# nothingHCP09 ‘Bella’ - Interview Transcript 23/04/2024 09:00am by Teams. 36 minutes.

0:0:0.0 --> 0:0:5.800  
Catherine Beresford  
Turn off the transcript because it's a bit unsettling. If you can see the transcript while you're speaking, it's off-putting.

0:0:13.620 --> 0:0:14.140  
HCP09  
Yes.

0:0:7.190 --> 0:0:16.550  
Catherine Beresford  
Right. OK. So, you should have a message up to say that it's recording and transcribing. Did you see that? Great. OK. So, you're happy to start.

0:0:16.670 --> 0:0:17.190  
HCP09  
Yes.

0:0:17.950 --> 0:0:38.30  
Catherine Beresford  
Lovely. OK then. So, to start off with, could you just tell me about your role in working with individuals who've got advanced liver disease? And as I mentioned before we started the interview, I’m particularly talking about those individuals who have experienced decompensation and are not on the liver transplant list.

0:0:50.90 --> 0:0:50.650  
Catherine Beresford  
OK.

0:0:38.730 --> 0:0:52.690  
HCP09  
Mm hmm, So, I I first became interested in this. Well, a little bit of background. So, both my parents were alcoholics, and my brother was an alcoholic.

0:0:53.40 --> 0:0:53.400  
Catherine Beresford  
Yeah.

0:0:54.210 --> 0:0:55.650  
HCP09  
Both my parents died from alcoholism.

0:0:56.180 --> 0:0:56.540  
Catherine Beresford  
Yeah.

0:0:59.880 --> 0:1:0.560  
Catherine Beresford  
Yes.

0:0:57.410 --> 0:1:1.410  
HCP09  
And so, I've always had an interest in alcohol, liver disease, however.

0:1:5.150 --> 0:1:5.350  
Catherine Beresford  
Mm hmm.

0:1:3.90 --> 0:1:6.170  
HCP09  
When I became a palliative care nurse.

0:1:6.410 --> 0:1:9.930  
HCP09  
And I started my training for my advanced practitioner.

0:1:20.90 --> 0:1:20.810  
Catherine Beresford  
I see.

0:1:10.500 --> 0:1:33.620  
HCP09  
And I decided to look a bit more in depth because I noticed we weren't getting many referrals from the gastro ward for patients with for patients with decompensated liver disease. However, when we were, it was always either day of death or day before death. Patients were very encephalopathic. They were very symptomatic.

0:1:34.980 --> 0:1:39.260  
HCP09  
They weren't prescribed just-in-case meds. There was no pain relief prescribed because.

0:1:44.550 --> 0:1:45.30  
Catherine Beresford  
Yeah.

0:1:52.30 --> 0:1:52.390  
Catherine Beresford  
Yeah.

0:1:39.740 --> 0:1:55.540  
HCP09  
Because there was this facade that they've got liver disease that they can't have this and they can't have that. So, I decided to do a little retrospective audit for the year 2021 just to see exactly how many referrals we had received.

0:1:56.820 --> 0:1:59.620  
HCP09  
And I was pleasantly.

0:2:1.540 --> 0:2:11.860  
HCP09  
Surprised to see that we'd only actually had out of over 1200 referrals in total to the hospital team. We had 36 referrals for patients with DLD.

0:2:12.440 --> 0:2:12.920  
Catherine Beresford  
Right.

0:2:19.340 --> 0:2:19.540  
Catherine Beresford  
Mm hmm.

0:2:22.990 --> 0:2:23.110  
Catherine Beresford  
Hmm.

0:2:28.410 --> 0:2:28.970  
Catherine Beresford  
Yeah.

0:2:13.730 --> 0:2:30.450  
HCP09  
Coming from [Name of place], although I don't originate from here, I'm fully aware that [Name of place] has a high, high prevalence of alcohol related liver disease and social deprivation, so, that gave me the incentive to think well, where are all these people dying and who's caring for them?

0:2:36.940 --> 0:2:37.60  
Catherine Beresford  
Hmm.

0:2:49.150 --> 0:2:49.590  
Catherine Beresford  
Yeah.

0:2:31.610 --> 0:3:1.930  
HCP09  
So, I started to delve a little bit more into this sort of topic, doing a lot more research, speaking to the alcohol liaison team here, speaking to the chronic liver disease advanced clinical practitioner who has clinics for chronic liver disease patients and some of the gastroenterology consultants. And again, I was really shocked by the initial response to me even being interested in, why does palliative care need to be interested in these patients, these patients.

0:3:8.830 --> 0:3:8.950  
Catherine Beresford  
Hmm.

0:3:2.550 --> 0:3:13.550  
HCP09  
And it was things coming back to me like, well, you know, the disease trajectory is very unpredictable and they're only young. You might make them drink again.

0:3:22.320 --> 0:3:22.920  
Catherine Beresford  
Yeah.

0:3:15.30 --> 0:3:29.270  
HCP09  
I don't have end of life or advanced care planning discussions because the doctors don't. So, it was all these sorts of very negative feedback, negative comments and I was just like, hold on a minute. These people was deserve the respect and dignity that everybody else deserves.

0:3:29.460 --> 0:3:30.20  
Catherine Beresford  
Yeah.

0:3:30.790 --> 0:3:33.270  
HCP09  
And so, I carried on with this Qi project.

0:3:33.590 --> 0:3:34.750  
HCP09  
For two years.

0:3:34.500 --> 0:3:35.60  
Catherine Beresford  
Yeah.

0:3:37.650 --> 0:3:39.330  
HCP09  
Sorry, I forgot what your question was.

0:3:39.340 --> 0:3:43.740  
Catherine Beresford  
No, it would. No, no, you're just telling me all about your role. Really. Yeah.

0:3:42.40 --> 0:3:47.880  
HCP09  
Yeah, So, basically, I got a lot more involved and trying to improve.

0:3:49.830 --> 0:3:50.470  
Catherine Beresford  
Yes.

0:3:55.40 --> 0:3:55.640  
Catherine Beresford  
Right.

0:4:3.350 --> 0:4:4.30  
Catherine Beresford  
Yeah.

0:4:7.460 --> 0:4:8.300  
Catherine Beresford  
OK.

0:3:49.160 --> 0:4:11.160  
HCP09  
Referral rates, therefore improving quality of life, having early advanced care planning discussions. I did some education sessions with the nurses on the gastroenterology ward. I did some presentations with the gastroenterology consultants at their mdts. I started attending ward rounds every week to try and highlight patients who may be appropriate for us.

0:4:11.730 --> 0:4:12.370  
Catherine Beresford  
Right.

0:4:11.630 --> 0:4:14.950  
HCP09  
To or maybe appropriate for community referral.

0:4:16.590 --> 0:4:25.190  
HCP09  
Again, that did see a massive increase in our referrals for a short period of time. While I did it, but then it went off the boil again once I stopped doing the board rounds.

0:4:24.240 --> 0:4:26.200  
Catherine Beresford  
Right. OK.

0:4:26.830 --> 0:4:30.270  
HCP09  
So, yeah, So, that's really where my interest comes from.

0:4:30.500 --> 0:4:31.220  
Catherine Beresford  
Yeah.

0:4:31.930 --> 0:4:33.610  
HCP09  
And it's sort of evolved from there really.

0:4:34.50 --> 0:4:41.530  
Catherine Beresford  
So, the quality improvement project is that is that sort of ongoing is it, has it led to other?

0:4:40.320 --> 0:4:43.0  
HCP09  
So, it's sort, it's it's finished.

0:4:42.880 --> 0:4:43.320  
Catherine Beresford  
Yeah.

0:4:44.320 --> 0:4:46.480  
HCP09  
It's finished.

0:4:48.580 --> 0:4:49.100  
Catherine Beresford  
Oh yeah.

0:4:46.520 --> 0:4:50.720  
HCP09  
I did a poster about it for for my quality improvement.

0:4:59.460 --> 0:5:0.60  
Catherine Beresford  
Yeah.

0:4:53.120 --> 0:5:0.400  
HCP09  
Unfortunately, I have seen there has been definitely an increase in referral rates, although still very low.

0:5:7.440 --> 0:5:8.160  
Catherine Beresford  
OK.

0:5:1.920 --> 0:5:10.760  
HCP09  
In the year 2023, I saw 4 - we saw 49 patients for decompensated liver disease, So, a slight improvement however.

0:5:11.140 --> 0:5:15.20  
HCP09  
On saying that 80% still died in hospital.

0:5:15.300 --> 0:5:16.60  
Catherine Beresford  
Right.

0:5:16.420 --> 0:5:21.20  
HCP09  
11% had only received palliative care input previously.

0:5:21.90 --> 0:5:21.650  
Catherine Beresford  
Yeah.

0:5:25.160 --> 0:5:26.0  
Catherine Beresford  
OK.

0:5:22.540 --> 0:5:26.620  
HCP09  
87% have never received any advanced care planning.

0:5:30.340 --> 0:5:30.900  
Catherine Beresford  
Yeah.

0:5:26.700 --> 0:5:32.900  
HCP09  
And 82% of these patients had a confirmed diagnosis of Child Pugh with a high prevalence of alcohol related.

0:5:39.30 --> 0:5:39.550  
Catherine Beresford  
Yeah.

0:5:34.700 --> 0:5:44.100  
HCP09  
So, from the Qi point of view it's it's finished, but then it hasn't finished from me. Still trying to support this cohort of cohort of patients.

0:5:44.90 --> 0:5:45.370  
Catherine Beresford  
I see, yeah.

0:6:0.140 --> 0:6:0.700  
Catherine Beresford  
Yeah.

0:6:6.210 --> 0:6:6.290  
Catherine Beresford  
Mm.

0:5:44.750 --> 0:6:14.350  
HCP09  
And trying to continue to improve the outcomes for these patients. We have had a few little wins. We've had a few. Again, it's difficult, sometimes these patients sometimes are still actively drinking. So, although referred to us, they don't want to take us on board. They don't turn up to appointments, but we've had a few wins where I've got managed to get a few of these patients to are living well and outpatients.

0:6:14.620 --> 0:6:15.300  
Catherine Beresford  
OK.

0:6:14.620 --> 0:6:18.820  
HCP09  
Where they're supported with social workers.

0:6:17.980 --> 0:6:19.740  
Catherine Beresford  
Yeah, yeah.

0:6:20.220 --> 0:6:24.740  
HCP09  
Complementary therapy, physio, psychological support, advanced care planning.

0:6:25.640 --> 0:6:25.760  
Catherine Beresford  
Hmm.

0:6:32.70 --> 0:6:32.670  
Catherine Beresford  
Yeah.

0:6:26.400 --> 0:6:38.720  
HCP09  
But again, we've only again 3 patients went to the Hospice to pass away. The majority again are still dying in hospital with late referrals to palliative care unfortunately.

0:6:38.410 --> 0:6:50.610  
Catherine Beresford  
Yeah. Yeah. So, I mean, you've given me some insight into it, but then like just sort of overall what services are people with advanced liver disease then typically accessing in your area?

0:6:52.480 --> 0:6:53.0  
HCP09  
Nothing.

0:7:0.690 --> 0:7:0.890  
Catherine Beresford  
Mm hmm.

0:6:58.640 --> 0:7:3.200  
HCP09  
I honestly don't know what they get. I don't think they get anything or very little.

0:7:6.480 --> 0:7:7.160  
Catherine Beresford  
Yeah.

0:7:11.210 --> 0:7:11.930  
Catherine Beresford  
Yes.

0:7:4.760 --> 0:7:12.640  
HCP09  
We have an alcohol liaison team here, but they don't just obviously see the DLD patients, they see any patients who come in with alcohol, liver disease.

0:7:13.10 --> 0:7:13.410  
Catherine Beresford  
Yeah.

0:7:14.440 --> 0:7:18.240  
HCP09  
They have, as I said, there's an ACP for chronic liver disease patient.

0:7:17.970 --> 0:7:19.570  
Catherine Beresford  
Right. OK.

0:7:20.40 --> 0:7:20.600  
HCP09  
Who runs a clinic.

0:7:22.400 --> 0:7:25.200  
HCP09  
Again, that's he has a massive caseload.

0:7:32.30 --> 0:7:32.470  
Catherine Beresford  
Right.

0:7:25.840 --> 0:7:36.320  
HCP09  
I don't know exactly how many of the patients on his caseload, which I believe when I last spoke to him, was over 600 patients, actually. How many of those patients are DLD rather than chronic.

0:7:35.310 --> 0:7:37.70  
Catherine Beresford  
Right, yeah.

0:7:38.140 --> 0:7:42.20  
HCP09  
But very little support. Minimal. Yeah, yeah.

0:7:40.110 --> 0:7:45.710  
Catherine Beresford  
Yeah, yeah. Is there anything that you think is working particularly well at the moment?

0:7:47.970 --> 0:7:48.450  
Catherine Beresford  
Yeah.

0:7:48.220 --> 0:7:57.60  
HCP09  
No other than. I think once we get them under our wing, we can try and achieve a more satisfactory death.

0:7:58.560 --> 0:8:6.600  
HCP09  
Where they're a bit more comfortable, but no, I think this this cohort of patients are really poorly cared for and let down.

0:8:5.80 --> 0:8:10.240  
Catherine Beresford  
Yeah, yeah. And how do how do people get referred to you then?

0:8:10.990 --> 0:8:14.470  
HCP09  
So, the gastroenterology ward will refer patients to us.

0:8:16.340 --> 0:8:24.340  
HCP09  
For symptom management. So, for instance, yesterday I had a lady who was referred to me 55-year-old lady with DLD heart failure.

0:8:24.750 --> 0:8:25.150  
Catherine Beresford  
Yeah.

0:8:26.180 --> 0:8:27.420  
HCP09  
Splenomegaly

0:8:40.90 --> 0:8:40.930  
Catherine Beresford  
Right.

0:8:43.280 --> 0:8:43.840  
Catherine Beresford  
Yeah.

0:8:29.620 --> 0:8:44.660  
HCP09  
Overloaded. But you know, when I went to see this lady, she wasn't aware. One that she was referred to palliative care. So, it was a shock to see me and two when I explained the extent of her disease and her co-morbidities.

0:8:47.110 --> 0:8:47.950  
Catherine Beresford  
OK.

0:8:49.840 --> 0:8:50.680  
Catherine Beresford  
Right.

0:8:54.990 --> 0:8:55.870  
Catherine Beresford  
Right.

0:8:45.340 --> 0:8:56.940  
HCP09  
And nobody had really told her anything. She knew she had a liver disease, which she didn't know. It was end-stage. She didn't know it was life limiting. So, again, it's very difficult conversations that we have to have because they've not been had by the leading team.

0:8:57.840 --> 0:9:5.560  
Catherine Beresford  
I see. So, you mean like you'll get the referral, but it hasn't actually been explained to the individual. And then yeah, is it?

0:9:11.670 --> 0:9:12.470  
Catherine Beresford  
Yeah.

0:9:2.670 --> 0:9:12.790  
HCP09  
No, and that's very common. It's very common that we have to basically be the ones with the bad news, giving them the full facts because nobody's actually been honest with them.

0:9:13.520 --> 0:9:19.120  
Catherine Beresford  
And what do you think about that then in terms of, yeah, how, how do you feel about that?

0:9:19.150 --> 0:9:26.710  
HCP09  
Well, I find it very frustrating. Very frustrating. But then on the other hand, I also, feel that we're better at doing it.

0:9:33.650 --> 0:9:34.210  
Catherine Beresford  
Yeah.

0:9:28.270 --> 0:9:38.710  
HCP09  
We're kind of, we're care. We've got more time to sit with them and explain everything and support them, whereas the consultant comes along, it's often thrown in a sentence and then they walk away.

0:9:38.970 --> 0:9:39.810  
Catherine Beresford  
I see.

0:9:44.480 --> 0:9:46.0  
Catherine Beresford  
Yeah, yeah.

0:9:40.150 --> 0:9:48.710  
HCP09  
So, although it's difficult and it's not really our job to do, we do do it because the outcome is usually a bit better for the patient.

0:9:49.50 --> 0:10:2.610  
Catherine Beresford  
Yeah. Yeah. So, you've mentioned some of them, but can you just tell me a bit more about the professionals that are involved in care for people with advanced decompensated liver disease in your area then So, that I can kind of get an overview.

0:10:7.340 --> 0:10:7.460  
Catherine Beresford  
Hmm.

0:10:4.80 --> 0:10:9.240  
HCP09  
So, again, it's it's it's difficult to say exactly what's going on outside of the hospital.

0:10:9.310 --> 0:10:10.30  
Catherine Beresford  
Sure.

0:10:20.580 --> 0:10:21.140  
Catherine Beresford  
Yeah.

0:10:10.800 --> 0:10:30.880  
HCP09  
You know, obviously when they come into hospital, they're usually actively treated, So, they'll have the alcohol liaison nurse if that's appropriate. If they're still actively drinking, they'll have. They'll have the medical team on the ward. They may have occupational health or physiotherapy if that's deemed appropriate.

0:10:37.840 --> 0:10:38.600  
Catherine Beresford  
Right.

0:10:31.650 --> 0:10:42.290  
HCP09  
They may be referred to the discharge team if they're homeless, they may be referred to the homeless team or may be known to the homeless team if they're homeless.

0:10:42.260 --> 0:10:42.820  
Catherine Beresford  
Yeah.

0:10:53.810 --> 0:10:54.650  
Catherine Beresford  
I see.

0:10:44.730 --> 0:10:59.930  
HCP09  
And other than that, there's not really much support for them. It's very much treat, recover, discharge and wait for the next exacerbation. Come back in treat and then obviously when that exacerbation turns into end of life, then they refer to palliative care.

0:11:0.390 --> 0:11:8.670  
Catherine Beresford  
I see. Yeah. And you're mentioning alcohol-related liver disease. Is that the main type that you tend to see in your area?

0:11:14.950 --> 0:11:15.70  
Catherine Beresford  
Hmm.

0:11:9.180 --> 0:11:16.20  
HCP09  
Definitely. So, 73% of the patients we saw last year - it was 76% - was caused by alcohol.

0:11:16.410 --> 0:11:18.970  
Catherine Beresford  
Right. OK. Yeah.

0:11:20.370 --> 0:11:21.890  
Catherine Beresford  
OK So,

0:11:36.610 --> 0:11:36.690  
HCP09  
Mm.

0:11:23.510 --> 0:11:38.430  
Catherine Beresford  
Again, you you're kind of giving me some of this information as we go along, but I just want to delve a bit deeper. So, it if people who've got advanced liver disease or their carers require support, advice or information, where it where do you, where do they go?

0:11:39.510 --> 0:11:40.70  
HCP09  
I don't know.

0:11:40.760 --> 0:11:40.880  
Catherine Beresford  
Hmm.

0:11:41.330 --> 0:11:42.650  
HCP09  
I don't think they go anywhere.

0:11:43.290 --> 0:11:43.410  
Catherine Beresford  
Hmm.

0:11:43.890 --> 0:11:46.770  
HCP09  
Unless it's GP land, I don't. I honestly don't know.

0:11:47.200 --> 0:11:47.320  
Catherine Beresford  
Hmm.

0:12:6.130 --> 0:12:6.850  
Catherine Beresford  
Yeah.

0:11:48.610 --> 0:12:12.610  
HCP09  
One of the things that we struggled with initially when we started this project or when I started it with my colleagues was sometimes these patients do recover from the admission and one of the things I was trying to do was to get earlier referrals that we could have advanced care planning discussions with these patients. And my team did struggle with this. At first, they were a bit like, well, what is it you want us to do, [name of HCP09], because they're not dying right now.

0:12:12.880 --> 0:12:13.720  
Catherine Beresford  
Right.

0:12:18.220 --> 0:12:19.180  
Catherine Beresford  
Yes.

0:12:20.940 --> 0:12:21.780  
Catherine Beresford  
Sure.

0:12:25.70 --> 0:12:25.870  
Catherine Beresford  
Yeah.

0:12:28.590 --> 0:12:29.310  
Catherine Beresford  
Yeah.

0:12:13.380 --> 0:12:44.300  
HCP09  
But what you don't understand and what I'm trying to get across is that these patients have a life limiting disease that could take their life at any point and the exacerbation could be their last. And it's about having those advanced care planning, making them understand that they have a life limiting disease. Now that's no longer curative and that, you know, we're going to be there to support them when they do need us. It might only be a one-off visit that they need just to introduce the service, to introduce the word palliative because obviously everybody thinks palliative's end of life.

0:12:44.230 --> 0:12:44.830  
Catherine Beresford  
Yes.

0:12:44.940 --> 0:12:47.980  
HCP09  
There's still a massive misconception around what the word palliative means.

0:12:47.680 --> 0:12:48.360  
Catherine Beresford  
Yes.

0:12:53.930 --> 0:12:54.50  
Catherine Beresford  
Hmm.

0:12:57.820 --> 0:12:58.540  
Catherine Beresford  
Yeah.

0:13:6.760 --> 0:13:8.120  
Catherine Beresford  
I see, yeah.

0:12:48.560 --> 0:13:10.80  
HCP09  
You know, it's and it's about educating them to say no, we're about symptom management, about psychological support, about making sure, you know, you've got a good environment to be in. You're going to be at the right place. And it took a while for even my team to get on board with that because they're often going up to patients who are ready for discharge and saying, well, I don't really know what to offer this patient.

0:13:13.120 --> 0:13:15.200  
HCP09  
Yeah, yeah.

0:13:10.480 --> 0:13:21.920  
Catherine Beresford  
Yeah, and that's the palliative care team. Is it the inpatient palliative care team? Yeah. Yeah. So, what? To what extent do you think individuals know or understand that they've got a life limiting condition?

0:13:23.300 --> 0:13:24.140  
HCP09  
Very minimal.

0:13:25.190 --> 0:13:33.750  
HCP09  
Very minimal. I mean I would say 90% of the patients I see, or I've seen, were not aware that it was life limiting.

0:13:34.430 --> 0:13:35.950  
Catherine Beresford  
I see, yeah.

0:13:35.370 --> 0:13:40.50  
HCP09  
They weren't aware that the prognosis is less than two years once they confirmed DLD.

0:13:39.850 --> 0:13:41.210  
Catherine Beresford  
Yes. Yeah.

0:13:49.810 --> 0:13:50.490  
Catherine Beresford  
Yeah.

0:13:53.480 --> 0:13:55.360  
Catherine Beresford  
Hmm. Hmm. Hmm.

0:13:41.700 --> 0:13:56.340  
HCP09  
And in fairness, most of them don't even survive two years. It's very rare that they survive two years. They have multiple hospital admissions, multiple comorbidities, multiple symptom burden, and nobody tells them they just treat them and send them home and treat them and send them home.

0:13:56.400 --> 0:14:7.160  
Catherine Beresford  
Yeah, yeah, yeah, that's interesting. Yeah, thank you. So, have you got any specific examples when you think the care provided for an individual in this situation was particularly positive?

0:14:12.960 --> 0:14:13.440  
HCP09  
No.

0:14:14.450 --> 0:14:14.650  
Catherine Beresford  
Mm hmm.

0:14:15.50 --> 0:14:15.450  
HCP09  
No.

0:14:15.850 --> 0:14:16.290  
Catherine Beresford  
Yeah.

0:14:23.40 --> 0:14:23.680  
Catherine Beresford  
Yes.

0:14:24.720 --> 0:14:25.320  
Catherine Beresford  
Yes.

0:14:16.990 --> 0:14:28.110  
HCP09  
Unfortunately no. Most of the patients I've had to deal with have been very symptomatic when they've been referred to us very distressed, usually actively dying.

0:14:28.570 --> 0:14:29.50  
Catherine Beresford  
Yeah.

0:14:30.150 --> 0:14:32.510  
HCP09  
I had a gentle I had a young young gentleman.

0:14:34.30 --> 0:14:38.30  
HCP09  
Probably about a year and a half ago now, only in his 30s was referred to us.

0:14:43.790 --> 0:14:44.590  
Catherine Beresford  
Right.

0:14:39.470 --> 0:14:47.710  
HCP09  
By 1 consultant and one of the issues we have is the consultants on the ward change every week, So, if you've got a long stay, you might have two or three consultants.

0:14:51.210 --> 0:14:51.810  
Catherine Beresford  
Yeah.

0:14:48.110 --> 0:14:58.670  
HCP09  
And obviously they all have different ideas and different plans, but this, this young chap was referred to us and I went to see him, and he was actively dying, looked very distressed.

0:15:6.270 --> 0:15:6.950  
Catherine Beresford  
Yes.

0:15:9.730 --> 0:15:10.570  
Catherine Beresford  
Yeah.

0:15:0.150 --> 0:15:12.710  
HCP09  
Wasn't prescribed any pain relief because he got liver disease and I'm trying to explain that he's dying, So, it doesn't matter about having paracetamol or having morphine or whatever you need. It's about keeping him comfortable and.

0:15:14.100 --> 0:15:17.60  
HCP09  
For three days I fought to get this gentleman.

0:15:22.320 --> 0:15:22.960  
Catherine Beresford  
Yeah.

0:15:29.380 --> 0:15:29.980  
Catherine Beresford  
Yeah.

0:15:36.620 --> 0:15:38.940  
Catherine Beresford  
He sure, yeah.

0:15:40.920 --> 0:15:41.480  
Catherine Beresford  
Yeah.

0:15:18.160 --> 0:15:44.680  
HCP09  
One, for the team to recognise that he was actively dying. Two to have conversations with his family. So, his mum came in on the day that I'd been he'd been referred to us and when she saw my uniform because on my uniform it's got [Name of] Hospice, which sometimes is not a great thing, but obviously we have to advocate that we work for the Hospice. And she was horrified, and she looked at me, said, what are you doing here? And I, you know, I tried to explain how sick her son was.

0:15:44.470 --> 0:15:45.230  
Catherine Beresford  
Yes.

0:15:48.470 --> 0:15:49.30  
Catherine Beresford  
Yeah.

0:15:50.960 --> 0:15:52.80  
Catherine Beresford  
Mm hmm mm hmm.

0:15:46.200 --> 0:15:52.760  
HCP09  
And she became very aggressive and obviously didn't want to speak to me, which is very understandable. Nobody wants to hear this about their child.

0:15:53.330 --> 0:15:53.450  
Catherine Beresford  
Hmm.

0:15:53.360 --> 0:16:5.360  
HCP09  
So, I arranged for an MDT best interest meeting on the on the Monday with the consultant with the the gentleman's mum, myself and the ward manager and the ward sister.

0:16:10.230 --> 0:16:10.990  
Catherine Beresford  
Yeah.

0:16:18.140 --> 0:16:18.980  
Catherine Beresford  
Right.

0:16:6.800 --> 0:16:21.0  
HCP09  
And I explained to the doctors and the ward system, we need to let this lady know that her son’s going to die. We need to prepare her. So, when I had the meeting on the Monday, it was a different consultant who hadn't met this gentleman because obviously it was Monday and it was his first day on the ward.

0:16:20.820 --> 0:16:21.660  
Catherine Beresford  
Yeah.

0:16:24.380 --> 0:16:25.100  
Catherine Beresford  
Yeah.

0:16:31.360 --> 0:16:31.960  
Catherine Beresford  
Yeah.

0:16:21.530 --> 0:16:32.330  
HCP09  
And he was very upset that this meeting had been arranged and he was quite angry at me because he felt like I was four steps ahead of him.

0:16:33.970 --> 0:16:34.90  
HCP09  
And.

0:16:34.290 --> 0:16:37.90  
HCP09  
The meeting didn't go very well. The mum stormed out.

0:16:40.0 --> 0:16:40.640  
Catherine Beresford  
Yeah.

0:16:43.830 --> 0:16:43.950  
Catherine Beresford  
Hmm.

0:16:38.650 --> 0:16:51.450  
HCP09  
She was very aggressive. His sister was very aggressive, they were very unrealistic, and he felt that I had overtaken. But what I tried to explain to him was that I had actually been four days ahead of him.

0:16:59.70 --> 0:16:59.590  
Catherine Beresford  
Yeah.

0:16:52.410 --> 0:17:7.690  
HCP09  
So, I'd seen this gentleman on the Friday, So, Friday, Saturday, Sunday. I'm fighting to get this man's symptom free and to be able to die with dignity. He'd only met him on the Monday. So, for a little while after that, he stopped referring to palliative care.

0:17:8.20 --> 0:17:9.740  
Catherine Beresford  
Oh, right, OK.

0:17:20.880 --> 0:17:21.520  
Catherine Beresford  
Yes.

0:17:9.210 --> 0:17:23.370  
HCP09  
And didn't want palliative care involved in these patients. However, this meeting on the Monday happened, and on the Tuesday when his family came in, the doctors wanted to speak to the family again because he deteriorated further, and he was seizuring.

0:17:30.640 --> 0:17:31.480  
Catherine Beresford  
Oh gosh.

0:17:23.900 --> 0:17:42.700  
HCP09  
And he was now on a syringe driver. Now whilst the family were talking to the doctors, unfortunately this gentleman died. And when the mother walked back into the behind the curtains, she found her son dead. Now all this could have been prevented had we started this four days before when I wanted to.

0:17:43.890 --> 0:17:44.330  
Catherine Beresford  
Yeah.

0:17:50.220 --> 0:17:50.740  
Catherine Beresford  
Yeah.

0:17:44.130 --> 0:17:53.970  
HCP09  
But because he was a young gentleman and they wanted to keep going and keep trying, all this distress was caused.

0:17:55.430 --> 0:17:58.870  
HCP09  
Which had an impact then on the referrals for a while after that.

0:17:58.750 --> 0:18:3.310  
Catherine Beresford  
Yes. Yeah, that sounds really challenging for you as well.

0:18:3.580 --> 0:18:11.900  
HCP09  
It was really hard because, you know, I had the patients advocate half the time, especially when they're encephalopathicand they can't speak for themselves.

0:18:20.310 --> 0:18:20.790  
Catherine Beresford  
Yeah.

0:18:31.610 --> 0:18:32.130  
Catherine Beresford  
Yeah.

0:18:13.300 --> 0:18:33.580  
HCP09  
It's really, really challenging because again, as I work for the Hospice, we're only an advisory service in the hospital. We, we are very well thought of and we're we're a team of 12, we do have, there's a lot of us, but we are only an advisory service, and we have to honestly keep people on side. But there also, comes a point where.

0:18:36.680 --> 0:18:37.440  
Catherine Beresford  
Yes.

0:18:34.420 --> 0:18:40.340  
HCP09  
Enough's enough and you know you have to vocalise your concerns and your distress for the patients.

0:18:40.630 --> 0:18:51.190  
Catherine Beresford  
Yeah. So, so, with all of that in mind, I guess how would you like to see how would you like to see things differently? How would you like it to be?

0:18:51.750 --> 0:18:59.550  
HCP09  
So, I'd like it that the doctors who are treating the patient have honest conversations when they're well.

0:19:1.30 --> 0:19:26.150  
HCP09  
In clinic setting, you know, or the ACP in the chronic liver disease, they start having advanced care planning discussions. They have honest conversations with the patients because often these are the ones that know these patients really well. They're really out of hospital. You know the ward sisters know them really well. You know, they'll say, oh, I've been looking after [male name], for instance, for two years. I know him really well. Why are these people not doing it? Why is it?

0:19:26.740 --> 0:19:27.420  
Catherine Beresford  
Yeah.

0:19:35.830 --> 0:19:36.430  
Catherine Beresford  
Yes.

0:19:26.470 --> 0:19:50.550  
HCP09  
I've always got to wait for palliative care. You know, they need to be honest and open when they're well enough So, that they can make these decisions and have advanced care planning and have discussions about preferred place of care, preferred place of death, you know? Do they want to be actively treated again and again and again when often this treatment's futile, it doesn't shorten or lengthen their prognosis.

0:19:50.260 --> 0:20:3.100  
Catherine Beresford  
Hmm. Yeah, yeah. So, leading on from that. Maybe just expand a bit about to you, what does good care in advanced liver disease look like for the sorts of individuals that we're talking about?

0:20:5.330 --> 0:20:11.90  
HCP09  
From when they referred to us and they're actively dying or from just from the diagnosis of DLD.

0:20:11.700 --> 0:20:16.340  
Catherine Beresford  
I guess from the diagnosis, when they first get that sort of decompensation really.

0:20:15.500 --> 0:20:22.620  
HCP09  
Yeah. So, I think what I'd like to see would be from the from the initial diagnosis is is an honest conversation.

0:20:22.720 --> 0:20:23.280  
Catherine Beresford  
Yeah.

0:20:27.170 --> 0:20:27.290  
Catherine Beresford  
Hmm.

0:20:36.660 --> 0:20:37.180  
Catherine Beresford  
Yeah.

0:20:40.800 --> 0:20:41.640  
Catherine Beresford  
Yes.

0:20:44.80 --> 0:20:44.200  
Catherine Beresford  
Hmm.

0:20:23.940 --> 0:20:45.820  
HCP09  
To then explain that no longer is it curative whether or not they change their lifestyle, you know, I know there's been concerns that, well, if you do that, then they're going to go out and drink. But if I have a young man with cancer and telling he's going to die, it's his still his choice to leave and go out and drink or smoke or take drugs or whatever. That's their choice. At the end of the day. But they still should be informed.

0:20:45.980 --> 0:20:46.460  
Catherine Beresford  
Yeah.

0:20:49.0 --> 0:20:49.200  
Catherine Beresford  
Mm hmm.

0:20:50.930 --> 0:20:51.410  
Catherine Beresford  
Yeah.

0:20:46.480 --> 0:21:5.0  
HCP09  
That this is now a life limiting disease that's no longer curative. That's the first instance that then should be discussions either with their consultant in outpatients, the chronic liver disease ACP, or even their GP about an EPaCCS. Have you heard of EPaCCS [Electronic Palliative Care Coordinating Systems]?

0:21:5.80 --> 0:21:6.440  
Catherine Beresford  
No, I don't think so.

0:21:13.340 --> 0:21:14.20  
Catherine Beresford  
Alright.

0:21:17.680 --> 0:21:19.640  
Catherine Beresford  
Yes, OK.

0:21:22.640 --> 0:21:23.120  
Catherine Beresford  
Yeah.

0:21:25.550 --> 0:21:25.750  
Catherine Beresford  
Mm hmm.

0:21:34.40 --> 0:21:34.720  
Catherine Beresford  
Yeah.

0:21:37.150 --> 0:21:38.470  
Catherine Beresford  
I see.

0:21:6.590 --> 0:21:38.750  
HCP09  
So, the EPaCCS is an electronic. It stands for electronic palliative care coordinating system, which is filled out by GPS and it's basically about having advanced care planning discussions. So, on there it would have things like where the patient's preferred care is where the preferred place of death is would, would they want recurrent admissions to hospital? Have they been prescribed there just in case medications? Are they on the low standards framework. So, all these things are on there that then can be shared.

0:21:46.510 --> 0:21:47.830  
Catherine Beresford  
Sure. Yeah.

0:21:50.520 --> 0:21:51.80  
Catherine Beresford  
Yeah.

0:21:39.170 --> 0:21:58.890  
HCP09  
So, if they come into hospital and you look at their impacts, it can tell you what's what's happened. Now, obviously it's not skull standards, it just, you know, people can change their mind but it but it it 1 informs you that they're aware that this is already been this discussion has happened. So, you know that they've already had these discussions and you can then take the conversation forward.

0:21:59.260 --> 0:22:0.580  
Catherine Beresford  
Yeah, yeah.

0:22:0.370 --> 0:22:1.810  
HCP09  
So, that So, that's another thing.

0:22:3.370 --> 0:22:6.450  
HCP09  
There could be a lot more community support.

0:22:6.490 --> 0:22:7.370  
HCP09  
For these patients.

0:22:12.380 --> 0:22:13.300  
Catherine Beresford  
Oh, OK.

0:22:18.550 --> 0:22:19.270  
Catherine Beresford  
Right.

0:22:21.380 --> 0:22:21.500  
Catherine Beresford  
Hmm.

0:22:24.360 --> 0:22:24.920  
Catherine Beresford  
Sure.

0:22:7.930 --> 0:22:30.410  
HCP09  
One of the things that I'm just about to set up is an advanced care planning clinic in at the Hospice. But initially this is on the background of a different audit for lung cancer patients. So, initially it is going to be lung cancer patients, but I'm very keen for it to then become open to people who've got DLD or even COPD, you know chronic chronic diseases.

0:22:30.530 --> 0:22:31.90  
Catherine Beresford  
Yeah.

0:22:31.890 --> 0:22:38.850  
HCP09  
So, they could be referred into that clinic when they're again still well enough. Not in a hospital admission when they're in a crisis.

0:22:49.600 --> 0:22:51.440  
Catherine Beresford  
Yes. Yeah.

0:22:39.700 --> 0:22:53.500  
HCP09  
To have these conversations, to see what supports available or needed at home, how the family are coping, you know, often the families don't even realise how sick these patients are because they just it's the norm for them, isn't it?

0:22:53.780 --> 0:22:55.260  
Catherine Beresford  
Yeah, yeah.

0:23:10.100 --> 0:23:10.660  
Catherine Beresford  
Yes.

0:22:56.760 --> 0:23:11.880  
HCP09  
And then obviously, symptom symptom burden, a quality of life is is usually very poor. You know, symptom burden is absolutely huge. The amount of different symptoms these patients get, it's about being able to control those symptoms as best as possible, you know.

0:23:12.280 --> 0:23:24.40  
HCP09  
With the safest medication that's available and there's there's plenty of medications out there that we can use to help with symptom burden, but everybody seems to be frightened because everything or you've got to be careful because they've got liver disease.

0:23:26.60 --> 0:23:26.460  
HCP09  
Yeah.

0:23:23.540 --> 0:23:30.940  
Catherine Beresford  
OK, OK. And why do you think that why, you know what is it about that then what's the where does that fear come from?

0:23:39.250 --> 0:23:40.50  
Catherine Beresford  
Yes.

0:23:45.390 --> 0:23:46.110  
Catherine Beresford  
Yes.

0:23:58.0 --> 0:23:58.840  
Catherine Beresford  
Don't they?

0:23:31.720 --> 0:24:0.200  
HCP09  
Well, it comes from being aware of prescribing. So, obviously things you know the drugs say reduce dose in liver disease or you know use caution in liver disease. But again, these are saying use with caution or use a low reduce. They're not saying do not use yet they see that, and they think well I'm not going to use that because it's a bit dangerous if liver disease because they haven't really they don't really know the full facts themselves they don't really understand the workings of the liver.

0:24:0.380 --> 0:24:0.980  
Catherine Beresford  
Yeah.

0:24:3.720 --> 0:24:4.480  
Catherine Beresford  
Yeah.

0:24:0.520 --> 0:24:12.560  
HCP09  
And how it's absorbed and you know how it how it distributes. So, you have to then go up and educate and say no, it's OK for this. It's OK for this drug, you know? Yeah.

0:24:9.410 --> 0:24:13.890  
Catherine Beresford  
Right. I'm with you. Yeah. Yeah. OK.

0:24:15.290 --> 0:24:37.810  
Catherine Beresford  
Thank you. What you've told me So, far is just very insightful and really given me an idea of, you know, some of the things that are going on where you're in the area where you work. While we've been talking, you know, sometimes when when you're having these kinds of conversations, something might occur to you that you haven't really thought about before. You know, you'd had this conversation today. Is there anything that sort of comes to mind when I ask that?

0:24:41.0 --> 0:24:41.800  
HCP09  
Yes.

0:24:43.760 --> 0:24:45.520  
HCP09  
More trying to get them to do more.

0:24:46.650 --> 0:24:46.850  
Catherine Beresford  
Mm hmm.

0:24:47.120 --> 0:24:52.120  
HCP09  
You know, trying to engage more with the advanced clinical practitioner in his clinic.

0:24:52.940 --> 0:24:52.980  
Catherine Beresford  
I.

0:25:0.330 --> 0:25:1.50  
Catherine Beresford  
Yeah.

0:25:6.300 --> 0:25:6.860  
Catherine Beresford  
Yeah.

0:25:10.250 --> 0:25:11.90  
Catherine Beresford  
Right.

0:24:53.840 --> 0:25:11.840  
HCP09  
To to start having these conversations. So, when I first started this, I did go and speak to this, this ACA, and we were talking about me joining his clinic initially to to support him with advanced care planning discussions and conversation, So, that.

0:25:13.540 --> 0:25:14.220  
Catherine Beresford  
Yeah.

0:25:18.540 --> 0:25:19.100  
Catherine Beresford  
Yeah.

0:25:12.320 --> 0:25:27.960  
HCP09  
We could learn from me and then carry that on, but unfortunately then did go off sick for long term So, it and it's never really got, you know, other things have come up and it's never really got talked about again. So, maybe that's something I need to relook at.

0:25:28.480 --> 0:25:29.320  
Catherine Beresford  
Sure.

0:25:33.710 --> 0:25:34.190  
Catherine Beresford  
Yes.

0:25:41.320 --> 0:25:41.760  
Catherine Beresford  
Yeah.

0:25:30.120 --> 0:25:42.760  
HCP09  
I do go to the upper GI MDT every Friday, and I do try and talk to the consultants, but again it's very hit and miss. They have a huge caseload. There's not many of them.

0:25:51.640 --> 0:25:52.520  
Catherine Beresford  
Yes.

0:25:43.140 --> 0:25:54.260  
HCP09  
They're very overstretched and as sad as it sounds, I feel like sometimes they feel like they want to treat the patients who are treatable rather than the ones who are not.

0:25:56.290 --> 0:25:56.610  
HCP09  
That.

0:25:55.930 --> 0:25:58.10  
Catherine Beresford  
Yeah. Tell me more a bit bit more about that.

0:26:6.130 --> 0:26:8.290  
Catherine Beresford  
Sure. Yes.

0:25:59.660 --> 0:26:9.20  
HCP09  
Well, I mean when I say that they don't want to treat them, I don't mean that because obviously, as I said, sometimes they treat, treat, treat and treat and don't realise when to stop, but obviously.

0:26:13.120 --> 0:26:13.720  
Catherine Beresford  
Yes.

0:26:19.780 --> 0:26:19.860  
Catherine Beresford  
Mm.

0:26:23.250 --> 0:26:23.930  
Catherine Beresford  
Yes.

0:26:10.470 --> 0:26:26.350  
HCP09  
There's a stigma attached to a lot of these patients. It's self-inflicted, they're still drinking. You know, they brought it on themselves. You know, whereas they might have somebody who's got lung liver cancer in the next bed who's never drunk.

0:26:26.460 --> 0:26:27.60  
Catherine Beresford  
Yes.

0:26:29.660 --> 0:26:30.340  
Catherine Beresford  
Yes.

0:26:27.830 --> 0:26:33.70  
HCP09  
Or they've got Nash. You know, these sorts of things. So, sometimes I feel like this cohort is just a bit neglected.

0:26:33.290 --> 0:26:34.650  
Catherine Beresford  
I get you. Yeah.

0:26:34.570 --> 0:26:36.530  
HCP09  
And and not really a priority.

0:26:37.120 --> 0:26:54.0  
Catherine Beresford  
Yeah. And something that's coming out a little bit from what you're saying, but it's also, come out of other interviews that I've done with healthcare professionals, these issues of services being under pressure. And then the impact on staff well-being. I'm just interested to hear your thoughts on on that really.

0:26:55.200 --> 0:26:59.200  
HCP09  
So, they they are. Gastroenterology is massively under pressure here.

0:26:59.830 --> 0:27:0.30  
Catherine Beresford  
Mm hmm.

0:27:2.760 --> 0:27:3.320  
Catherine Beresford  
Yeah.

0:27:0.440 --> 0:27:8.480  
HCP09  
We don't have enough consultants and one of our main consultants is leaving in a couple of months, which is going to be huge, huge loss.

0:27:9.90 --> 0:27:9.810  
Catherine Beresford  
Right.

0:27:10.240 --> 0:27:15.0  
HCP09  
We have a huge gastroenterology cohort of patients.

0:27:15.190 --> 0:27:15.590  
Catherine Beresford  
Yeah.

0:27:24.570 --> 0:27:25.210  
Catherine Beresford  
Right.

0:27:16.760 --> 0:27:27.120  
HCP09  
As I'm sure across across the country and that the service is just under serviced and overrun and there's not enough staff.

0:27:33.120 --> 0:27:33.840  
Catherine Beresford  
Yeah.

0:27:27.880 --> 0:27:39.0  
HCP09  
There has been money put in this last year. I know they are trying to improve these pathways So, I was invited as part of my quality improvement to join.

0:27:40.380 --> 0:27:41.100  
HCP09  
Have you heard of Aqua?

0:27:41.520 --> 0:27:42.40  
Catherine Beresford  
No.

0:27:43.160 --> 0:27:50.200  
HCP09  
I'm trying to think where it stands for. I can't even remember now it's an. It's an audit quality improvement project.

0:27:55.390 --> 0:27:56.30  
Catherine Beresford  
Yes.

0:27:51.680 --> 0:28:4.920  
HCP09  
And they're trying to improve the pathway for patients with DLD from door to discharge. And there's there's a pathway bundle that's that's been out for quite a long time for DLD have never seen it.

0:28:2.170 --> 0:28:5.250  
Catherine Beresford  
Yeah, yeah, I have seen that. Yeah.

0:28:8.550 --> 0:28:9.510  
Catherine Beresford  
Oh, OK.

0:28:5.40 --> 0:28:17.40  
HCP09  
Yeah, but it's never really been used in this hospital. It's been about, but nobody ever uses it. They don't ever use it in A&E, So, there's been a lot of focus on trying to reintroduce this up-front door and A&E.

0:28:17.210 --> 0:28:17.770  
Catherine Beresford  
Yeah.

0:28:17.450 --> 0:28:23.290  
HCP09  
For patients with DLD, but there's never, there's nothing on there for consideration of palliative care.

0:28:23.890 --> 0:28:24.730  
Catherine Beresford  
Oh, OK.

0:28:24.690 --> 0:28:25.10  
HCP09  
So,

0:28:33.90 --> 0:28:33.850  
Catherine Beresford  
Yes.

0:28:27.50 --> 0:28:40.170  
HCP09  
As part of my being on these meetings, I have got them to now add a consideration for palliative care on the form, in the hope that that might, even if it just puts it in their mind, that actually could this patient die on this admission.

0:28:40.130 --> 0:28:41.10  
Catherine Beresford  
Right.

0:28:44.160 --> 0:28:44.720  
Catherine Beresford  
Yeah.

0:28:42.50 --> 0:28:45.450  
HCP09  
And consider a referral to us so,

0:28:47.50 --> 0:28:48.250  
HCP09  
So, that's been helpful.

0:28:49.250 --> 0:28:51.810  
HCP09  
So, they're looking to employ.

0:28:54.50 --> 0:28:56.970  
HCP09  
More 3 new ACPs for liver disease.

0:28:56.980 --> 0:28:57.780  
Catherine Beresford  
OK.

0:29:0.600 --> 0:29:1.240  
Catherine Beresford  
Yeah.

0:28:58.330 --> 0:29:4.970  
HCP09  
That will work across the board, So, we'll do inpatient, community and outpatients.

0:29:4.810 --> 0:29:5.570  
Catherine Beresford  
Yes.

0:29:7.90 --> 0:29:11.690  
HCP09  
But we don't have like, we're not. We're not a leading centre for liver disease we don't have.

0:29:13.450 --> 0:29:15.290  
HCP09  
A liver disease centre as such. So, it's just everybody's thrown in together.

0:29:19.690 --> 0:29:20.210  
Catherine Beresford  
Yeah.

0:29:20.850 --> 0:29:21.210  
Catherine Beresford  
Yeah.

0:29:22.370 --> 0:29:33.930  
Catherine Beresford  
OK. Thank you. That was helpful to to understand. Is there anything else that you think I should know to better understand care experiences in people who've got advanced liver disease?

0:29:35.360 --> 0:29:39.240  
HCP09  
Not really. I mean, I I don't think I can make it any more negative, unfortunately.

0:29:40.240 --> 0:29:41.880  
Catherine Beresford  
Yeah, fair enough. Yeah.

0:29:45.230 --> 0:29:45.870  
Catherine Beresford  
Yeah.

0:29:50.700 --> 0:29:52.740  
Catherine Beresford  
Gosh, gosh.

0:29:56.950 --> 0:29:57.670  
Catherine Beresford  
Yeah.

0:29:59.20 --> 0:29:59.620  
Catherine Beresford  
Yeah.

0:30:5.550 --> 0:30:5.630  
Catherine Beresford  
Mm.

0:29:40.720 --> 0:30:7.560  
HCP09  
You know, it's just very negative, you know, I mean in [Name of place] in 2021 with the highest premature death rate of working people in the country, you know and and yet we still don't do much for these patients. If that's not a high enough stat for us to be opening your eyes. And when I talk to people about that and I say these stats, everybody goes, Oh my God. Yeah, we need to do a lot more, but we don't because.

0:30:14.930 --> 0:30:15.610  
Catherine Beresford  
Yeah.

0:30:22.100 --> 0:30:22.740  
Catherine Beresford  
Yes.

0:30:15.680 --> 0:30:24.880  
HCP09  
And patients, you know, So, it's just it's going to take a long time to support these patients and get their care journey improved I think.

0:30:25.300 --> 0:30:26.340  
Catherine Beresford  
Yeah, yeah.

0:30:27.700 --> 0:30:34.540  
Catherine Beresford  
That's I think that's everything that I need to ask you because you've given me, you know, really comprehensive information. Is there anything that you want to ask me?

0:30:39.490 --> 0:30:40.450  
Catherine Beresford  
Hmm yeah.

0:30:36.960 --> 0:30:41.280  
HCP09  
Not really. Just, I guess. What are you trying to achieve? What's your outcome?

0:30:47.580 --> 0:30:47.780  
HCP09  
Mm hmm.

0:31:0.480 --> 0:31:0.680  
HCP09  
Mm hmm.

0:31:3.360 --> 0:31:3.560  
HCP09  
Mm hmm.

0:31:10.760 --> 0:31:10.960  
HCP09  
Mm hmm.

0:30:41.770 --> 0:31:14.210  
Catherine Beresford  
Yeah. I mean, really, I think at this point, So, I'm part, you know part way through collecting the data and analysing it all and then you know, I have to write it all up and I really want to try and kind of get a theory together of care experiences in decompensated advanced liver disease through all the different perspectives which you know, I would then want to publish the work so that people can see what's going on, and talk at conference to share what what's happening, share where things are working well, where there's room for improvement. I mean, a lot of it's about shining a light

0:31:20.680 --> 0:31:21.240  
HCP09  
Yes.

0:31:28.490 --> 0:31:28.930  
HCP09  
Yeah.

0:31:39.620 --> 0:31:40.540  
HCP09  
Is.

0:31:14.530 --> 0:31:43.570  
Catherine Beresford  
On these issues as well, really. Do you know what I mean? Like actually saying, look, this is what's going on to kind of give give that, you know, evidence for why things might need to be changed in some places. You know, there's and there's variation across the country, which I'm guessing you probably already know. I mean you know I've spoken to a range of professionals across the UK and there's there's some really good projects going on. You know. So, yeah. Yeah, there are like there's a Hospice where

0:31:44.610 --> 0:31:49.330  
Catherine Beresford  
They've actually done like they did a quality improvement project and that's led to.

0:32:6.340 --> 0:32:8.60  
HCP09  
That fabulous? Yeah.

0:31:50.560 --> 0:32:13.800  
Catherine Beresford  
The patients actually having much more direct access to Hospice and they're working quite, I'll send you a paper because it's quite helpful and they're and they're still doing that. They've got a liver specialist palliative care nurse in the Hospice, you know. So, there are there are things like that, you know, but then it's, yeah, it just seems. Yeah. All right, I will.

0:32:15.290 --> 0:32:15.970  
Catherine Beresford  
Yeah.

0:32:9.770 --> 0:32:21.330  
HCP09  
That's really good. Yeah. If you can send me anything you've got that's of that's that I could possibly, you know, look at and try and do something with that. That's good practice. That would be really helpful.

0:32:40.960 --> 0:32:41.400  
HCP09  
Yeah.

0:32:43.60 --> 0:32:43.420  
HCP09  
Yeah.

0:32:47.170 --> 0:32:47.530  
HCP09  
Yeah.

0:32:20.190 --> 0:32:51.190  
Catherine Beresford  
Yeah. And I've spoken quite a lot with the staff there and you know, similar sort of to the way you're describing things about how you've got what I'm seeing is that you've got to have, you know, it doesn't take a lot, but it's having those individual professionals who are sort of motivated and want to try and do something about it and then work collaboratively with others to to sort of make changes. And sometimes it's about changing the culture. For example, you know, one of the people that I've spoken with spoken with.

0:32:54.840 --> 0:32:55.40  
HCP09  
Mm hmm.

0:32:51.270 --> 0:32:58.550  
Catherine Beresford  
The Hospice it did require a bit of a culture shift because they were very much sort of used to supporting people in that more traditional way.

0:32:59.0 --> 0:32:59.440  
HCP09  
Yeah.

0:33:1.510 --> 0:33:1.910  
HCP09  
Yeah.

0:33:7.110 --> 0:33:7.470  
HCP09  
Yeah.

0:33:13.180 --> 0:33:13.620  
HCP09  
Yeah.

0:32:59.130 --> 0:33:16.210  
Catherine Beresford  
You know, the people who had cancer and there was a bit of resistance initially to having people with say, liver disease who were alcohol related, liver disease in the Hospice, but then they've managed to kind of turn that around a bit. So, yeah, no, I'll send you that and you know.

0:33:18.10 --> 0:33:23.170  
Catherine Beresford  
I did write a paper as well based on my systematic literature review so, I can send you that.

0:33:23.240 --> 0:33:24.720  
HCP09  
Yeah, lovely. Thank you.

0:33:24.930 --> 0:33:36.810  
Catherine Beresford  
But the thing the biggest challenge I'm having as somebody that is not working with individuals with liver disease is is actually reaching people who have liver disease or their carers to interview them.

0:33:37.220 --> 0:33:37.620  
HCP09  
Yeah.

0:33:43.420 --> 0:33:43.740  
HCP09  
Yeah.

0:33:45.430 --> 0:33:45.950  
HCP09  
Yeah.

0:33:54.370 --> 0:33:55.50  
HCP09  
OK.

0:33:56.650 --> 0:33:57.650  
HCP09  
Yeah. OK.

0:33:59.980 --> 0:34:0.340  
HCP09  
Yeah.

0:34:8.940 --> 0:34:9.300  
HCP09  
Yeah.

0:33:37.400 --> 0:34:10.240  
Catherine Beresford  
Because you know, when working in diabetes, it's much easier because I've got my foot in the door. I know the right people. I know who you know, it's having those kind of networks. I am finding it difficult to recruit people who have got liver disease or their carers. So, if you have anybody that you think would be willing to speak to me, please do pass on my details. You know, I I can speak to them like this. I can speak to them on the phone. I will come to [Name of place] and speak to people if they're willing to speak to me because it's that that's the most important thing is so helpful. Speaking to individuals like yourself.

0:34:13.380 --> 0:34:17.140  
HCP09  
Yeah, absolutely. Absolutely.

0:34:10.670 --> 0:34:23.150  
Catherine Beresford  
At the same time, I've really got to speak to more individuals who've got advanced liver disease. You know, even if. Yeah. So, please pass on, you know my details and, you know.

0:34:20.310 --> 0:34:24.590  
HCP09  
I will. I will go and hunt some patients and I will go and ask them for you.

0:34:28.500 --> 0:34:28.900  
HCP09  
Yeah.

0:34:24.390 --> 0:34:35.910  
Catherine Beresford  
Even even honestly, even just one, I don't need big numbers, you know. But if anybody would be willing to speak with me, please ask them to reach out to me. I would love to speak to them and hear their views.

0:34:37.660 --> 0:34:38.500  
Catherine Beresford  
Yes.

0:34:39.790 --> 0:34:40.590  
Catherine Beresford  
OK.

0:34:41.740 --> 0:34:42.940  
Catherine Beresford  
Yeah, yeah.

0:34:35.30 --> 0:34:46.390  
HCP09  
Well, I'm going back to see this lady today after I spoke to you. So, I'll ask her. I'm meeting her and her partner at 2:00. O'clock So, because I'm partnered with her. So, I'll ask them if they'll be interested.

0:34:55.370 --> 0:34:57.130  
HCP09  
Yes. Yeah.

0:35:5.680 --> 0:35:5.920  
HCP09  
No.

# Addition from HCP09 on 29/04/2024

I wanted to be a nurse from a very young age but due to my childhood being some what dysfunctional, I left school at 14 with no qualifications. My parents separated when I was 14 and my mum did not think school was a priority in her life as she wanted me around to clean, cook and get her alcohol for her. My dad was in the British army and at the time of separation we lived in Germany. Both my parents where from Dublin, Ireland, so my mum took  us back there. However, our relationship was very difficult so at the age of 15 I got on a boat and came to London, as this was were my dad was. My mum was what I would class as an ‘ Ugly drunk’ and I never had any relationship with her after this and she died from COPD & Liver failure about 10 years ago. My dad was ‘ a quite drunk’, happy to sit in the pub all day drinking while reading the ‘Times’. He was a very cleaver man who had spent 26 years in the British Army, many of these years as a sergeant major, and although his drinking was not a cause of him being in the army, it definitely did not help.

Dad’s mum was an alcoholic as was his brother, one of his sisters and some of my cousins. On my mum’s side: mum’s sister was also an alcoholic and probably 3 or 4 of her brothers, although they did function. My brother who is 54 and has been in recovery for the last 3.5 years has been in and out of rehab and prison since he was about 14. So extensive family history… Irish background 😊

When I moved to London, Dad was not a great support and so I it went alone and at 16 got a job as a live in carer in a nursing home in [name of county] and this was my first job in nursing and I loved it. I remember whenever I wanted to catch up with dad, it was always in his local and I asked him one day why he didn’t try to stop drinking and his response was ‘ drink is my priority and then it’s you’.. this was hard to hear however, It made me realise that I was not going to change him and I just needed to except and be there when he needed me. It was a difficult time in our relationship and for a few years we were in and out of each other’s lives, Dad spent a few years homeless in London.

What I do remember is when he was nearing the end of his life, I found him in his flat in a bad way. He had been stuck in his chair for 3 days, the flat was in a terrible state and the food was all off in the kitchen. Dad had been incontinent in his chair as he was too weak to get up and he looked so unkempt. This was very sad to see as he had always looked after himself and his looks having been in the army. I rang his GP to see if he could come out and see Dad however, they didn’t have time for a home visit and just made the usual excuses, so I called 999 and got an ambulance. I remember the paramedic saying, ‘ I don’t think it is worth bringing him to hospital because there is nothing they can do for him’, but I insisted.

On arrival to AE, I could see everyone looking at us, Dad looked like a homeless man, and if I’m honest I did feel a little embarrassed. After some hours of sitting there Dad was called in by the doctor and I went with him. The doctor asked me why I had bought him into hospital and I explained that he was not able to care for himself and he was complaining of a lot of leg pain. It was at this point that I said ‘ please do not look at him as a homeless alcoholic, he is my dad and he has served in the British army for 26 years and deserves to be treated with respect ‘. The doctor asked if I could help to undress my dad, taking of the layers of top clothes , I was so shocked to see how cachectic he was and this really upset me. Knowing my Dad, I asked the nurses to help with his bottom half as he would have been horrified.

After much debate they agreed to keep him in over night to support his withdrawal and I returned the next morning to find him on a ward, in a soaking wet bed, with a cold food tray on his table. This seemed to be the same story every day I went before he self-discharged and although I spoke to the nursing staff daily and begged Dad to stay in, they didn’t care, and he wanted a drink. I was so cross with him that I didn’t call him and he was found dead 2 weeks later in his flat. Cause of death was fatty liver and decompensated liver disease.

Moving on many years and lots more to tell, I married a solider who I met in [Name of city] and we went on to have 2 children and we moved to [Name of city] ( [husband’s name]’s home town, when he left the army). I stayed as a healthcare assistant within the NHS for 16 years before my boss said to me one day, ‘ [HCP09’s name], when are you going to do your nurse training?’. How could I do my training as I left school with no qualifications and had no confidence in studying. My boss encouraged me to try and do my NVQ level 2/3, which I did and thankfully at that time this was a way in to do my training. Who would have thought, little old me would go on to pass her masters in advanced clinical practice and her maths and English GCSE’s at the ripe old age of 52 😊

I have always had an interest in homelessness and liver disease, and also the poor after care that ex-army personal receive however, my career has never taken my down this path until I came to palliative care and with time and persistence I hope to be able to improve the care/ journey and support needed for patients with DLD [decompensated liver disease], their families and or carer’s without stigma and judgement. Having first hand understanding of this addition can only hopefully help.

I hope this is ok, not sure if it is what you wanted, but just a very small in site