# Carer04 ‘Mabel’ - Interview Transcript by telephone 20/05/2024 at 10am. 61 minutes

00:00:00 **Carer04**

Yeah.

00:00:01 **Cathy Beresford**

Thank you. And I know that you've done the consent form and had a chance to look at the information leaflet, but have you got any questions at all, anything you want to ask me?

00:00:11 **Carer04**

No, no. Fine. Thank you.

00:00:13 **Cathy Beresford**

So, if at any point you do want to ask me anything, absolutely feel free. And if I ask you anything and it's not clear, please just get me to rephrase it. Or if there's anything I ask and you don't want to answer the question, that's absolutely fine, because how much you say is totally up to you.

00:00:31 **Cathy Beresford**

And I'm truly interested in your perspective, your views and experience. So, there's no right or wrong answer to anything. I'm gonna ask you.

00:00:41 **Cathy Beresford**

Is that OK?

00:00:44 **Cathy Beresford**

Lovely. OK. Thank you.

00:00:47 **Cathy Beresford**

It it sometimes it's helpful for me to ask the the first few questions just because when I'm reporting on the research, I mean everything's anonymised. But just to to show to demonstrate who I've spoken to.

00:01:00 **Cathy Beresford**

Kind of like the range of people. Would you mind confirming your age for me?

00:01:07 **Carer04**

Yeah, I'm [states age].

00:01:08 **Cathy Beresford**

Thank you. And what ethnicity do you consider yourself to be?

00:01:13 **Carer04**

[states ethnicity].

00:01:14 **Cathy Beresford**

OK. Thank you. And what region are you in? Again, it's all anonymised, but just to.

00:01:21 **Carer04**

[states region].Carer

00:01:25 **Cathy Beresford**

OK, lovely.

00:01:29 **Cathy Beresford**

Thank you. Thank you.

00:01:31 **Cathy Beresford**

Alright, so happy for us to start the sort of proper interview questions then.

00:01:38 **Cathy Beresford**

Thank you. Thank you. So please can you tell me a bit about who you've got experience of caring for?

00:01:46 **Carer04**

And it was my husband.

00:01:47 **Cathy Beresford**

Yes, and how long were you caring for him?

00:01:52 **Carer04**

Just with the four weeks.

00:01:53 **Cathy Beresford**

Gosh, so not very long at all.

00:01:56 **Carer04**

Yeah, no.

00:01:57 **Cathy Beresford**

So, from your perspective, can you tell tell me about?

00:02:00 **Carer04**

He was

00:02:02 **Carer04**

Disabled, but in terms of his diagnosis and death, that was four weeks

00:02:05 **Cathy Beresford**

I'm with you. Yeah, I understand. Yeah. So So tell me about your, your husband sort of journey from from diagnosis. Well, you know from from of receiving care. So perhaps from when you first knew that he was ill and until he died.

00:02:20 **Carer04**

Yeah. So the.

00:02:23 **Carer04**

He’d been tired for over 3 weeks, three to four weeks before any diagnosis and we just we had a viral infection, throat infection.

00:02:33 **Carer04**

And he got it.

00:02:34 **Carer04**

And he never seemed to he just was left with this tiredness and there hasn't really been there before. But he also had a lot of muscle wasting and physically disabled as well, and that seemed to increase over that period of time. And he just was looking more and more frail.

00:02:54 **Cathy Beresford**

Yes.

00:02:56 **Carer04**

That after that you look, you know you you will really look you look like.

00:03:01 **Carer04**

You've aged about 10 years.

00:03:02 **Cathy Beresford**

Really.

00:03:03 **Carer04**

If not more, something else going on here and I said I think you need.

00:03:07 **Carer04**

To see the doc, you should be over this by now. So, with all you know, coincidental. I think in some ways.

00:03:15 **Carer04**

Or reach for for to see the doctor for the doctor that they actually and the GP.

00:03:19 **Cathy Beresford**

Yeah.

00:03:24 **Carer04**

Straight away recognised that the liver was very large. Now my husband had been an alcoholic for many, many years over 20 years he struggled with alcohol and do this. He's had a period of of two years of abstinence and start to struggle a little bit with that and not drinking significantly.

00:03:30 **Cathy Beresford**

Yes. Yeah.

00:03:37 **Cathy Beresford**

Right.

00:03:43 **Carer04**

The drinking and started again.

00:03:44 **Cathy Beresford**

Yeah, yeah.

00:03:46 **Carer04**

And so we knew that cirrhosis of the liver already and.

00:03:50 **Cathy Beresford**

Did you?

00:03:51 **Carer04**

And yeah, so generally that had only been picked up and monitored, he was diabetic type 2 diabetes and it generally was only picked up.

00:04:05 **Carer04**

And monitored through blood for his diabetes checks

00:04:08 **Cathy Beresford**

Oh oh, I see

00:04:08 **Carer04**

He was nothing. Never really sort of referred anywhere. He never really saw the GP in between that for anything in terms of his liver.

00:04:19 **Cathy Beresford**

Yeah.

00:04:20 **Carer04**

And.

00:04:22 **Carer04**

And so when the GPsaw him she said that you know you liver’s enlarged had he was slightly jaundiced.

00:04:25 **Cathy Beresford**

Yeah.

00:04:30 **Cathy Beresford**

Yeah.

00:04:31 **Carer04**

Believe it was so subtle. I've never noticed it. Now we've had a it had an episode about a month before. It's just before this tired that started where he his eyes were really yellow. And I happened to just look at him

00:04:45 **Carer04**

This night and I said.

00:04:46 **Cathy Beresford**

Yeah.

00:04:47 **Carer04**

I think you’re jaundiced, and I said if it’s there in the morning and you you, you’re at the doc’s basically you know.

00:04:53

Hmm.

00:04:55 **Carer04**

It disappeared. It disappeared and now it to, to my eyes it probably disappeared, but it possibly a little lessened and his eyes look normal. So of course, the GP pick this up and that's it. And I told her about what happened.

00:04:56 **Cathy Beresford**

Yeah.

00:05:01 **Cathy Beresford**

Yeah.

00:05:08 **Cathy Beresford**

Yeah, yeah.

00:05:10 **Carer04**

And then she said it is very subtle. You.

00:05:12 **Carer04**

Know you literally have.

00:05:12 **Cathy Beresford**

Right.

00:05:13 **Carer04**

To put you know, eyelids down and up to and within with that, she.

00:05:16 **Cathy Beresford**

Yeah.

00:05:23 **Carer04**

Basically, we had to go straight to A&E and she contacted them and alerted them to asked us to go and then he was in A&E. We ended up actually in the wrong hospital. She wanted to go but.

00:05:41 **Carer04**

He was in A&E.

00:05:43 **Carer04**

You know, good sort of six hours.

00:05:45 **Cathy Beresford**

Yeah, yeah.

00:05:47 **Carer04**

Once they've done the blood and checks they've decided they wanted to do some CT scans but wanted to admit him because he's look, he's his liver function was all deranged and clearly that something serious was going on now. He had a blood test 3 weeks in that three-week period when he was on.

00:05:57 **Cathy Beresford**

Yeah.

00:06:06 **Carer04**

When he was tired, he actually had his.

00:06:07 **Cathy Beresford**

Yeah.

00:06:09 **Carer04**

Just before that and he had his and and you know, obviously when he died. And one of the things I asked the GP was.

00:06:18 **Carer04**

How? How could those look that being normal?

00:06:21 **Cathy Beresford**

Yeah.

00:06:22 **Carer04**

And he said he said literally, he said that that there was nothing that red flagged on the blood test.

00:06:27 **Cathy Beresford**

Right.

00:06:28 **Carer04**

And.

00:06:29 **Carer04**

He said other than the normal ranges of what he would have for his cirrhosis, it wasn't having deteriorated, having deteriorated and he said nothing that would have alerted us to and seen them immediately, you know, or.

00:06:34 **Cathy Beresford**

Yeah.

00:06:43 **Cathy Beresford**

I see.

00:06:46 **Cathy Beresford**

Yeah.

00:06:46 **Carer04**

So we thought he was admitted it.

00:06:49 **Carer04**

Was on a.

00:06:50 **Carer04**

Friday and and he had a CT scan of his chest and abdomen.

00:06:56 **Carer04**

On the Saturday.

00:06:58 **Carer04**

And and then he was on a drip all that weekend because hiss potassium and everything. Every everything I think was just completely. Yeah. Wrong. You know, it's it was dehydrated and.

00:07:07 **Cathy Beresford**

Yeah.

00:07:11 **Carer04**

On the.

00:07:13 **Carer04**

Monday. So, I I was going to go see him at at lunchtime and I got a call from him to day, look, the the doctor wants to see you and he wants to see it with you.

00:07:21 **Cathy Beresford**

Yeah.

00:07:22 **Carer04**

And I mean, I thought, well, if they want me there, then that's clearly something serious. And I thought it would be. I thought it would have been the cirrhosis, you know, that it had been his liver was feeling in that way and.

00:07:29 **Cathy Beresford**

Yeah.

00:07:33

Mm-hmm.

00:07:35 **Carer04**

Still no sign of any serious jaundice at this stage.

00:07:39 **Cathy Beresford**

Right.

00:07:41 **Carer04**

So he still looked a normal colour and.

00:07:46 **Carer04**

They took us into a room and more or less said to him that he had liver cancer or more about the needed to to meet and have an MDT to discuss it. However, there were five tumours in his liver and.

00:07:54 **Cathy Beresford**

Right.

00:08:00 **Cathy Beresford**

Yeah.

00:08:04

I see

00:08:06 **Carer04**

were five centimetres in size.

00:08:10 **Carer04**

And one of them, I don't know if it was the bigger one, but the one of the the tumours had invaded the portal vein. At that point, you know, I asked whether he was a candidate for liver cancer [transplant] and he said no because of the number and size of the the tumours.

00:08:17

Yeah.

00:08:29 **Carer04**

And effectively, you know, it was palliative care and there was nothing more that could do for him and the doctor.

00:08:35 **Carer04**

Talked about.

00:08:39 **Carer04**

You know, being able to possibly put a stent in and things like that, but but more being that that that didn't feel [name of person with liver disease] was well enough to endure any surgery because he was so frail. And I listened. He'd lost about half a stone in that that four-day period. It literally his weight just plummeted.

00:08:42 **Cathy Beresford**

Yeah.

00:08:48 **Cathy Beresford**

Yeah.

00:08:52 **Cathy Beresford**

Yeah.

00:08:59 **Carer04**

And.

00:09:03 **Carer04**

It was probably one of the hardest things I've had to [voice breaks up].

00:09:07 **Cathy Beresford**

Yeah.

00:09:10 **Cathy Beresford**

Yeah, sounds really that sounds really hard. Sounds really tough.

00:09:16 **Carer04**

It's it still gets when I think about it. I mean the doctor was absolutely fantastic. She was so caring you know.

00:09:19

Yeah.

00:09:28 **Cathy Beresford**

Sorry, who was that?

00:09:29 **Carer04**

Just that time, you know, and took her time talking to him, but he he never anything. I think he was just in shock.

00:09:39 **Cathy Beresford**

Yeah. Sorry, you broke up. You broke up just then. Who? Who did you say that was? Was that the doctor or the nurse?

00:09:45 **Carer04**

Sorry.

00:09:46 **Cathy Beresford**

Did you say the doctor?

00:09:48 **Carer04**

It was a doctor. Yeah, there was.

00:09:49 **Cathy Beresford**

Oh, yeah, yeah, yeah. So, they would. They took their time and.

00:09:49 **Carer04**

Two doctors.

00:09:54 **Carer04**

Yeah, yeah, absolutely brilliant. And you know, I I asked because I think, you know, he was just sat there at this stage in absolute silence and.

00:10:03 **Cathy Beresford**

Yeah.

00:10:06 **Carer04**

What can he expect?

00:10:10 **Carer04**

She said you, you know, I I can't tell you that, but you haven't, you know.

00:10:14 **Cathy Beresford**

No.

00:10:18 **Carer04**

And.

00:10:20 **Carer04**

More or less sort of try to.

00:10:24 **Carer04**

Didn't really, didn't really explain. You know what could happen whether you know the of that, what to expect. There was none of that described to us and that and I guess at that stage they probably thought it was too much to to, you know, to to tell.

00:10:27

Yeah.

00:10:37

By.

00:10:38

Next.

00:10:40 **Carer04**

And.

00:10:41 **Carer04**

But I was left thinking that like, well, well, what happens next, you know, she obviously then explained that the thing that they would do, an urgent referral to.

00:10:54 **Carer04**

The Macmillan team.

00:10:55 **Cathy Beresford**

Yeah.

00:10:58 **Carer04**

The palliative care team and.

00:10:59 **Cathy Beresford**

Yeah.

00:11:01 **Carer04**

But then realised that he hadn't had a CT scan of his head because one of the things that I had said was that he was getting stuck on words. So you.

00:11:09 **Carer04**

Got a little bit confused.

00:11:09 **Cathy Beresford**

Right.

00:11:12 **Carer04**

We want to double check that so we we then have to state and stay for to have that and then obviously they wanted the results back. So once they got that, they said that was all clear.

00:11:25 **Carer04**

That, that being some scar in in one of these longs that was a shadow, but they were convinced that that wasn't.

00:11:35 **Carer04**

It hadn't spread. They felt that it was definitely primary liver cancer.

00:11:39 **Cathy Beresford**

Yeah.

00:11:39 **Carer04**

And.

00:11:41 **Carer04**

The skull and possibly what he's had two episodes of when he's given up smoking many, many years previously he'd had.

00:11:47 **Cathy Beresford**

Yeah.

00:11:50 **Carer04**

And a couple of, you know, quite severe chest infections after that over the which were problematic and clear.

00:11:58 **Carer04**

So that they felt that that with that history was possibly from that rather than anything more sinister. They didn't feel like he was necessary. They they felt that by doing that that may actually speed up the whole.

00:12:04

Yeah.

00:12:15 **Carer04**

Spread of the cancer and that it could actually back. Yeah. Yeah. Right where you know where to going.

00:12:16 **Cathy Beresford**

OK.

00:12:26 **Carer04**

But it it it suddenly it became important.

00:12:30 **Carer04**

Well, what sort of cancer? You know? Yeah. You said liver cancer, but what type? And and I found searching for those answers online.

00:12:33 **Cathy Beresford**

Yeah.

00:12:37 **Cathy Beresford**

Did you?

00:12:39 **Carer04**

Trying to find, I mean I.

00:12:40 **Carer04**

Did so much reading all of.

00:12:41 **Carer04**

It that all week

00:12:43 **Carer04**

And I'm just trying to understand.

00:12:46 **Carer04**

What it was.

00:12:48 **Carer04**

The speed of it, what to expect with any complications, ascites, you know, all sorts of things. None of that was explained. And whether that you know whether that might happen.

00:12:50 **Cathy Beresford**

Yeah.

00:12:53 **Cathy Beresford**

Yeah.

00:12:59 **Cathy Beresford**

Right.

00:13:00 **Carer04**

You know [name of person with liver disease] literally called, just wanted to come home and he didn't want or anything. So, you know, and what he said to us was that the, the MDT that would have would be on the Wednesdays, that was the Monday. And on the Wednesday we got a call to go up to one of the other.

00:13:03 **Cathy Beresford**

Yeah.

00:13:19 **Carer04**

Hospitals and to see your consultant and by this stage he.

00:13:25 **Carer04**

And it was probably over about an hour's drive. But yeah, we'll have to do. And he was in.

00:13:33 **Carer04**

He had severe nausea by this stage.

00:13:35 **Cathy Beresford**

Yeah.

00:13:37 **Carer04**

Which should you know, happen within the the sort of day from coming home. Yeah. And we really struggled for that journey.

00:13:45 **Carer04**

It wasn't so much discomfort with it, and we then sat.

00:13:50 **Carer04**

But for about 3 hours in an A&E, wait where it was, it was new patient waiting area, then sat in a room with no windows. I mean, it was the the worst hospital I've ever seen in my life and looked up and.

00:14:04

Yeah.

00:14:04 **Carer04**

And then all right, no problem.

00:14:30 **Carer04**

Sorry.

00:14:30 **Cathy Beresford**

No problem.

00:14:33 **Carer04**

And so he told.

00:14:41 **Carer04**

Who was a liver specialist, Consultant. I think that point and more or less just said what the the previous doctor had talked to him about.

00:14:50 **Cathy Beresford**

Yeah.

00:14:53 **Carer04**

And just said that, you know, they they did feel that they agreed with the the diagnosis.

00:14:59 **Carer04**

That again, Palliative care team would be in touch and sent away and and that was it in terms of any hospital involvement in his care.

00:15:03 **Cathy Beresford**

Yeah.

00:15:05 **Cathy Beresford**

Yeah.

00:15:13 **Cathy Beresford**

Yeah.

00:15:13 **Carer04**

Well, diagnosis, that was it.

00:15:15 **Cathy Beresford**

Yeah.

00:15:18 **Carer04**

You know, and again I asked in terms of treatments whether there was anything that could help prolong his life, anything that would reduce any complications. And he said no.

00:15:25 **Cathy Beresford**

Yeah.

00:15:29 **Cathy Beresford**

Right.

00:15:30 **Cathy Beresford**

Yeah.

00:15:31 **Carer04**

There was nothing further that could do for him.

00:15:33 **Cathy Beresford**

Yeah. And so that was with them, was that with a liver consultant that appointment?

00:15:38 **Carer04**

Yeah, yeah, yeah. A specialist

00:15:39 **Cathy Beresford**

Did you see anybody anybody else at that appointment?

00:15:44 **Carer04**

No, no, that was it.

00:15:45 **Cathy Beresford**

Yeah.

00:15:46 **Cathy Beresford**

So then then what happened after that?

00:15:50 **Carer04**

Though we.

00:15:52 **Carer04**

We came home at the following day and got a call from the Community nurses and this is where it got really confusing and was I didn't know we we had a community nurse came out and did an assessment on him and and I said palliative.

00:16:12 **Carer04**

The palliative care team that apparently 2 referrals have now gone into them and nobody's been in touch.

00:16:16 **Cathy Beresford**

Yeah, yeah.

00:16:19 **Carer04**

And but we, you know, we'll organise everything and.

00:16:22 **Carer04**

So, he had there was an OT, that physio came out testing for equipment and he needed for home and the GP came to see him and did a Respect form for him and talk to him about, you know, whether he wanted to go to hospital for anything. And he said no.

00:16:31 **Cathy Beresford**

Yeah.

00:16:44 **Carer04**

He filled all of that in with the GP. GP also did anticipatory medications and looked what you needed so that at that point the.

00:16:51 **Cathy Beresford**

Yes.

00:16:57 **Carer04**

Has given him Tramadol.

00:17:00 **Carer04**

Because he wasn't experiencing any pain, it had pain. But on his left, his abdomen. He had two episodes of pain before his diagnosis, and it was like an overnight pain. And he's to suffer quite a lot with bowel problems and neuropathy and bowel.

00:17:04 **Cathy Beresford**

Yeah.

00:17:16 **Carer04**

And.

00:17:18 **Carer04**

And he's not actually experienced any pain in his liver at all. And she prescribed that she prescribed, I think, should put on Midazolam on the anticipating made and that was it. So of course, me reading, you know, and I thought, well, there should be other.

00:17:20 **Cathy Beresford**

Yeah.

00:17:31 **Cathy Beresford**

Yeah.

00:17:36 **Carer04**

Things on there surely.

00:17:37 **Cathy Beresford**

Right.

00:17:37 **Carer04**

And.

00:17:38 **Carer04**

And spoke to the community nurses and asked them and they said, oh.

00:17:41 **Carer04**

They would get in.

00:17:41 **Carer04**

Touch with the GP and just that that was, you know, there was other things.

00:17:42 **Cathy Beresford**

Yeah.

00:17:46 **Carer04**

That need to be on there.

00:17:48 **Carer04**

And and then none of that really happened. Nothing really happened, changed without that. The GP rang back and just said no. They were happy with what was on there and thought, well, what happens if there's complications and other other things, secretions and things that that will obviously increase. And all of that stuff.

00:17:56 **Cathy Beresford**

OK.

00:18:00 **Cathy Beresford**

Yeah.

00:18:08 **Carer04**

By this stage I was probably getting calls from Hospice at home.

00:18:14 **Cathy Beresford**

Right.

00:18:15 **Carer04**

The community and then disappeared at that point. And then I was getting calls from OT and Physio and they they sort of all the equipment out and they were absolutely fantastic. Blooming heck, I mean I didn't realise you could have much equipment you know.

00:18:24 **Cathy Beresford**

Yeah.

00:18:28 **Carer04**

It was it.

00:18:28 **Carer04**

Was crazy. So at that point we decided we didn't want to bed downstairs. He was. He was still managing the stairs.

00:18:34 **Cathy Beresford**

Yeah.

00:18:36 **Carer04**

But we've got a commode.

00:18:39 **Carer04**

And then.

00:18:41 **Carer04**

We didn't hear anything from the community nurses for two weeks and.

00:18:45

Yeah.

00:18:48 **Carer04**

He obviously, you know, was his appetite was was really crappy. He fluid intake was.

00:18:53

Hmm.

00:18:54 **Carer04**

Into.

00:18:55 **Carer04**

Crap. And I was like, really worried I was.

00:18:56 **Carer04**

Thinking like and.

00:18:56 **Cathy Beresford**

Yeah.

00:18:57 **Carer04**

I got preoccupied with that. Like, you know, just drink. Please drink, drink something, you know and.

00:19:02 **Cathy Beresford**

Yeah.

00:19:04 **Carer04**

I think it's, you know, after his death, you know, and and reading things about the dying body and listening to people, you know, part of caring about it. I thought, oh my God, you know, I felt really awful. I.

00:19:12

Yeah.

00:19:17 **Carer04**

Felt like I was.

00:19:20 **Carer04**

Pressuring him into to doing that and it was desperation of.

00:19:21

Yeah.

00:19:23 **Cathy Beresford**

I see.

00:19:25 **Carer04**

Hanging on to him, you know.

00:19:26 **Cathy Beresford**

Yeah.

00:19:27 **Carer04**

When I think about.

00:19:29 **Carer04**

But nobody nobody explained any of that to me. Nobody.

00:19:33 **Carer04**

Explained any of.

00:19:34 **Carer04**

That and you know, when I sort of reflected over the last few months, I.

00:19:41 **Carer04**

I'm not thinking [name of person with liver disease] died in shock. He he never he never had. He literally. He nearly slept for four weeks. You know, he the first few weeks he was up and about and he was watching the TV and he was on his phone. All of that was gradually sort of, you know.

00:19:43 **Cathy Beresford**

Do you? Yeah.

00:19:55 **Cathy Beresford**

Yeah.

00:19:58 **Cathy Beresford**

Again.

00:20:00 **Carer04**

Yeah.

00:20:02 **Carer04**

Most of the time he slept and need, or at least getting to drink something. And and we have bouts where we would eat something and seem to enjoy it and then, you know, you wouldn't want anything. So that went on.

00:20:15 **Carer04**

For four weeks.

00:20:16 **Carer04**

But the care and the nurses kept asking us.

00:20:20 **Carer04**

Wanted anybody in to help.

00:20:22 **Cathy Beresford**

Right.

00:20:23 **Carer04**

And I had no, you know, I'm, I'm coping up coping, OK.

00:20:25

Hmm.

00:20:27 **Cathy Beresford**

Yeah.

00:20:29 **Carer04**

It was exhausting, but I wanted.

00:20:30

Hmm.

00:20:32 **Carer04**

And it was the last thing I.

00:20:33 **Carer04**

Could do for my husband, you know, while.

00:20:33 **Cathy Beresford**

Yeah, yeah.

00:20:36 **Carer04**

Really, really tough.

00:20:38 **Cathy Beresford**

Yeah.

00:20:38 **Carer04**

And.

00:20:41 **Carer04**

It it felt like I needed to do that, and I needed to do that alone. I mean, I've had. I've got daughters

00:20:45 **Cathy Beresford**

Yes.

00:20:47 **Carer04**

Daughters.

00:20:48 **Carer04**

And.

00:20:49 **Carer04**

They were here as well. My mother come to help as well. So she was, you know, just doing all the housework and all of.

00:20:55 **Carer04**

Those things that.

00:20:55 **Carer04**

I could just focus on [name of person with liver disease] and my employer.

00:20:58 **Cathy Beresford**

Yeah.

00:21:01 **Carer04**

I mean, I work for the NHS and and my employer. I mean he my manager was absolutely brilliant. He just said, look, you know, we'll we'll book book annual leave off because I only work part time and I retired. So have that capacity to be able to do that and.

00:21:06 **Cathy Beresford**

Yeah.

00:21:12 **Cathy Beresford**

Yeah.

00:21:19 **Carer04**

You know, pulled out from work and and cared for him. So, I was lucky in that I could do that.

00:21:23 **Cathy Beresford**

Yeah.

00:21:30

The.

00:21:31 **Carer04**

Other parts I guess were.

00:21:35 **Carer04**

All for that two-week period. He then started to deteriorate in terms of his mobility and and put like a, you know, baby monitor and this was before. So, you then start to have problems on the stairs. And I asked if I could get a stairlift and I was told that I would have to pay for that.

00:21:53 **Cathy Beresford**

Yeah.

00:21:54 **Carer04**

Where I started to arrange to get that put in place and then I realised actually he was struggling. He was getting very unsteady on his legs and my husband was tall. So even though he, you know, was he lost weight, he was still a very tall man and very.

00:22:03 **Cathy Beresford**

Yeah.

00:22:12 **Carer04**

I felt quite risky on the stairs with him because he I was having to actually plant his foot on each step from the get him down steep stairs and I said look, I think we need to ask for the bed downstairs. We asked them, you don't want to do that at all.

00:22:26

Yeah.

00:22:30 **Cathy Beresford**

No.

00:22:31 **Carer04**

Too risky on the stairs that you’re gonna fall so he agreed. And we just rearranged the whole of the downstairs and.

00:22:34 **Cathy Beresford**

Yeah.

00:22:41 **Carer04**

I rang the physios and they arranged for.

00:22:45 **Carer04**

A bed to come for him, and that came literally the next day, you know, so that that we we didn't wait for any of the equipment. It was brilliant, you know, I've heard other people say that the wait, the wait days or week a week for for certain equipment but everything was in place and then.

00:22:57

I see.

00:23:01 **Cathy Beresford**

Yeah.

00:23:03 **Carer04**

The OT came out and.

00:23:07 **Carer04**

Assessed in for sliding sheets and all of that for the day, they had a mattress but then realised that the bed wasn't long enough for him. That happened at the contract to them again and said, look his feet and and he had. He had significant neuropathy in his feet, he'd actually had.

00:23:10 **Cathy Beresford**

Yeah.

00:23:16 **Cathy Beresford**

By.

00:23:25

Yeah.

00:23:27 **Carer04**

Been passed for over 4 years with a A, A charcot foot.

00:23:30 **Carer04**

Uh.

00:23:31 **Cathy Beresford**

Yeah.

00:23:31 **Carer04**

And.

00:23:32 **Carer04**

And so I was really, you know at ulcer in between his toes, I was really.

00:23:36 **Carer04**

Worried about that

00:23:38 **Cathy Beresford**

Yes.

00:23:39 **Carer04**

And.

00:23:40 **Carer04**

So they.

00:23:42 **Carer04**

Arranged for the equipment going to come back and put an extension on the bed and that took a couple of days for that to.

00:23:48 **Carer04**

Happen but all.

00:23:50 **Carer04**

Of that I.

00:23:50 **Carer04**

Felt like I was having the coordinate, and you know, obviously this one is that you know they were really, really responsive and.

00:23:52 **Cathy Beresford**

Yeah, yeah.

00:23:59 **Carer04**

And then.

00:24:02 **Carer04**

He started in into sort of like.

00:24:08 **Carer04**

The third week at you could see he was he was deteriorating, and the sleep was getting longer and longer and longer. So, you know, I was obviously delivering personal care to him and all the way through that they kept asking, you know, are you sure you don't want anybody to come and help you? What about nighttime? And I said the baby monitor.

00:24:16 **Cathy Beresford**

Yeah.

00:24:24 **Cathy Beresford**

Yeah.

00:24:28 **Carer04**

So I can.

00:24:28 **Carer04**

Hear him. And I've told him the.

00:24:29 **Cathy Beresford**

Yeah.

00:24:30 **Carer04**

There's any, you know, he needs me.

00:24:31 **Cathy Beresford**

Hmm.

00:24:33 **Carer04**

Couple of times where he tried to get up to go to the toilet by.

00:24:35 **Carer04**

Himself, you know, being stubborn and.

00:24:36 **Cathy Beresford**

Hmm.

00:24:39 **Carer04**

Both my I literally was tuned in so good.

00:24:43 **Cathy Beresford**

Yes.

00:24:45 **Cathy Beresford**

Yeah.

00:24:46 **Carer04**

But.

00:24:47 **Carer04**

He then started to use the commode and.

00:24:52 **Carer04**

Sort of week four. He it's really hard, isn't it? It's like.

00:25:00 **Carer04**

Everything becomes so jumbled.

00:25:02 **Cathy Beresford**

Yeah.

00:25:03 **Carer04**

That week.

00:25:06 **Carer04**

But I was.

00:25:07 **Carer04**

I mean, even though I had my daughters here, we've had - he become really, really confused and.

00:25:14

Yeah.

00:25:17 **Carer04**

At that up to that point, we haven't seen any palliative care and I had at the Hospice at home contacting me daily.

00:25:26 **Carer04**

And at one point I was on the phone to the community nurse and I was on a phone on the phone to the Hospice and I said.

00:25:31 **Carer04**

I have no idea who.

00:25:32 **Carer04**

I'm speaking to literally the so many people.

00:25:33 **Cathy Beresford**

Yeah.

00:25:36 **Cathy Beresford**

Yeah.

00:25:37 **Carer04**

Just leave it with me, she said. We will deal with you now from the Hospice, she said. I'll ask the one through so that you're.

00:25:41 **Cathy Beresford**

Yeah.

00:25:44 **Carer04**

Dealing with one.

00:25:46 **Carer04**

One person.

00:25:47 **Cathy Beresford**

Sure.

00:25:50 **Carer04**

And the first couple of days of that last week, he started to get really confused. No, actually, before the confusion he.

00:26:03 **Carer04**

Couldn't swallow it. He stopped being able to swallow, and he said I've got a bit of pain in the liver, but not not like, you know, severe pain said. What do you want to tramadol and by this stage the.

00:26:06 **Cathy Beresford**

Yeah.

00:26:14 **Cathy Beresford**

Yeah.

00:26:23 **Carer04**

The doctor had taken them off all of these. These medications, apart from pain relief because he was taken, you know, an absolute catalogue of stuff.

00:26:26 **Cathy Beresford**

Yes, yes.

00:26:31 **Carer04**

And I said, look, you know.

00:26:34 **Carer04**

Does he need to be on all of this and they said no, we're gonna take off everything. But it was me.

00:26:36 **Cathy Beresford**

Yeah.

00:26:38

Showing.

00:26:40 **Carer04**

Watching that and asking that the whole time, they just thought, you know, that's happened. It shouldn't have been down to me to ask about that. You know, like things like.

00:26:42 **Cathy Beresford**

Yeah.

00:26:47

Yeah.

00:26:51 **Carer04**

For cholesterol, for blood. No blood pressure, antidepressants.

00:26:53 **Cathy Beresford**

Yeah.

00:26:56 **Carer04**

And you think?

00:26:58 **Carer04**

You need all of that. Yeah. So all of that taken off.

00:27:04 **Carer04**

He'd also suffered prior to that, he'd suffered from severe constipation.

00:27:10 **Cathy Beresford**

Yeah.

00:27:12 **Carer04**

And couldn't go to the loo and was in so much pain and I'd rang the doctor and said look, he needs. He needs an enema or something and.

00:27:23 **Carer04**

Or suppositories we’ll try suppositories but they didn’t work, and this was by day three this was.

00:27:31 **Carer04**

This was probably the.

00:27:32 **Carer04**

First week after his diagnosis and.

00:27:38 **Carer04**

Said to the doctor.

00:27:39 **Carer04**

I think he needs an enema so prescribing.

00:27:41 **Cathy Beresford**

Yeah.

00:27:44 **Carer04**

And.

00:27:45 **Carer04**

4 chemists did not stock it. Ohh sorry. The prescribed enema. And I think it was a Micromax didn't work.

00:27:51 **Cathy Beresford**

Yeah.

00:27:53 **Carer04**

Then didn't work and then eventually prescribed a phosphate enema and no chemist had it. I had to bring around everywhere trying to try and find somewhere that could get me and and you know.

00:28:00

Right.

00:28:04 **Cathy Beresford**

Yeah.

00:28:07 **Carer04**

I've got about four of them.

00:28:08 **Carer04**

And I administered that myself, but that maybe because I'm a nurse and you know the nurse. Do you want me to come and do it or?

00:28:12 **Cathy Beresford**

Yes.

00:28:15 **Cathy Beresford**

Yeah, I see. Yeah.

00:28:16 **Carer04**

Do.

00:28:16 **Carer04**

You want to do it and I said I'll do it if not, I know what I'm doing, I mean.

00:28:19 **Cathy Beresford**

So.

00:28:22 **Cathy Beresford**

Yeah.

00:28:23 **Carer04**

But it was.

00:28:23 **Carer04**

It was. It was a bit like.

00:28:27 **Carer04**

Should I be doing this or should you be doing this you know and I I don't know that that I knew what I was doing. They didn't ask me to explain to them and I thought, OK, never mind. Anyway, I've given that and we thought we got him sorted. He was.

00:28:29 **Cathy Beresford**

Yeah.

00:28:34 **Cathy Beresford**

Yeah.

00:28:41 **Carer04**

Much more comfortable and.

00:28:44 **Carer04**

And then the last week, he asked her. I've tried to give him the Tramadol and he couldn't. He couldn't swallow it. So this was at at.

00:28:52 **Cathy Beresford**

Yeah.

00:28:56 **Carer04**

I think it was about 7:00 at night and I've been told that I had to ring.

00:29:04 **Carer04**

111 and asking for the palliative care team and that was how I accessed them, because to that point in the middle.

00:29:09

Yeah.

00:29:13 **Carer04**

And.

00:29:14 **Carer04**

I went through 111. I had to go through all of the.

00:29:17 **Carer04**

Questions and I said.

00:29:17 **Carer04**

Look, I was told if the palliative team you would put me straight through, I didn't have to go through all of these questions that you're asking. Husband is dying.

00:29:22 **Cathy Beresford**

Yeah.

00:29:27 **Carer04**

And and they said oh.

00:29:28 **Carer04**

Well.

00:29:29 **Carer04**

You need to go through the first time, and I thought this is ridiculous anyway.

00:29:31 **Cathy Beresford**

Yeah.

00:29:33 **Carer04**

I got through.

00:29:34 **Carer04**

To the the palliative care team contacted us. We'll come come out to see within about an hour and at that point they literally just took over. They they looked at all of the anticipated we made and said what

00:29:42

I see.

00:29:47 **Carer04**

What's going on? This needs to be all sorted out, sorted all out for all the medication.

00:29:47 **Cathy Beresford**

Yeah.

00:29:50 **Cathy Beresford**

Yeah.

00:29:52 **Carer04**

And updated all of the forms and and sort of the syringe driver. Put them onto and.

00:30:02 **Carer04**

Morphine, a very, very low dose of morphine at that point.

00:30:05 **Cathy Beresford**

Yeah.

00:30:06 **Carer04**

And.

00:30:08 **Carer04**

And then.

00:30:11 **Carer04**

He was fine.

00:30:11 **Carer04**

For about a day. And then he started to get really, really confused. He felt then he nearly fell.

00:30:16 **Cathy Beresford**

Yeah.

00:30:19 **Carer04**

Out of bed.

00:30:21 **Carer04**

And was absolutely insistent he needed the loo and I said look.

00:30:25 **Carer04**

You know, you're really struggling would would have a a rotunda in place. So, I got that, and it was working really well.

00:30:31 **Cathy Beresford**

Yeah.

00:30:32 **Carer04**

And and.

00:30:34 **Carer04**

The the second day of using that, I got him out the bed.

00:30:40 **Carer04**

Got him onto the the commode and when I came to go back. Stand back up he couldn't actually grip the rotunda.

00:30:45

Yeah.

00:30:47

Yeah.

00:30:49 **Carer04**

And he literally his hands were just he just couldn't grip at all. And I said, look.

00:30:52 **Cathy Beresford**

Hmm.

00:30:54 **Carer04**

I'm I'm going to need to get [daughter’s name] and I. I by this point. I had tried to avoid the the the girls being involved because of the personal care. I I wanted to, you know, maintain didn't didn't want to see their dad in that way and deal with that. So you know I had no choice. I had to call my my daughter.

00:31:03 **Cathy Beresford**

Yes.

00:31:07 **Cathy Beresford**

Yes.

00:31:12 **Cathy Beresford**

Yeah.

00:31:14 **Carer04**

And she'd have to help me.

00:31:18 **Carer04**

Get him back in. To stand him up.

00:31:19 **Carer04**

And get him back into the bed and.

00:31:24 **Carer04**

I guess the hardest one of the hardest things around the personal care was.

00:31:32 **Carer04**

Seeing his bodily functions change urine being not literally black. Stools just you know what, chalky and white and.

00:31:38

Yeah.

00:31:43

Yeah.

00:31:47 **Carer04**

And looking looking at that deterioration, you know and and realising that his body is dying and that's probably one of the toughest things that.

00:31:53 **Cathy Beresford**

Yes.

00:31:56

Yeah.

00:31:58 **Carer04**

His teeth started to go like really dark.

00:32:00 **Cathy Beresford**

Yeah.

00:32:03 **Cathy Beresford**

Yeah.

00:32:04 **Cathy Beresford**

Sounds really hard.

00:32:05 **Carer04**

Sorry.

00:32:12 **Cathy Beresford**

Take your time.

00:32:15 **Cathy Beresford**

If you need a break, it's fine.

00:32:22 **Cathy Beresford**

You're OK.

00:32:24

You know.

00:32:28 **Carer04**

I’ve not really talked through everything that happened.

00:32:34

Yeah, yeah, yeah.

00:32:36 **Carer04**

Anybody.

00:32:38 **Cathy Beresford**

Is this the first time you've had this kind of?

00:32:40 **Cathy Beresford**

You've really gone through everything like.

00:32:43 **Cathy Beresford**

Yeah, it's a lot to process, isn't it?

00:32:50 **Carer04**

It's.

00:32:55 **Cathy Beresford**

Yeah.

00:32:55 **Carer04**

Watching someone that that, you know, there is nothing you can do to prevent.

00:33:04 **Cathy Beresford**

No.

00:33:07 **Carer04**

But I.

00:33:07 **Carer04**

Guess.

00:33:09 **Carer04**

The comfort, the comfort that that I draw from it is that I did all I could and he was comfortable.

00:33:14 **Cathy Beresford**

Yes.

00:33:16 **Cathy Beresford**

Yeah.

00:33:17 **Carer04**

You know he didn't suffer and.

00:33:17

Yeah, yeah.

00:33:22 **Cathy Beresford**

It sounds like you really coordinated and advocated a lot for him.

00:33:30 **Carer04**

Yeah, yeah, I think it's.

00:33:35 **Carer04**

The the the sort of the couple of days of of that last week where you started to get confused. I realised, you know, he literally had lost all capacity at that point to.

00:33:44 **Cathy Beresford**

Yeah.

00:33:47 **Carer04**

All all of he was preoccupied with was what to get out of bed to go.

00:33:50 **Carer04**

To the loo.

00:33:51 **Cathy Beresford**

So.

00:33:51 **Carer04**

And trying to explain to him that he couldn't stand.

00:33:54 **Cathy Beresford**

Hmm.

00:33:56 **Carer04**

Not his ability to stand and I said that you're gonna hurt yourself, you injure yourself.

00:33:59 **Cathy Beresford**

Yeah.

00:34:02

Yeah.

00:34:03 **Carer04**

And we, you know, we don't deal with that and he just couldn't understand that at all all in his mind, he just was really.

00:34:12 **Carer04**

Getting upset because he wanted to go. The thing that that I would prevent them from doing that, and I felt awful, really awful. I felt like.

00:34:13 **Cathy Beresford**

Yeah.

00:34:20 **Cathy Beresford**

Yeah.

00:34:22 **Carer04**

You know that.

00:34:25 **Carer04**

Yeah, but I was stopping him from doing what he wanted.

00:34:30 **Carer04**

And not saying that I wasn't protecting them.

00:34:32

Yes.

00:34:35 **Carer04**

And looking out for.

00:34:36 **Cathy Beresford**

Yeah.

00:34:38 **Carer04**

I felt awful to felt really awful.

00:34:41

Yeah.

00:34:43 **Carer04**

Two days where he.

00:34:46 **Carer04**

I have.

00:34:48 **Carer04**

Literally, that's all he was trying to do was get his legs out of the bed and we will have to sort of restrain him. In some ways. You know, we will have to.

00:34:51

Yeah.

00:34:56 **Carer04**

And prevent him from doing that and kept in with help.

00:35:00 **Carer04**

[daughter] helping.

00:35:01 **Cathy Beresford**

Yeah, he was agitated, yeah.

00:35:04 **Carer04**

Very urge to just not, you know, he wasn't lashing out there, but he was. He was angry because.

00:35:12 **Carer04**

We wouldn't do what he wanted to do, you know, and that's all.

00:35:14 **Cathy Beresford**

Yeah, yeah.

00:35:16 **Carer04**

He wanted to.

00:35:16 **Carer04**

Do was get out of the bed

00:35:18 **Cathy Beresford**

Yeah.

00:35:19 **Carer04**

It's it's got to the point on the

00:35:21 **Carer04**

I think the second day.

00:35:23 **Carer04**

Where he.

00:35:28 **Carer04**

It got so distressed that I just aid to [daughter], look, you know, let's just lift up the commode and both me and my daughter did that and that that helped him. He just he called because he would get through by this stage, you know, he had a pad on. And I said just go in the pad, you know, it's OK just.

00:35:40 **Cathy Beresford**

Yeah.

00:35:47 **Cathy Beresford**

Yeah.

00:35:47 **Carer04**

Go in the pad. I'll clean it. Don't worry. And he just couldn't, you know, or everything.

00:35:51

No.

00:35:54 **Carer04**

Telling them I wanted to feel the toilet. You know, I don't want to do this and.

00:35:56 **Cathy Beresford**

Yeah.

00:36:01 **Carer04**

We did that and and that was at that point I I rang the.

00:36:06 **Carer04**

Nurse and said look.

00:36:08 **Carer04**

I think he needs to be catheterised, you know, I know that he'll still get that sensation.

00:36:11 **Cathy Beresford**

Yeah.

00:36:15

He.

00:36:18 **Carer04**

So distressed and and they came out.

00:36:19 **Cathy Beresford**

So.

00:36:23 **Carer04**

The palliative team had also been out that day to put Midazolam in his syringe driver to try to help, you know, calm him a little bit.

00:36:31 **Cathy Beresford**

Yeah.

00:36:34 **Carer04**

And they said, you know, you you might, you might try and pull the catheter out, you might try, you know, obviously and all that and and said. But once we've got this, you know, under control.

00:36:37 **Cathy Beresford**

Yeah.

00:36:44 **Carer04**

And you'll be a lot calmer. And and that should, you know, resolve itself basically.

00:36:50

Yeah.

00:36:50 **Carer04**

So they catheterised at that point when he was catheterised, he wasn't really aware he was, he was out of it, you know, in terms of the medication that that that had in the driver.

00:37:01 **Carer04**

And and.

00:37:05 **Carer04**

OK.

00:37:09 **Carer04**

And thinking about the medications and the syringe driver, that you know that the whole way through that they told us what they were doing, and you know, sort of the communicate that was really good and.

00:37:15 **Cathy Beresford**

Yeah.

00:37:22 **Carer04**

But that two-day period coping with him exhausted me entirely, and obviously because I knew I couldn't leave him and the following day.

00:37:27 **Cathy Beresford**

Yeah.

00:37:31 **Cathy Beresford**

Yeah.

00:37:34 **Carer04**

The.

00:37:36 **Carer04**

Hospice at home team rung and they said, look, you know, do you want anybody? And I said, yeah, I said I'd not - I've got enough people around to help during the day. I said but nighttime and I'm I'm not sleeping literally listening for him the whole time because I don't feel I can leave him and it's not safe.

00:37:48 **Cathy Beresford**

Yeah.

00:37:53 **Cathy Beresford**

No.

00:37:56 **Carer04**

And.

00:37:59 **Carer04**

And.

00:38:01 **Carer04**

For that night, I had slept on the on the chair in the living room with him, just so I could be beside him and keep an eye on him. And then.

00:38:06 **Cathy Beresford**

Yeah.

00:38:09 **Carer04**

The following evening, I got awake in night staff in and I have to say all of that was really.

00:38:16 **Carer04**

There was no stress around that at all. They just they they told me they would be, you know, they were there from 10:00 at night till 7:00 in the morning.

00:38:19 **Cathy Beresford**

Yeah.

00:38:26 **Cathy Beresford**

Yes.

00:38:28 **Carer04**

There were.

00:38:30 **Carer04**

You know, really respectful, and I barely knew they were here. And you know, they just said, look, you know, if you want us to wake you, we will. You don't. That's fine.

00:38:37 **Cathy Beresford**

Yeah.

00:38:40 **Cathy Beresford**

Yeah.

00:38:41 **Carer04**

And I said no, anything changes. I want you to to wake me and you know.

00:38:45 **Cathy Beresford**

Yeah.

00:38:47 **Carer04**

So I managed to.

00:38:48 **Carer04**

Have a couple of of good night’s sleep.

00:38:51 **Cathy Beresford**

Yeah.

00:38:53 **Carer04**

Well anyways.

00:38:55 **Carer04**

And and you don't stop like 5:00 in the morning till you can't really rest. So, you at least you got. I got some sleep and.

00:38:57 **Cathy Beresford**

Yes.

00:39:00 **Cathy Beresford**

No.

00:39:04 **Cathy Beresford**

Yes.

00:39:08 **Carer04**

Throughout that period, so they, you know, obviously in between that I would still provide that personal care to him and.

00:39:15 **Carer04**

Just sitting with him. You don't talk to him.

00:39:16 **Cathy Beresford**

Yeah, yeah, yeah.

00:39:19 **Carer04**

Be a presence like I said, even though he wasn't by this stage, he was pretty much unconscious.

00:39:27 **Carer04**

And then.

00:39:31 **Carer04**

I think kind of, yeah, all of the equipment pretty much all the equipment that will put in there to try and obviously get to the loo and stuff I'd put in the garage just to try and create some space because it was so cluttered in the living room.

00:39:44 **Cathy Beresford**

Yeah.

00:39:45 **Carer04**

And.

00:39:49 **Carer04**

I think the the the last day.

00:39:52 **Carer04**

I had woken up.

00:39:55 **Carer04**

Not 5:00 gonna come down the stairs for some reason. I just suddenly.

00:40:03 **Carer04**

I don't know. I don't know what it was, but I just suddenly woke up and come down, I thought. And then it's everything. Like his breathing has literally just changed and.

00:40:07 **Cathy Beresford**

Yeah.

00:40:11 **Cathy Beresford**

Ohh yeah yeah.

00:40:16 **Carer04**

That I don't think you know. He's got he's got much.

00:40:18 **Carer04**

Longer.

00:40:18

No.

00:40:20 **Carer04**

Thought that was I run that my other daughter said I think you need to come over.

00:40:25 **Cathy Beresford**

Yeah.

00:40:27 **Carer04**

And woke [other daughter] up and we spent.

00:40:30 **Carer04**

The whole day with him

00:40:32 **Carer04**

Playing music that he loved, reading passages of a book.

00:40:34 **Cathy Beresford**

Yeah.

00:40:37

Yeah.

00:40:38 **Carer04**

Reminiscing

00:40:40 **Carer04**

You know you clearly.

00:40:43 **Carer04**

It wasn't conscious, but you know, I like this sort of that. And and that went on until 6:00 at night, 5 past six, when I was reading that, my daughter said Mum, his breathing has just changed and it just became.

00:40:44 **Cathy Beresford**

No.

00:40:53 **Cathy Beresford**

Yeah.

00:41:03 **Carer04**

To be very laboured and because of that point was quite rapid but very deep.

00:41:09 **Cathy Beresford**

Yeah.

00:41:10 **Carer04**

Breathe rapid breathing and be like for hours.

00:41:14 **Carer04**

And by the stage, I mean by the stage, it was completely yellow, you know, week two he went completely yellow.

00:41:22 **Carer04**

And and.

00:41:26 **Carer04**

Nobody explained any of that you know. I've been left with it. Nobody. Anything. I mean all.

00:41:32 **Cathy Beresford**

Yeah.

00:41:36 **Carer04**

All the practical stuff was there everything, but you know in terms of support?

00:41:38

Yes.

00:41:41 **Carer04**

But the emotional support the the, the mental health aspect of nobody sat and spoke to [name of person with liver disease] or offered him opportunity to speak or ask questions.

00:41:42 **Cathy Beresford**

Yeah.

00:41:52 **Cathy Beresford**

Right.

00:41:54 **Cathy Beresford**

Yes.

00:41:54 **Carer04**

There was nothing, absolutely nothing offered to him.

00:41:59 **Carer04**

Without my presence or with my presence, you know.

00:42:01 **Cathy Beresford**

Yeah.

00:42:04 **Cathy Beresford**

Yeah.

00:42:04 **Carer04**

While he probably would not have accepted it.

00:42:08 **Carer04**

He was a very.

00:42:11 **Carer04**

A very quiet man and I think he, he, he probably met his head on this little there's nothing I can do. But you know, I I kept sort of trying to say to him as anything else I can do. Do you need anything? Do you need any?

00:42:13

Hmm.

00:42:25 **Cathy Beresford**

Yeah, yeah.

00:42:29 **Carer04**

And he said no and.

00:42:32 **Carer04**

So, I never pushed that because I thought he's clearly not ready. He's not ready to to question. He's not ready to even probably acknowledge what's happened to him. And. And so I have been left.

00:42:35 **Cathy Beresford**

Yeah.

00:42:43 **Carer04**

He, he, he he didn't need to have the time or the energy to come to terms

00:42:48 **Carer04**

With what was happening.

00:42:49 **Cathy Beresford**

Yes, I see.

00:42:51 **Carer04**

And and I guess the hardest bit for

00:42:55 **Carer04**

It it's the fact that he was not offered that which I think is the most important.

00:42:58 **Cathy Beresford**

Yeah.

00:43:00 **Cathy Beresford**

Yeah, I understand. Yeah.

00:43:04 **Carer04**

Forgotten about

00:43:05 **Cathy Beresford**

Yeah.

00:43:06 **Carer04**

You know, and the diagnosis that he's just been given, which is.

00:43:11 **Carer04**

You know about the worst thing you could ever be given.

00:43:13 **Cathy Beresford**

Yes.

00:43:16 **Carer04**

So exactly, I think is probably the bit that.

00:43:21 **Carer04**

Really let things down.

00:43:25 **Carer04**

You know a a while.

00:43:27 **Carer04**

We were being asked if we were OK before managing.

00:43:29

Hmm.

00:43:32 **Carer04**

We weren't given the.

00:43:34 **Carer04**

The level of information that I expected that I should have been.

00:43:36 **Cathy Beresford**

Yeah.

00:43:38

Yeah.

00:43:38 **Carer04**

On what to expect, you know what happened to a dying person and use of of of you know. But I I didn't know from the context. Just a moment. Liver cancer. I didn't know what.

00:43:43 **Cathy Beresford**

Yeah.

00:43:51 **Cathy Beresford**

No.

00:43:54 **Carer04**

What would happen. What to look out for.

00:43:55 **Cathy Beresford**

Yeah.

00:43:57 **Carer04**

I had to really start myself and educate myself, so I felt prepared and and look out for you.

00:43:57

Yeah.

00:44:04 **Cathy Beresford**

Yeah.

00:44:07 **Carer04**

Know.

00:44:10 **Carer04**

That the reason that was important was me understanding the the progress of of this cancer, but also making sure that he didn't suffer.

00:44:17 **Cathy Beresford**

Yeah.

00:44:21

Yes.

00:44:21 **Carer04**

You know, and not [inaudible] as quickly as I could be because I knew what to expect. So those elements were really, really poor, really poor and and.

00:44:32 **Cathy Beresford**

Yeah.

00:44:36 **Carer04**

The.

00:44:39 **Carer04**

That that day that he died.

00:44:43 **Carer04**

He.

00:44:45 **Carer04**

I got a call.

00:44:49 **Carer04**

I’d a call in the night before that arranged obviously for a support staff to come in that night, so I have to ring them and say, look he's he's died and.

00:44:54 **Cathy Beresford**

Yeah.

00:45:00 **Carer04**

That didn't. That message didn't seem to get to the right person because I got a call right about 7pm to say that they weren’t coming, and l have already advised that, you know, that he’d died and and.

00:45:04 **Cathy Beresford**

OK.

00:45:12 **Cathy Beresford**

Yeah.

00:45:16 **Carer04**

We have the palliative care team came out at 9:00 that night and certified that he had died.

00:45:27 **Carer04**

That was in and you know, obviously all of the.

00:45:29 **Carer04**

Throws of the.

00:45:29

Yeah, yeah.

00:45:29 **Carer04**

GP.

00:45:32 **Carer04**

That so

00:45:35 **Cathy Beresford**

Yeah.

00:45:37 **Cathy Beresford**

Thank you. You've given me so much information and really giving me so much insight into his experience and your experience as well.

00:45:47 **Cathy Beresford**

I suppose thinking about everything that you both went through and and your daughters as well.

00:45:54 **Carer04**

Yeah.

00:45:54 **Cathy Beresford**

In in view of that, what what advice would you give to professionals working with individuals who've got advanced liver disease and their carers?

00:46:03 **Carer04**

I think you know the the advice is is.

00:46:07 **Carer04**

Think about that, that person's just being given that diagnosis, you know, and.

00:46:15 **Carer04**

And afford them time, obviously for that to sink in

00:46:19 **Carer04**

But they need to visit that, revisit that with the person you know and actually ask, is there anything that you need? You know, do you

00:46:23

Yeah.

00:46:27 **Carer04**

Need to talk to.

00:46:28 **Carer04**

One of us about, do you need explained and for carers

00:46:28 **Cathy Beresford**

Yeah.

00:46:34 **Carer04**

Definitely explain and.

00:46:37 **Carer04**

What you know and.

00:46:43 **Carer04**

It's that disjoint, isn't it? Between, you know, the the Community nurses and the palliative care team that that confusion, I mean, who who's doing what? I mean, there was nurses coming or.

00:46:50 **Cathy Beresford**

Yeah.

00:46:53 **Cathy Beresford**

Yeah.

00:46:55 **Carer04**

Are you a palliative care nurse or

00:46:56 **Carer04**

are you community or what's the difference?

00:46:57 **Cathy Beresford**

Yeah.

00:46:59 **Carer04**

So, it's all of that and.

00:47:02 **Carer04**

But also, someone coordinating that rather than you having multiple, I mean, yeah, you know, you need, you need different professionals coming to see and to to deal with certain things. I get that. But someone coordinating that and and that you have not one or one team to contact and important and.

00:47:15 **Cathy Beresford**

Yes.

00:47:19 **Cathy Beresford**

Yeah.

00:47:23 **Carer04**

For me, probably people who.

00:47:27 **Carer04**

Did that the best was that that the Hospice at home team.

00:47:30 **Cathy Beresford**

Yeah.

00:47:30 **Carer04**

They seem to be the one of that being and and coordinated things.

00:47:32 **Cathy Beresford**

Sure.

00:47:35 **Cathy Beresford**

Yeah.

00:47:35 **Carer04**

And you know, and explained how that all worked because I hadn't a clue. You know, I think.

00:47:40

Hmm.

00:47:43 **Carer04**

I think one of the community nurses, you know, did a continuing healthcare assessment on him.

00:47:50 **Carer04**

And obviously I've never really explained about the funding. And yeah, how did this?

00:47:55 **Carer04**

You know, and and obviously I've got an understanding of that because of my background, a lot of families wouldn't have a clue of things. Do we need to pay for carers? And that was really, you know, and they didn't know that I was in the.

00:47:59 **Cathy Beresford**

Yes.

00:48:01 **Cathy Beresford**

Yes.

00:48:04 **Cathy Beresford**

Yeah.

00:48:07

Show.

00:48:09 **Cathy Beresford**

No.

00:48:12 **Carer04**

This should be explained not to to families. How? How would they know? But I I do feel that.

00:48:15 **Cathy Beresford**

Yeah.

00:48:17 **Cathy Beresford**

Yeah.

00:48:21 **Carer04**

That those those elements of that and elements of.

00:48:26 **Carer04**

I guess the.

00:48:28 **Carer04**

The care that I've.

00:48:29 **Carer04**

Given me having to reach out and contact and and.

00:48:35 **Carer04**

And there were elements of that. The only reason I knew to do that was because of my background. And I thought, what about families who haven’t got that?

00:48:40 **Cathy Beresford**

Yes.

00:48:43 **Cathy Beresford**

Yes.

00:48:45 **Cathy Beresford**

Yeah.

00:48:46 **Carer04**

You know, they're just left sat there thinking no one will come.

00:48:50 **Cathy Beresford**

Yeah.

00:48:51 **Carer04**

So that that there are elements of that.

00:48:53 **Carer04**

I think that they.

00:48:54 **Carer04**

Really need about.

00:48:55

Hmm.

00:48:57 **Carer04**

But the but the the.

00:48:58 **Carer04**

The main bit of it is the bit about the person themselves and be left with that diagnosis.

00:49:02

Mm-hmm.

00:49:05 **Carer04**

Sent home and not having anybody ask

00:49:12 **Carer04**

Do you want us to to explain to you about, you know, what could happen when you die and what things can occur to complications?

00:49:16 **Cathy Beresford**

Yes.

00:49:21 **Cathy Beresford**

Yeah.

00:49:22 **Carer04**

And and even if that person doesn't want to know the family, the family might want to know and might need to know.

00:49:24 **Cathy Beresford**

Yeah.

00:49:29 **Carer04**

You know.

00:49:29 **Cathy Beresford**

Yeah.

00:49:32 **Carer04**

And I think that's really important that.

00:49:34 **Carer04**

They’re offered that

00:49:37 **Cathy Beresford**

Yeah.

00:49:38 **Carer04**

Because if everybody's looking with doing the doing and and that the impact of that diagnosis and pending death.

00:49:47 **Carer04**

It wasn't really talked about.

00:49:48 **Cathy Beresford**

Yeah, yeah.

00:49:50 **Carer04**

Like you know.

00:49:51 **Cathy Beresford**

Yeah, yeah.

00:49:54 **Cathy Beresford**

When you know when you're.

00:49:55 **Carer04**

And I think about the anticipatory meds

00:49:59 **Cathy Beresford**

Oh yes.

00:50:01 **Carer04**

I felt like I was having to deal.

00:50:02 **Carer04**

With that, I was.

00:50:03

Hmm.

00:50:04 **Carer04**

No.

00:50:05 **Carer04**

And that shouldn't have been been for me to have to challenged: as this correct?

00:50:12 **Carer04**

You know that up until the point of when the palliative care team came to see him there wasn't anything in there, and he ended up having to have hyoscine because his secretion started, his chest got really rattly and gurgley that.

00:50:24 **Cathy Beresford**

OK.

00:50:26 **Cathy Beresford**

Yeah.

00:50:30 **Carer04**

That you know.

00:50:30 **Cathy Beresford**

Yeah.

00:50:31 **Carer04**

There was meds that were on there that hadn’t previously and and I kept thinking if they hadn't come out and done that again, I could have been running around ringing round and sort that out at the point of when you need, you know, so.

00:50:40 **Cathy Beresford**

Yeah.

00:50:43

Hmm.

00:50:50 **Carer04**

Yeah.

00:50:51 **Cathy Beresford**

Yeah, yeah.

00:50:54 **Cathy Beresford**

So, you know when you're having this kind of conversation and you're reflecting back on everything, sometimes something comes to mind that maybe you hadn't thought about before or that hadn't really occurred to you. Is there anything like that that sort of springs to mind?

00:51:14 **Carer04**

Can you just

00:51:17 **Carer04**

Receptions not very good.

00:51:19 **Cathy Beresford**

Ohh, can you hear me?

00:51:19 **Carer04**

Right. Can you just say that again?

00:51:20 **Cathy Beresford**

Yeah, sure. I was just saying that, you know, sometimes when you're having kinds of conversations. Oh, OK, hold on. Is that any better?

00:51:24 **Carer04**

Yes.

00:51:30 **Cathy Beresford**

Can you hear me?

00:51:33 **Cathy Beresford**

Yeah. Yeah. Sorry. Yeah. Sometimes when you're having this kind of conversation, something can kind of occur to you that perhaps hadn't. You hadn't thought of before. Is there anything that sort of springs to mind that perhaps you hadn't thought about previously before? We were talking about this.

00:51:50

Oh.

00:51:53 **Carer04**

Yeah, I can. I can see you though, do you that, that, that sort of comes to mind is is the, you know what happens when someone dies at home. So again, nobody explained to us what I should do and I thought, OK, so how does this work? Do I ring

00:52:07 **Cathy Beresford**

Yeah.

00:52:13 **Carer04**

an undertaker, none of that was again, none of that was explained to us and and I had to.

00:52:20 **Carer04**

Read up about well.

00:52:21 **Carer04**

Who do I? Who? Who should I?

00:52:22 **Carer04**

Contact when he dies.

00:52:22 **Cathy Beresford**

Yes.

00:52:24 **Carer04**

And then asked the palliative care team who, who do I? Who do I call? I don't call the GP, do I? And she said no. She said you call us on the 111 number. And I said OK, but nobody explained any of that to us. And again, you know what happens to his body. Does it stay here and then do I do I contact the Undertaker?

00:52:39 **Cathy Beresford**

Yeah.

00:52:44 **Carer04**

And arrange that.

00:52:46 **Carer04**

And how long can I have him at home all the sort

00:52:48 **Cathy Beresford**

Yeah.

00:52:49 **Carer04**

Of things like that, that.

00:52:50 **Cathy Beresford**

Yeah.

00:52:52 **Carer04**

You need to know about what to do and.

00:52:53 **Cathy Beresford**

Yeah.

00:52:55 **Cathy Beresford**

Yeah.

00:52:57 **Carer04**

You know, again, I've had to read and understand about what happened and cause I've never looked after someone at home and and I've never had any of my family die at home. So I I didn't know that, you know, and.

00:53:05 **Cathy Beresford**

No.

00:53:07 **Cathy Beresford**

No.

00:53:13 **Carer04**

So I I guess that's the other bit is you know what what happens after death?

00:53:15 **Cathy Beresford**

Yeah.

00:53:18 **Cathy Beresford**

Yeah, yeah, yes.

00:53:18 **Carer04**

You know what? What are the processes?

00:53:21 **Cathy Beresford**

That's a that's a really helpful point. Thank you. That's good to know.

00:53:26 **Cathy Beresford**

Is. Have you got anything you want to ask me now that we've sort of gone through everything?

00:53:34 **Carer04**

No, no, I think I mean, you know, the reason I put myself forward for this is because we've, we've done a bit of fundraising for the liver trust and and my daughter, my daughter ran in the marathon at [place name]. And and you know to raise money and and I think.

00:53:43 **Cathy Beresford**

Yeah.

00:53:49 **Cathy Beresford**

Oh yeah.

00:53:54 **Carer04**

The the the one thing that sort of sticks is.

00:53:58 **Carer04**

That [name of person with liver disease] had cirrhosis and you know when I've.

00:54:04 **Carer04**

He’d got it got copies of his medical records, I think was he was putting in for life insurance and he didn't get it. And and he was really incensed to why. And so he got his medical records to see what was in there. And so I ended up going through those and because I thought, you know, having been honest with me, you know.

00:54:06 **Cathy Beresford**

Yes.

00:54:18

Yes.

00:54:23

Yes.

00:54:23 **Carer04**

Had he told me about his liver?

00:54:27 **Carer04**

And and or. Had things got worse and he hadn't told me. And there wasn't. And when I looked back on years of records like he thought there was very little conversation in there from the GP about cirrhosis of the liver. You know that the the general conversation was you, you have, you know, you have to stop drinking.

00:54:34 **Cathy Beresford**

Yeah.

00:54:47

Right.

00:54:47 **Carer04**

And and it left me thinking, why was he never offered a scan? Why was he never referred to a specialist? You know, why was it he was only checked once a year for his diabetes?

00:54:51 **Cathy Beresford**

Yeah.

00:54:55 **Cathy Beresford**

Yeah.

00:55:00 **Cathy Beresford**

Yeah.

00:55:01 **Carer04**

And you know, that might not have prevented him from getting liver cancer. I know that.

00:55:05 **Cathy Beresford**

Yeah.

00:55:07 **Carer04**

But it it felt that it should have been closer monitored. It should have been more closely monitored and so that that's my reason for doing some of this because I just think you know, if if that that if that research and and that scanning can prevent someone from going through.

00:55:10 **Cathy Beresford**

You understand?

00:55:16 **Cathy Beresford**

Yeah.

00:55:23 **Cathy Beresford**

Yeah.

00:55:27 **Carer04**

Then then that, that, that that's something that's really positive because I don't think he had any concept he was at risk of liver cancer and you know, and and also the progression of the cirrhosis, I don't think anyone really explained that to him. You know so when that.

00:55:36

Yeah.

00:55:38

Yeah.

00:55:47 **Carer04**

Diagnosis landed. It was a real shock.

00:55:49 **Cathy Beresford**

Yeah, yeah.

00:55:51 **Carer04**

You know, and it it would have been anyway, but I think I think in his head it he thought it was his cirrhosis.

00:55:52

Yeah.

00:55:57 **Carer04**

That.

00:55:57 **Cathy Beresford**

Yeah.

00:55:57 **Carer04**

One of the problems.

00:55:59 **Cathy Beresford**

Yeah, that makes sense what you've said, yeah.

00:56:03 **Cathy Beresford**

I don't. I don't think I need to ask you anything else, because you've actually given me such a really. You know, you've explained everything so well and thoroughly. I feel like I've really got very clear insight into what you all went through.

00:56:17 **Cathy Beresford**

What what I do is.

00:56:20 **Carer04**

I know I'm a very good storyteller.

00:56:22 **Cathy Beresford**

No, you you, you really explained it so well. Sorry, I've just got a tickly cough. Hang on. What I will do is I have to go through. I have to transcribe the interview. So put it into words.

00:56:36 **Cathy Beresford**

But that's quite quick to do nowadays because the technology does it for you. But I have to sort of tidy it, cause it doesn't always pick up the the words correctly, and I'll anonymise it, you know? So if you put any names in, I'll just take them out and then what I'll do is.

00:56:49 **Cathy Beresford**

At some point within the next couple of weeks, I'll send it to you so that you can have a copy and also you can just check it and then if there's anything else you think of or anything you wanna correct, you know, feel free to do.

00:56:57 **Carer04**

OK.

00:57:02 **Cathy Beresford**

So.

00:57:03 **Cathy Beresford**

Now the research is I'm I'm due to finish interviewing people in October and then I I don't actually hand in the project until autumn next year, but I will, you know, I definitely give you a summary of the results at the end, but I I am thinking cause that is quite a long way away that I might actually.

00:57:06 **Carer04**

Yeah. OK.

00:57:23 **Cathy Beresford**

Just jot an e-mail to people before that as well, just to let them know you know how I'm getting on because I know it's nice to be kept in the loop of what's actually.

00:57:31 **Cathy Beresford**

Happening.

00:57:32 **Carer04**

OK.

00:57:33 **Cathy Beresford**

But you know, if at any point you don't wanna hear from me or you do wanna hear from it, you know, you just let me know because I don't wanna be intrusive. But at the same time I wanna make sure that you're getting information if you want it sort of thing. I'm not. Don't worry. I'm not gonna be like contacting you on a regular basis or anything. But it's just like making sure that you you do know what what happens to all of this.

00:57:42 **Carer04**

OK. No, that's fine.

00:57:54 **Cathy Beresford**

And so really what I'm trying to do is kind of get like this sort of holistic overview of what people's experiences are. I mean, you know.

00:57:57 **Carer04**

Yeah.

00:58:01 **Cathy Beresford**

Really there is.

00:58:02 **Cathy Beresford**

I've spoken to quite a few people now and it does depend on where you live in the country, what services you access, what type of liver disease you've got. But there's some things that are coming up time and again and then some things which are variable.

00:58:15 **Cathy Beresford**

If that makes sense, so you know the thing about wanting information and not always getting it. You know, I I am hearing stuff about that.

00:58:19 **Carer04**

Yeah, yeah.

00:58:23 **Cathy Beresford**

But is there anything else you want to say before I before I finish the interview?

00:58:30 **Carer04**

No.

00:58:32 **Carer04**

No, that's fine, Catherine, that's brilliant.

00:58:33 **Cathy Beresford**

Yeah. And I, you know, one final thought thought actually is because it, you know it's it's it's I. I hope you found it helpful to actually talk through it. I know it's painful and it's hard to have these sorts of conversations, but sometimes it can be helpful as well. But do you have anyone else that you can talk to or?

00:58:53 **Cathy Beresford**

Yeah.

00:58:55 **Cathy Beresford**

But you know, if you did ever want to talk to me, please do.

00:58:56 **Carer04**

Yeah, I mean, I've I've had, I've had bereavement counselling. So, yeah, I've I've. Yeah, I have, yeah.

00:59:00 **Cathy Beresford**

Have you? Yeah.

00:59:03 **Cathy Beresford**

That's positive.

00:59:06 **Cathy Beresford**

Yeah, well, I'm, you know, I will like when I send you.

00:59:09 **Carer04**

You know it's nothing.

00:59:14 **Cathy Beresford**

Term hi. Yes, sorry.

00:59:15 **Carer04**

Hello.

00:59:18 **Carer04**

Oh, sorry, no, I was just. I was just going to say, yeah, it's given me the opportunity to talk through.

00:59:23 **Carer04**

Some of it.

00:59:23 **Carer04**

But the whole story, I've never gone through, so it's been quite, quite emotional, but that again.

00:59:25 **Cathy Beresford**

Yes, yes.

00:59:29 **Cathy Beresford**

Yeah, yeah, yeah, I can completely appreciate that. You know, and I I truly value you doing that.

00:59:52 **Carer04**

Looked in entirely.

00:59:54 **Cathy Beresford**

I think we're, we're lucky cause the the receptions obviously not very good, but we're just coming to the end.

01:00:02 **Cathy Beresford**

Well, I'll, I'll.

01:00:03 **Cathy Beresford**

Wrap up now, but thank you so much and you know, please feel free to reach out to me if you want to about anything you know.

01:00:13 **Carer04**

OK. Thank you.

01:00:14 **Cathy Beresford**

Yeah, cause like I say, you know, I am a nurse myself and.

01:00:18 **Cathy Beresford**

You know, the research is important, but actually you know what you've been through. So you know you've been through a lot. And and I'm. I'm here as well. If you did want to to talk again just off the you know nothing to do with the interview. OK.

01:00:34 **Carer04**

Lovely. Thank you very much, Catherine.

01:00:35 **Cathy Beresford**

Thank you. Thank you so much. Take care. Alright, bye. Bye bye.

01:00:39 **Carer04**

Thank you.