# Carer06 ‘Vikram’- Interview Transcript. 14/06/2024 conducted by telephone at 09:30am55 minutes.

Please note that the interview questions start on page four, so that is where analysis will start from.

00:00:00 **Cathy Beresford**

So, I'll just explain a few things first before I start the actual interview.

00:00:07 **Cathy Beresford**

The first thing to say is that just, well, maybe to explain a bit more about me and and the the research and what I'm doing. So, as you know, it's to explore people's experiences of care when they've got advanced liver disease.

00:00:20 **Cathy Beresford**

And I'm doing that through the perspectives of individuals who've got advanced liver disease and also through healthcare professionals and individuals like yourself who have caring responsibility for somebody.

00:00:34 **Cathy Beresford**

Has got advanced liver disease and with the interviews there's no right or wrong answer because it truly is your perspective, your experiences. You know your views. So, there's no.

00:00:47 **Cathy Beresford**

Right or wrong.

00:00:49 **Cathy Beresford**

And if I ask you anything and you aren't sure of and you want me to rephrase it

00:00:55 **Cathy Beresford**

Or that's fine. Just say. Also, everything's voluntary. So, if I ask you anything and you don't want to answer it again, that's fine. Because how much information you give is completely up to you.

00:01:05 **Cathy Beresford**

You know.

00:01:07 **Cathy Beresford**

And also, I do know that sometimes when you're talking about some of these issues, it can be quite difficult and sometimes you know if people need to take a break or anything like that, that's also fine. So do just say in terms of who I am. So, I'm a registered nurse and I've been a nurse for years, but my background is actually previously in diabetes nursing. So, I'm not an expert in liver disease, but I've been doing this project now for almost two years.

00:01:34 **Cathy Beresford**

And and it's due to finish next year in the autumn.

00:01:37 **Cathy Beresford**

So, I'm sort of, I've I've I've interviewed most of most. I've done most of the interviews now. I've still got a few more to do, but that's just to kind of give.

00:01:47 **Cathy Beresford**

You a bit of.

00:01:47 **Cathy Beresford**

An overview really, so anything you.

00:01:51 **Cathy Beresford**

Wanna ask me?

00:01:53 **Carer06**

No, no, no. This is really helpful because just trying to understand really what you're hoping to achieve so

00:02:00 **Cathy Beresford**

Yes.

00:02:02 **Carer06**

That would be really helpful. So at least the information I share, yeah, of what you're trying to do.

00:02:07 **Cathy Beresford**

Absolutely. Well to answer that, because I think that's probably the main question that most people have really is is the aim is to try to find out what things.

00:02:19 **Cathy Beresford**

Are being done.

00:02:19 **Cathy Beresford**

Well, you know what? What's happening that's good across the UK for people but where are there issues, you know. So, how can we perhaps improve care. Because we know that there are areas that do need improving, you know? But but there's good practise going on as well. So, it's really to try to find out what's happening, what's going on, that's OK and good for people. And where are their issues that need to be improved. I mean, really the ultimate aim is to try to sort of have influence. To make a difference to people who have got advanced liver disease, you know it's not an enormous study, you know, it's qualitative research. So, I'm not speaking to huge numbers of people, but I am talking to people across the UK and building the picture. And then what I'm also doing is making sure that I go to conferences, go to meetings, to share what I'm finding and also writing up papers in journals so that people can see what's going on. So, I've had a couple of papers published, but I can e-mail you a bit more information about some of the stuff that I've been doing if you like.

00:03:26 **Carer06**

So, is this about sort of trying to understand the experience of patients and the healthcare professional in treating the liberties disease?

00:03:36 **Cathy Beresford**

Well, the main thing is really to understand more about people's experiences of the care that they receive. So that could be treatment, but it could be broader than that because it could be what support are people getting. And that includes carers as well because obviously you know you you are providing care to people and also you have your own needs too, so it's. It's quite a holistic overview of everything if that makes sense.

00:04:04 **Carer06**

No, it does. It does, so I understand. So, it is from the sort of health care point of view and actually leading on to doing some kind of development of interventions in health treatment. So, it's not specifically on the treatment. It's more on the health and care side.

00:04:26 **Cathy Beresford**

Yeah, I would say so. I would say yeah and and and that could be broader as well because some people have talked about social care. So, it it, it's really I don't wanna. I don't wanna be too kind of prescriptive really because it's about it's about how you view care as well, if that makes sense.

00:04:45 **Carer06**

But but not. Yeah. But it's not about sort of finding out new drugs. No, no, it is more about health than.

00:04:55 **Cathy Beresford**

Yes, it's about the service. I would say it's about the services and the support around those services.

00:05:03 **Carer06**

No, no, I understand now. That's fine. I understand.

00:05:06 **Cathy Beresford**

But hopefully, hopefully the questions will help help to kind of guide you a little bit as well.

00:05:13 **Carer06**

Yeah. No, that's absolutely fine. Let's ohh sorry.

00:05:17 **Cathy Beresford**

Lovely. OK, now before we do start so that I can report properly on, you know who I've been interviewing.

00:05:23 **Cathy Beresford**

In terms of the population, would you mind confirming your age, please?

00:05:31 **Carer06**

I am [confirms age] is that ok?

00:05:34 **Cathy Beresford**

Yeah, that's absolutely fine. Yeah. And then what ethnicity do you consider yourself to be?

00:05:41 **Carer06**

[confirms ethnicity].

00:05:44 **Cathy Beresford**

Thank you.

00:05:47 **Cathy Beresford**

Lovely and ohh you don't have to tell me exactly where, but roughly what area of the UK are you in? So, what sort of region?

00:05:59 **Carer06**

[confirms area]

00:06:00 **Cathy Beresford**

Ohh yeah that that's fine. OK, lovely. Thank you.

# Interview questions start here:

00:06:06 **Cathy Beresford**

Right. So, to start off with then could you tell me a bit about who you've got experience of caring for?

00:06:15 **Carer06**

Yes. Well, few people, my cousin. I lost my cousin to liver disease.

00:06:26 **Cathy Beresford**

Right.

00:06:27 **Carer06**

About about 12-14 years ago. He developed I mean.

00:06:36 **Cathy Beresford**

So, so sorry. So sorry to interrupt you, but for this I need to focus on anybody that you've got experience of caring for within the last two years so

00:06:47 **Carer06**

Right.

00:06:48 **Cathy Beresford**

In terms of the liver disease, so would you be able to tell me a bit more about that please?

00:06:53 **Carer06**

OK, well, my mother has got liver disease in the last two years, and it developed - she's got lot of multiple health conditions through her infection.

00:07:00

Yes.

00:07:06 **Cathy Beresford**

Yeah.

00:07:13 **Carer06**

UTI's and bile ducts. She then developed sepsis in liver.

00:07:21 **Carer06**

And and and now part of the liver is diseased and and she is having surgery to take that out. That's in the last two years.

00:07:30 **Cathy Beresford**

Yes.

00:07:39 **Cathy Beresford**

Yeah. Yeah. So, from your perspective, can you tell me a bit about your mother's journey of receiving care for her liver disease?

00:07:49 **Carer06**

Well, I would say specifically for liver disease, it was diagnosed quite late that she picked up the the liver disease.

00:08:04 **Cathy Beresford**

Oh right.

00:08:06 **Carer06**

Therefore, I don't know whether it could have been saved or not. So, from that point of view, because she's had lots of multiple health condition and she's frail anyway, her care general care was fairly good I would say. I’ve been a carer for her for the last five years.

00:08:25 **Cathy Beresford**

Yeah, yeah.

00:08:35 **Carer06**

Because of that, I will say the general care from healthcare professionals have been OK. Because of her other condition, but specifically for liver disease. There wasn't any additional care. The key -

00:08:47 **Cathy Beresford**

Yeah.

00:08:59 **Carer06**

- fact that I would probably share is that she wasn't picked up or the disease was not identified early.

00:09:09 **Cathy Beresford**

Yes.

00:09:11 **Carer06**

And therefore, that resulted in more damage than perhaps could have been, but after it was diagnosed that is, the care has been fairly good in terms of -

00:09:27 **Cathy Beresford**

Yes.

00:09:31 **Carer06**

identifying what can be done and how that care can be provided in terms of nutrition and in terms of surgical operation interventions.

00:09:36 **Cathy Beresford**

Yeah.

Yeah.

00:09:46 **Carer06**

At home, general advice in change of her dietary intake

00:09:57 **Cathy Beresford**

Yeah.

00:09:59 **Carer06**

has also had to be adapted so that the situation does not get any worse and

00:10:04 **Cathy Beresford**

Yeah.

00:10:10 **Carer06**

Yeah, I mean, that's pretty much it.

00:10:13 **Cathy Beresford**

Yeah. So, which which services has she accessed for care in relation to her liver disease then?

00:10:21 **Carer06**

Well, she gets she gets hospital treatment, and she gets injections. Her nurse comes in to give her injections. Yeah. Cope with the - oh the word just escapes me watch that yellowy when she becomes – oh jaundice.

00:10:46 **Cathy Beresford**

Ohh yes ohh I see. So, she had she has somebody come in for that does she to the home?

00:10:52 **Carer06**

So, the the nurse comes in to give her the injections for her jaundice. She's got other health conditions. I’m managing her other health conditions.

00:10:59 **Cathy Beresford**

Yes.

Yeah, of course.

00:11:12 **Carer06**

In terms of her COPD and her kidney failure. I’m managing that.

00:11:18 **Cathy Beresford**

She's got a lot going on, hasn't she?

00:11:20 **Carer06**

Yeah, yeah.

00:11:22 **Cathy Beresford**

So, when she goes to the hospital for the liver disease, is it the - is it a specific clinic that she goes to?

00:11:29 **Carer06**

She does go to the liver treatment clinic.

00:11:32 **Cathy Beresford**

Yeah. Who does she see there?

00:11:36 **Carer06**

The care nurse. Occasionally she will see the doctor or registrar, but it's usually the care nurse.

00:11:46 **Cathy Beresford**

Yeah.

So, is that, do you know, is that a liver specialist, nurse? Yes. Yeah. OK. Thank you. That's helpful to know. OK. [he confirmed that it is the liver nurse}]

00:12:01 **Cathy Beresford**

And but you maybe I'll just go back to something you mentioned that she was diagnosed with liver disease quite late. So how did she come to find out that she had liver disease.

00:12:12 **Carer06**

I think her hormone level had changed quite a lot. She was having. She was obviously going yellow so.

00:12:22 **Cathy Beresford**

OK. Yeah. So that was like the first sign, was it?

00:12:26 **Carer06**

Yeah, that there's something potentially wrong and because she was taking sort-of cocktail of medication. They thought it was to do with her kidney failure and her other - and she's had lots of UTI's - they didn't pick up the fact that she there might be an infection in the liver.

00:12:54 **Cathy Beresford**

Oh, I see. Yeah, yeah.

Yeah. So then then what happened?

00:13:00 **Carer06**

So basically, I mean as soon as they then identified, yes, there's a problem with the liver. Then she was scanned and and diagnosed and fairly quickly after that.

00:13:14 **Cathy Beresford**

Yeah. Did she have to - did she have to go into hospital as an emergency? Or was it all done as an outpatient?

00:13:21 **Carer06**

It was done as a planned - it it was done fairly quickly because she's already she is already an outpatient with other health conditions. So, she didn’t need to go to A&E.

00:13:28 **Cathy Beresford**

Yes.

Oh yeah.

OK, that's that's good to know, yeah.

00:13:45 **Cathy Beresford**

OK. So, you've mentioned that she's got the the doctor at the hospital, the liver nurse, and then the community nurses who come in and give her an injection. Any other professionals that have been involved in care for her in relation to her liver disease specifically?

00:14:04 **Carer06**

No. I mean her GP has been involved and that's about it really.

00:14:06 **Cathy Beresford**

Yes. Yeah.

And in what way was the GP involved?

00:14:15 **Carer06**

In terms of sort of medications, prescription and just being generally aware or.

00:14:19 **Cathy Beresford**

Yeah.

Sure. Yeah.

00:14:26 **Carer06**

Consultants are engaged because she's got other multiple health needs that they have to manage.

00:14:29 **Cathy Beresford**

Yes. Yeah.

Yeah, that makes sense.

00:14:35 **Carer06**

Yeah, because she's also got a heart condition.

00:14:37 **Cathy Beresford**

Yeah. So, so if you or she needed any sort of support or advice, any information about liver disease, well, where do you, where do you both go?

00:14:49 **Carer06**

In the first place to her care nurse.

00:14:53 **Cathy Beresford**

Ohh yes yeah.

00:14:55 **Carer06**

And then her liver specialist team in the hospital.

00:15:01 **Cathy Beresford**

So, the care nurse, do you mean the one - do you mean the liver nurse? Or do you mean the one in the community?

00:15:06 **Carer06**

No, no, the the liver nurse oh, who comes - who comes to give her the injection.

00:15:07 **Cathy Beresford**

Ohh yeah so Ohh, right. OK. So, somebody comes to give her an injection. Do you know if that's a district nurse or is that a specialist nurse?

00:15:21 **Carer06**

No, no, no. She's a district nurse.

00:15:22 **Cathy Beresford**

Oh well, I I'm with you. Yeah. Yeah, I'm with you. So you could you could speak to her.

00:15:27 **Carer06**

She’s a general nurse.

00:15:28 **Cathy Beresford**

Yeah, I I get you. So, you could speak to her if you needed to ‘cause she's coming in.

00:15:33 **Carer06**

Yeah, exactly. So, if there is, unless there's something very serious, then I will go to the specialist nurse. But if it's general advice, I.

00:15:40 **Cathy Beresford**

I see

00:15:43 **Cathy Beresford**

Need sure and how you.

00:15:46 **Carer06**

* particularly when it's to do with her, you know? Changing condition so that I'm not having a biased view.

00:15:54 **Cathy Beresford**

Yes.

00:16:01 **Carer06**

Yes, that she is seeing if there's something changing or not. Yeah. And also, on a basic sort of dietary - I mean generally I now fully aware of what kind of you know, diets.

00:16:18 **Cathy Beresford**

Yes.

Yes.

00:16:19 **Carer06**

All that, but if I need some guidance then I'll just speak to the specialist nurse in the hospital.

00:16:25 **Cathy Beresford**

And how did you find out about the diet side of things? Who gave you that information?

00:16:31 **Carer06**

The hospital nurse.

00:16:33 **Cathy Beresford**

Yeah. Yeah. So, if you need to get hold of somebody, you know, like well, I suppose that I appreciate the district nurses are coming in. But if if you if you needed to get a hold of somebody in between the visits. How do you get hold of people?

00:16:52 **Carer06**

I generally try to get in touch with the specialist nurse in in the hospital only because I have more faith I that I'll get the right advice. GP doesn't have the right -

00:17:04 **Cathy Beresford**

You know, OK, yeah.

00:17:05 **Carer06**

How?

00:17:06 **Carer06**

1. Advice from the GP, Two: I don't have much faith in the GP's, to be honest, that they are informed enough, so I generally tend to go to the hospital.

00:17:16 **Cathy Beresford**

Yeah. Have you got, like, a phone number that you can call or something like?

00:17:21 **Carer06**

I do. They don't come back to me, sort of. You know, it's it always goes to the answerphone. It doesn't get answered straight away. Sometimes they get back to me towards the end of the day, More likely, it's sort of next day.

00:17:30 **Cathy Beresford**

Yes.

Yeah.

Sure.

Yeah. So, it sounds like it's fairly quickly that you would get a response back?

00:17:46 **Carer06**

I won't call it fairly quickly.

00:17:48 **Cathy Beresford**

No. OK, sorry.

00:17:51 **Carer06**

From the patient my perspective, it's too long.

00:17:53 **Cathy Beresford**

Yeah.

00:17:57 **Carer06**

Because I'm going through lots of emotional challenges and and I just would like to be able to talk to someone who can give me some information if they can't sort out the problem, at least they can -

00:18:02 **Cathy Beresford**

Yes.

00:18:13 **Carer06**

Give me some sort of things that I could do, take the anxiety away and and not knowing when I'm going to get that phone call only creates more anxiety, more stress. So, from my point of view, I'm sorry, you know.

00:18:16 **Cathy Beresford**

Yeah, yeah.

I see.

Yes.

Yeah.

00:18:33 **Carer06**

It's it might sound from NHS point of view, professional point of view, that it’s are fairly quick, but you can imagine what a patient and a family member going through when they're waiting for 4-5 six hours.

00:18:37 **Cathy Beresford**

Yeah, yeah.

Yes.

I I I get you. Yeah, I understand. Yeah. And well out of interest then have you used any other services like outside of the NHS for example, some people I've spoken to they they also use various Internet resources or support groups. Do you use anything like that?

00:19:10 **Carer06**

I don't use Internet no because I'm not IT, savvy or techy, I don't rely too much on that information. I do tend to ring some of the charities to just get general advice.

00:19:25 **Cathy Beresford**

Yes.

Ohh yes, which ones would that be?

00:19:37 **Cathy Beresford**

OK.

00:19:39 **Carer06**

I tend to ring Carer UK.

00:19:42 **Cathy Beresford**

Oh yeah, yeah.

00:19:44 **Carer06**

I tend to take use a network of patient support groups in in my local area.

00:19:57 **Cathy Beresford**

Yes, OK. Thank thank you. That's helpful to know.

00:20:01 **Cathy Beresford**

So, have you got any specific examples of when the care that your mum's received for her liver disease has been particularly positive from your point of view?

00:20:13 **Carer06**

I think all of it has been positive at the minute. They did identify that there is problem with the liver and and the liver disease to be fair to NHS, I would say, yeah, I mean since then the general sort of care what, what I can do, what's going to happen, keeping me informed of how long it will take for her treatment and surgery. All that, and the fact that they're monitoring you, know that it's not getting worse.

00:20:53 **Cathy Beresford**

Yes.

00:20:55 **Carer06**

Yeah, yeah, as I said, because I'm lucky that she's had lucky in a in a very sort of - lucky is probably a poor choice of word, but lucky in the sense that she's had lots of other health conditions, is being already been looked after by the MDT team in the hospital.

00:21:18 **Cathy Beresford**

Yeah.

Yes.

00:21:25 **Carer06**

She’s on palliative care.

00:21:29 **Cathy Beresford**

Ohh, right. OK. So, does she have? Does she have palliative care team support then?

00:21:36 **Carer06**

Yes, she does.

00:21:37 **Cathy Beresford**

Tell me a bit more about that. How are they involved?

00:21:43 **Carer06**

As I said, she's got other health conditions, so they obviously ensuring that she's comfortable and her symptoms are not getting as -

00:21:56 **Cathy Beresford**

Yeah.

00:22:03 **Carer06**

They're not deteriorating fast enough, so they're trying to keep her -

00:22:05 **Cathy Beresford**

Yeah.

00:22:10 **Carer06**

Comfortable and resilient, I would say.

00:22:14 **Cathy Beresford**

Yes. Yeah. So, is it through, is it through like a specific team or or a Hospice that she's actually getting that support?

00:22:27 **Carer06**

It's. It's through the hospital palliatively.

00:22:30 **Cathy Beresford**

Oh, I see. Yeah. And. And what? And UM.

I'm just sorry. I'm just thinking about it, cause it's interesting what you're telling me because what I'm finding is that some people who have liver disease don't always get access to palliative care.

00:22:48 **Carer06**

Aah, but she she only got access to palliative care because of her other -

00:22:52 **Cathy Beresford**

Yes, that's what's that's what's that's what's occurring to me. So, what what's occurring to me is that she's got the palliative care team involved ‘cause she's got other health conditions and that -

00:23:03 **Carer06**

And she was already, and she was already under their care.

00:23:06 **Cathy Beresford**

Right. Yes, that's interesting. And yeah, OK. And do they give? Yeah. OK, maybe maybe I'll come back to that, cause that I'm I'm sort of just thinking about that that sort of quite that it's quite relevant because it there seems to be a bit of disparity in terms of people

00:23:19 **Carer06**

Yeah.

00:23:26 **Cathy Beresford**

having access to palliative care, but as you've pointed out, the reason she's got palliative care is because of her other health conditions, not because of the liver disease.

00:23:34 **Carer06**

Absolutely. Because I'm also a trustee of a large patient advisory group.

00:23:40 **Cathy Beresford**

Yeah.

00:23:42 **Carer06**

And and therefore I'm coming across other patients.

00:23:45 **Cathy Beresford**

Yes.

00:23:46 **Carer06**

Who have had other issues including liver disease and they don't get access to palliative care. And all those, I'm fairly informed and engaged.

00:23:51 **Cathy Beresford**

Yeah, yeah.

Yeah.

00:23:57 **Carer06**

And because I'm trying to provide the best care for my mother, I have had to drive and force being looked after by the palliative care.

00:24:01 **Cathy Beresford**

Of course.

Yes.

00:24:11 **Carer06**

As far as they were concerned that she was not weak enough -

00:24:11 **Cathy Beresford**

Yes.

00:24:17 **Carer06**

To be supported by palliative care because she's got CVD and COPD, and because then now she's got other organ failures. Referred to the palliative care because I I I work with an organisation -

00:24:29 **Cathy Beresford**

Yeah.

Yes.

00:24:37 **Carer06**

Cicely Saunders institute.

00:24:38 **Cathy Beresford**

Ohh yeah, I know yeah.

00:24:40 **Carer06**

Yeah. So, I understood about to ask for that help.

00:24:48 **Cathy Beresford**

Yes. Yeah.

00:24:49 **Carer06**

And and I think it is really sad that, you know, if I know about the system, then I I ask and then I get the support, but no one offers that support.

00:25:00 **Cathy Beresford**

Yes, that that's very interesting and it is reflective in what I'm hearing from some other people. Yeah. Yeah. Thank you. So, any specific examples of when you think the care that your mum's received for her liver disease has been particularly negative?

00:25:17 **Carer06**

I I think. Again, I go back to what I said earlier that because I have been managing all her health and care needs. Once I knew what it was, then I was able to drive and and get the necessary help and support for health care.

00:25:41 **Cathy Beresford**

Yes.

00:25:45 **Carer06**

My negative, I suppose, and I'm not blaming anyone.

00:25:50 **Cathy Beresford**

No.

00:25:51 **Carer06**

The technology is not there and it's it's not there. All the toolkits are not in place. It's as I said, her liver infection started, but there was no signs and perhaps she wouldn’t have had to have this liver disease.

00:25:57 **Cathy Beresford**

Yeah.

Yeah.

00:26:13 **Carer06**

If the the systems were in place or biomarkers were in place, which could have determined that there could be a potential risk of developing liver disease that-

00:26:27 **Cathy Beresford**

I'm with you. Yeah. So, sort of earlier detection could have been -

00:26:32 **Carer06**

Diagnostics.

00:26:33 **Cathy Beresford**

Yeah.

00:26:35 **Carer06**

If the diagnostic system was in place, so I'm not blaming anyone, but we're not gods. There’s going to be, you know, if the tools are not in place. So, the only thing I would recommend is - and that's why I get involved as a PPI member [in other projects].

00:26:39 **Cathy Beresford**

I understand.

Yes.

00:26:54 **Carer06**

And and support researchers are purely because-

00:26:56 **Cathy Beresford**

Yes.

00:26:59 **Carer06**

You know, it's people like us, we need to say perhaps to people like yourself who are who are the intelligent people to perhaps identify, are there any biomarkers, are there any -

00:27:05 **Cathy Beresford**

Yeah.

Yeah, I'm with you. Yeah. Yeah, that that's that's really relevant to what I'm hearing from other people. And some of the work that the British Liver Trust are doing, I think about trying to get earlier diagnosis.

So, I suppose thinking about the experience that you've had with and your mum's had, you know, if you could give any advice to professionals who work with individuals who've got advanced liver disease and their carers, what would you say?

00:27:44 **Carer06**

I think communication is, you know, and communication in all facets. Communication when they're having the interaction with the patient and the their loved ones to make it simple enough so that they feel reassured.

00:28:01 **Cathy Beresford**

Yes.

00:28:02 **Carer06**

Because at the moment, it is very patching at best it's - because, you know, I think everyone sort of is trying to do the right thing for really communicating in, in, in a, in a, in a effective way. I won't say meaningful but effective.

00:28:14 **Cathy Beresford**

Yes.

Yeah.

00:28:25 **Carer06**

They they try to say the right thing but doesn't mean the patient or their loved ones understand. I will I will say having access to that support.

00:28:39 **Cathy Beresford**

OK. Yeah. Yeah.

00:28:41 **Carer06**

You know, even if they go be given, especially when someone is on an advanced, as you rightly said, advanced liver disease, not early-stage liver disease but advanced liver disease. The one thing that the patient, if they're living on their own, or if they're living in -

00:28:49 **Cathy Beresford**

Yes.

00:29:01 **Carer06**

in their own homes, with the family support. All the family needs is someone to be able to talk to say, what do I do? I can see this symptom. And that, having that reassuring voice that they can speak to.

00:29:09 **Cathy Beresford**

Yeah.

Yes.

Yeah.

00:29:25 **Carer06**

A call centre person.

00:29:27 **Cathy Beresford**

Yeah.

00:29:28 **Carer06**

A actual specialist associated with that disease. Then the patient will feel, or the their loved ones will feel, reassured. They, talking to someone who knows what they're talking about because we become as a carer we become almost like a little child. We we don't know what to do. We want to help, but we know what to do.

00:29:55 **Cathy Beresford**

Yeah.

00:29:58 **Carer06**

And not being able to receive that guidance, you can imagine the psychological, the mental, emotional challenge -

00:30:13 **Cathy Beresford**

Yeah.

00:30:14 **Carer06**

That we go through and that knock-on effect that will have. Because I'm, you know, I'm fairly aware my mother's going to go.

00:30:22

Yeah.

00:30:23 **Carer06**

And she's not going to live forever.

00:30:26 **Cathy Beresford**

Yes.

00:30:28 **Carer06**

But once she’s gone, you know, if I haven't received that level of care, of advice from the healthcare professional, you can imagine as a loved one, you will always be questioning ‘did I do enough, could I have done more?’ and that psychological, emotional -

00:30:39 **Cathy Beresford**

Yes, yes.

00:30:48 **Carer06**

Burden that the patient’s loved-one will have to carry for the rest of their lives. What impact will that have on the health and well-being of their that that person?

00:30:53 **Cathy Beresford**

Yes.

Yeah, yeah, I hear what you're saying.

00:31:04 **Cathy Beresford**

That that's really, really helpful.

00:31:05 **Carer06**

So, I think access to information, access to communication in all facets, facets is important. And then finally, I will say access to whether it's treatment, whether it is medication, whether it is -

00:31:12 **Cathy Beresford**

Yes.

00:31:28 **Carer06**

Pain protection, symptom management. Access to that. You know what can A. first communication that this is inevitable and what can be done, but if that is saying people will understand and you know if there's a care plan in place.

00:31:50 **Cathy Beresford**

Yeah.

00:31:52 **Carer06**

And then people will understand that this is how many days they've got left or how long they've got left, and they'll manage that. But not knowing that.

00:31:54 **Cathy Beresford**

Yeah.

Yeah.

00:32:03 **Carer06**

And then even if you know it, if you can't get that that access to medication, you know, even if it's like painkillers and

00:32:11 **Cathy Beresford**

Yes.

00:32:14 **Carer06**

You see your loved one in front of you dying slowly.

00:32:17 **Cathy Beresford**

Yeah.

00:32:19 **Carer06**

Can be really quite difficult.

00:32:24 **Cathy Beresford**

And thinking about everything that you've just said, what opportunities has your mum had to discuss any of this with anybody, do you know?

00:32:37 **Carer06**

Well, quite a bit because she is intelligent, you know, she, you know, she used to be a secondary school, English literature teacher. Well, you know, she is intelligent enough to engage and understand, despite her failing health, she understands the reality. So, she's had enough support and.

00:33:06 **Cathy Beresford**

Yeah.

00:33:07 **Carer06**

Of what is happening to her and in in her case, I suspect probably because I am able to communicate and engage, I will call call. I will even go much more effectively because I don't try to demand anything. I don't try to be forceful. I try to engage because it is the reality of the situation. No one actually sort of doesn't do something because they don't care.

00:33:38 **Cathy Beresford**

Yeah.

Yeah.

Hmm.

00:33:50 **Carer06**

I start from a position that everyone is trying to do the right thing.

00:33:54 **Cathy Beresford**

Yes.

00:33:55 **Carer06**

It's just that sometimes those right things are not appropriate to the patient and and I'm able to articulate that. So, I think we are lucky that in my mother's case, she's received the right level of care. I. You know, maybe I am naive. Maybe I'm just too much of a simple person, but I I won't say that she has not received the right number.

00:34:21 **Cathy Beresford**

Yeah. Yeah, that's helpful. Thank you. So, I mean you've already kind of given me a really good idea about this, just through everything you've been saying, but maybe just to summarise in your opinion, what does good care for people with advanced liver disease look like?

00:34:38 **Carer06**

And I've already touched on that. I think the first thing you need to have clear information, yeah. Communication has to be very clear and simple. That a patient or their loved ones can actually understand, provide that empathy. It doesn't have to be done by, you know, a professor or a consultant specialist. Any health care professional.

00:35:07 **Cathy Beresford**

Yeah.

00:35:12 **Carer06**

Because all a patient and their loved one wants is that understanding of what is happening to them, what is going to be done to help them. So, communication is the first thing, access to the people, yeah.

00:35:18 **Cathy Beresford**

Yes.

00:35:30 **Carer06**

Not information, it’s to the people you talk to, to get that reassurance. Time and you know, and I don't mean that 9-5, I mean 24/7 because you know disease like that and -

00:35:34 **Cathy Beresford**

Yeah.

Yes.

Yeah.

00:35:47 **Carer06**

Pain or condition change doesn't just happen between 9-5. It happens on Saturday evening at 10 o’clock. So, access to people.

00:35:56 **Cathy Beresford**

Yeah.

00:36:03 **Carer06**

Of who they can talk to to get that level of care. And it doesn't have to be consultant that you're talking to. Just someone who works with the patient. You have a rapport with that person, or at least with that department.

00:36:18 **Cathy Beresford**

Yes.

00:36:19 **Carer06**

That you're talking to that when I ring that number and I'm talking to, I know exactly which department I'm talking to, who I'm talking to, and maybe that person was not the person I had engaged with, but I'm fully aware that that person is actually talking quite regularly with the person who is looking after my mum.

00:36:33 **Cathy Beresford**

Yeah.

I'm with you.

Yeah, that's that's.

00:36:43 **Carer06**

This of the and then finally access to medication or healthcare needs.

00:36:49 **Cathy Beresford**

Yeah.

00:36:50 **Carer06**

24/7 access.

00:36:51 **Cathy Beresford**

Yeah.

00:36:53 **Carer06**

That's what I would say is a good quality care.

00:36:56 **Cathy Beresford**

Yeah. Thank you. That's really helpful. That's, you know when when you're talking about all of these different issues, sometimes it can sort of spark your thinking and something can occur to you that you haven't really thought about before. Does anything sort of spring to mind while we've been talking?

00:37:14 **Carer06**

No, only that I'm aware. Not everyone has got someone next to them like my mother has.

00:37:23 **Cathy Beresford**

Yes.

00:37:24 **Carer06**

I'm aware there are a lot of people who don't have that access. I'm aware of people who are probably not able to communicate and engage with a professional. I will say, use an example of someone who has got mental health or dementia and and, you know, dementia is not a disease. It's a condition that they're trying to communicate.

00:37:48 **Cathy Beresford**

Yeah.

00:37:59 **Carer06**

But they're just not able to communicate. And people like Alzheimer's societies and Dementia Cares, and others have done so much in improving understanding of how to communicate, communicate how to engage with, and I think you can learn a lot from organisations like that, because not everyone is able to communicate and.

00:38:17 **Cathy Beresford**

Yes.

Yeah, absolutely, yeah.

00:38:29 **Carer06**

So, we mustn't start from a position that these people are being unreasonable. We must try to understand whatever they're asking for. They're they're probably not able to articulate. So, they're asking for that help and and.

00:38:44 **Cathy Beresford**

Yeah.

00:38:46 **Carer06**

And and assess can we actually help start from the position can we actually help them from

Rather than starting from a position where the person is being unreasonable.

00:38:58 **Cathy Beresford**

Yes. Yeah, thank you. And is there anything else you think I should know to understand your experiences as a career better?

00:39:13 **Carer06**

The only thing I will say is go and spend a day with one of those patients.

They're going through, I think if you have not, I mean you say you, you you worked as a nurse.

00:39:31 **Cathy Beresford**

Yeah.

00:39:32 **Carer06**

Not as a liver specialist, nurse.

00:39:34 **Cathy Beresford**

That's right.

00:39:36 **Carer06**

But you know, if you haven't worked as a liver specialist nurse. Then you wouldn't have probably come across a patient with advanced liver disease. So go and spend just one day with any patient.

00:39:49 **Cathy Beresford**

Yeah. So, what I did, that's that's a really good point. So, in my clinical background, you know, on the wards, before I was a diabetes nurse. I did. I did meet people who had advanced liver disease then. And I've also worked in a Hospice, but then that wasn't so much with people who had liver disease, because as we've talked about, a lot of the time, people with advanced liver disease don't get referred for palliative care. But the other thing I did before I started the research was, I spent a couple of days with the liver nurse and sat in her clinic as well, to meet people. And that was really good.

00:40:27 **Carer06**

All of those are non-relevant.

00:40:29 **Cathy Beresford**

Fair point.

00:40:31 **Carer06**

Because you're spending 5 minutes, you're spending, you're spending two hours with them.

00:40:33 **Cathy Beresford**

Yeah.

Yeah.

00:40:38 **Carer06**

And that won't tell you the full story.

00:40:40 **Cathy Beresford**

I know.

00:40:41 **Carer06**

It's like.

It's like you read a book as a, a, a biography about a person.

00:40:47 **Cathy Beresford**

Yeah.

Yeah.

00:40:54 **Carer06**

You might understand little bit about them, but you're not living, breathing that person. You really need to go and spend a whole day from the time you know a whole day and a whole night.

00:41:12 **Cathy Beresford**

Yeah.

00:41:13 **Carer06**

What challenge is there going to be.

00:41:15 **Cathy Beresford**

Yeah.

00:41:16 **Carer06**

From the time they wake up, you know, go through that 24/7 full cycle. And I think that one day will give you - willl still not give you all the information, but it will give you 70/80/90% of the information of what a patient they're going through. You can go to the clinic. You can be in a hospital - Hospice. You can be in a hospital ward. But.

00:41:38 **Cathy Beresford**

Yeah.

00:41:40 **Cathy Beresford**

Yeah.

00:41:48 **Carer06**

All those are artificial environments for 5 minutes, 10 minutes one hour, 2 hours, then not what the patient is going through.

00:41:59 **Cathy Beresford**

No.

00:42:02 **Carer06**

So that's what I would say.

00:42:03 **Cathy Beresford**

Yeah. Thank you. Yeah.

00:42:06 **Cathy Beresford**

Yeah, I think you know what you're pointing out is what, what I know to be true, which is that you can empathise, you know, when you're in in a position like mine, you can try and put yourself in someone else's shoes, but you can never really fully appreciate what they're going through can you?

00:42:26 **Carer06**

No, and I'm. I've got children. I, I've seen my children grow up. I've seen what my wife has gone through in childbirth and and going through pregnancy and giving birth to my children. You can empathise, I can feel what a woman might be going through.

00:42:47 **Cathy Beresford**

Yeah.

00:42:51 **Carer06**

But, I’m not a woman.

00:42:53 **Cathy Beresford**

Yeah.

00:42:54 **Carer06**

I can’t understand the pain, the psychological, the emotional, the physical pain that she went through, I won’t ever be able to understand.

00:43:02 **Cathy Beresford**

Yeah.

Yes.

00:43:06 **Carer06**

Empathise, but other and until you physically actually like you know, experience having the.

00:43:14 **Cathy Beresford**

Yeah, yeah.

00:43:16 **Carer06**

The closest thing I have had is when I've had kidney stones.

00:43:22 **Cathy Beresford**

Ohh yeah, I heard that they're very very painful.

00:43:25 **Carer06**

But the closest thing I can say, or you know I haven't had, but my brother has had piles, and so I can understand the kind of pain that a woman *might* have gone through during childbirth. But really, as a man.

00:43:46 **Cathy Beresford**

Yeah, yeah. No, I I totally understand what you're saying. And you know what, I mean that's one reason because I can't, you know, I don't have liver disease, I'm not a carer for someone with liver disease. And so, what I've tried to do is involve people as much as possible in the research. So, you mentioned that you've had experience of being involved in PPI. And that's something that I'm doing with this project, so I've got a public involvement group and it's made-up of individuals with liver disease and carers of individuals with liver disease. And and we we're meeting regularly and they're overseeing the project with me and I think that that's really important because they've got insights that I just will never have.

00:44:31 **Carer06**

Absolutely. And that's why you got the PPI group too, because you know there's never going to be anyone who will be able to go and live through that condition that you're researching into, and that's why your PPI group and.

00:44:44 **Cathy Beresford**

No. Yeah.

Yeah.

00:44:47 **Carer06**

But, in terms of your own, because this is your personal development and you state that you're trying to publish papers, publish and do conference speeches and and inform healthcare professional of what could or should be done if that is what, because this is to do with your personal development. I'm saying to you that the best way to communicate anything is to live through that.

00:45:21

Yeah.

00:45:22 **Carer06**

I'm suggesting that if you even go and spend one day. Full day, including the night with that patient, whether it's in the Hospice, whether it is in the hospital, whether it is in their own home, you will learn 90% of what the patient goes through, no level of PPI involvement, no level of sitting in an outpatients clinic appointment or sitting in a ward will teach you.

00:45:59 **Cathy Beresford**

Hmm yeah.

00:46:01 **Carer06**

That that's an artificial environment. It is. It is not. It is a fictional environment. It is not real real environment that the patient and their loved ones are going through.

00:46:14 **Cathy Beresford**

Thank you for your views on that. That's good to think about.

00:46:19 **Carer06**

Yeah, this is only for your personal development.

00:46:21 **Cathy Beresford**

Yeah, I understand. Yeah. Yeah, I understand what you're saying. I I just wondered. I mean, I'm I'm interested to know your thoughts on something. So, for this particular study, I I I have found it quite hard to recruit people to take part. And I mean, I'm doing fine now you know I'm. I'm on track with recruitment, but I am interested to know, you know, I'm talking to people about this. You know, what have you got any thoughts about that in terms of it specifically advanced liver disease being more challenging to recruit people to take part?

00:46:56 **Carer06**

Well, I'll say two things. It's not just liver disease, it's any advanced condition.

00:47:01 **Cathy Beresford**

Yeah.

00:47:03 **Carer06**

You will always find it difficult to recruit because the focus is not to help another the person. The focus is to help yourself.

00:47:12 **Cathy Beresford**

Yeah.

00:47:13 **Carer06**

Living on your own or whether you are a carer for someone who is because, you know, I have been a carer for my mother. I now understand and I understand her frailty and how much time she's got, so I'm able to therefore detach myself and do the PPI I work.

00:47:36 **Cathy Beresford**

Yeah.

00:47:37 **Carer06**

Really, if I was very new to this and and if I knew that my mother only had a week or month, I will not be thinking about getting involved in recruitment or helping else. Because I hope to give that last days with the loved one as best as possible because that will be the priority.

00:47:50 **Cathy Beresford**

Yes. Yeah.

Yeah.

00:48:01 **Carer06**

So so it's nothing to do with liver disease.

00:48:05 **Cathy Beresford**

Yeah.

00:48:10 **Carer06**

It's to do with any advanced disease.

00:48:12 **Cathy Beresford**

Yeah, I I think that's a fair point. Thank you. I was that that sort of fits with what some other people have said. But I was sort of, I'm just interested to know what people think about it.

00:48:21 **Carer06**

Second, and the second thing I will say about liver advanced disease specifically. They're particularly with some patients and and I'm not relating that to cultural, ethnicity or anything like that with some patients, ‘cause it's equally true for white patients, is there is such a stigma. That they just share that pain, that they're going through. So, they go inwards.

00:48:52 **Cathy Beresford**

Yeah.

Yeah.

00:48:58 **Carer06**

Because no, because no one likes to show their weaknesses with another person. So that's why because you're looking specifically for advanced liver disease, which people understand that it's infectious and in some cases, yes, it is infectious. But in some cases, it's not infectious.

00:49:10 **Cathy Beresford**

Yes. Yeah.

Yeah.

00:49:23 **Carer06**

So, people, there's so much stigma you hear about some other advanced disease, people will accept that, and even cancer, they now beginning to understand that it's not infectious and therefore they will go - people will visit them.

00:49:26 **Cathy Beresford**

Yes. Yeah.

Yeah.

Yes.

00:49:45 **Carer06**

Liver disease: there are so many people out there that think that, you know, even if you go into the house, you're going to pick up the infection.

00:49:53 **Cathy Beresford**

Yeah, I understand. Yeah. So, there's those misconceptions about it.

00:49:58 **Carer06**

Yeah, it's almost like COVID if you can't, you have to be two metres away.

00:50:03 **Cathy Beresford**

Yeah.

00:50:05 **Carer06**

It’s stigma, which is wrong. You know that and I know that but how do you explain that?

00:50:08 **Cathy Beresford**

Yes.

00:50:10 **Cathy Beresford**

Sure. Yeah. Yeah. Thank you for your view on that. That's helpful to understand.

00:50:17 **Cathy Beresford**

Is there anything that you would like to ask me?

00:50:21 **Carer06**

No, I think you made it very clear at the beginning what you're trying to achieve. So yeah, no, nothing from me.

00:50:30 **Cathy Beresford**

And what what I'll do is because, but so let me explain it. I'm I'm, as you know, I'm recording and what I can do is put the recording into word and then it it transcribes it for me. But the transcription I've noticed, and other people have commented on this as well. I've noticed that when you see the words on the paper: two things. One is it can look quite disjointed and disconnected and and and the other thing is you you don't get the tone, you don't get how something was said but and and I think that can be a bit that can throw people a little bit when they see the transcript and they can think well does this make sense? But I want you to be sure. You know that I will be the person who's analysing the data and I can listen to the recording again and when I'm analysing it, I listen to it as well as look at what's being said so, if anything. In the transcript, when I send it to you, if anything does look a bit funny and you think that looks weird or, you know, I didn't mean it that way, that it looks on the paper. Please be reassured that I know that cause cause I've spoken to you and it's me that's interpreting everything. But you know if there's anything when I send you the transcript and you want to add anything or clarify anything then that's absolutely fine. You know, you're welcome to do that, cause I'll send it to you next week. When I’ve just tidied it up.

00:51:51 **Carer06**

Two things. I mean, I won't have much time to look at it.

00:51:54 **Cathy Beresford**

You you don't have to. It's completely voluntary.

00:51:59 **Carer06**

And and you know, I'm. I'm doing this. Really just trying to share information.

00:52:04 **Cathy Beresford**

Thank you.

00:52:05 **Carer06**

Yeah. So hopefully it will help.

00:52:08 **Cathy Beresford**

Really, really helpful. Everything you've told me has been really insightful and really helped me to think more deeply about the issues, and there's a lot of crossover between things that you've said and what other people have told me. You know, I am seeing themes coming out of all of this.

00:52:25 **Carer06**

Sure. So yeah, I'm happy to assist in any way I can because I mean I got involved in this because I've learned so much. Yes, getting involved with other patients and doing and hearing about other research and that is why.

00:52:38 **Cathy Beresford**

Yes.

Exactly.

00:52:45 **Carer06**

I'm trying to encourage others.

00:52:46 **Cathy Beresford**

Yeah. Yeah, I appreciate that. One final thought I had and obviously it's completely voluntary. You don't have to tell me this, but do you know exactly what type of liver disease it is that your mum's got?

**Carer06**

No.

00:53:02 **Cathy Beresford**

No, ok. So, they haven't, they haven't confirmed?

**Carer06**

Well, they have, but I wouldn’t – I mean to be honest; I haven't paid any attention to that.

00:53:14 **Cathy Beresford**

No problem. That's fine. Yeah. Yeah.

No problem at all.

00:53:19 **Carer06**

Perhaps you can make sure that you can anonymise that.

00:53:25 **Cathy Beresford**

Well, everything I must say, that's the other thing. The transcript is anonymised. I make sure I go through everything and if you mention any names of places or anything I keep that completely, you know. It is all anonymised.

00:53:39 **Carer06**

Thank you. Thank you. That's all. Yeah, because I just don't want sympathy or any attention to myself. I just.

00:53:46 **Cathy Beresford**

No. So I'm the only person that will actually know your name. I do have my supervisors, and obviously, you know, for the purpose of, like, audit, if there was any concerns about the study, for example, or just for purely auditing purposes they can ask to check. You know who I've spoken to, what, where I've got data from, but everything's kept separate. So, I actually give you like a code. And when you see the transcript, it will say Carer07 **[I meant to say Carer06]** and there won't be any of your name or anything like that on it.

00:54:20 **Carer06**

Sure. Thank you. No, that's fine.

00:54:22 **Cathy Beresford**

OK. Alright. Then I I think that's everything I need to ask you then.

00:54:29 **Carer06**

Right.

00:54:30 **Cathy Beresford**

Yeah, alright, I'll e-mail you next week, but obviously you know, I appreciate your busy. No pressure to respond to me and I'll get in touch again later in the year and let you know how I'm getting on with the research as well.

00:54:43 **Carer06**

Wonderful. Not a problem.

00:54:44 **Cathy Beresford**

Alright then. Thanks ever so much. OK. Take care. Bye bye.

00:54:50 **Carer06**

Bye bye bye.