# **Carer03** ‘Alice’ Transcript. 01/05/2024 conducted by Teams at 09:30am.

0:0:0.0 --> 0:0:0.440  
**Carer03**  
Yeah.

0:0:-2.-690 --> 0:0:7.630  
**Catherine Beresford**  
Script because it can be a bit off putting if you can see the transcript, So, hide transcript, that's it, right. So, you should have a message up to say that it's recording.

0:0:7.770 --> 0:0:8.250  
**Carer03**  
Yeah.

0:0:9.30 --> 0:0:9.870  
**Catherine Beresford**  
Brilliant. OK.

0:0:11.410 --> 0:0:25.130  
**Catherine Beresford**  
All right, So, as I said, thank you so much for your time today. And I really do appreciate your insights. Could you to start with just give me give me a bit of information about the person that you have experience of caring for?

0:0:28.930 --> 0:0:29.410  
**Catherine Beresford**  
Yeah.

0:0:32.490 --> 0:0:32.930   
**Catherine Beresford**  
Yeah.

0:0:26.90 --> 0:0:33.890  
**Carer03**  
Yes. So, it was my dad who he had non-alcoholic liver disease.

0:0:33.930 --> 0:0:38.810  
**Carer03**  
Diagnosed around about May 2022.

0:0:39.50 --> 0:0:39.730  
**Catherine Beresford**  
OK.

0:0:40.370 --> 0:0:44.450  
**Carer03**  
And it was end-stage at that point really.

0:0:43.940 --> 0:0:45.980  
**Catherine Beresford**  
Right. OK.

0:0:46.90 --> 0:0:47.570  
**Carer03**  
But on reflection, I think.

0:0:49.250 --> 0:0:56.490  
**Carer03**  
Well, he he'd obviously had it for quite some time, but on reflection there was a lot of symptoms before that.

0:0:56.580 --> 0:0:58.180  
**Catherine Beresford**  
Oh, I see. OK.

0:0:57.790 --> 0:0:59.830  
**Carer03**  
So, So, yeah.

0:1:1.710 --> 0:1:10.910  
**Carer03**  
It, and it was me and my mum, who primarily cared for him. I don't live at home anymore, so, my mum kind of did like.

0:1:14.150 --> 0:1:14.870  
**Catherine Beresford**  
Yes.

0:1:16.40 --> 0:1:16.440  
**Catherine Beresford**  
Yeah.

0:1:12.270 --> 0:1:17.750  
**Carer03**  
Probably the majority of it and I stepped in as as well.

0:1:20.790 --> 0:1:20.870  
**Carer03**  
So.

0:1:28.250 --> 0:1:28.690  
**Catherine Beresford**  
Yeah.

0:1:21.310 --> 0:1:30.630  
**Carer03**  
Yeah. And in December 2022, that's when he started, but he had ascites. He's that's how they discovered the.

0:1:30.450 --> 0:1:31.570  
**Catherine Beresford**  
Oh, I see.

0:1:33.860 --> 0:1:34.420  
**Catherine Beresford**  
Yeah.

0:1:32.770 --> 0:1:38.250  
**Carer03**  
The liver disease, but in about December 2022, he started getting drained regularly.

0:1:38.740 --> 0:1:40.20  
**Catherine Beresford**  
Right, yeah.

0:1:41.50 --> 0:1:44.570  
**Carer03**  
So, yeah, around about every it was every two weeks at that point.

0:1:44.890 --> 0:1:48.250  
**Catherine Beresford**  
So, it sounds like it all happened fairly quickly, really.

0:1:47.860 --> 0:1:56.580  
**Carer03**  
Yeah, yeah, absolutely. But as I say, on reflection, it was quite evident before that had had were known.

0:1:56.710 --> 0:1:57.510  
**Catherine Beresford**  
Yeah.

0:1:58.720 --> 0:2:0.360  
**Catherine Beresford**  
I I see yeah.

0:1:58.180 --> 0:2:1.60  
**Carer03**  
If you know what I mean, had we known the symptoms and things like.

0:2:2.740 --> 0:2:10.220  
**Carer03**  
My mum kept saying to me because I got married in July 21 and she kept in an OK. He hasn't got a suit that fits.

0:2:11.700 --> 0:2:17.380  
**Carer03**  
He's putting on, he's putting on all this weight and he's he's not even eating, he and he must be secretly eating in the middle of the night in the bedroom.

0:2:16.940 --> 0:2:19.100  
**Catherine Beresford**  
Right, yeah.

0:2:27.200 --> 0:2:27.320  
**Catherine Beresford**  
Hmm.

0:2:18.720 --> 0:2:32.360  
**Carer03**  
So, but it was obviously that and his mobility was getting affected by the the weight gain, which was obviously a build-up of fluid because it really affected his legs as well mainly.

0:2:32.830 --> 0:2:33.550  
**Catherine Beresford**  
Oh did.

0:2:33.840 --> 0:2:37.80  
**Carer03**  
Yeah, he had. He had a lot of fluid retention in his legs.

0:2:38.640 --> 0:2:41.120  
**Carer03**  
As well as this big, massive stomach.

0:2:41.710 --> 0:2:46.230  
**Catherine Beresford**  
Yeah. Yeah. So, from from your perspective.

0:2:47.550 --> 0:2:52.750  
**Catherine Beresford**  
Can you tell me about your dad's sort of journey of receiving care for his liver disease then?

0:2:54.60 --> 0:2:57.580  
**Carer03**  
Yes, I would say it was a bit erratic to start with.

0:2:59.40 --> 0:3:2.480  
**Carer03**  
A lot of A&E admissions, a lot of time spent in A&E.

0:3:4.110 --> 0:3:6.710  
**Carer03**  
Kind of going over the same things.

0:3:6.280 --> 0:3:6.800  
**Catherine Beresford**  
Yeah.

0:3:8.270 --> 0:3:16.350  
**Carer03**  
And a lot just lots of hours in there and then going, so, we have a specialist emergency hospital.

0:3:25.870 --> 0:3:26.470  
**Catherine Beresford**  
Yes.

0:3:31.350 --> 0:3:33.150  
**Catherine Beresford**  
Right. OK.

0:3:17.950 --> 0:3:33.350  
**Carer03**  
Which is where he used to go. And then you once you've been in A&E, you'd be sent to a ward there, I think essentially with a view of going to a non-emergency hospital after that. But it never really happened just because it was still.

0:3:35.650 --> 0:3:36.210  
**Catherine Beresford**  
Oh.

0:3:33.950 --> 0:3:37.710  
**Carer03**  
Of COVID time. Then we're coming out the back end of it.

0:3:40.230 --> 0:3:45.470  
**Carer03**  
So, then we'd kind of get to a specialist liver ward.

0:3:46.220 --> 0:3:46.820  
**Catherine Beresford**  
Yes.

0:3:48.30 --> 0:3:52.510  
**Carer03**  
And it was just, I don't know, it was just erratic. Not a lot of information given.

0:3:53.210 --> 0:3:53.890  
**Catherine Beresford**  
OK.

0:3:55.200 --> 0:3:56.880  
**Carer03**  
About the disease.

0:3:57.580 --> 0:3:57.980  
**Catherine Beresford**  
Yeah.

0:3:59.950 --> 0:4:0.70  
**Catherine Beresford**  
Hmm.

0:4:4.90 --> 0:4:4.210  
**Catherine Beresford**  
Hmm.

0:4:5.810 --> 0:4:6.370  
**Catherine Beresford**  
Yeah.

0:4:11.860 --> 0:4:12.540  
**Catherine Beresford**  
Right.

0:3:59.70 --> 0:4:15.310  
**Carer03**  
At all. Just this is kind of what he's got and this is what we're going to do, where my dad was of that kind of generation where they're just like, yeah, yeah, OK. Didn't really ask any questions.

0:4:15.420 --> 0:4:15.980  
**Catherine Beresford**  
Yeah.

0:4:17.860 --> 0:4:20.20  
**Carer03**  
And wouldn't have asked any questions.

0:4:20.810 --> 0:4:20.850  
**Catherine Beresford**  
I.

0:4:21.100 --> 0:4:21.500  
**Carer03**  
And.

0:4:42.160 --> 0:4:42.800  
**Catherine Beresford**  
Yeah.

0:4:24.100 --> 0:4:43.780  
**Carer03**  
Doesn't. I don't know. He just he just said, well, they just know what they're doing. And he he didn't offer any information about what was going on with him. Well, they're his view was well, they're the doctors. And we always used to try and say, well, you do need to tell them some information So, that they know where to go.

0:4:52.290 --> 0:4:53.90  
**Catherine Beresford**  
Oh really?

0:4:46.690 --> 0:4:54.810  
**Carer03**  
So, I don't ever know that he fully understood the severity of it, and it was never. Yeah. And it was never discussed.

0:4:54.920 --> 0:4:55.760  
**Catherine Beresford**  
Wasn't it?

0:4:56.620 --> 0:5:0.460  
**Carer03**  
Not not that I'm aware of, and not that my mum's aware of.

0:5:0.590 --> 0:5:7.350  
**Catherine Beresford**  
I say yeah. So, when when he first got diagnosed, was that because he was admitted through A&E then?

0:5:7.210 --> 0:5:12.50  
**Carer03**  
Yeah. So, that come back from there's been on holiday in Scotland and.

0:5:17.140 --> 0:5:17.860  
**Catherine Beresford**  
Yeah.

0:5:13.590 --> 0:5:22.990  
**Carer03**  
It had some it had really bad, swollen legs before that. It's been at the GP and they're just they're putting one more tablets and they did go down.

0:5:24.590 --> 0:5:30.670  
**Carer03**  
And then they went on holiday to Scotland and they came back. And my mum said his legs are really, really swollen.

0:5:33.710 --> 0:5:35.630  
**Carer03**  
She said. I'm gonna ring the GP.

0:5:39.930 --> 0:5:40.530  
**Catherine Beresford**  
Right.

0:5:44.700 --> 0:5:45.260  
**Catherine Beresford**  
Yeah.

0:5:37.50 --> 0:5:47.290  
**Carer03**  
And the GP, they said they were going to get an appointment that day with the GP. They never phoned back, and she just said we're going to go to A&E. And I thought, oh, because that wasn't my dad either.

0:5:47.180 --> 0:5:48.220  
**Catherine Beresford**  
OK.

0:5:49.190 --> 0:5:52.830  
**Carer03**  
So. So, they went to A&E and originally thought he might have a heart condition.

0:5:53.440 --> 0:5:53.880  
**Catherine Beresford**  
Yeah.

0:5:54.440 --> 0:5:57.520  
**Carer03**  
But then, as they did more tests, they discovered it was his liver.

0:5:59.790 --> 0:6:0.270  
**Catherine Beresford**  
Yeah.

0:6:0.650 --> 0:6:3.610  
**Carer03**  
So, yeah, that's originally how it all came about.

0:6:4.610 --> 0:6:24.930  
**Catherine Beresford**  
Yeah. So, you've mentioned some of the services that he accessed for care in relation to his liver disease, like, you know, contacting the GP, A&E, getting admitted to hospital. Do you know what other services he had access to while he was unwell?

0:6:25.790 --> 0:6:25.910  
**Carer03**  
And.

0:6:27.180 --> 0:6:33.420  
**Carer03**  
As I say, in December he started to get drained every two weeks and that was is a liver specialist nurse.

0:6:33.660 --> 0:6:34.980  
**Catherine Beresford**  
Right. OK.

0:6:35.370 --> 0:6:40.650  
**Carer03**  
Who performed that. So, he did get allocated to her and she was fantastic.

0:6:41.430 --> 0:6:41.470  
**Catherine Beresford**  
I.

0:6:42.170 --> 0:6:45.650  
**Carer03**  
And very realistic about things.

0:6:46.170 --> 0:6:46.570  
**Catherine Beresford**  
Yeah.

0:6:47.870 --> 0:6:53.310  
**Carer03**  
I would say a lot more realistic than any of the doctors ever were.

0:6:53.880 --> 0:6:56.760  
**Catherine Beresford**  
Oh, I see. Tell me a bit more about that then.

0:6:57.250 --> 0:6:57.850  
**Carer03**  
So.

0:6:59.530 --> 0:7:3.90  
**Carer03**  
As I say, I don't ever think there was any discussion of.

0:7:5.500 --> 0:7:6.900  
**Carer03**  
The reality of it all.

0:7:12.420 --> 0:7:12.620  
**Catherine Beresford**  
Mm hmm.

0:7:9.10 --> 0:7:14.250  
**Carer03**  
I mean this this did say end-stage, but I don't think he understood that.

0:7:14.930 --> 0:7:15.610  
**Catherine Beresford**  
OK.

0:7:15.620 --> 0:7:16.100  
**Carer03**  
As.

0:7:18.980 --> 0:7:20.700  
**Catherine Beresford**  
Right. OK.

0:7:17.520 --> 0:7:21.160  
**Carer03**  
Like terminal, if you know what I mean.

0:7:21.200 --> 0:7:22.320  
**Carer03**  
I did and my mum did.

0:7:22.480 --> 0:7:23.120  
**Catherine Beresford**  
Yeah.

0:7:27.450 --> 0:7:29.370  
**Catherine Beresford**  
Sure. Yeah.

0:7:24.640 --> 0:7:32.920  
**Carer03**  
Or whether he just choose not to understand it, I'm not sure, but there was never any offer of a discussion of prognosis.

0:7:32.260 --> 0:7:34.20  
**Catherine Beresford**  
Right. OK.

0:7:34.710 --> 0:7:36.350  
**Carer03**  
And I think he would have said no.

0:7:36.720 --> 0:7:38.80  
**Catherine Beresford**  
Do you? Yeah.

0:7:37.860 --> 0:7:38.460  
**Carer03**  
I do.

0:7:40.320 --> 0:7:41.840  
**Carer03**  
But the offer was never there.

0:7:43.240 --> 0:7:43.760  
**Catherine Beresford**  
Yeah.

0:7:47.980 --> 0:7:48.740  
**Catherine Beresford**  
Yes.

0:7:43.150 --> 0:7:49.230  
**Carer03**  
And I know sometimes for I've I have worked in the NHS before with.

0:7:52.210 --> 0:7:52.650  
**Catherine Beresford**  
Yeah.

0:7:59.30 --> 0:8:1.30  
**Catherine Beresford**  
Yeah, sure.

0:8:5.770 --> 0:8:6.290  
**Catherine Beresford**  
Yeah.

0:7:51.150 --> 0:8:6.750  
**Carer03**  
A cancer unit and I know that sometimes the will with the patient’s consent speak to the relatives about prognosis, which I think would have helped both me and my man because.

0:8:12.790 --> 0:8:13.590  
**Catherine Beresford**  
It's OK.

0:8:7.980 --> 0:8:14.740  
**Carer03**  
And this is going to sound awful, and I do not mean it that way, but it's really heavy going, being a carer.

0:8:14.680 --> 0:8:15.480  
**Catherine Beresford**  
Yeah.

0:8:16.440 --> 0:8:18.800  
**Carer03**  
And just maybe knowing how long you're going to have to do it for.

0:8:18.230 --> 0:8:21.990  
**Catherine Beresford**  
Yeah, yeah, I understand. Yeah.

0:8:23.380 --> 0:8:28.300  
**Carer03**  
But [name of specialist nurse] was. [Name] was who was a specialist nurse, was absolutely fantastic.

0:8:29.350 --> 0:8:34.590  
**Catherine Beresford**  
So, where did your your dad go for his drains when he had them done?

0:8:33.330 --> 0:8:40.10  
**Carer03**  
So, he used to go to the day unit at [name of] Hospital.

0:8:41.660 --> 0:8:41.940  
**Carer03**  
And.

0:8:40.340 --> 0:8:46.220  
**Catherine Beresford**  
Yeah. And how did he? How did you? If he needed draining, then how did he arrange it?

0:8:47.210 --> 0:8:54.810  
**Carer03**  
So, actually it was at a point where they just automatically booked him in every two weeks.

0:8:53.900 --> 0:8:57.820  
**Catherine Beresford**  
I see. Yeah. Yeah. So, we could just go. He knew he was going to be able to go in.

0:8:58.10 --> 0:9:0.690  
**Carer03**  
Yeah. So, we just had when he left.

0:9:1.760 --> 0:9:3.760  
**Carer03**  
He would have his next appointment given to him.

0:9:3.740 --> 0:9:4.460  
**Catherine Beresford**  
Sure.

0:9:5.400 --> 0:9:17.880  
**Carer03**  
And they did change it to every three weeks because they weren't getting much. Often, they thought you could go sooner, but what they said was if they thought he needed draining any earlier to to ring.

0:9:18.310 --> 0:9:20.110  
**Catherine Beresford**  
Yeah. OK.

0:9:19.140 --> 0:9:22.20  
**Carer03**  
[name of nurse], [name of nurse] and would bring it forward.

0:9:21.310 --> 0:9:40.30  
**Catherine Beresford**  
I see. Yeah. Yeah. So, I suppose, actually, that leads on to my next question then. So, if your dad or or and you and your mum actually. But if you did need advice or support or information, where did you go and how did you access that information?

0:9:40.610 --> 0:9:44.490  
**Carer03**  
So, usually we would just ring the specialist nurse.

0:9:44.240 --> 0:9:46.720  
**Catherine Beresford**  
Yeah, I see. Yeah.

0:9:45.660 --> 0:9:49.980  
**Carer03**  
Yeah. I mean, we're never.

0:9:50.220 --> 0:9:53.540  
**Carer03**  
Really got any information about support groups or anything like that.

0:9:53.430 --> 0:9:54.630  
**Catherine Beresford**  
Right. OK.

0:9:58.690 --> 0:9:59.290  
**Catherine Beresford**  
Yeah.

0:9:59.470 --> 0:10:2.710  
**Carer03**  
That it possibly wasn't even a thought.

0:10:3.430 --> 0:10:3.470  
**Catherine Beresford**  
I.

0:10:5.230 --> 0:10:12.550  
**Carer03**  
At that point, and whether we would have had the time to access them, I don't know.

0:10:14.30 --> 0:10:16.870  
**Carer03**  
And it wasn't until afterwards I found that LIVErNORTH.

0:10:17.440 --> 0:10:17.800  
**Catherine Beresford**  
Yeah.

0:10:20.310 --> 0:10:20.510  
**Catherine Beresford**  
Mm hmm.

0:10:18.830 --> 0:10:28.590  
**Carer03**  
Facebook page and I thought, oh, that might have been helpful, but it honestly hadn't even been a thought. So, I think maybe if it was offered up.

0:10:32.20 --> 0:10:32.460  
**Catherine Beresford**  
Yeah.

0:10:38.250 --> 0:10:38.810  
**Catherine Beresford**  
Yeah.

0:10:30.420 --> 0:10:41.60  
**Carer03**  
Straight away or maybe like a little booklet or something given to patients with support services that aren't the hospital.

0:10:41.570 --> 0:10:43.90  
**Catherine Beresford**  
Yeah, I see.

0:10:42.240 --> 0:10:49.320  
**Carer03**  
Necessarily, I think I think that would be good because there is just so, much going on that sometimes it's not even anything you think about.

0:10:49.350 --> 0:11:0.990  
**Catherine Beresford**  
No, I'm with you. So, thinking about all the services that your dad did access in relation to his liver disease from, from your point of view, what do you think worked well?

0:11:2.740 --> 0:11:2.940  
**Carer03**  
Uh.

0:11:6.700 --> 0:11:7.540  
**Catherine Beresford**  
No problem.

0:11:11.130 --> 0:11:11.450  
**Catherine Beresford**  
Yeah.

0:11:4.550 --> 0:11:13.510  
**Carer03**  
I've made some notes, So, let me just consult them. So, I think the specialist nurses, I think they're just worth their weight in gold.

0:11:18.750 --> 0:11:19.430  
**Catherine Beresford**  
Yes.

0:11:16.90 --> 0:11:22.570  
**Carer03**  
And having those regular appointments for being drained because.

0:11:23.330 --> 0:11:24.130  
**Carer03**  
Originally.

0:11:24.250 --> 0:11:29.290  
**Carer03**  
Going through that whole process of A&E every time, like sometimes it was 11 hours.

0:11:32.810 --> 0:11:33.450  
**Catherine Beresford**  
Yes.

0:11:35.310 --> 0:11:35.990  
**Catherine Beresford**  
Yes.

0:11:38.400 --> 0:11:38.920  
**Catherine Beresford**  
No.

0:11:29.450 --> 0:11:39.450  
**Carer03**  
And that's a lot for somebody with. It's a lot for anybody, but somebody who's got a terminal illness, it's it's just not great really.

0:11:40.970 --> 0:11:41.490  
**Carer03**  
So.

0:11:42.890 --> 0:11:44.170  
**Carer03**  
I think that works.

0:11:52.810 --> 0:11:53.610  
**Catherine Beresford**  
Right.

0:11:44.770 --> 0:11:54.570  
**Carer03**  
So, that works really well. But I do think that it's a lot for the specialist nurses. So, I believe there was only two for the trust and I'm not sure.

0:11:56.130 --> 0:11:59.570  
**Carer03**  
Whether they just dealt with liver disease or the whole.

0:12:1.450 --> 0:12:2.330  
**Carer03**  
HPB package.

0:12:3.770 --> 0:12:8.90  
**Carer03**  
So, like all the cancers and everything like that as well.

0:12:7.130 --> 0:12:9.90  
**Catherine Beresford**  
Yeah, I see.

0:12:9.690 --> 0:12:14.570  
**Carer03**  
So, I feel like that's possibly something that they could do with more of.

0:12:16.750 --> 0:12:21.310  
**Catherine Beresford**  
Yeah, yeah. Was there anything else that you thought worked well?

0:12:21.390 --> 0:12:24.30  
**Carer03**  
So, actually, once he had his diagnosis.

0:12:25.950 --> 0:12:27.590  
**Carer03**  
So, after after.

0:12:32.610 --> 0:12:33.90  
**Catherine Beresford**  
Yeah.

0:12:37.190 --> 0:12:37.830  
**Catherine Beresford**  
Oh.

0:12:29.110 --> 0:12:43.310  
**Carer03**  
The GP didn't call them that day and he ended up admitted he actually decided to change GP surgery. So, is yeah, is new GP surgery were fantastic.

0:12:46.160 --> 0:12:55.520  
**Carer03**  
Once he got the diagnosis that they were just great and and really, really helpful So, that they were really good actually.

0:12:56.90 --> 0:12:57.410  
**Catherine Beresford**  
In what sort of way?

0:12:57.750 --> 0:13:1.190  
**Carer03**  
So, what? What my mum would regularly.

0:13:8.940 --> 0:13:9.540  
**Catherine Beresford**  
Yes.

0:13:2.630 --> 0:13:10.70  
**Carer03**  
Just ring them for so, towards the end he had quite a lot of pressure sores and things like that and.

0:13:12.940 --> 0:13:15.940  
**Carer03**  
He was on a lot of medications, so.

0:13:18.50 --> 0:13:21.570  
**Carer03**  
She would regularly be ringing them for district nurses.

0:13:21.650 --> 0:13:22.610  
**Catherine Beresford**  
OK, OK.

0:13:23.610 --> 0:13:25.770  
**Carer03**  
And access to other services so.

0:13:25.910 --> 0:13:26.30  
**Catherine Beresford**  
Hmm.

0:13:27.930 --> 0:13:28.890  
**Carer03**  
Occupational therapy.

0:13:29.150 --> 0:13:29.750  
**Catherine Beresford**  
Yeah.

0:13:31.550 --> 0:13:33.630  
**Carer03**  
What else? I'm sure those other things.

0:13:47.790 --> 0:13:48.750  
**Catherine Beresford**  
OK.

0:13:35.660 --> 0:13:49.60  
**Carer03**  
Yeah, they're always rang her back in the same day, usually within a couple of hours and everything. They're just sorted everything, actually. And I feel like these days that's quite rare for a GP surgery.

0:13:50.70 --> 0:13:57.790  
**Catherine Beresford**  
OK. Yeah. So, what, what other professionals did your dad have access to?

0:14:1.160 --> 0:14:1.360  
**Catherine Beresford**  
Mm hmm.

0:13:59.480 --> 0:14:6.40  
**Carer03**  
None that I can think of. Well, he did. He had a couple of appointments with consultant gastroenterologist.

0:14:7.660 --> 0:14:9.220  
**Carer03**  
Not many, I would say.

0:14:13.160 --> 0:14:18.0  
**Carer03**  
That I can think of, one had to be cancelled because he was admitted.

0:14:18.580 --> 0:14:19.260  
**Catherine Beresford**  
Oh yeah.

0:14:19.310 --> 0:14:21.950  
**Carer03**  
So, he actually only had two two.

0:14:23.740 --> 0:14:26.500  
**Carer03**  
In the space of 14 months.

0:14:31.560 --> 0:14:38.600  
**Carer03**  
Oh yeah, I think I mean that. That was it, that he'd never actually saw the.

0:14:41.300 --> 0:14:43.460  
**Carer03**  
Consultant he was under while he was admitted.

0:14:44.320 --> 0:14:45.40  
**Catherine Beresford**  
OK.

0:14:45.70 --> 0:14:50.310  
**Carer03**  
And it was always, I guess whoever was just on the ward, yeah.

0:14:48.970 --> 0:14:55.490  
**Catherine Beresford**  
Yeah, I I'm with you. Yeah, I did. Do you know if you have had any contact with the dietician?

0:14:56.850 --> 0:15:1.90  
**Carer03**  
No, he didn't. And that's one of the things that I was going to say.

0:15:1.650 --> 0:15:3.370  
**Catherine Beresford**  
Oh, alright, OK.

0:15:2.630 --> 0:15:9.310  
**Carer03**  
That I was just going to going to say, I feel like that is something that it could have benefited from.

0:15:11.930 --> 0:15:12.610  
**Catherine Beresford**  
Yeah.

0:15:13.0 --> 0:15:18.240  
**Carer03**  
Because obviously they've got to have such a low salt diet.

0:15:19.620 --> 0:15:23.260  
**Carer03**  
And actually when you go and look at all the salt content on things, it's really hard.

0:15:25.100 --> 0:15:34.980  
**Carer03**  
So, I think something like something contact with the dietician or even provided with maybe advice.

0:15:36.80 --> 0:15:37.240  
**Carer03**  
On meal ideas.

0:15:37.850 --> 0:15:37.970  
**Catherine Beresford**  
Hmm.

0:15:43.990 --> 0:15:44.550  
**Catherine Beresford**  
Yeah.

0:15:38.590 --> 0:15:53.350  
**Carer03**  
Even like a small booklet with like a two-week meal planner, there's something like that. So, yeah, I think you would have benefited from that. And I think my mom would have because she was like, oh, what am I going to cook for him?

0:15:52.920 --> 0:15:54.560  
**Catherine Beresford**  
Yes. Yeah.

0:15:55.640 --> 0:16:0.0  
**Catherine Beresford**  
So so, they were told to have to avoid certain things, but.

0:16:1.200 --> 0:16:2.720  
**Catherine Beresford**  
Further information.

0:16:1.470 --> 0:16:5.550  
**Carer03**  
Yeah, yeah. So, just told to have low salt.

0:16:8.390 --> 0:16:14.310  
**Carer03**  
And that was it. Or and drink no more than two litres of water a day.

0:16:14.610 --> 0:16:15.330  
**Catherine Beresford**  
OK.

0:16:17.660 --> 0:16:25.900  
**Carer03**  
So, that that was it. So, he he loved things like Bovril, which has got so much salt in it. Yeah.

0:16:24.760 --> 0:16:26.280  
**Catherine Beresford**  
Hmm. Oh yeah, yeah.

0:16:27.820 --> 0:16:28.340  
**Catherine Beresford**  
Yeah.

0:16:28.200 --> 0:16:28.640  
**Carer03**  
And.

0:16:39.540 --> 0:16:40.980  
**Catherine Beresford**  
Right, yeah.

0:16:30.170 --> 0:16:45.170  
**Carer03**  
The ward would give him that and it was one nurse who this was months later, one nurse went oh, you can't have that. It's far too salty. So, there's I think there's a bit of an education.

0:16:49.990 --> 0:16:50.630  
**Catherine Beresford**  
OK.

0:16:46.450 --> 0:16:51.90  
**Carer03**  
Thing as well for staff on staff on the ward and.

0:16:55.190 --> 0:16:55.830  
**Catherine Beresford**  
Yeah.

0:16:52.440 --> 0:16:56.920  
**Carer03**  
Don't want that to reflect negatively on on them because.

0:17:2.650 --> 0:17:2.850  
**Catherine Beresford**  
Mm hmm.

0:17:5.850 --> 0:17:6.450  
**Catherine Beresford**  
Yeah.

0:16:58.320 --> 0:17:10.0  
**Carer03**  
I mean, how do you, how do you remember for every single patient that you've got on on the ward, it's got to be really hard and as well. I'm not sure what information is.

0:17:11.480 --> 0:17:13.80  
**Carer03**  
Given to catering.

0:17:13.270 --> 0:17:13.830  
**Catherine Beresford**  
Yeah.

0:17:13.880 --> 0:17:19.40  
**Carer03**  
Within a hospital, I know that if, yeah, if you've like celiac.

0:17:23.20 --> 0:17:23.220  
**Catherine Beresford**  
Mm hmm.

0:17:20.760 --> 0:17:24.320  
**Carer03**  
Things like that vegetarian, and if you've got allergies but.

0:17:25.320 --> 0:17:31.200  
**Carer03**  
I'm not sure if it's communicated that somebody needs a little salt diet.

0:17:36.440 --> 0:17:37.320  
**Catherine Beresford**  
OK.

0:17:32.800 --> 0:17:37.760  
**Carer03**  
I just. I just don't know. I don't know if any of the meals that he got will low, low salt or anything like that.

0:17:38.990 --> 0:17:51.750  
**Catherine Beresford**  
So, you've given me a bit of an idea of this already actually, but but maybe just elaborate a little bit. So, thinking about the services that your dad received in relation to his liver disease, what what do you think does not work well?

0:17:57.710 --> 0:18:0.310  
**Carer03**  
Well, the lack of specialist nurses.

0:18:2.290 --> 0:18:2.490  
**Carer03**  
I mean.

0:18:3.670 --> 0:18:5.830  
**Carer03**  
They’re great, but they definitely need more support.

0:18:6.310 --> 0:18:6.990  
**Catherine Beresford**  
OK.

0:18:7.300 --> 0:18:8.980  
**Carer03**  
From a bigger team I would say.

0:18:17.840 --> 0:18:18.400  
**Catherine Beresford**  
Yeah.

0:18:21.780 --> 0:18:22.380  
**Catherine Beresford**  
Yes.

0:18:11.370 --> 0:18:22.730  
**Carer03**  
And I can't say that whatever had a negative experience with the specialist nurses, but I think it's just something that I observed.

0:18:22.770 --> 0:18:24.930  
**Carer03**  
They definitely need more of them.

0:18:29.720 --> 0:18:31.80  
**Carer03**  
I think going through A&E.

0:18:32.830 --> 0:18:36.390  
**Carer03**  
Is something that doesn't work well, feel like.

0:18:38.140 --> 0:18:39.540  
**Carer03**  
Maybe some sort of

0:18:41.90 --> 0:18:44.690  
**Carer03**  
Hotline a bit like people have when they have chemo.

0:18:44.810 --> 0:18:45.410  
**Catherine Beresford**  
Yeah.

0:18:52.310 --> 0:18:52.870  
**Catherine Beresford**  
Yeah.

0:18:46.80 --> 0:18:53.760  
**Carer03**  
For advice and things like that, I mean I'm aware all of these things cost money and the NHS doesn't have a lot of it.

0:18:54.450 --> 0:18:55.10  
**Catherine Beresford**  
Yeah.

0:18:58.640 --> 0:18:59.360  
**Carer03**  
And I think.

0:19:1.160 --> 0:19:6.400  
**Carer03**  
Not having honest conversations doesn't work well.

0:19:11.420 --> 0:19:12.300  
**Catherine Beresford**  
Was there?

0:19:8.120 --> 0:19:13.200  
**Carer03**  
There was a lot of false hope dangled, I would say, yeah.

0:19:15.840 --> 0:19:27.760  
**Carer03**  
The second to last time he was admitted to hospital. I mean, he could barely walk at that point. He was making it to the bathroom with a Zimmer frame, and that was about it.

0:19:26.970 --> 0:19:28.530  
**Catherine Beresford**  
Yeah, yeah.

0:19:28.810 --> 0:19:35.970  
**Carer03**  
And they said, oh, we're going to put you forward for a liver transplant. And this wasn't in front of me because I would have just said hang on.

0:19:36.550 --> 0:19:36.750  
**Catherine Beresford**  
Mm hmm.

0:19:37.650 --> 0:19:39.450  
**Carer03**  
Are you joking?

0:19:40.820 --> 0:19:41.340  
**Carer03**  
And.

0:19:43.270 --> 0:19:46.670  
**Carer03**  
And I I just honestly couldn't believe it and.

0:19:48.730 --> 0:19:48.770  
**Carer03**  
Feel.

0:19:49.850 --> 0:19:52.410  
**Carer03**  
Like those kind of things were always dropped when.

0:19:52.520 --> 0:19:53.280  
**Catherine Beresford**  
Right.

0:19:55.200 --> 0:19:56.120  
**Catherine Beresford**  
OK.

0:19:56.960 --> 0:19:57.480  
**Catherine Beresford**  
Yeah.

0:19:53.480 --> 0:19:59.720  
**Carer03**  
Nobody else was there and it was just him and he and he was thinking, right, Great.

0:20:0.270 --> 0:20:0.750  
**Catherine Beresford**  
Yeah.

0:20:5.20 --> 0:20:5.820  
**Catherine Beresford**  
Right.

0:20:0.530 --> 0:20:7.690  
**Carer03**  
Going to get, I get this liver transplant. And they said but you need to be much fitter but they never said how much fitter and.

0:20:7.450 --> 0:20:9.370  
**Catherine Beresford**  
All right, yeah.

0:20:9.300 --> 0:20:13.740  
**Carer03**  
So, and it was a fitness that he was never going to get.

0:20:13.340 --> 0:20:14.740  
**Catherine Beresford**  
I'm with you, yeah.

0:20:15.50 --> 0:20:27.650  
**Carer03**  
My mum spoke to a specialist nurse and she she just said I don't believe that we've said that at all, So, I just can't. Can't believe it. So, they're then having to firefight.

0:20:27.490 --> 0:20:28.50  
**Catherine Beresford**  
Yeah.

0:20:32.780 --> 0:20:33.420  
**Catherine Beresford**  
Yeah.

0:20:29.560 --> 0:20:35.520  
**Carer03**  
Conversations that that are being had and bring and essentially knock people back down.

0:20:35.790 --> 0:20:36.350  
**Catherine Beresford**  
Yeah.

0:20:43.670 --> 0:20:43.870  
**Catherine Beresford**  
Mm hmm.

0:20:37.160 --> 0:20:47.160  
**Carer03**  
So, I don't think that works very well at all. I think maybe a bit more education on being realistic with people.

0:20:45.400 --> 0:20:49.120  
**Catherine Beresford**  
Yeah, right. Yeah, yeah.

0:20:52.570 --> 0:20:53.610  
**Carer03**  
And I think there could.

0:20:52.740 --> 0:20:54.540  
**Catherine Beresford**  
How old? How old was your dad?

0:20:54.820 --> 0:20:58.380  
**Carer03**  
He when he died, he was oh.

0:20:59.170 --> 0:20:59.890  
**Carer03**  
You're asking us

0:21:0.400 --> 0:21:0.480  
**Catherine Beresford**  
Mm.

0:21:2.900 --> 0:21:3.780  
**Carer03**  
71.

0:21:4.630 --> 0:21:5.110  
**Catherine Beresford**  
Yeah.

0:21:7.400 --> 0:21:9.400  
**Carer03**  
So, actually these days it's not that old.

0:21:9.380 --> 0:21:10.20  
**Catherine Beresford**  
No.

0:21:11.90 --> 0:21:11.530  
**Catherine Beresford**  
No.

0:21:12.750 --> 0:21:20.110  
**Carer03**  
But the last consultation he had with a consultant went along.

0:21:20.140 --> 0:21:20.780  
**Catherine Beresford**  
Yes.

0:21:21.490 --> 0:21:28.650  
**Carer03**  
And they just said, well, we manage well, we'll just manage your symptoms. And I thought it's a bit vague for him.

0:21:28.780 --> 0:21:29.820  
**Catherine Beresford**  
Right.

0:21:30.20 --> 0:21:32.740  
**Carer03**  
On what that actually means.

0:21:32.330 --> 0:21:33.250  
**Catherine Beresford**  
Yes.

0:21:34.300 --> 0:21:40.740  
**Carer03**  
So, I kind of piped up and said, well, there's been a little bit of.

0:21:41.20 --> 0:21:44.620  
**Carer03**  
False hope given on the ward and a liver transplant was mentioned.

0:21:49.240 --> 0:21:50.760  
**Catherine Beresford**  
You yes, yeah.

0:21:46.380 --> 0:21:52.180  
**Carer03**  
Is that realistic? I knew the answer, but I was aware he [dad] didn't and he said no.

0:21:52.580 --> 0:21:53.420  
**Catherine Beresford**  
OK.

0:21:53.590 --> 0:21:56.310  
**Carer03**  
And you won't be getting a liver transplant.

0:21:57.230 --> 0:22:2.830  
**Carer03**  
We actually very, very, very rarely transplant anybody over the age of 70.

0:22:3.590 --> 0:22:4.270  
**Catherine Beresford**  
OK.

0:22:4.310 --> 0:22:7.590  
**Carer03**  
Because they tend to not be fit enough.

0:22:7.630 --> 0:22:7.710  
**Carer03**  
So.

0:22:10.90 --> 0:22:10.930  
**Carer03**  
That was.

0:22:12.250 --> 0:22:13.650  
**Carer03**  
We put that.

0:22:16.70 --> 0:22:17.750  
**Carer03**  
That information was only given.

0:22:18.500 --> 0:22:18.700  
**Catherine Beresford**  
Mm hmm.

0:22:19.910 --> 0:22:20.470  
**Catherine Beresford**  
Yeah.

0:22:21.510 --> 0:22:22.190  
**Catherine Beresford**  
Yes.

0:22:18.810 --> 0:22:22.330  
**Carer03**  
When prompted when asked for and.

0:22:23.950 --> 0:22:27.990  
**Carer03**  
Yeah. I just think that should never have been put on the table.

0:22:27.980 --> 0:22:29.540  
**Catherine Beresford**  
Yeah, yeah.

0:22:30.510 --> 0:22:34.70  
**Catherine Beresford**  
And how long was that appointment before your dad actually died then?

0:22:38.800 --> 0:22:41.440  
**Carer03**  
Maybe about six weeks.

0:22:41.620 --> 0:22:42.940  
**Catherine Beresford**  
Yeah, not long then.

0:22:45.230 --> 0:22:45.790  
**Catherine Beresford**  
Yeah.

0:22:47.430 --> 0:22:47.550  
**Catherine Beresford**  
Hmm.

0:22:43.40 --> 0:22:49.400  
**Carer03**  
No, no, not at all. Six weeks maximum, actually.

0:22:51.360 --> 0:22:54.480  
**Carer03**  
Yeah, so, So, not long at all.

0:22:55.260 --> 0:23:2.820  
**Catherine Beresford**  
And what care did your dad have between that appointment then and the time leading up to when he actually died?

0:23:3.390 --> 0:23:5.550  
**Carer03**  
And so, he was.

0:23:7.670 --> 0:23:8.390  
**Carer03**  
At home.

0:23:8.670 --> 0:23:9.710  
**Carer03**  
Not not when he died, but he was.

0:23:15.330 --> 0:23:16.130  
**Catherine Beresford**  
Yes.

0:23:11.650 --> 0:23:19.650  
**Carer03**  
At home, just cared for by me and my mum, district nurses in to redress wounds and things like that.

0:23:18.790 --> 0:23:20.270  
**Catherine Beresford**  
Sure.

0:23:26.10 --> 0:23:26.690  
**Catherine Beresford**  
Yeah.

0:23:21.50 --> 0:23:26.730  
**Carer03**  
And then he was admitted into A&E again.

0:23:29.120 --> 0:23:32.480  
**Carer03**  
So, then he had about 10 days hospital care.

0:23:32.640 --> 0:23:34.520  
**Catherine Beresford**  
Oh, OK, yeah.

0:23:34.300 --> 0:23:36.220  
**Carer03**  
Before he died, and he died in hospital.

0:23:36.660 --> 0:23:38.380  
**Catherine Beresford**  
What - when was that roughly?

0:23:38.290 --> 0:23:41.810  
**Carer03**  
That was 21st of July last year [2023].

0:23:42.180 --> 0:23:46.100  
**Catherine Beresford**  
Yeah. Yeah. So, it did all happen quite quickly, really, didn't it?

0:23:45.340 --> 0:23:47.980  
**Carer03**  
It did, yeah, it it progressed.

0:23:51.830 --> 0:23:52.550  
**Catherine Beresford**  
Yeah.

0:23:49.380 --> 0:23:57.780  
**Carer03**  
Fairly quickly, especially at the end because we you didn't go in a hospital any worse than what he had previous times.

0:23:56.970 --> 0:23:59.730  
**Catherine Beresford**  
Right. OK. Yeah.

0:24:0.150 --> 0:24:0.710  
**Carer03**  
So.

0:24:1.810 --> 0:24:6.410  
**Carer03**  
And then it just became more evident. I thought, yeah, this is it.

0:24:6.700 --> 0:24:7.500  
**Catherine Beresford**  
Did you?

0:24:7.580 --> 0:24:8.60  
**Carer03**  
Yeah.

0:24:9.300 --> 0:24:14.220  
**Catherine Beresford**  
Yeah. So, when he when he was in hospital in that last admission.

0:24:15.600 --> 0:24:20.280  
**Catherine Beresford**  
Were there, you know, was there any mention of palliative care or any anything like that?

0:24:20.780 --> 0:24:21.740  
**Carer03**  
None whatsoever.

0:24:22.130 --> 0:24:22.610  
**Catherine Beresford**  
No.

0:24:32.150 --> 0:24:35.310  
**Carer03**  
No, it's not. Yeah. No. Yeah, yeah.

0:24:29.860 --> 0:24:36.780  
**Catherine Beresford**  
Yeah. Sorry. I'm just reflecting on everything you've said. It's a lot to think about, isn't it? Yeah, yeah.

0:24:37.920 --> 0:24:44.440  
**Catherine Beresford**  
But but you felt but you've but you. But from what you're telling me, you felt like you did know that that he was going to die.

0:24:43.400 --> 0:24:45.160  
**Carer03**  
Absolutely, yeah, yeah.

0:24:45.580 --> 0:24:47.340  
**Catherine Beresford**  
And do you think what about your mum?

0:24:50.970 --> 0:24:54.370  
**Carer03**  
So, he was moved from the emergency hospital to.

0:24:55.880 --> 0:24:59.840  
**Carer03**  
[name of hospital], where he usually gets drained, and.

0:25:2.140 --> 0:25:2.860  
**Carer03**  
I think it was.

0:25:4.290 --> 0:25:6.570  
**Carer03**  
A couple of days before he died.

0:25:6.700 --> 0:25:7.260  
**Catherine Beresford**  
Yeah.

0:25:8.10 --> 0:25:12.130  
**Carer03**  
I think she maybe said feel the same.

0:25:13.80 --> 0:25:17.760  
**Catherine Beresford**  
I see. So, you, you two to sort of were able to talk about it with each other?

0:25:18.540 --> 0:25:20.820  
**Catherine Beresford**  
Yeah, yeah.

0:25:17.800 --> 0:25:23.80  
**Carer03**  
Yeah, absolutely. Always honest between us and yeah.

0:25:27.820 --> 0:25:28.500  
**Carer03**  
No.

0:25:22.540 --> 0:25:29.20  
**Catherine Beresford**  
Yeah, but it, but it wasn't a conversation that you would have had with your dad.

0:25:29.60 --> 0:25:29.140  
**Catherine Beresford**  
No.

0:25:29.350 --> 0:25:30.190  
**Carer03**  
He wasn't.

0:25:31.820 --> 0:25:35.580  
**Carer03**  
Don't know that it would have.

0:25:35.660 --> 0:25:37.580  
**Carer03**  
Impacted its journey positively.

0:25:37.450 --> 0:25:39.410  
**Catherine Beresford**  
Yes, I understand. Yeah.

0:25:39.350 --> 0:25:45.550  
**Carer03**  
I think he might have been the kind of person to take a load of tablets if he knew.

0:25:44.160 --> 0:25:47.280  
**Catherine Beresford**  
Yeah. OK. Yeah, yeah, I understand. Yeah.

0:25:46.980 --> 0:25:47.420  
**Carer03**  
Yeah.

0:25:48.170 --> 0:25:49.650  
**Catherine Beresford**  
Yeah, I'm with you.

0:25:50.970 --> 0:25:54.970  
**Catherine Beresford**  
Thank you for sharing that. And that's really.

0:25:54.990 --> 0:25:56.230  
**Catherine Beresford**  
Really helpful to understand.

0:25:57.960 --> 0:26:0.760  
**Catherine Beresford**  
What happened to him? Yeah, so.

0:26:2.280 --> 0:26:13.960  
**Catherine Beresford**  
Thinking about what you know, everything that you've you've been through and what your dad went through, in your opinion, what does good care for people with advanced liver disease look like?

0:26:16.980 --> 0:26:17.740  
**Carer03**  
I think.

0:26:19.360 --> 0:26:22.280  
**Carer03**  
More information about what to expect.

0:26:24.840 --> 0:26:25.400  
**Carer03**  
Maybe.

0:26:25.700 --> 0:26:37.860  
**Carer03**  
Things to look out for, like the confusion that can happen because the first time that happened, that was a shock to our system. It was like a different person had ended up in the house.

0:26:38.610 --> 0:26:39.450  
**Catherine Beresford**  
Yeah. OK.

0:26:40.60 --> 0:26:40.620  
**Carer03**  
And.

0:26:46.530 --> 0:26:46.850  
**Catherine Beresford**  
Yeah.

0:26:53.670 --> 0:26:53.790  
**Catherine Beresford**  
Hmm.

0:26:43.280 --> 0:26:57.600  
**Carer03**  
Just information about the peritonitis that they get. Even down to things like their sleeping patterns can change and the colour of their urine because that was all. I've never seen anything that colour before ever.

0:26:55.860 --> 0:26:58.580  
**Catherine Beresford**  
Yeah, yeah, yeah.

0:27:0.80 --> 0:27:0.200  
**Carer03**  
And.

0:27:2.610 --> 0:27:6.290  
**Carer03**  
As I said before, information about.

0:27:8.50 --> 0:27:8.50  
  
Diet.

0:27:12.960 --> 0:27:14.80  
**Catherine Beresford**  
Oh, of course, yeah.

0:27:8.90 --> 0:27:16.930  
**Carer03**  
And I think information on what benefits people can get, what what help they can get because that that wasn't offered up.

0:27:17.580 --> 0:27:17.700  
**Catherine Beresford**  
Hmm.

0:27:19.10 --> 0:27:22.250  
**Carer03**  
I just happened to mention it because of where I've worked previously.

0:27:23.270 --> 0:27:23.710  
**Catherine Beresford**  
OK.

0:27:28.840 --> 0:27:29.520  
**Catherine Beresford**  
Yes.

0:27:23.490 --> 0:27:31.130  
**Carer03**  
And I know that people with terminal illnesses are entitled to certain benefits.

0:27:33.130 --> 0:27:38.690  
**Carer03**  
To help with things, I mean not that my mum and dad's struggled for money because they didn't.

0:27:39.340 --> 0:27:39.460  
**Catherine Beresford**  
Hmm.

0:27:41.680 --> 0:27:44.360  
**Carer03**  
But for anybody who was.

0:27:44.340 --> 0:27:44.900  
**Catherine Beresford**  
Yeah.

0:27:45.680 --> 0:27:47.0  
**Carer03**  
Struggling for money?

0:27:48.400 --> 0:27:51.80  
**Carer03**  
They could probably really, really do with that advice.

0:27:50.640 --> 0:27:51.360  
**Catherine Beresford**  
Yeah.

0:27:52.720 --> 0:27:54.400  
**Carer03**  
Because my mum and dad did get.

0:27:56.700 --> 0:27:59.500  
**Carer03**  
Some benefits and they used it for things for a cleaner.

0:28:0.170 --> 0:28:0.530  
**Catherine Beresford**  
Yeah.

0:28:1.30 --> 0:28:5.630  
**Carer03**  
Things like that that my mom couldn't keep up with while caring for my dad.

0:28:4.730 --> 0:28:6.570  
**Catherine Beresford**  
Sure. Yeah.

0:28:8.880 --> 0:28:10.560  
**Carer03**  
Look what else I wrote.

0:28:13.960 --> 0:28:14.640  
**Carer03**  
I think.

0:28:17.450 --> 0:28:17.650  
**Carer03**  
And.

0:28:23.170 --> 0:28:26.730  
**Carer03**  
I want to see having more contact with a consultant.

0:28:31.500 --> 0:28:32.60  
**Carer03**  
All.

0:28:34.400 --> 0:28:37.600  
**Carer03**  
More like a bigger specialist nursing team.

0:28:41.510 --> 0:28:42.190  
**Catherine Beresford**  
Sure.

0:28:39.120 --> 0:28:47.800  
**Carer03**  
I mean, that's quite personal. I don't know what it's like elsewhere, but I don't know that it would harm the whole country.

0:28:47.880 --> 0:28:48.0  
**Catherine Beresford**  
Hmm.

0:28:53.200 --> 0:28:53.320  
**Catherine Beresford**  
Hmm.

0:28:49.520 --> 0:28:53.400  
**Carer03**  
And I think end of life care could be a lot better.

0:28:56.640 --> 0:28:57.0  
**Catherine Beresford**  
Yeah.

0:28:56.640 --> 0:28:59.160  
**Carer03**  
For people to have a lot more dignity.

0:29:0.700 --> 0:29:5.180  
**Carer03**  
I don't know how achievable that is, but.

0:29:6.620 --> 0:29:9.820  
**Carer03**  
It would be nice to think it's possible.

0:29:10.270 --> 0:29:10.830  
**Catherine Beresford**  
Yeah.

0:29:12.310 --> 0:29:12.670  
**Catherine Beresford**  
Yeah.

0:29:15.370 --> 0:29:21.170  
**Catherine Beresford**  
I think you've answered everything that I really wanted to know, to be honest, but.

0:29:25.910 --> 0:29:26.110  
**Carer03**  
Mm hmm.

0:29:32.430 --> 0:29:32.870  
**Carer03**  
Yeah.

0:29:21.190 --> 0:29:35.830  
**Catherine Beresford**  
Something that I would like to ask you is that you know when when you're having this kind of conversation it it makes you reflect and think about things and sometimes something comes to mind that you hadn't thought about before. Is there anything that springs to mind when I say that?

0:29:39.730 --> 0:29:41.90  
**Carer03**  
Don't think so.

0:29:44.310 --> 0:29:52.910  
**Carer03**  
No, maybe I'd I think maybe if his condition had been picked up sooner.

0:29:53.140 --> 0:29:53.740  
**Catherine Beresford**  
Yeah, yeah.

0:29:59.400 --> 0:29:59.520  
**Catherine Beresford**  
Hmm.

0:29:56.180 --> 0:30:4.540  
**Carer03**  
I don't know how that would have been possible because I'm just trying to think back about any GP appointments that he had and.

0:30:8.510 --> 0:30:8.630  
**Catherine Beresford**  
Hmm.

0:30:7.240 --> 0:30:10.600  
**Carer03**  
Things like that, whether he had blood tests or anything.

0:30:10.130 --> 0:30:10.770  
**Catherine Beresford**  
Yeah.

0:30:11.740 --> 0:30:14.380  
**Carer03**  
But I can't quite quite think that back I think.

0:30:16.100 --> 0:30:27.540  
**Carer03**  
Early diagnosis, I mean, I know years ago I'm talking. I was a teenager, he had, he did have an ultrasound and he was told then that he had.

0:30:29.480 --> 0:30:30.520  
**Carer03**  
A fatty lump on his liver.

0:30:31.50 --> 0:30:31.690  
**Catherine Beresford**  
OK.

0:30:32.770 --> 0:30:36.930  
**Carer03**  
But that was all we're heard and that was it. So, obviously it started.

0:30:37.290 --> 0:30:38.210  
**Catherine Beresford**  
I'm with you.

0:30:38.290 --> 0:30:40.730  
**Carer03**  
Over over maybe 20 year ago.

0:30:41.0 --> 0:30:41.800  
**Catherine Beresford**  
Sure.

0:30:43.420 --> 0:30:43.900  
**Catherine Beresford**  
Yeah.

0:30:46.410 --> 0:30:46.530  
**Catherine Beresford**  
Hmm.

0:30:52.400 --> 0:30:52.480  
**Catherine Beresford**  
Mm.

0:30:54.790 --> 0:30:55.230  
**Catherine Beresford**  
Yeah.

0:30:43.60 --> 0:30:56.380  
**Carer03**  
And I don't know what conversations had been that had, whether he had any or if he was just told he had this fatty lump on the liver and to change his diet. I assume that they would say that.

0:30:56.650 --> 0:30:57.50  
**Catherine Beresford**  
Yeah.

0:30:57.940 --> 0:30:58.60  
**Carer03**  
But.

0:30:59.200 --> 0:31:4.760  
**Carer03**  
Yeah, I think it sounds awful, but don't know if you really need to put the frighteners on people.

0:31:5.610 --> 0:31:6.50  
**Catherine Beresford**  
Yeah.

0:31:12.270 --> 0:31:12.470  
**Catherine Beresford**  
Mm hmm.

0:31:5.990 --> 0:31:13.750  
**Carer03**  
To make them realise how I'm not seeing everybody because if somebody told me that I'd be like, oh, right, yeah. I'll make the changes.

0:31:20.140 --> 0:31:20.540  
**Catherine Beresford**  
Yeah.

0:31:16.880 --> 0:31:22.400  
**Carer03**  
I think there's certain people who they just think, oh, right, OK. Like my dad probably obviously did.

0:31:24.320 --> 0:31:27.760  
**Carer03**  
How serious it could be down the line if they don't.

0:31:25.300 --> 0:31:29.140  
**Catherine Beresford**  
Yeah, yeah, I'm with you. Yeah.

0:31:28.720 --> 0:31:32.160  
**Carer03**  
Yeah. So, while it obviously didn't need any follow up.

0:31:35.250 --> 0:31:37.890  
**Carer03**  
It it's obviously just progressed from that.

0:31:37.700 --> 0:31:38.460  
**Catherine Beresford**  
Sure.

0:31:40.190 --> 0:31:46.270  
**Catherine Beresford**  
And is there something else you think that I should know to understand your experiences as a carer better?

0:31:48.940 --> 0:31:49.220  
**Carer03**  
And then.

0:31:50.60 --> 0:31:51.540  
**Carer03**  
It's just hard work.

0:31:52.50 --> 0:31:52.170  
**Catherine Beresford**  
Hmm.

0:31:53.500 --> 0:31:58.260  
**Carer03**  
I honestly never when people say they're a carer for somebody.

0:31:58.550 --> 0:31:58.950  
**Catherine Beresford**  
Yeah.

0:31:59.630 --> 0:32:9.590  
**Carer03**  
I just. I think, yeah, that's got to be hard work, but I've never understood anything like it, and especially when it's a family member because.

0:32:11.190 --> 0:32:11.830  
**Carer03**  
It can.

0:32:13.170 --> 0:32:14.610  
**Carer03**  
There's a lot of arguments.

0:32:14.900 --> 0:32:15.340  
**Catherine Beresford**  
Yeah.

0:32:18.80 --> 0:32:21.840  
**Carer03**  
But because you're the family member and.

0:32:27.800 --> 0:32:28.0  
**Catherine Beresford**  
Mm hmm.

0:32:23.510 --> 0:32:30.190  
**Carer03**  
The you can just essentially say what you want want to each other, but like it does cause a lot of friction.

0:32:29.980 --> 0:32:30.540  
**Catherine Beresford**  
Yeah.

0:32:32.120 --> 0:32:33.560  
**Catherine Beresford**  
Yeah, I'm with you.

0:32:32.850 --> 0:32:35.50  
**Carer03**  
And it, and I think for me.

0:32:36.140 --> 0:32:39.540  
**Carer03**  
It wasn't just my dad. It was my mum as well.

0:32:39.610 --> 0:32:40.210  
**Catherine Beresford**  
Yeah, yeah.

0:32:41.180 --> 0:32:45.180  
**Carer03**  
So, she's. I'm trying to think she is.

0:32:46.400 --> 0:32:46.960  
**Carer03**  
Coming up to be.

0:32:48.180 --> 0:32:50.620  
**Carer03**  
74.

0:32:52.540 --> 0:33:1.940  
**Carer03**  
And she is a little she's 5 foot 1, 7 stone. My dad was 6 foot 2 and 17 stone so.

0:33:1.790 --> 0:33:2.310  
**Catherine Beresford**  
OK.

0:33:8.310 --> 0:33:8.830  
**Catherine Beresford**  
Yeah.

0:33:4.60 --> 0:33:14.60  
**Carer03**  
Caring for him, like especially the size of him. He’d be like, just help us up. And she was like, I can't. I'll end up on top of you.

0:33:13.190 --> 0:33:15.190  
**Catherine Beresford**  
No. Yeah.

0:33:16.660 --> 0:33:17.220  
**Carer03**  
I mean.

0:33:18.40 --> 0:33:18.920  
**Carer03**  
Yeah, I think.

0:33:21.120 --> 0:33:21.960  
**Carer03**  
As as.

0:33:23.620 --> 0:33:29.940  
**Carer03**  
Yeah, right. It's not just hard physically, mentally and just relationship wise.

0:33:29.350 --> 0:33:31.630  
**Catherine Beresford**  
Yes. Yeah.

0:33:31.220 --> 0:33:33.220  
**Carer03**  
And and and I.

0:33:37.720 --> 0:33:37.840  
**Catherine Beresford**  
MMM.

0:33:34.790 --> 0:33:39.510  
**Carer03**  
Not care for my mum, but make sure she was all right as well as well as my dad.

0:33:41.350 --> 0:33:44.790  
**Carer03**  
And I worked my job alongside it.

0:33:46.930 --> 0:33:47.690  
**Carer03**  
And that was tough.

0:33:47.840 --> 0:33:48.280  
**Catherine Beresford**  
Yeah.

0:33:49.440 --> 0:33:52.80  
**Carer03**  
I think I needed it.

0:33:52.560 --> 0:33:53.400  
**Catherine Beresford**  
Sure.

0:33:52.120 --> 0:33:54.40  
**Carer03**  
To keep distracted.

0:33:57.0 --> 0:33:57.840  
**Catherine Beresford**  
Yes.

0:34:1.110 --> 0:34:1.670  
**Catherine Beresford**  
Yeah.

0:34:6.990 --> 0:34:7.470  
**Catherine Beresford**  
Yeah.

0:33:54.880 --> 0:34:8.320  
**Carer03**  
Both had to take a lot of time out to take more appointments and stuff, So, I spent a lot of time making time up, working longer days and things like that. I mean, they were great, my job, but I think.

0:34:9.800 --> 0:34:13.80  
**Carer03**  
For somebody doing that as well, it is a lot.

0:34:14.120 --> 0:34:15.840  
**Carer03**  
Yeah, yeah.

0:34:13.260 --> 0:34:19.300  
**Catherine Beresford**  
Yeah, it sounds like it does sound like it. Yeah. Yeah, it's good that he had you both.

0:34:20.680 --> 0:34:20.920  
**Catherine Beresford**  
Yeah.

0:34:19.610 --> 0:34:23.930  
**Carer03**  
Oh yeah, definitely. I think if it was the other way round, we would have been stuffed.

0:34:25.880 --> 0:34:29.920  
**Catherine Beresford**  
Yeah. Is there anything that you'd like to ask me?

0:34:34.780 --> 0:34:35.380  
**Carer03**  
I guess.

0:34:39.210 --> 0:34:39.330  
**Catherine Beresford**  
Hmm.

0:34:45.900 --> 0:34:46.660  
**Catherine Beresford**  
Yeah.

0:34:36.980 --> 0:34:47.980  
**Carer03**  
From a diabetes point of view, why did why did you decide to research the liver disease? Because my dad did actually have diabetes as well. So, yeah.

0:34:57.220 --> 0:34:57.620  
**Carer03**  
Yeah.

0:35:5.350 --> 0:35:5.710  
**Carer03**  
Yeah.

0:34:48.260 --> 0:35:15.260  
**Catherine Beresford**  
Good question. Well, I did. I was diabetes nurse for 14 years and I really enjoyed it. But I knew that I wanted to sort of develop more in terms of research and I was I was doing some research with people who have diabetes, but it's quite hard to get funding when you're doing a PhD. And I actually saw this advertised because it's funded by a Hospice in Lewis Manning Hospice in Dorset and then the university. And when I saw it, it just.

0:35:25.310 --> 0:35:25.750  
**Carer03**  
Yeah.

0:35:26.990 --> 0:35:27.190  
**Carer03**  
Yeah.

0:35:33.360 --> 0:35:34.360  
**Carer03**  
Absolutely.

0:35:16.60 --> 0:35:47.780  
**Catherine Beresford**  
You know, like it was a bit of a light bulb moment because there was so many aspects to it that attracted me because it's about a long term condition, which is also, what diabetes is. It's about a condition which is often stigmatised because liver disease is associated with stigma, you know, in the same way that type 2 diabetes can be, you know, because it's seen as a condition which is related to your lifestyle and then it's about trying to find out what people's experiences of care are like.

0:35:47.820 --> 0:35:56.260  
**Catherine Beresford**  
Listening to what people are saying, and I actually think that is really valuable knowledge and insights to when you're trying to see what's working well.

0:35:56.950 --> 0:35:57.350  
**Carer03**  
Yeah.

0:35:56.850 --> 0:36:15.650  
**Catherine Beresford**  
And when you're trying to make improvements to care and it's about trying to make services that a person centred. So, that's why I was attracted to it and I have really been enjoying it. And you know everything you've said is interesting because you know there is variation in care across the country.

0:36:15.500 --> 0:36:16.420  
**Carer03**  
Absolutely.

0:36:16.850 --> 0:36:29.250  
**Catherine Beresford**  
And some services are set up quite differently, So, you know there's variations in access to specialist nurses in terms of whether you see a hepatology consultant or a gastroenterologist.

0:36:29.850 --> 0:36:36.410  
**Catherine Beresford**  
Who is more general compared with the hepatology consultant, where they're more focused on the liver. There are some areas where.

0:36:37.930 --> 0:36:47.130  
**Catherine Beresford**  
Services have actually got direct access to palliative care or Hospice, So, it is quite variable.

0:36:58.30 --> 0:36:59.30  
**Carer03**  
Absolutely, yeah.

0:36:48.730 --> 0:37:0.730  
**Catherine Beresford**  
And the reason I asked you about the dietician was because something that's come out of talking to people is that people that people want to know what to do about nutrition and have concerns about their diet.

0:37:1.580 --> 0:37:6.180  
**Catherine Beresford**  
But don't necessarily always have access to a dietician, and that seems variable.

0:37:6.370 --> 0:37:6.770  
**Carer03**  
Yeah.

0:37:14.630 --> 0:37:15.110  
**Carer03**  
Yeah.

0:37:7.560 --> 0:37:20.280  
**Catherine Beresford**  
So, there's a lot of things you've told me. There's a lot of crossover between what other people are saying, but then at the same time there is there are it's it's highlighting where there's differences as well.

0:37:20.830 --> 0:37:26.70  
**Carer03**  
Yeah, yeah. So, actually it's interesting that you say about the hepatologist and gastro.

0:37:30.650 --> 0:37:31.410  
**Catherine Beresford**  
Yes.

0:37:27.710 --> 0:37:36.550  
**Carer03**  
Thing because so my dad was under a gastroenterologist and we did ask to be referred, not necessarily for a second opinion.

0:37:37.10 --> 0:37:37.50  
**Catherine Beresford**  
M.

0:37:37.930 --> 0:37:40.170  
**Carer03**  
Or just weren't overly happy with.

0:37:44.400 --> 0:37:46.320  
**Catherine Beresford**  
Yeah, yeah.

0:37:48.570 --> 0:37:48.610  
**Catherine Beresford**  
I.

0:37:53.860 --> 0:37:54.460  
**Catherine Beresford**  
Yes.

0:37:41.830 --> 0:38:0.510  
**Carer03**  
The lack of information and support this was before we had the specialist nurse and and support, So, we actually asked to be referred to a hepatologist and they they actually rejected the referral and said the gastroenterologist or refer you to think it's necessary.

0:38:1.110 --> 0:38:2.510  
**Catherine Beresford**  
That's interesting. Yeah.

0:38:2.780 --> 0:38:5.380  
**Carer03**  
Yeah, that was actually really, really disappointing.

0:38:5.60 --> 0:38:6.420  
**Catherine Beresford**  
I wonder why?

0:38:6.620 --> 0:38:10.100  
**Carer03**  
I know, because everybody's entitled to a second opinion.

0:38:11.170 --> 0:38:16.130  
**Catherine Beresford**  
Yeah, but I wonder, why wouldn't your dad have met the criteria to see a hepatologist then?

0:38:16.390 --> 0:38:19.150  
**Carer03**  
Have absolutely no idea.

0:38:19.350 --> 0:38:19.950  
**Carer03**  
So, So, yeah.

0:38:19.640 --> 0:38:20.320  
**Catherine Beresford**  
Yeah.

0:38:22.230 --> 0:38:23.990  
**Catherine Beresford**  
Yeah. So, yeah.

0:38:23.250 --> 0:38:27.770  
**Carer03**  
And he just didn't want to push it. He didn't want to push it any further, So, I just left it. But.

0:38:25.400 --> 0:38:28.480  
**Catherine Beresford**  
No, no.

0:38:29.650 --> 0:38:30.130  
**Carer03**  
I just thought.

0:38:32.10 --> 0:38:35.730  
**Carer03**  
That's awful. And then when I joined that LIVErNORTH Facebook page.

0:38:35.880 --> 0:38:36.520  
**Catherine Beresford**  
Yes.

0:38:48.640 --> 0:38:49.240  
**Catherine Beresford**  
Yeah.

0:38:37.170 --> 0:38:51.570  
**Carer03**  
They actually mentioned something on. I'm not sure if it's on the website or on the Facebook page about how everybody's entitled to see a hepatologist, and I just thought that was very interesting because they're they're coming out of where my dad was referred.

0:38:51.770 --> 0:38:55.130  
**Catherine Beresford**  
Sure. Yeah. That's interesting in there.

0:38:56.170 --> 0:38:56.810  
**Catherine Beresford**  
Yeah.

0:38:53.410 --> 0:38:59.810  
**Carer03**  
To an. Yeah. Very interesting. Yeah, but I thought, oh.

0:38:59.850 --> 0:39:2.10  
**Carer03**  
It's not something you need to stew over now.

0:39:1.80 --> 0:39:14.40  
**Catherine Beresford**  
No, no, no. I I appreciate that 'cause that, that that doesn't necessarily help now does there? Yeah, and you know and actually you're still trying to process what's happened.

0:39:14.370 --> 0:39:15.730  
**Carer03**  
Exactly. But I think if.

0:39:20.420 --> 0:39:20.540  
**Catherine Beresford**  
Hmm.

0:39:17.880 --> 0:39:21.360  
**Carer03**  
If I knew anybody else who was in the same boat, I would get them to push for it.

0:39:21.810 --> 0:39:22.290  
**Catherine Beresford**  
Yeah.

0:39:22.730 --> 0:39:26.890  
**Carer03**  
And and just say no, you are entitled to it.

0:39:28.290 --> 0:39:28.570  
**Carer03**  
So, yeah.

0:39:29.360 --> 0:39:29.760  
**Catherine Beresford**  
Yeah.

0:39:30.250 --> 0:39:39.170  
**Carer03**  
I mean, we wouldn't have got any different answers, I don't think. But I feel like they might have been a little bit more realistic about the liver transplant situation.

0:39:36.410 --> 0:39:41.330  
**Catherine Beresford**  
Yeah, it's the conversations. Yeah. Yeah, I see.

0:39:41.450 --> 0:39:41.850  
**Carer03**  
Yeah.

0:39:42.550 --> 0:39:43.230  
**Catherine Beresford**  
Hmm yeah.

0:39:44.570 --> 0:39:48.530  
**Catherine Beresford**  
OK. Well, is there anything else you want to say before I stop recording?

0:39:48.540 --> 0:39:50.220  
**Carer03**  
No, that's all. Thank you.

0:39:50.300 --> 0:39:52.60  
**Catherine Beresford**  
Right. Let me stop recording.