noticed in Christmas - just before Christmas 2021 - my God, he looked terrible cause. He'd had some he - I'll tell you about it, but it was fall-related, fall-related and I think he'd had a bit of COVID or something.

*Yes.*

And then he died at the end of March. So I was full on [carer] really only for about 3 months,

*Oh, I see.*

But wow was it full-on, battling to get him, battling to get him diagnosed.

00:07:38 Interviewer - CB

*I see. Yeah, well, that kind of leads on to my next question really. So, So, from your perspective then tell me a bit about your stepdad's sort of journey of receiving care for his liver disease.*

00:07:54 Carer01

Right. Well. He'd had a had a fall in in the High Street, he tripped up, which now I know. Must have been because he had no muscles, basically because he was so wasted really

*Yeah*.

But because he wore jumpers and and what have you, and he was a tiny man anyway, um. Anyway, so, so kind of in we got used to. I think you've been losing weight over a couple of years, really. He was taken to the [GP] surgery patched up and absolutely nobody picked up - a member of the family, his cousin, took him to surgery - but nobody picked up the fact, they must have seen his arms or his knees or something. They saw bits of his body, but nobody seemed pick anything up [in terms of his ill appearance].

Then I visited, thinking he was all you know, he just had a fall, and he was fine - he said he was fine. And I I'd I'd visited some days later and hey, God, it's, it was like looking at a corpse basically. I've never, ever – something had happened, I think he might have had a bit of a COVID infection as well. Cos’ I talked to him on the phone and said ‘oh your, your breathing's odd’. But of course, now I know that's probably. I'm sorry, I don't know all the words,

that's ok.

probably the ascites and everything.

*That's OK. Yeah, yeah.*

00:09:23 Carer01

And and then I - this was literally over Christmas and by went visited him again and I noticed that his feet were swollen. Then I looked at his leg. I went. Sorry. Sorry. He don't he. Then he was knocked over again. Sorry, after the first fall. Probably in the High Street. This is what our village somebody in the village backs up and and and must have just touched him with the car, knocked him over.

*Yeah, yeah.*

00:09:53 Carer01

He then they took him home and he then patched his own elbows up. But he was 82 and he left the dressings on. So what had happened in this [inaudible] not only was he really ill with the liver disease, which I stupidly didn't know [about the liver disease] a lot of guilt here, mate. He, he, he left the dressings on and then of course they went funny. So, then he had an infection. So, when I saw him again all his his he was he, his legs were swollen and sweating.

*OK.*

*Right.*

00:10:28 Carer01

You know, with the water coming out of. It the liquid you - know what I mean?

*Yes, yes.*

00:10:32 Carer01

Sorry, I'm not very medically minded. The fluid is coming out. I thought, my God, he's got he. He might be getting Cellulitis. What the Hell's going on? So, I took him straight away to the [GP] surgery. They all whizzed about him and sorted out his legs and, um, gave him the stockings and it sorted his wounds out on his elbows and then he had to be taken in, Ohh twice a week for wound changes and then the doc- the nurse said to me ‘Oh, you need to come out of you need to change his Leggings every day’, I said. ‘I live 15 miles away-’.

*Right.*

00:11:11 Carer01

‘-Twice a day? You want me to come up twice a day?’ and also because of my health, I couldn't really. It. Sorry, it sounds like an excuse, but I cannot do mornings so I couldn't have got out there.

00:11:24 Interviewer - CB

*Yes, so, can I just clarify then? So, it was it, the nurse at the surgery that had suggested that?*

00:11:32 Carer01

It was realised at the surgery that he just had an infection.

00:11:35 Interviewer - CB

*But it was the nurse that was suggesting to you that you should go to the home his home and change his stockings?*

00:11:41 Carer01

Yeah.

*Right. OK.*

And I and I thought, hang on, this is this is crazy. And I knew I thought I can't deal with this.

*Yeah.*

I want to deal with it, but I know that physically I can't be there every, every single day,

00:11:55 Interviewer - CB

*Yeah. Did they know, did they know he had liver disease at this point?*

00:11:59 Carer01

No, no, that's, that, that is another story because I had to fight and fight and fight to get him diagnosed. That's just the beginning of it, I then.

00:12:09 Interviewer - CB

*Yeah. So, tell me, tell me about that. Tell me about how he actually got diagnosed and how what, how you-*

00:12:16 Carer01

What, what happened is that they arranged for him to see the doctor, they put in a doctor's appointment so that they could just check him over. It was a locum GP I discovered in the end.

*Yes.*

00:12:26 Carer01

And she was very brittle and at one point I said, I said ‘look, have you any help for carers?’ I realised that I was really then becoming a carer for my stepdad-

*Yeah, yeah.*

-rather than the member of the family that’s phoning him up and going ‘how you doing?’ and, you know, sending him bits and pieces and seeing him now and again, um, and the GP said to me, ‘you're not a carer’. I have never forgotten that. She said ‘You're not the carer’, so she would, she said. ‘Oh, then you know you. There's probably something on the notice board’ or ‘go and look it up’. It was something like that. She had no info for me. I meantime thought ‘I'm not blinking [substitute for swear word], I can't deal deal with him physically, he needs somebody out doing his legs, you know, keeping an eye on him’.

*OK.*

00:13:13 Carer01

Doing you know, just popping in on him every single day,

*Yes.*

but mostly for the stockings, because apart from anything else I’m a bit squeamish.

*Yeah.*

And they we have to fight to get them [the stockings] on, and I didn't want to tear his skin.

*Yeah.*

So, I I just went ahead, and I hired private carers from the village. One of whom actually knew him personally, so that was really good. So that they saved me. And I also contacted social services and said I've got this issue, but I mean I don't, I can't exactly what point of the journey that was and they were brilliant and they ultimately said look we'll fund some carers, but I didn't care. I I was going to pay for them anyway. Mind you, it's bloody expensive. So it would have been a bit of a mare, but I just thought that's it, he's got to get somebody in other than me. So that was that bit sorted, I then said - basically, he had massive his his stomach was getting bigger and bigger.

*Yeah.*

00:14:15 Carer01

And I had to ultimately, It was me and the liver disease charity. Sorry, liver disease - what is it?

*Oh, do you mean the British Liver Trust?*

00:14:30 Carer01

British Liver Trust. I rang-up their helpline service several times and between us, they obviously said they couldn't diagnose, but it was pretty damn clear

*Ah, OK. Yeah.*

00:14:38 Carer01

All this, it’s liver.

00:14:40 Interviewer - CB

*How, how did you work out? How did you realise to call them?*

00:14:41 Carer01

How did I realise?

00:14:46 Interviewer - CB

*To call the the British Liver Trust? What what made you realise?*

00:14:49 Carer01

Well, first of all, I knew he, I knew he drank. I mean, he wasn't a drunk, but I knew he had pints every night and had forever and, and,

*Yes. Yeah.*

00:15:03 Carer01

and he had a, he, he had ascites. I'm not – sorry, because the journey was because a lot of my emails were on the GP surgery system, so I wouldn't necessarily have a record of them. He had, he had swollen tummy. He had, his legs were swelling.

*Yeah.*

00:15:22 Carer01

So I thought, umm, you know, looks like a duck, quacks like a duck business. But the [GP] surgery said, ‘well, his liver tests were normal’. When I spoke to the LIver Trust-

*Yes, yeah.*

-the liver charity, they said. ‘Well, actually, what a lot of primary care don't know is that when people get really really to the end of it, their liver test kind of disease. So, you can have a normal liver test with decompensated.

*I see.*

00:15:49 Carer01

Yeah, so, so I actually I ended up having to insist he have a scan.

*Yes.*

00:15:59 Carer01

I mean, he was like a stick insect with a massive tummy. He was like something from Belson [concentration camp] except for his stomach.

*Yeah.*

00:16:07 Carer01

And I had to, I emailed for a scan. I also, on my e-mail to the GP surgery, because I've spoken to the charity said look, I'm worried about his, you know, he seems to be occasionally confused. Is it - and I I had to phrase it in a way that I wasn't going to offend their egos - but is it B1? Thiamine? And you know the two, the two. Sorry, I forgotten a lot of it because I’ve blanked a lot of it out

*Sure. Yeah, yeah.*

00:16:38 Carer01

but the two, the two kinds of confusions you get with-

*With liver disease. Yeah, yeah.*

00:16:41 Carer01

That disease, liver disease. And so how about this? You know, how about giving him thiamine. Also a a second appointment in the GP. I said, what about his vitamin D? You know, so I made them test his vitamin D, which seemed a bit silly, but you know, given in hindsight, you know, you know. And she, and they got it back right [vitamin D result]. It was through the floor as it would be. And she [GP] said ‘Oh, loads of people have low vitamin D,’ I'm like, wow. And I said ‘well, not that low’.

*Yeah.*

because I had to look at vitamin D for myself-

*Right.*

-with my own health. So, you know, boy, oh boy, did I have a fight. So first of all, [GP states] I'm not a carer. Then, I have to travel out and change his stockings, which physically was impossible and not very practical even if I'd been in full health. And then it's like, can he please have a scan? Can he-?Oh, and he was starving. OK, so clearly he wasn't eating.

*Yeah.*

He couldn't get anything down because of the ascites, it was so just distressing [sounds upset].

*Yes.*

00:17:51 Carer01

And, and I kind of nagged him a bit. I was getting a bit annoyed with him because he wasn't fooding. And then and then obviously I, when I realised, just he just couldn't do it, poor old love, I reined that back in. And, his cousins were nagging him about eating on the phone. And, and, but I did actually do him a meal one night and I was trying to get all - cause I'd checked his fridge and discovered he had things in there that were like decades old and he used to not decades, but really old and he used to be really, really good with his food after my-

*Yeah.*

-mum died, which was. He was widowed quite – My, he was my mum's second marriage and she died in 98 and he was only 60 I think when she died, so I can't remember. So, I'm the brains gone about 60. and he was used to looking after himself anyway, from his bachelorhood. So, he was so he was good on food. So, to see all that, I just, that was wrong.

*Yes.*

00:18:53 Carer01

So, then [laughs in disbelief] I was saying he needs some food drinks and so that I have to push that with the GP and it's like, ‘well, I can do you like a’ [trails off], you know, they just don't want to spend their budgets. Well, sorry, sounds a bit antagonistic, but, you know, I'm not having that. So anyway, and I was buying the drinks anyway.

*Yes.*

You know, I started to buy them, but I obviously with liver disease, you obviously need it’s not just normal drinks that they need. Anyway, so to cut a long story short, he finally got to the hospital. Oh, no [corrects self], he finally went to his scan.

*OK.*

00:19:32 Carer01

And then the the radiographer, is it a radiographer to do the scan?.

00:19:37 Interviewer - CB

*It-it's different people do them, sometimes it's a nurse. It-it depends. It might be a radiographer.*

00:19:43 Carer01

And I think it was. And she came out, she looked, she looked at me and she went ‘My God,’ you know, she's like, oh-my-God expression on her face and she said ‘Well, can he, you know, be admitted straight away? How would he be if he were admitted straight away, you know.

*Gosh*

And he, the thing is, he was a creature - I don't, I don't know if he had OCD or autism, but he was a creature of absolute habit. And couldn't lose control, you know, over the minutia of his life? And I thought, I thought that would be incredibly - I didn't – little, little realising what a struggle the rest of it would be, I thought, well, and she said ‘or, or we could get him in on another, you know the next you know we could get him soon again’.

*Yeah.*

And I thought, well, that probably would be better for his mental health to do it in a more in a less kind of panicked way. I don't - frankly, she said it, but I don't even think they could have admitted him. So, it's one thing somebody's saying that in radiography and it's another thing getting them admitted, isn't it?

*What, why - what do you mean, like, because there wasn't a bed or what?*

00:20:52 Carer01

Well, yeah, there might not be the bed there-

*Oh, I see, I see.*

00:20:54 Carer01

-there might not have been specialist to to assess him, to admit him, the time of day.

*Oh, I see.*

I mean, you know a radiographer can't work out what room is and what ward can they and whether

Or not the specialist would have actually said, yeah, that was the right thing to do. So, really probably what he should have had then was, I've forgotten all the words, but when they, when they drain the ascites

*Yeah, yeah.*

00:21:21 Carer01

That's probably what he could have done with then, but anyway, we did get to see the specialist, the doctor at the hospital.

00:21:27 Interviewer - CB

*Was that a liver doctor?*

00:21:28

Sorry?

*A liver doctor?*

00:21:33 Carer01

Yes, well, it well, it wasn't a liver department it he was it. The department was gastroenterology

*Yeah, yeah.*

and he he he said he was the only liver doctor there. And he had one specialist nurse and he was struggling.

*I see.*

00:21:49 Carer01

It was worse than that, really, because when I when I did take my stepdad there, he's profoundly deaf as well, so he had hearing aids in

*Ok.*

and a bit of confusion and feeling very ill. The specialist nurse wasn't there that day. The liver doctor was really busy and and looking at well this was in March 22, so he-

Right.

00:22:17 Carer01

-was on. He was obviously getting - February 22, January - February 22 - And he was obviously getting that huge tranche where nobody had been looked at through COVID and he-

*Yeah.*

-said to me, he clearly was ground down, so I got to see the NHS staff on their knees and admitting it and he said ‘when they say to your the NHS, the NHS is is breaking it isn't. It's broken.’ Lovely. But, he was a nice man and he cared about his-

*OK.*

-I mean, he cared about his patients, he said ‘I'm seeing people now I should have been seeing a year ago.’ And he also basically gave me my stepdad terminal diagnosis. They were speaking quite quickly and my stepdad couldn't hear any of it, so I uh, he said ‘Oh, he's got another’ I can't even think - about six months, six to eighteen months or something. It was something like that. Six months, and I thought looking at the old dear, I thought ‘Christ is it much is as much as that?’ And the thing is, I I then kind of got sent away with this man [stepdad], and it's like to me to give him his diagnosis.

00:23:37 Interviewer - CB

*OK.*

00:23:38 Carer01

And I thought, ‘my God, I can't’. He's an anxious man anyway, like to get him to go to a doctor. He's like, months and months. It'll help. Like he had a tumour on his head once. And my God, he we finally got, you know, a bit nagging and his friend nagging, he went to the doctor. Anyway, so I was then thinking I've got to give my stepdad a terminal diagnosis. What?

00:24:02 Interviewer - CB

*So, sorry can I just check with you, can I just double check something then? So, how was the information relayed to you without him knowing?*

00:24:13 Carer01

Because he couldn't hear, he was sitting next to me.

00:24:14 Interviewer - CB

*Right, right, I'm with you, I'm with you. OK, yes, OK.*

00:24:16 Carer01

But he couldn't hear. Also, and the doctor had a slight, I don't know what nationality he was, but just a slight accent. I mean, not much, but when you're quite deaf and you're struggling with the hearing aid and you're really, really ill and you're 82 and you're a working-class bloke

*Um-hm*

who, anything with the doctor or whatever is, you know

*Yeah.*

How do I put it? The age of deference, let me put it that way.

*Yes. So he, so he didn't, he didn't know w*hat the doctor was saying at that time?

00:24:56 Carer01

No. And he said, well, I'll get him in - I can't think. And, he basically this doctor, I came away with impression the doctor was nice. He cared. My stepdad was dying, and they were going to do what they could for him, but because the specialist nurse wasn’t there, we had no TLC. All I had was two, well, it wasn't the nurse's fault. My stepdad was deaf, and so he spoke loudly so when they called his name, he went yes in a really loud voice and they just tittered. Ohh I just thought, my God this is not really what I want and um I was a bit shell-shocked, really.

Yes

So, because I've had breast cancer, I've had the I've had the kind of different treat[ment], you know. You get leaflets and people fuss over you a bit and you sit down with the nurse afterwards.

I see

Even if the nurse is rushing off, you know somebody is there to just, you know. You get bits of information - I had a pack, I went away with a bag, you know - bag of stuff from Breast Cancer Now or whatever-

Yes.

-this [experience with stepdad] was like the absolute opposite, and I thought, ‘my God’, you know, ‘breast cancer gets that, and liver disease gets something else.’ I'm shocked. I'm a bit feisty, you know, but I, I try to be quite accomodat[ing] you know, not feisty with - not, I try not to get over accommodating really ‘cause, because if you have issues with the medical staff, you don't want, you don't want your - the - you don't want the, the patient to be getting the fall out, do you? If you have problems,

I understand.

but so, the doctor was nice, and - but it and he said he was gonna write to him and, and so on, and sorry, I’m just reliving it – awful, the whole thing, yeah [sounds upset].

*Take your time.*

00:26:52 Carer01

Yeah, I mean it was very traumatic.

Yeah, it does sound it.

00:27:01 Carer01

It was the same hospital I had my treatment as well. So, of course the whole thing becomes a bit complex, doesn't it?

Of course.

So, in the end I thought I cannot have [stepdad’s name] - oh

00:27:11 Interviewer - CB

It's alright, I'll, I'll take that out. It's alright.

00:27:14 Carer01

I can't have him opening a letter. Again, I've, ‘cause I've had letters myself that were copied into the GP and you think well, you know, they don't make very good reading, do they?

No.

I, I thought I can't have him opening that, and seeing that, and I haven't even told him yet. And so I said to them, I rang up and I asked the service ‘please - your secretary, especially, please don't send the letter out without letting me know first or liaising with me because I just cannot – it would be too cruel for him to see that,’ although he did get stuff that he then saw. [she was concerned about her stepdad seeing the information in the letter before she had a chance to explain his illness to him].

OK.

00:27:58 Carer01

Well then, I phoned a charity to say what do I do? So how, what do I? You've got a terminal diagnosis, but I don't want to. I don't want him to be terrified in his last weeks.

Who, who which charity was that? Do you remember?

00:28:12 Carer01

It was a charity that had a woman’s - I can probably e-mail you later, but it was a charity named after a woman.

It's not Marie Curie is it?

00:28:22 Carer01

No, it wasn't. I'd never heard of it before.

Oh, OK.

00:28:25 Carer01

It wasn't a big charity.

How did you find out about it?

00:28:29 Carer01

I googled, I googled, I mean, but people say don't go on to Google. if I haven't been on to Google, the helplessness that I would have had would have been awful.

Yeah, yeah.

I wouldn't have found the I wouldn't have found the liver charity.

Yeah.

00:28:44 Carer01

I wouldn't have known any of these things. I wouldn't have that, I mean. I'm - I'm not - I'm reasonably well up kind of on medical for, for for a normal person on medical things, but livers. I’d never, never come across liver issues before. So I'll try, I'll, I'll probably e-mail it [to you]. But, I rang up and they deal with families where they're dealing with dying members of the family, I think.

Yeah.

Terminally ill, families, and I - I just said ‘I don't know what to do. What do I do? Do I – I mean I didn’t even know how to do it frankly’ [sounds tearful]

*Yes, of course.*

[crying]

You ok? It's alright to take a break.

Ok, so, he never knew he was dying. So, he was denied the truth, but I think because I [crying]

had a stage 3 cancer diagnosis myself,

Yes.

I knew how terrifying it can be. Well, I was only stage three, I don’t know what I am now, but um, I knew from my experience, and I also knew him. And I didn't, I didn't want his last months to be like months of terror,

Yeah.

00:30:29 Carer01

So, um he didn't live as long as we thought we had anyway. So anyway, so um, so I left it and just said, ‘can you please just not send the letter out straight away because we haven't sorted this thing out really.’

Yeah.

00:30:46 Carer01

It was like he'd gone from being, living on his own and hiding the fact - he never said he wasn't well, you know, he never said we, I mean, he, he was a funny old stick. And I had a relative in Ireland he knew had died and he never told us.

Yeah.

And it was, it's funny. He was like a very, very private man.

Yeah.

00:31:13 Carer01

So, I just said to him I'm so sorry I didn't realise how ill you were.

Yeah.

00:31:18 Carer01

He was like a tractor. He just went on and on and on and on and on. Anyway, he did. Uh, the, the, the doctor put him on. I can't even remember the name of them. What's the medication which helps the ascites drain?

00:31:34 Interviewer - CB

I'm just trying to think which one it would be. I'm not sure. Well, no, because I'm, I was thinking of Lactulose, but that's more for the confusion. But anyway, they put him on a medication. Go on. It's alright. It doesn't matter which one.

00:31:48 Carer01

Yeah. So that when he went in for to have it done in the hospital,

Yes ,

It wasn't hard enough. His stomach wasn't hard enough. They wouldn't-

Right. OK.

-do it [drain the ascites]. So, we'd had this great hoohah of dragging him in because he lived in the village, so I had to drive out from my town to the village, pick him up, drive into the town the other side. So, I mean, I suppose, for me it was only a 30-mile trip but getting him out the door and you know,

Yeah.

And, and we got there and then he was waiting, and it was in one of these day clinics where you go in and you just- I can't think of the name. I'm so sorry,

00:32:36 Interviewer - CB

It's alright. Was it like an outpatient service so he could go to get it drained there?

00:32:40 Carer01

It is, but it was not like an outpatient clinic. They call it something else. So, it's where you, it's like an urgent procedure, but it's not A&E. It's in between out patient clinic and A&E and I, Day case? Day Patient Care? That kind of thing.

00:32:48 Interviewer - CB

I know.

Yeah, yeah.

00:32:56 Carer01

But my God, did the wheels grind slowly. So, we were hanging around for hours and hours, really. Then to be sent home, and I think that happened twice

Um-hm

and then I –um, what else? I mean, the struggles with the [GP] surgery. Well, I suppose they seem a bit all mixed up, but we were taking him - me or the carers - twice a week to get his wounds looked at and his legs looked at and his ascites looked at twice a week. But that was obviously mixed in with me saying to the GP, you know, ‘can he have a scan?’ Or ‘what about this tablet?’’ What about that?’

Sure.

The doctor gave him Thiamine in the end.

Um-hm

The doctor said he'd get palliative care to contact him and I said, could you please get them to contact me because he's a deaf, you know, so that I can liaise with them.

Yeah, yeah.

00:34:04 Carer01

But, in the event they did turn up pitch, up for with the with the air cushion for him without me knowing and he apparently refused it,

Right.

because he didn't want it. Um. What else, I can't think. He then, but I think because he hadn't had his ascites drained, yeah, and the tablets weren't doing the trick. He basically ended up getting sepsis.

Right.

I took him into - he ended up, the carer called up A&E, and I caught up with him at A&E. Uh, he died in A&E.

Oh.

Not from the sepsis, which they possibly had got under control.

Yeah.

And I was with him actually, in they allowed me. Well, no, they didn't allow me and I beat my way in.

Yes.

00:35:02 Carer01

So that I was and I was allowed to stay with him, but I was sent off for five minutes because, because he was so clogged up. His lungs were so clogged up.

Yeah.

He, the doctor, one of the young doctors said would give him a bit of physio on his chest. Well, now in hindsight, I should have thought hmm. I made him have a bit of a drink, one of his build-up drink things saying ‘Well, if you're gonna be in here and you're not going to admitted to the ward for ages, you'll need a bit of goodness in you’ which he hated and he said, ‘I hate it’,

Yeah.

but cut a long story short, physiotherapy meant that he brought up the contents of his stomach and choked to death.

Oh, oh gosh.

Yeah [pauses].

It's alright. Do take your time. I know it must be really hard reliving this.

[crying].

00:36:02 Carer01

The police had to come because it was not a normal outcome or something, and then I had to identify, then the doctor suggested I see his body and I said ‘I don't want to’. But she said ‘well, we think it's a good idea’ and I did [see his body] and it wasn't a good idea.

Right.

And I then also had to identify him to the police.

Oh gosh yeah.

00:36:26 Carer01

I'm, I'm really, obviously feel very guilty.

Ohh, it sounds like you did an awful lot for your stepdad.

I fought. I fought like a lion for him.

Yeah. You, you obviously were a big advocate for him and you were looking out for him as much as you could.

00:36:50 Carer01

I was banging every door I could, but the problem was um firstly, I twigged too late. I knew something was wrong with him, but I couldn't work out what it was. And I kept thinking, you’re wearing baggy Jumpers but of course he wasn't wearing baggy Jumpers, he’d just lost the weight. And because I hadn’t seen him very much you know, because of Covid

Yeah.

00:37:13 Carer01

-and because my own health is crap. Obviously, I'm filled with guilt, but I mean, since I got the handle on it, I was fine. But it doesn't matter how much you kind of fight, there's something always going to go wrong and fighting. I mean to have to when he got on the surgery-bed thing, trolley, for the for the doctor to inspect his stomach. To watch him, desperately with a big, huge stomach and no muscles, like a little skeleton, fight to get on that trolley. And then have to say look have to e-mail them, commit them on to scan on an e-mail and then because she said, well, look, we don't know what it is. So we're just going to have to let it and see what happened. Like what? Shouldn't somebody be scanned-

Yeah.

00:38:09 Carer01

-when they look like that anyway? What was that? Was that age discrimination? What was that? Was it class discrimination because he was just an old builder? I just don't know, I mean,

Yeah.

00:38:26 Carer01

surely if anybody presented looking like that, you think ‘we'll send them off for a scan’.

00:38:30 Interviewer - CB

And is this a, I just want to be clear, So, are you talking about when he was at the GP surgery for this?

Yeah.

OK, So, roughly when would that have been?

00:38:42 Carer01

Well, because everything happened in such a concentrated time, I think that was in - actually I've got the calendar. Do you want to hang on a sec, and I’ll get my calendar out? I might work it out.

Yeah. I I was sort, I suppose. I was just wondering at what point he got diagnosed. You know, it sounds like it started all sort of like you said, just before Christmas. And then it was March, that he actually died.

00:39:06 Carer01

When he was diagnosed basically on the soon as the liver doctor saw hime, he just said straight away what it was obviously.

Yeah,

I mean and the and obviously the radiologist thought, ‘that's a load of ascites. That's not right. Good God, that's terrible’. I mean, even I'd worked that out because I'd looked it up,

Yeah.

I'm not, I'm I'm sure the surgeries [unclear] did that. No, man, what can I say?

I think it just got worse and worse quite quickly. So, I mean, maybe it wasn't quite so bad when he first went to the surgery.

No, I understand.

00:39:49 Carer01

Did you try to make

00:39:51 Interviewer - CB

Did, so one thing I was just wondering, do you think that, so obviously I know your stepdad didn't get to hear exactly what was being said by the liver specialist. So did he, did he come to know what his diagnosis and his prognosis were?

00:40:13 Carer01

No.

Right.

00:40:15 Carer01

He knew – I told him his liver was shot basically.

Yes, yes.

00:40:22 Carer01

So I I said it's his liver. He also saw notes that got sent and he was I think he was a bit cross with me because I said, they asked me about his drinking, you know, like how many units and that and I said what I thought, and they wrote it down and he saw-

Yeah, yeah.

00:40:38 Carer01

-it and he told a friend, ‘oh, you know – Me- name [I.e., Carer01], said I had X amount a night, I don't.’ Well, the fact is I know that he had in previous years-

Yeah, yeah.

00:40:52 Carer01

-had that that much so. So he he did see that it was there and he saw he he his note said cirrhosis. Although of course it's spelt pretty weirdly, I mean he was a reader. He wasn't illiterate or anything.

No.

So, I'm guessing he saw cirrhosis. Your liver, I think I said ‘your Liver is totally massive’ something.

Yeah, yeah.

00:41:16 Carer01

So, he knew he had liver, liver disease.

Yeah

00:41:19 Carer01

But he he didn't have his prognosis - the prognosis was wrong anyway; it was far too optimistic.

00:41:26 Interviewer - CB

I understand. Yeah. Yeah. It I just want, I just wondered because it sounds like you had been able to get some information yourself, and I wondered If he, if he asked you questions or if he, I don't, I don't know, I just. Yeah. I just wondered.

00:41:44 Carer01

No, I don't think he thought, you know what? He just wasn't a well man, obviously.

And that he was exhausted, and it was just willpower that got him through.

No, no.

00:41:54 Carer01

And he was one of these people that like, if you if you he was only if you said I'll meet you at two he was there at 1:45. He absolutely every single time he’d phone it's 7 o’clock on the dot. Absolutely,

Sure. Yeah.

00:42:07 Carer01

he'd do it if he said he was gonna do it, he'd do it. He was the most reliable person on the planet, and that included getting up in the morning even if, and he probably felt like dying.

Yeah, yeah.

00:42:18 Carer01

He was one of these people and so he was, he battled through, which in a way, he hid a lot of his-

Yeah.

-illness, I mean, inadvertently, just because he's one of these people that always coped regardless of how he felt.

So, I've got my calendar here, I took him to the surgery for the wound to his elbow on the 11th of January. However, he the previous, I think before Christmas, somebody had taken him to the surgery to be patched up after a fall, and I'm surprised they didn't notice his state of health then.

Yeah.

But I say that, but I do know that actually in primary care , I don't know, people are pretty fixated. So you go in for one thing and they'll deal with that, and they won't necessarily think. ‘Well, while the old boy’s here, he doesn't look very well I’ll give him a quick look over’, I mean that just doesn't seem to happen nowadays. So anyway, so that was 11th of January, took him back to the nurse.

OK.

Yeah. No, it's it's OK. That gives me a bit of an idea.

00:43:32 Carer01

Well, I can tell you when he saw the doctor, probably. He had an ultrasound scan on the 3rd of February.

Can I Um, can I just ask you something?

Yeah,

You've given-

[speaking at the same time]

No, it's alright, you've you've given me so much information. You've really-

00:44:02 Carer01

Sorry the 18th-

00:44:02 Interviewer - CB

Go on.

00:44:03 Carer01

I've got the date of the doctor appointment. If you want the diagnosis date

Sure.

18th of February.

OK. Thank you. So, it did all happen fairly quickly, didn't it. I suppose what I'm wondering because you know you give me a really kind of good insight into the journey from your point of view. You know, I'm I I have a a sort of a sense of of what things, you know, didn't perhaps go the way you would have wanted them to have gone. Uh. There's two things that I'm wondering. I'll, I'll just ask them separately. So. So one is, was there anything where you felt things were more positive? Have you got examples of care that you felt actually were positive?

00:44:47 Carer01

Yes. The doctor, the liver doctor clearly was fighting a lone battle and doing his utmost. He, umm my stepdad had a Saturday appointment for a procedure, he had to do a procedure actually and I can't - It was, what was the procedure? It wasn’t [pause]

Don't, don't worry. It's OK. Yeah, yeah.

00:45:21 Carer01

I can't even remember what. There's some kind of procedure, but he actually did it at the weekend. He had a little Saturday clinic. So, you know, you know, I knew the man cared. Let's put it that way. So that that was good. Positive experience of care, well, see the liver specialist nurse when she did come back. You know it was all her she just happened to be off the day that we went into for, for the diagnostic appointment. I mean, she saw him when he went into this day clinic thing where they're they were due to drain it and they, they didn't

Yeah, yeah.

00:46:02 Carer01

and I said, well, you know. But but they said he said blah blah blah. And they got the liver nurse down and she was lovely. She was lovely. The doctor was lovely.

OK.

00:46:18 Carer01

The radiologist, you know? I -

Tell me. Tell me a bit-

00:46:20 Carer01

can't, can't fault their attitude.

Yeah. OK. So yeah, tell me a bit more about what you mean when when you say they're lovely. What, what does that mean to you?

00:46:28 Carer01

Whatever, kind. Well, the doctor, obviously was knowledgeable and cared about his patients and was obviously sad that he couldn't see everybody and so on and so. So, I mean obviously got the sense that he wasn't being off-hand and said so he he he seemed to be dedicated if overworked.

Yeah, yeah.

00:46:50 Carer01

She she was very good with, you know, she had the [liver] nurse had good caring skills and spoke to him and spoke to my stepdad, you know, because sometimes – how do I put it - if somebody's a deaf old man, there's all sorts of different ways that that old, older people get treated in the hospital, and sometimes they're they're they're kind of semi-ignored or laughed at or just they're and sometimes they're actually addressed as human beings that they really are.

Yes.

And you know, that's what you know they they they sent me. So she treated him like, she spoke to him, explained things to him and treated him like the sort of human being that he was. When he died, the, the doctor and the nurse sent me a letter, a letter of sympathy.

OK.

00:47:44 Carer01

And I and she said she also gave me, offered me because I rang up and said, look, I'm really concerned, you know, because he's missed these just because he the tablets just stopped him having the drainage or so it meant he was in between a rock and hard place, really. He wasn't bad enough to, to need, to have that that the drain

Yeah

00:48:10 Carer01

but too bad to be coping. The tablets weren't coping well enough. Does that make sense?

Yes.

He's like in the middle. She did offer me before she went on leave at a 9:00 AM appointment so that she tried to fit me in an emergency appointment to bring him in.

Sure.

00:48:26 Carer01

The problem was, is, that I had to get from where I live to get out to my stepdad, get him ready and by then he couldn't, he was really, really struggling in the morning. I couldn't have got him there. I literally couldn't have gotten there without staying the night that his place even then. But I couldn't stay

Yeah, yeah.

the night at his place because they lost the because the sheltered housing's guest room wasn't, they didn't have the key or something, I can’t remember.

Yeah, yeah.

00:48:58 Carer01

So, sorry, I am sounding a bit panicky, aren't I? It's all just bringing it back really.

No, it's OK. Yeah.

00:49:03 Carer01

So, examples of good care. Well from primary care I think your primary care had known that normal liver tests didn't actually rule out liver disease. We might have had a better situation.

Yeah.I see.

00:49:26 Carer01

The nurses in primary care were, were good doing his legs the leg bandages and things because, you know, we had these sorry, had a bit of a wound on the leg as well as the wound on the elbow.

Oh yeah, yeah.

00:49:41 Carer01

So. the nurses were good.

00:49:45 Interviewer - CB

Well, what, what do you think, based on your experience then and and what you've sort of just relayed to me, how, how do you think things could have been better or different? You know, based on what you've said?

00:50:01 Carer01

Well, firstly, well primary care or secondary care.

00:50:06 Interviewer - CB

Whatever you think, really, I think it's whatever, it's whatever you think based on what you what you in your stepdad went through? Yeah.

00:50:08 Carer01

OK, well.

00:50:12 Carer01

How could we listen? One: prime primary care - if they've got an elderly man who's not well in front of them they perhaps have a quick check. I mean that would have taken 5 minutes, OK and surely an old man who's, who underneath his clothes looks like that is, of course, a concern. So, it it stuff wasn't picked up early enough, either by me, but certainly not by them. And I, I would never normally see him without, you know, any part of his body. So, they did. The GP should have recognised [my] caring responsibilities. OK, I wasn't a live in carer

Yeah, um-hm

but he was all I had, and I think by the carer definitions I was a carer. And so, I wasn't given any support there. I thought social services were absolutely brilliant and ironically – they're usually not. I shouldn't have had to have demanded a scan. I shouldn't have to e-mail doctors. I shouldn't have to go through the full, you know, online course on what is liver disease to get my stepdad who's in the terminal stages of liver disease a scan.

Yeah, yeah.

00:51:37 Carer01

I shouldn't have to e-mail and suggest confusion issues, therefore, maybe Thiamine.  You know, I don't even think that was picked up. So, I was left juggling all that, plus I was also trying to get carers into place and trying to get his appointments for the surgery just for the routine stuff sorted. I mean it was just, it was like a full-time job.

*Yeah.*

There should have been a specialist nurse at my appointment with the doctor because then maybe rather than, you know, the doctors are so busy, then maybe I wouldn't - I could have had a proper discussion with someone about well ‘this is his diagnosis, this is his prognosis. How do we manage it?’

*Yeah.*

I kind of go away and work [out what to do], well do my best and I feel permanently guilty about it.

*Yeah, yeah.*

00:52:38 Carer01

So, I feel sort of traumatised by that really.

*Yeah, yeah, yeah. I can understand that I can understand that.*

00:52:43 Carer01

I mean And I think there has to be and this this isn't, this is a general NHS issue really, but what do we do when there are people who are vulnerable or elderly, and we're communicating health stuff to them, and it they just get it in the CC’d (carbon-copy) letter that goes through GP full of clinical and quite frankly - you know, a life expectancy on the clinical letter is not something someone needs through their door.

*Yeah.*

There needs to be something Better than that.

*Yeah.*

Really. But I mean, that's, I know that the NHS is struggling to cope with just appointments, really.

00:53:26

*Can I just, can I just come back to something because you, you mentioned that your experience with social services was brilliant. What was brilliant about it?*

00:53:40 Carer01

I rang up and the person I spoke to was very experienced and she twigged that it was his care issues were not run-of-the-mill. Came out to the visit and supported me. Because I got these private carers in place straight away so that he'd have somebody doing his legs and that straight away I mean fortunately,  I did that out of my own money. Um, other people probably wouldn't be able to do that, but even so, she was quite fast in saying ‘yes,’ you know, ‘let's sort it out. Yes, I'm looking at it. It looks like we can send some of that care.’ So, they acted very quickly, which meant that I could, I could think right I can give him the care you know, I can book the carers in for what he needs. If I was a bit worried about him and the carers were so flexible, I could say ‘can you do an extra hour, or can you come in and and make sure you've got something in the in the fridge? I can't do that.’ They would. They were doing extra things like one of the carers made him like nutritious milky jellies at home and bringing them in for him and.

*Right.*

they were doing everything they could to keep the nutrition going into him and and they did that because I knew that I could afford to pay them because social services had been so quick off the mark.

*Yeah, yeah.*

00:55:22 Carer01

I mean, some people wait weeks and weeks for them. But look at the timeframe that I was working at. They were pretty good.

*Yeah. Yeah. Thank you.*

00:55:34 Carer01

Sorry, I just feel like I've moaned and moaned. But I mean just.

00:55:36 Interviewer - CB

*No, no it no. I asked you to tell me all your thoughts and that's what I you know, I wanted you to tell me things from your point of view. That's. That was what I wanted you to do. And you. And you're doing that.*

00:55:46 Interviewer - CB

*I suppose one thing I'm wondering is, you know when you talk, when you, when you go through something like this, when you talk about this experience, sometimes things occur to you that you might not have thought about before. Is there anything now that you're sort of reflecting on it that you that you had perhaps wouldn't have thought about otherwise?*

00:56:14 Carer01

I suppose it's that the individual bits did their bit at the time, to the best of their ability. Well, no, they didn't [laughs] - I can't - the primary care just seems very poor but

*OK.*

Well, poor. Well, perhaps it was to the best of their ability. They did try, actually, because I took him in for the first time, they were all over him like a little swarm and I was really pleased with them. So, I think every little bit tried their bit at the time. But it doesn't, that doesn't create a proper journey for the patient. They're just bits that happen to randomly work or not work on the day and.

*OK.*

00:57:00 Carer01

I, I was desperate to keep him out of hospital because I because he didn't, he, didn't he - he not one place he wanted to be. He would not want to be in hospital. So my so my what I tried to do was to give him what I felt either he would want or that that he would want, if you know what I mean. That was absolutely clear that he would want, though not to spend weeks in hospital, he would have just gone absolutely crazy – he wouldn't even take a cushion [as mentioned earlier] he was so independent. So, I don't know what I was gonna say there so,so the whole, the whole thing seems to be trying to keep him out of hospital, but as comfortable, not just physically, but emotionally comfortable as well. And I and I felt that, but because there was so much to do with ferrying him about and um, the carers and the doing the shopping and keeping the flat clean cause, cause he was starting to become incontinent, you see. So, I was having to go to the flat and wash carpets where he couldn't get to the toilet in time.

*Yeah, yeah.*

00:58:20 Carer01

So physically there was masses to do so. It just felt like a massive caseload, I suppose, and there's just nobody to share it with, really, and I speak because it happened in a short space of time. If, if palliative care were would have come in really late anyway, so I don't know. I don't know. We just got him too late basically.

00:58:42 Interviewer - CB

*OK, OK.*

00:58:48 Interviewer - CB

*And I I I think I've. I've probably asked you. All the questions I need to because you've explained everything. But is there? Anything that you want to ask me?*

00:59:02 Carer01

Well, I mean anything I want to ask you, I don't think you can comment on which is is, is XYZ normal and should he have had that and should have something else and should I have done this and should I have done that and I don't think you're really in a position to say any of that, really.

00:59:13 Interviewer - CB

*Well, I well, well, to be fair. Just so I'm you know, you're clear about who I am. So, I am a registered nurse, but I'm actually, my background is as a diabetes specialist nurse. So, I'm yeah. Yeah. So liver isn't my primary specialty. So, although I'm doing this research with people who've got liver disease and their families and professionals, it's not my background. So, in a sense, I'm a bit of an outsider, if you like. So, I definitely wouldn't be able to tell you the right answer-*

00:59:46 Carer01

OK.

00:59:46 Interviewer - CB

*-to those things, you know, look, but just what I would say to you, and this is just this is both as a professional and as a person. You know, I I feel that you did what you could for your dad - your stepdad in in the way that you were able to. And I would wonder, I wonder what support, if any, and this isn't to do with the interview now. This is just person to person. What support have you got? Or have you know, have you got or have you been able to access because it's important that you have that opportunity as well?*

01:00:29 Carer01

I'm, I've got a husband here and he’s fine. I think that might be because of the and cancer treatment and the illnesses that I that I had before it meant that it means I'm just not physically very robust and I'm not very emotionally robust now and I think a lot of

*Yeah, yeah.*

01:01:00 Carer01

I think it was very traumatic. It would have been traumatic for anybody. It would been traumatic for anybody [sounds tearful] but I think I'm just feel very guilty, but I don’t think anyone can really help me with that.

01:01:13 Interviewer - CB

*But have you?*

01:01:15 Interviewer - CB

*You have go and know what you going to say. You've had some counselling, have you?*

01:01:18 Carer01

I mean, I had a I, I had a bit of counselling from you know –Macmillan gives you a little bit of counselling because I would be I was very.

*Yes, yeah, yeah.*

01:01:32 Carer01

down about my own situation but the trouble with counselling, of course you feel absolutely fine while you're having it, you know I don't really need that. But no, it's just it's just, it's just, I've just had a bad, bad 10 years and I think because I've had a bad 10 years I wasn't there for my family when they needed [sounds tearful]

01:01:52 Interviewer - CB

*But you couldn't help that if you're dealing with your own health issues as well.*

01:01:57 Carer01

Well, there's always more we could do and we always know that there was more that we could have done, yeah but I'm I'm I don't know. I'm. I'm a bit cross. It was such a fight to getting diagnosed.

*Yeah, understand. Yeah.*

01:02:14 Carer01

I just think that was that was wrong. So so essentially so I didn't realise you were diabetes specialist background, but yeah, essentially liver test normally will show up a problem but when when it gets quite advanced as the nurses were saying, blood tests can just be totally misleading.

*Yeah. Yeah. Understand. Yeah. Yeah.*

01:02:34 Carer01

And if there's anything that I'd want primary care to know, it would be that [re. the blood test results] because there must be a lot of cases of cirrhosis out there that just aren't being picked up and advanced disease in elderly people.

*Sure, sure.*

01:02:50 Carer01

And do you know what the NHS is not a place for old people. It really isn't. And I don't know what anybody would do this about that because he couldn't even, no way could he advocate for himself. I, I don't know what we do about that, and I I just think it's important that the that the kind of consideration and concern that I was shown by a breast cancer team in the hospital - because breast cancer has got a higher profile now, hasn't it, and it's a big thing and people pushed and pushed, and women have pushed and it's as far as I know, I know it's not perfect, but at least breast cancer is seen as something that needs a bit of proper handling emotional handling. Why isn't liver disease treated like that.

*Yeah, yeah.*

01:03:43 Carer01

I've not got, not one leaflet or anything from hospital. I did offer to buy them a load of leaflets for their cirrhosis patients, you know the Liver Trust leaflets

*Yeah.*

And they said yes, but then I then said, well, how many do you want? And they never got back to me, which didn't shame. He was 82, he's not gonna go online,

*No, yeah.*

01:04:13 Carer01

Well, where was the, where was the patient info? Where was the family-patient info? Where was the how to manage your disease info? You know, a quick garbled appointment with a doctor who's doing his best, but it's clearly overworked. It's not really, it, is it when somebody's terminally ill.

01:04:38 Interviewer - CB

*OK. Well, thank you. I thank you so much. I mean you've given me so much to think about and you've given me you've given me so much information. So, I will end the interview, but I'll just explain next steps. So, what I will do is I'll transcribe the interview. And then I'll send you - I'll e-mail it to you so you can check it and make sure it's accurate reflection of what we've discussed today. And I saw that you've ticked on the consent form that you would like some follow up information at the end of the study. So, I will be providing that the study is not due for completion until where are we now? Just trying to remember the date. I think it's, I'm due to submit in in two years, actually, the whole document. So, you would be expecting to receive information before that, but I'm you know, I'm going to be available on e-mail if you ever want to check in with me and find out what's happening, you know, do feel free. And if you think of anything.*

OK.

**Interview ends here – the following is wrapping up the telephone call, so I have not tidied-up the transcription after this point.**

01:05:44 Carer01

You is this is. Is this. Sorry forgot is it for PhD?

01:05:45 Interviewer - CB

Go ahead.

01:05:47 Interviewer - CB

Correct. That's right. Yeah. So I'm in the second.

01:05:50 Interviewer - CB

Year and the this year?

01:05:51 Interviewer - CB

Is the data collection year and then in the final year I have to write everything up.

01:05:59 Carer01

And do you routinely copy in people?

01:06:01 Carer01

Who, like the British liver?

01:06:02 Carer01

Trust and that.

01:06:04 Interviewer - CB

So with regards to the British Liver Trust, I definitely will be sort of attending relevant, not necessarily that them. It depends what they've got, but things like conferences and writing papers and things.

01:06:16 Carer01

I was just thinking they need because I I said I'd give them feed. Sorry, talk Cody. But I said I'd give them.

01:06:21 Carer01

Feedback. But if they're going to get.

01:06:23 Carer01

Lots of patients feedback anyway.

01:06:27 Carer01

It says you.

01:06:28 Carer01

Need to go through the mail again.

01:06:30 Interviewer - CB

Ohh, you mean you you mean you?

01:06:33 Interviewer - CB

Sorry, so just.

01:06:34 Carer01

Your paper.

01:06:35 Interviewer - CB

So will my paper be will inform the British Liver trust of my paper?

01:06:41 Carer01

Sorry, yeah.

01:06:42 Interviewer - CB

Well, my my intention would be my intention would be to put to to publish the final work.

01:06:49 Interviewer - CB

So then everybody would have access to it. That would be what I would be planning to do. So I've already written a paper based on the available.

01:06:57 Interviewer - CB

Chair if that makes sense. But then once I've written once I've written all this once, I've done all the data collection I would write this up into a paper that could be available to anybody to read.

01:07:00

Yeah, yeah.

01:07:11 Carer01

Yeah, I mean, I just, I just, I thought what he went through is pretty ghastly. And I just think.

01:07:18 Carer01

So if it's any help to.

01:07:20 Carer01

Anybody else that would?

01:07:21 Carer01

Be brilliant.

01:07:21 Interviewer - CB

Ohh thank thank you. Like I said, I really appreciate your time and I will. I'll e-mail you your copy of your consent form and I'll e-mail you a transcript and and and and also I don't know if you've had a look, but have you ever looked at the website called Cruise CRUSE Bereavement support?

01:07:31 Carer01

OK.

01:07:40 Carer01

Ohh yes I.

01:07:41 Carer01

I'm. Yeah, that's lovely. I'm, I'm well kind of briefed in.

01:07:42 Interviewer - CB

Yeah. OK.

01:07:45 Carer01

That, as I think I've got a.

01:07:45 Interviewer - CB

Fair enough.

01:07:46 Interviewer - CB

Yeah, no fair, fair enough. And and and just one thing I did want to say is that I know that when when you talk about something like this and it is something that's quite traumatic, you know you you might feel a bit upset after this. And so you know, if you do want to e-mail me or anything, I do understand, you know and.

01:08:06 Interviewer - CB

Like I do really appreciate the effort that you've taken to speak with me because I know it's not easy.

01:08:12 Carer01

No, no, that's that's fine. No, that's it. Just it it.

01:08:18 Carer01

I didn't give feedback to the hospital, would feel like attacking and but so it's quite good to give feedback to somebody. Yeah, somebody else driving it all right, but look, good luck with your your PhD and everything.

01:08:29 Interviewer - CB

Thank you so much.

01:08:33 Interviewer - CB

I I will. I will let you know the outcome. So even if you have to wait a.

01:08:37 Interviewer - CB

While I will definitely do a report for you that everybody will get. Yeah. Alright. Thanks so much. Take care. Alright bye.

01:08:39 Carer01

Right.

01:08:42 Carer01

OK, you take care. Alright, bye.