

Geeta and Sheena Access to healthcare

Sheena

Since we've been in touch with LOROS so it was like halfway through mum's journey. That's when our journey got a lot easier. The consultants and the specialist nurses there, and the way they organise all the different organisations and they actually interact.

So they'll interact with the ventilation team or the occupational therapy team, whereas before there was no connection of those services. Everything's a lot smoother.

Any concerns you have or any problems, they're there all the time. They're amazing. So they have their own consultants and the specialist nurses there, but that it just is reassuring for us because we arrange mum's care, mum's appointments, just to have someone else to go to, someone that's a specialist just for advice and guidance.

And even like when we're having problems with sort of the caring company and was always someone else to go to that we can turn to. And they are very supportive, not just to mum to the whole family. Although they don't provide the counselling and stuff like that, but it's a really big help. I'll always be grateful.

They also offer like a day therapy. It was a three month period that mum could go. It was every two weeks and it was such a good social thing for mum to go to because mum was so happy. She looked forward to going.

They would arrange transport with the escort that would come and take mum. So she didn't have her regular carer, she didn't go with family so that was mum's freedom to be away from everyone and everything and the activities that they did there.

Mum really liked it. She came home with lots of things she had made and yeah, she sometimes is reluctant to go out. She'll make excuses saying it's cold or it's dark or it's raining, but you never had an issue getting on the LOROS line and going, yeah, no, she loved it.

It was only for a short period because of funding, but I think it's due to start in February. So she's excited to go back.

I do feel like if there was a regular sort of day centre or day therapy, it would really help patients' emotional wellbeing as well. And it gives us a break as well. That, "Okay we're not worrying about who's looking after mum? Where is she?"

We know she's in safe hands because there's lots of doctors and nurses there, and just seeing the happiness in her face when she came back made us really happy as well.

I think we were assigned one of the nurses anyway, because she's an MND specialist that works at LOROS so it was just sort of a smooth transition. We knew she worked at LOROS there, so it wasn't sort of scary for us because we were like, that's the organisation she works for.

She's really resourceful and she's involved a lot in mum's care. When she suggested sort of visiting, it wasn't really a challenge or an obstacle for us to sort of overcome and think, oh God, it's a hospice.

When you go there, it's a really beautiful—

Geeta

Really nice place.

Sheena

—environment. Yeah, mum likes going.

They've got gardens, they've got lots of flowers, lots of artwork. So it's very peaceful. When we do go, we go for mum's doctors appointments there now, so when we're there, often we'll just have a little walk around or roam around the actual building.

Geeta

Staff are very nice.

Sheena

Yeah. Staff are lovely and it's accessible for mum as well. Another thing as well is having mum's, some of my mother's appointments there, mum feel safer than when we go to a hospital because when we go to the hospital there's two elements.

Mum feels like she's going to catch an infection from somebody. It feels a lot safer for mum to go to the hospice for her appointments. And second thing, after mum's hospital admissions, if we have to go to the hospital for an appointment mum's angry, annoyed.

Even if we're driving past the hospital, she'll turn her head the other way so she doesn't look at the hospital so it doesn't feel like she's going to a medical appointment.

Going to the hospice because the environment. So yeah. Yeah, because, because when mum's been to hospital a few times and it's led to a couple of really long admissions, mum gets scared.

So even if we're going to get a checkup or we've called a paramedic out, or we've gone to A&E. The first thing mum will say to them before she will explain any of the symptoms, is, "I'm not staying I'm going home". Because she's deteriorated both times, quite a lot while she's there.

So she's associated hospital admissions with that deterioration. But we don't have any issues or dramas going to mum's appointments at the hospice. It's a really nice environment that's created for patients.

And so the term that's, that people, sort of associate with the hospice isn't scary. It's not a bad place. It's really nice.