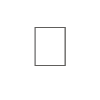
# PWLD03 ‘Robert’ - Interview Transcript 16 May 2024, 09:30am by Teams

 **Catherine Beresford** 0:03  
Transcript 'cause that's a bit off putting So, that we don't have to see it.

 **Catherine Beresford** started transcription

 **PWLD03** 0:08  
OK, just let.

 **Catherine Beresford** 0:09  
OK, So, you should have a message to say that it's recording and transcribing. Is that right?

 **PWLD03** 0:14  
Can't see anything.

 **Catherine Beresford** 0:16  
OK. I just So, you know it is because I can see at this end. So, it's got a message for me to say it's recording lovely. OK, thank you.  
So, much for your time today. So, to start off with, can you tell me about your journey of receiving care since you found out that you have liver disease?

 **PWLD03** 0:38  
Yeah. So, in January on January the 5th, 2020, I was at home.  
And I'd gone for a shower and not come back and cut. Long story short, mum found me hallucinating in the bedroom.

 **Catherine Beresford** 0:53  
Gosh.

 **PWLD03** 0:54  
And that was that was well, later that we found that that was hepatic encephalopathy.

 **Catherine Beresford** 1:01  
Yes.

 **PWLD03** 1:04  
So, yeah, it was. I can still remember what happened to me, but I can't remember anything. I can remember what happened when one came to the bedroom, but I can remember nothing then until I was on the ward about four or five days later on the Royal [Name of place] Infirmary in [Name of place], on the [Name of place] suite. I've been on an acute ward for two days. I've had act scan on the brain. I remember nothing about this. And in those in those first four or five days, mum was told on several occasions when I was in and out of consciousness.

 **Catherine Beresford** 1:19  
Right.  
Yeah, yeah.  
Right.  
Yeah.

 **PWLD03** 1:40  
That I wasn't going to live, but it it was extremely likely that I would pull through because I was very young. I was diagnosed with hepatic encephalopathy. I had cirrhosis, cirrhosis of the liver.

 **Catherine Beresford** 1:53  
Yeah.

 **PWLD03** 1:54  
Decompensated liver and ascites. And again I and I remember nothing of anything that first four or five days until I woke up.

 **Catherine Beresford** 1:56  
Yeah.  
I see, yeah.

 **PWLD03** 2:05  
I just spent a month in hospital.

 **Catherine Beresford** 2:09  
Right.

 **PWLD03** 2:11  
On the on the [name of] suite.  
The I've got to be honest, the care I received it well, the nurses and the doctors there, they saved my life. I can't have thanked them enough for what they what they for me. I still go and see them now. And I write to them because everything I do now is dedicated to the - used to come in. I always remember they used to call me the miracle man on the ward because nobody nobody expected me to survive.

 **Catherine Beresford** 2:20  
Yes.  
Really.

 **PWLD03** 2:36  
Yeah, they weren't cool. Yeah, but on in, in that month in hospital.

 **Catherine Beresford** 2:37  
Yeah.  
Yeah.  
Mm hmm.

 **PWLD03** 2:43  
I couldn't walk properly or because of the, because of the liver cirrhosis I it was so severe that I had to have a Zimmer frame and all the time I was in hospital. Yeah, I never. I can still remember the physiotherapist walking down the wall with his Zimmer frame. Still, remember it clearly and thinking that must be for the two guys in the bed next to me. The older guys, and she's sort of.

 **Catherine Beresford** 3:01  
Yes.

 **PWLD03** 3:07  
Come to me. Who was that for? She said it's for you. I won't need that. She said. Oh, I think you will. And. And you know we progressed. We progressed from that until a walking stick. But in all fairness, the care in hospital was was was excellent.

 **Catherine Beresford** 3:10  
Yeah.  
Yeah.

 **PWLD03** 3:23  
A lot of it, obviously. I was out of it most of the time, was still with the hepatic encephalopathy. I was still hallucinating.

 **Catherine Beresford** 3:26  
Yeah.

 **PWLD03** 3:31  
Really badly not making what at times I know I wasn't very pleasant, which has always been one of my regrets, but that's unfortunate.

 **Catherine Beresford** 3:32  
Yeah, yeah.

 **PWLD03** 3:39  
Side effects of HE.

 **Catherine Beresford** 3:41  
Yeah, yeah. And and what about since then? Since you came out of hospital?

 **PWLD03** 3:46  
Since then, both this. When I came, I mean when I came out of hospital and I've said this on a number of occasions, the nurses and the doctors and my own doctor did what they can. But I left hospital with my medication and a diet sheet.  
I didn't have anything to tell me about HE, my mum and my brother had come up from London. They didn't know there was no, there was no.

 **Catherine Beresford** 4:06  
Right.

 **PWLD03** 4:12  
And I spoke, I spoke about this a couple of years ago. I went down to to London to speak to a group of MPs about this pathway and in certain parts there was no pathway for me.

 **Catherine Beresford** 4:22  
OK.

 **PWLD03** 4:24  
There was no pathway when I left hospital. Nobody told me that, you know, with HE and all the rest, I won't be able to walk properly. I couldn't read properly. I couldn't write, couldn't dress myself. I was still falling.

 **Catherine Beresford** 4:29  
Yes.  
Right.

 **PWLD03** 4:38  
I had a nasty fall in the April.  
There was no there was no. There was no, no, there wasn't. I got a call from a hepatologist and a consultant. Would you know, in between that time, there was nothing.

 **Catherine Beresford** 4:49  
Yeah.

 **PWLD03** 4:51  
It was to tell me of how our my family, our my friends, you know, eat. I had a carer. It's I had. I won't say who from, but that they didn't even know when they came to see me. They didn't even know what my condition was. 'cause I was prone to what I used to call the wobbles because I was unstable.

 **Catherine Beresford** 4:56  
Right.  
Right.  
Yes.  
Yeah.

 **PWLD03** 5:10  
And I said, I don't any fuss if you're out and I don't want any fuss, just find me somewhere to hang on to and I'll do it. I don't want you know, but they don't even know that. All they said was well, we're just, we didn't. We're just here to take you out for an hour. We don't do your washing. We don't do your cooking.

 **Catherine Beresford** 5:15  
Yeah.  
Right.

 **PWLD03** 5:26  
And I felt lost.

 **Catherine Beresford** 5:26  
So, was that sorry, was that social, like social care or was that? Yeah, I see. Yeah. Yeah.

 **PWLD03** 5:29  
It was, yeah, it was. Yeah, it was. It was organised by the hospital, which was fine. I agree to all of that. I'm not. I'm not again with the hospital. No issue with that. But there was nothing. There was no, there was no no pathway at all.

 **Catherine Beresford** 5:40  
Sure.  
Yeah.

 **PWLD03** 5:47  
Not even from a mum. You know my mum and she describes she's written her own story online as well as mine. About.

 **Catherine Beresford** 5:53  
I sure.

 **PWLD03** 5:55  
My behaviour with hi was, you know, the difference between me today.

 **Catherine Beresford** 5:56  
Right.

 **PWLD03** 6:01  
Four years ago it was and and obviously when I I didn't know how badly I behave. But if I'd have known all people would have known, it would have been a lot better. But that was that was the biggest issue. It was was until I found the British Liver Trust in 2021.

 **Catherine Beresford** 6:06  
I.  
Yes.  
Yeah.  
Oh, I see. Yeah. Yeah. So, tell me a bit more about that.

 **PWLD03** 6:22  
Well, in towards the back end of the year, I I was getting better. I was still struggling, but I knew I had to do something. I needed to learn more about my own liver condition, but also, more about hepatic encephalopathy, So, set about in January I thought, well, I'm going to find it as a local - this is pre COVID of course.

 **Catherine Beresford** 6:36  
Yes.  
Hmm.

 **PWLD03** 6:44  
I wanted to find out if there was a local group that I could. I wasn't driving then, but I could go to see or or telephone and I'll just Google them and they came across an organisation called the British Liver Trust and I've never.

 **Catherine Beresford** 6:49  
Yeah.  
Yes.

 **PWLD03** 6:57  
Never heard of them. They were signposted, but I left left hospital and I emailed, filled in an online form which you have to give all your conditions and stuff. And then within about two or three days.

 **Catherine Beresford** 7:09  
Yeah.

 **PWLD03** 7:10  
Had an e-mail back from the lady called [name of person] then was the group coordinator of all the support groups.  
She contacted me and then we had a telephone call and I was frightened and she. But, you know, I've always said this and she almost could. She didn't have to drag me kick into screaming, but she cajoled me.

 **Catherine Beresford** 7:25  
Yeah.  
I see.

 **PWLD03** 7:31  
Very nice, she said. Come come to - we've got a meeting next week. Spend, I've never done Zoom before, she said. We'll have 15 minutes with me. We'll have a chat and see how you feel, and I've always said that hour and 15 minutes changed my life forever, yeah.

 **Catherine Beresford** 7:34  
Yeah.  
Sure.  
Yeah.

 **PWLD03** 7:48  
I've never, never changed my opinion on that because.

 **Catherine Beresford** 7:51  
Yes.

 **PWLD03** 7:52  
Suddenly met people that I saw. I didn't know what Zoom was like. Mum does it for her church so, she told me what to expect, but.

 **Catherine Beresford** 7:59  
Yes.

 **PWLD03** 8:00  
It's all a sea of smiling faces and people that were helpful and.

 **Catherine Beresford** 8:04  
Yeah.

 **PWLD03** 8:04  
'Cause they were talking that could relate to what they were saying. That's the first time I could really relate to.

 **Catherine Beresford** 8:09  
I'm with you, yeah.

 **PWLD03** 8:11  
I didn't feel I didn't feel stigmatised. That was able. I felt safe, which is the most important thing. I felt safe to be able to talk about what was happening to me, what happened and obviously I think I spoke too much about the drinking, my drinking in the past. It was where I was now.

 **Catherine Beresford** 8:15  
Yes.  
Yeah.  
Yeah.

 **PWLD03** 8:31  
But I wished I'd I wished I'd had them in. Maybe not, not in, it might have been difficult in the very early days, but certainly I would. They were around or organisations like them. I know there were organisations affiliated to the hospitals but.

 **Catherine Beresford** 8:31  
Yeah.  
Yeah.  
Yeah.

 **PWLD03** 8:48  
But for me personally, yeah, that that was the that was the hour and 15 minutes mid-January 21 that changed everything for me really.

 **Catherine Beresford** 8:55  
Yeah, yeah. So, tell me a little bit more about that like, because obviously that was in 2021. So, how have things been since then?

 **PWLD03** 9:04  
Yeah. Well, from personal point of view, I haven't had a drink. Now. I think the other day I was 1600 days so but haven't had a drink. I've only ever thought about it once and that was a very the first Mayday bank holiday. It was only a very brief fleeting thought the weather was nice enough. What I'll be doing now, I don't know what I would have been doing, but it only cost me. But I made a promise when I left hospital. When I left the day I left hospital. Then when the doctor was discharging me, I

 **Catherine Beresford** 9:10  
Hmm mm hmm.  
Yeah.

 **PWLD03** 9:33  
I said to I promise you, I'll get better and I can still. I can still picture it, I could take you now to what it was. And she said no. Don't promise me. Don't promise us. Promise yourself. If you promise yourself. And and I did that and I'll never break that promise. Because the care that was given me not just by the nurses and the doctors and the consultant by the alcohol team that came to see me. And I was very privileged last summer to do a presentation back at the hospital about recovery and it was part of the alcohol team. So, it was a really good way to repay them. And you’ll know this I think the people the nurses and the doctors and the alcohol team see it as their job. But I can’t put enough words into how much it’s meant to me and my family

 **Catherine Beresford** 9:38  
Yes.  
Yes.  
Yeah.  
Yeah, yeah.  
Yes. Yeah.

 **PWLD03** 10:28  
For what they did for me. But no, I think that'll be become a granddad twice.

 **Catherine Beresford** 10:30  
Yeah.

 **PWLD03** 10:34  
In the last four years.

 **Catherine Beresford** 10:36  
Yeah.

 **PWLD03** 10:37  
So, all of those things, there's no bigger reason for me to stay. Well, and I've been involved in in I started off with a webinar for the British Liver Trust about my journey, my drinking journey from from 17 up to the two years ago, three years ago, right up to today. But I've, I've.

 **Catherine Beresford** 10:41  
Yes.

 **PWLD03** 10:59  
Because I've been involved in in different research projects and things like that. One that one. Yeah. Even the one last night as well. What I've noticed is.

 **Catherine Beresford** 11:05  
Have you? Yeah.

 **PWLD03** 11:11  
Is everybody that I've met in the different seminars and the research projects I've never met nice people because everyone's got the same goal.

 **Catherine Beresford** 11:18  
I see, yeah.

 **PWLD03** 11:19  
Yeah. When you when I worked in teams before I was I'll it was very different. It was a different type of thing. But I think to become involved in for me it's about giving back as well. It's about getting about giving back and trying to ensure that as many people as possible don't go through what I went through or what I put my family and my friends through I mean take for instance yesterday I picked up my oldest granddaughter from preschool for the very first time now that was huge and they're not just seeing a picture of me saying that I'm playing a really big

 **Catherine Beresford** 11:38  
Sure. Yeah.  
Yeah.  
Yes.

 **PWLD03** 11:55  
big part in their lives and I just try and do as much as I can to keep well.

 **Catherine Beresford** 11:56  
Yes.  
I see.

 **PWLD03** 12:01  
Don't eat as well as I should do, but I think that's that's probably again part of possibly the addiction in terms of certain things that you know the addictive behaviour in terms of sweets and stuff like that. You know, I'll keep as fit as I can.

 **Catherine Beresford** 12:12  
Yeah.  
Yeah.  
Yeah.

 **PWLD03** 12:18  
But I don't ever want to go back to where I was and have no intentions. I know it's obviously you don't know me, but.  
I'll never go back. Never, ever 'cause. You know what The thing is, when people have not just when my mum and my friends, obviously my family and my daughter put so much faith in me. I don't want to. I don't have to go. Oh, I've done. You know I can't do it. I can't do it. I know. I know that. I know that even if I tried one drink it, no, it wouldn't. We were talking about this last night. It wouldn't be that one that would kill me. It would be.

 **Catherine Beresford** 12:43  
Yeah, I understand. Yeah.  
Yeah, yeah.

 **PWLD03** 12:55  
The 9th or 10th. But and I've got a lot of loyalty to my doctor as well. I've got a lot of loyalty to those that that, and the British Liver Trust and all the friends I'm. I've got a loyalty.

 **Catherine Beresford** 12:55  
Yeah.  
So.  
So, the doctor you're talking about is that the which which doctors that?

 **PWLD03** 13:12  
It's my own GP. My own? Yeah. 'cause. I have to go in in the six weeks after I came out of hospital, I had what I discovered was a gross edoema was extremely unpleasant.

 **Catherine Beresford** 13:13  
Oh, I see. Yeah.  
Right.

 **PWLD03** 13:25  
I didn't know what it was. I went to see him and within 45 minutes of seeing him, I was back in.  
The [Name of hospital].

 **Catherine Beresford** 13:33  
Really.

 **PWLD03** 13:34  
So, yeah, it was. Yeah, it was. It was quite dangerous, but I let it go on too long again.  
So, yeah, I did. I didn't. I one of what it was. I thought it would go away. It was unpleasant to say the least.

 **Catherine Beresford** 13:42  
Yeah.  
Yeah, yeah.  
So, thinking about, obviously you've mentioned some of the services that you've accessed for care in relation to your liver disease.  
Are are there any other services that you that you access at the moment or that you've been accessing in the last sort of couple of years?

 **PWLD03** 13:58  
  
Yeah, I've I have recently spent five weeks with a psychologist, a counsellor at at the local surgery. Yeah. 'cause. I was struggling with low self esteem.

 **Catherine Beresford** 14:12  
Oh yeah.

 **PWLD03** 14:19  
And that that's been an incredibly valuable 5 weeks.  
A lot about.  
A lot about more about myself being more, understanding things and setting boundaries.

 **Catherine Beresford** 14:29  
Yes.  
Yeah.

 **PWLD03** 14:35  
She was really, really good. It was, it was. It was my doctor that put me on to her. And she, you know, she invested a lot of time in me and equally with the same, you know, and I and I, you know, I've got all the she's given me a great amount of tools to use, you know, when I'm when I'm feeling low because I think the problem is with.

 **Catherine Beresford** 14:40  
Yeah.  
OK.

 **PWLD03** 14:58  
I was drinking and all the rest of it. I left it go on too long, but now I don't, I think.

 **Catherine Beresford** 15:02  
Yeah, yeah.

 **PWLD03** 15:04  
And to reach out, but that would that, that, that have reached out for.

 **Catherine Beresford** 15:10  
And and what about? What about? Like any liver specialists, are you seeing any liver specialists now?

 **PWLD03** 15:16  
Every six every six months. In fact, I've got. I've got, actually, I've got. I've got a consultant's appointment on my birthday. Ironically, 'cause they come through with a list. So, that's at the [Name of hospital]. That's about every I think it might be. It might be a bit longer this time, but every six months I see a liver specialist. The consultant.

 **Catherine Beresford** 15:18  
Yes.  
Yeah.  
Yeah.

 **PWLD03** 15:37  
I'll put the [Name of hospital] for a check-up with everything and going through all the meds and how I've been and I've have have an ultrasound every six months.

 **Catherine Beresford** 15:42  
Yeah.  
Yeah. OK. So, if you needed any support or advice or you know, information about your liver disease in the meantime, then what, what, what would you do?

 **PWLD03** 15:47  
And.  
If I had an issue if I was really struggling, I would. My first port of call in all fairness, which I've done before, would would be to ring the British Liver Trust Nurse. Nurse. Yeah, I I had an episode.

 **Catherine Beresford** 16:04  
Oh, really? Yeah, yeah.

 **PWLD03** 16:11  
Of HE little while ago, and it was so. It was scary for my friend who was with me and.

 **Catherine Beresford** 16:14  
Yeah.

 **PWLD03** 16:19  
So, immediately I rang the British Liver Trust, spoke to other nurses there and they talked to me and then advised me to go and see the doctor, which I did do straight away and and and it was it was resolved before we sort of came

 **Catherine Beresford** 16:21  
Yes.

 **PWLD03** 16:34  
to a conclusion of why that episode had been building and starting it had lot of us to do with with stress related, but it was pretty scary that I could turn to them straight away.

 **Catherine Beresford** 16:42  
I I.  
Yeah, yeah.

 **PWLD03** 16:47  
And then obviously my doctor, because he I don't always, I don't see him for everything. I mean, I've got a problem with my feet again, which is related to the liver. I have neuropathy and it's horrendous at the minute. So, I don't need to see him for everything, but he's the one that I see. If you know, he'll ring me. He's really good. He's been amazing.

 **Catherine Beresford** 17:05  
Oh, you. Is this the GP you're talking about? Yeah.

 **PWLD03** 17:07  
My GP. Sorry. Yeah, my GP. Yeah, I see him for my own check-ins. I'll contact him about every three or four months.

 **Catherine Beresford** 17:12  
Yes.  
And you say you said that he's really good. So, tell me what it is about him. That's really good.

 **PWLD03** 17:19  
Hey.  
You well, I think.  
He understands, he doesn't stigmatise me. He is, he is just. He's just a really, really nice guy and I feel as though 'cause. I I think one of my biggest regrets, I hope I'm not going on too much, is that is, is, and I've always said this is that is lying to him. You know, when I was still drinking, I'm going there seeing him and he'd ask me how much I drunk. And I never told him the truth and I wished I had because I know he'd help me either help my he is now.

 **Catherine Beresford** 17:40  
No, no.  
Yes.  
Do you? Yeah, yeah.  
Yeah, yeah.

 **PWLD03** 17:59  
And just the way he's been with me all the way through and and and after it was, all I can tell him anything. I mean, I told him, you know, about how I was feeling immediately. He redirected me to the counsellor, the surgery straight away within the day, I've got an appointment.

 **Catherine Beresford** 18:12  
To to the to the what? Sorry.

 **PWLD03** 18:15  
To when? When I told her about how I was feeling, I was feeling really, really low and I I can't deny that that there are certain days that I still struggle.

 **Catherine Beresford** 18:17  
Yes.

 **PWLD03** 18:26  
But he immediately directed me to the to the lady [counsellor] that got the surgery and within two days and appointment was made. And you know, I know that he'll he'll look after me. I know that's his job and all the rest of it. But he does. I feel safe, I suppose, with him as well that I can tell him anything. I don't want to see him for everything. I don't. I won't go and see him.

 **Catherine Beresford** 18:43  
Yes.  
No.

 **PWLD03** 18:47  
For things unrelated, if you will, because he’s busy, but but now he's he's been really good with me. I just yeah, there's a bond, if you like coming over. He has as a patient. And I'm. I'm from just another patient. But to me, to me he's been he's been a godsend.

 **Catherine Beresford** 18:50  
Yeah.  
Yes.  
Yeah. So, you've already given me some examples, but is there anything that stands out in your mind of when you think care that you've received has been particularly positive for you?  
Specifically in relation to your liver disease.

 **PWLD03** 19:20  
I think in hospital the nurse will do it. The nurses were were amazing. They were. They used to come and see me in the morning to see how I was. It was it was, it was. And when I went back, when I went back the second time with a gross oedema, it was almost. It was like a lot because I was really frightened when I was on the acute ward, I was. I had to go back onto the [Name of place] suite I was really scared that they think I'll that because I was drinking. And I remember speaking to still remember her name. [Name of person], I said when you when you book me into the lab, when you promised that you'll tell her I'm not coming back because I've been.

 **Catherine Beresford** 19:29  
Yeah.  
Yes.  
Yeah.  
Oh yeah, yeah.  
Yeah, yeah.

 **PWLD03** 19:57  
Drinking again and in all fairness.  
In all fairness, she did so, and it it was just.

 **Catherine Beresford** 20:00  
Yeah.

 **PWLD03** 20:03  
Again, it didn't bother me, although I was in a lot of pain and it was quite concerning, it didn't bother me 'cause I knew I was in good hands. You know what I mean?

 **Catherine Beresford** 20:10  
Yes, yes.

 **PWLD03** 20:12  
I'm not just saying this because of your profession because that you can. I've said this a time or two.  
Yeah. In in hospital. I thought the care where is. See, I owe them everything.

 **Catherine Beresford** 20:22  
Yeah, I see. And on the other side of the coin, have you got any examples of when you think the care you received for your liver disease has actually been negative for you?  
Yes.

 **PWLD03**

Yes. It’s the day I left I suppose in many respects. There not being. Although there was a call from a hepatologist every three, I can't remember exactly. Wasn't regular there wasn't, there wasn't the information. I, I I just a bit after I joined the British Liver Trust. I had a book about hepatic encephalopathy in the little car that I put in my wallet, just to if it happened to me. And and. And I'll keep it in the car. It's like it's a booklet which you update to your doctor's appointments, and it gives all the symptoms. I didn't know about that. I should have been given something.

 **Catherine Beresford** 21:01  
Yeah.  
Hmm.

 **PWLD03** 21:14  
That or something like.

 **Catherine Beresford** 21:15  
I see.

 **PWLD03** 21:17  
I mean, I have the diet sheet, which is fine, but I should have been given.  
I should've been given a lot more tools.  
When I left hospital and that's not the hospital's fault. That's the fault of whoever's 'cause I know in certain parts of the country; you get assigned to living here when you're in hospital and when you're out of hospital.

 **Catherine Beresford** 21:38  
And did did. Did you? Did you have you had a liver nurse?

 **PWLD03** 21:41  
No, didn't have one in hospital, no.

 **Catherine Beresford** 21:44  
Have you had one subsequently?  
And what about a dietitian?

 **PWLD03** 21:51  
Had a diet sheet, but I haven't really had a dietitian follow it up, but I don't have to have an issue with that 'cause. I know I can. I don't have too much of an issue with that because I know that I know what I should.

 **Catherine Beresford** 21:56  
Yeah.  
OK. Yeah.  
Sure.

 **PWLD03** 22:06  
What I should and shouldn't do, and I think it's just as I probably don't I well my freezer freezer. I do a lot of batch cooking. I know what I can do, but sometimes I swear, but when I'm busier, it doesn't. It's not a problem. It's when I'm not busy that.

 **Catherine Beresford** 22:08  
Yeah.  
Yeah, yeah.  
Yeah.

 **PWLD03** 22:21  
It's to do all things, but no negative care is the care I didn't receive there isn't there wasn't a pathway.

 **Catherine Beresford** 22:29  
I see. Yes, that's interesting that you say that, yeah.

 **PWLD03** 22:31  
If you're in somewhere like Wales, when I when I went down to London to speak to the MPs they had a map of Britain and it was a different health boards in green, amber and red. I think it was. Don't quote me on that. And if you look at certain part, most of Wales is green.

 **Catherine Beresford** 22:44  
Yeah.  
Yes.

 **PWLD03** 22:49  
And then Central Scotland, I think is green and parts of London are green. But a lot of the other parts of the country, there's no there's no set pathway. I did an interview last year with Easel about hepatic encephalopathy, and that was one of the questions they asked them about the pathway because they want to learn more.

 **Catherine Beresford** 23:08  
Yes. Yeah. So, for you, it was the fact that you've got this positive care in hospital, but then when you left, you were sort of left to get on with it.

 **PWLD03** 23:19  
Yeah, I describe myself as a as a lost soul.

 **Catherine Beresford** 23:23  
Really.

 **PWLD03** 23:24  
Yeah, I was 'cause. I lived on my own, I still do not. No, I'm not. I'm not not. I'm not using that as an excuse.

 **Catherine Beresford** 23:26  
Yeah, yeah.  
No.

 **PWLD03** 23:33  
I've got friends here. I don't like. It's used to friends, but when life is changing you, I couldn't even. I couldn't even get up off the floor. Nobody was having to crawl because I my legs wouldn't work properly and having to use a walking stick and the toilet in stuff. When you're using Lactulose and all those things, I didn't know anything I didn't know.

 **Catherine Beresford** 23:34  
Yeah.  
Yes.

 **PWLD03** 23:55  
And here we have things of assist that you know and you don't know that it's gonna get better, but then when you speak to people like I did and obviously now as I've gone along and I've grown So, much as a person, I think being involved in the different projects, I mean, gosh, there's all sorts, all sorts of different trials and research projects where the paper where the patient's voice is is.

 **Catherine Beresford** 23:59  
Yeah.  
Yeah.

 **PWLD03** 24:21  
Is needed now more than ever with liver disease, I think.

 **Catherine Beresford** 24:24  
Do you? Yeah.  
Tell me a bit more about that.

 **PWLD03** 24:30  
Yeah. I mean, there's a current project that I'm on now. It's part of the [name of] liver project based up in [City name] project I'm involved in is [name of project], which is raising awareness for the early detection of liver cancer.

 **Catherine Beresford** 24:46  
Yeah.

 **PWLD03** 24:47  
And and that's been incredible because I didn't know that I was vulnerable to that. I didn't know how it would affect certain communities and certain deprived areas didn't know about health inequalities. I do now.

 **Catherine Beresford** 24:53  
Hmm.  
Yes, yes.

 **PWLD03** 25:02  
But again working, I didn't know anybody when I first went into that room back in. Gosh, I think it was August last year, but you're part of a team that's all got the same goal.  
We did a big presentation in [name of city] in front of about 60 or 80 people and that was one of the proudest moments of my life, I think.

 **Catherine Beresford** 25:23  
Yeah, yeah.

 **PWLD03** 25:25  
But I've done also, yeah.

 **Catherine Beresford** 25:25  
Oh, thank you. Yeah. Thank you for sharing that. That's helpful to know. So.

 **PWLD03** 25:29  
Yeah, I don't. I don't know all sorts of different. It sounds like if it would sound like I was bragging 'cause I'm not 'cause I was even saying to my daughter am yesterday, it seems unreal, and I think of.

 **Catherine Beresford** 25:31  
Yeah.

 **PWLD03** 25:42  
The things I've done and people listen and and I just do it. I did it one last year and I was.

 **Catherine Beresford** 25:43  
Yes.

 **PWLD03** 25:49  
I stood at a lecture. I never used to lecture before, but because my story never changes, you see story never changes.  
Yes, but do you know what I do have all this, Cathy. I stay positive all the time. I've always stayed positive and and done as I've been told.

 **Catherine Beresford** 25:56  
Yeah.  
Yeah, yeah.  
I see, yeah.

 **PWLD03** 26:05  
And listen.

 **Catherine Beresford** 26:07  
Yeah, that's interesting.  
So, after having all these experiences of care for advanced liver disease, what advice would you give to somebody who's just discovered that they've got advanced liver disease?

 **PWLD03** 26:23  
The first piece of advice would be to cut back to the point where you cease drinking alcohol.

 **Catherine Beresford** 26:31  
OK.

 **PWLD03** 26:31  
Like if you've got that, I think abstinence is the only way that things will start to improve because it lifts a huge cloud, and it lifts a huge cloud from those around you as well because they will notice the change before you do.

 **Catherine Beresford** 26:43  
Yeah.

 **PWLD03** 26:46  
And my advice would be, do you know what I'll give them? I've given them the advice that I was given at my very first British meeting. British Liver trust meeting by a guy called [Name]. He said to me, first of all, PWLD03, he said you've got to stay positive.

 **Catherine Beresford** 26:59  
Yeah.  
Yeah.

 **PWLD03** 27:04  
He said secondly, he said you have to do as you're told by your doctor, your consultant, your nurse, your nurse practitioner and if they tell you to do, you should do because they want to get you better. And he said, and he and he said finally, he said you have to want to do this. You have to want to get better and that and that is the key one I think is you have to, you have to want it because it's not just yourself, it's affected. It's it's it's everything around you.

 **Catherine Beresford** 27:22  
Yes, yeah, yeah.  
Yeah.

 **PWLD03** 27:35  
I look how my life has changed. Now you lose friends. It won't deny that you'll lose friends. 'cause, you're not part of the group that goes out drinking or or. That's their main way of socialising. So, you have to expect that. And that is hard. That's happened to me with three what I thought were close friends that had known over 80 years between the three of them that speak to us for four years. But what you will find is you'll meet So, many new friends along the way.

 **Catherine Beresford** 27:49  
Yeah.  
Yeah.  
Yeah.  
Right.  
Yeah.

 **PWLD03** 28:06  
Come proper friends, not just mates, acquaintances, proper friends and and I think.  
Is is always have hope because.  
I I started to think there was no hope for me, but there is if you can just look for the light at the end of the tunnel and it will get brighter. Honestly, it will get. I never thought mine would, but if you have hope and like I say and and try and do different things and I started to do some crash, you know to fill the time that I would have been a sat in my apartment during that I got involved with an artist group. I started doing art some craft after that work and doing a bit about history and stuff like that. They were my worst subjects at school but again what it does.

 **Catherine Beresford** 28:23  
Yeah.  
Yeah.  
Yes. Yeah.  
Yeah, I see.  
Yeah.

 **PWLD03** 28:47  
Talk to me different people and find skills that you.  
You never thought you you had to 'cause. Obviously. You're not gonna have to fill that time that you would have been in a pub, in a restaurant or home drinker. I was a home drinker.

 **Catherine Beresford** 28:57  
Yeah, yeah.

 **PWLD03** 29:02  
But find find different things but believe believe you can get better because but like I say, the people around you will notice the change quicker than you do and that's that's what I found really interesting because you're more coherent. You think about things different.

 **Catherine Beresford** 29:16  
Yeah, yeah, yeah.

 **PWLD03** 29:19  
Yeah. You're more amenable shall we say.

 **Catherine Beresford** 29:23  
Thank you. And so, thinking about your experiences again, then specifically in relation to the care you've received for advanced liver disease, what advice would you give to professionals who work with individuals who've got advanced liver disease?

 **PWLD03** 29:40  
I didn't receive any, but I would say you have to remove the stigma. You have to treat people that's in it's illness, you know, and a lot of people say, well, nobody sat on your chest and poured it down your throat. I’ve heard all of those things. I've not from professionals but but but just treat them like like human beings. That they're patient and and if you treat them well.

 **Catherine Beresford** 29:48  
Yeah.  
Right.

 **PWLD03** 30:05  
I would say that they'll probably be like me, you know, they'll want to. They'll want to get better for you.

 **Catherine Beresford** 30:12  
Yeah.

 **PWLD03** 30:12  
Like I know that I wouldn't let my hospital down. I wouldn't let the nurses down because they came in daily and did their best for me.

 **Catherine Beresford** 30:16  
Yeah.  
Yeah, yeah.

 **PWLD03** 30:21  
Well, I know it's their job, but they were over there were I think they weren't, you know, they went over and above for me, but I think I'd say to the to help professionals listen to the patient and talk to the families as well. Let the families be more aware of of why they're in this position and what to expect when they come out of hospital as well. I think really important.

 **Catherine Beresford** 30:31  
Mm hmm.  
Hmm.  
Yeah.  
Yes.  
Yeah. Yeah. Thank you.  
Hmm hmm.

 **PWLD03** 30:52  
And friends and just let them know what's gonna happen, especially if you got like HE or other, you know, conditions related to liver disease is keep them informed and and give them that hope as well be be positive with them.

 **Catherine Beresford** 30:55  
Yeah.  
Hmm.  
Yeah, yeah.  
OK, So, in your opinion, I mean you've given me quite a lot of ideas about this, but maybe you could summarise what do you think good care for people with advanced liver disease looks like?

 **PWLD03** 31:19  
What do I think it looks like?  
Good care.  
Looks like getting involved with different groups. I would encourage anyone to get involved with the British Liver Trust, that's for sure.

 **Catherine Beresford** 31:37  
Mm hmm yeah.

 **PWLD03** 31:40  
And obviously there were other organisations, but I can only speak - I've found, but getting involved and listening to the right people as well. Listening to yourself and and.

 **Catherine Beresford** 31:44  
Yes.

 **PWLD03** 31:53  
And trying to realise how you how you can get better as well and and and go to the right, go to the right people, but don't let things go on too long like I did with the gross oedema for instance.

 **Catherine Beresford** 31:57  
Yeah.  
Yeah.

 **PWLD03** 32:04  
If you're feeding, if you're not feeling right and you're troubled, don't you know you must get on to it straight away because there will be the right people there to help you. But try and get. And when you're when you're in hospital, before you leave.

 **Catherine Beresford** 32:08  
Yeah.

 **PWLD03** 32:19  
Or at some point as quick as you can get the information, if you to turn to who, who, who is your point of contact when you leave hospital? Because obviously doctors are, you know, you may not get to see your own doctor like I have and surgeries are busy me all and I understand that there are you know there's there's hugely busy people but get as much information as you can and you get that to your family as well because it's very important that you stay you know you stay and have the life that you probably thought you never would have.

 **Catherine Beresford** 32:27  
Yes. Yeah.  
Hmm.  
Yeah.

 **PWLD03** 32:51  
I'm not just preaching here as well, because it is. It'll take you into a completely different world that you look back. I sometimes have like an out of body experience. I look at myself and I think how could I did get there but but like I say with the things I don't want anyone else to get there. So, just you just need to get as much information as possible as many numbers as.

 **Catherine Beresford** 32:53  
Yeah.  
Yeah.  
Yeah.

 **PWLD03** 33:16  
Again, if you've got a better pathway that that can alleviate a lot of that. But don't be fright, you know, don't don't be frightened that we'll say being a nuisance.

 **Catherine Beresford** 33:21  
Yes.

 **PWLD03** 33:26  
And keep asking questions if you're not getting the answers, keep asking until you do 'cause they won't.

 **Catherine Beresford** 33:31  
Yeah.  
Yeah, yeah.

 **PWLD03** 33:33  
They will come because there are support services out there and when you use them like I have in the last five weeks [the counselling], they can make a huge difference to you.

 **Catherine Beresford** 33:41  
Yeah, yeah.

 **PWLD03** 33:43  
Don't be fined.

 **Catherine Beresford** 33:44  
Yeah. Thank you for sharing that. I mean, how is your, how's your health now then would you say?

 **PWLD03** 33:51  
Apart from, well it is, it is.  
Apart from the neuropathy, which again I've got on to quickly, that is a nightmare at the minute that but I've I've got all the blood tests until they can ascertain what the problem is, but that is liver related unfortunately. But other than that I'm fine. I was walking a lot more than I was.

 **Catherine Beresford** 33:58  
M.  
Yeah.

 **PWLD03** 34:14  
But I feel, yeah, I feel I think physically I feel fine and happier than I was. I think I feel as though fog has been lifted. I'm fine. I'm happier. I got my sense of humour back most days.

 **Catherine Beresford** 34:19  
Yeah.  
Yeah, yeah.  
Yeah.

 **PWLD03** 34:29  
But yeah, I feel I feel I probably could do with losing a bit of weight, but I would say later, lose and and one of the medications that one doesn't help that but no and water retention and stuff like that. But you know I have to think where I was where I was and I think you know I'm over the glad to be alive situation. You know what I mean? I had that a lot in the 1st 12 to 18 months. But yeah, I would say I was healthy for my age.

 **Catherine Beresford** 34:38  
Yeah.  
Yes.  
Yeah.  
Yeah, yeah, yeah. Oh, thank you. So, you know when we're having this conversation, sometimes something can kind of occur to you that you haven't really thought about before. Is there anything, you know, that you've that that comes to mind when I say that?

 **PWLD03** 35:12  
In terms of.

 **Catherine Beresford** 35:14  
Just anything really. You know, just when you're having these sorts of conversations, sometimes it kind of brings things up in your mind that perhaps you hadn't really thought about before.

 **PWLD03** 35:20  
Yeah, it's. Yeah, it's still.  
It still is difficult to believe or to try and.  
Like yesterday I said to my daughter, that's to keep my emotions to check. And she said, oh, dad, you're only picking later up from school. But [my daughter] doesn't realise just how much that means to me [to be able to collect grandchild from school].

 **Catherine Beresford** 35:38  
Hmm.  
Yeah.

 **PWLD03** 35:42  
And I still I don't look back as much as I used to, but at times like yesterday, I look back and I think, gosh, but sometimes you can feel a bit guilty for doing that thinking. Why did this happen? Or my daughter might have always been like this? I don't know. That's happened. We've we.

 **Catherine Beresford** 35:42  
Mm.  
Yeah.

 **PWLD03** 35:59  
That's come between us.  
So, yeah, it's sometimes it is difficult for me to believe it. Do you know what it is as well, I think is that.  
I came when I became my trigger. Whatever word you want to use it, because I'd worked for a company for 23 years who treated me in a greeting card trade a lot longer. But they treated me appallingly. They didn't understand anything about me, how I was free. This was not to do with drink. And I sent me on a downward spiral, whereas now I feel I feel people want to listen in the environment I'm in. Like this morning when you contacted me, it was wonderful to get something like that.

 **Catherine Beresford** 36:37  
Yeah.  
M.  
Oh, that's good.

 **PWLD03** 36:42  
Want to feel that it does it honestly it means an awful.

 **Catherine Beresford** 36:45  
Oh, thank you.

 **PWLD03** 36:46  
I'm not just saying this, Cathy, but it is an awful lot that people like yourself are interested in. What I want to I think I'll tell you what though. I know we discussed this earlier. I think is that.

 **Catherine Beresford** 36:48  
Yeah.  
Yeah.  
Yes.

 **PWLD03** 36:59  
I I when I can't believe really. But I'm such an open book and there is nothing. When I did this interview for for EASL, for.  
That's the European Association for the study of the Liver.

 **Catherine Beresford** 37:11  
Oh yeah, yeah.

 **PWLD03** 37:13  
About my journey with hepatic encephalopathy, there'd be there'd be [name of person] who was leading the interview, she said. Why don't we have like, pre prepared questions? She don't want to distress you. And I said there's nothing you can't hold anything back. You have to ask me. And if it does distress me, it's. I don't have an issue with that because I don't want to hold up because I I think because I I hid things away. I in my dream for So, long. I don't want to hide anymore and I want to.

 **Catherine Beresford** 37:27  
Yeah.  
Yeah.

 **PWLD03** 37:42  
I feel so.  
What I went through.  
That that sometimes you have to hit rock bottom, don't you?

 **Catherine Beresford** 37:50  
Yeah, yeah.

 **PWLD03** 37:51  
I wish I hadn't, but I did. And that's the key. I can't, but I can't change that. I can't. That's what I was thinking. I can't. I can't. That's how I was summarised. I can't change the cards I was dealt with, but maybe I could change them for somebody else in their family.

 **Catherine Beresford** 38:01  
No. Yeah.  
Yeah, yeah, yeah. Oh, thank you. So, is there anything that you think I should know to understand your experiences of care for liver disease better? Is there anything else that you haven't said already?

 **PWLD03** 38:20  
No, I don't think so, Cathy. I think we discussed that is is the cause, the pathway really starts inside hospital, doesn't it? So, you things are So, you're not waiting to find out when you go out things I think that that things should be set in place because I would imagine that with lots of other.

 **Catherine Beresford** 38:23  
Yeah.  
Yeah.  
Sure.  
Yes.

 **PWLD03** 38:40  
Different conditions. There will be a pathway, So, when you before you leave the hospital, you are told what this is for, what's going to happen and in your family are told. I think it's a case of.

 **Catherine Beresford** 38:43  
Yeah.  
Mm hmm.

 **PWLD03** 38:52  
Making sure family and friends are aware as well.

 **Catherine Beresford** 38:54  
Yeah.

 **PWLD03** 38:55  
I believe that and not have to wait 12 months 'cause if I hadn’t found an organisation like the British Liver Trust I’m not pretty sure where I'd be.

 **Catherine Beresford** 39:01  
Yes.  
Yeah, I totally understand what you're saying there. That makes a lot of sense. And is there anything that you'd like to ask me?

 **PWLD03** 39:12  
No, no. I wish you really well with this. I hope it. I hope this it's a something honestly I do and I admire anybody. Like I'm not just again, I'm not just saying this. I admire anybody like yourself who's doing something like this to improve the experiences, care experiences for people like myself. Yeah, honestly.

 **Catherine Beresford** 39:15  
Oh, thank you.  
Yeah.  
Yeah, that's really positive. I mean, but the thing I mentioned to you at the beginning before we started the interview, but actually I am finding it hard to reach people who've got advanced liver disease who want to take part in interview. And I'm just wondering if you've got any thoughts about that.

 **PWLD03** 39:48  
You could contact the British Liver Trust.

 **Catherine Beresford** 39:51  
Yeah, I have done actually. But then I don't. Yeah, I don't know why, but they didn't. I don't know. I think they're quite selective in what they will advertise. And I don't know why they. I might. I might try again, but I have tried them a couple of times.

 **PWLD03** 39:53  
Have you have they not?

 **Catherine Beresford** 40:06  
And they they they're not very forthcoming. Probably they. I know they're promoting a lot of research.

 **PWLD03** 40:07  
Oh.  
'Cause, they're not. They're right there.  
Yeah, they're based near you. Aren't they, though at Winchester?

 **Catherine Beresford** 40:16  
Are they OK? So, the I'm based at the Bournemouth University for the project. Yeah, I might. I will try. I will try them again. But I I I just. I'm not sure why, but I think that they they are quite selective in what they will promote.

 **PWLD03** 40:17  
Do you?  
Yeah. Well, there are we there at offices in. They used to be.  
They probably got, yeah, they probably get a lot of.

 **Catherine Beresford** 40:35  
Exactly. They probably do. I mean, I've been, you know, I've gone through Facebook groups 'cause there's a lot of.

 **PWLD03** 40:37  
Definitely.  
Have you tried? Have you tried SMART Recovery?

 **Catherine Beresford** 40:43  
Liver.  
Oh no, I haven't.

 **PWLD03** 40:47  
Yeah, I've just done a couple of the SMART Recovery.

 **Catherine Beresford** 40:51  
OK, that's a good idea.

 **PWLD03** 40:53  
There are up here. There's Red Rose recovery.

 **Catherine Beresford** 40:58  
OK, I'll have a look at all those then.

 **PWLD03** 40:58  
And the well.

 **Catherine Beresford** 41:01  
Yeah. What was that last one?

 **PWLD03** 41:01  
The well, the. Yeah, the well, it's called the well, what I'll do is I'll I'll get that when I've I'll e-mail you, I'll speak the information in in cause the the well and red rose recovery do a lot of work.

 **Catherine Beresford** 41:04  
OK.  
Alright. Yeah, that would be kind, yeah.  
Yes, OK. And feel free. Feel free to to give my e-mail details to anybody that you think might be interested in taking part. And I am speaking to because of some of you know like what you're saying about family. I am speaking to carers as well you know. So, I have been speaking to people who are supporting an individual who's in this situation to get their perspective as well because obviously they've got their own insights. And like you said, you know, you had a period when you were really unwell and you didn't really know what was going on. And then so, sometimes relatives they have.

 **PWLD03** 41:19  
So, they're two.  
Yeah, I will do. I will do.

 **Catherine Beresford** 41:52  
They shed light on that side of things as well.

 **PWLD03** 41:54  
Yeah, that's good. When I was at when I was, there was an organisation called Achieve.

 **Catherine Beresford** 42:03  
Oh yeah, I could have a look. Yeah.

 **PWLD03** 42:04  
They're based up in the [region], have a look at them.

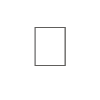
 **Catherine Beresford** 42:07  
I will. I'll Google all of these.  
Are you happy for me to stop recording?

 **PWLD03** 42:12  
Yeah, sure.

 **Catherine Beresford** 42:13  
All right. So, anything else you want to add before I do that?

 **PWLD03** 42:16  
No, thank you for. Well, thank you, Cathy for.

 **Catherine Beresford** 42:17  
Alright. Well, thank you. Thank you.  
OK, stop recording.

 **Catherine Beresford** stopped transcription