# PWLD05 ‘Dan’ – Interview Transcript 10th June 2024 by telephone at 14:00 (52 minutes)

00:00:00 **Cathy Beresford**

So, the first thing just to double-check with you then because I have to be clear about exactly who I'm, you know, speaking with in terms of the population. But obviously I will anonymise everything. Would you mind confirming how old you are?

00:00:16 **PWLD05**

[states age] next month.

00:00:18 **Cathy Beresford**

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

00:00:29 **PWLD05**

Well, [states ethnicity] really, but I'm trying to think of something a bit smarter.

00:00:30 **Cathy Beresford**

OK.

00:00:33 **PWLD05**

Than that.

00:00:34 **Cathy Beresford**

That's fine. What, [confirms ethnicity]? Alright. Lovely. OK. Thank you. Right. So really, then to start off with, can you tell me about your journey of receiving care since you found out that you have liver disease?

00:00:52 **PWLD05**

Yes.

00:00:54 **PWLD05**

Well, I've been taken to hospital and admitted. Hang on, on the third, yeah, 3rd of January.

00:01:07 **Cathy Beresford**

This year, OK, so it's all been quite recent then.

00:01:09 **PWLD05**

Yeah.

00:01:13 **PWLD05**

Yes.

00:01:15 **Cathy Beresford**

So so what was it? Were you admitted as an emergency or what, what happened?

00:01:20 **PWLD05**

I'm not quite sure of the the the the absolute details because I was suffering from liver failure and encephalopathy.

00:01:30 **Cathy Beresford**

Yes, I know. Yeah, yeah.

00:01:34 PWLD0

In the brain and that. So, I was seriously hallucinating for ages.

00:01:36 **Cathy Beresford**

Gosh.

Were you?

00:01:41 **PWLD05**

Yeah. So like, I actually to be straight with you, I've just got the dates off my friend who was the one that took me.

00:01:49 **Cathy Beresford**

I see.

00:01:50 **PWLD05**

To hospital. It’s my partner and my mate made me go in because I didn't actually think there was anything wrong with me, but I was probably wasn't acting right, and talking to my mum recently it shook her right up. Well, I I shook her right up because I just wasn't acting right when they

00:01:56 **Cathy Beresford**

Yes. No.

Did it.

00:02:08 **PWLD05**

were coming to visit me and, you know, I was just off my head really.

00:02:12 **Cathy Beresford**

Yeah, yeah. Must have been -

00:02:14 **PWLD05**

But not not through drink or drugs, just through that like, you know, encephalopathy.

00:02:20 **Cathy Beresford**

Yeah.

00:02:21 **PWLD05**

Yeah, yeah. So, it's the third of Jan to the 8th of Feb. I was allowed out and then I've been sort of in and out up until a couple of months ago really.

00:02:33 **Cathy Beresford**

So, it sounds like you've been through quite a lot.

00:02:35 **PWLD05**

Yeah.

00:02:37 **Cathy Beresford**

So which services have you accessed then in relation to your liver disease over that time?

00:02:45 **PWLD05**

Well, I was on [name of] ward in [name of hospital]. I've also is it ascites as well? Where

00:02:56 **Cathy Beresford**

Oh yeah, the ascites. Yeah, where you get the fluid in the tummy.

00:02:59 **PWLD05**

That's right. Yeah, that was really, that was getting really bad.

00:03:04 **PWLD05**

So, I had to be drained, so probably once every three to four weeks.

00:03:09 **Cathy Beresford**

Yes.

00:03:11 **PWLD05**

Because my sodium level was either too high or too low, I don't know which one it was, but they couldn't put me on these water tablets that actually helped dry up because of the sodium level, so I was having to be drained.

00:03:21 **Cathy Beresford**

OK.

00:03:29 **PWLD05**

Yeah, basically want every month really.

00:03:30

Yeah.

00:03:32 **Cathy Beresford**

Where, where did you get that done? Was it in hospital or in a clinic?

00:03:36 **PWLD05**

It was either in the ward or after that was in outpatients.

00:03:44 **Cathy Beresford**

Oh I see.

00:03:44 **PWLD05**

At the hepatology place.

00:03:46 **Cathy Beresford**

Yeah. And so, were you, when you needed it, were you able to just go and have it or did you have to arrange it? How did it, how did you get it done?

00:03:57 **PWLD05**

I was when I was allowed out of hospital, I would. Well, generally I'd go into hospital once I was let out on the 8th, sometime, I did have to go back in on a couple of occasions.

00:04:12 **Cathy Beresford**

Yes.

00:04:13 **PWLD05**

But mainly that was because of my stomach growing so big.

00:04:18 **Cathy Beresford**

Yeah.

00:04:19 **PWLD05**

And then they drain me. Then I'd be out again, but then it would be a case of I'd have an appointment to go back and

00:04:25 **Cathy Beresford**

Yeah.

00:04:25 **PWLD05**

After a couple of times, it was you could kind of gauge that I could go about 3 weeks.

00:04:32 **Cathy Beresford**

I see.

00:04:34 **PWLD05**

But if that was, that's what has been like a lot of, you know, quite unbearable really cause.

00:04:40 **Cathy Beresford**

Yeah.

00:04:42 **PWLD05**

I think the biggest drain they did was like 8.7 litres. You know, it's like or 6 bottles, two litre bottles of coke, you know? So, then you got you gotta carry that around with you. So, you can't really go anywhere. You can't do anything. Lay it down, laying down is uncomfortable. But I'd rather be at home rather than in hospital.

00:04:46 **Cathy Beresford**

Wow.

00:04:51 **Cathy Beresford**

Yeah, yeah.

00:05:01 **Cathy Beresford**

Yes, I see. Yeah.

00:05:04 **PWLD05**

You know, to go. No offence to the hospital, but I'd, I'd I'd rather be at home. I've, but I mean, I kept saying that to them. It's the best place for me to be able to recover is at home.

**Cathy Beresford**

Sure

00:05:15 **PWLD05**

Yeah.

00:05:18 **PWLD05**

You know, even even though I've been in the forces, I don't like being regimentalised to be honest.

00:05:23 **Cathy Beresford**

No.

00:05:25 **PWLD05**

You know that part of it I really, really didn't like. I know they have that.

00:05:28 **Cathy Beresford**

No.

00:05:30 **PWLD05**

But you know. I've come to the, I've been told that I should eat like little and often as much as I can, can't eat well generally, can eat. Not a lot of salt. I've had to completely change my diet. Not that I had a high - I didn't have a high salt diet anyway, but.

00:05:38 **Cathy Beresford**

Yeah.

Yeah.

00:05:51 **PWLD05**

But in hospital you get 3 meals a day.

00:05:53 **Cathy Beresford**

Yes.

00:05:54 **PWLD05**

So, and it's three massive, big meals, but I can't eat that because you've got very big stomach, there's no room for food as well and you gotta and you gotta drink plenty of liquids, which that also fills you up. So, it's it's quite difficult.

00:05:57 **Cathy Beresford**

Yeah.

00:05:58 **Cathy Beresford**

No.

00:06:03 **Cathy Beresford**

Yeah.

00:06:13 **PWLD05**

Hopefully I'm on the road to recovery now. Yeah, I haven’t been drinking for quite a while now.

00:06:15 **Cathy Beresford**

Uh, yeah.

Yeah.

00:06:21 **Cathy Beresford**

And are you getting any, are you getting, are you getting any support or any services with regards to that?

00:06:27 **PWLD05**

Yeah, yeah, yeah, yeah. I'm kind of booked in with outpatients. I mean, I go to hepatology once every I think it's every four weeks now. So, I go and see them, and they check it out. So, I have my blood taken.

00:06:34 **Cathy Beresford**

Oh yeah.

00:06:40 **PWLD05**

Before I go, so they they know if my everything's working inside. Alright. Ohh yeah. I've got support from the two nurses, [name of hepatology nurse] and [name of hepatology nurse].

00:06:45 **Cathy Beresford**

Yes.

Ohh yeah.

00:06:51 **PWLD05**

In hepatology. So, they're great. I mean, anytime I want if I need to, I can always get hold of them. Not that I've had to yet, but yeah. No, they're great.

00:07:03 **Cathy Beresford**

So, if you needed to get a hold of them, how would you get hold of them?

00:07:08 **PWLD05**

Well, it’d probably quicker to write a note on a pigeon and get a pigeon to fly there, but I'll I'll ring up the reception - hepatology to get through to them. It'd be the same - I've got a couple of numbers, but it always when I've I've rung before for something like an appointment change or whatever.

00:07:18 **Cathy Beresford**

Yes.

00:07:30 **PWLD05**

They're so, they're both so busy. They're never in like an office where they do do the like the, you know, I think they get stitched once a week or a couple of times a week you have to go in the office to see people like me. Other than that, they're flying around the hospital.

00:07:42 **Cathy Beresford**

Yes.

00:07:45 **Cathy Beresford**

Sure. Yeah.

00:07:48 **PWLD05**

So, but yeah, no, they'll get back to me like 24 hours or so, so.

00:07:52 **Cathy Beresford**

Yeah. OK. And so so from what you're telling me, then you've got the liver nurses, the consultant. Anybody else that's been involved in your care for your liver disease?

00:08:07 **PWLD05**

Well, when I’ve been in hospital there's been - doctors do their rounds, don't they? But.

00:08:12 **Cathy Beresford**

Ohh yeah yeah.

00:08:17 **PWLD05**

I don't, I'll be honest, I feel a little bit let down by that. You know, you can see they don't, they're either not telling you the truth

00:08:21 **Cathy Beresford**

Oh yeah.

Really.

00:08:27 **PWLD05**

They're not lying to you, but they're not, I don't - I thought that they weren't telling me everything.

00:08:29 **Cathy Beresford**

Hmm.

00:08:34 **PWLD05**

You know, I mean, it must be difficult. I mean, I'm not having a go at them, but I mean, I did say I said to them at one stage I said, look, I said you've all got guidelines to work to, but you would put your certain slant on a situation thinking that's the best thing to do.

00:08:54 **Cathy Beresford**

Yeah.

Yeah.

00:08:57 **PWLD05**

But another doctor, which in my, you know, one of there was like three or four doctors that did the rounds on this ward, and I asked one question, and I asked another one the same question, and I get a different answer which that then led me to believe that depending on who you see you get a different answer.

00:09:13 **Cathy Beresford**

Yeah.

Yeah.

00:09:17 **PWLD05**

I mean, it wasn't like the major like, ohh yeah, your left legs gotta come off and the other one said no, it's not your right leg, it’s just, you know, procedures that they were going to do and stuff and.

00:09:29 **Cathy Beresford**

I see.

00:09:29 **PWLD05**

Yeah.

00:09:30 **PWLD05**

I think my my my symptoms lasted a lot longer than what it does normally for people, so I think they were a bit confused about that, but instead of saying they're confused and they're not sure they they kept me in and then I.

00:09:39 **Cathy Beresford**

Ohh I see.

00:09:44 **Cathy Beresford**

Oh yeah.

00:09:48 **Cathy Beresford**

Yeah.

00:09:50 **PWLD05**

You know, like I was being kept in for no reason, which was quite frustrating when you really wanna be at home and you know you can be at home, someone's there to help me at home.

00:09:59 **Cathy Beresford**

Yes.

00:10:01 **PWLD05**

Because it's. Yeah, you know, and just been having a fat stomach. It's dizzy spells and passing out and stuff like that, so.

00:10:07 **Cathy Beresford**

Yeah, yeah.

00:10:11 **PWLD05**

But yes, no in general I haven't really got any complaints like that. They're niggly things really. But that's just having to

00:10:18 **Cathy Beresford**

No.

Yeah.

00:10:24 **PWLD05**

You know, put up with the situation, I guess.

00:10:25 **Cathy Beresford**

Yeah.

00:10:29 **Cathy Beresford**

So, if you need like information about your liver disease? Where where do you go?

00:10:35 **PWLD05**

I'll go and speak to the nurses.

00:10:36 **Cathy Beresford**

Yeah.

00:10:38 **PWLD05**

They seem to know more about it than anybody else. When you said just now about, I've got two nurses and a consultant. Well, I've never met the consultant.

00:10:47 **Cathy Beresford**

Right. OK.

00:10:48 **PWLD05**

That the girls will write up - well the ladies, but they'll write up what the interview that we had contained. if they had any concerns or whatever, then he'd [the consultant] obviously read it sometime in the next few weeks and then I might get. I've had a couple of returns back just saying, well, basically what they said in the interview and that was it. That's from the consultant.

00:11:16 **Cathy Beresford**

Yeah.

00:11:18 **PWLD05**

So, I've not had to meet him or haven't met him.

00:11:20 **Cathy Beresford**

I see. I see. So really the care is led by the [hepatology] nurses from your experience?

00:11:25 **PWLD05**

Absolutely. Absolutely. Yeah. Yeah, they're, I mean, they're the people at the coal face, you know, they mean they they seen lots of people like me. Not you're not you'd say, your average nurse, but your hepatology nurses. They’ve seen it before. They know the difference. Find the symptoms. I've been totally straight with them as well, regarding my drinking and the previous drug taking and stuff like that.

00:11:32 **Cathy Beresford**

Yeah.

00:11:36 **Cathy Beresford**

Sure.

Sure.

Yeah.

Yeah.

00:11:48 **PWLD05**

Because I was absolutely well excuse my French. Oh, shit scared, you know.

00:11:52 **Cathy Beresford**

Yeah, yeah.

00:11:54 **PWLD05**

Yeah, possibly might have had to have a transplant. If not, they would think maybe I might about to have is it a stent?

00:12:06 **Cathy Beresford**

Oh, right, OK.

00:12:08 **PWLD05**

What they put in people's hearts.

00:12:10 **Cathy Beresford**

OK.

00:12:11 **PWLD05**

But to have that in my liver.

00:12:13 **Cathy Beresford**

Yeah.

00:12:14 **PWLD05**

It keeps sort of the outlet open as it were.

00:12:18 **PWLD05**

Yeah, but hopefully that isn't gonna have to happen because I'm getting better just with the tablets I'm taking and good eating and resting, really.

00:12:28 **Cathy Beresford**

I see, yeah.

00:12:30 **Cathy Beresford**

So, I mean, you've given me you've kind of given me a bit of example of it, but maybe I'll just be a bit more specific then. Have you got any specific examples of when the care you've received for your liver disease has been particularly positive for you? So, anything that really stands out?

00:12:49 **PWLD05**

To be honest again. I'll have to say it's all been through [name of hepatology nurse] and [name of hepatology nurse]. I've learned more about what's happened to me and what can happen to me through them. And I ain't got, I haven't got a thing really from the doctors. That's why I said that I don’t.

00:12:55 **Cathy Beresford**

Yeah.

Yes.

00:13:08 **PWLD05**

You know that they haven't really helped at all.

00:13:10 **Cathy Beresford**

Sure.

00:13:11 **PWLD05**

I'm in their rounds. There’s one or maybe three of them at the end of the bed, and they're in there scratching their heads and they don't really know why. You know, I think, you know, as I've come to find out, it's they didn't really know why it was taking so long, but they didn’t, they didn't tell me that.

00:13:27 **Cathy Beresford**

Yeah.

00:13:28 **PWLD05**

They weren't giving me the full picture. Do you understand what I mean?

00:13:32 **Cathy Beresford**

I do.

00:13:32 **PWLD05**

Yeah. But you know [name of hepatology nurse] especially, you know, because I've seen her more than [name of hepatology nurse]. I think she knows I'm a straight-up person. You know whether you know to a certain extent obviously because if you don't know somebody, you don't really know, but.

00:13:38 **Cathy Beresford**

Yeah.

00:13:52 **PWLD05**

But she's been, like, very informative, you know, explain things that I didn't know, which I could have done with knowing before. But then the problem was, like [name of hepatology nurse]said, I could have been told things and not remembered them.

00:13:54 **Cathy Beresford**

Yeah, yeah.

Ohh of course yeah.

00:14:09 **Cathy Beresford**

Of course.

00:14:10 **PWLD05**

Once the hallucinating started to finish. I mean I was seeing things in the clock face. I mean, the doctor had four four doctors in the room, and he said Ohh.

00:14:14 **Cathy Beresford**

Yeah.

00:14:21 **PWLD05**

Oh, one of them kept one of them, kept asking me to think of animals between ohh A&Z or something like that. Yeah, and it's all he used to keep asking me when he came in, I said don't ask me that, please, and then I just, I was getting fed up with that, you know that.

00:14:37 **Cathy Beresford**

Yes. Was it part, was it part of his assessment, was it?

00:14:42 **PWLD05**

Yeah.

00:14:43 **PWLD05**

But it was, you know, like a dog that's been the, you know, the new tricks, you know, it's like the same thing all the time. And it's like, well, I'm only gonna know so many animals anyway. I'm only gonna say the same as what I said last time. But there's obviously a deep doctory thing within it about my memory and stuff like that.

00:14:45 **Cathy Beresford**

Sure. Yeah.

Yeah.

00:15:06 **PWLD05**

Don't know how it came - Oh, that was it, I said something. I said, well, how would you feel laying in the room all the time and you all got all you got to watch is the clock face. And as I was looking at the clock face because I used to see little things moving around in the clock face, you know, like an old Swiss clock where you had like, a cuckoo clock that come out move across. Yeah. I can see like like Mr Ben [character] type people.

00:15:18 Speaker 3

Yes.

00:15:22 **Cathy Beresford**

Oh yeah.

00:15:31 **Cathy Beresford**

Oh yeah, yeah.

00:15:32 **PWLD05**

are coming out inside, moving to each other saying like hello or whatever, and then going back, disappearing into the clockface. And I said to the doctor, can't you see it? He said: See what? Can't you see the people you know, that's how hallucinations and things.

00:15:43 **Cathy Beresford**

Yes, yes.

Yeah.

00:15:47 **PWLD05**

I'm only just starting to remember some of these things, and I'm calling it a parallel universe because they're not dreams.

00:15:53 **Cathy Beresford**

No.

00:15:54 **PWLD05**

If you have to bet money, you bet money on what you've seen or what you think you've done.

00:16:00 **Cathy Beresford**

Yes. Yeah, it makes sense. It makes sense. What you're telling me then, that it it was a a confusing time and that then, yeah.

00:16:01 **PWLD05**

It's real. [seems real]

00:16:10 **PWLD05**

It was, yeah, when I was sucked in that it's very confusing. So, I was in their hands.

00:16:15 **Cathy Beresford**

Hmm.

00:16:17 **PWLD05**

Uh. But then, for some reason, well somehow, I then got C.Diff [infection] alright so then I was confined to my room, and they put a DOLs out on me as well. Before that I think you know. Yeah, you know.

00:16:24 **Cathy Beresford**

Oh gosh, yeah.

Oh really?

00:16:36 **Cathy Beresford**

Yeah, I do. Yeah. Deprivation of liberty. It stands for.

00:16:40 **PWLD05**

That thing. Yeah. So, I couldn't go out.

00:16:42 **Cathy Beresford**

Was it cause you were was it cause of the confusion?

00:16:45 **PWLD05**

Yeah, pretty much. But I didn't know that. I didn't know that. Or like [name of hepatology nurse] said, they might have told me, but I don't remember them telling me.

00:16:47 **Cathy Beresford**

No.

Sure.

00:16:53 **PWLD05**

So, it was like, you know, it felt almost like one step away from the straitjacket really.

00:16:57 **Cathy Beresford**

Yeah.

Yeah.

00:17:01 **PWLD05**

But yeah, thankfully that's gone. I'm still a bit hazy, still a little bit forgetful and stuff and remember things, but I can live with that. It might just be old age, but.

00:17:08 **Cathy Beresford**

Yes.

00:17:14 **Cathy Beresford**

I mean, again, you've sort of given me a bit of an idea of about this, but just to pinpoint it, any specific examples of when care you've received for your liver disease has been particularly negative for you. So, anything that specifically stands out in your mind?

00:17:33 **PWLD05**

Yeah, one thing, but then it's not really, it could have been, it wasn't really to do with my liver. It was just to do with the way I was treated once, and I was thinking that wasn’t very good.

00:17:44 **Cathy Beresford**

Tell me. Tell me about that.

00:17:45 **PWLD05**

Well, it was was. I was in a certain room because I had C.Diff and I had to be isolated from other people. I didn’t mind because I got me own room. But a girl, a young girl, was meant to be coming in. So, they had to rush me out of this room and put me in another room. I didn't really see why.

00:17:48

OK.

00:17:50 **Cathy Beresford**

Yes.

00:18:01 **Cathy Beresford**

Yeah.

00:18:03 **PWLD05**

But I think it was because she had to be close to the reception because I was close to the reception due to risk of running out the door, with me bag in me hands. And so, they put me in another room.

00:18:11 **Cathy Beresford**

Sure.

00:18:16 **PWLD05**

But I was half – well I was not halfway - just like quarter of the way into having a drain. So, I had the massive, big needle hanging out my stomach.

00:18:25 **Cathy Beresford**

Yeah.

00:18:27 **PWLD05**

And then a couple of nurses came and said: look we've got to move you. So, alright. So, they packed my gear, started wheeling me up the passageway. And I'm like, yeah, be careful with this.

00:18:37 **Cathy Beresford**

Yes.

00:18:38 **PWLD05**

You know it's hanging out sort of enough that you know, I didn't, I didn't really like having that done as it was but being rushed up the passageway for them to sort this other room out. And as we got to this next room, she went right into the side of a set of drawers and wacked this needle.

00:18:54 **Cathy Beresford**

Yeah. Oh, gosh.

00:18:57 **PWLD05**

Yeah, I wasn’t happy.

00:18:58 **Cathy Beresford**

No, I'm not surprised.

00:19:00 **PWLD05**

That I think.

00:19:02 **PWLD05**

This this was an old nurse, but it was like an old nurse that didn't give a shit, not an old nurse that’s kind and you know what I mean.

00:19:09 **Cathy Beresford**

I see, yeah, yeah.

00:19:11 **PWLD05**

It's, you know, I guess I don't know what the situation is, but I didn't really gel with her anyway. But this little that was it, really. That's the only negative thing I could say as.

00:19:17 **Cathy Beresford**

Sure. Yeah.

00:19:23 **PWLD05**

That, but it's just one of them things. They're rushing. They've got more than they can handle work wise because they've got like two nurses for 500 people to look after, you know, if you see what I mean.

00:19:36 **Cathy Beresford**

I do, yeah.

00:19:37 **PWLD05**

So, it's it can't always be - everything can’t always run smoothly.

00:19:42 **Cathy Beresford**

No, I understand what you're saying.

00:19:44 **PWLD05**

So, I do get it, but it's just not nice when you're on the receiving end of having a needle bent around in your stomach. It's but it's a hooked needle as well, so they like hook it in. So yeah, it did hurt. I was really not happy about that cause it hurt for quite a while.

00:19:50 **Cathy Beresford**

Yeah.

Hmm.

00:20:00 **PWLD05**

Yeah, couple of days. So, and yeah that it was just little little things, but because a lot of, you know, the earlier stages of the hospital and then when I came out like I said, I did go back now and again for drains, but it was little things more administration problems rather than.

00:20:14 **Cathy Beresford**

Oh yes.

00:20:21 **PWLD05**

Face to face problems. See what I mean? Like.

00:20:23 **Cathy Beresford**

Yes, such as?

00:20:26 **PWLD05**

Well, going in for a drain, oh it won't be for another day. So, then you're in hospital an extra day and you're expecting to be out whenever then it's like, you’ve drained me. I'm going to get ready to leave and ohh, no, we want to, you know, check your bloods again and this and that.

00:20:32 **Cathy Beresford**

Yeah.

00:20:45 **PWLD05**

But they don't give you a reason why. They just say that, and it leads you to believe that that could become could become an excuse to keep you in there. If you see what I mean. It’s like well you've sucked me like a vampire since I've been in here anyway, and then you want it again the following day. Which means I'm in there all day because they don't take the blood till a certain time and.

00:21:05 **Cathy Beresford**

Yeah.

00:21:12 **PWLD05**

Then you know what I mean. Just.

00:21:13 **Cathy Beresford**

OK. Yeah, yeah, yes.

00:21:14 **PWLD05**

It's like a small administrating, always administrating stuff, than the nurses.

00:21:20 **Cathy Beresford**

Yeah. Yeah. Like the practical side of it?

00:21:25 **PWLD05**

Yeah, yeah, the, the, the practical, the practical side, which to me is the nurses because they're the ones that are hands on, I didn't have a problem.

00:21:33 **Cathy Beresford**

Yeah, I get you.

00:21:35 **PWLD05**

Most nurses are like spot on because they're there, well, crazy as it might sound, they want to be there because they like helping people and people that wanna I wanna be looking after me, not someone that ‘I don't wanna work in Tesco’s so, this job will do’.

00:21:42 **Cathy Beresford**

Yeah.

00:21:49 **PWLD05**

If you see what I mean, you know?

00:21:50 **Cathy Beresford**

Yeah.

00:21:52 **PWLD05**

Yeah, but no, everyone seemed to be doing their job, but a lot of the time it was a job I didn't want them to do. Like when I had the DOLs on me and they weren’t going to let me out. And to me, there was no reason why they were keeping me in there anymore and.

00:22:09 **Cathy Beresford**

Sure

Yeah.

00:22:10 **PWLD05**

But that could have been my my own confusion as of the situation.

00:22:13 **Cathy Beresford**

Sure. Yeah.

00:22:15 **PWLD05**

But then I I keep saying that that. You know, it was just difficult. It was very because I keep, like I said, like I said to [name of hepatology nurse] about it, she said you could have been told, but you don't remember.

00:22:28 **Cathy Beresford**

Yes.

00:22:29 **PWLD05**

Well. In that case, then I should have had what they were doing in writing. So, alright, I might not have got it when they said it, but the following day I could have read that and gone. Ohh yeah, that's why.

00:22:34 **Cathy Beresford**

OK. Yeah.

Oh, well, yeah, I see. Yeah.

00:22:41 **PWLD05**

Rather than being kept in the dark.

00:22:43 **Cathy Beresford**

Sure

00:22:44 **PWLD05**

So, I did feel like that quite a lot of times. That's why I ran out of patience with being in hospital because I didn't trust them in the end.

00:22:52 **Cathy Beresford**

No.

00:22:53 **PWLD05**

You know the outpatients is fine. I can stay at home and go there once a month. I have my blood taken. Have a little yap, ask questions or answer a question and that's fine. I mean, if I was unwell today, obviously I'd have to go to hospital, but I really, really, really would avoid it. Avoid it, you know.

00:22:55 **Cathy Beresford**

Yeah.

Yes.

Yes. Yeah.

00:23:17 **PWLD05**

Just because of my my experience I had but that was the earlier experience rather than the latter, so it could have been my mindset rather than their mindset, you know the situation, but.

00:23:32 **Cathy Beresford**

Yeah.

00:23:36 **PWLD05**

I did have a - don't know how I got hold of her. She got a hold of me, but it was a a lady that like deals with ex-forces that have had problems or need help and they come out the forces and stuff.

00:23:45 **Cathy Beresford**

Oh yeah.

00:23:48 **PWLD05**

And in the end because they weren't, they weren't gonna let me out of hospital. I rang her, and within 24 hours I was out with the discharge note in my hand.

00:23:59 **Cathy Beresford**

And what had happened then? How did that happen?

00:24:01 **PWLD05**

I don't know. I don't know what she said, but I rang her up when I walked out the main entrance and said oh thank you so much.

00:24:08 **Cathy Beresford**

Yes.

00:24:10 **PWLD05**

That kind of goes to show that the why they were keeping me in was a bit pointless.

00:24:15 **Cathy Beresford**

I see is and is she. Is she a nurse or what's her?

00:24:19 **PWLD05**

No, no, she's not a nurse I can find her name if you want?

00:24:22 **Cathy Beresford**

No, it's alright. You don't have to. I just thought. I just wondered what her role was.

00:24:25 **PWLD05**

No, no, she's not a nurse. She's more. Well, I don't really know. She. I did have a good yap with her once. She works in the dockyard in [town name], like health and safety.

00:24:33 **Cathy Beresford**

Yes.

Alright, yeah.

00:24:40 **PWLD05**

And then left and then just does this sort of help [armed] forces people and stuff like that. It's somebody that can help you arrange things like needing a flat to rent and you know.

00:24:44 **Cathy Beresford**

I'm with you.

Sure.

Yeah, that's good.

00:24:54 **PWLD05**

Like to get somebody on their feet.

00:24:57 **Cathy Beresford**

That's good.

00:24:59 **PWLD05**

Yeah. So it was, it was really good. You know, like I said, she she got me out in 24 hours and that was just a phone call. She's up the line somewhere, not too far, but she's up the line. She's not in [name of city]. So, it was only a phone call that she made, and everyone jumped to attention – boom, that’s it. Pack your bags, there's your discharge note. In less than 24 hours. So, I was well chuffed with that.

00:25:24 **Cathy Beresford**

Yeah.

That was good. And you, you mentioned that you have got support at home. So, who who? Who supports you?

00:25:34 **PWLD05**

My partner. But I I don't need as much like looking after as I used to. I was kind of sofa-ridden as it were, but not.

00:25:45 **Cathy Beresford**

Were, you.

00:25:46 **PWLD05**

Yeah.

00:25:48 **PWLD05**

Carrying round and carry around a great big baby [swollen tummy].

00:25:52 **Cathy Beresford**

Yeah, yeah.

00:25:55 **PWLD05**

Got no energy, just trying to stock up on food. I mean, I lost two stone in weight.

00:26:00 **Cathy Beresford**

Wow.

00:26:02 **PWLD05**

So, I lost all my muscle. Mass is still gone. I'm trying to now put on weight, but like I said, I was trying to put on weight when I first came out, but it's really difficult to do when you've got several litres of poison in your stomach here.

00:26:14 **Cathy Beresford**

Yes.

00:26:16 **PWLD05**

They're isn’t enough room for everything.

00:26:19 **Cathy Beresford**

And have you had the opportunity to talk to anybody about the diet side of things?

00:26:19

Yeah. Yeah. So, I've, yeah, I've got a dietitian. Yeah, I. Yeah, I I can't knock the care at all, you know, it's all been like, laid on and all the offices there. Tomorrow I've gotta go and see back up to [town name] for bone density.

00:26:26 **Cathy Beresford**

Yeah.

Yeah.

00:26:40 **PWLD05**

I'm not quite sure why, but [name of hepatology nurse] booked me in for it when I went to see her last time, which was probably three weeks ago now.

00:26:52 **Cathy Beresford**

Yeah.

00:26:53 **PWLD05**

So, she booked me in for this.

00:26:55 **Cathy Beresford**

So, think and think, sorry to interrupt, just thinking about you know everything that's happened over the last few months then and the experiences of care that you've had, what advice would you give to somebody who's discovered that they've got advanced liver disease?

00:27:13 **PWLD05**

Possibly. Oh what, they've been diagnosed with it?

00:27:17 **Cathy Beresford**

Yeah. So, say perhaps if you think about if you could, you know, give anybody a a bit of advice, what would you say?

00:27:27 **PWLD05**

Well, if they had exactly what I had I had which is encephalopathy which so I think there's different types of like alcohol-related liver disease. if they had that then I personally wouldn't be sure who I was talking to even though I was talking to the person sat right in front of me.

00:27:35 **Cathy Beresford**

Sure. Yeah.

Yeah.

00:27:48 **PWLD05**

Because I know deep down, they don't really know what's going on. That's how. That's what I said. I'm not trying to - how bad it is. It is really that bad.

00:27:56 **Cathy Beresford**

Yeah.

I get you. Yeah.

00:28:02 **PWLD05**

But I don't know. I'm not really sure how to answer that.

00:28:06 **Cathy Beresford**

No, that's fine. That's OK.

00:28:08 **PWLD05**

Other that any stupid fool shouldn't have drunk in the first place! [both laugh]

Other than that. You know.

00:28:16 **Cathy Beresford**

Yeah, but I mean, there’s stigma sometimes, isn't there around liver disease?

00:28:22 **PWLD05**

Yeah, well, I didn't really think that until [name of hepatology nurse] actually said that to me, she said, look, we don't – when I first sort of met her, and that she said we don't have any. You know we don't think of it like that they just. I guess they just think as a of of the body as a machine and they're they're repair it rather than how you got that way.

00:28:44 **Cathy Beresford**

Yeah.

00:28:45 **PWLD05**

And they're only concern with your social life is you don't go down the pub. So other than that.

00:28:50 **Cathy Beresford**

Yeah.

00:28:56 **PWLD05**

Well, I don't think that I've had any sort of bad feelings towards me or stuff like that to be honest.

00:29:02 **Cathy Beresford**

Yeah, yeah, yeah.

00:29:05 **PWLD05**

Like I said, all the nurses were pretty cool.

00:29:08 **Cathy Beresford**

Hmm.

00:29:10 **PWLD05**

I'm pretty straight with everybody. I mean, if I don't particularly like them, I'll, I'll avoid them.

00:29:15 **Cathy Beresford**

Yes.

00:29:17 **PWLD05**

To avoid confrontation.

00:29:20 **PWLD05**

I wanna win and not always you can win. Best just to walk away. But no, I'd say 95% of all the people in the ward or anybody I dealt with spot spot on. Oh. That's other people often as well. Sorry, I’ve forgotten what it's called now. Something to do with, I can't, not a psychiatrist, but it's.

00:29:44 **Cathy Beresford**

Is it psychologist?

00:29:46 **PWLD05**

Something like that. But they ask you, I said to my partner cause she's a carer and her auntie has been a nurse as well. And they said, oh, that's like a dementia test that they give old people this same thing with, like, memory, where they'll ask you some questions and then re-ask, re-ask.

00:29:53 **Cathy Beresford**

Yes.

Oh yeah.

Right.

00:30:06 **PWLD05**

They'll give you a sentence saying, oh, Julie jumped over the fence at such-and-such farm and ran down the road, went to such-and-such town right then five minutes later they'll ask you who what was she called and what farmers. You know what I mean and then ask a question and it's basically a dementia test.

00:30:24 **Cathy Beresford**

Yeah.

00:30:26 **PWLD05**

And they said they did offer if I wanted to go in more often, I said, be honest I'll just let sleeping dogs lie. If I've got any problems, I've got your phone number and I'll ring you up and go in. But he said he'll leave it for 12 months.

00:30:40 **Cathy Beresford**

Fine.

00:30:41 **PWLD05**

So, no point in wasting their time and taking up a place that someone else really needs it. When I think I don't. But I did say if I’ve got problems, I’ll ring.

00:30:48 **Cathy Beresford**

Sure. Yeah.

00:30:52 **PWLD05**

So yeah, the the the roundabout care’s been good as well. You know having been booked into these different people and stuff, yeah.

00:31:00 **Cathy Beresford**

So, thinking about the experiences that you've had, then if you could give any advice to healthcare professionals who work with people who've got advanced liver disease, what would you say?

00:31:01 **PWLD05**

Just be straight up.

00:31:12 **Cathy Beresford**

Yeah.

00:31:14 **PWLD05**

I mean, it's like it's like knowing someone's gonna die but not telling them. And then it's like they well, you know, you're gonna die at the end of the week. I would have thought you wanna tell that person as quick as possible rather than leaving it a couple more days until you tell them then they've only got four, three days left.

00:31:14 **Cathy Beresford**

Yeah.

00:31:32 **PWLD05**

If you see what I mean, dust. I know that's a bit sort of severe, but just be straight.

00:31:39 **Cathy Beresford**

Yes. So, you you want honesty?

00:31:40 **PWLD05**

That's probably all. That's probably. Yeah. That's probably, yeah, that I, I don't think the nurses don't tend to know anything anyway. But I think that must frustrate them, because that makes them feel more like a robot just going through the motions of what they have to do every day to all the different patients, rather than knowing what's wrong with them. So, then they can have their own bit of care to that person. If it's you see what I mean.

00:32:06 **Cathy Beresford**

Yeah. Do you mean the nurse is on the wards?

00:32:09 **PWLD05**

Yeah, pretty much, yeah.

00:32:11 **PWLD05**

Yeah, but then that's more work for them having to read all these, you know, suss out all these things because they are just, they are overworked. Terribly, but that's how accidents happen, and mistakes happen I suppose.

00:32:22 **Cathy Beresford**

Yeah.

Yeah.

00:32:29 **Cathy Beresford**

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

00:32:29 **PWLD05**

If you're confused or well, not knowing, them being honest back with you.

00:32:51 **Cathy Beresford**

Yeah.

00:32:53 **PWLD05**

Doctors or nurses, whoever you know, just being completely straight with you.

00:32:56 **Cathy Beresford**

Yeah.

00:33:01 **PWLD05**

Well, dunno, it’s a bit of a hard question to answer.

00:33:04 **Cathy Beresford**

Yeah, it's OK. It's whatever you think there's no.

00:33:07 **PWLD05**

Yeah. That, that's it really. I mean, I can't. I can't really think of anything else. It's like I said, it's just honesty.

00:33:14 **Cathy Beresford**

Yeah.

00:33:14 **PWLD05**

I mean I don't know what they're told to say to you, but you know, it doesn't matter to me, I want to know. Good or bad, you know? Am I going to be. And then not say at the end of a couple of days: Oh, you're here for another week, you know. Little things like that and I know things might crop up where they think Oh yeah, that's a bit, that's levels high or that level's low. I mean, my blood pressure was really low from when I was admitted, and they're not allowed to let you out of hospital until it's at a certain higher pressure.

00:33:54 **Cathy Beresford**

OK.

00:33:57 **PWLD05**

I didn't really have that problem leaving the ward when I had to leave the ward and come in for a drain and leave cause my blood pressure was still as low as it was. Pretty much when I when I first went in.

00:34:10 **Cathy Beresford**

Yeah.

00:34:11 **PWLD05**

But when I had a drain in outpatients with some different nurses, not the ones I knew, they had to wait for my documents to get down to where they were. But they didn't believe that because I said look. But they said, oh, when you first came in here this morning, your blood pressure was like 100 and something I said. Yeah, because I was late. I like, ohh up. Hobbled up to the lift and up the lift and in. And then you gave did my blood. I said that's why it's high. Then it was down to below 50 or something.

00:34:37 **Cathy Beresford**

Yes.

Hmm.

00:34:46 **PWLD05**

And I said, well, I've been all relaxed all day. You've been draining me. I'm all chilled out, but she wouldn't let me out of that ward. Yeah, until they had got up towards 80, something 80 was like 79 or 80 or something, but they wouldn't let me out till it had

00:35:02 **Cathy Beresford**

OK.

00:35:03 **PWLD05**

gone up to that amount.

00:35:05 **Cathy Beresford**

Yeah.

00:35:06 **PWLD05**

But, but that's just protocol. Yeah. So, so they gotta follow that. But that's fair enough. You know, you can't blame anybody for that, but.

00:35:10 **Cathy Beresford**

Yeah.

Sure. Yeah.

00:35:18 **PWLD05**

Yeah, I think. Yeah, just possibly. Yeah. Being straight and possibly explaining a little bit more why they're doing stuff rather than what they're doing. Like taking your blood so well, you know, what's it being tested for? Stuff like that.

00:35:27 **Cathy Beresford**

Yeah.

Sure.

Yes. Yeah.

00:35:39 **PWLD05**

Just little things really.

00:35:40 **Cathy Beresford**

Yeah.

00:35:41 **PWLD05**

Big then was nothing big at all, but it's just gives you Peace of Mind that you sort of know what's happening.

00:35:48 **Cathy Beresford**

Yeah, I understand.

00:35:50 **PWLD05**

You know, I don't. I'm quite happy if I if I think the people that are in control of me know what they're doing, I'm quite happy to let them go and do what they gotta do, cause I've gotta trust in the fact that they know what they're doing.

00:36:03 **Cathy Beresford**

Yeah.

00:36:04 **PWLD05**

But. It must, it does help know exactly what they're testing for, so goes back to just being straight up and honest. I think that that, I can’t really say any more than that.

00:36:12 **Cathy Beresford**

Yeah.

Sure. Yeah.

00:36:19 **Cathy Beresford**

Thank you. That's helpful. That's helpful to know. While we've been having this conversation, you know sometimes I find that simply talking about these issues can bring up thoughts that you hadn't had before. So, is there anything that's occurred to you while we've been talking that perhaps you hadn't really sort of thought about?

00:36:41 **PWLD05**

No, not really. I could probably be a better candidate if I hadn't had encephalopathy. Because a lot of it, a lot of it. I can't remember. December, January when I was admitted, February. I can't, you know, it's all a blur and I think encephalopathy must have started a long time before I was admitted.

00:36:56 **Cathy Beresford**

Yeah.

Yes.

00:37:05 **PWLD05**

So, like I think really the end of last year and remember a lot, but I've got memories of while I was hallucinating.

00:37:16 **Cathy Beresford**

Yeah. So, was that the first time that you actually found out that you had liver disease then? Was that, you didn't know before?

00:37:25 **PWLD05**

Yeah.

No, didn't know at all. Didn't have any signs, didn't have a warning light come up like it does on your car.

00:37:31 **Cathy Beresford**

Sure.

00:37:32 **PWLD05**

Just the encephalopathy must have kicked in big time, and I was sort of delirious and drunk. And that was it. My partner and my mate, he took me in hospital, they made me go in. I was like I'm alright, but I wasn't.

00:37:47 **Cathy Beresford**

Yeah.

So, they took you.

00:37:52 **PWLD05**

Yeah.

00:37:54 **Cathy Beresford**

That must have been quite a big thing for them as well.

00:37:57 **PWLD05**

Oh yeah. Yeah. Yeah, it's been like a big toll on [name of partner] she's my partner. And my and my mum.

00:38:07 **Cathy Beresford**

Yeah, yeah.

00:38:12 **PWLD05**

Because they're trying to deal with - they're trying to deal with me, but they're not really dealing with me because I'm not thinking straight.

00:38:19 **Cathy Beresford**

Yeah.

00:38:19 **PWLD05**

And honestly, it sounds a bit ridiculous, but you would honestly swear blind and put a month - I don't bet, I don't gamble, but I would even put a month’s wages right down on what I was saying was the absolute truth. I'd actually done it. I've got a bit confused into like lately thinking well, where was I and what was I doing whilst I was having these hallucinations? But then I don't know whether they happened in while you were sleeping. Because they're not dreams, because a dream comes and goes very, very quickly and a lot of the time when you wake up, you can't remember it. If you can remember it, you'll forget it by the end of the day. See what I mean? Dreams are fleeting sort of things. This was like I could then wherever I was, it felt like for a couple of days, you know, just doing things, which were things that I might have done before but just different setups and a couple of different people within it, but crazy shit was going on, you know.

00:39:07 **Cathy Beresford**

Yeah.

Yes. Yeah.

00:39:25 **PWLD05**

You know, weird stuff. So, I can understand why they put they put the DOLs on me. Probably not, it's probably not best for someone to be walking around on the street like that.

00:39:34 **Cathy Beresford**

Yeah.

Hmm.

Yeah.

00:39:43 **PWLD05**

You know, so a bit of a catch 22 with me mind, isn't it?

00:39:46 **Cathy Beresford**

I understand what you're saying, yeah.

00:39:49 **PWLD05**

You don't know personally, and they don't know because they don't know. It's just, I guess their experience that that's why I trust [name of hepatology nurse] and [name of hepatology nurse]. They've got more experience than the doctors have of people that have been like me. But it's it's the same as anywhere. If you where you, if you work in a big place, where you’ve got a lot of big managerial stuff and all that. But if you want to go and find out something technical or how to do something, you go and speak to the bloke doing the job. You don't speak to the manager or something.

00:40:27 **Cathy Beresford**

Yeah.

00:40:28 **PWLD05**

He's just picking out what car he's getting next year and worrying about where him and his family gonna go on holiday, you know. You you wanna find out the process and the risks of a certain job or whatever, you're gonna speak to the guys doing it. That's the same there. I wouldn't even really want to speak to the consultant.

00:40:43 **Cathy Beresford**

Yes.

Right, I see.

00:40:51 **PWLD05**

You know, if he's, you know, he's university-trained doctor, done a little bit on the wards and then he's doing whatever he's doing now, which is driving around in an Aston Martin and going to the Golf Club and signing a few letters. But the nurses are the ones that specialise. They're the ones that know because they're around it every day.

00:41:16 **Cathy Beresford**

Yeah, I see what you're saying.

00:41:18 **PWLD05**

Yeah, if you get where I'm coming from.

00:41:19 **Cathy Beresford**

I do, yeah, yeah.

So, is there anything else that you think I should know to understand your experiences of the care that you've had for your liver disease?

00:41:30 **PWLD05**

No, I don't think so.

00:41:31 **Cathy Beresford**

You've explained everything really well. I mean, you've given me really good insight into you know what's happened over the last sort of few months.

00:41:42 **PWLD05**

Yeah. Yeah, I can't. You know, every other trip that I've made other than my first time, like the first time was about a month but it seemed, it seemed like a year that I was in. Now I kept thinking I'd missed Christmas, I've missed Christmas, but I did actually miss Christmas because I didn't realise it had come and gone. In January, I kept thinking Christmas was still coming.

00:41:57 **Cathy Beresford**

Yeah.

00:42:06 **PWLD05**

See, like you know the next month after and you know just. It it must be hard to look after somebody like that. Because it's hard for your partner and your and your mum to deal with you as well.

00:42:20 **Cathy Beresford**

Sure. Yeah.

00:42:24 **PWLD05**

You know, I thought I was in totally different places, a lot of the time. Still in under the hospital care, but in a completely different place. But there was, like, familiar faces in that place. And that seemed to go on for days. So, I don't know whether I was in the ward I was and just thinking that all these things were happening, or I was dreaming them. See what I mean?

00:42:37 **Cathy Beresford**

Yeah.

00:42:49 **PWLD05**

I still don't know.

00:42:49 **Cathy Beresford**

I do, yeah, yeah.

00:42:51 **PWLD05**

I don’t think anyone will.

00:42:52 **Cathy Beresford**

Yeah, it was a confusing time.

00:42:55 **PWLD05**

Yeah, very. So, I can't be. My care must have been alright when I was confused because I'm still here and I've got both arms and legs!

00:43:01 **Cathy Beresford**

Yeah.

00:43:02 **PWLD05**

So, my care must have been alright then. But yeah, I can only comment really on other times but.

00:43:09 **Cathy Beresford**

No, that's you've explained it really well. I mean cause I suppose I see it as an ongoing process. You know, you're still having care and treatment. You know you've got the care in the hospital, but then as you say, you still get your follow-up and you still need to have the option to contact people if you don't, you know. So, for example like if you

00:43:16 **PWLD05**

Yeah.

00:43:27 **Cathy Beresford**

If you were ill, like who's your first port-of-call? If things did get worse, who would you go to? Yeah.

00:43:33 **PWLD05**

I'll ring [name of hepatology nurse], you, [name of hepatology nurse], and just ask them what to do.

00:43:37 **Cathy Beresford**

Yeah, yeah.

00:43:39 **PWLD05**

I mean, my doctor signs my prescriptions at my surgery, but I've never even met the bloke, so there's absolutely no point of me going to see him, it’d take about two weeks to get my foot through the door.

00:43:43 **Cathy Beresford**

Right.

I see.

Yeah.

00:43:50 **PWLD05**

So, I’d go straight through to the horse's mouth. Speak to either [name of hepatology nurse] or [name of hepatology nurse]. Then, because I’m on these water tablets, I can't remember if it's called Spironolex [?] or something. I don't. I'm not really sure the proper name, but they're just called water tablets because they help dry things up. Well, I think when I go and see her next Monday

00:44:01 **Cathy Beresford**

OK.

Sure. Yeah.

00:44:10 **PWLD05**

That they'll take me off them because when they gave me an ultrasound last time, there was only a little bit of liquid left in there. So, hopefully over the last four weeks, it's dried it right out, but they have to be careful it doesn't start drying your liver out.

00:44:19 **Cathy Beresford**

Yeah.

00:44:26 **Cathy Beresford**

I see.

00:44:27 **PWLD05**

Right. So, one of my questions will be that there might be a time when I might have to ring them, because if I stop those tablets and then my stomach starts getting bigger again, that’ll be the first bump for a few months or a couple of months.

00:44:41 **Cathy Beresford**

Yeah.

00:44:43 **PWLD05**

So yeah, I'll have to let you know. But but but that that. Yeah, exactly. So that might be that'll be a position where I'm off those tablets then that condition might come back.

00:44:47 **Cathy Beresford**

Yeah, yeah, that makes sense. That makes a lot.

Hmm.

OK.

Yeah.

00:44:58 **PWLD05**

So, I don't know whether they'll crash me off the amount that I'm on or just drop them down a little bit by bit. I'm not sure how they'll do it. So that'll be one of my questions I'll ask.

00:45:09 **Cathy Beresford**

Sure.

00:45:10 **PWLD05**

I don't want to go back to that again [ascites].

00:45:11 **Cathy Beresford**

No.

00:45:13 **PWLD05**

I'm immobile then.

00:45:15 **Cathy Beresford**

Yeah.

00:45:17 **PWLD05**

Yeah, like I said, I haven't got the strength and not a lot of people - well, like I said, the biggest one was 8.7 litres. It's like it’s going to burst.

00:45:23 **Cathy Beresford**

Yes. Yeah.

Yeah. Yeah, no.

00:45:27 **PWLD05**

You know, it’s horrible, so I don't want that. Yeah, that would be my first port-of-call would be those.

00:45:34 **Cathy Beresford**

And I've I mean, to be honest, I don't need to ask you any questions any now because you've given me so much information. It's really helpful. Is there anything that you want to ask me now? So, what I what I'll do is the recording that I've made of our interview. I put it into the computer and then it it creates like it puts it into words for me. So, it's the transcript, but it does look a bit funny when it does that. So, I will tidy it up a bit, but it can look a bit sort of disjointed and a bit confusing, but would you like me to send a copy of it to you so that you've got a copy for your of your of your transcript for your records.

00:46:19 **PWLD05**

I I don't mind it. I I'm not. I don't want to say no, I'm not bothered.

00:46:24 **Cathy Beresford**

It's, you know what it. Honestly, it honestly it's completely up to you. So, I'll give you an.

00:46:30 **PWLD05**

I don't know, and honestly, I don't mind because I've had to go through my paperwork.

00:46:33 **Cathy Beresford**

Yeah.

00:46:34 **PWLD05**

Because that's something that you do end up getting ever such a lot of.

00:46:37 **Cathy Beresford**

Yes.

00:46:39 **PWLD05**

And I've gone through it and just sort of highlighted bits that are important for now, all stuff that I might need to relate to in the future. But yeah, you can send it if there's no trouble with it.

00:46:53 **Cathy Beresford**

It's no, it's no trouble whatsoever. It's more. It's more about whether or not you want it. It's.

00:47:00 **PWLD05**

Yeah. No. Yeah. No, that's cool. Yeah, you know.

00:47:02 **Cathy Beresford**

Fine. Yeah, it's a it it will. It will be a lot of pages cause I'll give you an example. The one I've done I've just gone through one today and I think it was about 40 pages. But you don't. It's totally up to you whether you read it or not and and also what I can do is put like a stamped addressed envelope. Do am I writing thinking you do you use e-mail?

00:47:24 **Cathy Beresford**

It's no, that's fine. So, what I'll do is I'll put a stamped addressed envelope in with it so that if you've got any comments or questions, you know if there's anything that you think ohh I'm not happy about that. You can just write to me and stick it in the post. Does that? Yeah. Is that alright or or is

00:47:43 **PWLD05**

Yeah. That's fine. Yeah. I don't think I'll have any. You know, I can. Whatever. What I've what I've said to you is, well, it's my experience and you know, it's not well, it's nothing. Well, yeah.

00:47:53 **Cathy Beresford**

Yeah, you've been very clear.

00:48:01 **PWLD05**

Really, it's just what I’ve personally experienced.

00:48:04 **Cathy Beresford**

Yeah, that's that's great. No, exactly. And that's that. You know what, that's exactly what I asked for. I wanted your experience, your perspective. There’s honestly no right or wrong answers at all.

00:48:15 **Cathy Beresford**

So, I'll I'll put it in the post for you and and I'm just sorry, I'm just thinking about the best way to do it. Would you prefer? I'll give there's two options. One is I put the stamped dressed envelope in there so you can write to me if you've got anything you wanna say or the other option is I could just ring you after a couple of weeks and say is there anything you wanna change your.

00:48:36 **PWLD05**

Well, why don't you do that? Just ring me. Ring me in a couple of weeks because, like I said, I'm gonna ask them questions Monday. When I got my outpatient and that we do with coming off these tablets. And is there a bit of it happening again? And so, I can give you a little bit of info on.

00:48:38 **Cathy Beresford**

Fine, yeah.

Fine. All right.

Fine.

Sure.

00:48:54 **PWLD05**

That if you want.

00:48:54 **Cathy Beresford**

Alright, OK. That's fine then. So I'll I'll stick it in the post. It might take a few days to get to you. So, it's a big it will, you know it will be a big chunky thing.

00:49:00 **PWLD05**

Right.

00:49:02 **Cathy Beresford**

But just honestly, no pressure for you to read through all of it. It's just that I wanna make sure you have it. If you want to look through it, if you.

00:49:10 **Cathy Beresford**

See what I mean?

00:49:10 **PWLD05**

Well, yeah, well, if I'm perfectly honest with you. Actually, I do. I do want it because I've.

00:49:15 **Cathy Beresford**

Fine.

00:49:17 **PWLD05**

Just thought that because I'm like on benefits, I mean I normally work. I worked all my life.

00:49:25 **Cathy Beresford**

Yes.

00:49:27 **PWLD05**

But I'm on benefits at the minute, and sometimes they want to, they they'll, like, write a letter or rings and they want to find out more information. If I'm not able to give them.

00:49:36 **Cathy Beresford**

Yes.

Yeah.

00:49:41 **PWLD05**

More full information. Also, I'm not quite sure, I mean unless they've got a doctor hanging around in their office, which I really don't think so. They're not going to understand some of the words that I can give them anyway. I mean, they might look them up, but they're not gonna know my full experience of what I've dealt with and what kind of recover from. So that might be handy.

00:50:00 **Cathy Beresford**

Yeah.

00:50:02 **PWLD05**

I mean to have. I have spoken to you, and you know this is like what I've I've what I'm trying. Yeah. What I'm trying to recover from.

00:50:05 **Cathy Beresford**

Yes.

No problem.

00:50:11 **Cathy Beresford**

Yeah, it might help you to remember things, mightn't it? Yeah. No, no problem. I I will. I will sort that out. Then this week, it's been really good to talk to you and to hear everything. And I just wish you all the best you know, with everything that you've been through because it, you know, it's it doesn't sound easy.

00:50:29 **PWLD05**

No, it hasn't been. It's. It's getting a bit easier now, but then that it's just easier for my brain as in I can do stuff because

00:50:36 **Cathy Beresford**

Yes.

00:50:37 **PWLD05**

I’ve watched everything possible I can watch on the telly.

00:50:40 **Cathy Beresford**

Yeah.

00:50:42 **PWLD05**

And like I said, I'm not. I'm not sort of sat on my arse all my life and looked out the window. I've been out working and running around and doing stuff and being trapped inside is a bit of a, I’m getting cabin fever terribly.

00:50:55 **Cathy Beresford**

Sure, sure.

00:50:57 **PWLD05**

So, I need to get out and about and it has helped that I can go out and take a dog for a walk a little bit and I'm still getting very out of breath. I don’t go far, but it's just I'm out and about a little bit more now.

00:51:04 **Cathy Beresford**

Yeah, yeah.

Yeah. Alright then. Well, that's it for today. Thank you so much.

00:51:16 **PWLD05**

OK, if you ring me in a what, a couple of weeks?

00:51:18 **Cathy Beresford**

Yeah.

Alright, lovely.

00:51:20 **PWLD05**

Yeah, cool. Alright. Yeah, you do that. Yeah, that's alright. You do the same sort of time. That's great. Any day you want.

00:51:22 **Cathy Beresford**

Thanks then.

Yes, no problem, no problem. I know that afternoons are better. That's fine then. OK, take care. Alright, bye.

00:51:32 **PWLD05**

OK. Thanks Cathy.

Addition 25/06/2024 when I rang him to see if he had anything to add / reviewed transcript:

* Lack of their understanding of the condition that you’ve got – the ward nurses. They weren’t fully aware. Sometimes I was acting out of my normal personality. Nurses on ward might not understand why I behaved that way. I may have been out of order.
* Specialise in that area. They need to know about those symptoms of encephalopathy. Surely, they could have written it down for me. I wasn’t sure what was going on. Sometimes the nurses could have been more supportive in that respect.
* One time I had to go back to be drained. I was on a ward rather than a side room. Why can’t you do the drip after teatime, rather than a time that doesn’t works for me.
* Conflict between hcp and pwld. Lack of knowledge how someone can act in my condition. How to care for that situation. Don’t need to know the ins and outs of the disease, but how people might act.
* Partner told me after being admitted in February (I don’t remember) I had a tube down my throat. I woke up and ripped it all out. I don’t remember things. More stuff in writing.
* If it wasn’t for carer I would have been better in hospital. But I did need care at home. She is a carer anyway. I needed that help. She’s been a diamond. – [i.e., couldn’t be at home when he was first discharged if she wasn’t there to look after him].
* He thinks that his carer may be willing to be interviewed too.