# Person with liver disease-01 (PWLD01) ‘Kim’

# Interview transcript 9th January 2024 by Teams

0:0:0.0 --> 0:0:3.670  
**Catherine Beresford**  
And you should get a message to say that it's recording.

0:0:4.560 --> 0:0:5.370  
**PWLD01**  
Yes, yeah, yeah.

0:0:5.960 --> 0:0:6.380  
**Catherine Beresford**  
Lovely.

0:0:8.660 --> 0:0:14.860  
**Catherine Beresford**  
And I'm just going to hide the transcription so that we don't have to see ourselves, you know, see what we're saying, because that can be a bit off-putting.

0:0:15.840 --> 0:0:16.590  
**Catherine Beresford**  
OK.

0:0:18.890 --> 0:0:19.840  
**PWLD01**  
Yeah, fine.

0:0:16.600 --> 0:0:20.130  
**Catherine Beresford**  
So you're happy to start? I thank.

0:0:20.140 --> 0:0:20.950  
**Catherine Beresford**  
Thank you.

0:0:19.850 --> 0:0:22.600  
**PWLD01**  
Fire away

0:0:20.960 --> 0:0:32.890  
**Catherine Beresford**  
Alright, so to start off with then could you tell me about your journey of receiving care since you found out that you have liver disease?

0:0:34.860 --> 0:0:35.480  
**PWLD01**  
So.

0:0:38.90 --> 0:0:41.510  
**PWLD01**  
I was rushed to the hospital on the 5th of May.

0:0:42.320 --> 0:0:42.560  
**Catherine Beresford**  
Yeah.

0:0:42.980 --> 0:0:46.810  
**PWLD01**  
My cousin turned up at my house and I was being sick.

0:0:46.820 --> 0:0:48.500  
**PWLD01**  
And then I could hardly stand up.

0:0:48.930 --> 0:0:49.330  
**Catherine Beresford**  
Right.

0:0:50.140 --> 0:0:50.650  
**PWLD01**  
I was.

0:0:50.720 --> 0:0:52.350  
**PWLD01**  
My body was so weak.

0:0:52.530 --> 0:0:52.670  
**Catherine Beresford**  
Yes.

0:0:52.520 --> 0:0:56.780  
**PWLD01**  
I was rushed to the hospital. Before that, I'd been having test because I've been losing so much weight.

0:1:1.130 --> 0:1:1.410  
**Catherine Beresford**  
OK.

0:1:7.320 --> 0:1:8.660  
**Catherine Beresford**  
Gosh, yeah.

0:1:2.810 --> 0:1:15.0  
**PWLD01**  
And when I say that I was losing like half a stone a week, it was horrendous, felt so poorly, and I kept going for blood tests and and they were all over the place.

0:1:15.310 --> 0:1:24.910  
**PWLD01**

So but one of the one of the things on the blood test, it came back as is it H HC125 or CA125?

0:1:25.420 --> 0:1:25.780  
**Catherine Beresford**  
OK.

0:1:26.820 --> 0:1:29.940  
**PWLD01**  
And that's something to do with ovarian cancer.

0:1:30.840 --> 0:1:31.340  
**Catherine Beresford**  
Right.

0:1:35.280 --> 0:1:35.500  
**Catherine Beresford**  
Yeah.

0:1:31.300 --> 0:1:37.260  
**PWLD01**  
So they sent me for an internal scan. I got there, they did an abdominal scan.

0:1:39.480 --> 0:1:39.720  
**Catherine Beresford**  
Yeah.

0:1:40.570 --> 0:1:46.240  
**PWLD01**  
The one hospital and there was looking at - my dad was with me. My dad comes to all the appointments - and they were saying there's nothing wrong.

0:1:51.550 --> 0:1:52.970  
**PWLD01**  
No, there's nothing wrong there. No, there's nothing wrong.

0:1:54.650 --> 0:1:58.640  
**PWLD01**  
So I was back to doctors [GP} because I'm still losing all this weight.

0:1:58.960 --> 0:1:59.210  
**Catherine Beresford**  
Yeah.

0:1:58.650 --> 0:2:0.900  
**PWLD01**  
And I said you sent me for the blah blah, blah.

0:2:2.50 --> 0:2:14.260  
**PWLD01**  
So anyway, cut a long story short, I was waiting for the next scan to come because they said there was nothing wrong with my liver and anything else going on in in abdominally.

0:2:14.800 --> 0:2:15.40  
**Catherine Beresford**  
Yeah.

0:2:16.300 --> 0:2:17.690  
**PWLD01**  
I was still being sick - it was horrendous. Umm, so my cousin came and saw me on that Friday the 5th and she said come on, get a bag packed I’m taking you. So, she took me to a different hospital.

0:2:31.140 --> 0:2:31.380  
**Catherine Beresford**  
Yeah.

0:2:32.310 --> 0:2:36.340  
**PWLD01**  
Uhm, and they took me through to triage and I was still - I was being sick, so obviously they give me bowls and stuff, did a blood test straight away and within 5 minutes I was in ICU.

0:2:44.410 --> 0:2:44.810  
**Catherine Beresford**  
Gosh.

0:2:45.880 --> 0:2:48.770  
**PWLD01**  
And three blood transfusions. It was it was scary. It was scary.

0:2:50.910 --> 0:2:52.350  
**Catherine Beresford**  
Yeah, yeah.

0:2:53.680 --> 0:2:53.920  
**PWLD01**  
Umm.

0:2:54.270 --> 0:2:54.980  
**Catherine Beresford**  
So did they.

0:2:55.310 --> 0:3:1.290  
**Catherine Beresford**  
So so can I just clarify from as far as you understand it, what kind of liver disease do you have?

0:3:3.10 --> 0:3:4.150  
**PWLD01**  
Alcohol.

0:3:4.640 --> 0:3:5.550  
**Catherine Beresford**  
Yeah. OK.

0:3:6.100 --> 0:3:6.360  
**PWLD01**  
OK.

0:3:6.800 --> 0:3:7.230  
**Catherine Beresford**  
Yeah.

0:3:7.270 --> 0:3:12.10  
**Catherine Beresford**  
So then, after you were in ICU, tell me a bit more about what happened after that.

0:3:14.0 --> 0:3:16.350  
**PWLD01**  
So they moved me up to the ward. I was only in there two days. They moved me up to the ward and I still couldn't walk on me own. They were, they were just brilliant.

0:3:23.790 --> 0:3:24.30  
**Catherine Beresford**  
Yeah.

0:3:25.430 --> 0:3:25.830  
**Catherine Beresford**  
Were they?

0:3:23.310 --> 0:3:29.770  
**PWLD01**  
They were absolutely fantastic and doctors absolutely amazing.

0:3:31.200 --> 0:3:31.710  
**Catherine Beresford**  
In what way?

0:3:31.640 --> 0:3:31.870  
**PWLD01**  
Just very informative and telling you. I kept saying to them:

0:3:39.430 --> 0:3:39.800  
**Catherine Beresford**  
Umm.

0:3:38.400 --> 0:3:40.590  
**PWLD01**  
‘Tell me what, tell me exactly what it is, and what I need to do’.

0:3:43.710 --> 0:3:43.880  
**Catherine Beresford**  
Yes.

0:3:47.140 --> 0:3:47.400  
**Catherine Beresford**  
Yeah.

0:3:45.110 --> 0:3:50.840  
**PWLD01**  
‘Just give it me in layman’s terms and and I will do whatever you say’.

0:3:51.350 --> 0:3:51.550  
**Catherine Beresford**  
Yeah.

0:3:51.130 --> 0:3:51.990  
**PWLD01**  
And so that's.

0:3:54.770 --> 0:3:55.320  
**Catherine Beresford**  
Yeah.

0:3:55.390 --> 0:3:56.40  
**Catherine Beresford**  
Yeah.

0:3:54.540 --> 0:3:56.650  
**PWLD01**  
So it was.

0:3:56.250 --> 0:3:57.830  
**Catherine Beresford**  
And so go on.

0:3:59.490 --> 0:4:0.350  
**PWLD01**  
Liver failure.

0:4:0.930 --> 0:4:1.130  
**Catherine Beresford**  
Yeah.

0:4:3.300 --> 0:4:8.50  
**PWLD01**  
And if I hadn’t got to the hospital, I would have been dead within three days.

0:4:8.380 --> 0:4:9.550  
**Catherine Beresford**  
Oh, my goodness.

0:4:10.30 --> 0:4:11.730  
**PWLD01**  
Yes, it was bad.

0:4:9.620 --> 0:4:13.240  
**Catherine Beresford**  
Yeah, yeah, yeah.

0:4:11.740 --> 0:4:13.450  
**PWLD01**  
It was it was scans, and MRI, CT scans, cameras down.

0:4:21.780 --> 0:4:22.0  
**Catherine Beresford**  
Yeah.

0:4:23.90 --> 0:4:24.430  
**PWLD01**  
Blood tests every day.

0:4:27.360 --> 0:4:27.520  
**PWLD01**  
Yeah.

0:4:26.880 --> 0:4:34.520  
**Catherine Beresford**  
And what services have you been accessing since then to help you with managing your liver disease?

0:4:35.970 --> 0:4:36.830  
**PWLD01**  
So when - I keep saying, I keep laughing at them when they say this because from the minute I found out I said ‘that's it I will never touch alcohol ever again’.

0:4:49.850 --> 0:4:50.250  
**Catherine Beresford**  
Right.

0:4:54.730 --> 0:4:55.340  
**Catherine Beresford**  
Ohh hello.

0:4:58.210 --> 0:4:59.170  
**Catherine Beresford**  
Hello, can you hear me?

0:5:3.860 --> 0:5:4.970  
**Catherine Beresford**  
Hi I can't hear you.

0:5:4.980 --> 0:5:6.350  
**Catherine Beresford**  
I think it might have cut off.

0:5:6.360 --> 0:5:7.200  
**Catherine Beresford**  
Can you hear me?

0:5:9.770 --> 0:5:10.680  
**Catherine Beresford**  
Oh, there you go.

0:5:10.690 --> 0:5:11.460  
**Catherine Beresford**  
I just caught you.

0:5:11.470 --> 0:5:14.0  
**Catherine Beresford**  
Then hang on, I think it might be the reception.

0:5:16.600 --> 0:5:16.850  
**Catherine Beresford**  
Hello.

0:5:21.50 --> 0:5:21.270  
**Catherine Beresford**  
Hello.

0:5:28.80 --> 0:5:29.140  
**Catherine Beresford**  
Hi, can you hear me?

0:5:37.320 --> 0:5:37.590  
**Catherine Beresford**  
Hello.

0:5:43.130 --> 0:5:43.330  
**PWLD01**  
Hello.

0:5:43.790 --> 0:5:44.420  
**Catherine Beresford**  
Oh, hi.

0:5:44.990 --> 0:5:45.90  
**PWLD01**  
I.

0:5:44.490 --> 0:5:45.640  
**Catherine Beresford**  
Yes, I can hear you.

0:5:45.650 --> 0:5:46.870  
**Catherine Beresford**  
Hello, can you hear me?

0:5:47.640 --> 0:5:48.730  
**PWLD01**  
I do apologize.

0:5:48.860 --> 0:5:51.860  
**Catherine Beresford**  
It's alright, I know what it's always the technology, isn't it?

0:5:52.600 --> 0:5:53.450  
**Catherine Beresford**  
It's I.

0:5:52.250 --> 0:5:54.230  
**PWLD01**  
I know and.

0:5:53.500 --> 0:5:54.480  
**Catherine Beresford**  
I just caught that.

0:5:54.490 --> 0:5:54.890  
**Catherine Beresford**  
You I.

0:5:54.940 --> 0:5:56.890  
**Catherine Beresford**  
I just what I I heard you say so.

0:5:56.900 --> 0:6:1.500  
**Catherine Beresford**  
I asked you which services you've been able to access since you got diagnosed.

0:6:2.480 --> 0:6:2.760  
**PWLD01**  
Yeah.

0:6:6.160 --> 0:6:8.270  
**PWLD01**  
Yeah, just the drug and alcohol team.

0:6:11.120 --> 0:6:11.650  
**Catherine Beresford**  
Ah, I see.

0:6:8.280 --> 0:6:16.430  
**PWLD01**  
But like I said, it just wasn't for me because I knew in in my head the the more they talk about it, I'm like this.

0:6:19.170 --> 0:6:19.490  
**Catherine Beresford**  
OK.

0:6:16.440 --> 0:6:20.100  
**PWLD01**  
This just I don't know, just not for me because it's never gonna happen.

0:6:22.90 --> 0:6:22.340  
**Catherine Beresford**  
What?

0:6:22.350 --> 0:6:22.920  
**Catherine Beresford**  
What do you mean?

0:6:24.100 --> 0:6:24.750  
**PWLD01**  
I'm never - I will never ever touch a drink ever again.

0:6:27.500 --> 0:6:28.330  
**Catherine Beresford**  
Ah, I see.

0:6:28.340 --> 0:6:28.830  
**Catherine Beresford**  
OK.

0:6:28.840 --> 0:6:29.130  
**Catherine Beresford**  
So.

0:6:29.140 --> 0:6:34.830  
**Catherine Beresford**  
So, you're you're explaining that you don't need that that that service because you've already worked that out for yourself?

0:6:33.490 --> 0:6:35.800  
**PWLD01**  
Yes.

0:6:36.170 --> 0:6:37.140  
**Catherine Beresford**  
That makes sense.

0:6:37.370 --> 0:6:40.720  
**Catherine Beresford**  
And what about in terms of actually your physical health?

0:6:40.910 --> 0:6:47.490  
**Catherine Beresford**  
Have you had to have any support or like check-ups or go to the hospital or anything like that?

0:6:48.630 --> 0:6:52.830  
**PWLD01**  
Yeah, I've been for two MRI scans.

0:6:53.410 --> 0:6:53.630  
**Catherine Beresford**  
Yes.

0:6:54.660 --> 0:7:0.950  
**PWLD01**  
Umm, blood tests and I see the consultant every six months.

0:7:1.320 --> 0:7:1.540  
**Catherine Beresford**  
Yeah.

0:7:2.860 --> 0:7:3.0  
**PWLD01**  
Yeah.

0:7:3.690 --> 0:7:4.280  
**Catherine Beresford**  
OK.

0:7:4.850 --> 0:7:13.440  
**Catherine Beresford**  
And and which, like professionals, have been involved in your care for your liver disease since you got diagnosed? So, like thinking about that very first time, who were the people that you've had contact with?

0:7:25.10 --> 0:7:25.250  
**Catherine Beresford**  
Yeah.

0:7:21.220 --> 0:7:26.530  
**PWLD01**  
To be fair, when I was in ICU, I don't even know I was.

0:7:29.240 --> 0:7:29.450  
**Catherine Beresford**  
Umm.

0:7:26.540 --> 0:7:34.940  
**PWLD01**  
I was like pretty much out of it, but then obviously in the ward, the nurses, consultants.

0:7:35.220 --> 0:7:35.480  
**Catherine Beresford**  
Yeah.

0:7:36.20 --> 0:7:38.270  
**PWLD01**  
That's it really.

0:7:38.360 --> 0:7:39.230  
**Catherine Beresford**  
Yeah.

0:7:39.430 --> 0:7:40.180  
**Catherine Beresford**  
OK.

0:7:40.550 --> 0:7:50.580  
**Catherine Beresford**  
And if if you need support, advice or information about your liver disease, where where do you go or where have you got that information or support from?

0:7:51.340 --> 0:7:54.500  
**PWLD01**  
On the, you know, on the on the Facebook?

0:7:54.960 --> 0:7:55.100  
**Catherine Beresford**  
Yes.

0:7:56.290 --> 0:7:58.940  
**PWLD01**  
The site [Facebook page] that you left a message.

0:8:0.720 --> 0:8:1.450  
**PWLD01**  
OK.

0:8:1.680 --> 0:8:1.960  
**PWLD01**  
I'll just.

0:7:59.290 --> 0:8:2.120  
**Catherine Beresford**  
Oh, yeah, yeah, yeah.

0:8:3.10 --> 0:8:4.10  
**PWLD01**  
Yeah, that's it.

0:8:4.130 --> 0:8:9.750  
**Catherine Beresford**  
So through other people who were sharing their experiences, you find that helpful?

0:8:9.600 --> 0:8:11.160  
**PWLD01**  
Yeah.

0:8:11.530 --> 0:8:12.60  
**Catherine Beresford**  
Yeah.

0:8:15.840 --> 0:8:16.120  
**PWLD01**  
The.

0:8:12.70 --> 0:8:17.690  
**Catherine Beresford**  
Any other organizations or any other health care professionals, anything like that?

0:8:18.880 --> 0:8:21.680  
**PWLD01**  
No. British Liver Trust to go on their website.

0:8:22.360 --> 0:8:22.700  
**Catherine Beresford**  
OK.

0:8:24.230 --> 0:8:26.110  
**PWLD01**  
Donating to them actually monthly.

0:8:26.690 --> 0:8:26.950  
**Catherine Beresford**  
Yeah.

0:8:27.220 --> 0:8:28.600  
**PWLD01**  
Uh, but yeah.No, that's it.

0:8:29.660 --> 0:8:30.150  
**Catherine Beresford**  
Yeah.

0:8:30.160 --> 0:8:30.550  
**Catherine Beresford**  
OK.

0:8:30.560 --> 0:8:30.950  
**Catherine Beresford**  
Thank you.

0:8:30.960 --> 0:8:31.850  
**Catherine Beresford**  
That's helpful.

0:8:32.280 --> 0:8:50.100  
**Catherine Beresford**  
And thinking back, I mean you, you ment-, you touched on it a bit already actually, but maybe you could just give me a little bit more of your thoughts about you said about the care that you received, what was particularly positive about it when you were getting your care in hospital?

0:8:50.170 --> 0:8:56.120  
**PWLD01**  
They were blunt with me and told me exactly how it were. ‘If you don't do this, you will die’.

0:8:58.120 --> 0:9:0.180  
**Catherine Beresford**  
Yes, I see.

0:9:1.420 --> 0:9:1.650  
**PWLD01**  
Yeah.

0:9:2.220 --> 0:9:4.240  
**Catherine Beresford**  
So it's the sort of honesty.

0:9:5.240 --> 0:9:6.140  
**PWLD01**  
Yeah, yeah, yeah.

0:9:6.640 --> 0:9:7.230  
**Catherine Beresford**  
Yeah.

0:9:7.240 --> 0:9:7.750  
**Catherine Beresford**  
OK.

0:9:8.300 --> 0:9:9.160  
**Catherine Beresford**  
And and and.

0:9:9.170 --> 0:9:12.910  
**Catherine Beresford**  
Was there anything on the other side of the coin that you found negative?

0:9:18.240 --> 0:9:19.10  
**PWLD01**  
Umm.

0:9:27.120 --> 0:9:28.220  
**PWLD01**  
No, I wouldn't say so.

0:9:28.930 --> 0:9:30.270  
**Catherine Beresford**  
OK, that's fine.

0:9:30.340 --> 0:9:30.560  
**PWLD01**  
No.

0:9:31.500 --> 0:9:36.60  
**Catherine Beresford**  
And who's been most helpful to you during this time?

0:9:37.470 --> 0:9:37.860  
**PWLD01**  
My Dad [laughs]

0:9:39.590 --> 0:9:39.830  
**Catherine Beresford**  
Yeah.

0:9:41.0 --> 0:9:41.140  
**PWLD01**  
Yeah.

0:9:41.780 --> 0:9:42.710  
**Catherine Beresford**  
Tell me more about that.

0:9:44.280 --> 0:9:45.350  
**PWLD01**  
He's just amazing. When I was in the hospital, I've got two dogs. So, he looked after the dogs, took them to his house.

0:9:53.630 --> 0:9:53.750  
**Catherine Beresford**  
Yes.

0:9:54.410 --> 0:9:57.450  
**PWLD01**  
He had a gardener in to get all me garden done. Cleaners in to give me house a good cleaning before I came home.

0:10:4.30 --> 0:10:4.210  
**Catherine Beresford**  
Yeah.

0:10:5.430 --> 0:10:6.300  
**PWLD01**  
Takes me shopping. He's just amazing.

0:10:7.880 --> 0:10:8.80  
**Catherine Beresford**  
Yeah.

0:10:8.710 --> 0:10:9.680  
**PWLD01**  
He is.

0:10:10.780 --> 0:10:11.420  
**Catherine Beresford**  
Thank you.

0:10:12.560 --> 0:10:26.50  
**Catherine Beresford**  
And after having these experiences of care, have you got, you know, if you had to give advice to somebody else who just discovered that they had advanced liver disease, what would your advice for them be?

0:10:27.560 --> 0:10:29.30  
**PWLD01**  
Just listen to your doctors.

0:10:29.500 --> 0:10:30.310  
**PWLD01**  
Don't listen - although I go on those sites [i.e., Facebook pages].

0:10:32.930 --> 0:10:33.130  
**Catherine Beresford**  
Yes.

0:10:34.710 --> 0:10:42.240  
**PWLD01**  
I don't take their advice if it like if the there was someone say ‘I'm taking this supplement, this supplement’.

0:10:44.360 --> 0:10:44.760  
**Catherine Beresford**  
I see.

0:10:47.180 --> 0:10:48.50  
**PWLD01**  
[inaudible]

0:10:48.700 --> 0:10:48.920  
**Catherine Beresford**  
Yeah.

0:10:51.890 --> 0:10:52.180  
**Catherine Beresford**  
Yeah.

0:10:52.190 --> 0:10:54.840  
**Catherine Beresford**  
So sort of keeping an open mind, you mean?

0:10:55.930 --> 0:10:56.160  
**PWLD01**  
Sorry?

0:10:56.760 --> 0:11:1.120  
**Catherine Beresford**  
Do you mean like keeping an open mind to what people are saying to you? Yeah.

0:10:59.860 --> 0:11:1.660  
**PWLD01**  
Yeah, yeah, yeah.

0:11:3.400 --> 0:11:6.400  
**Catherine Beresford**  
And thinking about the experiences of care that you had, umm, what advice, if any, would you give to professionals who are working with individuals who've got advanced liver disease?

0:11:15.700 --> 0:11:16.770  
**PWLD01**  
Don't be soft with them. Tell them the truth.

0:11:19.460 --> 0:11:19.800  
**Catherine Beresford**  
OK.

0:11:21.800 --> 0:11:22.40  
**Catherine Beresford**  
Yeah.

0:11:21.760 --> 0:11:24.370  
**PWLD01**  
Don't sugar coat anything, just be honest.

0:11:24.90 --> 0:11:25.970  
**Catherine Beresford**  
Yeah. OK.

0:11:28.670 --> 0:11:33.950  
**Catherine Beresford**  
And in your opinion, what does good care for people with advanced liver disease look like?

0:11:37.460 --> 0:11:40.270  
**PWLD01**  
As much information as possible. That's the thing, that's the one thing that's lacking.

0:11:45.150 --> 0:11:45.590  
**Catherine Beresford**  
Is it?

0:11:45.680 --> 0:11:46.830  
**PWLD01**  
Not don't.  
Yeah, you don't get - it's like, how can I say? I've put a hell of a lot of weight on.

0:12:0.120 --> 0:12:0.270  
**Catherine Beresford**  
Yes.

0:11:57.320 --> 0:12:0.840  
**PWLD01**  
Since being a lost obviously before I was losing weight on, so so much weight on.

0:12:3.560 --> 0:12:3.800  
**Catherine Beresford**  
Yeah.

0:12:7.230 --> 0:12:7.880  
**Catherine Beresford**  
Right.

0:12:4.150 --> 0:12:8.30  
**PWLD01**  
I’ve not got to see a dietitian or anything.

0:12:7.930 --> 0:12:8.160  
**Catherine Beresford**  
So.

0:12:8.170 --> 0:12:9.420  
**Catherine Beresford**  
So who were you going

0:12:9.430 --> 0:12:10.570  
**Catherine Beresford**  
Who were you going to see?

0:12:10.580 --> 0:12:12.310  
**Catherine Beresford**  
When, when that was happening then?

0:12:14.150 --> 0:12:15.900  
**PWLD01**  
Well, putting weight on?

0:12:16.690 --> 0:12:16.930  
**Catherine Beresford**  
Yeah.

0:12:18.340 --> 0:12:18.720  
**PWLD01**  
Nobody.

0:12:19.190 --> 0:12:19.640  
**Catherine Beresford**  
Yeah.

0:12:19.650 --> 0:12:20.260  
**Catherine Beresford**  
OK.

0:12:20.400 --> 0:12:23.240  
**Catherine Beresford**  
So if I can just rewind slightly,

0:12:28.240 --> 0:12:28.540  
**PWLD01**  
Yeah.

0:12:23.250 --> 0:12:29.790  
**Catherine Beresford**  
So you mentioned that before you went into hospital, you'd been losing a lot of weight and you'd been having tests done.

0:12:30.550 --> 0:12:30.920  
**PWLD01**  
Come on.

0:12:30.290 --> 0:12:31.860  
**Catherine Beresford**  
Who did you see about that?

0:12:33.290 --> 0:12:33.990  
**PWLD01**  
My GP.

0:12:35.340 --> 0:12:39.700  
**Catherine Beresford**  
And and did they ever detect that it was liver disease?

0:12:40.380 --> 0:12:42.20  
**PWLD01**  
No, no.

0:12:43.890 --> 0:12:44.130  
**PWLD01**  
No.

0:12:43.790 --> 0:12:46.730  
**Catherine Beresford**  
So, do you know how many times you saw your GP?

0:12:47.830 --> 0:12:48.620  
**PWLD01**  
Ohh God. About five times.

0:12:52.920 --> 0:12:53.760  
**Catherine Beresford**  
Oh, I see. OK.

0:12:56.950 --> 0:12:59.420  
**Catherine Beresford**  
And but they never they never actually realized that what it was?

0:13:1.250 --> 0:13:2.780  
**PWLD01**  
No, they kept saying there was nothing wrong.

0:13:4.460 --> 0:13:5.20  
**Catherine Beresford**  
OK.

0:13:5.30 --> 0:13:7.660  
**Catherine Beresford**  
And have you, have you seen the your GP since then?

0:13:10.310 --> 0:13:11.190  
**PWLD01**  
Yeah. And I'm gonna, I keep saying I'm gonna have to change doctors.  
They've had me medications wrong, they sent the blood test to the wrong results to the wrong doctors. They just, I don't know what's wrong with them, but they don't do what they're supposed to do.

0:13:31.20 --> 0:13:37.90  
**Catherine Beresford**  
And did you ever have any discussion with them about the the the liver disease not being picked up?

0:13:38.430 --> 0:13:38.670  
**PWLD01**  
Yeah. Yeah.

0:13:40.910 --> 0:13:41.600  
**Catherine Beresford**  
What did they, what did they say?

0:13:41.100 --> 0:13:44.720  
**PWLD01**  
Yeah, because, [quotes GP] ‘all we can do is apologize’.

0:13:47.70 --> 0:13:47.890  
**Catherine Beresford**  
Right. OK.

0:13:50.530 --> 0:13:52.0  
**Catherine Beresford**  
And what did you think about that?

0:13:53.210 --> 0:13:54.160  
**PWLD01**  
It's disgusting. I could have been dead.

0:14:1.670 --> 0:14:1.990  
**PWLD01**  
Yeah.

0:14:0.860 --> 0:14:2.590  
**Catherine Beresford**  
Yeah. OK.

0:14:2.920 --> 0:14:3.80  
**Catherine Beresford**  
Yeah.

0:14:4.400 --> 0:14:12.800  
**Catherine Beresford**  
So if if you could say anything, if you could say anything to to your GP, if you could say anything, what would you say to them?

0:14:14.700 --> 0:14:19.340  
**PWLD01**  
They want striking off for me because if they're doing that to me, how many more people are they doing it to? If there's older people like with with my medication, I can't remember which one it was,  
but I really needed that that particular and it just weren't there. They kept ringing: ‘Ohh no no’. Well, just like, Arrgh [in frustration]. And you're crying.

0:14:41.750 --> 0:14:49.820  
**PWLD01**  
But if they're doing that to me and they're doing it to an old person who doesn't realize they could be dead.

0:14:49.390 --> 0:14:49.980  
**Catherine Beresford**  
I see.

0:14:50.770 --> 0:14:52.940  
**Catherine Beresford**  
Say yeah.

0:14:55.910 --> 0:14:56.280  
**Catherine Beresford**  
Umm.

0:14:58.220 --> 0:15:13.490  
**Catherine Beresford**  
So yeah, let let, let's just think about what so in your opinion then what does good care for people with advanced liver disease look like if you think back on your own experience and what you've been through, and you could. sort of how you know what would the perfect kind of service look like for people who've got advanced liver disease?

0:15:25.590 --> 0:15:34.710  
**PWLD01**  
Well, obviously you go to the GP first, firstly, unless you're in an emergency situation like I were on that Friday.

0:15:35.250 --> 0:15:35.510  
**Catherine Beresford**  
Yeah.

0:15:36.880 --> 0:15:43.100  
**PWLD01**  
And someone competent and who knows what they're doing.

0:15:44.280 --> 0:15:44.640  
**Catherine Beresford**  
OK.

0:15:46.620 --> 0:15:52.330  
**Catherine Beresford**  
And then and then once once it's been diagnosed and and then the person knows what they've got.

0:15:53.460 --> 0:15:55.120  
**Catherine Beresford**  
But how do you see it after that?

0:15:59.770 --> 0:15:59.970  
**Catherine Beresford**  
Umm.

0:16:3.850 --> 0:16:4.510  
**Catherine Beresford**  
Right.

0:15:57.540 --> 0:16:8.960  
**PWLD01**  
I suppose it depends what level they are, because like I am now, I can control it at home and and not really poorly as to warrant to stay in hospital.

0:16:9.270 --> 0:16:9.530  
**Catherine Beresford**  
Yeah.

0:16:10.650 --> 0:16:14.10  
**PWLD01**  
But as I was that Friday, I had to go to hospital.

0:16:14.70 --> 0:16:16.720  
**Catherine Beresford**  
Yeah, yeah, yeah.

0:16:20.620 --> 0:16:20.860  
**Catherine Beresford**  
Umm.

0:16:17.260 --> 0:16:21.230  
**PWLD01**  
Again, please, this much family support as you possibly can I suppose.

0:16:23.350 --> 0:16:23.750  
**PWLD01**  
You know a lot.

0:16:23.70 --> 0:16:30.260  
**Catherine Beresford**  
And if you if you weren't, you know, if you're not, well, now if things you know where to change in some way.

0:16:32.800 --> 0:16:34.810  
**PWLD01**  
Like like.

0:16:30.270 --> 0:16:35.260  
**Catherine Beresford**  
And you actually did need some medical advice or support, where would you turn to?

0:16:36.50 --> 0:16:39.40  
**PWLD01**  
Yeah, I'd go to the hospital, I wouldn't go to my GP.

0:16:41.30 --> 0:16:43.280  
**Catherine Beresford**  
How how do you get hold of the hospital, if you need advice or support?

0:16:46.400 --> 0:16:47.580  
**PWLD01**  
I would just go to A&E.

0:16:48.150 --> 0:16:51.640  
**Catherine Beresford**  
Oh I see. Do you do you have contact with like a umm - do you have like a direct contact with the liver specialists or anything?

0:16:56.850 --> 0:17:5.880  
**PWLD01**  
Well, on the letter there is a telephone numbers for the Secretary and Bloods and Hepatologist.

0:17:6.310 --> 0:17:6.530  
**Catherine Beresford**  
Yeah.

0:17:7.550 --> 0:17:10.930  
**PWLD01**  
And whatever books you can do, it's just an answer machine.

0:17:11.910 --> 0:17:12.620  
**Catherine Beresford**  
What about, have you had any contact with like a, a liver nurse specialist or any anybody like that?

0:17:19.120 --> 0:17:25.530  
**PWLD01**  
No, the number on the form - it says for the liver nurse or whatever, but it goes to a different department.

0:17:28.930 --> 0:17:31.560  
**Catherine Beresford**  
OK, so am I right in understanding you don't, you don't normally see a liver nurse then?

0:17:34.980 --> 0:17:35.860  
**PWLD01**  
No, no, no.

0:17:35.580 --> 0:17:36.170  
**Catherine Beresford**  
No.

0:17:36.220 --> 0:17:36.890  
**Catherine Beresford**  
OK.

0:17:37.440 --> 0:17:47.710  
**Catherine Beresford**  
Alright, you know, sometimes when you're having a conversation like this it, you know, you might think of something that you hadn't thought about before.

0:17:48.700 --> 0:17:48.960  
**PWLD01**  
Yeah.

0:17:47.720 --> 0:17:49.220  
**Catherine Beresford**  
It can sometimes sort of trigger thoughts. Is there anything that's occurred to you during the interview?

0:18:7.10 --> 0:18:7.600  
**Catherine Beresford**  
Oh, hello.

0:18:7.330 --> 0:18:7.860  
**PWLD01**  
No, no.

0:18:7.610 --> 0:18:7.860  
**Catherine Beresford**  
Can you?

0:18:8.110 --> 0:18:8.650  
**Catherine Beresford**  
Ohh there you are.

0:18:8.660 --> 0:18:9.60  
**Catherine Beresford**  
No. Sorry.

0:18:9.70 --> 0:18:11.190  
**Catherine Beresford**  
Sorry, that's the thing about having the cameras off, isn't it?

0:18:11.200 --> 0:18:12.320  
**Catherine Beresford**  
You can't always tell - you're just thinking.

0:18:13.370 --> 0:18:13.710  
**PWLD01**  
OK.

0:18:13.370 --> 0:18:14.190  
**Catherine Beresford**  
Yeah, that's fine.

0:18:15.0 --> 0:18:22.900  
**PWLD01**  
And the only thing that really for me is the dietitian, because all they said was ‘No salt’.

0:18:23.630 --> 0:18:24.300  
**Catherine Beresford**  
Right.

0:18:24.310 --> 0:18:24.940  
**Catherine Beresford**  
OK.

0:18:25.70 --> 0:18:26.370  
**Catherine Beresford**  
So you. Yeah.

0:18:27.910 --> 0:18:31.580  
**Catherine Beresford**  
Are you saying that you would have liked you'd like to have a consultation with the dietitian?

0:18:39.200 --> 0:18:39.430  
**Catherine Beresford**  
Umm.

0:18:32.450 --> 0:18:41.110  
**PWLD01**  
Yeah, because if it's a like sometimes you just don't feel hungry do you. I kept

0:18:55.10 --> 0:18:55.270  
**Catherine Beresford**  
Umm.

0:18:43.800 --> 0:19:3.640  
**PWLD01**  
Having these episodes where I was all of a sudden and it just comes out really quick, me, I get really sweaty and when I say my head be wet through, I'm all dizzy and and it knocks me out for a bit. I don't mean it makes me fall.

0:19:3.600 --> 0:19:4.520  
**Catherine Beresford**  
Yeah, yeah.

0:19:6.930 --> 0:19:7.160  
**Catherine Beresford**  
Umm.

0:19:5.730 --> 0:19:12.910  
**PWLD01**  
But anywhere or if you have them in the kitchen, I'll go and sit down quick because I do feel that dizzy.

0:19:13.130 --> 0:19:13.470  
**Catherine Beresford**  
Yeah.

0:19:14.590 --> 0:19:17.280  
**PWLD01**  
You have to have something to eat straight away.

0:19:16.680 --> 0:19:18.510  
**Catherine Beresford**  
Yes. Yeah.

0:19:25.370 --> 0:19:25.610  
**Catherine Beresford**  
Yeah.

0:19:19.730 --> 0:19:26.880  
**PWLD01**  
And then within 20 minutes I feel alright, although really tired. Now, that's that's never happened to me before this [liver disease].

0:19:31.310 --> 0:19:31.690  
**Catherine Beresford**  
Right.

0:19:31.490 --> 0:19:33.780  
**PWLD01**  
So what was that - do you know what I mean?

0:19:34.520 --> 0:19:34.720  
**Catherine Beresford**  
Yes.

0:19:36.590 --> 0:19:37.270  
**PWLD01**  
I've not - they've just said ‘ohh no no no, I dunno what that is’.

0:19:43.20 --> 0:19:43.380  
**Catherine Beresford**  
OK.

0:19:43.780 --> 0:19:45.270  
**PWLD01**  
I’d like advice on that.

0:19:45.710 --> 0:19:45.920  
**Catherine Beresford**  
Who, who said that they didn't know what it was?

0:19:50.360 --> 0:19:50.870  
**Catherine Beresford**  
Right.

0:19:49.170 --> 0:19:54.540  
**PWLD01**

All the doctors have told me, GP umm, consultant.

0:19:55.20 --> 0:19:56.140  
**Catherine Beresford**  
Yeah, yeah.

0:19:58.250 --> 0:19:58.560  
**Catherine Beresford**  
Yeah.

0:19:58.570 --> 0:20:0.220  
**Catherine Beresford**  
So you'd like to speak to a dietitian?

0:20:1.910 --> 0:20:2.150  
**PWLD01**  
Yeah.

0:20:3.10 --> 0:20:3.760  
**Catherine Beresford**  
Yeah.

0:20:4.310 --> 0:20:11.230  
**PWLD01**  
And is there anything else you think I should know to understand your experiences of the care that you've received for your liver disease better?

0:20:15.720 --> 0:20:16.200  
**PWLD01**  
In what way?

0:20:16.880 --> 0:20:21.550  
**Catherine Beresford**  
Anything really, just anything that you sort of feel like you haven't said that you'd like to say?

0:20:25.180 --> 0:20:26.540  
**PWLD01**  
No, I don't think so.

0:20:26.720 --> 0:20:27.380  
**Catherine Beresford**  
No, that's OK.

0:20:28.470 --> 0:20:34.550  
**Catherine Beresford**  
I'm interested just sort of to to tell you that I'm for this research, I've been recruiting for a couple of months now and I'm speaking to health care professionals, I'm speaking to carers of people who've got advanced liver disease and then most importantly, I'm speaking to people who've got advanced liver disease themselves.

0:20:48.440 --> 0:20:48.710  
**PWLD01**  
Umm.

0:20:48.60 --> 0:20:54.250  
**Catherine Beresford**  
But I have found it quite difficult, quite challenging to reach people who've got advanced liver disease, and I just wondered if you've got any thoughts about that, really any thoughts about that at all?

0:21:2.860 --> 0:21:4.700  
**PWLD01**  
What, why they don’t wanna speak to you?

0:21:6.0 --> 0:21:7.320  
**Catherine Beresford**  
Yeah, I guess so. I mean, not that I would expect you to have all the answers, but just really, you know, any thoughts about it being so challenging to reach people?

0:21:24.310 --> 0:21:24.810  
**Catherine Beresford**  
OK.

0:21:28.860 --> 0:21:29.80  
**Catherine Beresford**  
Yeah.

0:21:15.150 --> 0:21:33.380  
**PWLD01**  
Yeah, I I think a lot of people are in my situation and a lot of them, it is caused by alcohol and I think like there was a lady who I was in the hospital with and was still in touch with each other although, not as much these days

0:21:33.540 --> 0:21:33.760  
**Catherine Beresford**  
Yeah.

0:21:35.430 --> 0:21:37.850  
**PWLD01**  
Because she's she's drinking.

0:21:38.480 --> 0:21:38.710  
**Catherine Beresford**  
Yeah.

0:21:40.0 --> 0:21:44.390  
**PWLD01**  
So and and I I think she feels embarrassed.

0:21:44.800 --> 0:21:45.60  
**Catherine Beresford**  
Yeah.

0:21:47.310 --> 0:21:50.120  
**PWLD01**  
Or like I don't know like she's failing herself.

0:21:52.850 --> 0:21:53.70  
**Catherine Beresford**  
Yeah.

0:21:55.410 --> 0:21:57.280  
**PWLD01**  
So maybe that's it. I don't know.

0:21:58.590 --> 0:21:59.240  
**Catherine Beresford**  
Yeah.

0:21:59.300 --> 0:22:0.150  
**Catherine Beresford**  
I see what you mean.

0:22:0.880 --> 0:22:1.60  
**Catherine Beresford**  
Yeah.

0:22:2.520 --> 0:22:3.140  
**Catherine Beresford**  
Thank you.

0:22:1.80 --> 0:22:5.890  
**PWLD01**  
Yeah, I'd say I don't think I don't - I mean, people might say that I was an alcoholic or what. I don't think I was. I think it was just circumstance and it - just binge drinking.

0:22:18.450 --> 0:22:18.650  
**Catherine Beresford**  
Yeah.

0:22:20.30 --> 0:22:23.230  
**PWLD01**  
And I don't think I relied on it as such.

0:22:23.410 --> 0:22:23.750  
**Catherine Beresford**  
Hmm.

0:22:24.430 --> 0:22:30.530  
**PWLD01**  
So for me it was just easy [to stop drinking] and it's never been never been a thought.

0:22:30.790 --> 0:22:31.440  
**Catherine Beresford**  
Yeah, I see.

0:22:36.380 --> 0:22:36.580  
**Catherine Beresford**  
Yeah.

0:22:32.610 --> 0:22:40.370  
**PWLD01**  
For a lot of people, it is shame and embarrassment where I'm like, dead proud that I've done it [stopped drinking] and I'm still here.

0:22:39.830 --> 0:22:40.860  
**Catherine Beresford**  
I I see.

0:22:41.290 --> 0:22:42.600  
**Catherine Beresford**  
Yeah, I see what you're saying.

0:22:42.610 --> 0:22:46.160  
**Catherine Beresford**  
Yeah, yeah, yeah.

0:22:46.210 --> 0:22:46.900  
**Catherine Beresford**  
OK.

0:22:46.990 --> 0:22:48.860  
**Catherine Beresford**  
Thank you umm.

0:22:49.720 --> 0:22:52.100  
**Catherine Beresford**  
And is there anything you would like to ask me?

0:22:53.800 --> 0:22:54.820  
**PWLD01**  
No, I don't think so.

0:22:56.740 --> 0:22:57.230  
**Catherine Beresford**  
Lovely. Thank you.

0:22:58.680 --> 0:23:9.40  
**Catherine Beresford**  
So that's all the questions that I need to ask you and what I have to do is I get all everything you've said - you know that you've said in the interview - I I do like it's a transcript. So, it's all written out.

0:23:14.280 --> 0:23:14.520  
**PWLD01**  
Yeah.

0:23:14.290 --> 0:23:23.910  
**Catherine Beresford**  
Ready for me to analyse but Teams is good because it does the transcription for me, but then I have to just correct it because you know it doesn't get certain words right.

0:23:24.380 --> 0:23:24.750  
**PWLD01**  
Yeah yeah

0:23:23.960 --> 0:23:30.450  
**Catherine Beresford**  
So I'll I'll tidy it all up and then later this week I'll email it to you and you're free to check it. And if you want to add anything or if you want to correct anything, you know, you're welcome to do so completely up to you.

0:23:36.380 --> 0:23:38.350  
**Catherine Beresford**  
And if you think of anything else, you know?

0:23:41.740 --> 0:23:41.990  
**PWLD01**  
Yeah.

0:23:38.360 --> 0:23:43.230  
**Catherine Beresford**  
Because sometimes when the interview is finished, you might go away and think, oh, I should have said X or Y.

0:23:44.30 --> 0:23:44.250  
**PWLD01**  
Yeah.

0:23:43.240 --> 0:23:47.80  
**Catherine Beresford**  
You know, feel free to email me if you do think of something.

0:23:48.590 --> 0:23:49.80  
**Catherine Beresford**  
Umm.

0:23:48.400 --> 0:23:49.320  
**PWLD01**  
Yeah, no worries.

0:23:49.230 --> 0:24:1.720  
**Catherine Beresford**  
And then I can also give you feedback about the study later on, when when the research is finished, it won't be finished for quite a while, though, because I've got the whole of this year to recruit and analyze.

0:24:8.420 --> 0:24:8.920  
**PWLD01**  
Yeah.

0:24:1.730 --> 0:24:13.530  
**Catherine Beresford**  
But at some point within the next couple of years, I can send you some information about what I found, because you might, you might like to know what what I found overall from everybody that I spoke with.

0:24:14.400 --> 0:24:14.880  
**PWLD01**  
Yeah, yeah.

0:24:15.650 --> 0:24:25.790  
**Catherine Beresford**  
And if you do, if you do think of anybody that might be interested in taking part, like you mentioned that lady, please feel free to pass on my details. You know, you know, I talk to people, obviously it's anonymous. I'm not here to judge anybody. I'm really here just to hear what their experiences are.

0:24:35.740 --> 0:24:38.130  
**PWLD01**  
Yeah, yeah.

0:24:35.430 --> 0:24:40.500  
**Catherine Beresford**  
Please do share but you know because I just want to speak to people really.

0:24:48.870 --> 0:24:49.170  
**PWLD01**  
Yeah.

0:24:51.830 --> 0:24:52.140  
**PWLD01**  
Yeah.

0:24:52.150 --> 0:24:52.920  
**PWLD01**  
Yeah, no worries.

0:24:41.410 --> 0:24:55.880  
**Catherine Beresford**  
So you know, if that lady that you mentioned would like to take part, just let her know that I'm, you know, more than happy to speak with her but appreciate it’s, you know, completely voluntary. And anything else you'd like to say before I stop the recording?

0:24:57.30 --> 0:24:57.940  
**PWLD01**  
No, that's good.

0:24:58.690 --> 0:24:58.820  
**Catherine Beresford**  
You.

0:24:58.830 --> 0:24:59.160  
**Catherine Beresford**  
Thank you.