# PWLD06 ‘Kevin’ – Transcript

# Interview 7th June 2024 by telephone at 12:00 (39 minutes).

00:00:00 **Cathy Beresford**

Just to say that anything I ask you, first of all, everything that's voluntary, so, you know if there's anything I ask and you don't want to answer, that's absolutely fine. Just say oh I'd rather not answer that or if there's anything that doesn't make any sense or you want me to rephrase it again, just say you know it every. It's entirely up to you how much you decide to say.

00:00:20 **Cathy Beresford**

And if you need a break at any point, again just just say because I know sometimes talking about some of these things can be quite difficult for people.

00:00:30 **Cathy Beresford**

And you know, I just genuinely appreciate you giving up, giving your time.

00:00:37 **PWLD06**

OK. Yeah.

00:00:39 **Cathy Beresford**

Fine, you know, So, we we can do, we can do as much as you as you're able to. And if you say to me, actually, I I can't do anymore then that is fine. Or if you wanna take a break then that's fine as well. OK.

00:00:51 **PWLD06**

Yeah.

00:00:52 **Cathy Beresford**

Thank you so much.

00:00:53 **Cathy Beresford**

Right. So, again, this is voluntary, but so that I can be clear with when I'm reporting on the data and and who I've been interviewing.

00:01:04 **Cathy Beresford**

Are you willing to tell me how old you are?

00:01:07 **PWLD06**

[states age].

00:01:08 **Cathy Beresford**

Thank you. And and what ethnicity do you consider yourself to be?

**PWLD06**

[states ethnicity].

00:01:18 **Cathy Beresford**

Thank you. OK. So, to start off with, can you tell me about your journey of receiving care since you found out that you have got liver disease?

00:01:25 **PWLD06**

From initially being diagnosed?

00:01:27 **Cathy Beresford**

Yeah, yeah, that would be good.

00:01:29 **PWLD06**

Basically, I had a problem with alcohol. I stopped drinking in June ‘22.

00:01:34 **Cathy Beresford**

Yeah.

00:01:37 **Cathy Beresford**

Yeah.

00:01:39 **PWLD06**

It had gone on for quite a long time prior to that with problems and trying to stop. I just could not get the help I needed. The GPs wouldn't prescribe the medication for withdrawal.

00:01:44 **Cathy Beresford**

Yeah.

00:01:46 **Cathy Beresford**

Right.

00:01:50 **Cathy Beresford**

OK.

00:01:51 **PWLD06**

And I'd go to hospital with problems with, like alcohol withdrawal. They’d basically treat us and send us home, and I was like well what do I do now?

00:01:55 **Cathy Beresford**

Yeah.

00:01:57 **Cathy Beresford**

Yeah.

00:01:59 **Cathy Beresford**

Yeah.

00:02:00 **PWLD06**

Speak to the GP and they wouldn't help. Just big vicious circle, and I'd already asked for help through with the alcohol services, but there was a huge backlog like covid was still *[inaudible]* remember, right?

00:02:04 **Cathy Beresford**

Right.

00:02:09 **Cathy Beresford**

Yes.

00:02:12 **PWLD06**

That's one thing you have to bear with us when the memory is not the best.

00:02:14 **Cathy Beresford**

Sure, sure.

00:02:17 **PWLD06**

Eventually, I had ascites and jaundice. I'd been to the hospital and there was like a 10 hour wait to be seen or something and I just discharged myself and went and the guy’d ring us several hours later and said: listen you’re going to have to come in.

00:02:25 **Cathy Beresford**

Gosh.

00:02:32 **Cathy Beresford**

Yeah.

00:02:34 **Cathy Beresford**

Yeah.

00:02:37 **PWLD06**

Said: you’ll have to wait like hours when you get here for a bed and stuff.

00:02:39 **Cathy Beresford**

Really.

00:02:41 **PWLD06**

Eventually I got to talk to me GP and they spoke to the GP as well and actually get into the [name of hospital] I got admitted straight away.

00:02:46 **PWLD06**

Yeah.

00:02:49 **Cathy Beresford**

Yeah. So, when roughly when was that?

00:02:51 **PWLD06**

That was June 2022.

00:02:52 **Cathy Beresford**

OK. Yeah. So, it's not really been all that long has it.

00:02:56 **PWLD06**

Two years.

00:02:57 **Cathy Beresford**

Yeah. So, it was, it was basically as a as an emergency that that you first found out?

00:03:03 **PWLD06**

I already knew I haven't had a problem.

00:03:05 **PWLD06**

Yeah, I had liver fibrosis I already knew I had that but it's it was a horrible time at that time. My brother died, and different things were going on. That's when I first got admitted back in June ‘22.

00:03:21 **Cathy Beresford**

Yeah, yeah, yeah.

And then tell me what happened, sort of after that then.

00:03:27 **PWLD06**

I got the alcohol medication. Obviously, they did blood tests and different things.

00:03:40 **Cathy Beresford**

Yeah.

00:03:41 **PWLD06**

But I.

00:03:41 **PWLD06**

Didn't get the drain done then, I got that done just four days after I got discharged. That's more because of me. They want to keep me longer, but I had funeral to go to or something so, I kind of wanted to get out.

00:03:48 **Cathy Beresford**

Yeah.

00:03:52 **Cathy Beresford**

Oh, I see.

00:03:55 **PWLD06**

Yeah. Yeah.

00:03:58 **Cathy Beresford**

And and what services have you been able to access then for care in relation to your liver disease?

00:04:05 **PWLD06**

And just the liver nurses first at the [*name of hospital]*.

00:04:11 **Cathy Beresford**

So, you have the liver nurses, any other healthcare professionals that you see?

00:04:16 **PWLD06**

GP, but that’s quite limited.

00:04:17 **Cathy Beresford**

Yeah.

00:04:20 **PWLD06**

Yeah, and also, it's kind of specialist.

00:04:22 **Cathy Beresford**

And you mentioned the drug and alcohol service team. Are are you involved with them at this time or have you been?

00:04:28 **PWLD06**

That that was a funny thing, but I actually got an appointment, but I’d stopped.

00:04:32 **PWLD06**

I had one appointment with them and they was like: I don't really know why you’re here for. And I was like, well I did need your help but it’s a bit late now.

00:04:36 **Cathy Beresford**

Right. Oh, I see. I get you. So. So, when you think about the services that you that you've been able to access since you were diagnosed with liver disease, what works well for you?

00:04:49 **PWLD06**

I know the the [British] Liver Trust was really helpful, that I would say that was probably the most helpful thing, to be honest.

00:04:55 **Cathy Beresford**

Really.

00:04:56 **PWLD06**

Speaking to other people, they were the same position. Similar positions to yourself.

00:05:00 **Cathy Beresford**

Yeah.

00:05:02 **Cathy Beresford**

So. So, what - Tell me a bit more about that.

00:05:05 **PWLD06**

Just like the Zoom meetings, there's different ones. There's like ones for alcohol. There's like, like a general one, there's ones - It depends what category you fit in. I kind of fit it in several different ones.

00:05:16 **Cathy Beresford**

And how how did you find out about it?

00:05:20 **PWLD06**

Err, research.

00:05:21 **Cathy Beresford**

What you you found out about yourself?

00:05:24 **PWLD06**

Yeah, I wasn't really signposted towards it or anything. I really no, I can't. I don't think they gives a leaflet in the hospital from what I can remember. I just googled it.

00:05:32 **Cathy Beresford**

OK.

00:05:37 **Cathy Beresford**

And and so, thinking about the services that you access then, what doesn't work so well for you?

00:05:44 **PWLD06**

It's it's quite hard to talk about it really because there’s very little in the way of services to really comment on.

00:05:51 **Cathy Beresford**

Right. Is that what you found?

00:05:52 **PWLD06**

Yeah, yeah, there's not really – I have found you have to be kind of more proactive yourself to be honest,

**Cathy Beresford**

Oh, do you? Yeah. In what sort of way?

00:06:03 **PWLD06**

Just like generally looking online to see what there is because you don't really get much information. I mean, I wasn’t aware of LIVErNORTH at all. That was through a friend who goes on the Zoom meetings with the [British] Liver Trust that made us aware of them. But I don't really have anything to do with them [LIVErNORTH]. It's just like I keep an eye on the feed, and the news.

00:06:10 **Cathy Beresford**

Right.

00:06:15 **Cathy Beresford**

Yeah, yeah.

00:06:25 **PWLD06**

Like if there's any – Because – how it all come about, she made us aware. I had a look at it, just to see what kind of things they did and the person who was in charge of it. I was having problems with the care of the [name of hospital] and I contracted LIVErNORTH to ask their advice.

00:06:32 **Cathy Beresford**

Yes.

00:06:40 **Cathy Beresford**

Yeah.

00:06:41 **PWLD06**

Because I wanted to transfer with the [name of other hospital], it was that that was basically the only contact really with them.

00:06:48 **Cathy Beresford**

Really.

00:06:50 **PWLD06**

Just see if there's any talks on that.

00:06:51 **Cathy Beresford**

Sure.

00:06:53 **Cathy Beresford**

So, you mentioned that there's a a liver nurse and and and and also, the GP then. So, tell me a bit more about how you know, what what they have done, or what you or you know how you access them, anything to do with them really.

00:07:10 **PWLD06**

GP's, like I say, they don't - my personal, from my personal opinion, this is from being with GP, doctors, like people down the hospital themselves, in general, people that aren't specialists in that area, it's very, very stigmatised.

00:07:24 **Cathy Beresford**

Right. OK.

00:07:26 **PWLD06**

It's like it gets discussed. All that matter - it's basically it's your stupid fault part that nobody pours it [alcohol] down your neck type thing, which I find quite alarming.

00:07:32 **Cathy Beresford**

I see.

00:07:35 **PWLD06**

Yeah.

00:07:36 **Cathy Beresford**

So, you're saying that that's with the ones that are not specialists?

00:07:41 **PWLD06**

I would say yeah, but definitely that's most of what it is. Tends - I don't know if it’s just something I pick up on but older, a lot of the older GP type people.

00:07:50 **Cathy Beresford**

I see.

00:07:53 **PWLD06**

Yeah.

00:07:55 **PWLD06**

It's just one of these things. I mean, I know people who it hasn't even been caused by alcohol and the kind of people make the assumption here and you think it's alcohol.

00:08:01 **Cathy Beresford**

Sure, sure. Yeah.

00:08:04 **PWLD06**

Which fair enough, mine is, but lots of people I know is have that kind of stigma. And and and I mean it's being genetic or various different things.

00:08:15 **Cathy Beresford**

Yeah.

And, are you still going up to a clinic at the hospital where you see the nurse or something like that?

00:08:21 **PWLD06**

I don't actually have a liver nurse now with the [name of other hospital]. They don't even have one.

00:08:24 **Cathy Beresford**

Oh, right. Oh, OK.

00:08:26 **PWLD06**

I'm. I'm not. I'm really - bearing in mind the [name of other hospital] are specialist hepatology hospital. They’re one of the best in the country anyway. I find that that's something I'm not happy with personally. It's just like there's no point of contact.

00:08:30 **Cathy Beresford**

Yes.

00:08:34 **Cathy Beresford**

Yeah.

00:08:40 **Cathy Beresford**

Isn't there?

00:08:41 **PWLD06**

No, it's like. The only work Tuesday or Thursday my consultant, the secretary for her. So, it's actually an absolute nightmare to contact anybody.

00:08:47 **Cathy Beresford**

Yeah.

00:08:52 **Cathy Beresford**

Oh, OK.

00:08:53 **PWLD06**

Oh, it's horrendous.

00:08:54 **Cathy Beresford**

Yeah, that sounds hard.

00:08:55 **PWLD06**

It was actually better at the [name of the first hospital].

00:08:58 **Cathy Beresford**

Well, so, with all of that in mind then, at the moment if you do need you know, support or advice about your liver disease where, where would you go then?

00:09:06 **PWLD06**

It's quite complicated. Normally the GP then ends up getting the brunt of it and or if it's something more urgent trying to contact the [name of other hospital], where if you ring the number you'd normally ring. It says: I'm not obviously if it's a Friday, I'm not currently in. Try this number and this number try just like passing the parcels, just like.

00:09:22 **Cathy Beresford**

Yes.

00:09:24 **Cathy Beresford**

Yeah, yeah.

00:09:27 **Cathy Beresford**

And so, thinking about everything you've been through over the last couple of years then, have you got any specific examples of when you think the care you've received for your liver disease has been particularly positive for you?

00:09:38 **PWLD06**

Like I say initially with the liver nurses that was it was good, the fact they had a number if you couldn't get them straight on, you left a message if they thought it was urgent they’d ring you back.

**Cathy Beresford**

Yes.

00:09:49 **PWLD06**

Yeah, that was quite good. You’d say that was fine. The the only issues I have with [name of hospital] was things getting forgetting to get done.

00:09:50 **Cathy Beresford**

Yeah.

00:09:56 **Cathy Beresford**

Right.

00:09:59 **PWLD06**

I'm a very complex patient in terms of I've got lots of other things going on, some of those because of that. Other things being knock on effect and some things that just don’t know yet.

00:10:07 **Cathy Beresford**

Yeah.

00:10:09 **PWLD06**

Yeah.

00:10:12 **PWLD06**

So, it's it is complicated, but it's just like problems with chronic pain. And when I initially got diagnosed, that I was getting the pain was nothing then compared to now. But,

00:10:23 **PWLD06**

Yeah.

00:10:25 **PWLD06**

Like pain management and they got that was like saying it was August, September, I got referred apparently.

00:10:27 **Cathy Beresford**

Yeah.

00:10:34

Hmm.

00:10:34 **PWLD06**

And then I asked erm, me next appointment was say was September, October.

00:10:39 **Cathy Beresford**

Yeah.

00:10:41 **PWLD06**

Well, actually I think it was Christmas I mentioned it again, it was around that time, and I asked in terms of like whether it being what was happening with the referral, she says: what referral? I was like with the pain management. And she was like, I haven't referred you for pain management. So, just it's taken till January this year to actually see them.

00:10:53 **Cathy Beresford**

Oh, OK.

00:11:01 **PWLD06**

From like the back end of June, the back end of ‘22.

00:11:03 **Cathy Beresford**

Yeah.

00:11:06 **Cathy Beresford**

And was the pain related to the liver disease or was that something else extra different things?

00:11:09 **PWLD06**

That's a mix of different things. Peripheral neuropathy, which you'll be familiar with with diabetes background, but obviously me liver itself, joints throughout me body All sorts of different things.

00:11:12 **Cathy Beresford**

Mm-hmm.

00:11:14 **Cathy Beresford**

Yes, yes.

00:11:24 **Cathy Beresford**

So.

00:11:24 **PWLD06**

Yeah, I've got more specialists and it's ridiculous.

00:11:29 **Cathy Beresford**

Yeah, it sounds like you're going through quite a lot.

00:11:32 **PWLD06**

But it's – I have seizures as well, but.

00:11:34 **Cathy Beresford**

Do you.

00:11:36 **PWLD06**

That starts straight after the first course of injections, whether that's coincidence. They'll say that they'll say it's nothing to do with it, you know, never have one in me life and it's started about 15 minutes after.

00:11:48 **Cathy Beresford**

Right.

00:11:49 **PWLD06**

So.

00:11:50 **Cathy Beresford**

OK, so, so, so, then, OK, so, so, you found it. Really. You found it helpful when you have the liver nurse as a point of contact. So, on the other side of the coin then does anything sort of stand out in your mind when you think that the the care that you received for your liver disease has been particularly negative for you?

00:12:09 **PWLD06**

That's just, for me there needs to be more of an approach or a central point of contact like that.

00:12:15 **Cathy Beresford**

Yeah.

00:12:17 **PWLD06**

Because I find a lot of that just kind of gets forgotten about. I’m not kept in the loop about anything.

00:12:20 **Cathy Beresford**

Right.

Yeah, yeah.

00:12:23 **PWLD06**

And it's - I mean to actually speak to a consultant. Even at the [name of hospital] was – they would say I’ll pass it on in, but I never heard nothing else. Constantly chasing all the time.

00:12:31 **Cathy Beresford**

So, you are you, are you due to have any follow-up with them with the the hospital where you're at now, with the specialist consultant then?

00:12:40 **PWLD06**

This is the next issue since I transferred to them, it was my first appointment was either December last year or January this year. I can't remember exactly what it was. I mean, this appointment they didn't have any of me notes, obviously got there.

00:12:50 **Cathy Beresford**

Yeah.

00:12:56 **PWLD06**

Do it yourself. Go through everything to them because they haven't been transferred over properly - the notes. Or she couldn’t access them. Whichever way it was.

00:12:59 **Cathy Beresford**

Yeah.

The appointment was fine. And then I had one recently, very recently. It was the last few weeks where – it’s like every six months. I had loads of questions, I had prior contact with them for weeks before with things that I had going on that I want to raise with them. They said, oh it’ll be addressed in clinic. Um, went in

00:13:19 **Cathy Beresford**

Yeah.

00:13:22 **Cathy Beresford**

Yes.

00:13:27 **PWLD06**

And I've seen junior doctor, you, or basically not a fully qualified consultant in 5 minutes and all they were interested in was a trial and I never got to ask anything they didn’t address anything I wanted or. The GP wouldn't help us. Basically, they said it's not our job, it's theirs. There's like the fact that I got told that it would be addressed in clinic.

00:13:39 **Cathy Beresford**

OK.

00:13: **Cathy Beresford**

Yeah, yeah.

00:13:49 **PWLD06**

And the symptoms – I don’t know if you've ever heard about hepatic encephalopathy?

00:13:52 **Cathy Beresford**

Yes, I have.

00:13:55 **PWLD06**

It’s symptoms around that, confusion, memory problems.

00:13:57 **Cathy Beresford**

Yes.

00:14:00 **Cathy Beresford**

Yeah.

00:14:00 **PWLD06**

Character changes. Things like that, it's quite an important thing.

00:14:02 **Cathy Beresford**

That is important. So, and have you have you had an opportunity to address it with anybody subsequently?

00:14:09 **PWLD06**

No, I raised it with PALS. I’ve had substantive healthcare, so I’ve raised it with them. They’ve apologised and I’ve got an appointment for this Monday coming.

00:14:11 **Cathy Beresford**

Oh, I see.

00:14:17 **Cathy Beresford**

Right. So, you've got. OK, that's interesting. So, that that kind of relates back to what you were saying about being proactive, doesn't it?

00:14:24 **PWLD06**

I know a lot of people would have just said it doesn’t matter and would have just carried on. I've I've had that much bother with different - It's like and also, I know it’s not relevant in this particular - neurology with the numbness. It's got just my feet. When I was diagnosed.

00:14:35 **Cathy Beresford**

Yeah.

00:14:37 **PWLD06**

But that that it would normally stay just where it is once you stop drinking, if you understand what I mean. But it hasn't. I've got it like halfway up me thighs. It affects me hands, affects me balance, coordination, pain, and neurology I had an appointment recently and basically got the letter back.

00:14:40 **Cathy Beresford**

Yeah.

00:14:56 **PWLD06**

And most of it was lies.

It’s like, I checked this, and I was like hang on, I didn't even take me trousers off.

00:15:03 **Cathy Beresford**

Yeah.

00:15:04 **PWLD06**

So, I had to contact PALS about that one. I’ve had great, great experience of a pain management.

00:15:06 **Cathy Beresford**

Yeah, yeah.

00:15:11 **Cathy Beresford**

Oh yeah.

00:15:12 **PWLD06**

Yes, at the Trust that was, she was very helpful.

00:15:14 **Cathy Beresford**

Really.

00:15:15 **PWLD06**

You know you can't actually help us with the pain at the end of the day be quite limited because obviously most pain killers are processed by the liver. So, you are quite limited. But she was very helpful, and I just had a one with [different department ?falls – couldn’t quite hear] which he was very good but just there’s so much crossover all the different conditions, because me blood pressure I have problems with

00:15:18 **Cathy Beresford**

Yes.

00:15:37 **Cathy Beresford**

Yes.

00:15:40 **Cathy Beresford**

Yeah.

00:15:41 **PWLD06**

Which has taken till now, two years. Because I've been complaining about collapsing and and feeling dizzy and not well.

00:15:48 **Cathy Beresford**

Yeah.

00:15:49 **PWLD06**

To be fair, that GP done blood pressure, you know, 24-hour test.

00:15:53 **Cathy Beresford**

Oh yeah.

00:15:54 **PWLD06**

That didn't show anything extremely out of the ordinary.

00:15:58 **Cathy Beresford**

Yeah.

00:15:58 **PWLD06**

But they done a tilt-table test on this last appointment and that showed me blood pressure plummets when I stand up, it doesn't fully recover.

00:16:04 **Cathy Beresford**

Oh, I see.

00:16:06 **Cathy Beresford**

Yeah.

00:16:07 **PWLD06**

They’re saying this is some kind of autonomic dysfunction, essentially. They don’t know whether it's the liver causing it. I’m getting genetic testing as well.

00:16:15 **Cathy Beresford**

Right. Yes. You certainly have got a lot going on, haven't you?

00:16:20 **PWLD06**

It's just nobody seems to know what's, because it's all different specialties, So, it's nobody seems to hear - talk to each other. They kind of know what might be causing it.

00:16:23 **Cathy Beresford**

Hmm.

00:16:32 **Cathy Beresford**

So, sort of thinking about how, you know, everything's been going on over the last couple of years, who's been most helpful to you during this time?

00:16:42 **PWLD06**

I’d say initially and up until I transferred [hospitals] probably the liver nurses to be fair. I always find the the first kind of line contacts tend to be the the best generally.

00:16:56 **Cathy Beresford**

Yeah, yeah. What about outside of sort of healthcare? Do you have anybody else that's that helps you out?

00:17:05 **PWLD06**

I have a carer. That’s me partner.

00:17:05 **Cathy Beresford**

Hmm.

00:17:10 **PWLD06**

No, not really, no.

00:17:11 **Cathy Beresford**

Yeah, yeah. So, after having all these experiences of care, what advice would you give to somebody who's discovered that they've got advanced liver disease?

00:17:25 **PWLD06**

Erm, it's quite hard, you shouldn’t have to do it yourself. The first thing I'd do is contact the Liver Trust.

00:17:31 **Cathy Beresford**

Yeah.

00:17:34 **PWLD06**

They’ve got nurses that you can ring up, speak to, and then they'll know what what there is about. Explain how to contact PALS.

00:17:39 **Cathy Beresford**

Yes.

00:17:43 **Cathy Beresford**

Yeah.

00:17:45 **PWLD06**

Are you are you aware of this organisation where you contact your, maybe your housing or care and talk about social prescribing and different things that I wasn't aware of any of these thibgs.

00:17:50 **Cathy Beresford**

Hmm.

00:17:55 **Cathy Beresford**

I see, yeah.

00:17:57 **PWLD06**

Even the GP surgery happen towards social prescribing, which can help you with various different things.

00:18:03 **Cathy Beresford**

Yeah, that's helpful to know.

00:18:06 **Cathy Beresford**

And what about thinking about, well, based on your experiences of care, what, what would you - what advice would you give to professionals who work with individuals who've got advanced liver disease?

**PWLD06**

What as carers?

00:18:21 **Cathy Beresford**

Yeah, So, if you're.

00:18:22 **Cathy Beresford**

Thinking about based on everything you've been through and if you could sort of have some influence and say in how people are are working with individuals in your sort of situation, what what would you sort of say to them?

00:18:37 **PWLD06**

Just there's gotta be more joined up. You gotta keep the patient kind of involved throughout again. And what's happening, why it's happening.

00:18:42 **PWLD06**

Yeah.

00:18:45 **PWLD06**

Yeah.

00:18:46 **PWLD06**

And things like that and actually listen because like half the time they don't.

00:18:47 **Cathy Beresford**

Yeah.

00:18:50 **Cathy Beresford**

do you?

00:18:52 **PWLD06**

That's my personal opinion.

00:18:53 **Cathy Beresford**

Tell me a bit more about that.

00:18:55 **PWLD06**

Where it's just I had several different liver nurses at the [name of hospital] and the first one I had I think she's more senior one. She was she's brilliant, but the ones I'd after that were not so good.

00:19:04 **Cathy Beresford**

Hmm.

00:19:08 **Cathy Beresford**

Right. OK. Yeah.

00:19:11 **PWLD06**

I mean, they've got an alcohol nurse and a lot of it back then was a bit of a blur, to be honest.

00:19:19 **PWLD06**

I've seen her just prior to not that long before I got admitted.

00:19:23 **PWLD06**

Yeah, I've seen it that long before I finished me care there. She was like, I didn’t even think you’d be here.

00:19:33 **Cathy Beresford**

Yeah.

00:19:37 **PWLD06**

That was the only other contact that I had with her.

00:19:39 **PWLD06**

Even if you’ve stopped drinking, you might need more help. But the thing is, once you stop, you don't get help.

00:19:43 **Cathy Beresford**

I see.

00:19:43 **PWLD06**

They don't. They don't realise that you - treating the problems that caused it in the 1st place. Do you understand what I mean? ‘cause you don't get any kind of mental mean, obviously you don't get any help towards the prognosis going forward.

00:19:48 **Cathy Beresford**

Yes.

00:19:57 **Cathy Beresford**

I'm with you, don't you?

00:19:59 **PWLD06**

You don't get any mental health help.

00:20:01 **Cathy Beresford**

Don't you?

00:20:02 **PWLD06**

Because you've got a lot of questions like.

00:20:05 **PWLD06**

Which you just don't have answers to. That's my really my biggest problem.

00:20:07 **Cathy Beresford**

Yeah.

Is it?

00:20:10 **PWLD06**

I just kind of didn't know where to turn. I mean, I'm just thinking have I got six months to live? Can I have a transplant? Can I not? I don’t know.

00:20:18 **Cathy Beresford**

So, have you had an opportunity to discuss any of those questions with anybody?

00:20:24 **PWLD06**

Erm, you could raise them yourself kind of with a liver nurse, but obviously it is a uncertain prognosis because you can't say you've got six months or a year.

00:20:30 **Cathy Beresford**

Yes.

00:20:33 **Cathy Beresford**

I see.

00:20:34 **PWLD06**

Etcetera. It. It does vary wildly between different people.

00:20:37 **Cathy Beresford**

Yeah.

00:20:38 **PWLD06**

But, you don't get any information that you can take away with you or you should get some kind of counselling.

00:20:41 **Cathy Beresford**

Don't you?

00:20:43 **PWLD06**

So.

00:20:44 **PWLD06**

Yeah, but be more more towards various conditions towards called clinical psychology and I got told there wasn’t the funding for it. That's what they actually said it was at the [name of hospital].

00:20:55 **Cathy Beresford**

Oh, right.

00:20:58 **Cathy Beresford**

I see. So, you that that's something that if you had the opportunity to have, you would like that, would you?

00:21:04 **PWLD06**

Yeah.

00:21:06 **PWLD06**

But I spoke to PALS about this and they should not have said that to you. Yeah, that's just wrong.

And I can only tell you what I was told.

00:21:13 **Cathy Beresford**

Yeah.

00:21:14 **PWLD06**

I was like, I've got multiple health conditions which affect me day-to-day life, and I'm not getting any support. The only thing I got self-referral was Talking Therapies and it's horrendous.

**Cathy Beresford**

Really?

**PWLD06**

I've, I've had it before. It's not targeted for this type of thing.

00:21:30 **Cathy Beresford**

Oh, I see. Yeah, I'm with you. Yeah.

00:21:32 **PWLD06**

It's more to me, mild depression and anxiety.

00:21:36 **PWLD06**

It's not, even though he's referred as just to back on the wait list, just for counselling, he says this isn't relevant to you, it's too complex for me.

00:21:43 **Cathy Beresford**

Right, I see.

00:21:47 **Cathy Beresford**

Yeah. So, it's that more sort of specialist support for somebody like yourself. I see what you're saying.

00:21:54 **PWLD06**

Because like, the social prescriber at the GP surgery was on long term sick. When I contact them, contact them for help they want and then I managed to somehow get the peer-management referral for the clinical psychology in this area, they've got one for the whole area. She's on long term sick.

00:22:10 **Cathy Beresford**

Yes.

00:22:14 **PWLD06**

Yeah.

00:22:14 **PWLD06**

It's just that I know the NHS is struggling.

00:22:16 **Cathy Beresford**

Yeah, yeah.

00:22:17 **PWLD06**

They really are.

00:22:20 **Cathy Beresford**

Yeah. Thank you. That's helpful to understand.

00:22:24 **Cathy Beresford**

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

00:22:32 **PWLD06**

Just everything being like I said, the only way I can put it is being more joined up.

00:22:36 **Cathy Beresford**

Yeah.

00:22:38 **PWLD06**

Where everyone talks to everybody, but it just doesn't, it just doesn't seem to work like that, where you have a central point of contact. I mean to me; you should have some way of contacting the consultant speaking to them.

00:22:44 **Cathy Beresford**

Yeah.

00:22:50 **PWLD06**

But fair enough if there has to be third party it has to be third, third party but I think needs once every six months for the consultant. Unless something drastically changes. I don't think particularly gonna you don't get very long, So, I kind of wrote up information before I went with any questions I wanted to ask and things like that.

00:23:12 **Cathy Beresford**

Yeah, yeah.

00:23:14 **PWLD06**

Because it seems to be the case of you have to ask the information rather than giving you it.

00:23:19 **Cathy Beresford**

Yeah, I I see. Yeah, I I can hear that from what you're telling me.

00:23:26 **PWLD06**

Because unless you research it yourself, you probably wouldn't know a lot of different things. You get your bloods done; you don't really ever find out what they mean.

00:23:34 **Cathy Beresford**

Right.

00:23:37 **Cathy Beresford**

So.

00:23:37 **PWLD06**

You know, every time I meet them, someone says our research and such, I says: what does that mean?

00:23:41 **Cathy Beresford**

Yeah, yeah.

00:23:43 **PWLD06**

To the point where like there's a couple of us who are quite clued up on it now. I have me bloods done, I know what they mean.

00:23:52 **PWLD06**

So, I'm quite medical knowledgeable anyway, I was prior to this, but obviously I've learned a little bit more about it.

**Cathy Beresford**

Yeah,

00:24:04 **PWLD06**

Because everything’s different

00:24:05 **Cathy Beresford**

Yeah.

00:24:10 **PWLD06**

That's because you know yourself how things work, for specific bloods would be like between 40 and 90, that's OK.

00:24:20 **PWLD06**

Well, for one I'll give you an example: me iron level. That would plummet up, go all the way down to the very bottom end and before they’d do anything.

00:24:29 **Cathy Beresford**

Yeah.

00:24:30 **PWLD06**

Rather than being proactive and giving us something to take all the time. If you understand me, stop me actually having to get an infusion done.

00:24:37 **Cathy Beresford**

Yeah.

00:24:38 **PWLD06**

So, I end up having to buy liquid iron to take. Then I wouldn’t have to have the infusion done. So, it's just like, well, why can't they do that?

00:24:40 **Cathy Beresford**

Right.

00:24:45 **Cathy Beresford**

Yeah, yeah.

00:24:47 **PWLD06**

It's just things like that. It's just.

00:24:51 **PWLD06**

Nutrition is another one.

00:24:53 **Cathy Beresford**

Is it?

00:24:54 **PWLD06**

I raised that at the last meeting I had. The five-minute appointment that I got after six months. I raised that and he just said, yeah, yeah, I'll refer. I haven’t been referred. That’s what I am saying. You just have to chase and chase and chase.

00:25:09 **Cathy Beresford**

So, is that a referral to a dietitian?

00:25:12 **PWLD06**

Yeah, well the [name of hospital] just organised that themselves when I was under them. They just said do you want to see a dietitian? I think it was like a few days later or a week later I’ve seen them. I think because I was struggling to eat and then and I was then back then.

00:25:22 **Cathy Beresford**

Oh yes.

00:25:24 **PWLD06**

It was like protein shake thing.

00:25:27 **Cathy Beresford**

Yeah.

00:25:28 **PWLD06**

Which really helped.

00:25:29 **Cathy Beresford**

Did it.

00:25:32 **PWLD06**

But, it’s not even in the letter from the consultation or anything, because you obviously get feedback letter from what was discussed and that's that and the other. And there's no mention of nutrition it.

00:25:39 **Cathy Beresford**

Yeah.

00:25:41 **Cathy Beresford**

Isn't there?

00:25:42 **PWLD06**

No, not the last one, no.

00:25:44 **Cathy Beresford**

No.

00:25:46 **PWLD06**

So, I’m having to buy me own type thing.

00:25:47 **Cathy Beresford**

Yeah, like you said, you, you're you're quite proactive.

00:25:52 **PWLD06**

Yeah, it's the same with medications, because obviously with different, like different departments, My GP will say: right, you'll get neurology [inaudible] here. I'll try and give you duloxetine medication to try and help your pain. And most people, as you would, would take it. And then you go to an appointment, and they say have you got any new medications? Oh, you shouldn't take that. It’s like, oh Jesus.

00:26:20 **PWLD06**

These are medical professionals. They should know this. So now it’s a case of you have to run everything -

00:26:25 **Cathy Beresford**

OK.

00:26:26 **Cathy Beresford**

Yeah.

00:26:27 **PWLD06**

I just think it's the only medications are GP should personally run past the hepatologist if they're not sure because it's the same way this thing would be involved and with the blood pressure problems and I am having to want to try – is it [name of medication]?

00:26:34 **PWLD06**

Yeah.

00:26:42 **Cathy Beresford**

I'm not sure, yeah.

00:26:44 **PWLD06**

And he thinks it's OK, but he's actually said I'm going to run it past them.

00:26:48 **Cathy Beresford**

OK. Yeah, sure. Yeah.

00:26:49 **PWLD06**

Which is the way it should be.

00:26:51 **PWLD06**

It was the same with pain management. There said the only option I think we possibly have is an lidocaine infusion.

00:26:53

Hmm.

00:26:59 **PWLD06**

Which I'm not sure, So, I'll run a past your consultant.

00:27:04 **Cathy Beresford**

Yeah.

00:27:05 **PWLD06**

GPs don't tend to, and some other ones don't either, not just GPs.

00:27:09

Hmm.

00:27:10 **PWLD06**

They just prescribe.

00:27:11 **Cathy Beresford**

Yeah.

00:27:12 **PWLD06**

Well, actually, look, I thought hang on. I'll. I'll look at this now. I'm not quite sure how that.

00:27:18 **Cathy Beresford**

Yeah, yeah.

00:27:19 **PWLD06**

Even paracetamol is funny, I mean you shouldn’t really take paracetamol.

00:27:24 **Cathy Beresford**

I see. Yeah. Because of the liver, yeah.

00:27:26 **PWLD06**

That's what I'm saying, most people take two paracetamol. I can only have one.

00:27:33 **Cathy Beresford**

So, well, you know when we're having this conversation, and obviously there's a lot that we've talked about, sometimes it kind.

00:27:38 **PWLD06**

Yeah.

00:27:40 **Cathy Beresford**

Of.

00:27:40 **Cathy Beresford**

Sparks your your thinking and you sort of think about things that you haven't really thought about before.

00:27:46 **Cathy Beresford**

Is there anything that's occurred to you while we've been talking?

00:27:52 **PWLD06**

Not really, cause this is the kind of conversation I have had with several people before, to be honest.

00:27:56 **Cathy Beresford**

Is it?

00:27:57 **PWLD06**

I’ve had conversations with PALS. I've actually had them with the hospital themselves.

00:28:01 **Cathy Beresford**

Yes.

00:28:05 **PWLD06**

And just speaking to one another, I mean on the meetings, we talk about it and things like that. Where there's been various different parties about it. I my personal opinion, I don't think anything will ever change.

00:28:16 **Cathy Beresford**

Don't you?

00:28:20 **PWLD06**

No. Same as anything, it’s all about funding.

00:28:21 **Cathy Beresford**

And how, what does that make you feel?

00:28:23 **PWLD06**

It's frustrating. It is, but that’s the way the world is isn’t it. I just don't think - because for instance, I had the conversation with a friend who does go on LIVErNORTH and does the Zoom meetings etcetera yesterday and she says they used to have because I said, why don't they and the consultations are - through the hospitals - give you paperwork to do: What works well, what would you like to be improved. To have it like on an ongoing basis?

00:28:49 **Cathy Beresford**

Yes.

00:28:52 **Cathy Beresford**

Yeah.

00:28:53 **PWLD06**

It will help patients, and it'll help them understand what works, what doesn't. She [the friend]. Says they used to do it but they just stopped. Well there you go, that's an example of that.

00:29:03 **Cathy Beresford**

Yeah.

00:29:06 **Cathy Beresford**

I mean, it's interesting what you say because one thing that I have found when I'm talking to people, I mentioned at the beginning [before the interview started], is that there seems to be variation in what services are available to people in different parts of the country.

00:29:23 **PWLD06**

Ohh definitely is.

00:29:24 **Cathy Beresford**

And some some people have access to different support. So, for example, I've spoken to somebody that actually has care through a hospice for their liver disease, and they were very positive about that. But that seems to be unusual.

00:29:43 **PWLD06**

Yeah, without tends to be, I can guarantee that person’s from the southwest probably.

00:29:49 **Cathy Beresford**

They are from the South.

00:29:51 **PWLD06**

Southwest.

00:29:51 **Cathy Beresford**

What makes you - it's not the southwest, but what makes you say that?

00:29:56 **PWLD06**

Well, I just I know most people know from liver groups are from various different areas. It's normally people from Bristol type area, Bournemouth, Southampton.

00:30:01 **Cathy Beresford**

Ah.

Oh, I see. Right

00:30:07 **PWLD06**

It tends to be the case in that that area anyway.

00:30:10 **Cathy Beresford**

So, you've you've noticed regional differences yourself?

00:30:13 **PWLD06**

Yeah. One thing I'll say is don't live in Wales. That's all I’ll say. If you live in Wales your’re pretty screwed because their Healthcare is horrendous.

00:30:22 **Cathy Beresford**

OK. Yeah.

00:30:24 **PWLD06**

That wasn’t the right word to use, but it gets it gets brought up quite often.

00:30:26 **Cathy Beresford**

Now I understand. Yeah, I get what you're saying. Yeah, I get what you're saying. Yeah.

00:30:35 **Cathy Beresford**

So, is there something else that you think I should know to understand your experience of care for liver disease better? I mean, you have given me a lot of really helpful information, but is there anything else you'd like to add?

00:30:47 **PWLD06**

Not off the top of me head. I mean, the hospice thing you’re on about obviously with the person it’s palliative care I’m assuming?

00:30:54 **Cathy Beresford**

Well, actually, you know what, what this particular area, they have a pathway that individuals who've got advanced liver disease, that's where where they've got decompensation, they can then have like dual care, so, they would be under the hospice, but they'd still be under the hospital as well. So, they're still actually getting, you know, like proactive treatment, but they know that they, they know that their life expectancy is shortened because of their condition, but actually they've, they've actually lived longer than they thought they were going to, perhaps because they were getting a lot of support.

00:31:35 **Cathy Beresford**

That was.

00:31:36 **PWLD06**

That's definitely true, yeah, it is. If you're getting good care, you are obviously it is going to improve.

00:31:43

Hmm.

00:31:44 **PWLD06**

Outcomes. The person I'm thinking of when you're talking about this, what you're talking about, it might actually be that person, as far as that, because I can't imagine that there would be that many.

00:31:55 **Cathy Beresford**

It it probably isn't actually thinking about because I know that they're not involved in some of those groups, but so there are, there are people out there. There are services out there, but it's as you're saying yourself as well, from what you know, from the people you know, it varies.

00:32:14 **PWLD06**

Because it's just me is. Think about her care. I mean, she she's recently died ther person I am thinking of and she had access to private, like, more, more private, you know, like detox at the start of our journey. We started at the same time; we met at the Zoom meeting. Here's the difference between what she received to what I received, and most other people receive.

00:32:34 **Cathy Beresford**

Yes.

00:32:34 **Cathy Beresford**

Yes.

00:32:38 **Cathy Beresford**

I see. I see.

00:32:40 **PWLD06**

It does vary wildly. She's like: I had detox like three times, private detox where I went in. *I* never got - I'll have to say there’s nothing like that up there. You've got no chance.

00:32:41 **Cathy Beresford**

Yeah.

00:32:43 **PWLD06**

Yeah.

00:32:54 **Cathy Beresford**

Yeah, yeah. I mean, just a final thought actually as well, is that I have found it quite hard to recruit people to this research, who've got advanced liver disease, and I just wondered if you've got any thoughts about that really?

00:33:14 **PWLD06**

It's it's probably a similar thing to what I've been discussing with me friend a lot, because we're trying to think of ways to help in terms of research going forward and studies and trials because she was asking me the same questions about, I don't know if you've heard the Promise trial [Faecal Microbiota Transplant (FMT) Therapy].

00:33:28 **Cathy Beresford**

I don't think I have actually. I’ll look it up.

00:33:31 **PWLD06**

Basically, it's about patients who have got I think they've had ascites but don't currently have it. Yeah, it's about faecal - it's basically they used to do it by endoscopy or colonoscopy where it's these basic faecal transplant but now it's, but now it's a capsule form. A freeze dried version.

00:33:50 **Cathy Beresford**

Oh yes, yeah.

00:33:55 **PWLD06**

There's, there's a lot of antibiotic resistance currently. It's basically about reducing the chance of infection, but just saying like have you any ideas because the uptakes been so poor.

00:33:59 **Cathy Beresford**

Yes.

00:34:02 **PWLD06**

Oh yeah.

00:34:07 **Cathy Beresford**

Right.

00:34:08 **PWLD06**

But this is the trial I was on about at the [name of other hospital]. It was just kind of like thrown at you. And then, like, the next day, he had no chance of thinking about it. I was already aware of it anyway.

00:34:10 **Cathy Beresford**

Yeah.

00:34:18 **PWLD06**

I was so unhappy with the appointment, how it went and that was all they were interested in. I'm not doing it because it is, but just because they have to go constantly backwards and forwards and follow-ups for two years.

00:34:19 **Cathy Beresford**

Yeah.

00:34:24 **Cathy Beresford**

Yeah, I see.

00:34:34 **PWLD06**

But it’s just this, this kind of thing. It's more the fact that a lot of patients are tired. Because it is an exhausting disease.

00:34:42 **PWLD06**

Yes.

00:34:44 **Cathy Beresford**

Yeah.

00:34:45 **PWLD06**

You have a lot of medical things going on to start with in terms of appointments. I mean, my whole life pretty much seems to be dictated by appointments.

00:34:46 **Cathy Beresford**

Yeah.

00:34:53 **PWLD06**

So, there is that aspect of that.

00:34:55 **Cathy Beresford**

Yeah, that does make sense that, that, that was sort of what I was thinking that people are not -

00:34:59 **PWLD06**

Like, what I said to you, it might sound like – what’s the best way to put it - it's it's got to be more fitting around the the patient, right, rather than the other way around.

00:35:10 **Cathy Beresford**

Yes, no, I agree. I.

00:35:13 **Cathy Beresford**

Think.

00:35:13 **PWLD06**

It's it's, it's quite hard, but it's quite hard to pin a date down.

00:35:17 **Cathy Beresford**

Sure.

00:35:18 **PWLD06**

It's quite. Like for me it's gonna be quite a lot of my things could be short notice – I can’t plan anything essentially.

00:35:23 **Cathy Beresford**

Of course.

Yeah. Yeah. Cos it's gotta be when you feel well.

00:35:27 **PWLD06**

If you said to me, can you do a follow-up phone call 2 weeks’ time, I couldn’t possibly

00:35:30 **Cathy Beresford**

no no, I understand. Yeah.

00:35:34 **PWLD06**

Because of medical kind of things. Because when you get appointments, you can't change them, otherwise you’ll wait another three months.

00:35:38 **Cathy Beresford**

Sure.

00:35:39 **Cathy Beresford**

Yeah, that makes sense.

00:35:41 **Cathy Beresford**

No, thank you. That's really helpful to know. To be honest, that's all the questions that I need to ask you. Is there anything else you'd like to ask me?

00:35:51 **PWLD06**

Not off the top of my head, no.

00:35:52 **Cathy Beresford**

Well, if there is, you know.

00:35:53 **Cathy Beresford**

If you do think of something and you want to check anything with me, feel free to drop me an e-mail. What what I'll do is after today, So, next week sometime what I have to do is I have to go. I I mentioned that I transcribed the interview. So, it's all written now.

00:36:11 **Cathy Beresford**

I use. When I do that, I do it on Word and it sometimes looks a bit funny, So, I will send it to you. But if it looks a bit funny, it's just because of the way that the the Word does the transcription, and it does still make sense to me. And obviously I can still listen to the recording if there's anything that doesn't make sense when I'm analysing the data, but I'll send you a copy of the transcript so that you've got it for your own record and also, so that if you did want to check it, you can. And if you want to add anything or change anything, you can.

00:36:42 **Cathy Beresford**

And and and I'm you know also; I will let you know what happens with the research I like I said it's not due to be finished until next year. But I was thinking I didn't really wanna leave it that long to just let people know what's happening, so, I will get something out this year just to sort of let just with a bit of an update on what's happening.

00:37:10 **PWLD06**

One thing I just thought of there, that’s quite beneficial, something I thought of a while ago, it is kind-of bringing up the past. This is something that would have been really good. It’s been a good conversation anyway, but I probably would have remembered a lot more about me care and how things were at the time.

00:37:22 **Cathy Beresford**

Yeah,

00:37:22 **PWLD06**

If this had been carried out back in ’22-’23. It’s like if patients got, like, a specific booklet which covered everything in terms of diet, what you do if this happens, what you do if that happens, and basically things like that. Basically, a diary in terms of you write the things down between your appointments like anything

00:37:35 **Cathy Beresford**

Yeah.

00:37:45 **PWLD06**

At the time because it does affect your memory as well, because you don’t sleep well.

00:37:47 **Cathy Beresford**

Yes.

00:37:49 **PWLD06**

Like I have problems with this, So, when you go to your appointment, they’ll go and have a look at it and the thing just thoughts, questions, anything like that.

00:37:54 **Cathy Beresford**

Yeah.

00:37:58 **Cathy Beresford**

Yeah, something to actually. Yeah, that totally makes sense. And I know that they do that in other types of conditions, don't they?

00:38:05 **PWLD06**

Yeah, because they do in kind of pain management and also, like CBT type thing.

00:38:11 **Cathy Beresford**

Yeah.

00:38:13 **Cathy Beresford**

Anything else you'd like to say before we end the interview?

**PWLD06**

No.

00:38:17 **Cathy Beresford**

Well, I I really, really appreciate you, everything you've told me. It's really insightful and I wish you you know all the best with everything because I can hear that you, you know, it's not easy. So, thank you so much. And I'll be in touch again next week.

**PWLD06**

OK. Thanks for your time.

**Cathy Beresford**

Alright. Thank you very much. Take care then.

00:38:38 **PWLD06**

Thank you. Bye.