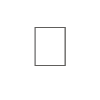
# Carer05 ‘Louise’ – Interview Transcript. 22nd May 2024 08:40am by Teams



 **Catherine Beresford** started transcription

 **Catherine Beresford** 0:08  
Hide transcription. That's it. Then we don't have to watch ourselves talking, right? So, it's it is recording now. Lovely. All right, So, thank you So, much for you for speaking to me today. I really appreciate it. Really. Just to start off with, can you just tell me who you've actually got experience of caring for? You don't have to give names or anything. And I will anonymize everything afterwards. But it was just to kind of understand who, who you're actually a carer for.

 **Carer05** 0:11  
Mm hmm mm hmm.  
OK.  
Brilliant 'cause. I'm not like a romantic partner, So, probably a carer partner. A carer partner friend.

 **Catherine Beresford** 0:39  
Yes.  
Yes. Yeah. OK. And and that's a male person, isn't it?

 **Carer05** 0:47  
Yes it is.

 **Catherine Beresford** 0:48  
Yeah. OK. So, from your perspective, can you tell me about that person's journey of receiving care for their liver disease? So, sort of thinking about, you know, when they first got diagnosed to where they are today in terms of the care?

 **Carer05** 1:06  
I'll be quite honest with you when you're caring for a loved one who's an alcoholic, there isn't a clear path, because what I found I actually found when I was a student nurse, attitudes within NHS in Scotland, definitely in England, it'd be described as someone with a pickled liver. I was asked was I a drinker as well.

 **Catherine Beresford** 1:14  
Right.  
Mm hmm.

 **Carer05** 1:31  
And definitely things that's quite hard really to to think of when he was diagnosed because.

 **Catherine Beresford** 1:36  
Right.

 **Carer05** 1:36  
And that when you're an alcoholic, you have got multiple things, mental health issues and you know, So, I think I first really noticed things when [name of person with liver disease] was drinking very heavily and it was, it was very volatile. And I was kind of like the target. But I don't know, maybe I've just my family upbringing and and maybe later went on to be a nurse with good teachers along the way.

 **Catherine Beresford** 1:40  
I.  
Yeah.

 **Carer05** 2:02  
I always I always saw him. I never actually saw and sober, So, I didn't really know who he was.

 **Catherine Beresford** 2:05  
Yes, yes.

 **Carer05** 2:07  
But I saw him as a human being.

 **Catherine Beresford** 2:10  
Yeah, yeah.

 **Carer05** 2:11  
And the actions that he had and what he did actually.  
Were I was going to say were because of something else and in my role to him was to keep him safe.

 **Catherine Beresford** 2:20  
Mm.  
I.

 **Carer05** 2:25  
And he was in and out of hospital then, and there was an old doctor. Doctor [name of doctor].  
And my first experience of [name of person with liver disease] in a big hospital was.  
When he was in a large hospital in [city name], might have been the general, I don't know, but I remember there was doctor [name] was nearly retiring and he had all the students round about him. And I was at the other end of the room, and he said to [name of person with liver disease], ‘well, we'd like to keep you and give you some treatment for your liver’. And of course, [name of person with liver disease] was an alcoholic and wanted to home for a drink. And I knew that I knew I couldn't stop him. Maybe there's a bit of an ego in it by standing by someone. But he would have died otherwise. So, I wasn't having that so, and I believe in fairness.

 **Catherine Beresford** 2:42  
Yeah.  
Yeah, yeah.

 **Carer05** 3:08  
And so, alcoholics are not treated fairly. So, I don't really like unfairness. So, I stood by I'm when you get you get to have an attachment to someone as well. But and when [name of person with liver disease] says, oh, she'll look after me [name of Carer05]. Me in the corner and.

 **Catherine Beresford** 3:11  
Yeah.  
Yeah.  
Yeah, yeah.

 **Carer05** 3:25  
Doctor [name of doctor] doesn't look at me. Doesn't thank me for the work I was doing with [name of person with liver disease] because he had a set view. He turned to his all his student doctors and said that's the problem, pointing at me.

 **Catherine Beresford** 3:30  
Yeah.

 **Carer05** 3:37  
And when he left the room, I feel emotional now talking about it. I burst into tears.

 **Catherine Beresford** 3:42  
Yes.  
Yeah, yeah.

 **Carer05** 3:45  
Because it was like saying I'm cause of [name of person with liver disease] die with alcohol when in actual fact I was the one that was trying to save his life or stop him from drinking because I knew people died from it and.

 **Catherine Beresford** 3:55  
Yes.

 **Carer05** 3:58  
I'd experienced that, and people tell me about it and and so, to do that to a young person who's trying to help somebody who doesn't drink or whatever, maybe he thought was a drinker, maybe made assumption, however.

 **Catherine Beresford** 3:59  
Yeah.  
Yeah.  
Yeah.

 **Carer05** 4:10  
Many failed rehabs after that. Many witnessing poor treatment in hospital.  
Where [name of person with liver disease] was taken to [name of] hospital, I think it was called then and was coming off alcohol. He wasn't ready for any rehabs. I know that, no, but they put him in the the day room, not the day room and people were visiting with kids screaming and you're coming off alcohol and your personality might not be the best. So, I went home and found the discharged him or whatever because.

 **Catherine Beresford** 4:33  
Yeah, yeah.

 **Carer05** 4:40  
It was just not. They just didn't really know. They were judgmental. They didn't want him there. And so, anyway. But round about that.

 **Catherine Beresford** 4:44  
Right.

 **Carer05** 4:47  
That time he was really drinking heavily, was still working at the university. He'd written one of the best papers, but he was extremely volatile to me because I guess he's seen me as like his conscience, if you like. And I knew that. And so, one day, I'll tell you one day I'm going for a newspaper. [inaudible]. It lived a quite a rough year. It was so icy. I nearly fell. And he got up and was going out for a bottle. Vodka. And I thought he won't make it back with that. But he did make it back with that because I thought he's now. So, the next thing was.

 **Catherine Beresford** 4:52  
Yeah.  
Yeah, yeah.  
Yeah.  
Yeah.

 **Carer05** 5:19  
I remember he got discharged from the local GP surgery then in [place] because maybe of his attitude or something, I don't know, but we had. We've had really horrific – I have had horrific abuse from social work in recent years, which is another story. But at that time a social worker came out and she was somebody was really kind and good. And she tried to to help that she's all heard [name of person with liver disease] had taken an overdose of Valium. And I said no, I said no, he hasn't. But he'd been given Valium to help him come off whatever. But he was jaundiced at that time because I'll be honest with you.

 **Catherine Beresford** 5:40  
Yes.  
Right.

 **Carer05** 5:51  
He was drink - he was doing home brew and this thing I would be pouring it out. That was disgusting stuff.  
So, I think a lot of the damage to his liver, apart from the fact that the deep comatose sleeps, depriving the brain of oxygen.

 **Catherine Beresford** 6:04  
Yes.  
Yeah.

 **Carer05** 6:06  
Doesn't really help, and his liver and both his liver and his brain were damaged. His brain shrunk, his brain was still working, although he did develop.

 **Catherine Beresford** 6:08  
No.  
Yeah, yeah, yeah.

 **Carer05** 6:17  
Through seizures and different things. I mean, [name of person with liver disease]'s illness is complex, however, So, it was that time he was jaundiced.

 **Catherine Beresford** 6:19  
I see.  
M.

 **Carer05** 6:26  
So, after that he moved to another house. And I mean this, this is very complex. Loads of stories are going about, but into the liver for the liver thing.

 **Catherine Beresford** 6:31  
Yes, yes.

 **Carer05** 6:35  
I must have been doing my nurse training or something at that time because he called me down to see his new flat and it's in the [name of] area and it was nice, flat, nice neighbours, but I didn't actually. He bought it. He bought it outright, but I didn't actually know where it was. I found it and I saw him. The place was a mess because that's that's like when he's drinking. But he called. He called me because he felt worried about his health. And so, I thought it's the first time I'd ever seen [name of person with liver disease] sober.

 **Catherine Beresford** 6:54  
Yeah, yeah.  
I see, yeah.

 **Carer05** 7:04  
And so, sorted him out. Went back home, and then I never heard your mum in a couple of weeks and so, went down to his house and I was knocking at the door and knocking knock. I didn't want to draw attention to myself but I couldn't get in and I went round a walk to a police station but there was nobody. It wasn't manned. And I came back and eventually he let me in. The place was like a rubbish tip and stinking. And he was. I didn't know at the time, but he was dying. I didn't know that. He just after I'd gone home, he'd continued to drink and.

 **Catherine Beresford** 7:06  
Yeah.  
Yeah, yeah.  
Yeah.

 **Carer05** 7:36  
He what, was I going to say, So, I tidied it all the place up and then we didn't speak much in a couple of days I was attending to him. He started.

 **Catherine Beresford** 7:39  
Yeah.

 **Carer05** 7:46  
To have bile coming out both ends, you know. And so, I panicked. He wasn't registered with a doctor. So, I'm phoning. Can I register with the doctor? I didn't really know what to do. Or you have to wait. There's a Friday. I think this is you have to wait till Monday. And sorry, I'm not going to give the whole story, but this was just the first time that it was quite serious. But.

 **Catherine Beresford** 7:48  
Right, yeah.  
Yeah.  
Yeah, yeah.  
No, it's OK. Yeah, sure.

 **Carer05** 8:05  
So, an old Asian doctor came out and he was lovely and really, I should have phoned an ambulance right away. I wasn't thinking.

 **Catherine Beresford** 8:12  
Yeah.

 **Carer05** 8:13  
And I said, ‘is he dying?’, and he went ‘If we don't get him to hospital’ though so, anyway, ambulance came, took him away without me because he was. He’s alcohol poisoning. And so, this is how the liver really got affected. And so, they took him to this, they took him to old hospital without going into all that detail. I mean, I was by the time I got on men there, there was a man sitting there. It was like something out of a comedy horror. I was up on the television because I'd done an old [name of TV show] and he had I was an extra in [the TV show] at that scene.

 **Catherine Beresford** 8:15  
Yes.  
Right.  
I see.

 **Carer05** 8:41  
Seems what I was up on, the television that was on and I thought this is it was so, and an Asian man was behind the curtain by this point. He was smoking a cigarette, and the nurse came in. She says, why do you get that out? We've got a man on oxygen here. And that was [name of person with liver disease] by this point. And then a man the other end. I went to talk to him because he'd been kind. And I said, oh, sorry. I thought he had a urinal bowl, and he pulled the bottle of beer out. So, you can imagine how weird it was. And then all of a sudden, [name of person with liver disease] eyes went behind. He said they were putting a catheter in him. And I think the issue for alcoholics, and we found this in Scotland as well when I worked there.

 **Catherine Beresford** 8:43  
Oh.  
Yeah.  
Yeah, yeah.  
Right.  
M.

 **Carer05** 9:14  
Is that you either don't medicate them at all, you don't medicate them enough, and they could die with delirium tremors, or you slightly over-medicate them, and you collapse them. And they didn't say to me, I think they should have been honest and told me that because I knew working in the game anyway, they said the next morning they’d phone me and they said he'll be on a ventilator. I don't even know what that was at that time. And so, he was an ITU.

 **Catherine Beresford** 9:35  
Right. OK.  
Yeah.

 **Carer05** 9:40  
And and I thought, Oh my God. And a guy came in from the university where he'd just written that. And it's in a little bit jealous because it was research and writing skills and said, oh my God, he's written one of the best papers.

 **Catherine Beresford** 9:52  
Bye.  
Really.  
Yeah.  
Yeah.

 **Carer05** 10:05  
So, that was the first-time kind of that I knew that he was really a. Oh, that would been the 90s.

 **Catherine Beresford** 10:09  
When when was that then?  
Gosh, OK. So, it's really gone over, it's been a very long time.

 **Carer05** 10:17  
I put it.  
Yeah, I've gotta say to you that when people are abusing me now because I speak out and I'm not an abusive person, but if you challenge people and they've not get good leadership, I've been reported to safeguarding and umpteen times and it was all wrong. And I never get any apologies for any of it, but I've had to just say I'm going to write a book about this, but I want to get my truth out there. But but in terms.

 **Catherine Beresford** 10:26  
Yeah.  
Yeah. Yes.

 **Carer05** 10:39  
Like [name of person with liver disease]'s liver. Yeah. Yeah. So, that was the first real kind of time. And I remember the nurses in ITU, you've got the creme de la creme. You've got one-to-one nursing.

 **Catherine Beresford** 10:43  
Yes.

 **Carer05** 10:49  
I remember thinking, she said, oh, she says. At least he's not drinking when he's in here. And I thought she's talking about he won't drink again. But that wasn't the case. But but I mean, then he started the seizure started and they were horrific, and they would go into hospital and they would discharge him or I would come home, find it had had a seizure but without giving him any treatment, was dangerous and people were. There was a lot of things happening, but.

 **Catherine Beresford** 11:05  
Yes.

 **Carer05** 11:15  
In terms of a liver, you know it's funny that because I was thinking about this meeting today and I thought it was just when I was reading about something else and I thought I never thought about it being cirrhosis, but well, I know it's cirrhosis, but I never it's at all that I'm thinking is 40%, but I've got him now involved with the gastro. He likes him, but I find that if I think if they're not carer friendly, I don't really like them, right. They don't understand that they don't understand [name of person with liver disease]'s mood. I would never say you couldn't go to him because [name of person with liver disease] really likes him because he's got a good relationship with him. But I feel he's let us both down, but I feel like some that's fine however.

 **Catherine Beresford** 11:22  
Yeah.  
Right, I see.  
Yes, yes.

 **Carer05** 11:51  
I managed to get him in with this guy who works at the - I can't even remember how he came across him, but he is a liver specialist, you know, and at one point he discharged [name of person with liver disease] and I was and [name of person with liver disease] ran out the room because I think you know what it was. Because [name of person with liver disease] was, I'd gotten we'd had a big end, got more. I got more of alcohol, but then a big situation arose where [name of person with liver disease] and the addiction service, which is really horrific and [name of person with liver disease] went back to drinking again. But.

 **Catherine Beresford** 12:00  
Yes.  
Yeah.

 **Carer05** 12:22  
Only small amounts but.

 **Catherine Beresford** 12:23  
I see.

 **Carer05** 12:25  
Four cans of beer every day, ale every day, but I managed to get more than that as well, but but I remember why he rushed out because the the guy from is an academic, but he's right into his he's right into liver and I'm in [name of person with liver disease]'s liver.

 **Catherine Beresford** 12:28  
Yeah.  
Yes.

 **Carer05** 12:41  
You know, and so, he said. Oh, well, you've got Doctor [name of doctor]. You don't really need me. But but before that, he said, what was it he said about [name of person with liver disease]? He said no [name of person with liver disease] said, oh, can I cut down to three? And he says no, you need to stop [drinking alcohol] or you'll die.

 **Catherine Beresford** 12:55  
Yeah, yeah.

 **Carer05** 12:56  
And that some people can't handle that honesty. That that's what I feel as well. And so, I'm an. Yeah, I mean, you can't drink anything at all. But actual facts. No. We've got a different problem with sodium where he's nearly died because, obviously. But we've got to look at the positive side of this. [name of person with liver disease] will be 70 in January. He's still alive! He's still alive because of my care. But I'm gonna pure as and everything so but.

 **Catherine Beresford** 12:59  
Right, OK. Do you?  
Yes, yes.  
Yes, yeah, yeah.

 **Carer05** 13:26  
That was the.  
Yeah, that was that. Was that. So, I managed to send that I had to get [name of person with liver disease]'s consent, of course, with everything I do. And he agreed to go back to him, but at least we could tell him then that he wasn't drinking, you know? So, that was good. And the relationship's better. But it's difficult because we usually see the gastro guy first and he does the he does the test for. It was only at LIVErNORTH that I found out that [name of person with liver disease] needed these two checks a year.

 **Catherine Beresford** 13:35  
Yes.  
Yeah.

 **Carer05** 13:54  
As I say so, the cancer checks. Yeah. Uh huh. But then he gets it, doesn't he? Hasn't had any ascites in recent in recent times because he's not drinking. No. And I mean, when he gets his results from his blood, he gets his results from his bloods.

 **Catherine Beresford** 13:54  
Oh, you are the ones to check that he hasn't got liver cancer? Yeah.  
Hasn't he?  
I see. Yeah, yeah.

 **Carer05** 14:13  
They will be. They'll say everything's fine. Well, everything. It doesn't mean everything's like fine. But then again, nobody knows what the liver is like. I mean that, that Austrian guy did an autopsy in a woman. That was a heavy drinker, and her liver was fine.

 **Catherine Beresford** 14:16  
Yeah.  
Yeah.

 **Carer05** 14:28  
He said so, nobody really knows. You could have a fatty liver half the, you know, these top doctors will give a talk and they say, well, we don't even know if you've got a fatty liver or whatever, you know, and different things.

 **Catherine Beresford** 14:29  
I see.  
Yeah. So, thinking about thinking about at the moment then what services does he access for the liver?

 **Carer05** 14:47  
Has liver he sees, twice a year he sees, pardon me, the liver specialist. Who is he's a professor at university and he's really presented his liver research.

 **Catherine Beresford** 15:02  
Hmm.

 **Carer05** 15:03  
I want to keep him on board because he has a liver specialist and although the other guy is quite high, he's quite high up in other things. I really won't. Oh, by the way, sorry I didn't tell you about Doctor [name of doctor]. I know this is backtracking a bit when I told you I was in tears that time.

 **Catherine Beresford** 15:06  
Yes.  
Oh yeah, that's OK.

 **Carer05** 15:19  
Well, I never. I've never abandoned [name of person with liver disease]. Even in the most harrowing of times in recent years. Also, when he was psychotic, and I was the target. But however.  
We met Doctor [name of doctor] just before he retired, actually, because our I said to the nurse, I didn't put a complaint or anything in. But I'd said you're not really upset me him doing that, you know, humiliating me in front of these people when I'm just trying to support somebody because they're abandoned and that doesn't tough love doesn't work for some people, they'll just continue on their path, however.

 **Catherine Beresford** 15:36  
Yeah.  
Yes.  
Yes.  
Sure.  
No.  
Yeah.

 **Carer05** 15:52  
And so, we met him at this meeting. This you wouldn't. It was the same guy. And he turned around and he wasn't lying. I think he was. He was nearly retiring before. Doctor [name of doctor], come on this thing. And he said, oh, I can see you're doing very well, [name of person with liver disease]. And your results are good.

 **Catherine Beresford** 16:01  
Yes.

 **Carer05** 16:08  
You've got a great support there.  
I didn’t know which way to take it! One one of the biggest problems, I think really well, there's a lot of problems in the NHS at the moment, but it's really not valuing the triangulation of care that is very difficult because people like [name of person with liver disease], very clever.

 **Catherine Beresford** 16:13  
Yeah, yeah.  
Yes.

 **Carer05** 16:29  
Sometimes will tell me to shut up if I speak, but I know that that's him, and I know that it's very important that your sense of self is felt in any discussion. I know that so, but it's difficult sometimes because and sometimes like anyway carry on. I'm way off the track but, but in terms of liver, yeah, I mean, if you're not going to listen to the carer and put them down that person.

 **Catherine Beresford** 16:30  
Yes.  
Yes, yes.  
No, that's helpful. Yeah.

 **Carer05** 16:55  
You know you have to work really hard if you're supporting an alcoholic and not, as I say, I've been.

 **Catherine Beresford** 16:58  
Yeah.

 **Carer05** 17:00  
Enough collapsed at meetings ‘oh she was drunk’ and actually drank, you know? And if I'd drank more than two drinks, I would have been sick or had a bad headache. But it wasn't. You know what I mean? So, it's it's a very hard journey. As I say, it's like an ergonomic study, almost, in caring. But then finding out the people that didn't want to help them at the time. But I'll say, I mean, one time when [name of person with liver disease] was in the [hospital].

 **Catherine Beresford** 17:04  
Yeah.  
Yeah.  
Hmm.  
I.

 **Carer05** 17:26  
You could see it was through his liver. He was having a lot of stomach problems, and he was in for investigation.  
I had to fight so, hard to get him in, but it was a Ward [number] or something. I don't if you are familiar with cages at the [hospital] on the staircase.

 **Catherine Beresford** 17:37  
No, no.

 **Carer05** 17:41  
A kind of safety thing and so, I was doing my nurse training, and I came down. I was so tired and back and forward happy he was in a hospital, and he was staying there, wasn't walking off and so I went to go downstairs, and he was clinging on to me. Please come back, please, to come back to his bed and [inaudible] with him, even though I'm so tired that had a few times and other things and he’s going: ‘those old dossers there on the floor’ I says, ‘what do you mean dossers?’ I wasn’t too thinking at the time it was delirium tremors. I wasn't thinking that. And I said I says I says, ‘Nobody there’ I said ‘are you talking about the patients?’ I said ‘that's not where the patients’ and and we got back in and I'm sitting, and he was calm when I was sitting with him but the care assistant - the nurse were giving out their tablets and the care assistant said in a voice I could hear

 **Catherine Beresford** 18:00  
Yeah.  
I I see, yeah.

 **Carer05** 18:30  
‘He would go to sleep if it wasn't for her’.

 **Catherine Beresford** 18:31  
Yeah, yeah.

 **Carer05** 18:33  
And I thought I'm gonna go in my bed. So, eventually, you know what it off. And I was able to go. But I phoned down to the then Ward [number] and I said, I don't know why actually, because I haven't really done much nursing training. And I says.  
It's 2:00 o'clock in the morning, I said I'm a bit concerned about my loved one. He's acting really strange up in the ward and they just said I'll just go to bed. He'll be fine. I had to get my head in the pillow. Catherine, when the the little Hospital family room that had the phone rang, they had got up to the wards. And I thought, oh, So, tired. So, I managed to get back up to the ward. There was a security guard in either end. And [name of person with liver disease] was in with [name of] Irish psychiatrist. And I was sitting listening. And where are you, [name of person with liver disease]? Or I'm in an experiment. It was completely, you know, psycho psychotic because of the. I mean, it was terrible. It wasn't.

 **Catherine Beresford** 18:58  
Yeah.  
Yeah.  
Yeah, yeah.

 **Carer05** 19:22  
Whatever.

 **Catherine Beresford** 19:23  
I'm with you.

 **Carer05** 19:23  
However, So, [name of person with liver disease] was outside the room, it was a bit like that scene from Greece when somebody's gone by the door, [inaudible] [name of person with liver disease] didn't have a bowl and [name of person with liver disease] was looking in suspiciously at me. Well, obviously he was psychotic and he thinks he's in an experiment back at [name of] University and they're trying to put put - they were maybe trying to take blood to do Something and he thought he was in an experiment and So, or even taking his blood pressure, any approach like that as they do and so, maybe happened just after I left, see if they'd let me stay, but they they wouldn't. But but it's not that these I was really tired but. And so, I said the psychiatrist said, ‘can you take him home?’

 **Catherine Beresford** 19:34  
Yes.  
Yeah.  
Yeah.  
Yeah.

 **Carer05** 20:06  
So, I say ‘are you're joking’. I mean, I've never left [person with liver disease] side. I've even hid under the bed rather than go home.

 **Catherine Beresford** 20:12  
Yes.

 **Carer05** 20:14  
This whole marks at the time and all the doors and who's trying to get in and kill me because he thought that I was. I was he conscience, really. But anyway, and so  
he, he said. ‘Can you take him home?’ I said, ‘can you not section him?’ Because I don't think sectioning has got too much stigma attached to it. And of course [person with liver disease] was annoyed when I said that later on.

 **Catherine Beresford** 20:29  
Hmm.  
Yeah, yeah.

 **Carer05** 20:37  
‘Is it what you wanted? Me sectioned’. Oh, see, it's [name of person with liver disease] section - It's a it's a medical treatment. It's a normal medical treatment for people to protect them. And he was like.

 **Catherine Beresford** 20:45  
Yeah.

 **Carer05** 20:49  
So, the psychiatrist says, ‘well, that ward that I rang down’, he said,’ well, I've rang Ward [number] and they won't take him because it's alcohol related’. So, so, what do you do then with that? The only other thing was he would have had to have sectioned them and so,

 **Catherine Beresford** 20:56  
Mm hmm.  
Yeah.  
Yeah.

 **Carer05** 21:05  
And he said to me, well, if I fear if I say he the guy just seemed really quite I was OK, I was OK with him. You know, some people you feel are textbook people.

 **Catherine Beresford** 21:15  
Yeah.

 **Carer05** 21:15  
And whether he was or whether he wasn't, I didn't feel that he was. And he said, ‘I've got a good relationship with him’. He said, ‘if I section him, I think that could be damaged’.

 **Catherine Beresford** 21:25  
OK.

 **Carer05** 21:26  
And and so, I had to take him home. I agreed to take him home and I sat up with him all day and things. And it was so, we that was, you know, and he'd had a few suicide attempts as well. So,

 **Catherine Beresford** 21:27  
I.  
Yeah, yeah.  
Yeah, yeah.

 **Carer05** 21:38  
But just.  
Everything associated with his lifestyle, with the, the illnesses, the see, the lack of oxygen, the toxins from the alcohol, the head injuries, the seizure, the body’s, the body, and everything's all interconnected, doesn't it all work in harmony. And so, yeah. So, when they start to get the seizures, actually when he worked in [another country], he told me. But it's quite difficult because people don't realise the main issue for me. You know, they'd gone on about his house later on and I thought well, the house was a state, he wasn't alcoholic. But my priority was rummaging through all the dirt and saving his life.

 **Catherine Beresford** 21:43  
Yes.  
Yeah.  
Mm.  
Yeah, of course. Yeah, yeah.  
Yeah, yeah.

 **Carer05** 22:15  
But they didn't get that. Would you get a carer’s allowance because of the state of his house? But that was him. I did his best I could, however, however.

 **Catherine Beresford** 22:18  
Yeah, yeah.  
Yeah.

 **Carer05** 22:25  
So, so, it's funny, you know, when you asked me that and I was thinking about it, I thought it's just kind of a blank because it's so many years and so many issues and so many things, but.

 **Catherine Beresford** 22:31  
Yeah.  
It's been a long time, yeah.

 **Carer05** 22:35  
Well, as you say, it's been a long, long time and he's still alive because.

 **Catherine Beresford** 22:37  
Yeah.

 **Carer05** 22:41  
Well, after you know, he eventually did. No, we went a lot of people [name of place] are a terrible place and I managed to. We had a male psychiatrist. He was textbook. Definitely when [name of person with liver disease] was doing well, sat with his Scottish as well, sat with his hands behind his head and said, oh, you're doing well, [name of person with liver disease]. Cause of all the care you're getting.

 **Catherine Beresford** 23:05  
Hmm.  
Yeah.

 **Carer05** 23:06  
Not because of your bravery and because of Carer05's support and the thousands of pounds she's spent doing that anyway. So, I mean, it's been quite a challenging journey, I think of all of those things. I managed to get. Yeah. But anyway, So, yeah, So, I don't want to go off the track.

 **Catherine Beresford** 23:11  
Yeah.  
Yeah.  
But thinking about I suppose So, thinking about perhaps the last sort of year or two. So, from what you're telling from what you're telling me, he he sees the the specialist a couple of times a year. And are there any other professionals that are involved in caring for him in in relation to his liver disease over the last couple of years?

 **Carer05** 23:28  
Uh huh.  
Yeah.  
Not really, no, because that's is is is developed, you know, the irony of it is.

 **Catherine Beresford** 23:45  
No.

 **Carer05** 23:51  
The irony of the whole thing is that when he stopped the drink in the four cans I was like, he was. He was used to the special of lifting things to drink, right? So, I bought a couple of beakers. He is so accident prone. I bought him a couple of beakers that I don't know if you'd use them for kids or adults, but out of [name of places] and they had a tight on lid. They were like a pint-sized plastic thing with a plastic straw. And can you give me a drink? You know, what a kid would do to go to bed.

 **Catherine Beresford** 24:01  
Yeah.  
Yeah.  
Oh yeah, yeah.  
Yeah, yeah.

 **Carer05** 24:20  
I'd fill it up with orange juice. Any giant gallon orange juice and gallons of pop.

 **Catherine Beresford** 24:21  
Yeah.

 **Carer05** 24:27  
And I thought to myself, nothing of it. It's not vodka they used to drink litre bottles of vodka, blue line cider, everything. And until he was passed out and.

 **Catherine Beresford** 24:31  
Yeah, sure.  
Yeah.

 **Carer05** 24:39  
Then, then he started to take a lot more seizures in the last year or so, and I thought, oh, he’s deteriorating. Well just think about Catherine, he's almost 70. He's been drinking since he was a teenager.

 **Catherine Beresford** 24:47  
Yes. Yeah.

 **Carer05** 24:50  
And even even stopping causes damage, I think as well. So, anyway, in all the seizures and everything like that, however, we were lucky to get a neuropsychiatrist, but that GP said he's a waste of space and we get her back. So, it's been a harrowing journey but and so,

 **Catherine Beresford** 24:52  
Yeah.

 **Carer05** 25:06  
He was taking all these seizures, actually, when I was I managed to get a job working from home and I'm a bit but that was good because in my breaks I would come and check and things and one time when I checked in them I couldn't rouse him.

 **Catherine Beresford** 25:15  
Yeah.

 **Carer05** 25:18  
So, I've had to phone during my break. I'm at work at the call centre, I said. I can't rouse [name of person with liver disease] and it was during that was during. sorry you asked for recent years. That was during the pandemic, but.

 **Catherine Beresford** 25:18  
Gosh.  
Yeah.  
Yeah.  
Oh.

 **Carer05** 25:27  
They wouldn't actually, obviously wouldn't let me go to the hospital, right? And so, I says, why have you got that big, you know, a pump in auction. And with that, you know, that big plastic clear thing you have? And they said, oh, we can't get oxygen in him and they were taking them away. And as the the paramedic was putting them in the ambulance, he said, have you got a DNA CPR thing. I said. I beg your pardon. And I says no, he's got, I've got power of attorney for [name of person with liver disease]. I know his wishes. He wants to be revived.

 **Catherine Beresford** 25:50  
Yes, yes.

 **Carer05** 25:53  
And after he's revived, oh, they they try and put that on the anyway, whatever your job. And so, so that was quite scary. So, So, that was the start of it, I think. And then he started having a lot of seizures, whereas before there were, he's got a great neurologist. So, she, she took over another great neurologist. And you know, I tell her every time because in the hospitals there was only get his medication changed when he had mood swings. She's managed to sort that out that he doesn't have those mood swings, you know less unless whatever. Because he's got encephalopathy as well.

 **Catherine Beresford** 25:53  
I.  
Yeah.  
Yeah.

 **Carer05** 26:26  
Intermittent, that is, but.

 **Catherine Beresford** 26:28  
I.

 **Carer05** 26:29  
And and So, he. So, what was going to say? So, how many fits And I thought all don't get me wrong, I have had anticipatory grief since I'm at him because of the drinking. But it's sad to increase because he was in all these seizures, and I've not had good experiences with hospital people because I do speak out. I speak out and that's it. So, anyway. And I don't mean in an aggressive way. It's usually them that are aggressive, but they turn that around. But anyway, So, he.

 **Catherine Beresford** 26:41  
Yeah.  
OK.

 **Carer05** 26:56  
And so, I sodium’s a bit low and then they discharge them. So, I never really thought any about that. But I was seeing somebody's son recently died of a low sodium in the paper because it's not something that's routinely checked with people.

 **Catherine Beresford** 27:06  
Yeah.

 **Carer05** 27:07  
And it's hyponatremia. I think it's good. But but he, well, I was going to say So, he kept having these fits and then at one point, his sodium was really low. And I remember this the the national A&E, the sister rather, she said I'm going to get Somebody down from must have an ITU I think it was because of [name of person with liver disease]'s unresponsiveness. But I know [name of person with liver disease].

 **Catherine Beresford** 27:23  
Yeah.  
Yes.

 **Carer05** 27:28  
I'll panic about a lot of things. About [name of person with liver disease] quietly, mostly, but I know him. He'll be like that. He'll go up and go to the toilet. He still needs to be observed and things, but he'll go up and go to the toilet and people think he's OK, you know? But they know. But I know that it takes his time is very slow, you know, coming round. But the guy came round, he was a lovely guy and he said he was a specialist doctor. And he said I can just see [name of person with liver disease] Actually he isn't totally unresponsive. And I was quite glad that he didn't go up there.

 **Catherine Beresford** 27:31  
Yeah.  
Sure, sure.

 **Carer05** 28:00  
I've seen he will be ventilated again and stuff. It wasn't that bad, but but he because he was asking the liver doctor once if he could have a detox, not the liver. Doctor, the gastro doctor. And this is one of the reasons why I'm not so keen in him. He's but I mean, he's a nice guy and he's like everybody, but I'm not keen because he's not treated me right and I think you should do that if you're not treating me right here. So, anyway.

 **Catherine Beresford** 28:00  
Yeah.  
I yeah.

 **Carer05** 28:25  
He put [name of person with liver disease] down for and put it in his Christmas card. I'll put you down for detox. Although he didn't really kind of need it because it was four cans, but it was four times every day.  
So, just observe it and he didn't do it. He didn't do it. And I think that was really struggling and at the surgery at the time had given [name of person with liver disease] a bottle of liquid morphine. Which [name of person with liver disease] was taken safely right? [name of person with liver disease] was the alcohol was thankful, [name of person with liver disease], but he was taking it safely. But then, unbeknownst to me, he had taken too much because that's what alcoholics do. They he took too much, and he called the paramedics. And I think a couple of weeks before that it about a month or so before that it went out. When I was at a meeting.

 **Catherine Beresford** 28:48  
Yeah.  
Yeah.

 **Carer05** 29:07  
And got a bottle of vodka, vodka and and so, that he hasn't done that recently. I think he's so frail, you know. And no, he hasn't because he's want to he's want to go on a holiday but we can't because we're waiting for an assessment and we did that we did actually managed to go to [place name] for a week alcohol was never mentioned or anything with it but however however he ended up in hospital when I was had paid for him to go where I was doing a poster presentation in [place] and he was meant to come with me last October but.

 **Catherine Beresford** 29:13  
Hasn't a yeah.  
Oh, I see.  
Yeah.  
In 2023.

 **Carer05** 29:39  
It got so critical.

 **Catherine Beresford** 29:49  
Yeah.  
Wasn't well enough, yeah.  
Oh, yeah, sure. Yeah, yeah.  
Yes.  
Yeah, mm hmm.  
Mm hmm.

 **Carer05** 30:08  
Kidneys are interlinked, aren't they? But?  
So, he developed this happening and so, they kept him in and he couldn't go with me and so, there is what I'm trying to say now is it's. But yeah, I still get back to this thing. He's almost 70. He's had a great life with me of taking abroad conferences. OK, one of the times he did have a seizure at [place], but they did a wonderful - he was treated well in the hospital, and it was an overnights, took another little seizure. But he's treated well. Staff are brilliant and he came out a wonderful dinner dance where there was booze flowing. We didn't have any.

 **Catherine Beresford** 30:28  
Yeah, yeah, yeah.  
Mm hmm.

 **Carer05** 30:46  
And everybody treated them really well, So, he's got happy memories of that. And then we went to [country]. I did. I didn't get to [city] for another conference the following year, but I wasn't in charge of organising that. So, there was no alcohol involved in that either, but. And he wasn't thinking about that, but.

 **Catherine Beresford** 30:55  
Yeah.

 **Carer05** 31:04  
I was going to say so yes. I mean, it's really been a problem.

 **Catherine Beresford** 31:07  
Can I? Can I just ask you? Can I ask you something then? Because it from from everything you know, you've given me so much information and I can really, you know, hear how much you know. You've obviously got such a huge role in supporting him.

 **Carer05** 31:14  
I know, I know.

 **Catherine Beresford** 31:22  
And thinking about that, if you need support or advice either of you, where where do you go? If either of you do need that?

 **Carer05** 31:30  
Nobody. There's nobody. There's absolutely nobody. It's a very lonely thing. And that's why my poster and I didn't even get to design a new poster [for work]. And [name of person with liver disease]'s gone when he was in hospital, he said. Because I had to visit him all the time, doing it, doing everything for him as well. But, you know, washing and shaving him, taking him out, bringing him food and taking, it's still there. And I actually wasn't very well because we both picked up COVID at the [name of] hospital. They didn't tell us it was on the ward, and he did all his jabs. I didn't have any jabs. But I was just a bit tired with it. So,

 **Catherine Beresford** 31:47  
Yeah, yeah.

 **Carer05** 32:01  
When I went to, when I went to [country], I was really quite exhausted, more than anything but.

 **Catherine Beresford** 32:06  
Yeah.

 **Carer05** 32:09  
There's not really anybody, but he said about the poster. I said, well that, yeah.

 **Catherine Beresford** 32:10  
So, if you so, if you had, if you had concerns about his. I I know obviously he's got a lot of health issues. So, the liver is just one part of what's going on. You know, I really appreciate that if you had concerns about him and you did need some help, who who would you call?

 **Carer05** 32:34  
And and specifically about what 'cause these problems in every aspect.

 **Catherine Beresford** 32:36  
Well, I suppose if I suppose if he I suppose if. Yeah, I yeah, I mean I guess I'm focusing on the liver. But of course, the reality is that is just one part of things and he's obviously got lots of different symptoms going on. But who's your first port of call?

 **Carer05** 32:51  
What it would be the GP, but they're not very helpful actually.

 **Catherine Beresford** 32:56  
In what way?

 **Carer05** 32:56  
Because when when the well, because the hospital write things about me that are just not true. And I'm an honest person, not true, they cover them. But I know national staff cover their back. It wasn't ours, but I didn't make cover my back. I had a 13 year, two years in a nursing home as an RM in when I gave up my job because actually, I was a blood borne virus counsellor. And when the medication became so good.

 **Catherine Beresford** 33:02  
Yeah.  
OK.

 **Carer05** 33:21  
Because it was really scary if you were diagnosed with hep C, hep B or any of them things. But medication works for most people, So,

 **Catherine Beresford** 33:25  
Yes.  
Yeah, yeah.

 **Carer05** 33:28  
They asked me, did I want to retrain, and you know, stay on with them and ask them. I said no, I said my heart wasn't in it because I think part of me knew that you have to, you have to give up your life basically for that person. But you still get abused as a carer or you still get. So, anyway, the hospital writing things down about me because a carer is not valued a family carer. Everything that they say is believed. So, it's quite difficult for me really. But I took. I took [name of person with liver disease] into the hospital to sorry to see a GP. But we've seen her before.

 **Catherine Beresford** 33:30  
Oh, I see. Yeah.  
Yeah, yeah.  
Yeah.  
I say yeah.

 **Carer05** 34:00  
And she's well, she's Chinese name, but she's lovely. But I says I'm quite concerned about [name of person with liver disease]'s. No, she said I'm writing about a letter for pain management because that was horrible. Talk down to me, [name of person with liver disease], and sent a cheeky letter. [Carer05] commandeered the interview. Well, I thought, well, if you know [name of person with liver disease], you'll know that that isn't true. That wasn't true. Because [name of person with liver disease] stopped speaking, then said I could speak. Right. And that's her and got everything wrong. So, she was wanting to speak to [name of person with liver disease] about that letter.

 **Catherine Beresford** 34:22  
OK.

 **Carer05** 34:29  
Anna [and I, not ‘Anna’] says. Really, I says, well, I've written to [names] MP about that letter because I'm looking into the care and support we need. Actually, somebody in the hospitals for carers of because I speak to, I speak to other people a lot older than myself.

 **Catherine Beresford** 34:36  
Yeah.

 **Carer05** 34:43  
One woman said to me, I wish I was a bit like you, because I started being assertive, you know? You know. A student nurse gave something to [person with liver disease] to sign, and I said he needs to read that first. And I said self do is self-discharge and before he gets sodium test because they they delayed, it wasn't his fault and he was fed up and.

 **Catherine Beresford** 34:48  
Say yeah.  
Yeah.  
Hmm.

 **Carer05** 35:03  
I said, well, he needs to read it and I said you haven't put your calls in this charge on that and they were So, and I says, well, he is not saying it and that woman, she emailed me, and she told me that the guy in the next video, a whole load of things. And she thanked me for the help that gave her. So, I think we need to kind of.

 **Catherine Beresford** 35:04  
Yeah, yeah, I see.

 **Carer05** 35:18  
Somebody independent there to support families because at the moment you're you're kind of abused. But you asked me who would help? Well, possibly haven't actually done it recently, because [name of person with liver disease]'s needs are so complex now. I'm just we're going with the flow because the main problem [name of person with liver disease] has is apart from his liver, is that his spine is crumbling because they wouldn't give him an operation at the time which he wanted. I wasn't sure because I've seen patients die with just a very minor -well look at Joan Rivers. Well, that was different, but maybe minor operation.

 **Catherine Beresford** 35:21  
Yeah.  
Yeah, yeah.  
Yeah.

 **Carer05** 35:49  
I wasn't sure, but I think he would have been OK with it, but it was just a real negative about it and so, they just, I says, well, what will happen then? So, basically his pain is crumbling, it's affecting his mobility and it's quite heartbreaking to see because we used to walk all over [place] area and everywhere and and so I'm trying to get an MRI for him just now. So, it's quite difficult. I'm not working myself here.

 **Catherine Beresford** 35:54  
But.  
Yeah.  
So, there's a lot. So, there's a lot, there's a lot going on and he's got, you know, lots of different health, lots of different aspects to his health. I can really hear that from what you're telling me. But I suppose one thing I'm interested to know is, from your perspective, what do you think good care in advanced liver disease looks like? What would you like care to be like for [name of person with liver disease]?

 **Carer05** 36:16  
Oh.  
Yeah.  
I think you know at the moment.  
I think really more information. I think LIVErNORTH definitely does that, but now I'm a carer. I can't really, [name of person with liver disease], in case you, I don't know. Obviously, it's that's pretty brief and keeps on from that was, although we'll have to leave next week. But for a day. But I think it's it's valuing the person that's supporting I've told you right from the get-go with Doctor [name of doctor]. I was degraded and [name of person with liver disease]. I was also degraded and blamed by his GP because I'd got a neuropsychiatrist in when [name of person with liver disease] was having it wasn't just seizures he was having add work from detox with [name of person with liver disease].

 **Catherine Beresford** 36:58  
Yeah.  
I see, yeah.  
Yeah.  
Yeah.

 **Carer05** 37:15  
Agreed he was ready to stop then, but I'd come in one day. I'd come in one day from Uni or work or someplace, and it was on 3 little bottles of cider. I think it was, but it was. It was less than 5%. That was working. My home detox with them and they had even taken his morning medication. He hadn't taken his bottle of cider. It was next to him because he was had a tech disorder from stop and drinking. Because I see the brain. I mean, it's suddenly stop if you know what I mean. But obviously he's suddenly stopped drinking litre, bottles of vodka.

 **Catherine Beresford** 37:34  
Yeah, yeah.  
Yeah.

 **Carer05** 37:47  
And I think good care is actually probably what I'm doing at the moment, trying to raise awareness. I'm raising awareness for families who know the person.

 **Catherine Beresford** 37:51  
Yes, yes.  
Yes, I'm with you.

 **Carer05** 37:58  
And yeah, So, we need to have that. The triangulation of care the the knowledge that actually bumped into a guy who I know it does exist, but I bumped into a guy called [name] and I'm sure I'd seen him at Some things before I was doing my presentation over and in [place]. And I said, do you? I wasn't sure.

 **Catherine Beresford** 38:02  
Yes.

 **Carer05** 38:20  
It's not good for faces, isn't, I said. Do you? Do you watch in dementia? And he said I used to? And I know I've just seen I said, oh, I'm going to present the poster on [name of condition] to raise awareness for it. And I'm now actually helping the [name of] study, but I know he was just talking to me. He said I'm going to a meeting. Just know that he was retired, and he said what's your name and who are you? And I said I'm just a carer and he gave me a bit of a. Oh he says don't say you're just a carer. I'm retired now but I am printed on to the doctors I was working with.

 **Catherine Beresford** 38:38  
Hmm.  
Yeah, yeah.  
Yeah, yeah.

 **Carer05** 38:50  
To listen to the the wife or the family or anything, and even when I worked in the care home one day I wasn't, I was a mental health nurse. But I worked with a wonderful.

 **Catherine Beresford** 38:52  
Yes, yes.

 **Carer05** 39:00  
Filipino nurses who really helped me and taught me a lot.  
And even they didn't know how to do this. Whatever it was, this treatment for the patient with that, and it wasn't a PEG feed because we did them, but it was something like that. And we'd phoned the GP and the GP said, ask her wife. She's been doing it for years. We are so discarded. We're actually, I was even asked when I took [name of person with liver disease] one day, reluctantly, because it was quite difficult in the drinking years, getting them to go to an appointment. But I worked really hard. They don't know how hard you work behind the scenes and and she so good care, really.

 **Catherine Beresford** 39:08  
Yeah.  
Yeah, I see.  
Yes.

 **Carer05** 39:34  
I was asked are you a drinker as well, [Carer05], you know, and I've been accused of being drunk when I've actually collapsed with high blood pressure because my blood pressure was through the roof. I think it's seen. And another time I don't get a drop fall going through the park.

 **Catherine Beresford** 39:36  
Yeah, yeah.  
Yeah.  
Yeah.

 **Carer05** 39:48  
I don't have a mobile phone and I don't think but somebody phoned. I fell, actually lost some teeth. I say no, that wasn't such a bad injury, but actually losing teeth is pivotal now because only as one state of dangerous and couldn't really get help for that either. So, this would as food's another and you know it's got to be specially made for him. So, it's all kind of issues, however.

 **Catherine Beresford** 40:12  
Gosh, yeah.

 **Carer05** 40:13  
And the paramedic said to me, can you go off the patient please?

 **Catherine Beresford** 40:17  
Oh my goodness.

 **Carer05** 40:19  
And I thought to see, you know, I don't think at the time going I sure just seen shock and the people I told you when [name of person with liver disease] collapsed. sorry. I've been reading stories about people in America, people who have actually died with fentanyl overdose and a bit Narcan was there. I didn't reach out different things and. And so, when [name of person with liver disease] actually took too much of the So, paramedics, everybody that some of them are front most are fantastic, but some have been horrific to me judgmental, and they haven't even - they're not good at the job.

 **Catherine Beresford** 40:24  
Yeah, yeah.

 **Carer05** 40:52  
So, they try and pick something on you instead of focusing on what's happening. And so, I was in shock when they gave him Narcan when they arrived. And so, you're in a shock, they don't understand shock. And these things, even a seizure, even open through hundreds of them. And so, they reported me to safeguarding since she wasn't listening. I mean, I saved his life umpteen times, got more for alcohol. I'm in shock because you're giving them Narcan. I'm studying people that have taken that. I'm in shock as if I didn't what to do and had saved his life. I had given up my life.

 **Catherine Beresford** 40:59  
Yeah, yeah, yeah.  
Yeah, yeah.  
Yeah, yeah.

 **Carer05** 41:23  
And so, what I'm trying to do is to raise awareness about what goes on behind closed doors and even Katie Price. Katie Price was talking one day in the radio, and she's not well liked because of different things. But I heard her talking about her, her first child, who's got additional needs. And she says she was talking about when he's out in public and he has mood swings and things. If people don't get him. And she said, and that's just getting them out the door. So, people don't even understand what it's like, you know.

 **Catherine Beresford** 41:27  
I.  
Yes.  
Yeah.  
I see. Yeah. Yeah, that makes sense. I think what I'm just, I mean, you've kind of alluded to it already, but I guess just one final thought I was wondering.

 **Carer05** 41:57  
I'm sorry, I'm off track. You were going to ask direct question.

 **Catherine Beresford** 41:59  
No, no, you're no, you're all right. I I I just wondered one final thought I had is if you, if you could, you know, advise professionals who are working with individuals who've got advanced liver disease and their carers, what would your take home messages be to them?

 **Carer05** 42:17  
Well, for me, looking back, I would say.  
People who have got a chronic disease that could kill them can actually lose, you know, clinging on to who they are as a person. And we've got advanced liver disease, that person can have multiple other conditions as well.

 **Catherine Beresford** 42:30  
Yes.  
Yes.

 **Carer05** 42:38  
And that that they are struggling with and it's quite heartbreaking for the person that's giving that, providing that care, the sacrifices in life - it's not sacrifices - I gave up nursing. I gave up my PhD, I was too stressed. I did get an MPhil out of it, but I'd like to be back to it one day but you’re giving up a lot and still. But your knowledge, as Doctor [name] said, the knowledge that they [carers] have is phenomenal. Don't write them off. Don't blame them if it's an alcoholic, don't blame them ‘oh you're enabling them’.

 **Catherine Beresford** 42:54  
Yeah, I see.  
Yes. No.  
Yeah, yeah.

 **Carer05** 43:08  
Because I met a young girl in the shop. So, or some. I remember talking about alcohol and she had. She had two little kids, and she was saying to me - sort of clothes shop. I was gonna get something for [name of person with liver disease]. And one of these nice shops. And she says, ‘oh, alcohol. Oh, yeah. My dad's took his own life. My sister found him hanging’ and she said ‘he wanted to stop’. And it's just really, expert carer's are really strong people.

 **Catherine Beresford** 43:23  
Gosh, yeah, yeah.  
Yes, yes.

 **Carer05** 43:34  
Please don't abuse them. Listen to them. But I was a senior nurse. I was respected and.

 **Catherine Beresford** 43:35  
Yeah, listen to them. Yeah, yeah, yeah.

 **Carer05** 43:40  
I met somebody from the care home when I was with [person with liver disease], one of the carers. Oh, that's [Carer05], she was a nurse with us. And I felt really, I felt it's a bit like [name of person with liver disease]. Anything I've done with [name of person with liver disease], I put in a whole system for him when I had a bit of money and, but he took a seizure outside and the drug addict drug addict followed them home, seen that he left the door open for me and come back empty that I hadn't even paid for it. And so, police did nothing. Kids were hitting [name of person with liver disease]. Police did nothing because [name of person with liver disease]'s an alcoholic.

 **Catherine Beresford** 43:46  
Yeah.  
Yeah.

 **Carer05** 44:10  
But listen to the carer, you know. Don't sort of judge them. The best people don't you know, people who are educated.

 **Catherine Beresford** 44:11  
Yes.  
No.  
Yeah.  
Yeah, yeah, yeah.

 **Carer05** 44:18  
They will know, but listen to the carer and value that person, even if they're, it's because, as I say to you, back in those days in [city], when the nurse said to me oh, he wasn't even a drinker, as if, you know, like, I mean, I learned a lot. I learned a lot of people and drugs when I worked in [place], I went there, and I said to people here have a creche. Then they said Carer05, and they were fantastic. They were kindness itself to the the women they worked with. It was a project where women were coming from [place].

 **Catherine Beresford** 44:29  
Yeah.  
Sure.  
Yeah.  
Yeah.

 **Carer05** 44:48  
And you know, actually was out in a visit to a wet house for women in [city] I wouldn’t have known that existed.

 **Catherine Beresford** 44:52  
Yeah.

 **Carer05** 44:53  
So, anyway, that's another story that and so there are people out there, you know.

 **Catherine Beresford** 44:54  
But that, that, that. Yeah, that's that's really that's really, really helpful. I mean you've explained that well, yeah. So, is there anything you would like to ask me or anything else you'd like to add?

 **Carer05** 45:09  
Well, not really. I just think that the prejudice is still there, you know, and it's it's not a meeting with LIVErNORTH they had a little conference thing and great speakers. And I remember one man whose son was waiting for a transplant, and ‘you're not giving them [transplants] to drinkers, are you?’ I know I had to take my [name of person with liver disease] was sitting next to me and I thought I'm working so hard because [name of person with liver disease], he [name of person with liver disease] hated himself. That's why he drank. Although he was a genius, he hated himself so,

 **Catherine Beresford** 45:13  
Yeah.  
Really.  
Yes.

 **Carer05** 45:38  
And so, I had to stop myself from standing up. But I said to.

 **Catherine Beresford** 45:41  
Yeah.

 **Carer05** 45:42  
[person at LIVErNORTH], I think it was [him] who rung said LIVErNORTH. I said, ‘Did you hear him?’ I said I had to stop myself with. That's prejudice. I understand. I understand that. Of course, because of limited livers and I get that. But.

 **Catherine Beresford** 45:46  
Yeah.  
Yeah.  
Show.

 **Carer05** 45:54  
And I get both sides of it, however, and he says, well, ‘The thing is, [Carer05], they said ‘some of the consultants have had liver transplants because they're drinkers and there’s prejudice, space and ignorance and, and there was a time when [name of person with liver disease] was - I’ll just tell you quickly. There was a time when [name of person with liver disease] was in the … iT was good at one point. You know, it depends on who's in charge of it. And there was a, there was a nurse there. I don't know if you know of her. And [name of person with liver disease] was [name of person with liver disease] was actually taking DTs at the time and the.  
[inaudible] Is that medicated properly. You know it, I'd say have a she'd say, oh, it's certain got upset and watching me plotting and planning and the the little guy come in, the security guard come in because he’s jumping up and down on the bed and he's going what's wrong, son? And he was great with him. However, the sister in charge of that ward, I thought she must be about the same age as me in her fifties and she's wearing a smock and she'd be pregnant. Well, you can have menopause babies I get that, but her name was sister [name] and I found out, I can't remember who I found out from, but somebody told me that she she was a beautiful person. Right? And I wondered how she got [name of person with liver disease]  
And apparently, and even [name of someone] had it, and there was a thing it wasn't hidden, which was good because you got to beat stigma. It was said that she was an alcoholic, or they didn't see that said she was a what's it called? A function - was a functional alcoholic secret drinkers which she was called and. And So, the thing is she was good, but a lot of people are prejudice. And I knew from my nursing days, you know, shouldn't nursing days that if you were involved in any way but the the [city] thing I remember saying to one of them how long were you with these women for this wasn't alcohol it was drugs but she said.

 **Catherine Beresford** 47:17  
OK. Yeah.  
I know, yeah, yeah.  
Yeah.

 **Carer05** 47:35  
Until they stop needing us. That's that's my motto. And I think the thing I would say is we have a triangulation of care, speak to the carer she's not having, she's not having a go at you. She's when she speaks up. It's not to make a complaint. It's just to say that she knows the patient's needs, you know, and the patient's needs. She knows it better, doesn't know as well as a patient, obviously, because they say to people that you'll never know. But she knows the likely actions or he - sometimes it can be a male carer. And if that person just has chosen to stay with that person

 **Catherine Beresford** 47:44  
Yes.  
Yeah.  
Yes, yeah, yeah.  
Yeah, yeah, sure.  
Yeah.

 **Carer05** 48:09  
They're not after their money.  
And they’ve thousands of pounds of debt, I've been accused of that. But the police, when they're psychotic, you know, like money or assets. Anyway, that's another story. But it's actually, I mean, I was lucky to get a job for four years in a call centre and in actual fact it was talking to families, so it was great. But that paid off £8000 in debt that I've never had that in my life from being a carer, you know? So, people don't understand it. They make moral, they make moral judgments. So, the thing I'd say is I'm trying to raise awareness for carers in general.

 **Catherine Beresford** 48:10  
No.  
Yeah.  
Yeah, yeah.  
Yeah.

 **Carer05** 48:40  
And I'd like to, I'd like to see somebody in the hospitals not just tokenism, I'm not just wee groups here and there.

 **Catherine Beresford** 48:40  
Yeah, that makes sense.  
Sure, sure.

 **Carer05** 48:49  
The very first time I stood up at I met Nicola Sturgeon. Once I did find her a bit odd, but I had a selfie with her. But when I used to go to the any kind of meeting, even at [city], when I stood up and said that I was a carer for an alcoholic, at first, I felt terrified because of the judgement. And yet people came to me afterwards, I didn’t mention it at the time at the time.  
But a nurse said to him that she had the same kind of prejudices people are people are not speaking about things. I think people would not die with liver failure and there was one night a guy came in with [name of person with liver disease] was in the hospital and there was jaundice. And he died during the night. His mother and sister were there. It was heartbreaking. And people who are mixing drinking and drugs are not treated well: ‘Oh, he's an alcoholic.’ They expect bad behaviour. So, raise awareness. Really. I mean, it's all kind of causes for liver, liver disease. And I'm quite sure that having gone to LIVErNORTH

 **Catherine Beresford** 49:15  
Yeah, yeah.  
Yeah.  
Yeah.  
Yeah.  
Yeah. Thank you. Yeah.

 **Carer05** 49:42  
There's not many. I don't meet any many alcoholics, if any, there.

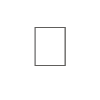
 **Catherine Beresford** 49:47  
Yeah, yeah.

 **Carer05** 49:47  
Just some really horrible things really, to raise awareness for the work that family does.

 **Catherine Beresford** 49:50  
Yeah, yeah.  
Thanks. Thank you very much. That's really helpful. Everything you've told me.  
I think that I can stop record recording now. No, that's it's great. You know, you've you've told me So, much. Are you happy for me to stop the recording?

 **Carer05** 49:59  
I know I've probably, I've probably I've probably gone on too much, yeah.  
Yes, yes.

 **Catherine Beresford** 50:10  
OK, I'm gonna stop the recording now.

 **Catherine Beresford** stopped transcription