# HCP05 ‘Tina’ Interview Transcript by Teams 17/04/2024 09:00am.

 **Catherine Beresford** 0:08  
Right. Hide transcript so it it's recording and it is transcribing as we go along, but I'm just hiding the transcript so that we don't have to see it as we're talking 'cause that can be a bit off putting.  
OK. So anything else you want to ask me before we start?

 **HCP05** 0:24  
No, that's fine.

 **Catherine Beresford** 0:26  
So for the purpose of understanding exactly who's been recruited for interview, who's taking part in the study, just ask you some questions about yourself. Now, would you mind just confirming your age?

 **HCP05** 0:39  
My age, I've I've just turned [states age].

 **Catherine Beresford** 0:42  
Thank you.

 **HCP05** 0:43  
Last week.

 **Catherine Beresford** 0:45  
Oh, happy birthday. And what ethnicity do you consider yourself to be? OK. Thank you. And how long have you been in your role that just give me an idea for?

 **HCP05** 0:46  
Thank you.  
[states ethnicity].  
Well, I was at the Hospice.  
About 16 years and I started the liver work.  
I first started in 2016.

 **Catherine Beresford** 1:14  
Yeah. OK. That's great. Thank you. Right. So, the first question really is just if you could tell me about your role in working with individuals who've got advanced liver disease and I'm specifically talking about those individuals who've got decompensated disease or or have been decompensated and the individuals that are not on the liver transplant list.

 **HCP05** 1:38  
OK, so I first started the work when I was a nurse practitioner, and I was based in what was then called day Hospice.

 **Catherine Beresford** 1:50  
Yeah.

 **HCP05** 1:51  
And my role at that time as a nurse practitioner was to kind of transition the old model of day Hospice into a new, more kind of dynamic.

 **Catherine Beresford** 2:05  
Right.

 **HCP05** 2:06  
Outpatient setting.

 **Catherine Beresford** 2:08  
Yeah.

 **HCP05** 2:09  
And the first thing after after I evaluated the service was that.  
The service was really only offered at that point.  
To mainly older White people with cancer.

 **Catherine Beresford** 2:25  
Yeah, yeah.  
Right.

 **HCP05** 2:30  
And it really it really looked more like a day centre than it did a day Hospice at that point.

 **Catherine Beresford** 2:37  
Yeah.

 **HCP05** 2:38  
So as part of the transformation I guess. I started to think about why we only offering services to cancer patients and who else should we reach out to?

 **Catherine Beresford** 2:51  
Yes.

 **HCP05** 2:56  
And back in 2016, that was a very novel idea. In the Hospice world.

 **Catherine Beresford** 3:00  
Hmm.

 **HCP05** 3:02  
Very few people other than that with non-malignant disease came to our Hospice or to any other Hospice so.  
I had had previously worked in [name of] Hospital so I had lots of connections, and I had a good connection with the liver, CNS and.

 **Catherine Beresford** 3:23  
Yes.

 **HCP05** 3:26  
I kind of picked liver disease as my first non-malignant disease because I had that good working relationship but but also because it felt like that's where the biggest need was.

 **Catherine Beresford** 3:33  
I see, yeah.  
Yeah.

 **HCP05** 3:41  
As a Hospice, the then director of nursing just said, oh, I'm not sure how we're gonna pay for it or or what we can provide. But should we dip our toe in the water? So that's what I did. So I did a small pilot. I connected in with the liver team with the hepatologist and the liver CNS started to go to their MDT, and it became apparent that there was a

 **Catherine Beresford** 3:50  
Yeah.  
Yeah, yeah.

 **HCP05** 4:10  
Absolutely massive issue.

 **Catherine Beresford** 4:12  
Really.

 **HCP05** 4:14  
Oh it it was. It was huge and

 **Catherine Beresford** 4:17  
Yeah.

 **HCP05** 4:19  
I kind of, so, back in the early 90s, I'd worked in London around the time of the HIV and AIDS epidemic and and that it kind of felt similar to that, this huge cohort of people with massive unmet need and massive stigma around

 **Catherine Beresford** 4:33  
Yeah.  
Yeah.  
Yeah.

 **HCP05** 4:46  
Disease.

 **Catherine Beresford** 4:47  
Yeah.

 **HCP05** 4:50  
And they met they met stigma, they met, you know, they weren't warmly received into the Hospice. So I was, I was kind of doing work at all different levels, changing culture in the Hospice transforming services, in the Hospice so that we could meet their needs. So then

 **Catherine Beresford** 5:01  
Yeah.  
I see.  
Yeah.

 **HCP05** 5:14  
That pilot basically showed massive unmet need. And then the work very quickly picked up interest kind of nationally, and people were asking me about it, and then I approached the Health Foundation and

 **Catherine Beresford** 5:31  
Yeah.

 **HCP05** 5:38  
They were. I applied to get some funding and I was successful that with that funding and that's where really, we'd then devised the shared care liver project.

 **Catherine Beresford** 5:49  
Yes.

 **HCP05** 5:51  
And that's the pathway that still exists. It's it's almost in the same format. It hasn't really changed because it doesn't really need to change.  
So yeah, we make we basically.  
Well, not me anymore, but the team at [name of hospice] basically sit on the MDT. They have really, really good

 **Catherine Beresford** 6:11  
Hmm.

 **HCP05** 6:18  
Communication networks and they will assess do a holistic needs assessment on people with advanced liver disease.

 **Catherine Beresford** 6:26  
Yeah.

 **HCP05** 6:28  
And then they will share the care of those people with the acute team.

 **Catherine Beresford** 6:34  
I see, yeah.

 **HCP05** 6:35  
So that's really, that's really where we came from.

 **Catherine Beresford** 6:39  
Yeah, yeah, yeah. No, thank you. You've explained that really well. Thanks. So, in view of that then

 **HCP05** 6:43  
Hmm.

 **Catherine Beresford** 6:47  
What services with advanced people with advanced liver disease you know who have got decompensation or, you know, a really quite unwell in in that respect, what services are they currently accessing then in your area?

 **HCP05** 7:02  
So.

 **Catherine Beresford** 7:02  
Tell me a bit more about how it works.

 **HCP05** 7:04  
Yeah. And I mean [Hospice nurse] might be able to tell you more up to date, but from what I understand, so they are all offered a holistic needs assessment with

 **Catherine Beresford** 7:08  
Sure. Yeah.  
Hmm.

 **HCP05** 7:18  
A senior nurse and at that assessment, they need to identify so they could be very medically driven interventions that they need, so they might need an ultrasound and ascites management for example.  
That kind of thing. But they can now get all of that in the outpatient setting in the Hospice.

 **Catherine Beresford** 7:45  
Right.

 **HCP05** 7:46  
They may need psychological support so they could access counselling services. They can act access spiritual services. They can access things like counsel - sorry, massage, Reiki, all those things to try and improve the general well-being and then

 **Catherine Beresford** 7:58  
Yeah.  
Hmm hmm.

 **HCP05** 8:14  
Can also and probably the most unique thing is that they can access advanced care planning, so we actually have those very difficult conversations with them about you know.

 **Catherine Beresford** 8:24  
Yeah.

 **HCP05** 8:28  
You're on this trajectory. We hope to keep you as well as possible, but in the event that that didn't happen, what are your wishes and and how can we support you and your loved ones doing that journey?

 **Catherine Beresford** 8:32  
Yes.  
Yeah.  
Yeah.

 **HCP05** 8:44  
I guess the other thing that is very unique is that we don't just support them, we support their carers.  
And their loved ones so their carers can tap into all of the

 **Catherine Beresford** 8:52  
Yeah.

 **HCP05** 8:58  
Carers support within the Hospice.  
And the beauty of it is that if they then get an acute episode, so say if they get acutely confused or

 **Catherine Beresford** 9:10  
Yes.

 **HCP05** 9:13  
They get an acute accumulation of their ascites, we then have got very quick access into the acute services and we literally just ring them, talk about what the presentation is, get them into hospital for the intervention and get them back out. And they also can access our inpatient unit beds.

 **Catherine Beresford** 9:20  
Right.  
Hmm.

 **HCP05** 9:35  
So rather than take up a hospital bed, say if they have to go and because, oh, I'm just giving an example. If, for example, they had to have their ascites drained for some reason in, in a hospital, they could do their recovery in an inpatient bed. If if we have availability.

 **Catherine Beresford** 9:43  
Yeah.  
Yeah, I see.  
Yeah, yeah.

 **HCP05** 9:57  
So they also have access to a palliative care consultant who works alongside the hepatologist so yeah, it's a very nicely rounded service.

 **Catherine Beresford** 10:11  
Yeah.  
Yeah, and. And so you've given me a really good sort of overview and I can see what's working well. Is there anything that you think doesn't work so well at the moment?

 **HCP05** 10:25  
I actually think it works really well at the moment because I think we've had a lot of time and a lot of experience to really fine tune the pathway.

 **Catherine Beresford** 10:33  
Yeah.  
Yeah.

 **HCP05** 10:36  
I wouldn't say - and obviously [name of palliative care nurse] may know differently, but I haven't heard of any negative feedback and in fact, we've never had negative feedback because I think the general consensus well all the

 **Catherine Beresford** 10:45  
Yeah, yeah.  
Hmm hmm.

 **HCP05** 10:54  
Research I did and all the qualitative was yet overwhelmingly, they suddenly felt supported.

 **Catherine Beresford** 11:02  
Yeah, yeah. Yeah. Thank you. So, I mean, you've given me some of them, but could you just give me a bit of an overview of all the professionals that are involved in care in the area then for those individuals because it sounds quite collaborative.

 **HCP05** 11:20  
OK, so all the all from both sides.

 **Catherine Beresford** 11:22  
Yeah. So, so yeah. So, give me a sort of idea because it sounds like they're all working well together the way you're describing it.

 **HCP05** 11:25  
Yeah.  
Yeah.  
So let let me try and think it through. So, it would be.  
Palliative care consultant hepatology hepatologist.

 **Catherine Beresford** 11:39  
Yeah.

 **HCP05** 11:41  
Liver, CNS and then outpatient lead nurse and then all the nurses within the outpatient department are all now very experienced so that staff nurses, HCAs they're all working together.

 **Catherine Beresford** 11:57  
Right.  
Yeah.

 **HCP05** 12:02  
From a carer's perspective we've got a carer's coordinator.

 **Catherine Beresford** 12:07  
Yeah.

 **HCP05** 12:09  
They have access to integrated therapies, so that is physiotherapy, occupational therapy, they get access to supportive therapies. So that is counselling.

 **Catherine Beresford** 12:28  
Mm hmm.

 **HCP05** 12:29  
Spiritual support.  
And then.  
How to think how we had to easy easily name them, but it's basically the things like Reiki, counselling.

 **Catherine Beresford** 12:45  
Yeah, yeah, yeah.

 **HCP05** 12:49  
They then get very specialist support if they want it around advanced care planning and that can be with any of the. It's usually the more senior nurses.

 **Catherine Beresford** 12:56  
Yeah.  
Hmm.

 **HCP05** 13:03  
They get phlebotomy services.

 **Catherine Beresford** 13:07  
Hmm. Yeah, yeah.

 **HCP05** 13:08  
And and then they get procedural services all at the Hospice. So that is a collaboration of Hospice staff that do those procedures, can't think of anyone else.

 **Catherine Beresford** 13:22  
Well, one of the things that has come up in some of the previous interviews is around dietitian support.  
Do you know if the individuals? Yeah.

 **HCP05** 13:31  
So they get dietetics, dietetics is accessed by the hospital 'cause we don't have a dietitian.

 **Catherine Beresford** 13:38  
Yes.

 **HCP05** 13:43  
And it it probably was a little bit of a sticking point at times, and I think we overcame it because we we we got a good connection with the Dietetic Department, but.  
Yeah, it that probably was a little sticking point in the early times. The other, the other collaboration we did was obviously with Alcohol and

 **Catherine Beresford** 14:13  
Oh yeah.

 **HCP05** 14:14  
Addiction services.

 **Catherine Beresford** 14:15  
Yeah, yeah.

 **HCP05** 14:17  
And again, that was a difficult collaboration because we were two polar ends of the health spectrum. But we definitely talk to them. We we definitely work in collaboration with those kinds of services.

 **Catherine Beresford** 14:36  
Yeah.

 **HCP05** 14:39  
Sorry.  
But yeah, dietetics would come from the hospital.

 **Catherine Beresford** 14:44  
Yeah, I see. Thank you. So.

 **HCP05** 14:47  
You might want to check that with [name of palliative care nurse] 'cause. She might have more up to date.

 **Catherine Beresford** 14:49  
OK, fine. Yeah. Yeah. No, that's OK. It was just because I had before I started this study, I hadn’t really appreciated the importance of nutrition. I mean, I know it sounds so obvious now, especially because I'm a diabetes specialist nurse, as you know, but, you know, and some individuals had mentioned issues around access to dieticians and nutritional support seemed to have sort of emerged as something that's quite important. So that's why that's why I mentioned it.

 **HCP05** 15:16  
Definitely.  
I'm kind of wracking my brains, Catherine, because I think we had some information that we used to give people, but again, check that with [name of palliative care nurse] because that my information is probably not in date.

 **Catherine Beresford** 15:29  
Yeah, sure. Yeah. Yeah.  
No, that's fine. Thank you. So, you've given me some idea of this, but maybe you could just give me your sort of summary of where you think people are going, you know the individuals themselves or their carers if they require support, advice or information, how are they getting that, who are they going to?

 **HCP05** 15:50  
I think they're doing a couple of things. I think they tend to go directly to the Hospice to the outpatient department and I think they do that because the phone gets answered quicker that the response time is much quicker and that's because

 **Catherine Beresford** 16:00  
Right.

 **HCP05** 16:11  
We have a little bit more time than perhaps the hospital.

 **Catherine Beresford** 16:13  
Yeah.

 **HCP05** 16:16  
They also know that we talked to the hospital. Everybody understands that everyone consents to that in their first assessment, and I think.

 **Catherine Beresford** 16:22  
Yeah.

 **HCP05** 16:29  
Most are quite savvy to that, and we'll talk to us even if it's something that is of a more acute nature they will, they do have good access to the liver CNS. Again, she's responsive, but she's one person.

 **Catherine Beresford** 16:47  
Right, yeah.

 **HCP05** 16:50  
So she's running a massive service.  
So I think they go to both ends of the pathway or both sides of it. But I think perhaps they come to the Hospice a bit probably first because

 **Catherine Beresford** 17:00  
Hmm yeah.  
Hmm.

 **HCP05** 17:10  
We're a bit more responsive because we can be.

 **Catherine Beresford** 17:12  
Yes. Is it like a helpline or something?

 **HCP05** 17:15  
No. Well, so there's a they have got access to it. Sorry, that's the other thing they have access to, which I've missed. They have access to our service which is called One Response which is a 24 hour, seven day a week helpline and if necessary, a nurse visiting

 **Catherine Beresford** 17:26  
Oh yeah.

 **HCP05** 17:35  
At home. So, they that that was massive, actually, you just jogged my memory. You know, they had nothing before that other than to contact

 **Catherine Beresford** 17:36  
Hmm.  
Yeah.

 **HCP05** 17:45  
111. With the best will in the world, those services don't understand the ins and outs of liver disease.

 **Catherine Beresford** 17:56  
Yeah.

 **HCP05** 17:57  
So they have access to that. So, they do have 24-hour access to the Hospice, but in working hours they can just call the outpatients.  
Department and one of the nurses will talk to them, but actually we also had or still have we have a she's admin, but she got to really know these these group of patients because she worked with me

 **Catherine Beresford** 18:25  
Yeah.

 **HCP05** 18:28  
On the project phase. So, she's very, very good at, you know, making them feel comfortable picking up all this is important, or this isn't so important. So, she was a very, very important part to the triage of these people.

 **Catherine Beresford** 18:37  
Yeah.  
Thank you. So, based on your experience then in relation to the, the, the changes that you made to your service and how you've developed it, what advice would you give to other professionals who might be sort of considering these sorts of changes to services like other hospices, for example or other specialist units?

 **HCP05** 19:11  
Yeah, I think you need to first of all find who you're going to collaborate with.  
And you need to find a way of how you're going to work because

 **Catherine Beresford** 19:22  
Yeah.

 **HCP05** 19:24  
that was so important because liver patients can deteriorate so rapidly and you need rapid access and you need rapid advice because many hospices aren't set up.

 **Catherine Beresford** 19:32  
Yeah.  
Right.

 **HCP05** 19:40  
To do that, you know with the best will in the world, that's not what a Hospices traditionally set up today.

 **Catherine Beresford** 19:49  
Yeah.

 **HCP05** 19:51  
I guess the locality of where your services are is also important. We were right next to a hospital, so I think that gives us a level of comfort around what we're doing.

 **Catherine Beresford** 20:03  
Yeah, yeah.

 **HCP05** 20:06  
I then think it's about, you have to be really, really change breakdown barriers. You have to be you have to want to support. The kind you know. I don't know if this is the right word, but they're almost the underdog. And you have to have a passion to make it work. And there were many, and you have to almost be brave because.  
This is why this kind of work is way outside those traditional remits.  
And I think there has to be flex on. So, for us there was definitely a level of flex a from us that there was definitely that but also from

 **Catherine Beresford** 20:54  
Yeah.

 **HCP05** 20:58  
The haematology point of view the the liver, CNS definitely, definitely had that degree of flex. Medical staff. Maybe not so much, but we worked at that, and I think the other thing is you have to go in it knowing that there is going to be quite healthy, quite challenging debate because you're working at two different spec ends of a spectrum. So, I would frequently challenge about proposed treatments, proposed proposed interventions because I could see that in front of me, was a person that was dying fairly imminently

 **Catherine Beresford** 21:41  
Yeah, yeah.

 **HCP05** 21:43  
And those were not comfortable conversations at times.  
And I had to also very quickly get a very in-depth knowledge of liver disease.

 **Catherine Beresford** 21:57  
Yeah, OK. Yeah.

 **HCP05** 21:59  
And.  
So yeah, that there definitely needs to be collaboration and flex between the two teams, and you have to have the ability to just have these very open and  
quite difficult conversations because that's where all the learning happens from everybody's side.

 **Catherine Beresford** 22:19  
Yeah, yeah. And was it challenging? Like, what sorts of challenges did you have in terms of, you know, you mentioned that the Hospice was previously more traditional in terms of the people that you were working with? Tell me a bit about how that transition to being more open and inclusive, how, how did that go down?

 **HCP05** 22:46  
Oh.  
I think for people that had worked in the Hospice for many years and at that point it was a very, very stable workforce. You know, people tended to come and work in a Hospice and then not leave until they retired.

 **Catherine Beresford** 23:03  
Yeah.

 **HCP05** 23:07  
So it was this very stable traditional workforce.

 **Catherine Beresford** 23:12  
Yeah.

 **HCP05** 23:13  
Who were really challenged by some of these patients, you know, some would turn up very drunk.

 **Catherine Beresford** 23:20  
Yeah.

 **HCP05** 23:21  
Some would turn up very sick, you know. We had a coupled with acute encephalitis we had, we had people come in with huge ascites and very confused, so it was really about selling the fact that my my job was to sell the fact that these were desperate people and I think once they became

 **Catherine Beresford** 23:38  
Yeah.

 **HCP05** 23:53  
comfortable with the people that they were, and once they became more comfortable with why we were doing what we were doing, then they completely embraced it. And actually, when I was leaving the Hospice, a nurse just said to me that I've worked with for a long time, she said.

 **Catherine Beresford** 24:05  
Right.  
Hmm.

 **HCP05** 24:15  
You changed the lives of so many people and you didn't know you did it. And I said to her, I was just the catalyst. I said you guys are the people

 **Catherine Beresford** 24:24  
Hmm.

 **HCP05** 24:27  
People that made the change, and I really strongly believe that because they had to go through so much, so soul-searching to to sort of kind of open their arms to this group of people.

 **Catherine Beresford** 24:35  
Yeah, yeah.

 **HCP05** 24:43  
They were also, I would say, much sicker patients than they traditionally seen in a day Hospice outpatient setting so that we yeah, there was some really hairy points where I I called ambulances and things like that, but again, that was probably where our richest learning was.

 **Catherine Beresford** 25:00  
Right.  
Yeah, yeah.

 **HCP05** 25:08  
So from a management point of view, from the Hospice point of view.  
I really had 100% support. I had a very

 **Catherine Beresford** 25:21  
Mm hmm M.

 **HCP05** 25:23  
I had a very dynamic and very innovative director of care at that point.  
And and I'm not sure if it would have worked with a different director of care.  
Because she kind of let the nitty gritty of how it worked. Sit with me.  
But she really, really embraced these people coming into her Hospice that were very different and it and she fought our corner, you know, with the then CCGs to then start getting funding. She fought anybody from a trustee level or yeah, from sort of a CEO level, who questioned. She really, really championed the calls and championed my work, really without

 **Catherine Beresford** 26:17  
Yeah, yeah.  
Yeah.

 **HCP05** 26:26  
testing me, if that - she believed in what I was doing, she could see the difference. And there were, you know, there were a few occasions where

 **Catherine Beresford** 26:27  
Yeah, yeah.  
Yeah.

 **HCP05** 26:36  
I had people. I interviewed quite a lot of people as part of the Health Foundation work, but then I would say would you mind talking to a director of nursing because I wanted her to see, you know, what's happened to you and understand. And I think that really helped sell the the pathway to the person who needed to know about it.

 **Catherine Beresford** 26:41  
Hmm.  
Yeah.  
Yeah, I see. Yeah, yeah.

 **HCP05** 27:01  
And.  
And actually after you know a little bit of resistance. I think it's big. It's probably become one of the proudest pieces of work that the Hospice have done.

 **Catherine Beresford** 27:20  
Mm.

 **HCP05** 27:21  
Because they've changed. I've changed the route and the lives of many, many people. It rippled out sort of nationally, and it changed how people thought about people with liver disease.

 **Catherine Beresford** 27:36  
Yeah, yeah.

 **HCP05** 27:37  
And I did a really interesting, there's a few interviews I did with staff at the beginning and at the end I'd have to try and dig them out. And it was all about preconceived ideas. You know, they thought everybody was an alcoholic.

 **Catherine Beresford** 27:52  
Yeah.  
Yeah.

 **HCP05** 27:58  
They bought it on themselves. Why are we doing that when cancer victims, you know?

 **Catherine Beresford** 28:00  
Yeah.  
Yeah.

 **HCP05** 28:05  
And at the end of it, it was night and day with those people every there wasn't one who still had that kind of misconception. Everybody understood.

 **Catherine Beresford** 28:15  
Yeah.  
Yeah, that's really interesting. Yeah.

 **HCP05** 28:19  
That liver disease. Yeah, it was really interesting.

 **Catherine Beresford** 28:22  
Hmm hmm.

 **HCP05** 28:25  
And I, you know, I presented to our trustees and all the way through the whole thing because I wanted everybody I was really passionate that I wanted people to understand what this group of patients are living through.

 **Catherine Beresford** 28:39  
Yeah.  
Yeah.

 **HCP05** 28:43  
And yes, some of them are it some of it is due to alcohol, but they never chose to end up where they are.

 **Catherine Beresford** 28:53  
No. Yeah.

 **HCP05** 28:55  
Did that answer your questions?

 **Catherine Beresford** 28:56  
Yeah. Yeah, no, that makes a lot of sense. Yeah. Thank you. So, throughout what you've been telling me, I've got a good idea of this, but it would be nice if you could summarise what you think good care in advanced liver disease looks like for people who've got, you know, decompensated disease and are not on the transplant list.

 **HCP05** 29:16  
OK so.  
Good care for a decompensated sick liver patient is about not just looking at their liver, it's about looking totally holistic and not holistically and not just about them.  
It's about the people around them, because if those people

 **Catherine Beresford** 29:40  
Yeah.

 **HCP05** 29:44  
Don't support them then they have nowhere to go.

 **Catherine Beresford** 29:47  
Yeah.

 **HCP05** 29:49  
And I think when you look at a liver patient holistically, they are very often very, very complex people.

 **Catherine Beresford** 30:11  
Yeah.

 **HCP05** 30:12  
No chance of improving the quality of their life.  
Now I think in my work that I probably underestimated that.

 **Catherine Beresford** 30:25  
Hmm.

 **HCP05** 30:26  
And I think most of my findings were you could almost resolve most of the liver issues.  
Or you could can you could symptom control most of them if you supported the patient holistically.

 **Catherine Beresford** 30:46  
Right.

 **HCP05** 30:48  
So we ran lots and lots of support groups and you know, we do that across the board for all different groups of patients. But they were amazingly well attended, and it was because they didn't have that opportunity because they were living under the  
stigma of liver disease.  
So they wouldn't have gone to a traditional support group because they felt embarrassed most of the time, but to sit alongside somebody inside, be able to say, why have you got liver disease? Oh, it's because I drank. Why have you got it? Oh, it's because I, you know, I've got an all time immune disease.

 **Catherine Beresford** 31:18  
Right.  
Hmm.  
Hmm.

 **HCP05** 31:33  
It just seemed to give them such a it it seemed to give them this strength and power back to know that other people were doing it.

 **Catherine Beresford** 31:43  
Yeah.

 **HCP05** 31:46  
And I know [the palliative care nurse] underestimates what she's doing now.  
But she, you know, so many of them are not decompensated any longer because they are compliant.

 **Catherine Beresford** 31:59  
Yeah, yeah.  
Yeah, yeah.

 **HCP05** 32:03  
And.  
I think you know that took a lot of work for me to understand.  
With the Health Foundation.  
Who just kept saying It is incredible that they've suddenly become compliant, but they've become compliant because they're supported holistically.

 **Catherine Beresford** 32:22  
Yeah, yeah, I understand.

 **HCP05** 32:24  
And.  
So I would say, yeah.

 **Catherine Beresford** 32:29  
Yeah.

 **HCP05** 32:29  
That holistic approach.

 **Catherine Beresford** 32:31  
Yeah.

 **HCP05** 32:33  
No, and not purely medical and not purely nursing. It's it's holistic from a medical and nursing approach.

 **Catherine Beresford** 32:33  
Thank you.  
Yeah. Thank you. Yeah, that fits in with what I'm seeing about how people can be decompensated, but then they with with their management, they can move into a situation where their liver disease is being managed and it is stable. So, it's not that, it's completely reversed. We know they've still got it. But it yeah, it's that. And that's what one of the things that makes it unpredictable isn't it? Because if they have that support and their conditions managed, then actually that can mean that they have added length of life as well.

 **HCP05** 33:09  
It.  
Yeah. And actually, I I don't know if you've seen it. I just went to see the Back to Black film with about Amy Winehouse.

 **Catherine Beresford** 33:26  
Oh, right.

 **HCP05** 33:27  
And.  
I I don't know if she had liver disease, but obviously she was alcoholic and she had been dry for I think a couple of years, and she then went on a kind of massive alcoholic bender. And that's what killed her.

 **Catherine Beresford** 33:48  
M.

 **HCP05** 33:48  
And my son was saying to me, why would that one, you know, do that and I said she was probably living with liver disease.  
And you know, they think or one more drink won't do it. Because I've been so well for so long. But that was a lot of the education we were doing about, you know, well, that was a lot of what I was doing in my assessments and reassessments. You know, you're doing really well, but you need to, we need to keep your diet good. We need to you can't drink, 1 drink can kill you.

 **Catherine Beresford** 33:59  
Yeah.  
Hmm.  
Yeah.  
Hmm.  
Hmm.

 **HCP05** 34:23  
So.  
But I think that ongoing assessment and the time that we were able to give them meant that they thought, actually, I can't do that and and we had a really, really interesting outcome to our work in that in some of the qualitative feedback we got that they said that they didn't want to let us down because of all the time and work we've invested. Yeah. So, they kept away from the booze, they kept away from the drugs or they kept taking their medication.

 **Catherine Beresford** 34:50  
Right. OK. Yeah, that's interesting. Yeah.

 **HCP05** 35:00  
Because they could see how invested we were in keeping them well.

 **Catherine Beresford** 35:04  
Yeah, yeah.

 **HCP05** 35:06  
But I thought that was really interesting, I think.

 **Catherine Beresford** 35:07  
Yeah, yeah, yeah.

 **HCP05** 35:09  
If you feel like you're being heard and stuff, you're gonna put the work in, aren't you?

 **Catherine Beresford** 35:16  
Yeah.  
So obviously we've talked a lot about everything throughout the interview and sometimes when we're having these kind of conversations, something could kind of occur to you that you perhaps haven't really thought about before. Is there anything that sort of comes to mind through talking about all of this?

 **HCP05** 35:37  
I think I've got most of it. I guess the main I had forgotten the huge part our community services played and that's because I probably wasn't embedded in it, but they played a massive part in the care of these people because of that helpline. Because of that we visit you and I know it's two in the morning, but we visit if you need us to.

 **Catherine Beresford** 36:00  
Yeah.  
Yeah.

 **HCP05** 36:06  
Yeah, I think.

 **Catherine Beresford** 36:06  
And that is that and that's the community is that are they part of the Hospice or? Yeah. Yeah, I see. Yeah.

 **HCP05** 36:10  
Yeah, we have Hospice community services and it's a massive service. And of course, we have the inpatient unit where prior to.

 **Catherine Beresford** 36:19  
Yeah.

 **HCP05** 36:23  
My work or at work, nobody had ever died in there of liver disease.

 **Catherine Beresford** 36:29  
Right. OK.

 **HCP05** 36:30  
And now it's it's fairly commonplace that if somebody does, but they definitely have the option to choose it is their PPD, but.

 **Catherine Beresford** 36:33  
Yeah.  
Yeah.

 **HCP05** 36:40  
It's not uncommon practice to have somebody dying from their advanced liver disease now.  
So.  
Yeah, I don't think I think I've covered most of it.

 **Catherine Beresford** 36:55  
Yeah, I know that I I feel like you've given me a really thorough insight and something that sort of, you know, interesting to know is I'm guessing, you know, I know that you you're aware of this, like the variation in terms of, you know, I'm speaking to a range of healthcare professionals across the country and what is available to people in terms of services, including palliative care and end of life care is variable. It does seem to vary.

 **HCP05** 37:11  
Yeah.  
Yeah. And I did a piece of work on that after the project was finished. I've got funding again through the Health Foundation called Spreading the Innovation.

 **Catherine Beresford** 37:26  
Have you? Yeah.

 **HCP05** 37:41  
And I think the conclusion of that piece of work was that actually this pathway is completely transferable. It could go anywhere.  
But it's almost where it was definitely bigger than us, for sure. And at that point.  
I either needed to go into it kind of full time and find funding for that, or but at that point it had definitely reached bigger than a Hospice. You know, we couldn't do that kind of national work.

 **Catherine Beresford** 38:07  
Yeah.  
Yeah, yeah.

 **HCP05** 38:19  
And I.  
And I still really believe that, but it's really transferable and I I mean, I still get quite a lot of people ringing me or emailing me about the work and how they can make it work. And you could definitely tweak it to, you know, where you're situated, how you set up is. But the issue is there's huge disparity in

 **Catherine Beresford** 38:26  
Hmm.  
Yeah.

 **HCP05** 38:48  
Hepatology provision.

 **Catherine Beresford** 38:51  
Hmm.

 **HCP05** 38:52  
And also hospices that we all want to take on non-malignant work.

 **Catherine Beresford** 38:58  
Yeah.

 **HCP05** 39:00  
They many hospices say that of course they do, because we should all be doing that. But there's tick in a box and then there's really tick in the box.

 **Catherine Beresford** 39:10  
Yeah, yeah.

 **HCP05** 39:12  
And.  
But I do feel not because it's the work that I've done, but I do feel that pathway could just be national practice, but it it's a big piece of work for probably a whole unit or something, you know, academia or?

 **Catherine Beresford** 39:31  
Yeah, yeah.  
Yeah, that so that works that you did. But did you say it was called spreading the?

 **HCP05** 39:35  
And.  
Yeah.  
Spreading the Innovation, I mean it was with the Health Foundation, so that.

 **Catherine Beresford** 39:43  
Would I be able to access that?

 **HCP05** 39:45  
I think so.  
Yeah. Sorry. Yeah, I I've probably. Or it might be on my.

 **Catherine Beresford** 39:49  
I'll have a look.

 **HCP05** 39:54  
Hospice laptop. I'll have a look if I can find it. I'll send it to you.

 **Catherine Beresford** 39:56  
Alright.  
Thank you.

 **HCP05** 40:00  
But that was really me spending a year going talking at national level about the work.

 **Catherine Beresford** 40:08  
Yeah.

 **HCP05** 40:09  
And the overwhelming was how do we do it? Tell us how we do it.

 **Catherine Beresford** 40:13  
Hmm.  
Yeah.

 **HCP05** 40:15  
Where do we get the money?

 **Catherine Beresford** 40:17  
Hmm hmm.

 **HCP05** 40:21  
And kind of.  
I don't know if you've ever spoken at conferences, but there's been many times when I've spoken about other things that I get a few questions and then everyone goes thank you very much and you carry on.

 **Catherine Beresford** 40:27  
Yeah.

 **HCP05** 40:37  
But.  
When I did that work, there was literally queues of people saying can you give me, Can I ask you how you did it? Because I think it. And I'm not saying that. That's my amazing work. I'm saying what I think the concept is simple.

 **Catherine Beresford** 40:45  
Yeah, yeah, yeah.  
Yeah.  
M.  
Yeah.

 **HCP05** 40:57  
And you can potentially do it quite cheaply.  
But you have to have, you know, you have to have a very good Hepatology department and you have to have a Hospice with trustees and senior managers that will embrace it.

 **Catherine Beresford** 41:16  
Yeah.

 **HCP05** 41:17  
But beyond that, you don't need a huge amount of money. You just need the will and the knowledge.

 **Catherine Beresford** 41:25  
Yeah.

 **HCP05** 41:26  
But there are other, you know, there's definitely been since I've finished my work, there's definitely very good versions of what my work.

 **Catherine Beresford** 41:37  
Yeah, I'm gathering that. Yeah. No, I'm. I've spoken to other others where there seems to be similar models. Yeah.

 **HCP05** 41:38  
It's not unique.  
Yeah. And I hope that, you know, I hope that that keeps happening. But I do feel.  
I not model but a national model of this collaborative working needs to happen because it is outstanding what happens to those patients with the right care.

 **Catherine Beresford** 41:59  
Yeah, yeah.  
Yeah, yeah, yeah.  
Thank you. That's really helpful.  
And yes, certainly if you do have any of that work, it would be really good to have a look at it.

 **HCP05** 42:13  
Yeah.  
I'll have a look. I've just gotta get my other computers, but I'll have a look.

 **Catherine Beresford** 42:17  
Yeah, sure. Yeah. Is there anything that you want to ask me?

 **HCP05** 42:23  
No, I think we've had a good.

 **Catherine Beresford** 42:25  
Yeah.

 **HCP05** 42:27  
Chat, haven't we?

 **Catherine Beresford** 42:28  
Yeah, yeah, definitely.

 **HCP05** 42:29  
I think it's great what you're doing. I think I think.

 **Catherine Beresford** 42:31  
Thank you.

 **HCP05** 42:34  
All of it really helps the call, and I think I've always been frustrated by the slowness of the change, but it's as the Health Foundation used to say to me all the time, it's a massive change. It's a change at so many levels.

 **Catherine Beresford** 42:37  
Yeah.  
Hmm hmm.  
Yeah. And like you say, it's a cultural change as well, isn't it? So, yeah.

 **HCP05** 42:57  
Oh, massively, massively, massively.

 **Catherine Beresford** 43:00  
Yeah.

 **HCP05** 43:01  
And it's also actually that's the other one thing that I haven't told you is it's a very significant shift for people with liver disease to come into a Hospice and it's very frightening for them. And we did a lot of work around that.

 **Catherine Beresford** 43:14  
Yeah.  
Yeah.  
Mm hmm.

 **HCP05** 43:22  
Because you say the word Hospice and it took a long time from both sides to break down those barriers, and that to make that change happen where you, they just said, oh, OK, we'll go to the Hospice. We were very lucky. You've seen the building. They had sort of almost a separate end of a building. So, I think that helped.

 **Catherine Beresford** 43:43  
Hmm.  
Hmm.

 **HCP05** 43:48  
But that's very significant.

 **Catherine Beresford** 43:50  
Yeah, yeah.  
Makes sense?  
Stupid question. I should I know that you're a nurse practitioner, but I should just double check exactly what your job title was when you were doing this.

 **HCP05** 43:58  
Yeah.  
Oh, oh, gosh. When I was doing that.

 **Catherine Beresford** 44:05  
Yeah.

 **HCP05** 44:08  
Uh advanced nurse practitioner.

 **Catherine Beresford** 44:11  
Yeah.  
And that was in palliative care. Yeah. Thank you. I just wanted to check that.

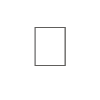
 **HCP05** 44:17  
Yeah.  
I've had so many job titles I can't keep up with them all.

 **Catherine Beresford** 44:26  
OK. And when so when you retired, what was your title at that point?

 **HCP05** 44:31  
Clinical projects.  
Hang on, I'm trying to remember clinical projects facilitator.

 **Catherine Beresford** 44:41  
Thank you.  
Right. I'll stop recording now. Let me just do that.

 **HCP05** 44:48  
OK.

 **Catherine Beresford** stopped transcription