# Interview Transcript PWLD02 (Person with Liver Disease) ‘Sidney’ and Carer02 (his wife) ‘Rose’.

# Wednesday 24th January 11am. Interview held in a side room in the Hospice.

# Transcript

00:00:00 **CATHY BERESFORD**

OK, lovely. So, I'm going to put that there. Let me put that on as well. OK, so it will go to sleep in a minute, but it's recording the interview. OK, so.

00:00:16 **CATHY BERESFORD**

Let me just get my clipboard please. Yeah.

00:00:18 **CATHY BERESFORD**

So, thank you so much for agreeing to speak with me today. I really appreciate your time. If there's anything I ask that you're not sure of, do ask me to clarify, but I'm really mostly interested in what you have to say.

00:00:34 **CATHY BERESFORD**

Your personal experiences and views, and there's no right or wrong answers. So, to start off with, could you tell me about your journey of care since you've been diagnosed with liver disease in your view?

00:00:54 **Carer02**

Do you want me to start?

00:00:54 **PWLD02**

Well, why not? From what point? the Hospice involvement or pre?

00:01:03 **CATHY BERESFORD**

I guess it's whatever kind of stands out in your mind, really. I mean, you know, when, when? How long have you had liver disease now?

00:01:12 **Carer02**

You were you were diagnosed with liver disease when you collapsed 3rd of June 2020.

00:01:25 **CATHY BERESFORD**

I see. So, it's been a few years now,

**Carer02** and **PWLD02**

yes.

**CATHY BERESFORD**

And what? Where did you go for your your treatment at that point?

00:01:32 **PWLD02**

[Name of local] hospital.

00:01:34 **CATHY BERESFORD**

And then what happened?

00:01:40 **Carer02**

Um, I can verbalise a bit easier.

00:01:42 **CATHY BERESFORD**

Yes, of course.

00:01:48 **Carer02**

[**PWLD02**] had kidney cancer for some time. He had the kidney removed and

00:01:50 **CATHY BERESFORD**

I see yeah.

00:01:55 **PWLD02**

[Inaudible]

00:01:56 **Carer02**

It was, it was just quite a few years and he collapsed, as I said on June the 3rd. They took him into hospital at [place name] and with their tests I can't tell you what happened because it was COVID. It was lockdown. They discovered that his organs had decompensated. His kidney - remaining kidney was.

00:02:13 **CATHY BERESFORD**

Yes, yes.

00:02:25 **Carer02**

Not producing very well from the time he had it, he was only working at 30 to 40%. Yeah, and unfortunately his other organs were compensating and

00:02:36 **Carer02**

He decompensated. His liver was shown to be working at only eight per cent by then. His spleen was enlarged.

00:02:47 **Carer02**

His uh.

00:02:49 **Carer02**

It's your kidney, your liver.

00:02:53 **Carer02**

Uh. Your spleen and pancreas.

**PWLD02**

Pancreas.

So, he developed immediately. He he became type 2 diabetes with dependency on insulin because

00:03:02 **CATHY BERESFORD**

I see.

00:03:06 **CATHY BERESFORD**

Yes, I.

00:03:10 **Carer02**

And his ascites was drawn off, wasn't it? As far as I know.

00:03:13 **PWLD02**

At [hospital] they was drawing it off that was 4 weekly. [draining ascites]

00:03:22 **PWLD02**

9 litres at a time.

00:03:24 **CATHY BERESFORD**

Can I just check something the liver disease, did they think that that was caused by the cancer?

00:03:32 **Carer02**

It it was probably initially because it was the his his left. He had a left sided nephrectomy in 2008. Yeah. And he carried on like that with in renal oncology and so forth and so.

00:03:43 **CATHY BERESFORD**

Right.

00:03:52 **Carer02**

On but he was carrying on quite well. They were keeping it under control, even though his other kidney was working at only he's still his was damaged and working at only 30 to 40%.

00:04:06 **Carer02**

But As for his - nothing had ever been checked, but he had normal checks for his liver function and that but nothing ever showed up until that actual date.

00:04:17 **CATHY BERESFORD**

So, I need to I need to be careful because for the research, I'm only supposed to talk to people that have got liver disease that is caused by something specific to the liver disease.

00:04:29 **CATHY BERESFORD**

Since then, have they given you any idea as to what caused the liver disease?

00:04:35 **Carer02**

Apart from decompensation.

**PWLD02**

No.

00:04:38 **CATHY BERESFORD**

Right. So, so they think it's because you've had kidney cancer as far as you you know.

00:04:43 **Carer02**

As far as we know, because we've never been given any information.

00:04:49 **PWLD02**

They kept it very quiet because the medication I was on.

00:04:50 **CATHY BERESFORD**

Right.

00:04:55 **PWLD02**

For something else.

00:04:58 **PWLD02**

I was on it too long. I should have been on it three months maximum.

00:05:02 **CATHY BERESFORD**

OK, OK. So, I'm thinking maybe maybe it's not right for me to to do the full interview with you because I don't want to mislead you. And the thing is that I'm really meant to talk to people who've got liver disease that - they could have other they could have other health conditions – but it has to be that the liver disease is the cause of the illness and the way I'm hearing it, it sounds like your liver disease was actually caused by your other health problems.

**PWLD02**

I can’t prove that.

00:05:38 **CATHY BERESFORD**

I know, of course. I appreciate that. Yeah.

00:05:41 **Carer02**

It's just that I can only show you I know if you don't mind, right? It's. [**Carer02** gets hospital letter out of bag with **PWLD02**’s diagnoses information on it. The first condition listed is NAFLD/NASH]

00:05:43 **CATHY BERESFORD**

Yeah, sure. No, I don't mind. Yeah. I don't want to tell you anything wrong, that's all.

00:05:47 **Carer02**

No, that's.

00:05:49 **CATHY BERESFORD**

OK. OK, fine. Now, thank you. That's you know what, that's actually really helpful because what it says on here, is that so I I can explain something to you then because it sounds like you you're not really clear about it yourselves. So, it says on here that you've actually got something called non-alcoholic fatty liver disease.

**PWLD02**

Yes.

00:05:50 **Carer02**

Yes.

00:06:09 **CATHY BERESFORD**

Mm-hmm. So non-alcoholic fatty liver disease is a type of liver disease in its own right, which is separate to the kidney disease. So, you have got kidney disease as well of course, as you said, you've got quite a lot of health conditions, but you have got this specific.

00:06:19 **Carer02**

Right.

00:06:29 **Carer02**

Gotcha

00:06:30 **CATHY BERESFORD**

thing. So I'm so glad you showed me that.

00:06:34 **CATHY BERESFORD**

But I hope that that helps you to understand too.

00:06:37 **CATHY BERESFORD**

That you've got - the thing is with our bodies, they're all completely connected and related, but you can have one condition that causes another, or you can have a condition that's caused by something in its own right. So fatty liver disease is a cause of liver disease. Does that sort of make sense?

**PWLD02** and Carer

Yes.

00:06:59 **CATHY BERESFORD**

But they will all have an effect upon one another.

00:06:59 **Carer02**

Yes, but that, that's.

00:07:03 **CATHY BERESFORD**

You know, and obviously you've got you, you were really poorly, and you had lots of things going on and then it's triggered all these other problems. But it does say on there you've got non non alcoholic I can't say it properly, but it means that it's a liver disease that is not caused by alcohol. Yeah. So, for some people who've got liver disease, it is caused by alcohol.

**PWLD02**

Ohh, right.

**CATHY BERESFORD**

OK. So now we've cleared that up. Look.

00:07:26 **CATHY BERESFORD**

You can carry on. So, you were in hospital. You found out you were decompensated, so you had all the fluid in the tummy, and you had to have all that drained off. And you obviously then had all these other health things going on. Tell me sort of what sort of happened after that. I mean, like, how

00:07:43 **CATHY BERESFORD**

Long were you in hospital for?

00:07:46 **Carer02**

I can't remember. Initially he was in hospital for 19 days? Yeah, initially, yeah.

00:07:55 **Carer02**

Came out.

00:07:56 **Carer02**

And I think it was the next.

00:07:58 **Carer02**

Week you had to go.

00:07:59 **Carer02**

Back for was it paracentesis?

00:08:00 **PWLD02**

OK.

00:08:03 **Carer02**

Yeah. And they drained off quite a few litres,

00:08:09 **Carer02**

He came out and two weeks later he was back in.

00:08:12 **PWLD02**

Back in

**CATHY BERESFORD**

Wow, yeah.

00:08:14 **Carer02**

In for more paracentesis and he and and we're draining him.

00:08:16 **CATHY BERESFORD**

Yeah, yeah.

00:08:18 **PWLD02**

It was a four-weekly cycle.

00:08:20 **Carer02**

Yeah. And then we.

00:08:21 **PWLD02**

With the Liver unit at [name of] Hospital.

00:08:23 **CATHY BERESFORD**

I see, yeah.

00:08:24 **Carer02**

Yes. And of course, the liver unit being overseen by Doctor [hepatologist], he telephoned [name of **PWLD02**] in September saying that he would like to refer [**PWLD02**] to the Hospice, yeah.

00:08:41 **CATHY BERESFORD**

Oh I see. Yeah,

**Carer02**

because there was absolutely nothing

**CATHY BERESFORD**

So was that the same year that you got the first episode of the ascites.

**Carer02**

Yes, from June to September.

Yeah, I see. Yeah. So actually, within that same year, they've then said to you that they'd like to refer you to the Hospice.

**PWLD02**

Yes.

**CATHY BERESFORD**

So, what were your thoughts at that point?

00:09:04 **PWLD02**

What the hell!

00:09:03 **Carer02**

Well, it was my really. Yeah.

00:09:07 **PWLD02**

You know, didn't really know that much about Hospice.

00:09:11 **CATHY BERESFORD**

I see.

00:09:12 **PWLD02**

We we'd only had one sort of connection with it with a neighbour, but they actually died in here,

**CATHY BERESFORD**

Right.

**PWLD02**

So, you know. Hospice itself is, you know, you people go ‘oh oh hospice, yeah, last legs’.

**CATHY BERESFORD**

Yeah.

00:09:30 **PWLD02**

Not always the case. you know, say Doctor [hepatologist] referred me. We we took it from there.

00:09:40 **CATHY BERESFORD**

So, what did they kind of explain to you was the reason for the referral?

00:09:47 **Carer02**

Shall I? –[checks with husband if she should explain]

You know.

00:09:48 **Carer02**

That's OK, really conscious because you get the word palliative and that's it. And you sort of the curtains drawn and then you think, oh, gosh, but I was listening the the reason was and he was never ever referred for for a.

00:09:49 **PWLD02**

You carry on.

00:10:06 **Carer02**

Kidney transplant

**CATHY BERESFORD**

Yes.

00:10:07 **Carer02**

and Doctor [hepatologist] explained that he wasn't really - due to all the things that were wrong with him he could not refer him for a liver transplant because

00:10:19 **CATHY BERESFORD**

I'm with you, yeah.

00:10:21 **Carer02**

he would be in the same situation still, so therefore there was nothing.

00:10:24 **PWLD02**

Yeah. Any any operation kind of virtually have.

00:10:28 **CATHY BERESFORD**

Yeah. With you. Yeah, yeah.

00:10:29 **Carer02**

Yes, and and he would probably not survive.

**PWLD02**

Any operation

**CATHY BERESFORD**

I see

00:10:38 **Carer02**

And so, he said the Hospice would be able to monitor him and it's holistic. It's not just ohh he's got a sort of this wrong this wrong and we were going to all different departments.

**CATHY BERESFORD** Yeah.

00:10:57 **Carer02**

it was totally looking after not just his body, but just, *and* us as a family.

00:10:59 **CATHY BERESFORD**

I'm with you.

00:11:04 **Carer02**

Yeah. Helping with rest and it was.

00:11:08 **Carer02**

Really quite eye opening, wasn't it really?

00:11:11 **PWLD02**

Yeah. Oh yeah. No, I mean, when I sort of first came here, yes, I was due for a visit anyway. I was sort of taken bad and we had to come back early from holiday [because he was unwell] and whatnot, you know, but [name of hospital] were doing it [paracentesis] every four weeks. Sometimes it was a fight to get in there.

00:11:36 **CATHY BERESFORD**

Was it?

00:11:37 **PWLD02**

You know, you know.

00:11:37 **CATHY BERESFORD**

In what way?

00:11:39 **PWLD02**

They just sort of, ‘oh, we haven't got the room’.

**CATHY BERESFORD**

And was this to get your drain drainage?

**PWLD02**

Yeah. So yeah, that's 8-9 litres at a time.

00:11:48 **PWLD02**

And it was all went to five weeks once, and I was, I was absolutely bursting.

00:11:55 **PWLD02**

Yeah, it was all getting to the point it was going to be needed to be done again and I came in here [to the hospice].

00:12:07 **PWLD02**

And Doctor [at hospice], I can't say enough about the man. [praise]

00:12:16 **PWLD02**

He done all the tests, X-rays, scans. Went through the whole thing. He's drained me once.

**CATHY BERESFORD**

Really? How come?

**PWLD02** laughs

00:12:26 **Carer02**

Because Doctor [at hospice] and [name of specialist nurse at hospice] literally right, micromanage his medication and everything. So, every time he comes, he has a blood test. And of course, it's a delicate balance.

00:12:30 **PWLD02**

He's doing something right.

00:12:46 **Carer02**

Between his kidney and his liver. And they're like, they manage it.

00:12:49 **CATHY BERESFORD**

I'm with you.

00:12:50 **PWLD02**

With that, I’m gradually getting better.

00:12:53 **CATHY BERESFORD**

So that's actually helping to manage your symptoms so that you're not needing to have the drainage done in the way that you were before?

00:13:01 **Carer02**

No [he is not needing drainage], he's regularly checked every time.

00:13:02 **PWLD02**

The only one [paracentesis] that was done here, I would have had that done anyway, you know it was on the point of it [i.e., it was due]. It's got to be done so, so I came up with, come back, phoned them up and said like you know about it. Come in and see us. You're coming in tomorrow.

00:13:19 **CATHY BERESFORD**

And that was here, was it? So, they can drain the the fluid off here [at the hospice]?

**Carer02**

Yes.

**CATHY BERESFORD**

Going back to when you had to have it done in the hospital and you mentioned it could be quite difficult getting in. When you needed to have it drained, how did you go about arranging that when it was done at the hospital?

00:13:39 **PWLD02**

Got in touch with the Liver nurse.

00:13:41 **CATHY BERESFORD**

I see. So, you have to call them, do you?

00:13:42 **PWLD02**

Yeah. When it needs draining again, you know.

**CATHY BERESFORD**

I see.

00:13:49 **Carer02**

Unfortunately, it, there is sometimes a a waiting list or things can't be done and It's the liver clinic, so it does close of an evening which has come. Yeah, well, the emergency, you'd have to go to A&E and so forth.

00:14:03 **CATHY BERESFORD**

I see.

00:14:04 **PWLD02**

It's just 9:00.

00:14:08 **CATHY BERESFORD**

Ohh so did you sometimes have to go to A&E then to get it sorted out? Did you - so on one occasion?

00:14:12 **PWLD02**

Yeah. Sometimes. Yeah, yeah.

00:14:14 **Carer02**

And and once and he waited so long in liver clinic, he did have the catheter in, right. And they sent him home with the catheter in, right.

00:14:18 **PWLD02**

It was so bad at the time and.

00:14:24 **Carer02**

To come back the next day because, yeah, it was so.

00:14:25 **CATHY BERESFORD**

Yeah, yeah.

00:14:30 **Carer02**

I know with the Hospice that that you are totally covered every which way. Night, day I can just phone and say something's wrong and they can advise me. Not necessarily think but advise what you can do for some other actually now, yes.

00:14:50 **CATHY BERESFORD**

So, are they your first port of call, are they? What is it like a helpline or that you have?

00:14:57 **Carer02**

No. Yes, it's.

00:14:59 **PWLD02**

Just phone up [specialist nurse at the hospice].

00:15:00 **CATHY BERESFORD**

Yeah, I see. Yeah.

00:15:00 **Carer02**

We phone One Response which is their sort of 24-hour telephone number or, if it's during the day, I phone the Hospice. Yeah. And someone gets back immediately or tells tells a a nurse will tell us. Or Dr [at the hospice] or whatever ‘get in’ or ‘go here’. Yeah. Which is very - as a carer, is very, very supportive, because otherwise you're just running around in circles.

00:15:33 **CATHY BERESFORD**

So, if you needed support, advice or information before you had that from the Hospice, who did you go to?

00:15:43 **Carer02**

Well, I'm sorry to say we could not go to the surgery, our GP, at all. It was literally

00:15:44 **PWLD02**

No, we have.

00:15:52 **Carer02**

told phone 111 or an ambulance and sometimes neither would you know be helpful really. And it was - it's been very difficult, hasn't it? If it hasn't been for the Hospice, for the people here. Yeah, [**PWLD02**] wouldn't be alive because he was only given a a life expectancy that they could judge just

00:16:21 **PWLD02**

-Year, if I'm lucky, 18 months.

00:16:27 **CATHY BERESFORD**

And that was in 2020, was it?

00:16:29 **PWLD02**

In 2020 and it's every time I go up the hospital now, they look at me and go. ‘What are you still doing here?’ [jokey voice]

00:16:35 **CATHY BERESFORD**

So, so you still go up to the hospital sometimes, do you?

00:16:38 **PWLD02**

Ohh yes to do visits Dr [hepatologist at hospital]

00:16:41 **Carer02**

We have regular

00:16:42 **CATHY BERESFORD**

Is that the liver clinic?

00:16:43 **Carer02**

That's the liver, doctor liver clinic.

00:16:44 **PWLD02**

yeah.

00:16:46 **CATHY BERESFORD**

Ohh I see. So how often do you have?

00:16:47 **CATHY BERESFORD**

To go to the liver clinic.

00:16:48 **Carer02**

Well, he only has to go to see.

00:16:51 **Carer02**

Doctor [at hospital]

00:16:52 **PWLD02**

Every six months now we have a laugh [**PWLD02** laughs].

00:16:53 **Carer02**

00:16:55 **Carer02**

[**PWLD02**] has regular checkups, blood tests and everything else here.

00:16:59 **CATHY BERESFORD**

Ohh I see yeah so.

00:17:01 **PWLD02**

But there's blood test done there as well, so.

00:17:02 **CATHY BERESFORD**

Yeah. So are there any other healthcare professionals or any other professionals that are involved in?

00:17:08 **PWLD02**

The diabetes people have been involved, you know.

00:17:10 **CATHY BERESFORD**

Oh yeah.

00:17:12 **Carer02**

Yes, yes, diabetes nurses. So keep in touch and yeah, I see and check that. Yeah, gradually the.

00:17:17 **PWLD02**

Yeah. Anything you want.

00:17:23 **Carer02**

The clinics and the kept in touch are now falling away. There's the vascular clinic for his adren- vascular clinic, the kidney clinic, when they found out he was palliative just.

00:17:34 **CATHY BERESFORD**

Yeah. For your other, yeah.

00:17:44 **Carer02**

And uh.

00:17:47 **Carer02**

No, you're still going to the osteoporosis clinic are you?

00:17:49 **CATHY BERESFORD**

So, you've got a lot of things going on, haven't you?

00:17:53 **PWLD02**

Ohh, Yes, yes. I’m a regular visitor [laughs]

00:17:53 **Carer02**

We sometimes sometimes the these, but you know it's again you have got the support.

00:17:56 **CATHY BERESFORD**

Yeah, yeah.

00:18:08 **Carer02**

Of literally the Hospice and uh, if they think **PWLD02** should have Uh X-rays or things like that for other things. Other things suddenly crop up and chest and things like that. Then they will get it. And of course, then we have to get the GP involved being referred if necessary.

00:18:32 **CATHY BERESFORD**

Yeah, I see.

00:18:35 **PWLD02**

I had a bit of a cough and talked to [doctor at hospice]'s ‘I don’t like the sound of that, go and have an x-ray’.

00:18:42 **Carer02**

So that's that's fine, but it was clear.

00:18:45 **PWLD02**

And sent me, sent me out at the X-ray up. He was up his a week later for something else and he went ohh. [**PWLD02**] said ‘I wanted a word with you and so I got your X-ray results back’.

00:18:46 **Carer02**

OK.

00:18:59 **PWLD02**

Here we go, you know, rollicking time.

00:19:02 **PWLD02**

So, I've been smoking since I was like 12, with a fireman for a lot of years. You know, it's I'm a long- runner.

00:19:05 **CATHY BERESFORD**

How I say?

00:19:13 **PWLD02**

And he's looked at, he went.

00:19:15 **PWLD02**

Would be honest, he said.

00:19:17 **PWLD02**

‘Your age’, he said. ‘I've never seen a healthier pair of lungs.

00:19:24 **PWLD02**

Said, ‘and you've got me’ said. ‘I don't know how you've done it’, he said, ‘but you have’.

00:19:30 **CATHY BERESFORD**

So, coming back to the liver disease again and thinking about the care that you've specifically had for that, I mean you've given me some good examples of care that's been positive and care that's been a bit more negative. Is there anything else when you think about the care that you've had that sort of stands out in your mind, focusing on the liver specifically?

00:19:52 **CATHY BERESFORD**

OK.

00:19:57 **Carer02**

Apart, apart from Doctor [hepatologist] actually concentrating on [**PWLD02**] and myself.

00:20:08 **PWLD02**

Yeah, he’s very good, very good.

00:20:08 **Carer02**

As what's actually his

00:20:11 **Carer02**

Yeah. Yeah, he he really does. He's an excellent [hepatology] doctor. Yeah, and I think, uh.

00:20:18 **CATHY BERESFORD**

Yeah.

00:20:23 **Carer02**

Be the actual joint efforts of the Hospice and Dr [hepatologist] have really been so beneficial, but apart from.

00:20:25 **CATHY BERESFORD**

Yes. Yeah.

00:20:35 **Carer02**

We really didn't have because of the the the times with COVID and everything we we we had very little yeah contact with with some of the other clinics and and things like that. Yeah.

00:20:49 **CATHY BERESFORD**

That makes sense, yeah.

00:20:52 **Carer02**

Because you were in-out, masks and everything.

00:20:55 **CATHY BERESFORD**

Thinking about um, I'm just going to probe a bit further. You know, when you're saying like he's an excellent doctor or when you've said some positive things about [specialist nurse at hospice], well, what is it about what, what is it that makes the healthcare professional excellent. In your opinion, what is it?

00:21:14 **PWLD02**

I don’t know, they've just got something that they can do, you know, it's it's not just one, that one, that one. You know, it's everybody up here. You know, there's always a lot of fun. We have a laugh.

00:21:27 **Carer02**

It's everybody.

00:21:31 **Carer02**

I think it's because myself, personally I think it's because they don't see [**PWLD02**] as just a liver. Yes. And you know, sort of you don't feel like you're a specimen in a bed and that you're a real human being and there's other things going on and age and everything else, but they treat you - I know it sounds horrible using this - as a human being. Yeah.

00:22:02 **Carer02**

And not.

00:22:06 **Carer02**

It's to everyone.

00:22:09 **Carer02**

It's not just to [**PWLD02**] as patient, but to me as [a carer] as well and it really does help with me.

00:22:17 **Carer02**

In between because they see him, but the other carers on him.

00:22:21 **CATHY BERESFORD**

Yeah. Yeah and yeah.

00:22:24 **CATHY BERESFORD**

[Asks **PWLD02**] Is there any Is there anything you'd like to add to that?

00:22:28 **PWLD02**

No, it's pretty much where it's.

00:22:33 **PWLD02**

You know, I mean, we do have a laugh and they're in and I'll come up with regular blood tests and you know, and I’m a bugger for getting blood out of! I really am a nightmare normally ends up when [hospice nurse] coming out with a big dart [venepuncture needle], you know, and I've just sort of for a laugh said ‘right, anybody can get three phials [of blood from me] out in one go gets the Toblerone!’

00:22:58 **CATHY BERESFORD**

Yeah. Yeah. So, you can have a laugh with them.

00:23:02 **PWLD02**

[Name of a nurse] come out, went - bonk! three phials So, giant size Toblerone! [laughs]

00:23:13 **PWLD02**

That's the sort of thing we do for a laugh know it's you.

00:23:14 **CATHY BERESFORD**

I get you. I understand. Yeah, I think I think, yeah.

00:23:18 **PWLD02**

You know.

00:23:19 **Carer02**

It's because they they also they treat *you*. I've watched them and of course **PWLD02** is deteriorating, but they've reduced his deterioration so much that I sometimes I don't see it, but I they, um, when they say it's quality of life.

00:23:43 **PWLD02**

Yeah.

00:23:45 **Carer02**

Not quantity. Yeah, in a sense, but here you get both.

**CATHY BERESFORD**

I'm with you.

00:23:51 **PWLD02**

Yeah. I mean the in-stay [inpatients at the hospice] right here for the draining [paracentesis] with [name of] Hospital, you went up there 10:00 in the morning, had a blood test got drained, got sent home. If they forgot to give you the anti-sickness tablets, you was back that night throwing up all over the place.

**CATHY BERESFORD**

OK.

00:24:12 **PWLD02**

Come in here [hospice] and they went ‘alright you're in tomorrow, Tuesday. Yeah. Behave yourself, you can go home Thursday’ and for three days? ‘Oh yeah. You know, we don't let you go until we’re happy’. [not a rushed experience]

00:24:28 **CATHY BERESFORD**

Right. OK. So that your symptoms are managed, you mean, yeah.

00:24:31 **PWLD02**

[inaudible], you know, and it was like, you could not ask for better.

00:24:38 **CATHY BERESFORD**

Thank you. That's that's so helpful.

00:24:40 **PWLD02**

Really couldn't ask for better.

00:24:43 **CATHY BERESFORD**

So, thinking about the experiences that you've had, if you were to meet somebody else who was diagnosed with advanced liver disease, what would your advice to them be about the care that they receive? Thinking about what you've been through?

00:25:01 **PWLD02**

Go and have a chat with them. Go and talk to them.

00:25:06 **PWLD02**

You'll be surprised.

00:25:08 **Carer02**

If you can be referred [to the hospice], it's not frightening. It's not. It's you., I know the words Hospice, palliative and things like that have always been so scary. People our age, any age but you will - it will be beneficial as far as we're concerned, it was highly beneficial, but also talk to your GP. [**PWLD02** laughs here]

00:25:37 **Carer02**

If you can talk, talk to your liver specialist about actually what's going on and if you don't understand the words, ask them what they mean. That's all I can say. Really. Just talk, try and talk to everyone if they offer.

00:25:51 **PWLD02**

Yeah, yeah.

00:25:56 **Carer02**

Yeah, palliative care, they take care. You just listen. Yeah, just listen, please.

00:26:01 **CATHY BERESFORD**

Yeah. Yeah. [to **PWLD02**] Why did you laugh when she said talk to your GP? Why did you laugh? [laughs]

00:26:11 **PWLD02**

You don't know our GP, it's no laughing matter, believe you me.

00:26:20 **Carer02**

That's just one little thing, and this does upset me. When **PWLD02** came out [of hospital], it was like, as I said, a big curtain closed. And the ward [staff] said, any problems he – **PWLD02** - must be referred to a dietitian because all they all they say is ‘cut out salt, cut out this, give you this’ and but you've got to be referred by your GP. I phoned the GP: ‘Why do you want to talk to him?’ I said: ‘Ohh. **PWLD02**'s just come out of hospital and I've got to be referred to a dietitian to control what's going on’. When I got the doctor on the phone, he said, ‘what do you expect me to do Mrs.[name of Care02]? I am so busy.’ [**Carer02** tries not to cry as she relays this]

**PWLD02**

That’s the attitude.

**CATHY BERESFORD**

Is it?

Care02

‘What do you expect of me?’ I said: ‘I don't expect anything, just a small referral.’ and he did it again when we had trouble with-

00:27:23 **PWLD02**

They don't read your notes.

00:27:23 **Carer02**

**PWLD02** was going through a bad period, and they were trying to help at the Hospice with his diabetes, he didn't. He was so sore. And you know the injections.

00:27:33 **CATHY BERESFORD**

Yes, yes.

00:27:39 **Carer02**

And everything. So **PWLD02** said he wanted to talk to a doctor just, and it had been all day, and I was worried. So, the diabetes nurse – the [clinic] one or whatever the actual clinic - phoned the GP surgery.

00:27:55 **CATHY BERESFORD**

Yeah, yeah.

00:28:04 **Carer02**

And, the GP that evening talked to **PWLD02** and persuaded him, you know, ‘things, it's going to be alright’, you know, ‘it's all, I know. You're fed up. You don't want to go on’. And our doctor phoned me in the morning [Carer 02 is trying not to cry] called me a liar, told me not to phone. Me a liar. And it wasn't even me [who had made the phone call, it was the diabetes nurse at the clinic who called the GP]

**CATHY BERESFORD**

Take your time. It must have been very upsetting.

00:28:32 **Carer02**

It can be, yeah.

00:28:33 **PWLD02**

We've had a bad time there.

00:28:39 **Carer02**

It can be when no one will talk to you. No one will help you, and you're literally phoning for an ambulance, and they say 7 hours and and you're watching your husband vomit himself to death [**Carer02** trying not to cry].

**CATHY BERESFORD**

Yeah.

**Carer02**

And I can’t tell you how [specialist nurse at hospice] was there for me. And that's what I mean, it's not just **PWLD02**. They're just there, just there.

00:29:17 **CATHY BERESFORD**

For you as well, yeah. It obviously makes a big difference.

**Carer02**

to tell them, you know, ‘so don't worry, we'll get this, we'll get that’ because it's such a lonely road. It can be.

00:29:23 **CATHY BERESFORD**

Yeah. Yes.

**PWLD02**

Yeah.

00:29:30 **Carer02**

A lonely road. And yeah, if it wasn't for them, I would probably be taking so many tablets, you know, sort of antidepressants and everything else, but you don't need them here [at the hospice] because everyone makes you laugh and makes you and lifts and lifts you, yes.

00:29:48 **CATHY BERESFORD**

Yeah, yeah.

00:29:50

Yeah, yeah.

00:29:52 **CATHY BERESFORD**

Ohh thank you so much for sharing that with me. That was really helpful to know that.

**PWLD02**

Yeah.

00:29:57 **Carer02**

Like anything with yeah, with **PWLD02**'s problem, we are told immediately, but by [specialist nurse at hospice], by the Hospice, after his the same day with his blood tests, and that that he is abnormally normal! [laughs]

**PWLD02** laughs

00:30:20 **CATHY BERESFORD**

I get you. Yeah. Yeah, yeah.

00:30:24 **Carer02**

Any little tweaks that have to be done with his medications.

00:30:27 **CATHY BERESFORD**

Yeah, sure.

00:30:31 **Carer02**

Again, that they're so sort of like positi-. He's fine, you know, he is fine. He's stable. Everything is stable. If it's not stable, then they do something about it.

00:30:42 **PWLD02**

Then they want to know why, and they look at it.

00:30:44 **Carer02**

Yeah, but we don't. We know. It's like everything we're of an age, but we know that.

00:30:52 **PWLD02**

[Hospice doctor] arranged his meetings with doctors over there (in the acute hospital] that are involved in liver and kidneys and you know, and he'll put together a meeting and they'll all sit down and talk about this and sort it out and see what they can do.

00:31:04 **Carer02**

But unfortunately, your your condition is mainly liver, which is is of course it. There was hardly anything working now three years ago and now you know anything he's.

00:31:19

Yeah, yeah.

00:31:23 **Carer02**

Yeah, no final.

00:31:23 **PWLD02**

It's just that only team, so.

00:31:24 **Carer02**

Point for you had cysts. Yeah, you had cysts in your liver as well, didn't you? They were getting worried about that. They.

00:31:32 **Carer02**

Haemorrhagic cysts.

00:31:33 **CATHY BERESFORD**

Ohh OK.

00:31:36 **Carer02**

They've gone.

00:31:40 **Carer02**

It seems to me that that that his liver's not growing back [**PWLD02** and care02 laugh], but that's it. I know it can regenerate itself, but not not that far!

00:31:49 **CATHY BERESFORD**

Yeah, sure.

00:31:52 **PWLD02**

Not that good! [laughs]

00:31:52 **Carer02**

Not that good, of course there is always, it it does, we know he's not going to get better.

00:32:02 **PWLD02**

No. It's just a matter of time.

00:32:04 **Carer02**

But we knew that anyway.

00:32:07 **CATHY BERESFORD**

So, thinking about that, that was so helpful. What you told me and also sort of the way that you were telling me what you'd sort of say to somebody that had liver disease. Yeah, thinking it slightly differently then, if you could tell healthcare professionals who work with people who've got liver disease. What, what if you could say to them, you know, ‘this is what I think care should be like’. What would you say?

00:32:37 **CATHY BERESFORD**

Anything you think really.

00:32:38 **Carer02**

Anything? I think for me again. Think before you say something that the person you're talking to has no knowledge whatsoever about what you're talking about. They're probably stunned, and if they [HCP] could just explain or find the words to explain what is actually happening and in sort of like layman's language, that and

[knock at the door]

00:33:19 **PWLD02**

Nobody in!

00:33:21 Speaker 4 [knocks on door]

I’ve come in to just check on tea, coffee, water requirement now. Thank you. OK. You OK? You.

00:33:24 **Carer02**

Thank you.

00:33:29 **Carer02**

Thank you. Thank.

00:33:32 **Carer02** [carries on]

Just to remember that this is a person.

00:33:33 **CATHY BERESFORD**

Just check it's still recording.

00:33:39 **Carer02**

This that this is someone that is, just look at them and and think before you say something, yeah.

00:33:45 **PWLD02**

Treat them like a normal person and don’t look at it as a sick person.

00:33:50 **CATHY BERESFORD**

Yes, yeah. And is there anything else you want to add [**PWLD02**]?

**Carer02** to **PWLD02**

You do it.

00:33:58 **PWLD02**

Thank you very much [laughs] She’s good isn’t she? [re. **Carer02**] ‘Have the ball it’s nice and hot!’ No, you just, you know. Do what you can for them and explain what you've been through. So yeah. And put them in the right direction. Yeah, you know, these people are here to help you. Yeah.

00:34:24 **CATHY BERESFORD**

Thank you. Yeah, OK, so, I - you know, I feel like you've really given me a very good idea about it, but in summary, what does good care for people with advanced liver disease look like in your opinion? Like to summarise?

**PWLD02**

Here. Here. Yeah. [The hospice]

00:34:49 **Carer02**

Yeah. Yeah.

00:34:59 **PWLD02**

Seriously. Without a doubt. Food's nice as well.

00:35:01 **CATHY BERESFORD**

Is it?

**PWLD02**

Yeah.

**CATHY BERESFORD**

You get good food. Yeah. It makes a difference, doesn't it? Did you ever? You know I mustn't forget to ask. You mentioned that you had to get a referral to the dietician. Did you get that referral through the GP in the end?

**Carer02** and **PWLD02**

No.

**CATHY BERESFORD**

Right.

00:35:19 **Carer02**

It was literally, um, the dietician. Because we we try phone actually phoned [place name] health service, [place name] Health service, [place name], trying to find out just a little bit of information we needed. And it was literally phoning the liver clinic and the dietitian happened to be there.

00:35:44 **CATHY BERESFORD**

Oh, I see, so that you managed to get one in the end because you organised it yourself, yeah.

00:35:48 **Carer02**

She. She overheard. And then we got all the information the the **PWLD02** needed fortified drinks.

00:35:58 **CATHY BERESFORD**

Yeah, I'm with you. Yeah.

00:35:58 **Carer02**

And things like that.

00:36:00 **Carer02**

All to do with the liver that he was, he was having sort of disease related malnutrition, but apart from that until just by accident, phoning the liver clinic about his ascites, the dietician was there. And the [name of nurse at clinic], I think it was in the liver clinic, wasn't it? One of the nurses in the liver clinic, she actually said, oh, well, you know, ‘Mrs. [name of **Carer02**] had difficulty getting through to you’ due to COVID and she said: ‘Ohh’, and that was it. We had floods of lovely information.

00:36:41 **CATHY BERESFORD**

Oh, that's good. Yeah.

00:36:42 **Carer02**

Again, through like the liver clinic. Yeah, because [name of nurse at the liver clinic] was, she was marvellous as well. I I know you [**PWLD02**] don't remember a lot of that, but for me contacting those clinics and things, but I know absolutely nothing, no support from the GPs at all. OK. Yeah, not even now.

00:37:05 **PWLD02**

Absolute waste of space [the GP]

00:37:07 **Carer02**

He doesn’t know honestly and truly, he doesn't even know that **PWLD02**'s palliative.

00:37:12 **PWLD02**

He's got no idea, he doesn't read notes. None of them down there, read notes. According to one of them, I'm grossly obese.

00:37:21 **Carer02**

But you had a BMI.

00:37:22 **PWLD02**

I had a bad time once and I was up to 18 stone. I've lost 4 1/2 stone of that, you know, where's this ‘grossly obese’ bits come from? You [GP] haven't looked at the notes have ya?

00:37:38 **CATHY BERESFORD**

Yeah.

**PWLD02**

You know. Not not for some. I mean one of them. He stands 8 foot away. He's still wearing COVID stuff. masks, though, the lot, you know? And he's like ‘Stay back there’ and you know he won't touch you, he won't communicate with you. What’s the point of going to going to see him? There is none.

00:38:01 **Carer02**

None. There is none, so sorry.

00:38:03 **PWLD02**

You listening?

00:38:05 **Carer02**

We have other big problems as well.

00:38:06 **PWLD02**

You you might as well go sit up [acute] Hospital for four or five, six hours. See a doctor up there. That’s how long it takes.

**CATHY BERESFORD**

Yeah.

00:38:15 **PWLD02**

Yeah, I don’t know what your local hospital’s like.

00:38:20 **Carer02**

But we haven't really had a bad experience with

00:38:21 **PWLD02**

Looks like a slaughterhouse down there on a Saturday night [A&E]. It's -

00:38:26 **Carer02**

Really haven't had a bad experience with the liver consultant Dr [name] at all, he's been marvellous. And here [hospice], marvellous, uh. I know sometimes it could be the luck of the draw with what consultant and things you get. Again, if you can ask questions, if your brain is actually working at the time or have someone with you who will ask questions.

00:38:50 **PWLD02**

He'll answer the question for you. He will explain it to you. [the hepatology consultant]

00:38:55 **Carer02**

Yes. Yeah, yeah. Because sometimes.

00:38:57 **PWLD02**

You know, I might not understand it, you know, can you sort of explain that to me a bit more.

00:39:03 **CATHY BERESFORD**

Yeah, I see. Yeah, yeah, yeah.

00:39:06 **Carer02**

And I I also carry a bag with me as you can see and I've usually got a large notebook and write it down.

00:39:13 **CATHY BERESFORD**

Very, very useful, very useful. I can't remember right and.

00:39:21 **PWLD02**

[Jokes to the researcher] Do you want to copy of that list?

00:39:27 **CATHY BERESFORD**

[Laughs] I don't need it. So, you know when when you're having this kind of conversation and you're reflecting back on everything you've been through over the last few years. Is there anything else that kind of springs to mind that you'd like to share with me about your experience?

00:39:47 **PWLD02**

Nothing really.

00:39:49 **Carer02**

No, you are saying.

00:39:51 **PWLD02**

You know, we just keep plodding, plodding through life. I mean, we've we've got a serious problem at the moment.

00:39:54 **CATHY BERESFORD**

Yeah, yeah.

00:40:00 **Carer02**

But it's with with [**PWLD02**]’s liver

00:40:02 **PWLD02**

We get through it

00:40:07 **Carer02**

Liver complaint. As I said, it's been surrounded by so many other all

00:40:11 **CATHY BERESFORD**

Yes, yes, yes. Yeah. Because it's not the only thing that.

00:40:13 **Carer02**

All I can say is that.

00:40:15 **Carer02**

You have to live with. Yeah, really overwhelming, but.

00:40:20 **Carer02**

The liver part of it, yeah, we’re quite good. Like once we've we've had loads of support that way. And and I think.

00:40:22 **CATHY BERESFORD**

Yeah, yeah, I see.

00:40:29 **Carer02**

We could really sometimes kiss doctor [hepatology consultant]'s feet for referring you, because no one else did. It was only the liver clinic that did. But as for

00:40:38 **CATHY BERESFORD**

Yeah, I I see.

00:40:43 **Carer02**

helping other people with liver disease, all I can say is the actual people, please take someone with you.

**PWLD02**

Yes, good idea.

**Carer02**

That can remember because you can't. That can go over it with you, and if the I know they haven't got a lot of time, these consultants and not, but if you could just slow down and fa to people and try and explain different.

00:41:12 **PWLD02**

[Hospice doctor] gives you that time.

00:41:15 **Carer02**

It is such an awful time, you know.

00:41:18 **PWLD02**

You know, he doesn't rush through it and go ‘Oh I gotta go now’.

00:41:23 **Carer02**

That's, that's it. Entirely. You. You're sitting sitting there like a rabbit in headlights. You. What way do you run? But if people.

00:41:35 **PWLD02**

In fact, he's a very nice guy anyway. You know, his whole manner and his attitude towards people.

00:41:37 **CATHY BERESFORD**

Yes. Yeah, but.

00:41:43 **CATHY BERESFORD**

But you feel you get that time and you can ask questions and then if you've got someone with you, it helps, I see

00:41:49 **PWLD02**

Yeah, one day there was an elderly couple out there was her first visit here. Yeah, and she'd been referred from the hospital. Yeah.

00:41:53 **Carer02**

I think you know if you have someone with you.

00:42:00 **PWLD02**

And she said I hope the bloody food is better than it is over there [at the acute hospital].

[Laughs]. I sort of leaned over and went ‘You'll like it. Believe me. I've been in here’. I said, ‘the food is nice’. I said, ‘all this staff are nice’ I said, ‘they’re helpful’.

00:42:18 **CATHY BERESFORD**

That's good.

00:42:25 **PWLD02**

The food - you order what you like for breakfast, I do. They laugh [the staff]. They said, ‘what do you want for breakfast’, I went like, ‘toasted bacon and tomato sandwich’ for a laugh, and I got a toasted bacon and tomato sandwich.

00:42:26

Did you. Yeah. Yes [laughs]

00:42:47 **PWLD02**

Yeah. [laughs] Be careful what you say! But I do like ‘em.

00:42:52 **CATHY BERESFORD**

So sometimes you've had to stay over here, but sometimes you just come in for the day. Do you?

00:42:57 **PWLD02**

Yeah. So, so with the blood tests, yeah.

00:43:00 **PWLD02**

So, if I'm gonna be drained [paracentesis], it's it's it's it's very dangerous.

00:43:02 **CATHY BERESFORD**

Yeah, I'm with you. Yeah, sure.

00:43:05 **PWLD02**

In for 10:00 or go through all the procedures.

00:43:08 **CATHY BERESFORD**

Yeah, yeah.

00:43:10 **PWLD02**

What not. Do it following day. Yeah. Scanned. He [hospice doctor] scanned it every time - you're supposed to, but I've had scans - drains over the hospital where they haven't scanned it. They're taking potluck where they're going with that needle.

00:43:16 **CATHY BERESFORD**

Yeah, sure.

00:43:28 **PWLD02**

You know he'll [hospice doctor] he will scan it every time. Drains it.

00:43:33 **Carer02**

You haven't been through all the facilities at the Hospice. Again, it's all linked. There's the physio for breathing and for your other limbs just to make sure that your whole body is is sort of

00:43:38 **CATHY BERESFORD**

I'm with you.

00:43:49 **Carer02**

incorporated not just one little bit of you, but as for as for **PWLD02**'s condition, no matter how the the liver disease formed, I think we've been very lucky, yeah.

00:44:12 **CATHY BERESFORD**

And is there anything that you want to ask me?

00:44:18 **PWLD02**

Any good hotels in Bournemouth [laughs]

00:44:20 **CATHY BERESFORD**

[laughs] I think there are some nice hotels there.

00:44:22 **PWLD02**

There is actually. There's one on the top of the hill.

**CATHY BERESFORD**

It's very nice. Lovely sea. Lovely sea front.

**PWLD02**

Five stars on the top of the hill, stayed there.

00:44:29 **Carer02**

Do you think, has has has the medical system, have they got time to do what Hospice does for patients?

**PWLD02**

No. Going through my head.

00:44:50 **Carer02**

That's that's why you're you're going in. I hope that it will be incorporated more.

00:44:58 **CATHY BERESFORD**

Yes. Yeah.

00:44:59 **Carer02**

All the systems and systems I hope it will be incorporated more.

00:45:04 **CATHY BERESFORD**

So, do you mean do you mean that some of the things that you get here [at the hospice] could actually be more integrated into what people have in hospital?

**PWLD02** and **Carer02**

Yes.

**CATHY BERESFORD**

Yeah, I see what you mean.

00:45:04 **Carer02**

Because it's the If if if that could be because it's become very, very cold and clinical and too, too busy. And I've, of course, they're too busy. I have to get everyone in and through, but perhaps with liver disease and other diseases that can be sort of end of life, hmm. Or long term and you're not going

00:45:52 **CATHY BERESFORD**

To yes, yes, yeah.

00:45:53 **Carer02**

To have a transplant and things like - even if you do - perhaps then an incorporation of this, what's going on here.

00:45:59 **CATHY BERESFORD**

Yeah. Yeah. So that rather than it being so separate where you have to come to a Hospice to get that, that actually there's more of a kind of Hospice approach within the hospital?

**Carer02**

Yes

00:46:11 **PWLD02**

You know you still come in expecting sort of six months possible life expectancy. I'm still here. You know, it’s down to the staff here.

00:46:20 **Carer02**

And others.

00:46:23 **CATHY BERESFORD**

Makes sense what you've said. Yeah. I mean, I, in response to what you've said, something that I'm seeing because I'm speaking to people across the UK is that there's quite a lot of variation in terms of what services are available to people depending on where they live and that in some areas there are good relationships between hospital staff and hospice staff, so that care is a bit more like what's happening here. Yeah, but actually, what's happening here does seem to be not as common. And and some people never have access to Hospice. I'm I'm afraid to say.

**Carer02**

Ohh. That's a shame.

**CATHY BERESFORD**

But that's one of the reasons why I'm doing the research. Because what we want to try and do is to see what what is, what does good care look like and what you know so that we can share that and where are there areas that need to be improved so that we can start to have a more standard system really, you know this is a very small study, it's not gonna change the whole system. I wish it could, but you know, I do go to conferences, and I will write about it in a publication that healthcare professionals read to try and spread the word about what people want from services, what care is good, what care is not good. Do you see what I mean?

00:47:48 **Carer02**

Yes, yeah, definitely and It's only by people like yourself going out and seeing what's actually happening and asking. Yeah, what's actually happening. Yeah, that things may change.

00:48:04 **CATHY BERESFORD**

And the good thing is, well, is that I'm speaking to healthcare professionals too. I'm interviewing like nurses, doctors.

00:48:05 **Carer02**

It can change.

00:48:12 **CATHY BERESFORD**

And there are many people who really want to make things better, you know?

**PWLD02**

Yeah.

**CATHY BERESFORD**

So, there's lots of people that are trying to improve things and make sure that the kind of experience that you've had in the Hospice should be more universal. Really.

**PWLD02**

Yeah.

00:48:28 **Carer02**

Should be more available, yeah, because apart from being referred by Dr [name of hepatologist] I don't think **PWLD02** would have been with me another Christmas.

00:48:42 **CATHY BERESFORD**

No. Yeah. So, thank you so much. Is there anything else you want to say before I stop the recording? It's been absolutely brilliant to listen to you. I could listen to you for hours.

00:48:48 **Carer02**

No, thank you for listening to us blathering.

00:48:58 **CATHY BERESFORD**

Right. Let me unlock this.