# PWLD04 ‘Lennie’ Interview Transcript. Conducted by telephone 17/06/2024 at 14:15. (Rescheduled from 07/06/2024) 37 minutes.

00:00:00 **Cathy Beresford**

OK, alright. Well, let's give it a go and see if it if it works. If if it doesn't, then I can always pause it and then finish off later if if it's too hard to hear you like, I'll see how we get on. But before we start, would you mind just confirming how old you are?

00:00:27 **PWLD04**

How old am I?

00:00:28 **Cathy Beresford**

Yes.

**PWLD04**

[states age]

00:00:31 **Cathy Beresford**

[confirms age]. Thank. Thank you. It's just because when I'm writing up the report, then I say how old people are but everything's anonymised. So, you know it will all be anonymous. And what ethnicity are you?

**PWLD04**

Sorry?

00:00:47 **Cathy Beresford**

Are are you [states ethnicity]?

00:00:51 **PWLD04**

Yeah. I’m [confirms ethnicity], yeah.

00:00:53 **Cathy Beresford**

Thanks. OK, alright. So, the first question I wanted to ask you was really if you could just tell me about your journey of receiving care since you found out that you have liver disease.

00:01:07 **PWLD04**

Well, I was a cocaine addict yeah. For 30 odd years.

00:01:16 **Cathy Beresford**

30 odd years, yeah.

00:01:18 **PWLD04**

Yeah. Nothing really changed until I got divorced and I started drinking a bit more. It's all self-inflicted but basically, no one else is to blame, there's no one to blame but myself. You know, I was going drinking, and I was coming home, or what I was doing.

00:01:46 **Cathy Beresford**

Yes.

00:01:47 **PWLD04**

A lot of it, I don’t remember it because I was always off my head all the time.

00:01:54 **Cathy Beresford**

Yeah, yeah, yeah, that sounds hard.

00:02:00 **PWLD04**

Very difficult time on that, but yeah, over the last 30-40 years, very difficult. It’s not just me that it’s affecting, affects the family as well, yeah. I’ve been changed for three-four years now. I would never go back to it. *[inaudible]*

00:02:21 **Cathy Beresford**

Yeah. Ohh I didn't catch that last bit.

00:02:34 **PWLD04**

I said, I would never go back to the state that I was in.

00:02:37 **Cathy Beresford**

Yes, yes, I understand. So, when did you, when did you actually find out that you had liver disease?

00:02:45 **PWLD04**

I got admitted four years ago, March 3rd.

00:02:50 **Cathy Beresford**

Yes.

00:02:52 **PWLD04**

And then they take me around to the whole yellow *[difficult to hear]* and they said, I had jaundice. They took me to the ward. They got all my family and they said ‘[name of PWLD04] has got 48 hours to live’.

00:03:09 **Cathy Beresford**

Oh, my goodness. So, they said you had 48 hours to live?

00:03:15 **PWLD04**

Yeah. If I’d live through this situation and what they were doing to me, I would never been here today. If I’d had one more drink that weekend, I would have been dead.

00:03:27 **Cathy Beresford**

So, were you rushed into hospital?

00:03:32 **PWLD04**

Yeah, I was rushed into hospital. My doctor said ‘bloomin heck’ like. ‘You’ve gone too far, over the top’, I said, ‘I know.’ *[background noise making it difficult to hear]*

00:03:49 **Cathy Beresford**

Yeah. So, is that your GP?

00:03:53 **PWLD04**

Yeah, my GP yeah.

00:03:57 **Cathy Beresford**

So, you saw- Sorry, I was just clarifying; so, you saw your GP and then she arranged for you to go to hospital. ‘Cause of the jaundice?

00:04:09 **PWLD04**

Right. An ambulance was outside within about ten minutes. Called ambulance and that was it, I was rushed in.

00:04:17 **Cathy Beresford**

An ambulance? Gosh.

00:04:20 **PWLD04**

Yeah. Blue light all the way.

00:04:23 **Cathy Beresford**

So, it's been going on for a few years now, then.

00:04:28 **PWLD04**

Yeah, yeah, yes. It’ll never be the same - the liver, that’s the only organ in the body that will grow back, yeah, and I’ll never be 100% again like. I was expecting that to happen. I was paralysed from the waist downwards, and, through the drinking and that sort of stuff. It’s affected my leg. I had a heart attack. You know, I had bleeding on the brain. I had bleeding on my heart. Everything like, you know.

00:05:05 **Cathy Beresford**

Yes.

00:05:07 **PWLD04**

There’s no way, I told my son, your dad’s *[inaudible]* intensive care.

00:05:19 **Cathy Beresford**

Sorry, I'm sorry. I'm sorry *[due to difficulty hearing*]. I just caught that you said you were in intensive care. How long were you in intensive care for?

00:05:26 **PWLD04**

I was in there for two months. On a life support machine.

00:05:32 **Cathy Beresford**

Yeah.

**PWLD04**

I come round again. They had to make a decision whether to turn, to switch the machine off, or keep me going. And at the end of that hour, I come back to life again.

00:05:49 **Cathy Beresford**

Yeah, so that's, so that's a lot that you've been through.

**PWLD04**

Oh definitely, yeah. It’s your mental health as well see.

00:05:59 **Cathy Beresford**

Yes, I can imagine that.

00:06:07 **PWLD04**

I just take each day as it comes. I don’t take it for granted. If I wake up tomorrow morning, I’m happy. You know?

00:06:10 **Cathy Beresford**

Yeah, yeah.

No, you know everything you're telling me is so helpful, but the only thing is it's a little bit muffled and I'm just wondering if it might make sense for me to speak to you when you're inside, because I I think it's just cause there's a lot of background noise. Are you are you gonna be going home at all?

00:06:47 **Cathy Beresford**

You you, you're at home now?

00:06:50 **PWLD04**

Hang on. No, no, no. *[he went somewhere else to try and improve the sound]*

00:07:01 **Cathy Beresford**

I'm just thinking that I don't really miss anything you're telling me, but things are not quite catching because of the background sound, so I don't. I don't. I don't mind calling you when when you're at home like. Even tomorrow, I don't mind.

00:07:23 **PWLD04**

That’ll be alright.

That should be better now, yeah. *[I got the impression he wanted to continue the call and tried to go somewhere to improve the sound]*

00:07:45 **Cathy Beresford**

Yeah, that does sound better. Yeah, that does sound better. So so can I ask can I ask you then,

what services do you access for care in relation to your liver disease, then?

00:07:58 **PWLD04**

I have a *[inaudible],* I’ve got a mobility scooter yeah.

If I need to go anywhere, my son comes down and pick me up and take me, you know.

00:08:13 **Cathy Beresford**

Yeah. And and do you go to do you go to appointments at the hospital or at a clinic?

00:08:19 **PWLD04**

Yeah, I go to the hospital every time and that's £15 every time.

00:08:24 **Cathy Beresford**

Gosh, yeah. So how often do you have to go up to the hospital?

00:08:30 **PWLD04**

Well, I get tested every three months, to see if I’ve been taking any drugs or alcohol or anything like that, you know?

00:08:40 **Cathy Beresford**

Yes.

00:08:44 **PWLD04**

But I’ve been all clean every time I’ve been. I’m not going to go back to it.

00:08:44 **Cathy Beresford**

Yeah.

00:08:54 **Cathy Beresford**

No and and you go, do you see, who do you see? Like, do you see nurses, doctors who are you seeing about your liver?

00:09:05 **PWLD04**

I see a consultant, doctors and nurses.

00:09:07 **Cathy Beresford**

Ohh yeah OK.

And and and what works well for you then when when you go to see them?

00:09:17 **PWLD04**

Nothing really because we basically just sit down, and they ask me if I’ve got any problems. And I say no, I’m the same as last time. But then you know, I feel grateful. At least they're keeping up on top of my medicals.

00:09:33 **Cathy Beresford**

Yeah, I get you, yeah.

00:09:38 **PWLD04**

They haven’t left me to get on with it, you know. So yeah. They’ve been very good to me.

00:09:44 **Cathy Beresford**

Say that again.

00:09:49 **PWLD04**

They’ve been very good to me with the service, the after service. All that sort of stuff. If I need anything. *[inaudible]* but some people have been unlucky you know.

00:10:02 **Cathy Beresford**

Yeah. So so thinking a bit more about the way that they've been good, did you say that you can call them if you need to?

00:10:10 **PWLD04**

Yeah, yeah, I just ring them up.

00:10:12 **Cathy Beresford**

Ohh, I see. And who would you speak to if you ring up?

00:10:19 **PWLD04**

I’d speak to [name of nurse]

00:10:19 **Cathy Beresford**

What is that, a nurse or a doctor? Ohh, I see. So, you can get through to the nurse and ask.

00:10:27 **PWLD04**

Yeah, get through to the nurse, consultant, anyone.

00:10:32 **Cathy Beresford**

I get you.

Yeah. And is there anything that doesn't work so well for you?

00:10:40 **PWLD04**

Well, it’s the walking I can’t do because it’s affected my legs, see.

00:10:46 **Cathy Beresford**

Yes. Yeah.

00:10:48 **PWLD04**

They’re very painful. Yeah, you know after that that sort of thing I had to learn to walk again you know *[inaudible]* the wheelchair.

00:10:59 **Cathy Beresford**

Yeah. So how do you actually get to your appointments?

00:11:05 **PWLD04**

I get a taxi.

00:11:08 **Cathy Beresford**

Yeah. And then that, that's what you were saying. It costs £15?

00:11:11 **PWLD04**

£15 each way. Thirty quid.

00:11:14 **Cathy Beresford**

Gosh.

00:11:20 **PWLD04**

Can’t put a price on a lift. You know, I don’t mind paying it.

00:11:25 **Cathy Beresford**

No. Yeah.

And

00:11:25 **PWLD04**

But saying that, I’ve got that COPD like.

00:11:32 **Cathy Beresford**

Oh, I see. Yeah. So, it's so it's not just your liver, you've got other health things that affect you as well.

00:11:42 **PWLD04**

Ohh yeah. Yeah, yeah, yeah, yeah. I’ve got cirrhosis of the liver, I’ve got brittle bones, I’ve got a hernia, I’ve still got bleeding on my heart*, [inaudible]* on my heart they didn’t want to chance *[inaudible]* at the minute*. [I think he was saying he needs something done to his heart, but he is not well enough for it to be done].*

00:12:02 **Cathy Beresford**

Yeah. So, if you're not well, who's your first port of call? If you're if you're not well.

00:12:13 **PWLD04**

It’s my son yeah. Or, my sister, anybody like.

00:12:19 **Cathy Beresford**

Oh, say that again.

**PWLD04**

I’d ring my sister, or anybody.

00:12:23 **Cathy Beresford**

Right, yes. So, you've got you've got family to support you.

00:12:28 **PWLD04**

Oh yeah, 100 percent 100%.

00:12:32 **Cathy Beresford**

Yeah, yeah.

And when you're thinking about the care that you've had for your liver disease. Have you got any specific examples of when it's been particularly positive for you?

00:12:44 **PWLD04**

Not really, because you’re looking at a lifetime illness.

00:12:49 **Cathy Beresford**

Yeah, yeah.

00:12:52 **PWLD04**

Never ever gonna get back to the same like you used to be like, you know.

**Cathy Beresford**

I do. Yeah.

00:12:57 **PWLD04**

I don’t feel regret, you know I've got 2 granddaughters, and they say, ‘come on Grandad.’, and I says, ‘I can’t do it’.

**Cathy Beresford**

Yeah.

00:13:07 **PWLD04**

Oh, my goodness like, you know.

00:13:07 **Cathy Beresford**

Yeah.

00:13:19 **PWLD04**

But I do make the most of it, I don’t sit there, and I enjoy myself like.

00:13:21 **Cathy Beresford**

Yes. Yeah, I'm thinking about the care that you've had, like from the health services and the professionals. Does anything stand out in your mind that's been particularly positive in that respect?

00:13:37 **PWLD04**

It was absolutely fantastic, absolutely fantastic. Unbelievable. I had a nurse looking after me 24/7 at the time I went in there for the first three months I was high risk of - what do they call it - and and the nurse looking out to me 24/7 you know.

00:14:03 **Cathy Beresford**

Yes. Yeah.

00:14:09 **PWLD04**

At some stage I felt like, I just wanna give up like.

00:14:12 **Cathy Beresford**

Did you?

00:14:14 **PWLD04**

Yeah. For the sake of a pint of beer. And the way it goes on and on. And you think, when’s this gonna stop. It's gonna stop somewhere. Yeah.

00:14:27 **Cathy Beresford**

Yeah.

00:14:34 **PWLD04**

You know the cocaine and things like that, you know. And I was thinking, it's gotta stop I was enjoying it, but all good things come to an end don’t they.

00:14:35 **Cathy Beresford**

Yes, yeah.

00:14:48 **Cathy Beresford**

And you said that you felt like, you know, you kind of wanted it all to end in a way because it was so difficult. But what was it that turned things around for you and made you start to feel a bit more positive?

00:15:03 **PWLD04**

It’s when I see my children there. And they said, ‘Dad you can do this. You can do this.’

00:15:08 **Cathy Beresford**

Yes, yes.

00:15:10 **PWLD04**

‘You’ve got it, got it,’ I said, ‘I’ll do my best, I will do it.’ And I’ve never let them down.

00:15:18 **Cathy Beresford**

Yeah, I understand.

00:15:25 **PWLD04**

Even my mum said, ‘nah he’s not going to last.’ And when I finally come through, she said, ‘I don't know how you done it.’ Even nurses at the hospital, and the consultants, they’d say ‘how did he survive all that? Nobody could take it as much as you have. Stainless steel!’

Yeah, but you know

00:15:51 **Cathy Beresford**

Yeah.

Yeah.

00:16:10 **PWLD04**

It’s very difficult at times. Yeah. When you're in company that's like with my friends and that, it's OK. But it’s when you come back and you’re on your own, then you start thinking what an idiot I was. But that’s life though isn’t it, you just got to you got to get down on the path. You gotta go for the future, like, you know.

00:16:30 **Cathy Beresford**

Yeah. Yeah. And you, you mentioned that it can affect your mental health. Have you had any opportunity to talk to anybody about any of those feelings?

00:16:42 **PWLD04**

Nah, nah, I’ve done it myself.

00:16:43 **Cathy Beresford**

Yeah.

00:16:46 **PWLD04**

I’ve done it myself; you know.

00:16:46 **Cathy Beresford**

Yeah.

00:16:49 **PWLD04**

I’ve had to try and make myself stay positive and not negative and get on with things.

00:16:58 **Cathy Beresford**

Yes.

00:16:59 **PWLD04**

I was going in the pub, and I was thinking, I’ve had enough of this *[inaudible],* you know.

00:17:12 **Cathy Beresford**

Yeah, so, so did you stop? So, you're saying that you stopped going to the pub?

00:17:19 **PWLD04**

Yeah. Don't go there no more. No, thank you.

00:17:22 **Cathy Beresford**

No, and.

00:17:26 **PWLD04**

I went away last year with my children to Turkey. We went there and that was nice. And I’m going back again this year.

00:17:33 **Cathy Beresford**

Oh, for a holiday?

00:17:36 **PWLD04**

Yeah, yeah. So, get we all the transport.

00:17:40 **Cathy Beresford**

Yeah. So, you've been able to get away and have a break?

00:17:44 **PWLD04**

Yeah, yeah. I get away for 10 days. And that I love it, you know.

00:17:49 **Cathy Beresford**

Yeah.

Yeah.

00:17:51 **PWLD04**

Always looked after by the people at the hotel, you know, it's never too much *[inaudible]*

00:18:06 **Cathy Beresford**

Say that again.

00:18:11 **PWLD04**

They’ve got a mobility scooter for me when I get to the Hotel.

00:18:16 **Cathy Beresford**

Brilliant

00:18:29 **PWLD04**

When I get to the hotel, I check in and I get pushed in a wheelchair, and they push me through to the gate at the airport and I haven’t really got to do nothing really.

00:18:34 **Cathy Beresford**

7.

00:18:37 **Cathy Beresford**

So, you can enjoy your holiday.

00:18:39 **PWLD04**

Yeah. It’s stress-free you know.

00:18:54 **Cathy Beresford**

So, if if you think a bit more about the care that you've had for your liver disease. So, for example, when you've been in hospital or when you've been to clinic, anything like that. Have you got any examples when you think the care has been more negative for you?

00:19:09 **PWLD04**

Really, they haven’t done no medical thing for me. All they do is put me for scans to make sure I’m alright. They can’t help – do nothing for my liver. It’s completely destroyed.

00:19:22 Cathy Beresford

Yeah. OK.

Yes.

00:19:27 **PWLD04**

So unless it's somewhere ever go back right here now.

00:19:34 **Cathy Beresford**

Yeah. So, so sorry, just cause it's hard to hear, so are you saying that really, at this point, it's more just about kind of trying to keep you well because they can't, they can't do anything to to change what's happened to your liver now?

00:19:50 **PWLD04**

No, no, they can’t do nothing, nothing.

00:19:51 **Cathy Beresford**

Yeah.

Yeah.

00:19:55 **PWLD04**

Obviously, I had so many blood transfusions when I was in the hospital, they cannot get the right level of thickness of blood. I’m on blood thinners and all that.

00:20:08 **Cathy Beresford**

Yeah.

00:20:12 **PWLD04**

If I cut myself, it doesn’t stop, you know.

00:20:15 **Cathy Beresford**

Right. OK. So, you you bleed easily?

00:20:19 **PWLD04**

Yeah, yeah, I bruise easily.

00:20:22 **Cathy Beresford**

Yeah, yeah.

00:20:24 **Cathy Beresford**

So, throughout the last sort of four years, while you've had liver disease, who's been the most helpful to you, would you say?

00:20:34 **PWLD04**

The doctors and nurses at [name of] Hospital.

00:20:36 **Cathy Beresford**

Yeah. In what way?

00:20:39 **PWLD04**

So.

00:20:41 **Cathy Beresford**

What is it, what is it about them?

00:20:44 **PWLD04**

Well, it’s the way they talk to you, and they try to put positive stuff in your mind instead of negative. That’s what I want to hear, you know.

00:20:56 **Cathy Beresford**

Yes, yes.

00:21:03 **PWLD04**

You will – obviously, they don’t beat around the bush and say you will get better, you will get better. I said just tell me. She said, you will not. You will not get better.

00:21:05 **Cathy Beresford**

Sure. Yeah, yeah.

00:21:18 **PWLD04**

Yeah.

00:21:22 **PWLD04**

I’ve never been out of work in my life, but when they said I was finished with work, that was it for me. I thought oh god.

00:21:27 **Cathy Beresford**

Yeah.

Yeah.

00:21:30 **PWLD04**

Well, I’ve adjusted to it now, yeah.

00:21:32 **Cathy Beresford**

Yes.

00:21:34 **PWLD04**

Well [inaudible] I never get bored. [something about how he thought he would get bored if he didn’t work, but he has adjusted to it and doesn’t get bored].

00:21:40 **Cathy Beresford**

Yeah.

00:21:41 **PWLD04**

I’ve got me football and Sky and me parrot, stuff like that, and I never get bored of because there’s always so much to do, you know.

00:21:50 **Cathy Beresford**

Yes.

Yes.

Yeah.

00:22:08 **PWLD04**

Why would I want to sit indoors when I can go for a ride. I get on me scooter *[inaudible]*

00:22:14 **PWLD04**

Something.

00:22:17 **Cathy Beresford**

Ohh no, no, it's alright. Carry on, what did you say?

00:22:21 **PWLD04**

Well, sometimes you know. It's like when they deliver more medication and all that, that’s sort of bang-on like, you know.

00:22:31 **Cathy Beresford**

Ohh, you get your medication delivered straight to your door?

00:22:35 **PWLD04**

Yeah. They come to my door, and they deliver my milkshakes as well.

00:22:41 **Cathy Beresford**

Yes.

That the the nutrition drinks?

00:22:48 **PWLD04**

Yeah, that’s right yeah. I have 24, a month’s worth of them.

00:22:56 **Cathy Beresford**

Yeah. Who organ - who organised that for you?

00:23:04 **PWLD04**

The hospital.

00:23:04 **Cathy Beresford**

Yeah.

00:23:19 **PWLD04**

I had to have all this done and all that done. And I had my medication put into a blister pack. Because they sent me home with all this, these tablets and I thought, ‘have I had that tablet?’ and I don’t think I did, and I ended up taking an overdose [by mistake]

00:23:31

Gosh.

00:23:41 **PWLD04**

And my carer said he’s doubled-up on his tablets. My doctor was across the road, and he told all this to me. He said, ‘do you remember?’ I said, ‘yes, I was feeling ever so tired.’

00:23:47 **PWLD04**

Well, this and I had millions of tablets and boxes, you know.

00:23:50 **Cathy Beresford**

Yeah.

00:23:52 **PWLD04**

And he said, give me them. And I think I went into hospital for about a week to recover from this overdose. And when I got back, the the lady from the pharmacy come and knocked on my door. Said ‘here are [PWLD04] have these blister packs. I said what do I do with them? And then, they give me a carer for two weeks to help me deal with the tablets because I’d got a lot of brain loss, a lot of memory loss. That had affected me.

00:24:28 **Cathy Beresford**

Yes, yes.

00:24:35 **PWLD04**

I was terrible really.

00:24:37 **Cathy Beresford**

Yeah. So, you needed that bit of extra support to be able to take your medication properly.

00:24:43 **PWLD04**

Yeah, they’ve done all that for me, and said, ‘right then [PWLD04] you OK?’, I said, ‘yeah.’

So, when she come in the morning, I just put them all [this part is difficult to hear, but PWLD04 is explaining how the carer taught him to take his tablets]. Well.

00:25:21 **PWLD04**

I'll come back in and see you. See you. OK? Yeah. OK, no problem.

00:25:30 **Cathy Beresford**

So, who was it? Who was it, was it the pharmacist you said that came back?

00:25:36 **PWLD04**

Yeah, she sorted out all the tablets in the blister pack.

00:25:38 **Cathy Beresford**

Yeah, yeah, yeah, that's good.

00:25:43 **PWLD04**

It was fantastic, like you know.

00:25:45 **Cathy Beresford**

And and can I just check something? Did I hear you correctly? Did you say you had to spend a week in hospital because of that?

00:25:52 **PWLD04**

Yeah, yeah because I took too many tablets.

00:25:57 **Cathy Beresford**

Yeah. Sure, OK.

**PWLD04**

I thought blooming heck, like you know.

00:26:02 **Cathy Beresford**

So, you, I mean, you know, you've been through such a lot and you've obviously had a lot of experience with different healthcare professionals and services because of lour liver disease.

**PWLD04**

Oh yeah.

00:26:13 **Cathy Beresford**

So, in your opinion, what does good care for people with advanced liver disease look like?

00:26:30 **PWLD04**

Well, the only advice I can give them really is think twice about what you are doing. Because, you know think seriously about the cocaine the 1st letter is always the best bet you know because you know that first one you want another one, then you want another one. Then you want another one.

00:26:40 **Cathy Beresford**

Yeah.

Yeah.

Yeah.

00:26:51 **PWLD04**

You can’t control it. My advice is, you know, if you want to do it, carry on. If you want to listen to me and I'll tell you the truth about my background. I died twice in that hospital, and I come around.

00:27:10 **Cathy Beresford**

Yeah, gosh, so they had to resuscitate you?

00:27:14 **PWLD04**

No, I come round on my own.

00:27:17 **Cathy Beresford**

Right. OK.

00:27:20 **Cathy Beresford**

Say that again. You had. You did what?

00:27:21 **PWLD04**

I got to the gates of heaven.

00:27:25 **Cathy Beresford**

Oh, OK, yeah.

00:27:29 **PWLD04**

I got there and my dad was there. And he said, ‘son, what the hell are you doing with yourself?’ he said, ‘you get down there and you look after them boys.’

00:27:38 **Cathy Beresford**

Yeah.

00:27:39 **PWLD04**

And I just opened me eyes then.

00:27:42 **Cathy Beresford**

Yeah, yeah.

00:27:52 **PWLD04**

The following morning, my mum came, and she says, ‘did you see your dad yesterday?’ I says, ‘yeah’. She says, ‘yeah he come and told me, he moved the covers, the covers over, gave me a kiss and that and said “it's gonna be OK”.’ But he’s up there now [in heaven].

00:28:00 **Cathy Beresford**

Yeah.

Yeah.

You know if if is there any advice that you would give to professionals like you know, doctors and nurses and other professionals, is there any advice you would give them to be able to support people who've got advanced liver disease?

00:28:24 **PWLD04**

No, there's not really, because when you get to these, that all they can do is do so much to look after you. You’ve got to actually help yourself. Instead of laying there, and feeling sorry for yourself, you can't expect them to just basically, how can I put it, them to come and help you 24/7. You gotta help yourself.

00:28:51 **Cathy Beresford**

Yeah, yes. Yeah, I understand what you're saying. Yeah. So, you feel that it’s from the person themselves that has to take take -

00:29:01 **PWLD04**

Yeah. That's why, you know, you can't just sit back and let everybody do it. It's just. You know, they’re not gonna be there all the time are they.

00:29:11 **Cathy Beresford**

No. Yeah.

00:29:14 **PWLD04**

They’re the professionals, they did a good job. Don’t they, you know.

00:29:18 **Cathy Beresford**

Yeah.

Yeah.

Yeah.

00:29:34 **PWLD04**

Yeah, you're out sort of thing right now [inaudible]

00:29:37 **Cathy Beresford**

Yes.

00:29:39 **PWLD04**

Do all your medication and all that sort of stuff. So, I was taking all these tablets, but they won’t do my liver any good. They said, we wouldn’t give them to you [unless you needed them] I was on 32 tablets a day.

00:29:41 **Cathy Beresford**

32?

00:29:50 **PWLD04**

32 tablets a day I was on, so now I’m taking about 15 tablets a day now.

00:29:53 **Cathy Beresford**

So, they've got it down to 15 a day?

00:29:57 **PWLD04**

Yeah, yeah, it's just. I've been doing what they are telling me to do. Yeah.

00:30:01 **Cathy Beresford**

Oh, I see. Yeah, so, you mean you've, you've been taking the advice that the doctors and nurses have given you.

00:30:10 **PWLD04**

You've go to. You’ve got to take it seriously. It’s your life isn’t it, you know.

00:30:12 **Cathy Beresford**

Yeah.

Yeah, I understand.

00:30:17 **PWLD04**

You can’t think I’ll take this one now, I'll take this one later on and all that sort of nonsense.

00:30:22 **Cathy Beresford**

Yeah, yeah, yeah.

And is there anything else that you think I should know to understand your experience of the care that you've had for your liver disease better?

00:30:35 **PWLD04**

Well. Yes, it is a very serious disease, and I would never get in that state again. Never, ever.

00:30:41 **Cathy Beresford**

Yeah.

Yeah.

00:30:49 **PWLD04**

To see your children, you know. And they’re like in a room. The kids can’t even see you or give you a kiss and they couldn’t even touch you; you know. And they was getting upset. You know.

00:31:02 **Cathy Beresford**

Yeah.

00:31:03 **PWLD04**

And I said to the nurse, I can’t cope with this no more.

I said, ‘can you give me the injection to put me to sleep’.

00:31:15 **Cathy Beresford**

Yeah.

00:31:18 **PWLD04**

I felt that ill. And she said, ‘[name of PWLD04], it’s coming off tomorrow’.

*[inaudible]*

00:31:21 **Cathy Beresford**

Yeah.

00:31:23 **PWLD04**

It was a horrible experience; I wouldn’t wish it on my worst enemy. [when he was critically ill]

00:31:31 **Cathy Beresford**

Yeah.

No.

00:31:40 **Cathy Beresford**

One one thing I wondered was whether you before this happened to you, did you really know very much about liver disease before?

00:31:54 **PWLD04**

No, I didn’t have a clue.

00:31:54 **Cathy Beresford**

Yeah.

00:31:57 **PWLD04**

It was only when my friend saw my leg and he said, ‘you’ve got water on one side of your leg [inaudible], you wanna get that sorted.’ So, I thought, right I’d better go down the doctors. That’s it, no more drinking, no more smoking or nothing like that. But you’ve got to change your lifestyle, you know.

00:32:05 **Cathy Beresford**

Yeah.

Yeah, yeah.

00:32:17 **PWLD04**

But some people can’t do that.

00:32:20 **Cathy Beresford**

Yeah.

No, I know.

00:32:36 **PWLD04**

You’ve got to do it yourself, ‘cause noone’s gonna help you, you know.

00:32:38 **Cathy Beresford**

Yeah.

Yeah.

Yeah. You know, when we've been talking about this, sometimes it can prompt thoughts in your mind that you hadn't really thought about before. Does anything that spring to mind when I say that?

00:32:55 **PWLD04**

Not really, no.

00:32:58 **Cathy Beresford**

Yeah.

And is there anything you'd like to ask me?

00:33:04 **PWLD04**

Not really, no.

00:33:06 **Cathy Beresford**

No, you've given, you know you've given me a lot of information and insight you know, into everything that you've been through, and I mean, my impression is that it happened quite suddenly, in a way.

00:33:21 **PWLD04**

Yeah. Oh, it did yeah.

00:33:23 **Cathy Beresford**

And you didn't.

00:33:23 **PWLD04**

Yeah, ‘cause you’re out with your mates one night, and you’re on the beer. And the next you wake up [inaudible]

00:33:24 **Cathy Beresford**

Yeah.

Yeah, yeah.

00:33:39 **PWLD04**

You're in trouble, really.

00:33:43 **Cathy Beresford**

Yeah.

00:33:45 **PWLD04**

*[inaudible].* It was terrible.

00:33:47 **Cathy Beresford**

And have you have you, since that first time in hospital, have you had to go back and stay in hospital at all?

00:33:57 **PWLD04**

Oh yeah, quite a few times.

00:33:59 **Cathy Beresford**

Yeah.

00:34:00 **Cathy Beresford**

So, when was the when was the last time?

00:34:05 **PWLD04**

I think it was about 12 months ago.

00:34:07 **Cathy Beresford**

Yeah, so not not recently.

00:34:11 **PWLD04**

No, no, no, no. I’d got a water infection.

00:34:15 **Cathy Beresford**

Yeah, yeah.

00:34:17 **PWLD04**

[inaudible] affecting me in all sorts of different ways.

00:34:22 **Cathy Beresford**

Yeah.

00:34:26 **PWLD04**

I said, ‘water infection, would it do that?’ and she said ‘yeah because you -‘ I’d got ten blood transfusions while I was in there because I had more alcohol than blood in my system see.

00:34:38 **Cathy Beresford**

Yeah, you've been through a lot you've been through a lot, haven't you?

00:34:44 **PWLD04**

Oh yeah.

00:34:50 **Cathy Beresford**

Just before I finish just one thing. I wondered that. You I'm quite interested to hear your perspective on this. So, I'm I have I am managing to interview enough people now, but I have found it quite hard to reach people who've got advanced liver disease to talk to them about their experiences. And I just wonder if you've got any views on that?

00:35:17 **PWLD04**

Ohh no, not really. It's just you're doing this to yourself, aren't you? You’re taking a substance, and you can’t really say, you know. ‘Cause you’re all enjoying yourself ain’t we? *[I’m not quite sure what he means here. Perhaps, that people are preoccupied so that might be why they don’t want to speak with me].*

You get too much of it *[inaudible],* that’s all I can say.

00:35:32 **Cathy Beresford**

Yeah.

Yeah. Yeah. So that's OK. I don't need to ask you any more questions unless there's anything else you want to add.

00:35:52 **PWLD04**

No, there's nothing at all.

00:35:55 **Cathy Beresford**

So, what I have to do is as I told you I was recording it, so I have to it, put it into the computer and then it comes out as a typed-out words and so that's the interview transcript. Would you like me to post you a copy of the interview transcript?

00:36:16 **PWLD04**

No, it should be all right.

00:36:18 **Cathy Beresford**

OK, that's fine. That's OK. That's fine. And towards the end of the year, I'll write up a little summary of what I've been finding so far. Would you like me to send that to you so you can just find out a bit more?

00:36:21 **PWLD04**

Alright.

00:36:34 **Cathy Beresford**

About what I've found.

00:36:37 **PWLD04**

Yeah. Ok then. Yeah.

00:36:41 **Cathy Beresford**

Are you happy for me to end the interview now?

00:36:45 **PWLD04**

Yeah, no problem.

00:36:48 **Cathy Beresford**

Thank you so much for agreeing to talk to me so openly and to share your experiences, because I really do appreciate it.

00:36:58 **PWLD04**

No problem.

00:36:59 **Cathy Beresford**

It was good to talk to you and I hope you have, you know, good luck with everything.

00:37:08 **PWLD04**

Yeah. Yes. If you think lucky, you will be lucky. Think positive, you will be positive.

00:37:12 **Cathy Beresford**

Think positive.

00:37:15 **PWLD04**

Alright.

00:37:17 **Cathy Beresford**

Take care. Thank you. Bye bye.