

HOW DOES IT FEEL FOR ME?

Joyce / November 2019

HOW HAS YOUR HEALTH BEEN IN IN THE LAST MONTH?

Not good, obviously I think its worry, stress about my daughter (having been critically ill in hospital). It's not being able to talk to anyone on my own which would help. I can't walk very far, the pains in my legs are just the same. I am run down and if I'm not careful I really do think I'll have a breakdown.

YOU WANTED TO TELL ME ABOUT YOUR DAUGHTER'S CARE IN ST JAMES' HOSPITAL...

All I can say is thanks to the Resus, the ICU, and obviously the ward she's been on in Jimmy's (J10, then moved to J12). They never left her side, and ICU were coming up to see her twice a day, sometimes three times a day to make sure she was OK. She had wonderful treatment.

WHAT ABOUT HEALTH PROFESSIONALS YOU'VE SEEN FOR YOURSELF?

I think I've seen Jenny (Community Matron) who is very good, Richard (who takes the blood) and spoken to the doctor yesterday.

WHAT MAKES JENNY, THE COMMUNITY MATRON GOOD?

She's straightforward, honest, she explains. She's always at the end of the phone if we need her. She makes every effort to come out or get one of the team to come out day or night to see us if we phone. She's always, always in touch with the doctor after a visit and I think the quality of her care is outstanding.

DID YOU WANT TO SAY ANYTHING ABOUT YOUR CARERS THIS MONTH?

One is in a world of her own, she doesn't rush for nobody. She'll be down to come at such and such a time and you can guarantee she'll be late. I think it was half past seven she was due to come last night, and she came at quarter to nine. The other one is a brilliant sitter where she can sit down and natter, natter, natter, but the care side of it, unless she's got someone with her to prompt her, no way! She's not a carer, she's a sitter.

HOW IS IT FOR YOU AND EDGAR, BOTH LIVING WITH LOTS OF DIFFERENT HEALTH CONDITIONS?

Well, Edgar always has been worried for me and he does do most of the things for me. If I get up and try and do anything, he plays pot with me because he thinks I'm going to fall. And of course, I get up, I try and because of my health it affects my balance. I haven't told Edgar but I've had two near falls going down to the bathroom. I've got to think for both of us when it comes to that. He does worry a great lot about me, and of course if he's worried, then I'm worried. The thing that worries me most is if he falls, like he did yesterday, I can't get to him to help him. And that cuts me in two. I can't get there, even if I did get there, I'd have to stay on the floor, I wouldn't be able to get up. My immediate reaction is to get to him, and then when I get to him I want to phone somebody and I've left my phone back on the table. I've thought about getting a pendant emergency button [instead of on my phone like I have now] but do I stay the way I am, without putting pressure on my family? Because if the alarm goes off, it goes through to them.

That's another thing with Edgar, he's had quite heavy nose bleeds and he's been told if they last longer than 15 minutes he has to call ambulance. Every time he sneezes, I'm thinking 'oh no, not another one!' and then his arms because he's got such thin skin, they start to bleed, they just pop and bleed. I'm forever watching him, if you like, and I'm trying to observe his colour, and his how can I put it, his relaxation (he shakes).

Sometimes you need to talk to the Community Matron on your own so you've got a sounding block, because on the medical side of things, you need that, so that they can see how you're looking, how you're feeling. The one to one is very important. I don't want him [Edgar] to lose his independence but I would like him to accept a little more help from people. I think it would do us both good to have someone to talk to on our own. At the moment we're usually both in the same room when they come. It would do Edgar good to be able to talk more about how he feels about me.

HAS YOUR CARE FELT 'JOINED UP'?

The locum doctor came out and I showed her my wrist which was swollen, the pain was awful when I moved my fingers. She sent me to have an x-ray at LGI and took some bloods. One thing that I can say is that these tests I've had done three or four weeks ago, I've had no results come back from the doctor, nothing. It's strange because I thought that all these tests and that, the results go straight back to your GP and I've not heard a thing. It's many a time I'm sat here and I'm trying to hold my cup and I have to literally put my other hand on it so I can pick up the cup, and I can't move it without the shakes. Without the results, I don't know whether it's my arthritis, osteoporosis or what.

I often don't get to know about my test results. I can ring up and they tell you a bit. Jenny (Community Matron) is allowed to tell me so much, and if there's anything wrong she would. I think it's a must that you know about them (test results) because I've always said if you know what's in front of you - what you've got, not what you'd like - then it will help you come to terms with it. I get cross when no one gets back to me, I'd just like an explanation, even if there's nothing wrong it would put my mind at ease.

HOW HAS COMMUNICATION FROM HEALTH PROFESSIONS BEEN?

If the doctors or medical team were more up front then it would help me to understand what they were saying to me. Simple things like naming of tablets, or when a new company has taken over and you're thinking 'What's this? I don't know this', and you're having to ring the chemist to find out if it's the same tablet, just a different name. And if they'd just said the name had changed. When I could I'd go up to the chemist, I'd go up and ask them, but I feel I've lost that now because I get them delivered. I have medication reviews but it's the same thing over and over again. I'd like to have an update really, I would like to know if it's possible that they (the different tablets) would (a) disagree at some point with your insides, (b) whether some of them contain things that are not really needed and (c) if you could ever OD on any of the medication. You need to know what your body is taking in.

IF YOU COULD HAVE CHANGED ONE THING TO MAKE YOUR EXPERIENCE BETTER THIS MONTH, WHAT WOULD IT BE?

Having the option of having a one to one with my Community Matron. It's very important to have a sounding board.