# HCP10 ‘Edward’ - Interview Transcript. 27/03/2024 by Teams at 12:00-12:35. Total 31 minutes.

0:0:0.0 --> 0:0:0.800  
Catherine Beresford  
OK.

0:0:0.130 --> 0:0:3.530  
HCP10  
Yes, it says recording and transcription. Yep.

0:0:15.0 --> 0:0:15.440  
HCP10  
Sure.

0:0:3.530 --> 0:0:16.730  
Catherine Beresford  
Lovely. Just thinking 'cause. I quite like to hide it so that we don't have to watch ourselves. Yeah, I'm just going to hide the transcript. Otherwise it's a bit off putting when you can see it coming up. OK. Lovely.

0:0:18.90 --> 0:0:34.10  
Catherine Beresford  
Right. So to start off with, obviously I appreciate you're a GP, but could you just tell me a bit more about your role in working with individuals who've got advanced liver disease and I'm specifically focusing on individuals who've got decompensated liver disease.

0:0:42.940 --> 0:0:43.300  
Catherine Beresford  
Yeah.

0:0:36.550 --> 0:0:59.390  
HCP10  
People could be as a new acute presentation as in they newly become unwell. That would be probably the most common scenario or they could be people with long term chronic liver disease that has been chronic and managed and then suddenly they become unwell and and they decompensate and have lots of symptoms.

0:1:0.310 --> 0:1:6.710  
Catherine Beresford  
Yeah. So I guess in that situation then you are probably the first port of call for such individuals?

0:1:6.140 --> 0:1:13.260  
HCP10  
Yeah, I would. I would think so are you think and are you thinking about people with liver diseases across the board, so of all causes?

0:1:25.600 --> 0:1:26.720  
HCP10  
Yeah, yeah, yeah, yeah.

0:1:13.870 --> 0:1:31.750  
Catherine Beresford  
Yes, absolutely. I mean the the only thing I'm not focusing on is people who've got liver disease secondary to something else. Say, for example, if they've got cancer and then they have liver metastases. So yes, I am looking at a range of liver disease, yes.

0:1:32.90 --> 0:1:33.650  
HCP10  
Hmm, because they could have.

0:1:45.340 --> 0:1:45.540  
Catherine Beresford  
Mm hmm.

0:1:47.980 --> 0:1:48.740  
Catherine Beresford  
Yes.

0:1:35.530 --> 0:1:51.850  
HCP10  
The new liver symptoms and signs based on something like carcinoma of the head of pancreas, which would be an an acute obstructive picture that is something we we might see reasonably often well and they're not not often, but that would be a common GP presentation.

0:1:53.470 --> 0:1:54.70  
HCP10  
That kind of thing.

0:1:52.340 --> 0:2:3.620  
Catherine Beresford  
I'm with you, so I guess I guess from what you're saying for you, it's often like the the initial presentation that you might be encountering people.

0:2:1.10 --> 0:2:5.730  
HCP10  
Yeah, the yeah, the new, the new jaundiced patient, for example.

0:2:5.570 --> 0:2:14.770  
Catherine Beresford  
Yes. Yeah. And so what would be the kind of what would be the kind of pathway that that would then proceed that person?

0:2:23.930 --> 0:2:24.730  
Catherine Beresford  
Yes.

0:2:39.520 --> 0:2:39.920  
Catherine Beresford  
Yeah.

0:2:42.900 --> 0:2:43.300  
Catherine Beresford  
Yeah.

0:2:14.970 --> 0:2:44.770  
HCP10  
Yeah. So if they if if if we didn't have an established diagnosis, then we'd be doing blood tests that come at that consultation. I wouldn't be sending them away. I'd be doing blood tests there and then and then usually based on how well or unwell they were and what those blood tests tell us we'd be, we'd be looking at doing some imaging or of course, if they're unwell and have got acute signs and symptoms that might suggest there's an acute problem, then we'd we'd admit them to hospital because that would be the best place for them.

0:2:44.960 --> 0:2:56.360  
Catherine Beresford  
Yeah, I'm with you. I mean something that's come out of some of the other interviews I've done is actually around challenges in diagnosing liver disease. And I just wonder if you've got any thoughts about that really.

0:3:5.890 --> 0:3:6.90  
Catherine Beresford  
Mm hmm.

0:3:17.190 --> 0:3:18.590  
Catherine Beresford  
Yes, yes.

0:3:20.770 --> 0:3:21.770  
Catherine Beresford  
I'm with you, yeah.

0:2:57.150 --> 0:3:28.30  
HCP10  
OK, so classically, there's supposed to be two kinds of pictures you see, isn't there? There's a hepatocellular type of liver damage picture they might see on the blood tests, and then there's an obstructive type picture that we might see on the on the blood test. And I suppose there's also also the what's the patient been doing part of? So, you know, the history. The history is very important. If it's somebody that, you know, if it's somebody that has no other cause for their new presentation of liver disease.

0:3:32.160 --> 0:3:32.960  
Catherine Beresford  
Yes.

0:3:40.580 --> 0:3:41.260  
Catherine Beresford  
Yeah.

0:3:28.480 --> 0:3:58.200  
HCP10  
You're going to and they, let's say they're younger, let's say in their 30s, and they don't have an alcohol or drug or or medication or other drug issue. They could have, you know, they could have autoimmune hepatitis for example, or they could have infect, they could have infective hepatitis that's presenting or they could have a new hepatic cellular problem or they could have an obstructive problem of new impacted gallstone in the common bile duct, they're less likely to be the patient that presents later on in life which.

0:3:57.900 --> 0:3:58.420  
Catherine Beresford  
Yeah.

0:4:1.920 --> 0:4:2.560  
Catherine Beresford  
Right.

0:3:58.920 --> 0:4:4.480  
HCP10  
Most commonly would be painless, obstructive jaundice. So they just come in bit and well bit of weight loss.

0:4:4.660 --> 0:4:5.220  
Catherine Beresford  
Yeah.

0:4:5.40 --> 0:4:8.920  
HCP10  
They've they've turned yellow and they're they're wondering what that's about.

0:4:16.990 --> 0:4:17.70  
HCP10  
Mm.

0:4:9.200 --> 0:4:22.240  
Catherine Beresford  
Yeah, yeah. OK. And and so in in the area where you're working, because I'm talking to people across the UK, what services to people who have got advanced liver disease typically access?

0:4:29.580 --> 0:4:29.620  
Catherine Beresford  
M.

0:4:32.760 --> 0:4:33.120  
Catherine Beresford  
Yeah.

0:4:36.800 --> 0:4:37.560  
Catherine Beresford  
Right.

0:4:42.590 --> 0:4:43.350  
Catherine Beresford  
I see.

0:4:23.300 --> 0:4:47.20  
HCP10  
Well, there'd be. Yes, there'd be the gastroenterologist locally, so they'd be [name of] Hospital and [name of] Hospital. We we send most of our patients to [name of hospital] and they would have gastroenterologist and hepatologists there. But they would, they would be. It's nothing particularly specialist I have to say so. They would be often, I suppose they might be referred on for other other reasons.

0:4:47.510 --> 0:4:48.150  
Catherine Beresford  
Yeah.

0:4:47.520 --> 0:4:50.80  
HCP10

But we've got, you know, we've got local speciality.

0:4:50.720 --> 0:5:2.160  
Catherine Beresford  
Yeah. OK. And are there any other professionals that tend to be involved in, in care for people who've got, like decompensation in the area where you're working then?

0:5:10.870 --> 0:5:10.990  
Catherine Beresford  
Hmm.

0:5:19.360 --> 0:5:19.880  
Catherine Beresford  
Yeah.

0:5:4.830 --> 0:5:24.150  
HCP10  
I can't think otherwise. I mean, maybe dietitians occasionally, depends on the on the trigger and the reasons for their disease. I suppose it could, there could be autoimmune causes, but that's going to be hepatology, rheumatology. Perhaps if it's complications from other diseases.

0:5:24.320 --> 0:5:24.960  
Catherine Beresford  
Yes.

0:5:31.860 --> 0:5:32.380  
Catherine Beresford  
No.

0:5:26.270 --> 0:5:37.230  
HCP10  
People sometimes can have heart failure presenting with ascites, but that's usually not going to not going to kill them, and it's not usually the liver dysfunction that's going to cause harm. It's usually the the fluid overload that causes harm.

0:5:36.600 --> 0:5:43.440  
Catherine Beresford  
Yeah, yeah. What about, like any kind of specialist nurses or?

0:5:44.800 --> 0:5:45.480  
Catherine Beresford  
Anything like that?

0:5:58.630 --> 0:5:59.470  
Catherine Beresford  
I see.

0:6:0.720 --> 0:6:2.720  
Catherine Beresford  
Yes, I see. Yeah, yeah.

0:6:12.960 --> 0:6:13.640  
Catherine Beresford  
Yeah.

0:5:44.400 --> 0:6:14.40  
HCP10  
Yeah, well, they'll be. There'll be. Yes, I suspect strongly that there'll be. There'll be special specialist nurses within the within the Directorate of Gastroenterology. But I don't suppose we get to choose if we refer people to those people. Do you know what I mean? That tends to be a a secondary care driven thing. So if I referred somebody to the colorectal clinic, for example, for a colonoscopy, if it, if it turns out that they see a specialist nurse and they're all sorted out, that's great. Fine. I'm doing that.

0:6:16.170 --> 0:6:18.250  
Catherine Beresford  
No, I understand. Yeah, yeah.

0:6:14.260 --> 0:6:20.60  
HCP10  
That wasn't my. That wouldn't be my decision. That'll be them internally and internally managing their workload.

0:6:20.280 --> 0:6:36.560  
Catherine Beresford  
Hmm. Hmm. And as far as you know, then. So people who've got advanced liver disease, if - or their carers - if they, if they need to support advice or information, where do you think they're currently going for that in in the area where you're working?

0:6:35.540 --> 0:6:48.140  
HCP10  
Yeah, I suspect chronically 'cause, they'll have a diagnosis and they'll have something of a treatment plan. There probably will be some specialist nurses in there in the gastro clinic that would. That would be the first port of call.

0:6:48.490 --> 0:6:49.170  
Catherine Beresford  
Yeah.

0:6:50.620 --> 0:6:52.740  
Catherine Beresford  
OK. Anywhere else that you're aware of?

0:6:54.0 --> 0:6:55.160  
HCP10  
Not that comes to mind now.

0:6:55.120 --> 0:7:9.960  
Catherine Beresford  
No. OK. And what about for you yourself? I mean, if you require a sort of any particular, because obviously I know - you know, I've worked as a practice nurse, so I know it's, you know you're generalist, so if you need more guidance or advice, where do you go?

0:7:10.820 --> 0:7:15.340  
HCP10  
Yeah, that would be depend on the timeframe. So if it was something that.

0:7:27.360 --> 0:7:27.840  
Catherine Beresford  
Yeah.

0:7:41.520 --> 0:7:41.720  
Catherine Beresford  
Mm hmm.

0:7:16.820 --> 0:7:44.260  
HCP10  
Wasn't urgent. Often we would do advice and guidance referrals so they they form quite a a useful pathway for information. So we could do advice and guidance to to gastro when when I say gastroenterology mean hepatology within that within within gastroenterology I wouldn't necessarily think to try and get in touch with the with the specialist nurses personally that's just something I haven't I haven't done but that's probably because I haven't felt no felt the need to do that.

0:7:46.350 --> 0:7:47.110  
Catherine Beresford  
Yeah. OK.

0:8:5.210 --> 0:8:5.730  
Catherine Beresford  
I see.

0:7:46.520 --> 0:8:7.160  
HCP10  
It's a sometimes you might get a patient that's got deranged liver function, not decompensated liver disease, but deranged liver function. And you've done all the simple, straightforward things and then not they're not unwell, necessarily, and they might not even have a liver disease. They've just got these out of kilter, bloods, and you know, GPs are going to check.

0:8:10.650 --> 0:8:11.210  
Catherine Beresford  
Yeah.

0:8:8.720 --> 0:8:16.200  
HCP10  
Autoimmune hepatitis markers. They're going to check, they're going to check infective hepatitis, they're going to do iron levels for hemochromatosis.

0:8:26.880 --> 0:8:28.400  
Catherine Beresford  
Yeah, yeah.

0:8:37.380 --> 0:8:38.60  
Catherine Beresford  
I see.

0:8:43.790 --> 0:8:44.430  
Catherine Beresford  
Yeah.

0:8:16.790 --> 0:8:47.230  
HCP10  
Keen ones [GPs] might even do copper levels for Wilson's disease, but and A1 antitrypsin. But at some point you draw a blank and go: We've done all this with the and they've, and they've had it, and they've now had an ultrasound and that's normal. So what we're going to do, and so we want to sometimes we want to draw a line under it and say we've done everything we need to do and we don't might do advice and guidance for that or we might or we might do it at an earlier stage where, you know, you don't feel the need to test every single thing under the sun. You just want some guidance about next investigations.

0:8:53.870 --> 0:8:54.150  
HCP10  
Yeah.

0:8:47.600 --> 0:9:6.640  
Catherine Beresford  
I'm with you. I mean, it sounds like quite a lot of what you're describing is around sort of diagnosis, investigation. What about once somebody actually has got, if you think back to people that you've looked after, who've got like advanced liver disease, what role do you sort of feel you then have with those individuals?

0:9:13.690 --> 0:9:14.450  
Catherine Beresford  
Oh yeah.

0:9:29.160 --> 0:9:29.720  
Catherine Beresford  
Yeah.

0:9:30.940 --> 0:9:31.620  
Catherine Beresford  
Right.

0:9:6.660 --> 0:9:36.940  
HCP10  
Yeah, I think making sure or hoping that and monitoring them whilst they're waiting for their next treatment plan. So I've got a I've got a patient who's in his 70s who three or four years ago presented maybe a little bit longer that presented new with with a chronic active hepatitis and it was autoimmune and he's he's gone on to have a liver transplant. So he's he's done well, but he would be quite unwell during his active phase.

0:9:37.130 --> 0:9:37.730  
Catherine Beresford  
Yeah.

0:9:42.220 --> 0:9:42.900  
Catherine Beresford  
Yeah.

0:9:37.190 --> 0:9:53.590  
HCP10  
And our job would be just to monitor his monitor, his bloods, and keep him healthy, have a low threshold of treating him with an over. If he gets a little infection here and there, we might have a low threshold for treating with antibiotics and just, you know, keeping a little closer eye on him, really.

0:9:59.170 --> 0:9:59.530  
HCP10  
Yeah.

0:9:59.900 --> 0:10:2.20  
Catherine Beresford  
Of working with such individuals.

0:10:2.310 --> 0:10:11.950  
HCP10  
As as yeah as patients. So if they've got, if they've got chronic autoimmune hepatitis, I've got patients with with that, I've got patients that have got alcoholic liver disease.

0:10:16.740 --> 0:10:17.300  
Catherine Beresford  
Yeah.

0:10:26.300 --> 0:10:26.940  
Catherine Beresford  
Yeah.

0:10:31.670 --> 0:10:32.70  
Catherine Beresford  
Mm hmm mm hmm.

0:10:13.320 --> 0:10:32.200  
HCP10  
So. So with that as well, they would, they would be the commonest things that come to mind. So and some people have, you know long term changes in cirrhosis, some people just have chronic active hepatitis and a couple of people with hepatitis C.

0:10:32.360 --> 0:10:37.80  
HCP10  
They've they've generally got that they've generally come from abroad and brought their hepatitis C with them.

0:10:37.220 --> 0:10:37.780  
Catherine Beresford  
Yeah.

0:10:38.800 --> 0:10:42.560  
HCP10  
But they're often just monitored, monitored at the hospital and monitored by us.

0:10:53.140 --> 0:10:53.340  
HCP10  
Mm hmm.

0:11:2.730 --> 0:11:3.530  
HCP10  
Oh yeah, 'cause.

0:10:43.20 --> 0:11:7.900  
Catherine Beresford  
Yeah. OK. So quite a lot of it's around sort of monitoring and yeah, OK, thank you. And sort of thinking about some of the individuals that you've worked with, have you got any specific examples of when you think the care provided for an individual who had advanced liver disease? And I'm focusing particularly on the individuals who aren't on the transplant list now was particularly positive, you know, is anything kind of that stands out in your mind?

0:11:9.0 --> 0:11:9.760  
HCP10  
So somebody.

0:11:20.50 --> 0:11:20.690  
Catherine Beresford  
Yes.

0:11:29.180 --> 0:11:29.820  
Catherine Beresford  
Yeah.

0:11:33.880 --> 0:11:35.80  
Catherine Beresford  
I see, yeah.

0:11:13.250 --> 0:11:44.210  
HCP10  
No individuals that stand out is having, you know, a fantastic experience. I have to say, but certainly people that have been unwell had had. Usually it's going to be a mechanism that's manageable. So it's going to be an autoimmune type, hepatitis that's made them acutely and well. Then then there's a handle on their illness as in they've they've got a diagnosis and a treatment plan and they're on a, you know, a a treatment therapy, a biological or something to to control their symptom, their symptoms and they remain, they they become well again.

0:11:44.450 --> 0:11:47.810  
HCP10  
And they're having having a happy, normal life. Yes, I certainly see that.

0:11:46.830 --> 0:11:53.710  
Catherine Beresford  
Yeah. Yeah. And what about any situations where you think things were were more negative?

0:11:55.250 --> 0:12:6.330  
HCP10  
I've got a good example for you some years ago now, probably 15 years ago, when I was before I was then I was my first, was GP in [names area], when I so maybe 2003.

0:12:11.110 --> 0:12:11.510  
Catherine Beresford  
Yeah.

0:12:7.850 --> 0:12:25.410  
HCP10  
I had a young girl who was an, you know, 20s who was an alcoholic and she was advised to reduce her alcohol, reduce her alcohol, never really did and she became unwell with a, you know, jaundiced and well and and was admitted to hospital. And they remember her calling me from [name of hospital].

0:12:33.520 --> 0:12:35.240  
Catherine Beresford  
Gosh, yeah.

0:12:36.910 --> 0:12:38.110  
Catherine Beresford  
Gosh, yeah.

0:12:39.900 --> 0:12:41.180  
Catherine Beresford  
Yeah, yeah.

0:12:26.210 --> 0:12:41.730  
HCP10  
and told me that. Oh, nice to speak to you, Doctor. Just want to tell you that I've been told that I'm gonna die and there's no treatment for me. And she died a couple of days later. She just rang me just to say she's been told there's nothing they can do.

0:12:42.560 --> 0:12:42.880  
Catherine Beresford  
Yeah.

0:12:44.760 --> 0:12:48.160  
Catherine Beresford  
No, it's the situation. Yeah. Yeah.

0:12:41.850 --> 0:12:49.370  
HCP10

So. So I'm not saying that's just in that treatment was bad, but it was it. No, it was a very bad experience for her. It was a bad situation for her. So that stuck in my mind.

0:12:49.810 --> 0:13:2.890  
Catherine Beresford  
Yeah. Yeah. I mean, yeah, it's something that's coming out from some individuals that I talk to because I'm hearing, you know, very mixed experiences. But yeah, some some individuals, things have happened quite quickly.

0:13:3.120 --> 0:13:3.560  
HCP10  
Yes.

0:13:4.10 --> 0:13:4.850  
Catherine Beresford  
Quite suddenly.

0:13:6.290 --> 0:13:16.450  
Catherine Beresford  
And then they they, you know, it's then it's sort of thinking about how you know how they are supported after that, what what services they have access to that sort of thing.

0:13:22.600 --> 0:13:22.720  
Catherine Beresford  
Hmm.

0:13:36.820 --> 0:13:37.540  
Catherine Beresford  
Yes.

0:13:44.280 --> 0:13:44.960  
Catherine Beresford  
Yeah.

0:13:50.130 --> 0:13:50.850  
Catherine Beresford  
Yes.

0:13:16.810 --> 0:13:51.210  
HCP10  
Yeah, I suppose for her it was just all too soon and too all-encompassing. And she just had liver failure and was gonna die, wasn't she? So, so unfortunately. And I think there's a number of people that particularly, you know, things like alcohol induced cirrhosis or other types of cirrhosis, but certainly alcohol ones where they've been unwell, they've had they've sort of feel they've messed up their life and they've caused this terrible thing to happen where they've had liver failure and they come out of, they come out of and they can be very well afterwards. And then if they clean themselves up and have a new.

0:13:57.480 --> 0:13:58.600  
Catherine Beresford  
Yeah, yeah.

0:14:1.260 --> 0:14:1.460  
Catherine Beresford  
Mm hmm.

0:13:51.790 --> 0:14:7.830  
HCP10  
They have always got this nagging thing in their mind, but one thing could go wrong and their liver's gonna pack up. So. So I think they're left with a chronic anxiety, sometimes a chronic sort of medical anxiety that they're living and borrowed, living on borrowed time would be the phrase, I think.

0:14:7.220 --> 0:14:13.860  
Catherine Beresford  
Yeah, yeah. And what what sort of services are there locally for individuals in that situation?

0:14:15.120 --> 0:14:21.200  
HCP10  
Not that I'm particularly aware of, have to say me reassuring them usually is. That is the thing because.

0:14:21.240 --> 0:14:25.680  
Catherine Beresford  
What about like, do they have access to like the drug and alcohol services and that kind of thing?

0:14:31.700 --> 0:14:31.820  
Catherine Beresford  
Hmm.

0:14:24.960 --> 0:14:32.80  
HCP10  
Oh, yes. So yes, yes, they. So there would be a local drug and alcohol service in in [name of area].

0:14:32.520 --> 0:14:32.920  
Catherine Beresford  
Yeah.

0:14:36.150 --> 0:14:37.470  
Catherine Beresford  
I see.

0:14:33.240 --> 0:14:42.360  
HCP10  
That they would be signposted to if that was appropriate, or they could. OK they some people take it upon themselves, don't they? So they might go to.

0:14:42.380 --> 0:14:49.700  
HCP10  
AA meetings or or some people choose not to because some people don't. Doesn't suit them. But there are those support mechanis systems.

0:14:51.230 --> 0:15:4.630  
Catherine Beresford  
So, I mean, you've already kind of given me a bit of insight into it, but from your perspective as a GP, what challenges do you think there are in supporting individuals who've got liver disease when it's more advanced like in the decompensated stage?

0:15:8.980 --> 0:15:9.100  
Catherine Beresford  
Hmm.

0:15:12.890 --> 0:15:13.690  
Catherine Beresford  
Yes.

0:15:16.680 --> 0:15:17.320  
Catherine Beresford  
Yeah.

0:15:24.350 --> 0:15:24.990  
Catherine Beresford  
Yeah.

0:15:5.320 --> 0:15:30.520  
HCP10  
All the challenges are cause the prognosis is poor so so bit like having heart, you know, advanced heart failure. The outcomes are generally not going to be very good and I suspect some I suspect the people that have these diseases and these illnesses know that they're not going to be very good. So yeah, there's there's support but it it can be almost like palliative care really, you know.

0:15:29.940 --> 0:15:38.180  
Catherine Beresford  
Do you do you have? Do you? So what kind of you know what sort of palliative care is there for people?

0:15:52.570 --> 0:15:53.130  
Catherine Beresford  
Hmm, OK.

0:15:37.200 --> 0:15:55.560  
HCP10  
Yeah. So yeah, that's a good question. So we do have access to Sue Ryder nurses, so and they don't just see people with cancer. So they could see people with decompensated liver disease. That's what that's that's very true. They could see people with end stage COPD and.

0:15:57.720 --> 0:16:10.640  
HCP10  
What else comes to mind like motor neurone and things like that? So so you know these people are all on a pretty sticky wicket. So those people will get involved with, you know, the other supportive services, the pastoral care type, you know.

0:16:11.400 --> 0:16:11.880  
Catherine Beresford  
Yeah.

0:16:11.640 --> 0:16:17.280  
HCP10  
Things that they need sort of emotional support and sort of life planning and things like that.

0:16:17.780 --> 0:16:30.180  
Catherine Beresford  
Yeah, yeah. And and what about some of the discussions around sort of end-of-life care and those sorts of things? I mean, who who's having those conversations with with those individuals, do you think?

0:16:37.590 --> 0:16:38.150  
Catherine Beresford  
Yeah.

0:16:43.710 --> 0:16:44.230  
Catherine Beresford  
Yeah.

0:16:31.400 --> 0:16:46.160  
HCP10  
GPs to a degree. But honestly that our job is such a sort of firefighting, 10 minutes, 10 minute consultation job these days there there's this seems to be the very limited time. So I would suggest that it probably would be.

0:16:48.120 --> 0:16:54.680  
HCP10  
Sometimes friendly nurses that we have so, so they might have more time for our patients, but probably would be palliative care.

0:16:56.160 --> 0:17:3.560  
HCP10  
Teams like Sue Ryder, who would actually sit down and look at respect forms and end of life care plans and what they would best do.

0:17:4.410 --> 0:17:6.170  
HCP10

Patient wishes things and stuff like that.

0:17:7.680 --> 0:17:25.560  
Catherine Beresford  
I mean something that's come up in some of the previous interviews with the healthcare professionals that I've spoken to are issues around services being under pressure and the impact that can have on staff well-being has emerged and and then possibly on on in you know patients as well. Have you got any thoughts about that?

0:17:27.400 --> 0:17:29.720  
HCP10  
I think everything's under stress and strain so.

0:17:31.600 --> 0:17:38.640  
HCP10  
This people with advanced liver disease just take their take their place in that queue. Don't they really or or take that place in the in what's able to be offered.

0:17:39.60 --> 0:17:39.540  
Catherine Beresford  
Yeah.

0:17:40.440 --> 0:17:44.320  
HCP10  
I don't. It is. Yes, it's a difficult situation I think.

0:17:51.720 --> 0:17:51.840  
Catherine Beresford  
Hmm.

0:17:46.320 --> 0:17:52.640  
HCP10  
Generally, palliative care nurses and district nurses do a do a very good job and management manage quite well.

0:17:53.210 --> 0:17:53.650  
Catherine Beresford  
Yeah.

0:17:53.900 --> 0:17:56.140  
HCP10  
In these circumstances, they're usually very experienced.

0:17:56.530 --> 0:18:4.210  
Catherine Beresford  
Yeah. And in your opinion then, what does good care in advanced liver disease look like?

0:18:12.920 --> 0:18:13.40  
Catherine Beresford  
Hmm.

0:18:16.460 --> 0:18:16.860  
Catherine Beresford  
Yeah.

0:18:22.910 --> 0:18:23.30  
Catherine Beresford  
Hmm.

0:18:5.540 --> 0:18:36.500  
HCP10  
Well, I, from a medical perspective, there is of course people being on the right tablets or it's right medication having having access to their GP to do some the monitoring the the GP or the patient having access to secondary care in case there's a big problem. So you know if if they become suddenly unwell or let's say he's an example, you've got patient with decompensated liver disease that's got that's got large ascites and they and they're going to hospital and they have their ascites drained.

0:18:36.470 --> 0:18:37.70  
Catherine Beresford  
Yes.

0:18:50.590 --> 0:18:51.390  
Catherine Beresford  
Right.

0:18:54.110 --> 0:18:54.830  
Catherine Beresford  
Yeah.

0:18:56.760 --> 0:18:57.480  
Catherine Beresford  
Yeah.

0:18:59.20 --> 0:18:59.180  
Catherine Beresford  
Yeah.

0:19:4.830 --> 0:19:4.870  
Catherine Beresford  
I.

0:18:37.250 --> 0:19:10.450  
HCP10  
And they know that their ascites are going to return, sometimes weeks, no, maybe months, but days, weeks later, they they would be best served by having a pathway back into the ambulatory care ward or the Gastro ward. That's not try and get a point with your GP. Get your GP in. Oh, yes, you've got massive ascites. How are we going to? You knew that already. You know, they needed that. It would be useful. And I think they do sometimes have an access route back into the hospital where they can have their ascites drained because they can contact the ward, so to speak, or contact the ambulatory day unit.

0:19:11.410 --> 0:19:12.530  
HCP10  
That that does happen.

0:19:17.240 --> 0:19:17.680  
HCP10  
Yeah.

0:19:11.40 --> 0:19:19.520  
Catherine Beresford  
Is that in your? Yeah. So where you're working now is that do you find that they do have that that they can, they can access it?

0:19:24.90 --> 0:19:25.10  
Catherine Beresford  
Fair enough. Yeah.

0:19:28.300 --> 0:19:29.620  
Catherine Beresford  
Yeah, yeah, yeah.

0:19:35.250 --> 0:19:35.970  
Catherine Beresford  
Yes.

0:19:19.600 --> 0:19:37.200  
HCP10  
Yes, I mean we I don't have any patients in that situation at the moment. I have to say and and and I'd probably go months or sometimes years without without having those those acute patients, but I certainly recall patients getting sorted out that didn't require me to make the phone call every time.

0:19:39.620 --> 0:19:40.740  
HCP10  
Which is good, which is good.

0:19:37.290 --> 0:19:44.530  
Catherine Beresford  
I'm with you. Yeah. OK. That's helpful to know. Yeah. Anything else that you want to say about that?

HCP10

I suppose if these patients become more and more unwell, they need district nurse referrals to look after their care needs at home, which generally happens quite well. And, then of course palliative care services if -

0:19:53.710 --> 0:19:53.910  
Catherine Beresford  
Mm hmm.

0:19:55.350 --> 0:19:55.710  
Catherine Beresford  
Yeah.

0:20:1.990 --> 0:20:2.190  
Catherine Beresford  
Mm hmm.

0:20:10.770 --> 0:20:11.290  
Catherine Beresford  
Yeah.

0:20:13.300 --> 0:20:13.660  
Catherine Beresford  
Yeah.

0:20:2.280 --> 0:20:16.720  
HCP10  
- Support If they people are recognised to come to the end of life and also to recognise that sometimes it's not time to go into hospital anymore, so people need to come to, certainly people eventually come to the conclusion that they've had enough of going into hospital.

0:20:16.500 --> 0:20:17.780  
Catherine Beresford  
Hmm yeah.

0:20:20.420 --> 0:20:37.500  
Catherine Beresford  
Yeah, some. So when I'm asking all these questions and you're sort of talking through it or something, sometimes something can kind of occur to you that you hadn't thought about before. So while we've been talking, is there anything that sort of come to your mind that hadn't really occurred to you before we'd started talking?

0:20:46.920 --> 0:20:47.760  
Catherine Beresford  
Yes.

0:20:50.140 --> 0:20:50.860  
Catherine Beresford  
I see.

0:20:55.290 --> 0:20:56.490  
Catherine Beresford  
Right, yes.

0:20:58.490 --> 0:20:59.170  
Catherine Beresford  
No, no.

0:21:0.740 --> 0:21:2.300  
Catherine Beresford  
Yes, yes.

0:20:39.60 --> 0:21:14.940  
HCP10  
The only thing that comes to mind is actually that people that seeing decompensated liver disease is not that common in general practice, but they actually. But they're actually quite interesting patients in this in the sense that they've got loads of nice signs and symptoms to see. Do you know what I mean? So we, we, my son's about a bit maudlin but you know you do go to medical school to learn about medicine and see people with diseases and when they come in you know, nice and yellow and and and and swollen up and they've got all the kind of abnormalities that you'd expect them to have and you treat them appropriately and they get better a bit.

0:21:15.290 --> 0:21:15.890  
Catherine Beresford  
Yes.

0:21:15.650 --> 0:21:19.290  
HCP10  
That that kind of works for me I.

0:21:19.330 --> 0:21:20.930  
HCP10  
There can be quite satisfying patients to treat.

0:21:17.530 --> 0:21:32.490  
Catherine Beresford  
Yeah, I understand. Yeah, yeah. Yeah, that's interesting. Yeah, that makes sense. What you've said. And is there anything else that you think I should know to better understand care experiences for people who've got advanced liver disease better?

0:21:44.780 --> 0:21:45.380  
Catherine Beresford  
Yes.

0:21:47.300 --> 0:21:47.500  
Catherine Beresford  
Mm hmm.

0:21:52.600 --> 0:21:53.40  
Catherine Beresford  
Yeah.

0:21:33.630 --> 0:22:4.310  
HCP10  
I just, well, they're a broad church, aren't they? So. So you've got somebody who might be extremely fit and well and healthy that through no fault of their own developed an autoimmune condition that might be mild. So they that they, they they might do very well all the way to my patient who needed a liver transplant. So you got those, you got those people then you've got the alcoholic liver disease group and it's and it's not it's not that it's the liver disease that's

0:22:5.230 --> 0:22:5.750  
HCP10

The common denominator.

0:22:6.520 --> 0:22:6.960  
Catherine Beresford  
Yeah.

0:22:9.730 --> 0:22:10.10  
Catherine Beresford  
Mm hmm mm.

0:22:12.980 --> 0:22:13.20  
Catherine Beresford  
I.

0:22:16.760 --> 0:22:17.200  
Catherine Beresford  
Yeah.

0:22:19.860 --> 0:22:20.500  
Catherine Beresford  
Right.

0:22:6.310 --> 0:22:34.790  
HCP10  
But people with chronic alcohol problems tend to be really, really hard work as patients. And I think if you ask well, you probably ask other GPs who are your nightmarish patients to deal with. And Alcoholics tend to be quite hard work not to label them all in the same group, but they can to be quite, you know, they're obviously they're self-harming in a way. They're obviously they're often.

0:22:34.830 --> 0:22:36.670  
HCP10  
Mentally, in a bad place.

0:22:41.910 --> 0:22:42.590  
Catherine Beresford  
OK.

0:22:45.520 --> 0:22:45.560  
Catherine Beresford  
I.

0:22:58.400 --> 0:22:58.960  
Catherine Beresford  
Yeah.

0:22:37.110 --> 0:23:1.510  
HCP10  
They tend to be very, very self-pitying and you know, hard work and they often struggle to give up alcohol at all sometimes and and they can cause they they know they're causing themselves massive harm and they do. They can be quite a challenging group because you got one person who want who was fit and well and wants to get well. And one person who's just watching themselves slowly commit suicide, basically. And I've seen that a few times.

0:22:59.940 --> 0:23:2.380  
Catherine Beresford  
Yeah. So it's quite different, yeah.

0:23:3.70 --> 0:23:13.870  
HCP10  
And then you've got the, you know, older person who might be presenting with, you know, hepatacellia carcinoma or pancreas with the head and cancer name of the head of pancreas or other.

0:23:15.850 --> 0:23:16.650  
Catherine Beresford  
Yes.

0:23:14.810 --> 0:23:26.650  
HCP10  
Cancers in that area and the prognosis are always poor, aren't they? The prognosis are really generally bad, and if they don't know they're bad, then they soon find out. You know, often people have an inkling, but yeah.

0:23:23.960 --> 0:23:27.880  
Catherine Beresford  
Yeah. So it's quite a range. Yeah, yeah.

0:23:29.600 --> 0:23:30.40  
Catherine Beresford  
Yeah, that.

0:23:28.70 --> 0:23:30.710  
HCP10  
Those would be the three groups that I'd I would consider most.

0:23:31.810 --> 0:23:34.850  
Catherine Beresford  
Yeah, that makes sense.

0:23:34.890 --> 0:23:40.930  
Catherine Beresford  
OK, let me see. I think I've actually asked you everything I need to let me just double-check if there's anything else.

0:23:42.900 --> 0:23:45.140  
Catherine Beresford  
Yeah, you've, you've answered all of that really.

0:23:48.750 --> 0:23:51.550  
Catherine Beresford  
Yeah, I mean, is there anything you'd like to ask me?

0:23:58.840 --> 0:23:59.520  
Catherine Beresford  
Yeah.

0:23:52.480 --> 0:24:3.40  
HCP10  
So what I know you're obviously doing this part of your PhD. What are you? What are you hoping to sort of achieve by my answers? What are what are you are you getting the information that you want or you?

0:24:2.720 --> 0:24:12.960  
Catherine Beresford  
Yes, I am. Yes. Yeah. Yeah. Because it's all about, really. I'm trying to understand the care experiences through the perspectives of, you know, the most important is obviously the people who've got liver disease themselves.

0:24:13.90 --> 0:24:13.450  
HCP10  
Yeah.

0:24:27.510 --> 0:24:27.710  
HCP10  
Mm hmm.

0:24:29.480 --> 0:24:29.560  
HCP10  
Mm.

0:24:14.320 --> 0:24:37.560  
Catherine Beresford  
But you know, it is about trying to get a real kind of holistic view of of the reality of care for those individuals. And so you know, it's been important to speak with carers as well because obviously they have unique insights and they often see things from a different perspective and their understanding, things that perhaps the person themselves doesn't see or isn't having to experience, you know, especially, especially if they're very, very ill.

0:24:38.190 --> 0:24:38.390  
HCP10  
Mm hmm.

0:24:38.540 --> 0:24:48.580  
Catherine Beresford  
But also to you know, especially I think as a healthcare professional myself, having worked with people who've got diabetes, I I I also think it's really important to understand.

0:24:50.60 --> 0:25:7.220  
Catherine Beresford  
Care from the perspective of people providing it so that we can sort of understand what are the things that are working well, what are the barriers and then bringing that all together to create a theory of care experiences because that's the type of research that I'm doing.

0:25:26.430 --> 0:25:26.710  
HCP10  
Mm hmm mm.

0:25:8.350 --> 0:25:28.670  
Catherine Beresford  
What I'm doing is sharing what I'm you know I analyse as I go along, so sort of sharing what I'm finding with different groups include, you know, patient groups, but also with healthcare professionals. So for example, talking at conference and writing, you know, writing papers and stuff I've written, I've written a paper about it already.

0:25:39.820 --> 0:25:40.100  
HCP10  
Mm hmm mm.

0:25:29.990 --> 0:25:41.590  
Catherine Beresford  
So that you know to sort of see what is happening, well, where could there be improvements and also for services to learn from each other because there seems to be quite a lot of variation in the country. So there's some.

0:25:42.470 --> 0:25:52.790  
Catherine Beresford  
That have got, you know, really quite interesting and unique ways and pathways, you know, really close links with Hospice, for example.

0:25:52.830 --> 0:26:11.230  
Catherine Beresford  
Where people are actually getting quite a lot of their care actually at the Hospice, even if they're not necessarily end of life. So you know, they're getting supportive care palliative care, but also because it's so you know it can be quite ambiguous and the disease trajectory seems to be a bit unpredictable sometimes.

0:26:15.490 --> 0:26:16.250  
Catherine Beresford  
Yes.

0:26:20.0 --> 0:26:20.600  
Catherine Beresford  
Yes.

0:26:22.880 --> 0:26:24.440  
Catherine Beresford  
Yes, yes.

0:26:26.470 --> 0:26:26.950  
Catherine Beresford  
Yeah.

0:26:11.540 --> 0:26:28.980  
HCP10  
I think that's certainly true. Yeah. So you can get people that are really unwell and then actually they're they're going to, they're often going to hospital and then they can come out actually quite well for a bit. So those people with the larger ascites or the, the other thing that the other thing that people get is.

0:26:34.580 --> 0:26:37.660  
Catherine Beresford  
Oh yeah, like encephalopathy and yeah, yeah.

0:26:39.300 --> 0:26:40.140  
Catherine Beresford  
Yes.

0:26:45.230 --> 0:26:45.950  
Catherine Beresford  
Yes.

0:26:47.480 --> 0:26:49.120  
Catherine Beresford  
That's right, yeah.

0:26:30.230 --> 0:26:52.350  
HCP10  
What's the description? It's a sort of, you know, it's this. It's the neuropsychiatric problems caused by. Yeah, that's what encephalopathy. So you get people really knocked off there and they can go into hospital. And and I think they focus a lot on clearing out their GI tract, don't they? And and and doing that kind of whatever detoxifying them somehow. And these people can actually come out and well again so.

0:26:51.440 --> 0:26:56.400  
Catherine Beresford  
Yeah, exactly. I mean, 'cause actually one. So when I started the project.

0:26:57.640 --> 0:27:25.720  
Catherine Beresford  
The because it's being funded by hospice, they the focus at the beginning was palliative and end of life care experiences, but we changed it because when I started speaking to people with liver disease and healthcare professionals and when I did the literature review, it became really clear that it was too, it's too ambiguous. It's too unclear when you know, people don't know if their end of life necessarily or that the care that they're having is palliative. It's not, it's not always clear and it's not always clear to healthcare professionals.

0:27:36.270 --> 0:27:36.430  
HCP10  
Yeah.

0:27:26.270 --> 0:27:47.950  
Catherine Beresford  
Either for exactly the reason you said, I mean one of the gentlemen that I've interviewed, he got told. I think he got told four years ago that he had six months to live, you know? But then you'll have somebody you know. And then I've had another lady who has managed to stop drinking. But then if she starts drinking again, it could change, you know? So it's not always obvious.

0:27:48.400 --> 0:27:48.720  
HCP10  
Yeah.

0:27:49.150 --> 0:27:56.910  
Catherine Beresford  
And and then also you know say for example that gentleman I just mentioned to you, he did have access to palliative care and Hospice.

0:28:2.120 --> 0:28:2.960  
HCP10  
Absolutely.

0:28:14.640 --> 0:28:14.800  
HCP10  
Yeah.

0:27:57.460 --> 0:28:20.140  
Catherine Beresford  
And actually that intervention has contributed to extending his life, you know? So that's why I'm not just focusing on those that specifically, I'm looking at it more, as you know, people who've experienced decompensation but not on the transplant list. So it, you know, it potentially could be end of life, but it's not definite.

0:28:32.390 --> 0:28:32.830  
Catherine Beresford  
Yeah, yeah.

0:28:33.620 --> 0:28:34.100  
Catherine Beresford  
Sure.

0:28:35.90 --> 0:28:37.290  
Catherine Beresford  
Yes, yes.

0:28:39.480 --> 0:28:40.480  
Catherine Beresford  
Yes.

0:28:41.760 --> 0:28:42.280  
Catherine Beresford  
Yeah.

0:28:44.670 --> 0:28:45.630  
Catherine Beresford  
Right.

0:28:50.100 --> 0:28:51.620  
Catherine Beresford  
Yeah, yeah.

0:28:20.980 --> 0:28:53.860  
HCP10  
Yes, and I suppose I don't. I don't know whether it's relevant, but as time goes by, people like me or not, me personally, but people in my shoes just don't see as much of this stuff anymore. Do you know what I mean? They lose so many more people just go straight to hospital. So, you know, lots of GPS would know wouldn't wouldn't know the first thing to do if they saw an acutely jaundiced patient walk in the door. I think they might might struggle a little bit. So yeah. And so seeing lots of unwell people is a good thing in a in a in the in the experience setting. Put it that way.

0:28:54.100 --> 0:28:59.260  
Catherine Beresford  
Yeah, I know that makes sense because some of the individuals I've spoken to had gone via A&E.

0:28:59.700 --> 0:29:2.20  
HCP10  
Yeah, yeah, that's quite common these days.

0:29:0.700 --> 0:29:4.500  
Catherine Beresford  
Yeah, OK. Yeah. Why do you think that is then?

0:29:8.680 --> 0:29:9.440  
Catherine Beresford  
Right.

0:29:6.160 --> 0:29:29.880  
HCP10  
I think it's. I think it's largely access. I mean my practise is you know quite, very good for access. So we we don't know, that's just we're fortunate. But if you do all your consults via some kind of advice and guidance sort of E-consult thing your whoever's triaging those is just going to go oh, you've turned yellow. Oh, and you've got you know, you're feeling unwell, go to hospital.

0:29:32.760 --> 0:29:33.200  
HCP10  
So.

0:29:28.440 --> 0:29:36.200  
Catherine Beresford  
Yeah, sure. Yeah. Yeah, I'm with you. Yeah. Yeah. So the way that we consult with people has changed.

0:29:36.290 --> 0:29:36.970  
HCP10  
I think so.

0:29:37.410 --> 0:29:41.690  
Catherine Beresford  
Yeah. Is there anything else that you'd like to say before we wrap up?

0:29:43.380 --> 0:29:45.20  
Catherine Beresford  
No. OK, that's great.

0:29:42.230 --> 0:29:46.190  
HCP10  
Don't know. That's fine. I'm I've I've. I've talked more than I normally do.

0:29:48.660 --> 0:29:49.180  
Catherine Beresford  
Thank you.

0:29:49.220 --> 0:29:51.620  
Catherine Beresford  
Thank you. Thank you. All right.

0:29:47.790 --> 0:29:51.950  
HCP10  
That's it. I've I've doubled my word count for the for the whole morning.

0:29:56.890 --> 0:29:57.410  
HCP10  
No problem.

0:30:5.840 --> 0:30:7.400  
HCP10  
Well, good luck with that. Excellent.

0:30:7.960 --> 0:30:16.600  
Catherine Beresford  
So it'll be a little while before I can give you feedback, but I will send you update about what's happened. You know what I find in the research?

0:30:20.850 --> 0:30:22.370  
HCP10  
Yeah, and and when?

0:30:17.940 --> 0:30:24.60  
Catherine Beresford  
And so, you know, you can sort of, you know, hear where I'm at, basically. And if you think of anything else, feel free to e-mail me as well.

0:30:24.690 --> 0:30:29.170  
HCP10  
OK. That's no that's no problem. And when you all PhD department, what are you going to do after that? Then what are your plans?

0:30:35.290 --> 0:30:35.370  
HCP10  
Mm.

0:30:28.750 --> 0:30:39.550  
Catherine Beresford  
Well, while I've been doing my PhD, it's at Bournemouth University and then they do let you teach if you want to. So I have been teaching undergraduate student nurses.

0:30:40.830 --> 0:30:44.230  
Catherine Beresford  
So I'm wondering whether I might. I'm thinking I definitely like.

0:30:54.610 --> 0:30:54.930  
HCP10  
No.

0:31:3.750 --> 0:31:3.950  
HCP10  
There.

0:30:44.550 --> 0:31:7.70  
Catherine Beresford  
Doing that so I might continue doing that, I think the question is do I and and I like research, but then I'm thinking do I still want to do some clinical as well? So that's a bit you know if you can't do everything, but I've got to try and I am missing diabetes a bit as well. But you can't do everything. So it's trying to narrow it down and decide. But I'm definitely enjoying the teaching that's really rewarding.

0:31:7.230 --> 0:31:7.950  
HCP10  
OK, it's cool.

0:31:9.790 --> 0:31:11.190  
Catherine Beresford  
Yeah. OK.

0:31:12.250 --> 0:31:14.370  
HCP10  
Yes, my pleasure.

0:31:11.270 --> 0:31:17.270  
Catherine Beresford  
All right then. Well, thanks ever so much for your time. Let me just just put my camera back on. Right. I'm going to stop recording.