healthwatch
working together in West Yorkshire

A selection of stories about Palliative and End of Life Care

A 2024 Healthwatch Book

Included are a selection of 24 stories about End of Life Care in West Yorkshire.

This storybook is about End of Life care and contains content that some people may find upsetting.

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Chapter 1:

> [Everything] was early on decided with the care plan, [it] had parts which were questions about religious desires and needs.

[My son] was diagnosed with Batten’s in 2013.

He started having seizures in 2012, so we took him to the GP, and he was diagnosed in April. Then we were given a link to palliative care team and palliative care pathway. [With Batten’s] basically kids are fine until the age of two and then they start showing seizures, hearing loss, mobility loss and they can't eat or do anything for themselves, and my son was the same.

He lasted a lot longer than doctor expected because he was really poorly in the beginning. In 2015, we thought that he wouldn't make it, it looked really bad, he couldn’t eat anymore. It looked like he was going to pass, and then he kind of perked up, then the gastroscopy was put in in 2015 and that helped us to administer medication properly and [manage] the fluid issue as he couldn't eat anything.

And then he had good few years at school. We needed them [medical staff] less at that time. We did see them all the time in school and there was always care planning to be done. But he had school, [for a few years he] attended more school than hospital. But then in [a few years later] he had severe pneumonia and it kind of became more regular to go back to hospital again.

He had pancreatitis without any reason, and then he had COVID as well. [With] the pancreatitis and pneumonia he ended up in hospital, but for COVID he was home. Then the last couple of years he was mostly home because we also decided to keep him home. The decision was made to keep him home, so the nurses and the doctors more came [to our] home from the children's hospice, and the palliative care team whenever we need them.

[Everything] was early on decided with the care plan, [it] had parts which were questions about religious desires and needs. They had a whole section where we discussed what we would like to do if things happened or what we want involved and stuff like that. So, it was already written down.

When he had pancreatitis [towards the end of his life], he was in hospital for about five to six weeks, and he needed a lot of cannulas. That was our first big episode [for a couple of years]. He had been in for short periods for seizures and stuff like that, but this was the first time that he went for that long. It just was too much for him. The cannulas were just too much.

Towards the end we started [that] every time somebody pushed his hand or foot, he would move it. So that told us that he was in a lot of pain.

> **So, the plan was made to keep him home. Because it looked like no matter what they did, it wouldn't be beneficial, [the decision] was more about comfort -**

Then [he had] a scan, an EEG because we were worried that he was having this weird episode where his eyes were rolled up while he was asleep. We need to do that because there was a possibility of him passing away because of a seizure. Then that told us that [he] had very minimal brain activity. So, on the basis of that, [APPROX 6 MINS] we all - us and the doctor from the children's hospice and the palliative care nurse – we all discussed the idea that we would keep him at home no matter what happens now. We had a meeting in my home, and we discussed all the possibilities we can do.

So, the plan was made to keep him home. Because it looked like no matter what they did, it wouldn't be beneficial, [the decision] was more about comfort - that he's comfortable and he's in an environment [with] his family, we are a very small family so we couldn't be in hospital all the time.

So, the decision was made that whatever happens, he would be here with his family in his own room in the house. The first time we did the end-of-life care plan [many years prior], the decision was made that we're not going to do any sort of resuscitation or intubation, that was already decided [that] I'm not going to do it. Because it was explained [to us] that it's going to be futile, they'll just be another thing to [give him] pain and then take care of as well.

[APPROX 7:45] So [the palliative care nurse] made it possible that we had everything at home, including oxygen, all the machines and all the medication like morphine and specific injections and stuff like that. So, they [the staff] brought everything home. And they signed up on the paper that we didn't have to - say it happened on the weekend - we can say to them [we've got a] written paper that we don't have to go to hospital. We just want to keep him home.

We have known [the palliative care nurse] for a while, we met the first time in 2021, and we have known the doctor for a lot longer. [Because they knew us, they] kind of knew what we were thinking. [The doctor is] amazing anyway, she just suggested that this is the best scenario for [my son], just to keep him more comfortable and we could still change our mind. We were told that if we would say on the day with her, “OK, now we want to take [him] into hospital”, we could still do that.

[APPROX 10:30] To figure out our son, you had to know him. It was a lot more complicated than it looked. [The palliative care nurse] knew him, so she always kind of chipped in the way she thought we should do things with him, even though she might not be on the case. Because she was here a lot. I mean, she was here when things were really bad in 2015/14. So, she saw us almost every day in the hospital, home everywhere.

I think the people around [my son] did everything [they could]. The main thing we couldn't do was to save him, but everything else that was possible, they all did it, whether it was school or healthcare nurses or doctors. People who knew him longer could make better decisions about [my son]. Not that the doctors [at hospital] weren’t qualified, but it just the people who knew him […] the doctor would always make sure that things were done the way she would want them because she, or the palliative care nurses would come, and the children’s hospice would come [to the hospital wards]. They would come and make sure that things are done. And I think they did whatever was possible, whether it was to keep him home or get him into school to learn. They helped wherever possible.

We only had our school, the children’s hospice and palliative care team at the hospital in Bradford, so [they all coordinated with each other]. [The school] were really good with him.

Again, it was about building a relationship. We knew them since the beginning of the journey. They helped a lot. [For example] my father-in-law had a heart attack. [The school] kept [my son after hours] so I could go see my father-in-law. They were really good with them. They gave us the best years we could have.

If things were going bad during the nighttime, [we knew to ring] the children's hospice. During the day, [it was the] palliative care team. If nobody picks up - they normally did, but if there's some reason nobody picked up – [we would] ring the children's hospice and they will find someone to get here.

The last day when [my son] died, it was Saturday afternoon. So, the nurses came during the day to see him because he was not having a good day. Whenever that happened, they came more regularly just to make sure that everything was OK, because we knew anything, even a small temperature, could do it. They came during the day to check him and then they came when he died. I rang them and they asked me if I wanted them to come, so they came and they stayed for longer than I think their [scheduled] time was. I think they need more people to help like [the staff who helped us]. When they have one [staff member per family] it's too hard for them.

I rang them and they asked me if I wanted them to come, so they came and they stayed for longer than I think their [scheduled] time was.

The children's hospice I think are best at this because they have more experience with kids like [mine] on a daily basis. The hospital in Bradford might not have that many. Whenever we went, [my son] was one of fifty kids who were there with chest infections. At the children's hospice, it's this [kind of thing] 24/7 and all of them are [like my son], with different conditions, so they they're seeing not just the medicines, they also seeing the cultural differences. I met a Syrian lady, and we had different people from different parts of the country, speaking different languages. Some of them did not understand well as they didn't speak English. So, they [the staff at the children's hospice] are used to it.

[Juggling looking after my terminally ill son with my other children] just had to be done. [APPROX. 11:40] I realise now how many hours there are in a day. [Laughs] Because he's not here now, so you realise how long the days [are], you kind of didn't realise it was just like a routine. You wake up. You did his medication.

Especially the last couple of years. I always had to ring everybody, somebody, anybody, whether it was palliative care nurses [at the hospital] or the children's hospital, or I had a video call or phone call with someone about his medication.

Since COVID, it’s more online prescription and all [my son’s] medications had to be ordered on different days! Because he had different amounts of different medication, so they all didn't finish at the same time. So you had to order on certain days. So there was always something to do. There was no time to think. We just did it. It was 10 years. It became life.

We don't know [how we’re doing as a family, following on from my son’s death]. We have to figure it out. It's just no matter what I do, it's still a long day. There's a lot of hours still left [in the day] at the moment, I'm realising.

Like we went shopping, we did the cooking, the other day we went to the park, we came back, we did cooking, we did shopping as well that day and still we had the whole evening left. I think, over the 10 years [with my son] I stopped realising how long the days are because it was school, then home for the last couple of years when he was more home. So I would drop [my other children] off at school, come back, I had to do his stuff. It's just there's more time [now]. I think also that the people in my life were doctors and nurses and they’ve not disappeared, but it's kind of like I'm alone again. I’m going to have to find a job to do something.

I think also that the people in my life were doctors and nurses and they've not disappeared, but it's kind of like I'm alone again.

I was already doing counselling before [my son] passed away, with the hospital. I talked to [one person] and my husband talks to [another]. The psychology team at the hospital and my daughter are doing an art project. So, we are all [getting support].

We had been seeing all these people [medical staff] for about 10 years. It's just weird without all those people. I don't have to ring them anymore and see them almost every day. It's weird. Even if I talk to them now, what's the conversation going be? Because the conversation was about this medication, or this is happening. [Before] I don't think we went anywhere where people didn't know [my son], he was known at both hospitals in Bradford and the children's hospice. I spent a lifetime with them. So I kind of know… like I know their kids' names and their partners or their families. They kind of became more than just nurses because we knew each other for so long. You meet parents and they complain about doctors and nurses and we kind of don't know what they're talking about because wherever [my son] went, everybody just really was nice to him.

I would have kept them [the relationships with the medical staff] if I could. I keep saying to [the link nurse with the palliative care team] “don’t leave” because she is only one still with me. She says “I'm not going anywhere” but I just can't imagine my life without all these people I've known for so many years. I was fairly new in England when [my son] got poorly. I was just starting to meet people. [The medical staff] kind of became more important than anybody else.

Chapter 2:

> I've known the nurse since when my daughter first got diagnosed with her condition.

I lost my daughter. She was fine when she was born and then when she turned two, she couldn't sit up herself, so she started falling. I took her to the doctors, they started doing tests and stuff. And then as we were waiting for the results to come back - my daughter could eat at the time, so I'd made her a sandwich - she started choking on it and going blue. [From then on] she couldn't eat anymore. She had to be fed through a tube through her nose. And then a little bit after that, she got the... is it the PEG in her stomach? She had to be fed through that. From the age of two until she was eight, it's just been a rocky road really. Hospital appointments and everything else. But [the link nurse for the palliative care team] has been great, she's been supportive all the way through it. And that's what I've needed really. I've known the nurse since when my daughter first got diagnosed with her condition.

My daughter went to a special school. She had her carers coming in to help me as well, just to give me that little bit of time. They helped wash her hair and help me wash her hair and stuff. And I had my family around me as well, but [it was] even better with the nurses' support. My daughter had a smile on her face when certain nurses were coming in. The children's hospice were involved as well and they were a great support.

My daughter died at hospital. I was a bit in two minds really [about where I wanted my daughter to go at the end of her life] because I was sort of in that situation before, where I've been at hospital and then they've said "ah, you know, it's not looking good, where would you want her to go?" And I did say I wanted her to go to the children's hospice. But then one time we did take her and then she pulled through, which was good, but I think the next time [it happened], I think they were sort of 'umming' and 'ahhing' and I had to make that decision whether I wanted to move her from the hospital to the hospice and then if she passed away when we were taking her there… So I had to make that decision and I just thought "well, [let's] leave her here". You know, it just saved all the travelling and everything. And then when she did pass away, they did take her over to the hospice.

We had like a care plan sorted and everything. It was difficult because we had that many hospital trips and everything and we thought this is it, and then she'd pull through. Then when it did come to it, it was just like, she's done that much fighting. I'm still struggling because it'll be coming up to two years in December [since we lost her]. I've got other kids at home. So, you know, it's a tough one, it's supporting the kids as well as myself and I think if I didn't have my kids, I'd probably be in a lot worse state. But I'm trying to keep strong for the kids.

I did get some [bereavement] support from the children's hospice. They did counselling. They even did it for the kids as well. But that was only for so long, so that's finished now. But they did say if we did need them, get in touch. Even meeting people [hospice] that I've never met before [through] these counselling sessions who have gone through similar. I thought that was a big help as well.

The support that I got from the nurses and everything was good. If I needed to do anything with the other kids or anything, that's where the nurses were there just to give me that time with my other kids and they'd be there to watch my daughter.

If I was worried about anything and I needed some advice about anything [I could ring the hospice].

I don't think that they [the services] could improve on anything. I think everything was good with them.

Chapter 3:

He didn't do doctors very well, didn't do hospitals, he was absolutely terrified of hospitals.

Dad was a typical Yorkshireman really. He kept himself to himself, but he had a heart of gold. He would suss you out before he would really accept you. He was a very quiet man. He would help anybody. If he knew that anybody was in need, he was there.

He did various jobs right throughout his life. His main thing was because he was brought up in the times where he believed that the men were the breadwinners, they provided for the family. So he did quite a lot of jobs he didn't really like. He worked in engineering and bakeries and factories. He'd done all sorts, but the main one really [was] he absolutely loved working at the bakery. He didn't have a lot of free time because he worked a lot. But then he loved being around his family when he had free time and being outdoors. We had allotments, he loved nature and just teaching us stuff. But then he also was really good in darts and dominoes teams and people from pub teams wanted him on their team because he was a damn good player, you know?

But he played for quite a few, the only problem being when they were playing each other! He had a really good mathematical brain. Like with dominoes, nobody really wanted to play with him at one point because he knew what you've got in your hand. He really was absolutely fantastic at it. He didn’t pass it on to us!

Familywise, we were a little unit. There was just me and my mum, my dad, my sister, and then my grandma and granddad on my mum's side.

His health deteriorated in 2001 when he was diagnosed with angina. And he was just going through the process of being diagnosed when my mum suddenly passed away of a really quick illness and that had a massive impact on him. I don't think that he ever got over it. In 2003 he had a triple heart bypass.

And then in 2015, he was diagnosed with vascular dementia. He’d had it a few years prior to that, but we just couldn't get into the doctor's because he didn't do doctors very well, didn't do hospitals, he was absolutely terrified of hospitals. And he had a bad fall so me and my sister told him “You need your wounds checking”, so we got him to the doctors that way and got him in for the memory tests.

He went downhill from 2015, because he was suffering with psychosis. But then the major impact really was when lockdown happened, he got a really bad chest infection and he didn't get over it properly, really. He used to go to the one of the pubs just for a daily catch-up with people for a couple of hours to get out and about, but because there were no pubs or anything, it messed with him.

And then it got that he wasn't very safe at home anymore because he was wandering, and he would ask anybody to take him to the bank. We got in a private care company, but more for companionship really, rather than the physical care, just to make sure that he was safe. But then it got that he wasn't safe, and he had to go into care because he was being quite physical as well towards me which... dementia is an absolutely horrid illness. I think there needs to be more research into it and more advances in the treatments, because if you've ever come across the dementia side of it, it not only kills the person but watching him change, I became sort of the adult in the relationship, rather than his daughter, you know. In a way, you grieve the loss while they’re still alive.

Watching him change was exceptionally hard. People just think, oh, well, you know, they're just forgetting, they're getting old. It's not like that. My dad was quite with it and even towards the end, you could see he was tormented in his mind. Nobody really understands it, I don't think, and I don't think anybody will unless you live in it, as in being a sufferer [of dementia].

He moved into the care home in February. He had had one seizure prior to going in, just out of the blue where he stopped breathing. And he was unconscious and unresponsive and everything. An hour after leaving him [at the care home], he had another major seizure where he was unresponsive and stopped breathing and everything. In the care home, he passed away maybe 11 times.

Within the first 48 hours of being in the care home, he caught pneumonia.

> **There needs to be more [staff], especially up on dementia units.**

There needs to be more [staff], especially up on dementia units. There needs to be more interaction. They [residents] are kicking off a lot of the time because they're bored. Because they don't do anything, they never see outside. He was there just under 12 months; they took him outside in the garden three times in the whole time. The thing that helped my dad [was that] he was always an outdoorsman; he was always sat in the garden. They [the residents] need that. The care was very minimal. I went every single day, because I couldn't just walk away from my dad and it broke me because I saw that some of the carers are damn good, but some of them aren't. And the residents, a lot of the time, they don't have anybody.

I complained to the home because… the amount of falls that I've reported and I was the first there [to find the resident] - it shouldn't happen, but then if I didn't complain and raise it, who would?

In July, he had a major seizure. And he collapsed outside and stopped breathing. I had taken him out [because] it happens in a lot of care homes; it seems to be the most vulnerable get shut away upstairs and I think it's wrong.

He came back around, but the care staff didn't even know where the emergency buzzers were. We were on the residential unit. I was holding his airways open. This led him to go in into A&E again.

During the hospital visit, because he never did well with hospitals anyway, but with dementia it just... it messed with this system, because it was unfamiliar. It became apparent that hospital wasn’t [a good environment for Dad] because it was very physical towards me, and it wouldn't let the healthcare professionals doing any tests or anything on him.

There wouldn't be a good end to treatments and stuff because of the dementia and everything. And they wanted to do more further testing but do it as an outpatient. He was OK until we went into the room with the consultant [who diagnosed dementia] and he attacked the consultant and also attacked me. And it became apparent then that that was it, there were no more interventions. It really broke me.

So, we got back to the care home and the staff were asking how it had gone, and I told then it's the beginning of the end, because they were always insistent that he was nowhere near the end of life.

We did the advanced care plan which we had to fight for because the doctor didn't really think it was the right thing. But then from my dad's side, it's not fair, really [to keep taking him to hospital]. Is it beneficial for my dad having him upset, going to hospital for them not to do anything, but just to keep him there?

[A few months later] he had another massive seizure. He was going [actively dying]. I knew he was going. A nurse patted him on his chest and went “you're not going”. And he came back. And it's like, “really?” [i.e.: is this really the best thing for the individual?] And then he was put on palliative care because we [the family] said “look, enough is enough, this isn't right anymore”.

It was hard. I was letting him know that it was OK for him to go and the nurses and staff around me said “he's not going anywhere. He's fine, he's not that bad.” I could see he had end-of-life signs for months before he died, but the staff said, “you're just looking out for things”.

The day before he got put on end-of-life, I got a phone call at 7 in the morning saying, “his breathing's changed, you need to get here.” We waited 12 hours for a doctor to come out to basically say that he was end-of-life. His meds had been in the home [for months] but we couldn't administer them until the GP had been.

It shouldn't be that you wait 12 hours.

Even when the doctor come out, he was insistent that [my dad] had got an infection and really should be going to hospital. And I went “but you know that that's not our plan”. And he basically wanted me to make the call and I said “I can't do that. That's my dad.” He was my life after my mum [died]. People don’t understand what a massive impact [dad’s death] has had on me. But that at the end was just wrong. Nobody should have to make that call.

I suggested to the home that when [a resident] is on palliative care, when you ring up [the GP], it needs to be flagged [that the patient is on palliative care] and our request for a visit needs to be instant. It shouldn't be that you wait 12 hours. Something needs to change because the home were saying it wasn't down to them. He shouldn’t have been in pain for all that time. The home were saying that it's not their duty and the doctors are saying it's not theirs.

The other side to it when it was decided that it was end of life [i.e.: Dad was actively dying], the drugs weren't consistent. Say that they were due at 4 o'clock, somebody should have come early because it takes time because of the kind of drugs that they are, they've got to get them signed off and get them checked and double checked. It should have been that somebody should have come half an hour before they were due. [Instead] it was me chasing them and that's not right. Then they were running around to try and get [the drugs] authenticated.

Dad was still on the dementia unit at this time, it was really noisy, and that's wrong. He should have been moved downstairs into the nursing unit. Nobody should have to listen to the noise, and other residents [were] walking into his room.

The staff did pop in [to check in on me]. I'd made relationships with some of the care staff, but my dad was a big impact on other people. He wasn't the easiest guy with dementia, they did come in but more to say their farewells to my dad, which was heartbreaking to watch. But the management did come in just to check in.

It was hard. Watching my dad die over four days was horrendous. Nobody should have to go through that. I think it's wrong that people have to watch that because that's the images I've now got of my dad. My life did revolve around my dad. Now I've got a massive void which I'm finding incredibly hard.

I'm privileged that I've had a specialist nurse support me since 2020. I couldn't have done it without her. I don't think people realise just talking somebody helps, especially when there isn't much support out there either. My family died with my dad. He's gone, but now the realisation really is that I'm alone, which is hard. It's a hard conversation to have [when someone has died]. We never really spoke about death or anything up until my mum died, you know?

I think [what] made it hard [was] that had to fight for everything all the time in that care home. I've had to fight for him. People need to see [end-of-life care] from a different perspective. It needs to be more transparent about what goes on and you've got to put yourself in their shoes. There should be dignity. There should be care. [I mean] it's basics, it's major basics [that need improving]. Older people do take up a significant amount of funding and things, but it shouldn't be that they are brushed under the carpet because they don't matter anymore, because they're the end-of-life, they still deserve the best.

It's hard at the minute because all the professions are all backing away [from me] because my dad's not here and I get that, I really do understand that. But that's also hard as well.

Companies [i.e.: employers] and things need to be more supportive, but also, I get that if you've never had to deal with losing somebody, you don't understand and maybe you want to back off because you don't want to even think about it. I mean, just in my current workplace, I had time off [and when I came back the expectation was] that I should have been back to normal.

I told them that he was on palliative care [but when I came back the attitude from others was] “oh well, he's gone now. That's it. End of chapter.” And I can't do that, you know? People do need to show that they care. When I did go back [to work], it was too soon. I don't think anytime really would have been right in a way, but I've learned the hard way. I'm still an absolute emotional mess. My concentration has gone completely. It's had a massive impact on me.

[Before he was medicated] he was still talking a little bit, but as soon as medication was given, he didn't talk again really. And that was hard. I know that every death is different and everything, but reading up on different things I was hoping that you'd have that that clear moment [to say goodbye], but that didn't happen with my dad. The staff didn’t tell me that he might not be able to talk after the medication.

I still think that I could have done better for my dad. He never wanted to go into a home. I don't think anybody really does.

Most of the homes do dementia care, but then actually when you get to the nitty gritty, they do dementia care if [the person is] newly diagnosed or they are end of life. There needs to be more places [for people in between]. If I had all the money in the world, I'd have dementia villages. The need to be safe in the community but also have the freedom to live their lives.

Chapter 4:

> **He'd been in a care home for about 21 months. He was there at the family’s behest because he had Alzheimer's disease.**

Dad was just shy of 83 when he died. He'd been in a care home for about 21 months. He was there at the family’s behest because he had Alzheimer's disease. He's from outside Yorkshire originally.

I think he got his diagnosis in 2017, but we had thought that there were some odd things before that. He submitted his tax return late and that was the first real massive sign that that there was something not right. So, we eventually persuaded him to go to the doctors. We thought it was a hearing problem. We thought he was depressed after Mum's passing, he was definitely lonely and reclusive because of it, but actually I think with the benefit of hindsight, once we realised that he got some sort of mental disability, I think it was the early onset of that.

He was very sporty. He's played football semi-professionally, back in 1950, then when football became no longer viable, he played cricket locally for a long time. He was secretary of the Cricket Club and then when he couldn't play cricket anymore, he played golf. So he played sport all his life. And in terms of jobs, he was a municipal engineer for local government.

When he retired, he was involved in various clubs and societies, so he'd always been quite active in the community, but after Mum died, he definitely withdrew.

So we got to 2018 and we got a diagnosis. He was definitely starting to need a bit more support. And then of course COVID came along, so nothing happened. But when we were coming out of the other side of lockdown, it was becoming apparent that he couldn't cope on his own anymore. So we looked at care homes [where he lived outside of Yorkshire]. For one reason and another, they weren't right. And then literally at the bottom of my garden is a care home, so it was quite a big deal, but he moved here. When he first moved in, he just needed a little bit of support. I mean, provided that meals were provided and obviously things like his washing and his bedding was changed, he could wander about and socialise, and he still had some capacity. But his deterioration was quite rapid in the last six months of his life. He had a fight. He lost the ability to talk. He could answer “yes” or “no” and sometimes he could be quite coherent, but it was getting less and less frequent. So, in the last three or four months, he was getting more and more dependent on the people and [his care home] is only a care home. It's not a nursing home.

When the tax return debacle happened [before his Alzheimer’s diagnosis], I bullied him into doing his power of attorney. So there was a bit of a conversation there [about his wishes for the end of his life]. But because of our own [lack of] experience, mine and [my sister’s] and Dad’s experience of Alzheimer's disease, I don't think we fully anticipated how it would be. I don't think he knew what was coming.

I didn't know if they were nurses. I didn't know if they were doctors.

As a family, I don't think we really think ahead like that. My sister’s not quite as worldly wise. Dad was a bit avoiding. So quite a lot of those sort of things got pushed along by me. I retrained as a teacher when Mum died and obviously my own kids have gone through GCSEs, so it all happened at a busy time. It was never the right time and I'm the one who at that time was travelling [to see him]. When we were keeping Dad afloat, we were too busy doing things like changing the bedsheets and mowing the lawn to talk about end-of-life care. So, I just think we avoided it as a family because there was always something more important. I think it's like talking to your children about periods or sex, it's much easier when it's a long time in the future, when you're 77 or 78 and you've been diagnosed with Alzheimer's and you've just nursed your wife to her death, it's a bit close to home then, it was too late. It was too personal.

I don't really know where the end of life [care] started. For a little while we couldn't go in to see him because of a sickness outbreak in the home. And he was getting a bit challenging about taking any of his meds. He was always quite a proud man. I mean, he used to wear a shirt and tie to clean the car. So having [a vomiting and diarrhoea bug], even with his capacity as it was at that time, I think he would have been quite mortified that he couldn’t sort himself out.

After Christmas we went [on holiday] for a month. When we were away, he definitely seriously declined. He started to become quite violent, quite agitated, quite aggressive and because of his sporting background, his upper body was very strong and if he didn't want to do something, he could make it very clear that he didn't want to do it, and it was starting to be an issue. So I had two weeks, even though the care home manager was really good, when I was seriously worried that he was going to be given notice to the extent that it was keeping me awake at night.

The way they tried to deal with it, because it was aggression, was to get his GP involved and through that the rapid access team. I didn't know if they were nurses. I didn't know if they were doctors. I didn't know if they were consultants and the [care home] manager was getting really frustrated with them because it felt to her and to me like they didn't do anything about it. In my view, [on one weekend] he was overmedicated. I don't think it would have made any difference to the outcome, but he was definitely overmedicated.

Then he had another fall, and at this point he was manic. He wasn't sleeping, he was wandering up and down the corridor. They moved him to what they call their dementia wing. Somebody's suggestion was that they put the mattress on the floor, which doesn't fit with the way that [the care home] is because it is more like a hotel, but it was the only way they could... because he didn't have the strength to bear his weight from the floor, it meant that once he'd gone to bed, he stayed in bed and once that happened, I think he gave up really.

[It was a] combination of he gave up and his decline was accelerated. So, for me that was that was the end of the stress because [the manager] said she would keep him there [in the care home] if she possibly could. For me that was the beginning of his end of life [about two months before he died]. But I don't know how medical professionals mark it.

> **I found it frustrating that I wasn't always there when the conversations happened...**

I found it frustrating that I wasn't always there when the conversations happened, despite the fact I could be there in five minutes. I found that very difficult because he didn’t have capacity, it was like having a four-year-old child. He probably didn't understand what was going on at that point and I felt like he was very vulnerable. So that bit was very difficult.

Once he was bedbound, the community nursing team started coming out. [The nurse] that I saw most frequently was really good. I don't think I really knew what was going to happen, but I'd realised that he was dying.

Every death is special and personal, isn't it? Probably in Dad's case, I think it was probably a bit exacerbated because I didn't want him to go to hospital. I mean, I don't know how they'd have coped with him in hospital. I think he'd have been really frightened. And obviously if they have a COVID outbreak or something like that, and the ward gets closed then that would have just been impossible. So, I don't think there would have been an ideal solution in Dad’s case. What we did was the least worst, if that makes sense.

And then if you're working in the community, obviously doctors and whatever else, they're pulled all over the place so they can only come when they come. But it's very frustrating from the relative and the patient's point of view because you can't kind of get hold of it and manage it. And equally, you know in Dad's case, they've probably seen loads of Alzheimer's patients - but they haven't seen that one.

I think I probably saw the GP that was allocated to [the care home] three or four times. And she was very nice. But she's just busy and they've got 40 residents. They will all need to be talked about when she goes. So that was tricky. Dad was reluctant even when he was well to have assessments. I think he was suspicious of it, probably because he didn't understand it. And also, he was, to put it politely, he was of his generation and she was an Asian woman. She was very nice, but that was frustrating, not always being there when she was talking about Dad's case.

Going on to the community nurse, she was fabulous. To start off with, they were giving him injections. And because I was there all the time, you could see when whatever discomfort he had was starting to build up because he was more restless in his bed. So then I would say "I think it's time to have jab". And she would come out. And that probably happened three or four or five times, I don't know. And it was the community nurse that suggested that he went on a driver. I thought she explained it very well actually.

I don't think we were [offered support as a family after Dad died]. I don't remember being offered anything and had I been offered anything, I think I would have declined it. If I need anything, I think I've got enough family support that I would seek it out. Whether we'll need it in six months' time, only time will tell.

> **It's not joined up enough. From where I was sitting, it felt like they didn't communicate with each other. And even when they did come out, they weren't well informed.**

If I could change something, the thing that I would change wouldn't be the death, because the actual last four or five days, in a hideous way… I was there, I knew what was going on, he was calm - that bit was alright. The four or five weeks before that were very stressful for everybody concerned. The management team at [the care home], Dad, the staff at [the care home] and us as a family and I think the agencies that were involved (because I don't know who they all were)… It's not joined up enough. From where I was sitting, it felt like they didn't communicate with each other. And even when they did come out, they weren't well informed. But they don't appear to know anybody else from their own agency who's been out and what other agencies have done in the meantime, and that needs to change. How? I have no idea.

They come, but they just responded to the crisis. They don't know what the background is and that's very stressful and I really think that people who are in my dad's position who don't have a family - I can't bear to think about that. They really are in a very unfortunate position because you just have to fight for everything that you want and I was lucky that the care home manager [and I] got on very well, she understood what I was saying and why I was saying it and I think she was kind of on my side. I think I was very lucky that she was the manager there. I think other people would have just said “we're a care home and this is too hard”. She was very good, and she I know for a fact, rang, emailed, badgered the rapid access team and they were... I think they were poor.

Chapter 5:

“I felt Mark didn’t get the respect he deserved at the end, he suffered and there was nothing we could do.

My husband Mark died aged 69 years at home. I felt Mark didn’t get the respect he deserved at the end, he suffered and there was nothing we could do. No one listened to us, and this will last have a lasting impact.

Mark started to feel ill in June, he saw his local GP and the diagnosis was sinusitis. He was given antibiotics, but it didn’t improve. At the end of June, he kept feeling very tired and was sensitive to smells, causing nausea. He went back to the GP.

On the Friday, he was booked in for a blood test. At 3am the following morning (Saturday), the test centre called to say Mark had had an abnormal blood result and needed an urgent blood transfusion and to prepare to go to hospital, he would ring back with details. When he rang back, we were told that the registrar didn't need him to go but he needed to go to the health centre as soon as they opened on Monday morning. This caused a lot of anxiety.

I spoke to the on-call registrar who reassured us that a blood transfusion wasn’t necessary at that time. He was asked if he was a drinker and said that it might be liver related.

> **She told me it wasn't urgent and that it was a waiting game.**

On the Monday morning we went back to the GP, he had low platelets, the nurse took a follow up blood test. On Tuesday the GP confirmed from the first blood test that it was an abnormal result. Mark was not referred. The GP was seeking advice from haematology and gastrointestinal consultants, this advice was an e-consultation via email. He said the advice [took] usually less than a week, we would need to see the GP then and would be referred to a specialist haematologist and he was told that within a week an appointment would come.

I couldn’t help Mark, he needed more oxygen and couldn’t breathe properly, he had to sit outside to be able to breathe. I tried to phone the health centre but got to voicemail, so I visited and spoke to the GP receptionist to ask if the advice had been received. She informed me the email had only been sent that day as the secretary had been on leave. She told me it wasn't urgent and that it was a waiting game. I asked for advice, she said there was no point seeing a GP until the advice was received.

Mark's health was getting worse and we still didn't have advice. On Monday, I took Mark to A&E. They took a series of tests where he was told he had gallstones and an infection and then he was admitted to a ward at another hospital. He was told he needed a camera and a scan.

Then Mark was moved to the surgical ward. Scans revealed he had nodules on the liver and kidneys, the radiographer told him it was cancer. Following this, Mark asked to speak to the consultant in private during the ward round. He took Mark out to a corridor on his own. I wasn't there with him at the time, so I wasn't informed of any of this at the time or afterwards. The consultant told Mark that he shouldn't have been told it was cancer as this was his opinion, but he thought he was right that there was probably nothing they could do for him.

Mark was in ill health and had an acute infection at this time and he couldn't remember all the details about the conversation.

On Friday, they took a biopsy, then he was moved to the ward just after midnight. Mark told me he thought they'd moved him there to die.

There was no visiting, so I couldn't see him. He told me he had to drink from a spout cup, it felt really degrading for him.

They were organising a Multi-Disciplinary Team (MDT) meeting and Mark came back home. On discharge, the ward sister said to us that if the MDT haven't been in touch with us within the next three weeks, then to give them a ring. We weren't given any information about the MDT and didn't know how we would hear anything or who we would hear from. We weren't given any details of who to contact or what to do if Mark deteriorated.

Mark really struggled to eat when he came home, he lost weight, was in pain, extremely tired, very sick and his mental health went downhill. He was scared, he thought he had been sent home to die. We waited for the results of the biopsy. There was no discharge letter or anything sent to the GP.

While in hospital, Mark was diagnosed with a massive infection, but they didn't know where it was.

A few days later, I received a text message from the GP asking us to come for the next available appointment. I rang the GP and the next appointment available was in about a week's time.

When we saw the GP, they didn't have any details about Mark. I felt the appointment was a waste of time. This appointment was a follow up from the e-consultation, the advice was for the GP to refer Mark. The GP said they would make a follow-up appointment with a haematology specialist.

While we were with the GP, they mentioned a DNR [do not resuscitate] order and we didn't know why.

After lots of waiting, we were given the results from the biopsy; it showed skin cancer on the liver. Mark was referred to the MDT and he was trying to get them together for a meeting.

A few weeks later, Mark's symptoms were getting worse, he was sweating really badly and was shaking.

I rang the [cancer charity] team, they told me to ring the MDT in Leeds for a full assessment of his symptoms. When I rang Leeds, they told me we were out of area. Mark had not been able to eat for over one week, he'd lost weight rapidly and was hallucinating.

One of the doctors apologised to us on behalf of the Trust for what Mark was experiencing. He said he was disappointed in the lack of support.

I called 111 and was on hold for 40 minutes. Then it took them a further hour for a GP to call me back. When they did call me back, we started the conversation, then the doctor said he had to take another call and would call me back.

In the afternoon, we managed to see a GP, who said we had to go straight to hospital, as Mark had another infection. The GP tried to call the switchboard at the hospital to let them know Mark was coming, but the doctor couldn't get through. I was handed a note and told to give it to the hospital when we reached there. The GP said if any problems on the journey to the hospital that I should call 999.

When we arrived at A&E, the receptionist and staff were lovely. We were seen by the sister and nurse who cried when they saw Mark. One of the doctors apologised to us on behalf of the Trust for what Mark was experiencing. He said he was disappointed in the lack of support.

Mark was very unwell, he had low blood pressure and he told me he didn't feel right. The nurse told the doctor, but the doctor said he wasn't unduly concerned. The doctor didn't come and see Mark.

Mark told me that he felt the nurses and doctors lied to him all the time. I asked for better communication between the staff and I, as this could've helped give Mark better support. But there was a change and handover of staff in August, and I felt this made things even worse.

Mark couldn't keep food or medications down. I was worried that they might send Mark home, but the doctor reassured me that they wouldn't send someone home who was so malnourished.

The next day, Mark was sent home.

(Mark had been given new drugs, even though coming home wasn't on the cards, his notes said he'd eaten and drank a bit of coffee and had two mouthfuls of cereal).

A doctor at the hospital spoke with the Palliative Care team, they were treating him for a gall bladder infection, there was lots going on that needed the Leeds MDT. I was told there would be a three-week wait. They told us that Mark may have been treated at the local Oncology department or Leeds depending on the service available. They said to be prepared in case the MDT team say there is no treatment available.

I spoke to the nurse, she said the Palliative Care team were due to come to our home, but they couldn't come as they were short staffed. I called them again and they said they couldn't come because we are out of area.

I rang the hospice, but they said they hadn't received a referral yet, then it would be triaged once the referral comes. I wasn't given any timeframe or told how to follow it up. And we still didn't know his prognosis.

I called the GP and asked them to come out and visit. He came to visit and while he was with us, he said they didn't have any update from the hospital. The GP called the hospital and while on speaker, I heard the hospital tell the GP that it was a junior doctor on shift and they hadn't filled out any paperwork. They said they would send on a copy. But this never came.

When the GP spoke to me, he seemed optimistic that even people with advanced cancer can receive treatment to improve the quality of their life. We were never told Mark had advanced cancer.

The hospice rang the GP the following day and said Mark should've come out of hospital with an Anticipatory Prescription (AP). A doctor was going to write an AP after the call from the hospice and said I could collect it in half an hour. But when I collected the prescription for morphine, it was written incorrectly and could not be given to me. (The prescription was for Haloperidol injection – this can only be given by a district nurse, if a driver is fitted. Mark didn't have a driver fitted). Mark was only receiving co-codamol to relieve his suffering.

A few days later, I rang 999 for an ambulance, Mark was losing blood from both ends including vomiting.

An ambulance came and a district nurse. The district nurse contacted 111 to request an assessment by a GP but Mark deteriorated before he came and was admitted to A&E.

A doctor came for an assessment and the district nurse said they would arrange for a suitable bed to be delivered. It arrived a day later than planned. And when it was delivered it was too short for Mark, so he couldn't get comfortable and straighten out his legs.

At A&E he was diagnosed with a gastrointestinal bleed. At 2am I left the hospital; Mark had been given a blood transfusion and antibiotics. An endoscopy showed he had stomach ulcers.

When I went to visit Mark he was really depressed, he was refusing to see me as he thought I knew more than I did and that I was colluding with medical staff. We still hadn't heard anything from the MDT team.

I spoke to a designated nurse who spoke to a cancer nurse specialist, she said she'd call the next day. I arranged to meet the nurse specialist in hospital the day after that. She told me that the MDT meeting was arranged for about a week later. It had only been referred to them two weeks prior, after the GP had chased it up.

Mark came home, he was drinking a little. He was able to sit up, he sat in the conservatory, ate some soup and then went back to bed. He was very tired and had a bad night. I thought this was because he was uncomfortable in bed due to it being too short. I suggested food that he might like, but he couldn't even speak.

I rang the hospice in tears as Mark was so ill, in constant pain and very agitated. The hospice called me and said someone was going to visit Mark in hospital. When I explained that he'd already been discharged, they said they were going to call us for a video call. I held the phone to Mark. She said that he was at end of life.

> **No one communicated with me that Mark would need moving in the bed every two hours.**

They informed me that a district nurse would come to put a driver in to give morphine. A GP visit was arranged so we could do a DNR form. We couldn't put in a referral for a Marie Curie nurse because that can only be done Monday to Friday, and it was a Saturday.

The district nurse saw the bed Mark had been given and said it was the wrong bed and that an extension was needed. This was ordered along with the sides, but it couldn't be fitted as this needs to be done with the patient out of bed. And Mark couldn't get out of the bed.

I spoke to a charity that supports carers and the district nurse and asked for a review. The charity called the hospice for a review as the doctor hadn't seen him. The hospice and the GP came to visit Mark.

Mark was given morphine through a driver. No one communicated with me that Mark would need moving in the bed every two hours. I felt there had been no preparation and at this stage I was told to apply barrier cream to help prevent bed sores.

From when Mark was admitted to hospital until his death, we did not meet with anyone to discuss his diagnosis or prognosis. He said to me "I always thought that if you get cancer, you are looked after". How wrong this was, he suffered so much both physically & mentally. I will never forget him begging me to end his life.

I feel that Kirklees Care Charter is not worth the paper it's written on. It's a good charter, but it didn't happen for us.

I don't know if the hospital where he was admitted as an emergency wrongly assumed that everything was in place in terms of support. They had all the information from our local hospital. He was discharged with nothing in place and having now seen his records, I feel it was an unsafe discharge.

The MDT was due to meet two days after Mark passed away, they still met and I received a phone call that day to say that they were going to offer chemo and immunotherapy. They were unaware that he had passed away.

I know now what the prognosis was for Mark, but if there hadn't been delays in referrals, he may have been well enough to have the treatment to ease his suffering and to help us to plan and prepare. Families should not have to spend all their time trying to get the support their loved ones need in the last few weeks of life. There needs to be a process in place so this happens.

Chapter 6:

> **“The staff at the hospice and hospital palliative care team have been an absolute lifeline to both of us but possibly more to me.**

My experience around end-of-life care has been in supporting my husband. He was diagnosed with liver failure some time ago. As part of the assessment/screening process for a liver transplant he was found to have an oesophageal tumour which excluded him from progressing onto the transplant list. The treatment options of the cancer have been significantly limited by the liver condition.

We live in Leeds, have two grown up children (stepchildren to me). My husband is retired but previously worked as a supervisor for an engineering company. He was an active member of the local Caravan & Camping Club serving on their committee for many years and we enjoyed spending holidays and weekends travelling across the country, with our dogs, in the caravan. Our travels have been curtailed by his deteriorating health, but we now foster for the Dogs Trust which has offered us both a new interest that keeps us busy.

The staff at the hospice and hospital palliative care team have been an absolute lifeline to both of us but possibly more to me. By chance, my husband came into contact with a palliative care doctor on placement with the Liver Day Unit at the hospital. On reflection, up to this point, his care had followed a medical model, with no/little discussion given to what he felt was wanted/needed. I'd go so far as to say no one ever thought to ask. The contact with this doctor gave him the opportunity to express his thoughts about what was important to him. One example I can think of is the repeat endoscopies. My husband found endoscopies extremely distressing. For the medics it gave a measure of disease progression but would not have changed the prognosis or treatment options so held no value to him. It wasn't until he spoke with this palliative care doctor that he worked out how to share his thoughts regarding treatment options and with their support decided to decline future endoscopy examinations unless it was for treatment. His fear was that he would come across as being difficult or ungrateful. The palliative care doctor helped in communicating his thoughts directly with the oncology consultant.

Having found the hospice and palliative care inpatient teams such a valuable support, I shared my experience with a friend who was caring for her terminally ill husband. She was often sharing with me the challenges of co-ordinating her husband's care/treatment via the GP and oncology team with ever increasing levels of frustration. When she did request a referral to the palliative care team it was declined saying it wouldn't be accepted as he was still on 'active treatment'. He passed away around eight weeks later in A&E in circumstances that were very distressing for the whole family.

In my experience, early contact with the palliative care team can have a massively positive impact on the end-of-life journey for the whole family. Could self-referral onto the palliative care team be an option for the future?

I took time off work initially to enable me to attend appointments with my husband. This helped with the initial ‘information gathering’ regarding his illness but also learning about who was who and who offered what.

Emotionally it has been very turbulent at times, a rollercoaster. Our local hospice is now our key contact, by choice. No matter the query they help us unpick the issue and direct us to the right agency or make contact on our behalf.

My husband has had quite specific pain-related issues when he developed spontaneous osteoporotic spinal fractures which had a significant impact on his quality of life. He was suffering with debilitating pain which was challenging to control and harrowing for the family to have to watch. His mobility deteriorated significantly as did his ability to self-care independently. After a number of months, there was little/no change despite input from a number of community resources and an inpatient stay. Our clinical nurse specialist and a doctor from the hospice called to see him at home and referred him directly to the hospital pain team. In more general terms, we have been offered a diverse range of advice regarding managing his ongoing pain from both hospital and community sources which was very confusing but again we have found that the palliative care doctors offer consistent and reasoned symptom management so again over time have become our ‘go to’.

It can be a lonely place caring for a family member who has a life-limiting condition. Whilst there are community support organisations there is nothing that I have found specific to end-of-life. A buddy system or the ability to contact someone who has experience of the journey – possibly a specific support group linked with local carers charity [would be helpful].

Chapter 7:

> **The doctor who told us was compassionate in how he explained it to us.**

My dad died aged 70 at hospital in Calderdale.

Dad had collapsed at home, so it was unexpected. My mother gave resuscitation, the paramedics did [too] and got him breathing again and he was taken to A&E at Calderdale. In hindsight I knew then he wasn't going to come out of it, but he was a fit and healthy man, and we did everything to give him a chance.

The paramedics were amazing, A&E were amazing, the start of ICU (Intensive Care Unit) was too.

The anaesthetist explained how high-risk he was and he was taken into the ICU. They intubated and ventilated him.

On day six, they wanted to wean him off sedation to see if he came around and they wanted to do a scan. He was breathing but the doctor told us the brain scan results meant the likely outcome was poor. The doctor who told us was compassionate in how he explained it to us.

We agreed to withdraw support but we wanted to wait until family members had returned from a trip so everyone could say goodbye and so we could support each other. We agreed a day and time. It was from then our experience changed.

While communication with us until then was good, there was a different consultant each day and I don't think they communicated well between professionals: we'd be told one thing then the next day told something different, so the information was inconsistent.

Also, straight after we'd agreed to withdraw support the organ team came in very quickly. It felt like we had just made the most difficult decision and we had no time to process it before we had to think about something else. As we were giving dad a few days to allow family to get back, there was time to delay it [speaking to us] even for a few hours. Dad was registered as an organ donor but in the end it wasn't possible.

We had agreed on the Sunday but on the Saturday morning a doctor called me and I felt they were a bit shirty with me, asking when we were coming as support was being withdrawn today. We were distraught, some family had not got back and it wasn't what we agreed. I said, "please don't do anything when we are not there".

Earlier in the week we had asked about a referral to the hospice, and I was assured the Palliative Care Team would look at that. When I heard nothing, I phoned the hospice and they had no record of him but I was told there was a bed for him. The sister was lovely, she took his name and details, but I still today do not know why no-one from the Palliative Care Team came to see him or made the referral to the hospice.

Me, my mum, and brother didn't leave him. For all of us this was the first family trauma we'd experienced, and we were moved into a side room off ICU.

Then we were told ICU needed the bed and he was being moved. I was worried he wouldn't manage being moved but understood if they needed the bed for another person. I asked a nurse to give him some analgesia and anti-anxiety medication and I was told that would be done when he was moved onto the new ward.

When the time came to move him a bed, a really thin mattress arrived that I didn't feel would be comfortable or suitable for him. In the end the ICU nurse allowed him to stay in his bed but she said, "this is our bed we want it back" and labelled it.

We packed everything up then were waiting for 2 hours.

They wanted to put a facemask on him as it was policy, but he was hyperventilating. We then had to walk through four wards and saw and heard things that were distressing.

The room we were moved into was filthy, then the ICU nurse didn't even say bye, she just left.

The two nurses on the new ward called him 'sir' but I asked they use his name. I asked for the medication we were promised, and they said they weren't allowed to give it. There had been no communication with ICU about this. The healthcare assistant was lovely and she got a bed for mum to lie on.

The next morning the smell was horrendous, the day sister came in and we told her and she ran the shower, which didn't help. We were told it was the drains in the new building. She apologised for the state of the room and she said she would ask about the Palliative Care Team referral to the hospice.

> **I felt he didn't get the respect he deserved at the end and I didn't want to think of that happening again.**

She asked if I knew dad has pressure sores, which we hadn't been told about. She was a fantastic nurse and really compassionate.

After he died, I stayed to help wash him and walked to the mortuary, I was told it wasn't what people did but it was what I wanted. I knew I couldn't go in, but I wanted to accompany him as far as I could.

I still don't know why the transfer to the hospice was not made, the palliative care team (PCT) didn't assess him. I called them and left voicemails and no-one ever got back to me. The PCT was inaccessible and unresponsive.

It's documented we requested the hospice, but the palliative pathway isn't well thought out for adults. For patients in ICU, the PCT should be automatically visiting to see if they can assist.

After dad died, I phoned PALS not because I wanted to complain but because I felt I didn't want anyone else to experience what we did; I thought about older people who may be alone or people who cannot advocate for themselves. I felt he didn't get the respect he deserved at the end, and I didn't want to think of that happening again.

I phoned PALS and waited on hold for 45 minutes, spoke to someone who was lovely, she gave me her email address and I sent an email with the points I'd made and I felt PALS did their best. They didn't respond [i.e.: give me a final response] in the 90 days and towards the end of the year I contacted them to say I felt, as it was getting near Christmas, I wanted some answers.

In November we met with the ICU sister, ward matron and palliative care doctor and it was a productive meeting, they acknowledged Dad's last hours of care were not acceptable and the hygiene on the ward was something they were horrified about. They have since told me the consultants in ICU work three shifts so there is more continuity and I feel reassured by that.

I was also told the two nurses who told us they couldn't give him medication on the last ward were bank nurses, but in my opinion they should still have the skills required to contact the palliative doctor on call, to know the procedures and pathways and give medication to the patient's needs.

I still don't have answers about the hospice request, but the staff need to realise the knock-on effect. It was only because I had contacted the hospice and had given them his name that we were eligible to access 12 weeks of counselling. Had I not done that it would be harder to get the support after. This isn't just about what happens in the hospital, our experience has had a lasting impact.

Because we had a poor experience it's marked our family's grief. When I get all the answers I will reflect, process, and look for some space. But the reason I want to tell our story is for the staff to hear and for the people commissioning the service to put in place a palliative pathway that listens to families.

Chapter 8:

> **I know my faith will be considered at home, I do not know if the staff know what this means for me.**

I had breast cancer in 2016 and 2017, I was very worried then and had lots of treatment which made me feel very poorly, but I received good help and got better. I put on a lot of weight which I struggled with afterwards and I didn't feel so good about myself. I didn't get any help to lose weight.

I have had checks ups since, I always got a letter to tell me, but I think one was delayed when the country was in lockdown.

I decided [when I was being treated for cancer in 2017] I didn't want a removal [mastectomy] but I regret that now.

It was in September last year I had a check-up and the tests seemed to take longer to get than before. Eventually the cancer was back and was very dangerous and I have felt more poorly with this treatment. Then they told me it is just about managing the symptoms and I did not understand for a while what that meant.

I do not know the names of the departments or organisations, it is just one hospital to me, but the staff are very good, and I feel safe with them.

I know I will die. I feel very worried for my children. They are [in their mid to late teens] and that is a very difficult time for them and for my husband. We get support from our [South Asian] community, I prefer that and so I know I will stay in my community and not go to the hospital when I am going to die.

I know my faith will be considered at home; I do not know if the staff know what this means for me.

I have not been asked by the doctors or nurses anything about my feelings, they have not been able to tell me how long I will live. I have been given more appointments, but I do not know what they are for.

Chapter 9:

> **There was some nice nurses, one would always smile which helped my worries.**

Late person's wife:

In the months leading up to my husband's death he had Covid and recovered but developed a gag reflex and difficulties swallowing foods so he found eating difficult. He was having further tests about this. He was admitted to hospital several times before he was diagnosed with pneumonia and organ failure. He was treated at two hospitals across West Yorkshire.

I know he did not tell me very much about his condition, he had to translate for me, so I know he chose what to tell me.

We were given lots of information about pancreatic cancer but some of it I did not understand in the leaflets.

I felt I knew how to keep him comfortable, and he didn't tell me very much about the medication he had, and I wasn't with him when he had medicine at hospital. When he was admitted to hospital, he was very poorly and we think he had Covid, and he got better and came home. But he continued to be weak.

He went to [another two hospitals in different parts of West Yorkshire] another time, in an ambulance all times. He could not eat and we had to cut food very small for him, like with a baby.

I did not know why this happened. He was very ill, he struggled with breath.

I could visit. There was some nice nurses, one would always smile which helped my worries. She would offer tea or water. Once I changed the chair to a bigger one and next time I visited she had moved the bigger chair next to him which I found kind.

I understand English but not to speak well, she used hand gestures to help me understand, like when he had an extra pillow for his head.

It was a shock when he died. They called me to say he moved to another area [ICU], my brother spoke with them and we visited but he could not breathe by himself. It all happened very quickly and was distressing, he was struggling and looked in pain. It wasn't cancer, it was the breath issue that he died from so that wasn't what we were expecting.

We get support [from the Muslim community] and from our family and I am thankful for that.

Late person's son:

I was 17 then, 18 now.

I didn't go to hospital for his appointments so did not know if we were told everything, but I knew from how often he was going into hospital that it was bigger than we were told.

Because of Covid and the visiting rules I felt we as children could not attend when we wished to. It seems there were many rules that meant visiting was difficult. My uncle and mother dealt with it all. When I visited him once I was asked who I was, I told them I was his son and they did not seem happy I was there. I was in my school uniform so maybe they felt I was too young.

My dad once told me as I was the oldest boy, I would have to lead my family more, but I did not think about that at the time.

My dad died in hospital, but I know he would have preferred to be at home. His body was released quickly for a burial our faith requires.

We receive much support from family, my uncles, and the wider community so the gap left by my dad is there but we feel helped by others.

Chapter 10:

> Our own doctor said she didn't agree with it, but she had to go along with it because she had ordered it.

My husband and I got married in 1959. We had our son and then a daughter. Towards the end of his life, he was quite happy to be at home and sit and watch television. He and my daughter were absolute pains: every Sunday the jigsaw would come out and they could do 1000-piece jigsaw on an afternoon. We camped a lot when the children were young because we couldn't afford anything else. And I arranged it all, and he did eventually manage to put the tent up, but he wasn't a chap that got involved with other people. He liked his home and he preferred to eat at home.

He never told you anything about his past life, mainly because he was born in the 1930s, so it was a time of... people were very poor. His father was a miner. He did his national service. And because he knew he would get better paid if he signed up for three years, he signed up for three years.

When he was in hospital getting end-of-life care, I kept saying to [the hospital staff] that he is bleeding [internally]. [They said] "no, he's not, that's not blood".

[Before he started receiving end-of-life care] there was a doctor at the surgery. She insisted that he had a colonoscopy. But it was a different type of colonoscopy because they did it with lights. Our own doctor said she didn't agree with it, but she had to go along with it because she had ordered it. And that was the beginning of the end.

Later, my husband had been admitted to hospital [again]. By this time, he had lost a tremendous amount of weight. When we were there, we'd booked to go away on cruise, and he was so insistent that we went on this cruise. In the end the doctor wrote it up and said he could go, but when he came back, if he was no better, he had to go straight back into hospital. It never happened. I rang the surgery and rang the surgery. And then our doctor that attended us on a regular basis, she just turned up on the doorstep. My husband looked dreadful and shouldn’t have been at home. She told me to ring for an ambulance because if she rang, we would be waiting ages for it. I took the bloods [the doctor had taken] with me, because they were going to try and take bloods [at hospital] and they couldn't ever get blood from my husband at all. [When we got to the hospital] eventually they decided after they tried various times - people don't listen in the hospitals, they think that you have no idea what goes on - they decided that they would accept these bloods from me. He never came out [of hospital] again.

> **[His ward] was the filthiest place. The men were at the far end. It was a huge, long ward with little bays off.**

[His ward] was the filthiest place. The men were at the far end. It was a huge, long ward with little bays off. The men were at the far end and forgotten. The women were further down. Most of them had dementia and they claimed the nurses' attention. All the time that my husband was in there, I never saw a nurse other than the ward manager, when he realised my daughter was a nurse.

I went in at 9 o'clock every morning and the first thing I did was lift the urine bottles and take them down to the sluice. Nobody visited [the male patients] during the night. Not once did they try to get my husband out of that bed and sit in a chair as my daughter repeatedly asked them. But no – [the attitude was that] he was an old man, well into his 80s.

I'd go in the morning and he would be slipped right down the bed and I'd say to him "has anybody moved you up during the night?". I'd go find care assistants - not nurses, they didn't attend to him - fortunately there was two lovely girls. I'd say, "come on, girls, let's get him up in the bed". And at least four times during the day I had to get them to come and lift him up in the bed.

When my husband died, [I saw] they had actually put on his notes that he refused to eat. He couldn't eat what they were giving him. He had false teeth and he had lost a lot of weight so his teeth didn't fit. He couldn't put them in. Not once in the whole time he was in that hospital did they give him a meal that he could eat other than soup. And if a soup had vegetables in it, he couldn't [manage it]. I was told that I could bring food from home but there was nowhere I could cook it or heat it. I never once saw one doctor with my husband.

Even the beds [were a problem]. My daughter had to actually draw it to their attention that there were beds that would make him more comfortable.

Three days before he died, there was a voice behind me. “How long have you been married?” And I ignored it. And I went to find the sister in charge that day. I said, “who's that woman that has come in and asked me how long I've been married?” She says that's the discharge coordinator. “Just a minute. Discharge? Do you think you're going to discharge him?” She said “well, it’s on the cards”. I said, “you can't discharge him because he can't come home”. “I can't look after him,” I said. “I'm disabled myself.” Eventually, they decided not to. My daughter believes that if they had discharged her dad, he would have died going home in the ambulance.

My husband died and I stood there and they were coming to prepare him, we said “wait”. They pulled back the covers and my husband's body looked like a skeleton. It was awful.

[When he was dying] how could they give him painkillers when they couldn’t give him anything to stop the bleeding and recover? I still think he could have recovered. There was no nursing at all.

If you’ve got someone you love dying, you don't complain, because it could make it worse for that patient. So, we didn’t complain at the time. [I know from other experiences that] PALS don't do anything.

[The staff] treat people like idiots. It doesn’t matter how much education you've got at any time, at that period of time, the patient and the family are the experts, because I know everything that happened, you [the medic] didn’t. You’ve only come into a little bit of it.

The only thing I can be thankful for [at the hospital] is that nobody stopped me staying all day. I stopped all day [when] a nurse never, never came back. They told me all the time that they were understaffed.

I think the only thing you can do [as a carer] is to make sure that you're told everything, which I don't think I was. I think they assumed that I knew without asking [me], which is wrong. Because a relative is sitting with someone, whether they're dying or otherwise, does not give the nursing staff the authority not to go and see that patient.

Chapter 11:

> **He went and got us a cup of tea each. He was that sort of doctor, fantastic.**

I want to start in 2016 when I noticed there was something wrong with my husband. [The speaker and her husband were living outside of West Yorkshire at this time.] We've been married a long time, so I knew something wasn't right. The practice nurse noticed as well that there was something wrong, so she referred him to the GP. He saw the GP, he said you're a very, very fit man for your health, for your age. So we didn't take him anymore, nothing was done. I was still concerned about him then.

[A year later] I went down to stay with my brother and my daughter came down with her children to stay with my husband. I got a phone call from her to say that that dad's not very well. Two doctors came and then later a nurse came in and I could see she didn't agree with the diagnosis at all. And I was by then very worried - very, very worried. The next day there was a knock on the door and it was our old family doctor and within five minutes he said to my husband "you've had some sort of stroke and you've got to go straight off to the hospital". And I can tell you, my daughter felt so guilty because she thought it was all her fault and she hadn't done enough for her dad.

So, he went into hospital. They looked after him very well. The physios were excellent. They got him back on his feet and we had lots and lots of support.

We moved house [to West Yorkshire] and my husband was OK. I had a lot of support from [a local carers' charity] and a lady who works there. She's been absolutely a great friend.

[Last summer] I heard a bump in the night and it was my husband. He had fallen out of bed. I just couldn't on my own get him back in bed. So I pulled the mattress off the bed, rolled him on it and tucked him in and he was fine. But in the morning, I went and got one of my neighbours and she insisted on calling an ambulance. I must say the doctor in A&E was wonderful. He couldn't have been kinder. He couldn't have been more helpful. He went and got us a cup of tea each. He was that sort of doctor, fantastic. And he said to me, "I'll just keep him in overnight if he needs any more tests, but as far as I can see, he's perfectly fit and ready to go home".

Once he got to the ward I asked, could he come home? And they said they couldn't bring him home because we weren't in their area, although we pay our council tax there apparently, we're not in their area and they couldn't arrange for him to be brought home. It had to be done through a different hospital. I was incredibly frustrated because they phoned the other hospital and they refused to take him because he already had a bed, and so he was like, you know, he was just kept out of area, becoming bedridden, he was becoming more incontinent, and in fact, he became totally incontinent and in the end he couldn't stand up. And he wasn't getting stimulation or anything.

Eventually, the other hospital agreed to take him. And there again, he was put in a ward where there was absolutely no stimulation at all. There was no radio, no television. He loved listening to music and there's nothing like that whatsoever. I went in every day and to give him his evening meal. But because of what was happening [with his deteriorating health] I had to feed him, he couldn't feed himself and he was beginning not to talk very much either. All the time I was begging them to let him come home because they could have brought him home in five minutes. That's how close we are to our hospital. A social worker told me she would give me all the help we needed to get him home. [At this point, the speaker's husband had been in hospital for several weeks.]

When we first went in, [we saw] a young doctor. Otherwise, all the time he was there, we didn't see a doctor. No doctor came up to speak [to us], and we hardly saw a nurse. We just saw helpers who came around with his meals and things like that. So it was very unsatisfactory from my point of view anyway. But otherwise, the social worker was very kind.

> **I just couldn't believe [it]. They hadn't asked me, hadn't told me they hadn't discussed it with me or anything.**

So the next thing that happened was that I went in to give my husband his tea and his bed had gone. I said, “where's my husband?” And they said “oh, he's been moved to [name] care home.” I said “where's [name] care home?” So I was absolutely astounded. But then suddenly a nurse came right up to me and she said he's actually not left the hospital at the moment. I just couldn't believe [it]. They hadn't asked me, hadn't told me, they hadn't discussed it with me or anything. So the nurse told the ambulance workers to go and have a cup of tea. While she was doing that, I phoned my daughter and she dashed along with the children and it was dreadful. We tried to find out why he was being moved and it just sounded as though they were trying to dump him out of the hospital. They sent a really young… I think she's probably a doctor, a really young doctor around to speak to us and I felt really sorry for her. She had a mask on. She looked frightened. We weren't angry or anything like that, we were just upset, and she kept on saying the same thing in this monotone. And I thought I knew she'd been on a course where she'd been taught how to speak to patients who are upset. In the end we just had to agree that my husband went because they said he couldn't stay there anymore.

So he was moved off by ambulance to somewhere where we didn't know where it was. When I got up there the next day, it's much nicer than I was expecting and he was in the room all on his own, just laying there. And I knew this was really bad news.

I spoke to the manager, and I said, “why can't I take him home? Why can't he be brought home?” The social worker had arranged for a hospital bed to come here, so he had a hospital bed in the house. Why couldn't they just bring him home?

I just didn't understand it anyway. The manager said I'll arrange for him to come home and two days later he was home. But the trouble was, by then it was much too late. I knew that.

> **I just couldn't praise them enough how they looked after my husband, how kind they were to me. They deserve a medal.**

We had wonderful carers, mainly two men. They were fantastic. I just couldn't praise them enough how they looked after my husband, how kind they were to me. They deserve a medal. They were very unassuming, very friendly. They spoke to me very well and they just looked after my husband. They didn't want any help from me. They just took over in the room he was in and looked after him with complete competence. Anything that they could do to make it easier for him, they did.

Unfortunately, he was only home for six days [before he died].

When my husband was home, I could tell that he was dying. He was in such a poor state that I realised myself… I wanted him to die with dignity. He was at home. We all wanted him at home. The district nurse called in a couple of times. She was really nice. She said the GP will come in to see him, so I said, "are you telling me you've ordered the GP to come in?" because obviously we hadn't had anything whatsoever to do with the GPs and she just laughed. So I knew that she had told him he's got to come in. He was very polite. At the end, the GP said to me and "I'll call next Wednesday if he's still alive". So at least I knew that then that he didn't expect him to last for another week.

After that I was told that I must write to the hospital about what had happened and I didn't want to, really. But anyway, I did write to them and it's on their email thing and you just write to it. And then I got an acknowledgement to say they're really sorry what had happened and it was all being passed forward, and the matron there would be in touch with me, and it might take a while, but I never heard from her [more than six months later].

Another thing that happened [was] when we had the priest at my husband's church calling in to see him occasionally, and then they moved him [from the hospital] and the priest went in to see him and said, "where is he?", they said "we've got no record of him being in this hospital".

The social worker tried to be helpful, but she'd gone away on holiday when they moved my husband, so she didn't know anything about that and I couldn't turn to her. And there was no one else for me to turn to in the hospital whatsoever for help. The only person who helped me was the nurse. I wasn't asking for help. I just wanted him home, you know? All our family did. I just wasn't listened to whatsoever.

The doctor in A&E who offered us a cup of tea made a real difference. We've been very lucky as a couple. We haven't hardly been to hospital and so we hadn't got the experience. So for someone to be kind to you and just go out of their way just a little bit just to speak to you. Those are the things that have meant a tremendous difference to me.

I've got my own car, so I could drive up to [the care home]. But what if I hadn't had? How would I've got there? It's totally impossible. It just wasn't taken into consideration.

I'm a very lucky person because I've got children and grandchildren, and they've been absolutely brilliant. I have had a lot quite a lot of nights where I wake up in the night and try to go through all that happened to my husband. I think anyone would try and work it out. Did I do something wrong? Should I have been more adamant? But you can only be yourself in the end, can't you? I wasn’t offered any bereavement support.

The lady from the local carers’ charity has been really great. She started a luncheon club once a month and my husband and I were [there] at the start of it and I still go. It's really good because I've got always got [the charity worker] there or anybody, because there's about 16 people go now. It's really useful because I can talk to them not just about my experiences but [they’ve given me] suggestions, things that I've used for my husband when he's been ill. And I really appreciate that. People should be encouraged to join [groups like these] if they can. People are relaxed and it's not like being in the hospital ward when you're trying to catch someone's eye. [In hospital] no one came up and said, “this is how we're handling it” or “this is what's going on”. There were always people standing on computers. I'm sure they were working, but that's what [their] role seemed to be, standing at the computers and when you went around to the desk you could see the people on the computers, but there was no one at the reception desk, you just had to stand there and either go away or to stand there till someone did turn up.

Chapter 12:

I want to share her memories and my life experience with her in a nice way and I want people to know who my daughter was and what she has left behind.

[My daughter] was born normal but after her birth she started having epilepsy fits and everything and then one thing led to the other and after a few months, the doctors find out that, she had… I don't know how to pronounce the word… cerebral palsy? This kind of issue, which means that she was having developmental delay, which was a global developmental delay. So basically, [it was] slowing everything. And then due to that, she had all the complications in life as well. I lost my daughter last year, she was 12.

[The grief] is [very fresh] but I have been going through psychiatrist appointment and that has benefitted me a lot. So I am more confident and more able to speak about her now. And I want to share her memories and my life experience with her in a nice way and I want people to know who my daughter was and what she has left behind.

She was an adorable young girl. She really loved dancing, singing, music. She was really cheerful in that. She was a ballet dancer for a few years, she went to primary school, then secondary school for a few weeks, but in those few weeks, she won all her teachers' hearts. They all missed her so much, when they found out about her illness and passing away and everything. They were really in shock as well. She was one of those children, you meet her and she stole your heart. She had a really, really nice bubbly personality. I didn't know until, when she was gone and when I received all those lovely messages from everywhere, whoever knew her, all those messages and all those condolences and everything. I've kept all everything, when I look back at them, I'm like, wow, I didn't know you meant so much to everyone.

I have two teenage girls, then a boy, then it was [my late daughter] and then I have a younger daughter, but she [my late daughter] was just the centre of attention. Whatever we used to do, we used to see when the time got closer, how she is - planning holidays, planning birthdays, planning anything, we used to always wait, we would see how she is, and then we will go ahead. My children were all so nice to her. They did everything according to her and nobody complained. I think we were really lucky to have her.

She taught us to see the world from a different angle. As a normal human being, when you are a child, you have dreams: I'll grow up, I'll get married, husband, children, family then that's it, you've got everything. But with her, no. When I had my three children, I thought, yeah, that's it, my world is complete now. Nothing else.

But when she came along, she showed me the world from a different angle, how to appreciate every moment, how to live in every moment and how to cope in every moment. She has taught us how to be more independent, more confident and more mature. She has made my children really mature before their age and they respect and love everything that comes in their life, whether it's good, whether it's bad, we always say to each other just stay positive [as] she has showed a lot of positivity.

She got along with all the services very well. In the beginning I was quite like confused because, when you have three normal children and then you have another child and she was born normal, it was just afterwards, she started having everything. So obviously when the doctor told me probably she is not going to be the same as your older children, I never believed it, because it was too hard to take in as well. When your pregnancy was normal, when your delivery was normal, and then all of a sudden everything comes up, you know, every day [there's a] new surprise. My mind, my body, nothing was accepting it. I was like, “no, I'm sure you're wrong”. She will be slow, but she will catch up to it. But then after a year of struggling and understanding and everything, then I realised “you know what? Whatever the doctors are saying there are, she might be one of those, you know, different children.” In the beginning, when they were giving me all those new services, help and everything, I was like, “no, I don't want anything”. But then I thought to myself, after a year, she might need them. Let me give it a try, slowly, slowly, we'll try everything and then that's how I slowly, slowly, slowly, started taking up all the help that she needed, and I found it really useful, really helpful.

Like community nurses, like portage, like speech and language therapies, like physiotherapies. Everything I started taking it slowly, slowly and it did help her a lot and she enjoyed it as well, so it was really nice.

Whatever the doctor used to say, I was like, “yes, we'll go ahead with it”. I can still remember her doctor. She started looking after my daughter around about at the age of 6 to 7 months until today, so she was her doctor from really young age, so whatever the doctor used to say, I used to agree with it. I was like “because you know her better than me now, I know her as a child, but you know her as a patient and a child”, so whatever [the doctor] used to introduce, I'll go ahead with it.

That's why when I when I lost my daughter, it wasn't just losing her, it was losing the contact with everyone that knew her. Because we built such a relationship with everyone, it was such a sweet, nice relationship. So, you know, it wasn't just losing her, it was losing everything to me. It was like losing the whole world. My phone, my home was, constantly like, phone ringing, this appointment, that appointment, this project, that project, you know – [I would] keep in touch with everyone and visitors used to just come and go, you know, social workers [would say] can I come visit your daughter? [It was] definitely no appointment needed. Anytime they used to pop around. She had teachers from school as well when she was off sick. They used to come home to visit. So, it was really a busy life. And then once she was gone everything was quiet. So, it was a, a big change of life. It wasn't just losing my daughter; it was losing everything.

It was really hard in the beginning. I was so busy with her, I used to keep a diary. Today this appointment, today that appointment, doing this, doing that, going for this measurement, going for that - you know, really busy. And now it's like, I'm sitting [there], what shall I do? Because even at home, constantly “oh it’s her medicine time”, “it’s her milk time”, “changing time”, “order her nappies”, “order her feeds”, “order her medicine” - constantly all that work. And then once she was gone, everything was gone, finished, and I lost my… how shall I say it - like my identity, because wherever I used to ring, [it was] “hi, who's speaking?” “[daughter’s] mummy”. So I was known by just her [name] – “[daughter’s] mummy” but now, when I ring somewhere [and they ask] “who's calling?” “It's me, [name].” “[Name] who?” With her [I] was just [name’s] mummy. So it wasn't just losing her, it was losing my identity as well, losing everything.

The first few months of losing her, I was just like one of those babies, when you put them in a corner and they’ll be crying and struggling and don't know what to do, because life with her was like we were inside a glass box. We always had limited things, because for her we gave up everything, because she was our first priority and then it was us. So we gave up everything. We had everything really limited - going out [was] limited, enjoying [was] limited, doing everything [was] limited and then all of a sudden, she passed away, the box just broke. All the walls fell down and we got everything unlimited, but we didn't know how to use it.

> **Because of her I'm going out to do my health and social care course.**

All the family, we were all clinging to each other, thinking where to start, how to start because it was 12 years, not 12 days, 12 weeks, 12 months – [it was] 12 years. All of a sudden our timetable [and] everything changed, so it was really hard in the beginning, but thank God with the help of the palliative nurse and with the help of my psychiatrist, I've came to this point today where I can express my feelings, but in a nice way because I have always held her in my heart, I don't want to let go of her, but now I want to use her with me in a nicer way. Because of her I'm going out to do my health and social care course. I'm trying to do a few placements in schools, my aim is to try to work in an SEN school, these kinds of schools, where I think I can find her in them. I have always been a housewife. I've never been anywhere. I was quite scared, quite shy, quite, you know, just a "to myself" person, but she gave me all these things, so I want to use it in a nice way. I don't want to put it back away and be what I was.

[The service was understanding of my needs as a person from a South Asian background] and it was according to whatever I wanted, according to however I wanted. Like for the funeral, for all those things, whatever way I wanted, I was given. Even in the hospital, she was looked after by mostly English nurses and everything. But they know how we want our end-of-life patient to be. The male nurse that looked after my daughter in her last days was really, really good.

I obviously really want to thank him personally, but I just don't want to go to that place because it was [...] it's still got those memories, but he was really, really caring for her. He found me a Quran Cube and put some Quran verses on for her because he knew that was the things we need in those times and he was really nice to her. So [in terms of] our culture, our religion, [with] the way it was, they gave me all that respect. They looked after everything, it was really nice and it was really, really touching my heart as well. He asked for the Muslim scholars to come speak to us and it was really nice.

My daughter's own paediatric doctor was always there, even just when she used to go for appointments, and she used to be admitted in the hospital for any like chest infection or any other things. She used to come and visit and then in her end-of-life days, she was constantly coming up [and] checking on her. She was speaking to me and they were really open about everything as well. A few other staff from the children's staff who knew my daughter, they came. So I was given all the information and everything that I needed to know. They were telling me everything, so it was I knew what was coming, I was expecting [it].

Because my daughter went a few times to the children's hospice, they knew her, they knew about her. They were told it's her last few days. So, they came round and they were all there. So, it was everyone was working together. I was up to date with everything.

They were always around us, always asking not just how my daughter, but even us as family, how we were doing. It was really a good experience. A few times, she was really ill [and the doctor] sent her to intensive care. They treated her, they did everything for her. This time I was thinking of doing that as well, persuading the doctors, but like the doctor said, “how many times are you going to send her there, and are you gonna make her go through all those pains and everything?” Somewhere down the line we have to stop that, we can't keep doing that. So, it was a bit upsetting, obviously, but then you have to think “what they are saying, they've got right”. So that's why we just went with whatever the doctor's decisions were.

Whatever they used to say to me, my husband was from back home [Pakistan], so he doesn't understand English, I had to explain it to him and then explain it to my children. So, there were times where I used to explain everything to everyone [about] what’s coming, what's going to happen, what we will be facing, how we will be and in all of this, obviously, religion, faith is the biggest thing. So, in our religion and in our faith, we have been taught and learn to handle everything with patience in these kinds of situations. So, we as parents give our children a normal education, but Islamic education as well. So my children, they go to Islamic mosques, and they learn everything. So, whatever I was telling them, they knew what we are going to be facing and how we are going be facing [it]. So, we as a family, we all knew what was coming and you know how to face it and the doctors, the staff team, nurse, they helped us in every way as well.

It was OK [for me to take on the role of explaining things to the family] because for my family, I'm the role model. So, if I were to show the weakness side of mine to them, they would have shattered more. That's why whatever I was going through, and I have always every good and bad with my daughter, I was always there. I didn't want to give that time away. I was like “whether it’s hard, whether it’s easy, I'm going to be doing everything” because I have never given anything of my daughter to anybody [in terms of] responsibility, it was always me. Whether it was hard, easy, painful, anything, it was just me and her. So I didn't want anyone else to distribute this news. I mean, if my family members were strong enough to stand by me, then that would have been different. But like I say, I'm the eldest so they look up to me as well, so to be honest, I didn't have anyone to stand with me. I was the only one, so that's why I did everything on my own. Today, I'm thinking, it was good I did it on my own, because probably I might be regretting it if I didn't.

It was [a huge responsibility], and probably because of her love and her affection [it] made me stronger. And I wanted to do everything for her my way so that I never regret [anything]. Because she was given to me. I always say this to myself, because in our religion and faith, we always believed that God chose these families to be given these children. So, I always used to say to myself I was the chosen one, so I am going to fulfil my duties in the best possible way, because what our religion and faith [tells us is that] we have an afterlife.

So, in this life my daughter couldn't express, she couldn't talk, she couldn't tell anyone, but in the afterlife, God is going to give her everything.

So, one day when she's standing face to me, I don't want her to say to me, “mummy, you didn't do this job properly, you didn't do this job properly”. [Instead] she can stand and say “mum, I'm proud of you, you've always done everything for me in a perfect way”. So, you know, I used to always have that in my heart. I did everything for her myself, even the last moment, dressing her up, giving her her last shower. I did that myself. Even putting her in her coffin. Everyone was like “we’ll pick her up and we’ll do this”. I was like “no, I’ll do it myself”. I did everything and her dad laid her coffin in the grave so that is I think the proudest thing as we both parents did. We did everything for her, I always did everything, so these were the last moments that I wanted to do everything as well.

She passed away in hospital because she went in with a chest infection. It was a constant. She was ill in December, she had a dose of antibiotic and everything, but then again in January, she fell ill. She went back again, she spent again a few days in hospital, then she was discharged. She came home, but then again in February, she went [back] in there.

> **We were planning about our future. I didn't know that was her last appointment in school and her last day in school.**

I can still remember [it was nearly] the half term holiday, just the last day we had a school meeting. I went in with her and they were talking about her progress, how good she's doing and everything, and her teacher was like “after the holidays we want to start her with this swimming and everything” to give her all that sort of… I don't know what you call that, hydrotherapy or whatever it is, [to] relax her muscles and do all that. [They said] “so, you better start buying her swimming costumes” and all these things. We were planning about our future. I didn't know that was her last appointment in school and her last day in school. After that, we came back home, and she went ill again.

[The doctor] did mention to me that, when her time comes, she will have constant illness and she will be constantly in and out of hospital. But even then, it never clicked, it never clicked that when she was ill again [with the] chest infection, when she went back into hospital, the nurses, the doctors were like “this is her third time coming in, so you need to be prepared” but I was like, “no, she's strong” because she was. There were times where she fought back her illness and everything, but those were when she went to intensive care, when they put her on a ventilator and everything, but obviously this time was, you know […] probably that was her time of going as well because everything is planned. So that was the time she went in for a chest infection and they kept her in. They did her treatment, but probably that was the fatal chest infection. She spent the Monday, Tuesday, Wednesday and then Thursday [in hospital]. Thursday was the day they said it to me. Her infection has spread and now, it’s gonna be hard. So that was the time.

And then that was the time when [the doctor], all the palliative nurses and every everyone got together. Then they told me that "you have to start preparing now. This is going to be the last [few days of your daughter's life]."

The staff was really good, really good in handling [things] physically, emotionally, and always there whenever I needed them. Those were like COVID days, [with] COVID restrictions and everything, but they were like, it doesn't matter if your family members want to come and visit your daughter and be with you and everything. They were allowed and everyone, all my relatives came, [to give] moral support and it was really nice. All the nurses that looked after my daughter were really nice, really sweet, because most of the nurses were those nurses who saw her from childhood. So, you know, they were quite upset as well. They were like, "oh, we will pray for her, but you just need to be strong". So, it was a good experience.

Every time my daughter used to go to the hospital, she was given a separate room, because she was an epileptic child. And [she had] all the other complications. Very rarely when there was no room available, they used to put her in a ward. But other than that, she was always given a special room. We were always in a separate room so in that in that sense I was really comfortable because we both used to have a special room, just me and her. And a few staff coming in [and] there were people coming bringing toys to the hospital. So the stays in the hospital have always been really nice. She was well looked after. And it was always a good, good time. I never had any issues or complaints. Whenever I used to leave with her, it used to be always a big smile, so it was really good.

There used to be times where I used to wait for five to six hours [in hospital]. Once one of the nurses said to me “my God, [daughter’s] mummy, you've got so much patience”, because I think that night we waited round about six hours to be seen by the doctors. I said, “what can I do?” I mean, I can't fight, I can't argue, and I know you guys [the staff] are struggling as well, because most of the time there used to be just one doctor. So, whenever I used to ring [the hospital], they used to be like “just bring her in”. And when I used to take her in, I used to not go through A&E, it used to be straight to the ward. The first thing they used to do was give her a bed because if she had a chest infection, she would be drowsy.

A few months back, just by saying my daughter’s name, I used to just break down. But these few months, I’ve learned a lot and I want to use her, I want to share her stories and share her experience to people and they say to me, “oh, we wish we could have seen her”. That will make me feel proud because she was such a lovely person. Whichever nurse looked after her, whenever I used to go back to the hospital, they used to be like, “oh, we saw her name on the board”. And they were like, “we are looking after her. We're taking care of her. We know this young lady”. That used to make me really happy. There are [hard] times and rollercoaster rides, even now, when I really, really miss her because she was with me for 12 years, a big chunk of my life and all of a sudden, it's gone. Everyone is like, “oh, learn to move on”. But I don't want to move on. I want her to be moving with me. So that's what I'm trying to do now.

Chapter 13:

> **But he loved life, he loved dancing, he loved travelling, he loved his grandchildren, he loved his great-grandsons so much.**

Dad was a lovely, kind, gentle man. He was 93 [when he died]. He'd always lived in Wakefield. He was a policeman. He was very well known in Wakefield. Everybody seemed to know each other then. He had two children, myself and my sister who lives down south. For the last 10 years, he'd looked after Mum, who had been diagnosed with dementia. She's still going strong. There's so many different kinds of dementia, hers is severe memory loss. For the last few years, I was looking after them both. And then Dad started with minor TIAs and blackouts, he just said he was falling, but it was blackouts and he ended up having to go into hospital because he injured himself quite badly on the last fall. And that was in the August, and it was until the April that he eventually went into a care home. Not through my choice. Then obviously I had to take over full-time care of Mum. But he loved life, he loved dancing, he loved travelling, he loved his grandchildren, he loved his great-grandsons so much. They were his world.

Dad had been very independent. When it was COVID he kept going out in the car every day to the supermarket. We were saying “you mustn't do it, Dad, I'll do your shopping”, but he was insistent that he wasn't going to get the plague, as he called it. He just thought he'd carry on his normal and just laughed about it and that was Dad.

> **He wouldn't have carers in, he didn't want people intruding in his life, he was a very private man.**

I think it was summer 2020, and he got admitted [to hospital] because he'd fallen and cut his head open, various things. I went with him. At that time, they didn't want me to stay in A&E and I insisted, I said I'm not leaving him in A&E on his own, he's 92. He got admitted. We weren't allowed to go see him at that time then in hospital because it was COVID times and they decided then he needed to be assessed as to whether he needed to go into a care home or not. So he got assessed, and they said he needed 24-hour care. It was assessed [that], yes, he could come home. He suddenly started doing strange things, getting up in the night, opening the doors at 4 in the morning, so we knew he was deteriorating. He had another fall. This went on for eight months. He wouldn't have carers in, he didn't want people intruding in his life, he was a very private man. But then in the April, it got worse, he was admitted again. And that time then, we had a lovely care coordinator, and we found him a care home, a small care home, not the one that the authorities wanted to put him in, and he went into a lovely care home, where he was for over a year, until he died.

During the time in the care home, he got worse. They were very caring of him. They did struggle a little sometimes because he was going back to his old days when he was in the police, thinking he'd got to be in certain places and quite often we had to get called up there to calm him down. Both my son and daughter assisted in that.

He went into hospital a couple more times. The last time he went into the hospital, they found out that he'd got COVID. So again, we couldn't go see him. I used to go up to the hospital every day and take him clean clothes. He had a care coordinator there who wasn't very nice at all, and she kept saying to me, "well, you know, your dad's got capacity". I'm saying, "well, it's quite clear he's not got capacity to make his own decisions". She's saying he wants to go home. I'm saying, well, he can't go home, he's in a care home. And she really talked down to us at that time.

I would try ringing the hospital 20-30 times in a day [but there was] no answer. To me they should have someone permanently on that phone line on the ward. Someone to take calls, to pass messages on. So we didn't know how Dad was, especially when he was put on the COVID ward, we'd no idea what was happening to him. Trying to get someone to call you back was really difficult. I think it was one or two doctors that actually called. But I think it was the fact that you couldn't speak to someone face-to-face, especially when you're told your dad's got capacity [and you know] he hasn't. This is why we have the power of attorney to help that and just because somebody says they want to go home, they don't understand the implications of what would happen to them, when they get home.

And I think they didn't treat the relatives of the person as individuals because, let's face it, not every family is the same, and not every family have got relatives that care for them. And when I did get through to anybody, I was made to feel, you know, “we're too busy, we've got enough on”. But it's our relative.

The last time he went into the hospital was December 2021. And I know that they're busy in hospitals, but Dad wasn't incontinent. If he needed a wee, if someone came and took him to the toilet, he would get there. But no, in their wisdom they decided to insert a new kind of catheter to make life easy for themselves, so they didn't have to bother with him as much, which I thought was quite hard. He came out of hospital into the care home and obviously this catheter was the kind that has to be removed by a surgeon. It had barbs on it, and he decided to pull it out. So once again he went into hospital. At this time, again, I couldn't go see him, but I did blow my top, and he eventually came out just before Christmas 2021, into the care home again.

I had a conversation then with a consultant of geriatric medicine at [the hospital], who was, I must say, extremely lovely. I couldn't see her, but she phoned me and had a long conversation and we talked then about what would happen to Dad because he was deteriorating. And she said, we suggest that we will only admit him if he actually falls and really hurts himself like if he breaks a leg, or if he cuts himself and can’t stop bleeding. So we decided that was the best course of action and there was medication put in place if the district nurses needed it to make him more comfortable. As it happened, we never needed that medication.

> **I think there's not enough people [who] praise the care of care homes.**

Dad suddenly started going downhill towards the end of April 2022. At that time, I was looking after mum too. She was in hospital because she'd fallen and broken her collarbone before I could get up there to sort her in the morning. So I was dealing with two at once and my children were both very good at helping to calm the situation. The care home rung me 10 days before dad actually died and I was going to see him every other day anyway. And they said Dad’s really going downhill. So I was there every day. My sister came up for the last few days of his life. And the care he got in the care home [… it’s an] amazing little place and the staff have been there, some of them, 20 odd years. The residents are like the second family. The way they looked after us was just second to none and there were actually two vacant rooms at the time when dad was in his last few days. So me and my sister were asked if we would like to stay overnight for the last few nights, which we did. We didn't sleep, but we could hear the carers going in in the middle of the night. And although dad was not eating or drinking for a week at that time, they were going and they were still talking to him when they were changing him, changing his bed. One of them actually sat with him through the night. And I could hear her, she kept saying “I'm still here”. And then we would go in as well. So I think there's not enough people [who] praise the care of care homes. I know not all care homes are the same, but I can just say they were absolutely amazing.

I think it was important [to treat people compassionately] because we knew what Dad [was like] as person, and we knew what he'd been like and what he was like at that time, and when you don't get treated very nicely, it's like they're just being treated as a number. But when someone actually takes time to ring you and discuss his care [it makes a difference]. The people at the care home, they were... I mean, their care was constant from day one. They were very, very caring. But towards the end they also cared for us. And let's face it, they're not nurses. They are care workers who have studied to get extra qualifications, and you could tell that they really cared about the person that they were looking after and he wasn't just another resident, he meant a lot to them, and we ended up like their family. And now, sadly, my mum's had to go into care. And she's gone into the same care home because it was tried and tested, and we knew it was the best place for her. So I think someone actually taking time and speaking to you directly, about care and your dad. [was helpful]. At the end, it was just very, very peaceful when he died.

[I'd tell other people in the same position as we were to] think about what you want for your loved one and for the family. Insist that you actually speak to someone in person about their care. Someone of authority or someone that you feel that you can trust wherever they are at the establishment or the hospital. And as hard as it is, stick up for your principles and what you believe is right and what you want, and what you think your loved one would want. We knew what dad wanted. We knew that he wanted to just slip away. He kept saying he'd had enough. He wanted to go, and being the stubborn one that he was, he just wouldn't at the end, and he kept us waiting.

I think it's an important thing, end of life's important and you've got to remember that so many people remember it in a really, really bad way. But the last 10 days of dad's life, we know he had the best possible care by the staff at the care home. And like I say, they're not nurses, but when the time was needed, they got the district nurses in to see Dad regularly. And we were content knowing that he was getting the best care.

I think [knowing that Dad's last days were peaceful] probably did help us get through the grieving process, but it's the first person that we've lost as a family. So when people say about grieving, I had no idea what you were supposed to do when you're grieving. I think I just got into action and did what I what I needed to do. [My sister] was away so I dealt with sorting things out and I was quite OK doing that and I think it was my way of dealing with things. And I think for my children, and especially his little great-grandsons who loved him very much [...] they could talk about great-grandad, and they knew he'd died and he'd gone to heaven, because he was old. And I think because we were not angry after Dad died, I think that's a good reflection on the children because if you're annoyed and upset and angry about how things have been, then they do pick up on it. So you have to deal with that side of it in private when you've not got other people around you.

I believe if someone dies in a hospice then they are offered bereavement support by the hospice, but because Dad didn't, we weren't offered any [bereavement] support at all. Dad's mental health psychiatrist who he's under with him having dementia, he actually phoned me a couple of days after Dad had died and said how sorry he was, and that meant a lot.

And you know, it wasn’t just about “[your dad has] died and he's not on my books anymore”. He actually took the time out. He met Dad on a couple of occasions. We sort of chatted on the phone and that meant a lot. That meant a lot. But no, we were offered nothing [in terms of bereavement support]. I think if it had been offered, I don't know if I would have taken it at that time. I think I'm finding this this week harder, reliving what we went through with Dad because it's a year tomorrow since he died. I wouldn't have taken it at the time because I wasn't in bits as such, I was upset. But no, if the offer was there, I would have kept the letter if I did need it.

Chapter 14:

A conversation had happened between the community nurse and my mum around end of life.

Mum was a wonderful person; she was Scottish and very proud for that heritage. She was 82 when she died and her whole life had really been spent around her children. I'm one of four, and then there was her grandchildren, and we were all her pride and joy. She was very family orientated and she loved to knit and do anything for the family, and she was just a wonderful person.

To be honest, I wasn't aware of any advanced care planning. Mum was very protective of her family, so that might have been why she didn't tell us about it - because she didn't want to upset us or worry us. A community nurse used to come to see Mum in the later stages [of her illness] at home, and I remember noticing in the community nurse’s bag some form or something and it had a Mum's name on it and “DNR” on it, which I knew was “do not resuscitate”. And I remember thinking, “oh gosh, I don't like the look of that”. But then equally, I didn't broach the subject with my mum and certainly not with the community nurse. But what that told me, I think, was that a conversation had happened between the community nurse and my mum around end of life.

As this point [she had] been diagnosed with cancer of the oesophagus and lung cancer. She was diagnosed in the February, and she died in April, and that was a lot quicker than I was expecting. But again, I don't recall many conversations around the end of Mum's life. It was just - and this reflects on mum as a person - it was more a case of each step [at a time]. So, if she had to go for an endoscopy at different points, we just focused on that really so, with regard to advanced care planning, as I say, I wasn't aware of any, but I do think perhaps a conversation had been had between the community nurse, who was absolutely wonderful, and my mum.

Once we got the diagnosis, I think we all just collectively assumed that she would end up in [the local hospice]. I do vaguely remember a conversation with Mum about... or rather Mum said “well, if there's a bed, if there's a place [I’ll go there]”. I guess the thing is we didn't know much about the process. We've not come across this situation before (my dad had died very suddenly at home), so we hadn't had that the same situation and I remember thinking, when she said there might not be at bed, I then thought, “gosh, well, what happens then?”. We didn't know. But we just always assumed that they would find a place for her. I don't know. It's a strange thing to think of now.

I went to see her at the end of March. I went to see her at home and the community nurse was there and it looked like she'd aged 10 years overnight. There was a sudden difference, and I was quite shocked and I got upset.

And in fact, the day after she was like Mum again.

The community nurse was brilliant because she said - you know, she was so caring about me, which under the circumstances, she was obviously having to look after Mum, but then obviously taking time out for me - and she was saying, it's not easy to deal with etcetera. And she really helped me. It was at that time when she said, "I think now is the time for your mum to go to [the hospice]". I'm the youngest [child], so I was a bit upset and I think I also said something about "oh, I have to tell the others". And the community nurse said, "would you like me to ring one of them?" And so, I said "oh yes, yes please", which was so kind [of her]. And so she rang my sister cause she's the eldest. They had a conversation on the phone, and it was sort of agreed. I just remember being in Mum's flat with her and the community nurse just sorting it all out. It was amazing, really. And then I just stayed with her. Some patient transport turned up and she went in

At some point, we went to [the hospice] and she was all settled in and everything. And in fact, the day after she was like Mum again. Whereas she seemed to have aged suddenly when she was at home, it was like she'd gone back to how she was.

I had been in [the hospice] before many years before. I had had a friend who was also end-of-life. She was only young. There's just some kind of atmosphere there, I think. It's just such a lovely atmosphere, even though people are at end-of-life.

All the staff, whether you are just walking past them in the corridor there [or whatever], they smile or look at you at least - acknowledge you. And they're just all very respectful. All the staff I came across were really nice in with regards to Mum when we were in Mum's room, different staff would come in at different times checking on her and [they were] very respectful and not appearing to be in any rush. They had other people see too, they had other work things to do, but they weren't rushing in any way. They'd chat to me or my sister or whoever was there and take a real interest in us as a family, not just Mum. You couldn't fault them. And I remember the consultant coming in and again was very nice. I think she did say "if you've got any questions, ask me, ask us".

The bank where I was worked has been going through a restructure and I'd opted to take voluntary redundancy because I've been there for quite a long time and at that time, I knew Mum had been diagnosed with cancer and I thought, well, I'll take the redundancy and then I can be there for Mum. Because I had been accepted for the voluntary redundancy and the bank also knew my mum was poorly, I was very lucky and they said almost "do what you like, work when you want to come in, when you want. So if you want to go see your mum, do that". So I was given a lot of flexibility around that, but it was an unusual situation really. And of course, at the hospice you can visit anytime. So that was really useful.

I didn't reach out to any services [for bereavement support]. I was aware that [the hospice] did provide some bereavement support.

In fact, after Mum died and we all eventually left the room that Mum was in and we went into another room, it was mentioned there to us. I didn't reach out for any bereavement support because I guess I didn't think I needed it. Obviously, it was a very upsetting time [but] Mum's death was managed. When my dad died, he literally dropped down dead. It wasn't a managed situation, so I felt that [Mum's death] had been managed and there wasn't really anything that could have been done any different.

There was just one thing that took me by surprise at the time and I have reflected on it. Mum went into [the hospice] and we knew obviously what was wrong with her. When we used to go see her when she first got there, it was almost like she'd rallied. She was back to [being] Mum. So we'd go around, and we chat and it was fine. And then when I got the call at six in the morning to go in, it's this bit that's... I don't know if it can be improved. We went in and Mum was very agitated and she couldn't speak. She did have cancer of the oesophagus. The day before, she'd been speaking fine. I didn't expect that [she wouldn't be able to speak]. And that shocked me. It was upsetting because I was never going to hear Mum's voice again. So that took me by surprise. Now, whether that wasn't talked about because Mum had said to the consultant [or] our mum had deliberately not told us when she knew that that was going happen, I don't know. Because of the type of cancer Mum had, that obviously affected her speech and you just think, "if only I'd known the day before that she was going to lose her speech at some point, I would have told her I loved her". When she couldn't speak, she was making noises [and I] knew she was saying "I love you".

So I'm saying it back. But I couldn't hear her say anything. So that's why it just sticks in my mind.

So anyway, she was agitated but the staff were helping. And then at some point they said, “we'll make her feel more comfortable”. And of course, you say “yes, yes, you do that”. But then it was like she went to sleep. She didn't die on us at that point. It was probably about four hours after that that she actually died. But of course, once they've made her comfortable and she's gone to sleep, then that's it, really. And it I just didn't expect any of that. I don't know what I did expect really. So what I'm saying is I think what would have helped me better would have been at some point when she was in [the hospice] someone saying “so this might happen, or that might happen, if your mum becomes agitated, we'll offer to give her whatever it is and then as a result of that she may then fall asleep and then die in her sleep” to set out what's going to happen.

Chapter 15:

> **She would still have a laugh with them, and she'd have a laugh with us, wouldn't she? But she hated the thought that she couldn't do what she used to do.**

Speaker 1: [Mum] was a very strong person, she was strong willed. She was very feisty. Basically, she just kind of wanted her own way all the time. And when she didn't get it, that's when she'd get feisty and bad tempered, and she found it very difficult being ill because she couldn't do what she wanted to do, and she didn't like taking help from anybody. But she was very feisty in the beginning, but then she got to be quite sweet.

Speaker 2: Yeah, she did. She got to be lovely.

Speaker 1: We could sort of look after her. She was the post-lady in our village for years, so a very fit lady. She did everything for herself. She had a car. She went out all over and things like that. But then when my dad died, she went down. My dad died four to five years ago. We thought [my mum had] depression, but it wasn't. And then we had other things. My sister died. Then my brother died. So we thought it was all depression. But it wasn't it. She had a scan and they just said it was age-related memory loss and things like that, but then she had other things going [wrong].

She had diabetes, which we didn't find about until we looked into it, and then she struggled walking and things like that.

Speaker 2: She had an operation on her leg.

Speaker 1: Oh yeah. When she was a post-lady, she fell twice and broke her leg. And then she had an ankle fusion all on the left leg and then she fell over the dog and she broke her hip. It was from the hip she started to deteriorate. She didn't like us looking after her. She didn't like carers going in, but she did get used to him. And they were good with her. And she would still have a laugh with them, and she'd have a laugh with us, wouldn't she? But she hated the thought that she couldn't do what she used to do.

Sort of from that, last year she got an infection. And I took her into [hospital], then from there she went in a hub for three months, which was quite good, actually. She was doing everything that she needed to do. She was sat eating her meals and things like that. She couldn't walk from the pain. And she was on a high dose of codeine, and they didn't like that with her being elderly and what have you, but when they dropped it, she couldn't walk. Then she came out. She was absolutely fine. She couldn't walk but we did used to try walk with her. And we were getting on fine, we looked after my mum continuously back-to-back with the carers. And then I got some night sitters in because I was exhausted because I was working as well. [My sister] was working as well. And then she just got unwell in December. She'd been vomiting, she wasn't taking anything down and she wasn't weeing and things like that.

So, they took her into [hospital] and they said she's got an infection. They confused us at the hospital because one person told us it was sepsis then somebody else told us it wasn’t, then somebody else told us it was E Coli, then somebody else told us [something else]. She had an intravenous drip. Then she went on to oral antibiotics. But she got delirium. But not the delirium where they run about, there's another kind of delirium where they just sleep and sleep.

Speaker 2: Then they told us that my mum needed… this was actually Christmas Eve… they actually said that she might be in over Christmas. And then they came back and said, well, actually, we need the bed. So your mum's going to have to go home, or else we're going to put her in another ward. Which we found out that they don't look after them properly [or] as good in there. So as a family [we decided] because she's got everything at home, she came home. The discharge nurse told me “Your mum's better off at home. You've got the care in place.”

Speaker 1: But then that was a nightmare. My mum was discharged on Christmas Eve evening. The discharge team couldn't even get my mum into the bedroom because they’d not asked us about the measurements. Me and my husband had to get my mum off the trolley into a wheelchair and lift her into bed because they said, “we'll have to take her straight back”. And I said “no. No, no, no, no, no, no, no. You're not. We will do it.” They sent my mum out with not enough meds. I was traipsing around on Boxing Day trying to get more meds for my mum.

It wasn’t the discharge people's fault. And they said, “yeah, you shouldn't be doing this, but we understand how you feel and that, but we can't do it [i.e.: carry her into the house]”. And we just said, “well, we'll do it then”. Because my mum is not going back. [In hospital, my sister and I were doing the caring] back-to-back. She would go in the afternoon and then I'd go in at four o'clock. And we did that all so my mum could get fed and things like that, because the nurses were on strike as well. Don’t get me wrong, they tried. But we did have to ask for a lot of things.

Speaker 2: We found that basically they [the patients] weren’t getting fed. [The staff] would just come and take the plate away. My mum couldn’t feed herself. Because they were so rushed off their feet, they would leave the dinners and come back [and say] “have you finished?” [Some of the patients] didn't answer. My mum was nonverbal. Sometimes they didn’t like me being there because I saw a lot of things.

Speaker 1: We knew from my mum what she wanted. We’d looked after her for six years.

Speaker 2: They were too busy. There was just not enough staff.

Speaker 1: [Mum passed away] at home. We did the ReSPECT form and everything because my mum always wanted to stay at home, and we made sure she stayed at home.

Speaker 2: She kind of slept herself away. She just slept an awful lot.

Speaker 1: They ended up telling us that it was an E Coli infection. They kept my mum on these antibiotics, but every time these antibiotics stopped after like three or four days, my mum would spike. So, I had to keep calling them out again and there would be some more and some more. And the GP told me that sometimes antibiotics in older people don't work. Then they told us that my mum would probably come round, but she never did come round properly so we questioned that. And then the GP came out and she said, “I think you need to get [the hospital] involved”. Because we kept asking “is my mum end of life?”. And they told us no. They said she’s nowhere near end of life, but we knew [she was]. And then the GP got the hospice involved. [The hospice] rang up [and said] they've got the referral and everything and they were coming out to see my mum. We'd had three or four weeks of my mum spiking. [My sister] had had to have the ambulance out because my mum fitted one day. But she calmed down a bit, her temperature came down and we said we'll leave her at home, she's fine. I then panicked one day and rang [the hospice] up and said “you need to come out and see my mum. The date you've given us [is too late], you've got to come out and see my mum.” And she said to me, “why do you think that I need to come out and see your mum?”. I said, “because my mum's dying.” She says “what makes you think that? According to my notes, she's not. She's not.” And I said “she is. I can tell. I've been here before. I can tell. I can tell what's going on.” I could tell. They [the hospice] then came out in late January in the morning. They brought the appointment early. She ordered us a new bed for my mum because we had a hospital bed, but she needed a pressure mattress.

> **She said, “let me check for you and I’ll find out”. And it turned out they’d been sat on our GP’s desk for over a week.**

They would never allow us to have any cot sides in case my mum fell out we had to have a crash mat on the floor. [The staff member from the hospice] ordered that. She ordered anticipatory meds. We were told two weeks before that we needed anticipatory meds in the cupboard, and [the hospice worker] asked where they were and if I haven't got any yet. I hadn’t got any morphine, nothing. She said, “let me check for you and I’ll find out”. And it turned out they’d been sat on our GP’s desk for over a week. Luckily, we had a little bit of morphine that we brought from the hospital, and she told us to use that. But that prescription had been sat on the desk and it should have been really in that cupboard for the district nurses to use if they needed to. They brought the cot sides for us on that same day. They fitted them when the [hospice] nurse was there. Then [my mum’s] breathing was really loud. So I went [back to her house]. And I said I said to [my sister], I think you better come home, I think my mum's going.

Speaker 2: [There were] all these people coming in on that particular day, I thought it was a bit undignified.

Speaker 1: We got the drugs from the chemist at three o’clock and my mum died at 4:15. We got her settled. We got her on her side and everything. And her breathing just went.

Speaker 2: She was [breathing] like a little goldfish, you know. It was so gentle and lovely. And then she just opened her eyes, and that was it.

Speaker 1: I did her hair and everything. She smiled and then... [The hospice] were good in a way, but not too good because they wouldn't listen to me. District nurses were supposed to come out every day when my mum came out of hospital, I had to push all that.

Speaker 2: You had to drive everything, didn't you?

Speaker 1: Yes, it was awful. It was awful. I had to push. I was absolutely worn out with it all.

Speaker 2: And even the carers... some days it was absolutely like they didn't care.

Speaker 1: But I was on top of them all. And they didn't like it. I got CHC [Continuing Healthcare] for my mum in September when she came out of the hub, that was a bit of a fight, but I got it. She was supposed to have four calls a day and then some night sits and it was supposed to be an hour on the morning, three-quarters of an hour at lunch time, three-quarters of an hour at teatime and three-quarters of an hour at the night. But it wasn't because my mum was bedbound, so they didn't really need to do that.

Speaker 2: Twenty minutes and that was it, wasn’t it?

Speaker 1: And that really annoyed me. But I said my piece but it’s too late now. I went away last week. That's the first holiday I've had for five years.

Speaker 2: And she said she felt guilty when she was there.

> **Then she just said, “don't you have any guilt feelings about your mum because you've done everything that you can”. But nobody listened to me.**

Speaker 1: [The hospice] sent a thing through [about bereavement support]. The hospice nurse rang me [after mum’s death] and she said “you were right” [that mum was close to death]. Then she just said, “don't you have any guilt feelings about your mum because you've done everything that you can”. But nobody listened to me. Nobody would listen. The district nurses and hospital were the ones who said mum wasn’t end-of-life.

Speaker 2: There were people in and out all the time and my mum was dying. And to me that’s undignified. They [the equipment team] were taking bits that my mum didn't need anymore. It wasn’t peaceful.

Speaker 1: But to be fair, they didn't know. Everybody was telling us that my mum was just bedbound. Which was frustrating for us.

Speaker 2: I wouldn't have allowed them in that room [if I’d been told she was dying].

Speaker 1: Everything I wanted for my mum, the bed, the bedsides instead of the crash mat on the floor, they wouldn't… I rang I don't know how many times. “No, you can't have one.” And on the day that my mum died, they brought all this.

Speaker 2: It was just horrendous.

Speaker 1: I could manage it, but there's people that can't. There's people that are on their own and things like that.

Speaker 2: Like the continuous healthcare, there's a lot of people out there that are entitled to that but there's a lot of people who don't know about it.

Speaker 1: I've filled in I don't know how many forms in since my mum's been ill. But when my mum was in the hub when she first came out of hospital last year, I asked for a meeting before she was discharged and I said, "I want you to do a checklist on my mum before she comes out". And the physiotherapist in that room said "you won't get that. Only people that go into care homes get that." I said, "I think you might find that you're wrong, if you look at your paperwork". And bless this sister or whoever she was, she said anybody can get it if they need that amount of care. So there's all this misinformation sometimes. Somebody else might have said "oh right, we won't bother". So some people don't have sufficient information when they're going into these meetings and trying to help people. You're not asking for… you're not begging. It's a medical need for that person. And [services] aren't proactive about it. I wasn't [looking after myself while caring for my mum]. When CHC got involved, [the staff member] actually said "you need night sitters". She said, "because you've got carer's stress". Because my mum had one of these things on where, if she fell, it buzzed to Leeds City Council. So I was getting calls on a night at 2, 3, 4 o'clock in the morning, and I was trudging round to my mum's because I didn't have a camera at that time, and she would be fast asleep in bed but she'd knocked the buzzer. Or the bed alarm was faulty.

I got sick to death of them coming out with bed pads. Terrible. Absolutely terrible. And then in the end, we got a camera put in and then we got night sitters. And we got them every night, but only at the back end [of the experience]. The night sitters were actually quite good. They were very good.

They were from the same firm [as the carers] because I'd said [to the care company] that they were allowing us to have night sitters, and if they knew anybody, rather than getting an outside agency that we didn't know, which is a bit traumatic when you've got used to this company coming in. And she said, I do have some people who have been on care, but they can't work through the day, but they can do night sits. But you can meet them all before they come, which was good.

Speaker 2: They changed my [mum’s wet clothes]. We had to change my mum three times a night because of an infection. She had to be meticulously clean. And they did. They noted it. I used to watch on the camera and see them carrying my mum. [Laughs] To be honest, sometimes I'd be going round at 10:30 at night just to chat to them. They were absolutely fine and nice.

Speaker 2: Some of the carers were good at speaking nicely with my mum. With certain ones she used to repeat what they said.

Speaker 1: She would sing with them. But there were others who... they’re just doing the job, aren’t they? The only thing that we found was that a lot of the staff came from another company. And they went in and did it really, really fast. And I actually said “you can't do that. You cannot do that with my mum. You've got to give time”. When she was able to get up, you've got to give her time to get up. You've got to give her time to come round.

You've got to stay [for the contracted] time. And there were certain ones that were really good. Really, really good. But I did have to be on top of them up all the time. But they're still friends with me! [Laughs]

[As a family carer] you do it, you just do it. You go on automatic pilot. And I was working as well. I've come here today [to speak to you] because I do think it needs to be joined up because… it's all over [all the different services required]. It needs to be more fluid.

Speaker 2: And also, when Mum died, two carers, two girls came back, and they washed her and dressed her. I thought that was lovely of them.

Speaker 1: [The carer] messaged me and said, “can I come and see your mum?” and I said of course. She walked through the door; it was her and another girl and she said, “we want to get your mum changed”. I asked if she was sure and she said, “we want to do that”. We were amazed. She was only a young girl. But we had a good relationship with them.

Speaker 2: Actually, I think for me, I would like a bit of counselling. I've actually been going online and doing a bit of reading. I'm thinking some days I'm fine, some days I'm not. I think the hardest part is mainly because my mum's house is still there. And every time I go, it's difficult.

Chapter 16:

> …it was emotional support. That was the most important.

[My friend and I] became friends when we were in Infant School, and I would say that was when we were about five years old. We went through Junior School together, we went through grammar school together. She stayed on in school and she went on to college and became a teacher. I left earlier than that. I got married very young and she was there when my children were born. We lost touch for a number of years, then we renewed our friendship and, eventually, she was diagnosed with lymphoma. She was married [but] she never had any family so when she became ill, there was just the two of them. I recognised it was important for her husband to keep up with his activities, so we organised that. I took her out two afternoons a week to give him some respite from caring for her. She went through chemotherapy, and I sat with her during that process and eventually she was referred to a day hospice. I went with her and she went there for, I think, about a year [to] 18 months before she passed. She eventually passed in that hospice. She was in her 70s.

She was very, very frightened [about dying] and she needed reassurance all the time. She needed support and her husband was very good in some respects, but he was not an easy person. And so she needed a lot of emotional support and as well as being able to go out and get away – she would say, can we can we go over the hills and far away? So, I used to drive her over the hills towards Howarth and back, and we would stop and have a picnic. In the later times when she couldn't eat very much, she just had the odd cream cracker and drinks, but it was emotional support. That was the most important. [We were] trying to look at her eventual death, which she understood, and how we could take away some of the fear.

When she had the chemotherapy and I was with her and very fortunately, [I knew] the nurse in charge very well. And as she was there getting some results, and this led the nurse to sat to her, have you thought about the hospice? And she immediately simply rocked back in a chair, hands over her face. [She said] “Ohh, no, no, no, no.” And I said, hang on, [the nurse] is not talking about going into a hospice. She's talking about going to the day centre and she completely missed that, that bit of the conversation, all her mind focused on was the word “hospice”. [She thought] “I'm dying now”, [as if the nurse were] suggesting her going now. And I said no, that is not what we're looking at here. We're looking at you meeting up with other people with the same problems that you've got, facing the same difficulties that you have and being able to talk to other people and their friends. And she said she would go if I would go with her. And so, I did.

> **…we went to a countryside park where there was a lake, and our ambition was to walk all the way around it.**

She made friends with a lady who [also attended] and they got on extremely well and I think she provided a lot of emotional support, even though she was going through the same situation herself I think the emotional support is as just as important as anything else.

The other thing that my friend did receive towards the end of her life was the very loving care of hospice. And the pain relief. We were able to go at any time. [At the very end] I talked to her about our childhood and the things we've done at school and the fun we'd had, and just kept on talking to her even though she couldn't respond.

I think she was very supported, particularly when she went to the day hospice because it wasn't an unhappy place. It was a very happy place, she was given relaxation. I don't have any problem myself in talking about end of life because I've had a lot of training. I know a lot of people can't talk about it, but it is important that you talk about it to that person gently and find out what are their fears.

One experience we did have in the early stages, when she was still able to walk a little, [was that] we went to a countryside park where there was a lake, and our ambition was to walk all the way around it. It wasn't very big, but we did, and we walked around and then we sat on a seat part way around, and I told her a story which is used with children dealing with death, and it was about a dragonfly. Believe it or not, as we sat on this seat, a dragonfly came, and it was in front of us. And then and it stayed there, and she watched it. And then we walked the rest of the way and it followed us. And that was very meaningful to her. It gave her a great deal of comfort because the story is that the dragonfly was a little buggy in a pond, and one day it crawled up the stalk and was out the other side and his friends couldn't see it anymore. But it could see them. And so when it got out the other side, it turned into beautiful dragonfly. And it's something I've used a lot with people who've been bereaved because it does bring a measure of comfort, in a Christian way, in as much as you may not be able to see that person anymore, but they can still see you.

There was a lot of comfort there in that for her. I guess this is very deep but it's how you have to be with somebody [who is dying]. It's no use brushing things under the carpet with people. Somehow or other you have to enable them to talk about it, and to rationalise as much as possible - this is a process that you're going through. The body is a machine. The real person is the soul, and at the point of death the soul flies free and [my friend] could equate that with the dragonfly.

I have a lot of friends around me, and one of them is a counsellor. In that situation [when you are supporting a dying person], you have to be able to talk about it yourself. So I was able to talk about it to her, and what we were going through.

[When I worked] in residential care, [I found] that a lot of the staff found it very hard because they do get very close to people who are living there. It becomes small family in its own way, and they found it hard when someone that passed away - they found it very hard to go to the family and say “I'm sorry”, because they would feel grief themselves. The way we got around that was that we shared together [as staff], we became a little group who supported that person and supported each other. I said to them, you must remember that family have known [the deceased resident] a lot longer than you have, and therefore if you keep quiet about it, that's hurtful. They might be upset if you say, “I'm sorry”, and talk about the person, but tears are natural, it’s not a problem. The important thing is that you express what you're feeling about that person and how much you cared about them, because that is comforting to relatives.

I think the hospices have got it very right because all the staff are very aware of people's feelings, even visitors’ [feelings]. They will come in and offer cups of tea and say, “are you alright?” in a very gentle way.

I think it's important not to just sit there in silence [when a person is dying]. You have to be maybe thinking beforehand about “what can I say?” What stories can I tell or even read a book or something to keep the sound because we're all aware that the sound is the last of the senses to go.

[I think there should] perhaps be more training in terms of the person who's going through the process. I know we can't experience that until we experience it ourselves, but what would you want if it was you? What would your needs be? And it's not about just the physical [needs] and medication, it's about the emotional. I think there [needs to be] more training on emotional care. What is the current training for end-of-life care not just in specialist but in general nursing and home care? Is there specific training at the moment enabling [staff] to deal with it? People are very busy, and I know in the care sector [there is a] crisis because we're so short of people. Do managers have the time to support the staff who are supporting that [dying] person? Basic counselling skills [should be seen as] a prerequisite for training in any care industry and being able to listen and to get emotionally involved with the person whilst remaining professional.

Chapter 17:

> He was very independent. He did his own washing; he did his own cooking and I'd get his shopping once a week.

My dad would have been 92 this year and he was fighting fit really up until the last few weeks. He liked his sport when he was younger, and he liked to go to the club and have beer. He liked a little glass of red wine and having a walk up to the British Legion club twice a week. He had looked after my mum, who had had dementia. She was type one diabetic from her early 20s, so my dad had looked after my mum quite a lot up until 2020 when my mum passed away.

My dad worked very well with [mum's] carers but he took over everything and he actually admitted that he didn't realise how much my mum had done because he was one of those men that didn't do anything until my mum was poorly. But he took over all the jobs. So my mum passed away and obviously his life changed slightly. He lived only five minutes away from me. So, my dad relied on me really.

He was very independent. He did his own washing; he did his own cooking and I'd get his shopping once a week. But up until the end of last year, he was driving his car to ASDA, so he was a very independent man and enjoyed very good health.

He only really became ill a few weeks before he passed away. He had had a couple of falls, and he started getting very frustrated that he needed to go to the doctors.

Then maybe in the New Year I noticed that he was losing a little bit of weight, and he wasn't quite as good on his feet, a little bit unsteady. And he stopped going to the club, which was only 100 yards up the street. He was obviously getting a little bit nervous about getting about. So his mobility just started worrying me a little bit. I got the practice nurse to come. And she checked him over, but he was very reluctant to talk to her.

Then I suggested that maybe he might want a little bit of help - carers sort of help - which he accepted.

One Saturday, he'd always been one for getting up bright and early and he didn't get up. He didn't feel like it. And I'd noticed that it wasn't eating as much, in fact, very little.

[Not long after he rang and said] "I've fallen". I'd actually arranged on the Monday for the practice nurse to come and see him. So [the next morning] I went round at half eight and he was still in bed asleep. I left him asleep and basically that's when he just started to go downhill. He went down very, very, very quickly [and died 11 days later].

Any conversation about illness and death, my dad didn't want to speak about it. He was quite touchy about that. But what he had done was he filled in a DNR [Do Not Resuscitate order] and [the nurse] said that was one thing that he wanted.

The practice nurse said he was very poorly and [she] would get an ambulance now and get him to hospital and he said “no, I'm not going to hospital”. He was adamant. So he was then referred to the Frailty team, which were very good, and things started moving quickly, and also we got the Neighbourhood team, who got him up and out of bed straight away.

The Frailty team had come on the Tuesday straight away in the afternoon, [and] a nurse who fed back to the consultants. That was all very good. The nurse said that he would come back on the Wednesday after he fed back.

The nurse came once again [on Wednesday], he said to me that if I wasn't there, they would call an ambulance because at that stage he just wasn't able to look after himself. So [I knew] it was literally days [until my dad would likely die]. So you do look back and now I think… my dad didn't want to go into hospital, but you also wonder if you could have done anything else.

[Dad dying at home] was a rollercoaster.

They sent the physio, the physio brought in a commode, but he was past that stage, he was bedbound by Thursday. He was in a double divan so you can imagine [how hard it was for] the carers to try to get to him. But the other thing was he literally couldn't sit up, so my brother stayed as well, it was a case of my brother lifting him up and then wedging himself behind him because we couldn't get him to sit on the back wall because there was a too big gap.

> **We said if that was going to be the case, then don't bother sending anybody. We'll do it ourselves because it wasn't fair on [the night sitter]. And it wasn't fair on us, really.**

I rang Thursday and said, “when's the bed coming?” said they said “oh, we haven't got an order for a bed.” So, then I rang the Neighbourhood team and they said, “oh no, the order’s not been put in”. I think they said it was something to do with costing, but I don't know whether it just hadn't been processed. So I was saying, look, if it’s a case of money, I’ll just put it on my credit card, but we need a bed.

My dad was constantly shouting for us [to ask for things]. He was getting weaker and weaker. So they did actually put it through as a matter of urgency. And we got the bed Saturday afternoon, but obviously we've gone all those days [and] through the night trying to lift him up to give him a drink.

We never left him from that Tuesday. There was either both myself and my brother or one of us all the time.

I've gone through [death] with my mum as well. In June 2020 my mum passed away, she went downhill a lot quicker than my dad. To a certain extent, we had the Neighbourhood team coming in who were lovely. And they did ask if we were OK. It was very tiring.

We did have a night sitter, but we couldn't leave him because we couldn't sit my dad up [until we got the hospital bed]. After one night sitter assessed my dad, they called and said, “you can have three out of seven days”. I said he needs somebody there all the time. She said, “if you leave the drink by the side of him, can’t he get himself up?” I said he can't sit up. So they did actually say “we'll reassess him”, so that was OK.

Unfortunately, one of the night sitters… he was only young. He'd only been in the job three months. I don't think he had any experience in end of life. He had absolutely no idea. We said if that was going to be the case, then don't bother sending anybody. We'll do it ourselves because it wasn't fair on [the night sitter]. And it wasn't fair on us, really. It was better that we did the support.

We then did get some NHS night sitters who were absolutely marvellous. And you did actually feel that you could actually go in the other room and try sleep a little bit. They were very supportive, and they knew a lot about end-of-life care. They were just so, so calm. They knew what they were doing. So professional. Such empathy with us.

But we did have a bad experience and unfortunately it was the night before my dad passed away and we'd gone through a lot with the syringe driver, etcetera. All the meds and a night sitter arrived, who seemed very nice and had been in the job a long time. And then we got a phone call from their office to say that they were sending somebody else. Well, it's only a small bungalow and there was my brother staying, I was staying.

I said, well, should I ask [the current night sitter] because he's OK and the office said it's not up to him, it's up to us, we're sending someone.

My brother had to leave my dad to go and really be hospitable [to the new night sitter when she arrived]. As she walked into the room, we were waiting for some more meds because the syringe driver wasn't sufficient. My dad was quite agitated. We got the district nurses because the syringe driver needed topping up, which obviously is a bad experience to watch your loved one go through all that. And I was sat on a chair next to my dad, he was really tired. The night sitter came in and said what an awful week she had had - this is to somebody who's been watching their dad slowly get worse – and I went and got her a chair. She sat in the bedroom as well, so that there was my dad in the bed and there was the other sitter. And then she went "I can't believe it. My patient passed away 20 minutes before I got there, so I've had to come here". My dad could hear this. I just couldn't believe it. And so and I said to her "Why have you come here?" She says "well, I can't go back to the office and my patient had died". So, I said "so we're just a base?". She let that team down.

The night sitter started to talk to [the other night sitter] across the bed. First, she did speak to me a little bit and I wasn't really in a mood for conversation, so she would just say [to the other night sitter] "do you know so and so in the office?", talking across my dad. I'm not one for confrontation, and I could feel myself getting worked up.

So I just said, “do you think I could have some time with my dad alone, please?” So they moved into the sitting room. I could hear [the night sitter] talking in the living room. And obviously I'm tired, it's three o'clock in the morning and I just said, “do you mind? You've just told me to try and get some sleep, and you're talking so loud, I can hear you, my dad can hear you, my brother can hear you. I don't really think there's any need for you to be here”. She just looked at me. I thought that she might have said “look, I think it'd be better if I go”, but she didn't. She's stayed there and I could hear her whispering.

We never knew who we were going to get [from the night sitting team] and one night we actually rang and said “look, don't send a sitter” because it was going to be the carers, not the NHS. We decided that we would look after my dad between us. However, what we didn't realise was an NHS sitter was coming as well. At ten o'clock at night, we got a knock at the door from an NHS sitter. We said we had cancelled, and he said, “oh, sorry, that didn't get through to us. Do you mind us coming in?” And he had a word with me, and he was lovely. He made me feel that I could actually leave him and just nip home.

[Earlier that day, Dad had been in a lot of pain] and the nurse had come, and she said “I'm going to come up with a plan. Leave it with me, we'll get something sorted”. At 3:30 we’d not heard anything, so I rang and spoke to the receptionist who said “no, they're not doing anything at the minute. We're not giving [any medication].” I couldn’t really understand that. That night was the night we were going to look after him ourselves. But the NHS night sitter, with my brother, really dealt with my dad, if that sitter hadn't been there, we would have really struggled.

> **After Dad died, one of the district nurses did say “do you want a bereavement [support] appointment?” But nobody got in touch.**

I think my dad went unnecessarily in a long time in quite a lot of pain and agitation. The next morning, a nurse came. She got the meds to him. That should have happened the morning before.

Eventually when my dad did get the syringe driver, it obviously wasn't strong enough, so we had to wait for the district nurse to come, and they must have topped it up. But then they said, “this will last for four hours”. But then you're waiting for four hours and you thinking we've got to wait now; we’ve got to report it then we’ve got to wait for them to come out. We had a few top-ups and that's where the rollercoaster is, us knowing that actually he does need that top-up and then having to ring the district nurse and say he needs something, and then waiting for them to come. That that was the hard bit. We were having to ring up several times. Don't get me wrong, they were there pretty quick, but we were on countdown thinking that it's going to run out again in four hours.

They topped the syringe driver up on the Friday lunchtime and he passed away at one o'clock in the morning. We were absolutely exhausted because we'd hardly had any sleep in the last 11 days. And because we did have confidence in [the final night sitter], we did [get some sleep].

I was listening to my dad breathing all the time with one ear. And then I'd wake up. But then the night sitter came in and he said, “I don't think he's got much longer”. That expertise was brilliant, you know. We were both there [my brother and I].

After Dad died, one of the district nurses did say “do you want a bereavement [support] appointment?” But nobody got in touch.

Most of the district nurses were absolutely marvellous. I wasn't looking forward to a care company coming in again [after bad experiences with my mum’s care]. [But] they were amazing. The two girls that came were so considerate to my dad and they were amazing to me.

I think possibly I didn't understand the stages of somebody passing away. I had no idea. And I think for somebody to be warned, this is how it could go… It would have been a big help. With my dad, I was always wondering “do I give him a drink? Is he going to get to that stage [where he can’t drink]?” I think for a family who's got to go through that… I thought people just passed away and I didn't realise that there's a lot of things going on for them to eventually [die].

[If professionals were clearer about what dying can entail] it might also change people's opinion of whether they want to stay at home or whether they want their loved ones to stay at home.

[On the other hand] the night sitters were very good at explaining, and also put their personal stance on it and showed a lot of empathy. [Apart from the one member of staff who wasn’t so good] the NHS night sitters were an absolute must.

I think [the grieving process when someone has died at home] is hard because your memory [of your relative] is a difficult one with pain. And that’s difficult to get over. Whereas I've lost grandparents and have not been with them [when they died], and I remember them a lot better. Especially with my dad, I have the feeling that he went through a lot in his last few days. [Dad] knows that we were there, so for him it was a good thing. But I think it's very hard [for families].

I just think “why didn't I do that?” Going through everything in my head. “I shouldn’t have done this, why didn't I do that?” And that's the hard thing. In fact, I just said to a district nurse [when she came to see my dad] “when I get anywhere near [my own death], I'm going to tell my kids to put me in a hospital and leave me there and not come to see me, because I said I don't want my kids to see what I’m seeing”. I think if you do pass away peacefully, you’re very lucky.

Chapter 18:

It was the first time going back to hospital in Leeds after our first daughter passed away...

We've lost two daughters in the last four years. Our daughter [who passed away more recently] was born in January this year. She was with us for five to six weeks.

During the pregnancy, we were told she might have issues. She did have growth issues; she might have other issues. Within the first 30 minutes of life, she was given CPR twice. A few days on, the scans and everything was done. We were told she had a blockage source in her nasal airways, so she struggled to breathe, and she was on a ventilator. We then moved [the care] to Leeds with hope of an operation. It was the first time going back to hospital in Leeds after our first daughter passed away and it was just a bit of a coincidence that everything was the same. Same consultants, same room. So that was a bit difficult.

At Leeds, they compared notes with our first daughter, and they said it's very similar and that she's actually got the same syndrome as our first daughter, which is very rare.

It's called You-Hoover-Fong syndrome. In one in, I don't know... 100 million, or 100 or 200 million people, there's a chance. So, it's incredibly rare. There's not much research done about it, but we're both carriers of it and we knew beforehand there's a 25% chance of it happening again.

I think it was towards the end of January, we were told we can't do anything for her. We took her off the ventilator and we were told it's more than likely within a few minutes she'll pass away. Well, she kept going, kept going, kept going, learnt to breathe through her mouth. We managed to take her home. She lasted three weeks without a ventilator, which everyone was amazed. And then she passed away in mid-February.

Without [the care coordinator from the perinatal palliative care team] we would have been lost. Genuinely, honestly, we would have been lost without her love and support. And without the doctor's guidance, even to the other doctors, we would have been lost. They supported us 1000%. They listened to us, talked to us. Took on both of our [my wife's and my] suggestions and all of that. Absolutely brilliant they were. When we took her home, it was our decision, but I think they wanted they would have liked us... because we made it clear we wanted to take her home. I think we were due to take her home on the Thursday. And then she had a couple of episodes where she stopped breathing, and literally we were about to go home in an hour or two. And even then, the doctor said, “look, I'd love you to take her home, but I don't want anything to happen to her overnight on your first day home”, so then we delayed it to Friday. [There was] absolutely brilliant support when we got home.

The Bradford Care Team, the consultant, the palliative care coordinator, the hospice team. We had everything proper. Everything set up.

I think the end-of-life care was brilliant. They came together [as a team]. They had a meeting together, all the three to four departments. We were shown around. We were going to be discharged from the baby unit, we were already given access and walked around the children's ward. They had a meeting, they kept us informed what happened in the meeting. Then they had a meeting with us guys, my family were there, the doctor, the palliative care nurse, the Hospice team, the Bradford care… outpatients care team. So that was a good group of people that were there supporting us all the time and each of them knew what to do. Literally I can't fault the end-of-life stuff.

Before we were taken to the hospital in Leeds, we were given the impression that it will be able to do an operation. And then to go to the hospital and within a couple of days to find out, no, there is no operation, there's no chance of an operation, it was a bit heart-breaking and devastating. I’ve spoken to the Bradford palliative care coordinator about that just to say, look, that false hope that was given to us, that shouldn’t have been given. Before we moved to the hospital in Leeds, we had a meeting. And [being] the way I am, I always make notes and in the two or three weeks I was there, I had a reputation for coming to doctor rounds in the morning with a long list of questions. So, in the meeting we had a lot of questions and it was very, very clear that we were going to the hospital for the operation. And that's what was disappointing.

> **The nurse keeps in touch with us a couple of times a month. Maybe every week sometimes she’ll call to say hello and ask how we're doing. If she wasn't there, I don't know what we’d do. She's perfect for that role.**

But other than that, it was absolutely brilliant. Even to the extent of… every little detail of what happens or who do we ring or who should we expect to come out or how long they might take, every little detail was given to us from the services. Whether it was the Bradford team, or whether it was the hospice team, or even the consultant. The guy is absolutely brilliant.

We had contact details for the night, for the day, for the weekend. Everyone knew about us and because obviously we lost our first daughter four years ago this, we were given extra care and attention, which was really good. We literally had like a good book full of information that was given to us. And they talked to us. [The palliative care coordinator] was in contact almost every day. The nurse keeps in touch with us a couple of times a month. Maybe every week sometimes she’ll call to say hello and ask how we're doing. If she wasn't there, I don't know what we’d do. She's perfect for that role. Obviously because we lost our first daughter four years ago, we've got… it's probably the worst comparison you can do, but we've got something to compare it against. And I think we would have… I don’t know whether easier is the right word, but it would be better to cope with if we had someone like her back then, four years ago. And if you compare it to the service that we received [then]…

I never give 10 out of 10 to anyone, so if I mark it 9 and a half out of 10, I'd probably give four years ago 6 or 7. So it's vastly improved.

She gave support to my son, and she'll still keep talking to him as well. Sometimes on the phone. The support they've given to him is... I mean, to lose a sibling when you're three is difficult but you don't understand it fully. But when you're seven years old to lose another sibling, the effect that it's had on him as been really, really, really bad, really negative. And the support they've given him, the Hospice team, the palliative care nurse. Even the school's been brilliant. I think the hardest thing was, the day we were told they couldn't do anything for our daughter, we came home and the first thing our son asked was, is she coming home? The effect it had on him has been crazy. He's a big Man United fan and the palliative care nurse found this out. We didn't say anything to her, but she emailed Manchester United, and she's asked them if we can get some tickets and they've agreed as well. There's three tickets for us she's arranged. So to go the extra step is brilliant.

We were given options for Muslim priest or lady or someone to come talk to us, during and even after, so we were offered that support. So anything that we requested in terms of Islamic traditions, we were allowed to do. There was stuff that I didn't ask, obviously because she's on ventilator, in the position that she was in, so I didn't ask but, once they took the ventilator off and she was alive without any support, they absolutely allowed us to do whatever we wanted. Even when they said, "look, she can pass away". We already said to them, "Islamically, we like to bury within 24 hours".

Because I was scared to take her home in case she passed away at home and then there's a postmortem or, you know, it takes two, three, four days. So I told them this is what we want, we don't want anything to come in the way when we take her home so it's going to take three or four days [to bury her]. She passed away at 8.30 and the hospice team came out at 10:30, eleven o'clock to give a cold cot. They were there for about an hour or so and at seven in the morning the doctor and palliative care coordinator came to sign the paperwork off. And I was at the registrar by half nine to sign the paperwork off and she was buried at three o’clock. So, it was absolutely spot-on. I think they understand the way these things have to be done, so they do take it into account even without you asking really.

[Speaker’s wife:] We're doing OK now. It’s just, in my heart, one part of my heart is closed for our daughters. I don't want to open it again. When sometime somebody talks about them, I feel sad, but I don't want to open it again.

I think [my wife] probably at the stage now where she doesn’t really like talking about them as much as she used to two or three months ago. It hits you just at random times. But because you've been through it twice, it does make you a hell of a lot stronger. Probably weaker at the time when it happens, and the few weeks that follow, but I think overall, 100%, it makes you much, much stronger. And to lose two is just crazy because we've sort of lived the whole thing all over, especially at the hospital in Leeds because it was the same room, the same office, same consultant.

And when we were told they can't do anything for our second daughter, we were literally on the same sofa in the same positions that we were three or four years ago. Same words uttered to us.

I think if you build a relationship with [staff members], then it's a bit easier to share with them. So, for example, when our first daughter passed away, we didn’t have that person [like the palliative care coordinator] to talk to or fall back on or just sort the little stuff out. Because we didn't have that person to talk to or to lean on, it was much more… we were still given the option for all the support and everything. But because you don't have that connection with someone, that relationship with someone, it doesn't matter how much support that person offers you, you might go for it, but you won't be 100%. But this time around, because we had that connection and that relationship, and because we were given that a little bit extra care from the palliative care coordinator and the doctor, we could lean on them just for support, just for a general chat.

Would I suggest anything different for going forward? No, I don't think there's anything really that I'd sort of go back and change. Everything was done how I wanted it to be done. And the support that we received was absolutely phenomenal, honestly. Even the nurses are absolutely brilliant. Honestly, they would all come in and we were there, after taking her off the ventilator, we were there for two weeks in hospital. And everyone would just come in and they'd be amazed.

> **The services that gave us the aftercare, the end-of-life treatment, before or after [they were] absolutely 100%.**

So, on the Friday, for example, we took off the ventilator. Another Monday we had a rush of nurses coming just to see her. But as long as there's someone, or two or three people, there who have that connection with families, have that relationship with families, you know, those people are definitely needed 100%.

We had a lady there who came to see me and my wife just for mental support. About two months ago, Bradford started a new thing for families who have lost children just to meet up and just talk. So that was the first one. There weren't many of us there, but it was the first one and it was good to talk to just other parents, not online, just face to face. If it does happen again, we'll go. There's not many people who have lost two. And we like to know the feelings and opinions or just talk to people who have lost two. And just to see what they say or even if we ever, ever come across - I don't think we ever will but - the same syndrome, maybe.

The services that gave us the aftercare, the end-of-life treatment, before or after [they were] absolutely 100%.

Chapter 19:

> She was a mum and a really lovely stepmother and a really lovely mother-in-law.

My mother-in-law was 66 years old and had an absolute love of life. She'd worked all of her life as a care worker and really took pride in taking care of the people that she was responsible for. She had got grandkids. She was a mum and a really lovely stepmother and a really lovely mother-in-law. Just a really warm, kind nurturing type of person

Conversations were really quite difficult with all parties involved in my mother-in-law’s care. It was tough because she chose to die at home, but there wasn’t really a coordinated approach in terms of the services that were involved in her care. And she was always quite a humble character and never really wanted to make much of a fuss, so therefore organisations would contact her, and she had reduced capacity nearing the end, so she didn't always understand the wider aspect of what was going on with her health. And the people would ring her and say, “how are you doing?” This could be the cancer nurses, or it could in fact be a GP or it could be the care workers that came in a couple of times a day. And she would say that she was fine, it was just her legs that didn't work, but that everything else was OK - and things weren't OK.

Nothing was OK. And it was really quite tough in trying to engage with the services [as a family member] because of course no one can share information with you, which I totally appreciate. GDPR is a massive thing that I have to adhere to too [in my job], but it certainly felt like these services didn't even want to listen to your concerns, let alone provide any type of support or feedback which was really quite tough.

So, we were left at times with absolutely no information, not knowing how to care for my mother-in-law. The registered nurses would come in once a day in order to change, for example, her syringe driver. And that would be the only qualified nurse that we would see on a daily basis. Their time is very limited. They are there literally to change the drugs in the device and to change a battery. They're not really there to answer any queries or concerns that you've got and can't really comment on that because they don't have the information themselves. So that was really quite harrowing because people were looking at me almost as someone that was coordinating the entire operation. During that time, I actually lived there because her husband had just had a stroke as well, so he didn't have much capacity nor physical ability to be able to care for his wife.

It had a real emotional impact, trying to actually navigate through that system is really quite tough. We didn't even have a list of telephone numbers of people to ring. We just got given one telephone number and the rest of the information I had to find myself, which was tough.

And I am used to finding information, but even to navigate through that was just a nightmare. It was one of the most harrowing things that I've ever experienced, and still, I'm quite traumatised by the entire thing. It was tough.

[We needed to see a palliative care nurse] a week or so before my mother-in-law actually passed. We were given a telephone number at this point to ring. She was called a cancer nurse, but I've got no idea of which service she actually represented. There was one particular person that was our case worker and I tried to contact her on multiple occasions to be told that either she was on annual leave or not available and that a call-back would come. And of course, the callback did come, but the callback came to my mother-in-law. And then my mother-in-law would say she's fine. By this point, the cancer had metastasised, and she wasn't able to lift her legs. I was terrified the hip was going to fracture. It was obviously going to fracture. You could see the bones because she had very little body mass.

All that I needed was for a nurse to come out and review the situation, because I knew that her health was in a massive decline at this point. At no point we were told ever that you've probably got X amount of time left, so we were always left wondering. Because I'm quite savvy in terms of looking at people's health, I knew that we were in the final stages, but none of her other family knew that, nor my mother-in-law, so she is still planning when her hair grows back, she's going to have this colour put on and her grandchild's birthday.

The palliative care nurse rang my mother-in-law, so I rang them back literally within five minutes of that phone call ending. I was on a work call myself at the time and overheard the conversation and just had that moment of “oh, no, like they've rung her and I'm not going to get any answers here again”. Within two minutes I've rung back, and they were just like, “at the last appointment your mother-in-law said she was absolutely fine”. And I'm like she is not absolutely fine. “Well, she's told me that she's fine today.” And I'm like, yeah, because she thinks that she is fine today. But she is not fine today. I'm really worried about this hip. I don't know how to manoeuvre her. I'm not trained in lifting and handling. I need for someone to come out and just tell us what we should be doing in between the care people coming out, who incidentally were there for, I think, 15 minutes on a morning and 15 minutes on a night, which wasn’t enough time to care for her. In between times, no one should be sat there left in a soiled condition, and her not being able to toilet herself did mean that I had to do quite a lot of the work involved in making sure her care needs were met.

During that phone call, I literally had to beg for someone to just come out and see her. Which they did, and I felt absolutely relieved. The second that they said that a nurse would be available and that someone would come out either later that day or the day after, it was just such a sense of relief. And when they came, they were wonderful.

The lady sat down at the side of my mother-in-law, and she actually looked quite shocked in terms of how her health had declined quite quickly and talked through quite a lot of things in terms of this is how to lift, this is how to move and if anything were to happen in terms of the fracture occurring that there wouldn't be any sort of wider consequence to myself. Obviously, that is such a worry as well. And [she explained] that it was a part of the progression of the cancer. It was all quite pragmatic, but I don't mind pragmatic. I quite like to be told how things are. I'm not really bothered about the emotional side of discussing care at this point.

She arranged for a sheet to come which was called a slide sheet so that I could put that underneath my mother-in-law and almost slide her around rather than having to lift her. And she showed me how to manipulate her legs using a towel that was rolled up so that I could move both of her legs at once in order to not hurt her. It was that practical support that had been needed for about four weeks prior to this. And just such a tiny thing like a sheet and how to roll a towel up to move someone's legs made a world of a difference to the quality of life that she had left, but also sort of the emotional drain that it had on us. I used to do the care Monday to Friday and my partner did the care over the weekend. And for him, obviously, he's there caring for his mum. Ultimately was up to us to care and to be able to even share that information with him and to say if your mum needs to get up, then instead of having to move her around and maybe her nightie will be up, which he found really quite tough at times, we can give her a little bit of dignity now.

> **Thank God for Google. Thank God for the Macmillan website. Thank God for all of those things, because without that, I wouldn't have had a clue what to do.**

To be able to teach him how to do that and reduce his stress meant the absolute world to me, but again, it shouldn't come to a point where you're having to beg for the bare necessities in terms of care for someone.

[It was helpful to be told what to do] in a really pragmatic matter of fact [way], in layman's terms, we're not bothered about the long terminology for lots of different things. All that you need to know at that point is what you need to be doing at any given time, and to have really clear, concise instruction and direction.

Because there's not that 24-hour care provision [when a person is dying at home], you do find yourself in the carer’s role. If you were to go into a job and someone said to you “you're just a care worker today. There you go. There's all these people, they're reaching the end of life. They're all terminal, just get on with it”, everyone would be horrified. But when someone chooses to spend their last weeks, days, months at home, that is literally how it is. You just thrown into this world of something that you've got no experience of. Thank God for Google. Thank God for the Macmillan website. Thank God for all of those things, because without that, I wouldn't have had a clue what to do.

Everyone avoids you when you're going through situations like this, because people just don't know what to say. Everyone's aware of what's occurring and what's about to occur. But there's no one really that wants to engage in those conversations just because they don't understand it. I’m quite a talker anyway, so I found a circle, even if they didn't really want to be a part of those conversations, they were made to be a part of it. But for other people, I can imagine that that is quite difficult, and certainly for my partner at the time, he had no one to have these conversations with. And my mother-in-law’s husband had no one to have this conversation with. On a weekend they were still in the mindset that she might even recover from this, and you sat there thinking to yourself, there's no recovery from this. And maybe if there have been other people to have those conversations with, it might have helped for them to understand the situation without all of the emphasis all of the time being on me to do [it], which was actually quite a chore because ultimately, I'm telling them information that probably wasn't information that I necessarily wanted to share.

So as much as I found my people, I also found it quite difficult to speak to her husband and son because of the emotional attachment that they had, that I could maybe detach myself from when I'm speaking to people outside of that situation. It's hard work [holding a family together].

I couldn't gather any paid time off and we couldn't afford for me to not work either. So work were really flexible in terms of the hours, as long as my working hours got done it was fine. But the consequence of that meant that once my mother-in-law’s carers were done on a night, I'd log on and do a couple of hours.

Then of course if an incident occurred in the night, that was just another nightmare to sort of navigate through. It's really tough. The [family] dynamics are hard, holding the family together is hard, being the strength for everybody else and actually crumbling yourself is hard. And the wider support of friends, family isn't necessarily there, and it shouldn't be assumed that it is there because people do find it difficult dealing with death.

When the condition’s terminal and you've got a limited amount of time left, you have to just take that on the chin. You know this person is not getting better and it's about making the quality of care as good as it can be during those times and just creating memories. Not even particularly for the person that that is on the end-of-life, but making sure... for example, I did hand casting with her son and her husband so that they had just that little bit of something in the future. But again, even talking about that, and what we were going to do, some of the family just refused to accept that it was needed because they couldn't accept that death was imminent.

ReSPECT forms were predominantly a Leeds thing at the time. So in this area, people didn't actually know what the ReSPECT forms were, which in turn caused massive complication because all of the plans for everything is written in there, but the carers weren't aware that that's where everything was documented, so we had to go through the old process of getting, for example, a new DNR because they wouldn't accept the one that's within the ReSPECT forms and things like that.

> **One of the most harrowing things that occurred - and I think it's important that this is shared - is the care from the GPs.**

In terms of how it's impacted on my life, for a while after her death and still to some extent to this day, I believe that I was suffering from PTSD and I was obsessed almost with death in terms of, at any moment, any one of us could die and had a real emotional impact on me afterwards. Up to the point where now I've got wills written, I've got a funeral plan in place because it all really does drive home how quickly things can change and how important it is to have provisions in place. I wouldn't want any of my children having to look after me in the same way that that we had to.

One of the most harrowing things that occurred - and I think it's important that this is shared - is the care from the GPs. So, a general practitioner, they're not specialists in every subject. We all know that, and I appreciate that. But to have someone come into someone's home where they're dying and to actually tell me that I needed to take this person to A&E for a scan because they thought that she'd had a stroke was one of the most dreadful experiences of my life.

To actually carry someone out to the car, to try and get them in the car, when of course [because of her hip] she couldn't manoeuvre herself in a way to get in and out of the vehicle [was terrible].

We managed it and we managed to get her to A&E [only] to then be told that no one could stay with her because we were just still within lockdown and the whole COVID thing. [I had to] actually say “this person’s on palliative care, I am not leaving her”. We'd been sent here unnecessarily and [they] just left [her] in a waiting room in a chair and she's crying because it's so uncomfortable for her to be then. Then [we were] moved into side room where she did have more dignity, which was great. But to then be told by a nurse there that this was all because of progression, and luckily the nurse that was working in A&E that day had worked before in oncology, so she really had an understanding of the situation and she actually went up to the oncology department and brought someone down to have a chat with my mother-in-law because still at this point, she is telling everybody that she's fine, that she's going to get well from this, that everything's sort of OK and that she probably has had a stroke. And it was the cancer in the lymph nodes that was causing all of these symptoms.

It was evident that it wasn’t a stroke. It never was a stroke. But for the person to come down from oncology that day like they did and actually take half an hour out of their day to have that conversation with mother-in-law and to say that “we can prescribe more steroids. This [symptom], however, is a part of the cancer” and for me to not have to have that conversation with her meant the absolute world.

And I really want to drive home that GPs need more common sense in dealing with end-of-life care. It's pointless sending someone to A&E at this point.

Even if she had had a stroke, there was nothing, literally nothing that could have been done and when I'm there and I'm saying that it's the steroids that we're reducing down that's in turn causing the lymph nodes to expand and this is in turn causing the whole of the face droop and the slurred speech and the inability to eat and drink, and to be looked at and almost scoffed at and [for them to] say that these are symptoms of a stroke and to make that decision to send her to A&E was absolutely barbaric. To have a common-sense type approach to those situations, rather than looking at symptoms and just textbook reading, would be ideal. More training needs to be given. It's unfair to expect a GP to come out and care for someone at the end of life when they don't have the necessary skills to do so, there needs to be either a bank of GPs that are specifically there to do this, or a specialist in each surgery, or just someone to take that role because it was bad for the GP. I felt embarrassed for him, but I also felt really disappointed in having to drag someone through a nine-to-ten-mile journey in that state to just be left with no dignity when we arrived, it was horrible.

At the time, I very definitely considered [making a complaint]. I wrote everything down. I've still got everything written down so that at the point that I do feel like sharing the information, it's all there documented - days, times, dates. But I was so depleted that I just couldn't do it. My emotional health took an impact after this and consequently me and my then partner split up so we're no longer together. So, I had all of that and becoming a single parent and everything else.

So, I've not done that [a complaint], but only because I have not had the capacity in order to do that, so this [conversation] is the first time that I've actually spoken in such a way about the care.

I think that'd be wonderful [if people and services had] conversations beforehand as you're going through this situation to say “would it be OK if in six weeks’ time after the event of the death we [services] were to contact you to check in to see how things have gone and gather some feedback, to even see the support that you need for the recovery?” But there's nothing, there's no contact. The person dies, the funeral happens and that's that. It's just like it never happened.

Bereavement support is really quite sparse in terms of, if she'd have died in a hospice [it would be] quite readily available, but because she chose to die at home, it's not something that's offered. And yeah, you can seek that support out, but you shouldn't really have to do that. You're just absolutely depleted. You've given absolutely everything in order to make sure that this person is as comfortable as possible until the end, and then afterwards… it’s like two bereavements because you've got this person that's no longer there, but then you've got this huge empty space because the care takes up such a huge amount of time that actually you're left just floundering - like, you know, what do I do now? I have work in order to fill the gap, mostly. But it's a lonely time after the event of a death. It's really lonely.

Chapter 20:

> **I think the services that looked after Mum understood what mattered most to her.**

My mum actually met my dad and they were married out in Bahrain. All three of us [children] were born there. When they came back to this country, they had a newsagent's and then after that, my dad went into teaching and my mum became a school secretary. For years she was a very well organised person. She could run a school with her eyes shut. And she was prolific at baking, sewing, quilting, you name it. She could do amazing things and made several wedding cakes and just loved doing things for people. And she loved family. She loved seeing the grandchildren, great-grandchildren. She was just amazing at being able to create and craft and make. And she was 91 when she passed. She died at home with us.

I think the services that looked after Mum understood what mattered most to her. It's very difficult because Mum wouldn't have been able to express really what she wanted. In terms of mental capacity, she would forget things within a minute, so she would, for definitely the past year, if we saw a doctor, she would look to make me to answer for her [because of her Alzheimer's disease, which was diagnosed in 2019].

She would not have been able to say what she wanted because she couldn't think to answer questions that well. She did want to remain at home. If she had become so poorly, we'd had discussions with doctors that we didn't want her admitted to hospital and things like that. And she was she was quite happy to be here.

My mum, up until her memory issues, was a very frugal lady and said, “there is enough money there for me to go into her home when I can no longer live on my own.” But as she got older, she didn't want to leave and we wouldn't have got her into a care home, I'm sure it would have been a battle, so the decision was made for her to come here [to my home], and she was very happy to be with family. So, there was never any discussion.

The GP surgery’s care of my mum was excellent. But would say that once she moved in, there was no backup for us or my mum, nobody ever came and said “yeah, you're doing OK” or “you might need this”. We had no physiotherapist in which we could have done with it because of her walking. There were times where I would have to sit mum in a wheelchair to get her from A to B within the house and then days later, she could walk with me by her side and I think we could have done with, not like a social worker type of person, but definitely if there is… I don't know whether you would class it as mental health or the unit that first diagnosed Mum with the Alzheimer's as memory nurses and things like that. I think something should be in place that we can say “can you just come and see that we're on the right track, that we're doing the right thing? Does she need anything else to help with daily living?”

When Mum got on the end-of-life care, a physiotherapist came and said “no, you're doing that wrong, you're doing that wrong, you're doing this wrong”, but it was too little, too late.

We rarely had the same sitter overnight. We always showed them the book with the emergency contact number if mum was in pain through the night. And some would look very perplexed and say where do you keep the details in case we need to get anyone out? Some would definitely move mum around in the bed through the night because the bed sore that she had was quite bad. And because we never knew who was coming in, which is another [issue], that made us quite anxious. Overall, yes, they did look after Mum through the night. But medically, training wise, I don't think some of them were up to the job if I'm being completely honest.

When Mum was put on the driver, the nurses knew her time was days, not weeks. Her last night it was an agency worker and for me she didn't… I got up and mum was in pain. I actually stayed downstairs that night and said to the agency lady, if there's any problem, just come through and get me. And so, for me to come through and find that mum was in pain, she needed the driver with more medication, it was upsetting. So that would be my recommendation, if the nurses know when it's getting to that stage, I think an NHS person through the night is better qualified than an agency worker. I know it's very difficult to judge, but a lot of them do have a really good sense of when it's getting near the time. So that for me, if I could put the clock back, I would have preferred somebody medically trained with her on her last night because to get up and see her in pain and very uncomfortable wasn't nice for her.

> **They went from chemist to chemist, and they did so much to try and get the pain relief into Mum that, for me, yes, they were doing their job, but it was lovely to know that they cared so much and were working together.**

[Some staff] really made a difference. There were two nurses that that came that morning [when Mum died] because I'd had to ring to say she is in pain. [During] the daily visit that we got from nurses, you know, you'd get to know them. It wasn't always the same person. But unfortunately, the nurse that had been two days previously hadn't organised the pain medication to be there for the driver. So that morning that mum was in great pain, we didn't have enough meds here. When she came on shift at 7 o'clock, one of the nurses came. She immediately got onto a coworker and said we need to stop what we're doing and get this. They went from chemist to chemist, and they did so much to try and get the pain relief into Mum that, for me, yes, they were doing their job, but it was lovely to know that they cared so much and were working together. And as soon as she came in with pain medications, the other nurse went on. And I feel so blessed that it was those two that were there that morning because I knew that she was getting the best care possible. For me, they excelled, and when they had visited before they were lovely with Mum.

Most of the nurses, all of the nurses, called her by her first name and spoke directly to her, but you could tell [with] some of the nurses it's almost as if it's a tick list which, you know - I'm sure everybody has busy days. And then others, it was definitely on the more personal, bedside manner level.

For me, once Mum went on end-of-life care it was such a relief to know that everything wasn't on myself and my husband because we really got to a stage where we weren't coping, so it was just amazing to see everything go into place. I also think that initially when you're getting phone calls and people saying “oh, this is going to happen, this is going to happen, this is happening” and it can be a little bit overwhelming. So for anybody just starting out on it, maybe they need a meeting with somebody or a conversation with somebody, maybe a week into the experience, just to say “how are you doing? Have you got this number? Is everything working?” The nurses' hub line was excellent. I felt like I could ring them day or night so that was brilliant. But it was definitely overwhelming to think I've got carers coming in. I've got a phone number here for them. I've got this here for so and so. So [it does] not necessarily [need to be] from the GPs or anything, but just somebody to say, “is everything working for you?” Because it can be overwhelming to have all these people and numbers and phone numbers and everything.

A specialist nurse came quite a few nights, and she was wonderful. And you knew that Mum was in very good hands.

I do appreciate that everybody with Alzheimer's, they are going to be different. The only other issue we had was when somebody had sent a lady from [the hospice]. She spoke to us and then she said, “I'll just go chat with your mum”. And she was talking about end-of-life care, and what Mum would like and a lot of questions. Nobody had actually been having these conversations with Mum [to tell her] that she was dying. Nobody said, “you're on your last legs, Mum”. We just said “you're not very well, you're a bit poorly” because that was the way we dealt with Mum because to actually look her in the face and say “you’re dying” … we didn't do that. So, it was quite upsetting that somebody actually came in and started directly asking questions to Mum and indicated to Mum that she was dying. We hadn’t done that.

The lady who came from [the hospice], she walked out the door saying, “oh, she's not near end of life. She won't need [medication]”. And within three days Mum had passed.

I honestly think the end-of-life care for us was just a godsend. It was a blessing. It gave us the ability as a family to spend every day with Mum until she passed. We couldn't have coped without it.

Chapter 21:

"And because he said he loved flowers; they moved him into this room and opened the doors and let him look out onto the garden.

[My husband] was a man of firm beliefs and standards as we all got to know nearly every day. [Laughs] He loved opera, he loved gardening. Obviously as he became ill, he couldn't do anything in the garden, but he still loved it. He found a Greek island and we went there for 12 years from 2005. We only missed one when he had his operation. His consultant was brilliant. She planned his chemo appointments around his holidays.

He had 69 sessions of chemo with about three appointments around every one and I always [joked to him] "you couldn't even get to 70!"

We were told he had six months. He'd had [cancer] for seven years and [when you get the terminal diagnosis] it doesn't seem real. I mean, as I said, the consultant was lovely at Leeds, and she just said there's nothing more we can do. We went from "we've got an arsenal of drugs we can treat you with", to just that there's nothing more we can do. I wanted to ask, but I didn't - [My husband] just said "how long [have I got]?" and she said up to six months. It's a shock. It just seems to go over your head.

I remember coming out and walking up the corridor and just thinking… but [the consultant] actually wrote to me [after I emailed once my husband had died] and she said, “in a way, I believed he'd go on forever”.

[My husband] and I didn't particularly talk about his cancer at all, but I remember he had a doctor at the surgery and his doctor, of course, was the best, and I had a different one, and mine was [also] the best! And I'd gone out one day and he said when I got back, “your doctor rang. He said he wants to come and see me”. And it was just before Christmas and [the doctor] said he'd come in the New Year. My husband said to me “I'll believe that when I see it”, [but] doctor [did come] round and he discussed it then. [The doctor] was brilliant.

[My husband] had strong beliefs about what he wanted and [the hospice] did everything around him. Whatever he wanted, they did. They moved him, presumably as he was getting worse - and I didn't even realise [that he was declining], stupid that I am - they moved him into a room on his own. And because he said he loved flowers; they moved him into this room and opened the doors and let him look out onto the garden. They [made sure he] faced the garden deliberately.

He did sign the DNR when he was admitted [to the hospice]. I'd actually said [to him, when the GP came to the house] “would you like sign that?” [And he said] “no, no, no”. And I said to the doctor [at the hospice], who was lovely, I'm a bit concerned [because you’re] letting him do what he wants. I said, “surely he should be eating properly?” He said to me - it didn't go into my head at all – “I often find this when patients get to the end of life that they don't want anything to eat”.

So I said, “so what you're telling me basically is I'm talking a load of rubbish!” [Laughs] He said “no, he but we do let them do what they want”. I said I’d take that on board.

When he was moved into this room with the garden, I used to go and I was there every day, all day. One of the carers came up and she took me outside and she said, “I just wanted to say that if you'd like to stay tonight, there is bed here for you, you can have it”. Of course [I realise now that] he was going to die. He was close to death. But she didn't say that. And I said I can’t because I've got the dog to look after [at home]. So, I said I’ll come back first thing in the morning. Of course, they rang me at seven in the morning and said he’d died. Maybe it was me being stupid, but if she just said “we think it's likely that his death is imminent” … maybe she didn't want to upset me. I don't know. But that's the only thing that I can say I wish they'd said to me.

Chapter 22:

> Because there was no diagnosis, you couldn't really give them treatment.

Speaker 1: We lost two children. One was a little girl, then we lost our son. When he passed away, he was 10 years old, and [our daughter] was 5. They both had the same condition. [Our son] had a totally different personality [from our daughter.] She was different. She was always in a bad mood. She was bossy. And our son was very calm. But they had so many problems, so they were always in pain, and they had a severe disability. There was no diagnosis. So violent fits were something which we were dealing with every day and maybe in a day [they] could have five, six, seven seizures which were visible. And the ones that were not visible, they were having them as well. When they were a little baby, they're having like 20 or something. And they were not controlled, even though they were on medication for it.

Because there was no diagnosis, you couldn't really give them treatment. So we had Buccal at home. We kept Buccal at home to use in an emergency, but the seizures were that bad, and there were different types of seizures that they had. We understood which seizure to treat, which not to treat because of experience as time went by. Some seizures wouldn't stop with Buccal or emergency medicine, and some would.

So, the seizures were... 10 minutes was normal, and then for them to come out of it could take about an hour. So, but this is just the way it was. The medicine made them calm down, slowly, slowly. But it takes time.

And then they had a scoliosis. [Our son] had more severe scoliosis and because of that, both his hips dislocated. So, [he was] in a lot of pain all the time and [had] teeth grinding and stuff like that. So obviously, we couldn't go upstairs. We should sleep downstairs. I was with [our son] on one side. And [my wife] used to look after [our daughter] on this side.

We eventually we did get care. We were getting 10 hours a week and nightly. [Overall] we had three [care] companies. The Community Team, they could not give us night care. They said we've got a staff shortage.

We were getting one night. It started off with one night. It wasn't enough, really, to be honest. Not enough for the parents to get rest. So, it was only one night a week we used to get. And then eventually it moved on to - I mean, we were the type of people that don't complain you know, we just get on with stuff. So then eventually...

Speaker 2: [My husband] left his work for the kids. Because we got two kids and no family here. So, if we go hospital and then one of the kids is at home, we always need to be there. So, I was always there. I couldn't work because it was too difficult for [my wife] on her own.

I came from Pakistan, so my English was not that good as well.

Speaker 1: You couldn't plan anything. You don't know what's going to happen in because of these seizures, they were so complex. It was difficult to know what's going to happen next, so you're always on edge, so you couldn't plan anything. [My wife] hadn't been to anyone's wedding, you know. So, any places where we had to go, we couldn't go if we didn't have the care. The 10 hours a week when we had care, we did plan things. So when we got the care from the NHS, that helped us out. Because when they came in, then we could go do some shopping or do something.

We used to have one night and then eventually [we got] to three nights. When my daughter passed away, after that, they gave us three nights. Even then, maybe I would have to wake up one night and come down because he used to grind his teeth and if he is grinding, he could bite his tongue. He could bite his lip so the even the carers, they weren’t a great help. They would get scared because of the bleeding. And sometimes they didn't know whether to give him Buccal or how or what to do. So, I had to come down. Yeah, but apart from that, the care that we did get was a good help.

They [the community staff] always made time on the rota every year when we [would] all sit together, and they have a chat with us. They always said we can make any decision [we] want [for the end of our children’s lives].

And there was the children’s hospice as well. We could have chosen to go there [at] the end time as well or stay in hospital. Or even come home. So, we always had everything explained to us very, very nicely and they told us everything.

Speaker 2: The children's hospice is a very nice place. They help us.

Speaker 1: But every family is different, you know. We were more comfortable with being at home, that end time being at home, but as it happened, it happened in hospital. We decided to go with flow.

The hospice had a care plan as well. So, whenever we went in, there was always a conversation about the care and what we wanted.

They always listen to us, and they always give us that support and give us the choice. If we wanted to go to the hospice at the end time we could go there with the child. So, they give us that choice as well.

When our kids get poorly, they get chest infection or something, sometimes [we went] so many times there. My son, he was really, really poorly and the doctor said maybe this is the last time, but he always recovered slowly, maybe after two weeks or something. You know that treatment is [available] from the hospital. It was necessary for him, so obviously when we think it is time, we want to go hospital. Because we always think he always gets better.

So, our first choice was to go hospital and treat him. [Our son] passed away with Covid. He ended up getting caught. We all got it.

In that time, we were having an extension [built on the house]. His room was getting made. We were all in one room, and when we found out, I think it was too, too late. We all had that.

When my daughter passed away, it was a Friday. We're Muslims. In Islam, we believe that when somebody passes away, we bury them straight away. So it was on a Friday, she passed away on Friday. We did the funeral on Friday. So, everything happened quickly. So that was a really good service that they provide.

> **...because we just get on with it, we don't like to complain. If there's something serious, we will ask for it. If it isn't, then if we can do without something, we'll just manage.**

Speaker 2: And they always asked what we needed.

Speaker 1: [My wife] learned most of her English by going to the hospital. By dealing with them she had no choice [but to learn].

Speaker 2: Because I don't have time to go to English classes or somewhere. Whatever I know, I just speak.

Speaker 1: So that's how she learned her English by communicating with the nurses and the doctors. Because I wasn't always there because we had the two kids.

One was at home, one was in hospital, but if the girl was in hospital, she was with her. If the boy was in hospital, I was with him. So, it was always like that.

The children’s hospice gave some help [with bereavement, after the children’s deaths]. We've got two other kids now. So with them and we’ve got family as well... It obviously was very sad and when they passed away, our family, they always come.

Speaker 2: Yeah, they gave them a lot of support. And my neighbour. I’ve got really good friends from the hospital. The same families [who’ve been through experiences] like [us]. They were in a similar position. [These] parents when my kids passed away are still in touch. Because you get to know people when you're in the same situation and you get to talk to each other, you try to help them [with] what you know, and they try to tell you what they know. To a person who has normal kids, they don't understand. But if I speak to someone who has kids the same [as ours], they understand.

Speaker 1: Everything from the NHS Community Care [has been good]. And we've had good support from everyone, even the hospital.

Like I said earlier on, though, because we just get on with it, we don't like to complain. If there's something serious, we will ask for it. If it isn't, then if we can do without something, we'll just manage. But there was one point [I’d like] to mention when we had both of the kids and [our son] was on oxygen. Because he had a scoliosis, which pressed onto his lungs, he couldn't breathe, so he needed oxygen. He was on 2% oxygen. [Our daughter] had a chest infection at that time, and it took... Whenever she had a chest infection, she goes on oxygen but this time it took quite a long time to come off. So, she needed 0.5 or something. And she needs it every day.

Then the doctor thinks to send us home with oxygen. And they said the Community Team, they will come and keep an eye on her.

Speaker 2: And unfortunately, at that time really, nobody came, you know for like three or four…

Speaker 1: Yeah, we came home and we thought she needs 0.5 oxygen. And she was on that 0.5 all the time. And after a few days we are just 0.5 and she gets a cold and cough again. And my son was there as well. So, they both get poorly, and we noticed they were a bit more sleepy and when we pick her up, she gets heavy all of sudden and then we took them both to hospital. The oxygen was really, really low. [Our son was] always on oxygen, but for [our daughter it] is a new thing. But her oxygen is really low. More than my son's. So, they both was in the same room. But they were really, really ill I think, that time. And that was a mess. It was like the last thing for her. So, she passed away, you know, after the night? She spent one night in hospital, but her oxygen was not going up. Because they had fallen that low, it was more difficult for her to come back. And what I'm trying to say here is we were asking for a monitor [at home] to check the oxygen because we never had a monitor.

You know, nighttime we couldn't sleep properly because we were always scared [of] if we fell asleep. Because [our son], he was very quiet. He doesn't make noises. So once it happened, like his oxygen came out and he gets really, really…

Speaker 2: Blue, he went blue. And all of a sudden, he wakes up and when we see him…

Speaker 1: And I said “[son’s name]”, and he was completely gone. He wasn't moving. He was there. His feet were all cold, and his eyes were open.

Speaker 2: Yeah, he was not moving.

Speaker 1: And his eyes were just... Basically, we nearly lost him, and he was all blue and so I rang for an ambulance straight away and put his oxygen on full. We didn't have a monitor, so I was buying....

Speaker 2: Yeah, we bought it from eBay.

Speaker 1: You know the ones [fingertip oximeters]. We used to check with that, but it didn't give you any accuracy, but we needed the monitor. And I'm talking for other parents where, if they are in a similar situation, I think something like that should be provided. And we asked for it. And the Community Team, they can only do things when they get the order from the consultant. Now we talked to the consultant.

Speaker 2: [The consultant said] the machine is expensive, and we can't give it to everybody. That's what they said. But you know it's not expensive because, end of the day, we know we're not going to keep it. We're going to give it back if we don't need it. So, I think things like this [could be improved] because... I talked to another mum, her son passed away as well, but she said the same thing.

Speaker 1: My daughter passed away and at that time my son was very, very ill, when we went for the funeral, and we come back to hospital that time they said they stopped my son’s medicine and they said he can't make it this time. My wife was pregnant with our little baby.

And so, I went to bury my daughter. When I came back to the hospital. [Our son] was - they said this - we think we're going to lose him. So, they stopped giving him the antibiotics and they stopped giving him the nebulizers every hour because they thought this. So, when I came back from the funeral and then I hear this and then I'm thinking now we're going to lose [our son] as well. So, then I did speak to the doctor. They did listen to me. They listen because I said, “look, no, just lost my daughter, and my wife is pregnant. And if we lose [our son], then this is going to be really bad for her. And if you just listen to me and if we could get him back on the antibiotics. You know, if we if you can just do that, please.” And they did listen. So, they did do that and after four or five days he opened his eyes. And then he lived.

Speaker 2: Yeah, it took 15 days. You know, we stayed. Me and my husband. We both stayed with him in hospital. And after 15 days he came back home.

Speaker 1: He slowly, slowly improved. Then he came back. So, he lived another two years.

Speaker 2: Yeah. So, we did then get the monitor because the thing that we said we don't...

Speaker 1: I said I'm not going home without it. Because we were scared now because we know if we had the monitor at home with [our daughter] ... And if we had [the monitor] at home, we could have checked [and] put that on her and checked her oxygen. If you know the oxygen is dropping, then you can get rushed to the hospital quick. And this was where because we didn't have a monitor, we didn't know what was going on, even though she was on the oxygen, we didn't know.

Speaker 2: But she was only 0.5. I think she needed more that time.

Speaker 1: So, we didn't know her oxygen levels. The only thing I could say was - even the community – nobody came. Three to four days, you know? So that's where we're just a bit disappointed. Three to four days and then, when we took her to hospital, it was… She was getting heavier when we took her there, it was too late, you know, and that was her last time.

I think [we spoke about this afterwards] to the Community [team], maybe we did it. We must have mentioned it to the Community.

Speaker 2: We didn't take it [our complaint] like too big, but…

Speaker 1: At the end of the day, we as Muslims, we believe it's in God’s hands and it happens. But I think all the kids that are on oxygen should have this monitor. They should be a compulsory thing for them. Without the monitor you don't know what's happening. And especially at nighttime.

They knew we were the type of family that we're not going to ask for something if we don't need it. We'll only ask for something if it's very important. We never really ask for much care.

Speaker 2: Yeah, you know, when carers come, we’ll leave the kids. So, then we just leave them, you know, in peace. And then we go out for a bit. You know [since] my daughter passed away? Whenever the carers come, we always go graveyard and spend some time. Or the house shopping. Just do the things you need to do.

> **So, I just want you to know [that] anyone who's in this situation when they ask for something like a monitor, it is very important to give it to them.**

Speaker 1: We knew families who get more care. But we weren’t [getting more]. We used to care for our kids ourselves. We used to get three nights. That was at the end. We when we had the two kids, we only got one night. We never complained to them. We wanted more nights. [There are] families who get seven nights, and it's all about complaining [to get what you want], but we never did that. So, the only complaint I did to do was about this monitor. Because it was something that we needed, we didn't get it at the time that we needed it. So, I just want you to know [that] anyone who's in this situation when they ask for something like a monitor, it is very important to give it to them. Apart from that, if we talk about the Community Team, [it was a] brilliant service. They've always helped. Even the hospital.

Chapter 23:

> **I told [the doctors] I didn't know anything about [the hospice]. They provided everything. They arranged everything.**

[My husband] had lung disease. One side had gone black. So five years ago, he was in hospital in India because the water had gone in [his lungs]. He wasn't smoking, but he was eating a chewing tobacco.

Then when we came back from India, he had no salt in his body, no sodium. And then they put the drip in, and they did everything in hospital [in Leeds]. He had the X-ray, [and the doctor] says your lungs have gone black, you're not going to live long. [That was] five years ago that they told my husband. Then in 2022, [the staff] says your lungs have collapsed now, [they’re] no good completely and you're going to die in six months.

I told [the doctors] I didn't know anything about [the hospice]. They provided everything. They arranged everything. I didn't know none of this. [My husband] didn't want to go hospital. He liked it here [at home] and he felt great here.

[The staff from the hospice in Leeds were] nice people. They all of them come to see my husband and then afterwards, when I came back from India [after my husband had died], they come to see me as well. They were really nice people, very nice.

We did everything [all my husband’s care] here [at home]. I looked after him. The nurse [from the hospice] was coming to see him every two weeks, three weeks sometimes. They checked his sugar because he had diabetes and [because of] things like this breathing problem [he had] no strength at all, my husband. So they gave morphine to my husband.

[At first the] doctors wouldn’t give [my husband’s medication] to me. One day I went to see the doctor. But then hospice nurse came, and she put everything down and they gave it to me. He knew he was going to die sometime, but he wanted to be in [India].

You [don’t get] a lot of time really [when I tried to phone the GP surgery], because when I pick up the telephone, they never [pick up] the telephone. It's very, very bad. I worried and I cried sometimes, but what can you do?

Indian people go [to India in] October, November, December because of the cold in this country. We went to Heathrow, [that took] two hours, another eight hours to Mumbai and another five hours to go to our town.

[When we got] home [in India], he was a little bit better, he was not bad and then he had a shower, sleep, food. He was talking to everybody. People come to see my husband and he was talking very well and we just had good food. Everybody came to see him in the nighttime. His breathing was bad. [One day] the doctor had just come in and the ambulance was just there and his breath was gone. Just like that.

Some people take time [when they are dying], moaning and shouting and screaming. But he ended just like that. It was very, very, very peaceful, a lot of people say he's a lucky guy. Not many [people are] lucky like that.

We are Hindu. I buried [my husband] in India because he wanted to go there and he loved it there as well. So we did a lot of praying there, beautiful praying there in India.

Chapter 24:

> **He's just a normal little boy. He obviously didn't know different anyway.**

Ibrahim was born in 2004. Full term, no issues during pregnancy or anything, everything was absolutely fine. He was born in summer 2004, like normal - a day or two at hospital, discharge, came home, everything was wonderful. I think it was about a week after I noticed, we noticed that he was breathing a bit heavy. [My sister] came over and explained to us, “look, I think last night… this doesn't seem normal to me”. And she says yes, I mean, definitely there's something, he might have a chest infection or something we need to get checked out. And then we took him into hospital nearby. It was just a chest infection or whatever, to start treating with antibiotics or whatever it was. I suppose at that time he was only a few weeks old. So, there's only limited stuff you can do anyways. We were there and then…

And then, slowly, slowly, his dependency on oxygen started to increase, so I think we spent about three months at [hospital] and then after they had done whatever they could do, they thought that maybe we're missing something. So, we got sent to hospital in Leeds to basically continue the investigations and everything at the time.

I was working as a sales manager for this company, and we had a daughter. She was two years older than Ibrahim. It was a difficult time because I'm working full time, and Mum, she had only arrived in the UK in 2001. So she'd only been here a couple of years and stuff, so she's still familiarising herself as well and then suddenly, [we were facing] this kind of stuff. So, she found it very difficult at hospital obviously. You know, the language barrier and everything else. I mean, even if you understand the language, talking to medical professionals you have to have a certain level of understanding.

So, it got a bit difficult. I mean, for me as well, because I would get up in the morning and drop my daughter off, get off to work and come back at six or seven o’clock in the evening [and go] straight to hospital. My daughter's still there, so I’d sit there until 11 or 12 at night. I’d try to get a hold of the doctor to see what's going on, what's happened? And even in the evenings, it's like, “oh, we'll find out”. You know, some nurses might know some little bits, but nothing [substantial].

This carried on for a few months and, to be honest, from where we were, it was nothing [serious]. Nobody had mentioned anything in the sense that this could be something... this severe. Treatments were being done, everything, and, and I mean, he's kind of... he's OK. I mean, even though he's on oxygen, he's a lively little kid. He's just a normal little boy. He obviously didn't know different anyway.

So they did some lung biopsies and whatnot. And then they thought it might be due to reflux, so they do some minor procedures like a Nissen’s, just to tighten the stomach muscle and maybe that might stop it.

At the same time, they thought “let's just put a gastrostomy, a feeding tube in as well, because we don't know” - later on, it might be due to the feeding and stuff. It was [at] four weeks when he had the two minor procedures. But I mean, as time went on and there were no answers - there was “we've tried this. We've tried this, we've done this, we've done that”. And six months went by and we as a family were all over. And then the doctor has called us in and he says, “look, we've tried everything, we've put in [this] and now we've taken the biopsy. We've sent the samples of…” I think they've sent them to America and all sorts of different places. We just have to wait for the results and other than that, there's nothing much we can do. I say, “look, if you know from the medical side of things, you're saying that you've tried everything, and you've done [everything]. And if we're just here and he's being cared for, we'd rather just go back to Bradford. You will still be liaising with the teams and if something comes up, we can always come back or whatever, but it would be easier for us. So, in the end we kind of moved back to Bradford hospital.

Again, [it was the] same thing, it was just investigation, investigation, investigation, see what's going on and whatnot. But in the meantime, his oxygen requirements were creeping, creeping up, creeping, creeping up. And before you know it, [he needs] four or five litres of oxygen per minute. And he’s stuck in his little cot. And then then I got called back in by the hospital in Leeds and [the doctor] says, “look, I just want to have a chat with you and just to let you know what to expect from a medical perspective at least anyway”. And he says “look, I, we don't think he's going to make it past another few months really. So I just want you to be aware of that. You need to do your preparation.”

That was… there was, I mean, when I say shock… I mean to an extent it was, because I have a science background myself. I have a BSc in chemistry, so the procedures, understanding the probabilities or whatever it is, I have some kind of [knowledge]. And I could see that we're not getting anywhere, but I didn't think that this is what they're talking about. That was the point when I thought whether he's got six months, or whether… whatever he's got, you know, what's the point? I just graduated a couple years ago. I’m starting out in the world, and I've got a daughter, I've got a son now, my family is complete and we’re just moving on really. And then when he told me that, suddenly, I was like, “wow, what, what,” you know? So, I decided, I said there and then, I don't care - he's the most important thing for me. I don't care about anything else. I resigned for my position and obviously my wife was six months in hospital in Leeds and it was so hard for her and stuff. So I said to her and my daughter, “here's a ticket. Go see your mum in Pakistan. Go chill out for a bit, I'm here now. I'll deal with it.” And that was it. That's when my love story starts with my son.

Ibrahim defied every prediction. The doctors couldn't believe it. [They said] what on earth [is going on with] this kid, you know? How can he manage? If you ever saw him, regardless of what he was going through, he was smiling. He's full of life. He's full of beans. He's just full of love.

His thing was just families, to be honest with you. He liked doing a lot of things, but his main thing, his main thing was Mum, Dad, brothers, sisters, uncles, aunts just to be around him all the time. He just loved family gatherings and family events and going out, with not just us but the more people, the merrier.

He was just so full of life, it was unbelievable, and it was almost like as if he knew that his life is short, but what kind of two year old, three year old, four year old… what do they know?

He was just so full of life, it was unbelievable, and it was almost like as if he knew that his life is short, but what kind of two year old, three year old, four year old… what do they know? He was just… I say blessed, but I mean it was just so unbelievable, to be honest. So he was a bit of a unique [person], in the sense that he defied the medical teams from Bradford to Leeds to London.

We ended up in hospital in Bradford for about three years. In that time, I got more fully involved in every aspect of his [care]. I didn't go down to looking at numbers and blood results and understanding things, making sure everything that everything that needs to be done is being done and we're not leaving any stones unturned and all that kind of stuff, but literally all it was, was nobody, nobody had any clue. Nobody had any idea what to do with him. So, we're in hospital and we get up in the morning. We're off to hospital, we know we're spending the whole day there, we're coming back to bed in the evening at 10, 11 at night once he's asleep, and now we're coming back home. And this routine is just continuing and continuing, and you couldn't, I couldn't miss anything because I had to be there all the time.

Because anytime the doctors or any teams that came, I had to know exactly what's going on, who's doing what, what's the thought behind it? Because I was just one of those, you know. I have to just know everything about everything.

That's what it was like because initially he was just another patient on the ward, wasn’t he? And everybody's trying to help him and see what we can do. But as time went on and I got more involved, the doctors, the consultants, the ward staff, everybody knew about us... Everybody knew me and what our expectations are and, literally, we became family, we were part of the set up on the ward. We were part of the staff; it was like our own house. Can you imagine? We spent three years in the ward with the same people, with the same staff, you know? It was almost like family. They were really good with us in that sense. They took my daughter. They’d take her, take her out if the nurses were free in the lunch breaks. It wasn't like [we were] patients but more like family then. But from the medical side of things, there's no progress because it was a conundrum. They’d never seen anything like it before. They couldn't understand it. They couldn't figure out what was going on.

But the thing was for him, he was stuck on this little cot and because he needed oxygen, about two or three, four litres per minute, it was difficult for me to get him out and all this kind of stuff. And he ended up in a little plastic box covering just his chest and top part. So rather than having to have the mask on all the time, they could pump oxygen in there. And so he's got some certain percentage of oxygen in there. So he can at least not keep the mask on. Can you imagine him being in a cot with a plastic box covering just this part?

And just his legs sticking out? Initially I was a bit like, “OK, we’ve got to be very careful”. But now I was there full time, as things progress they saying there's more we can do here. I had a chat with the consultants, and I think once they understood this guy seems genuine [i.e.: I seem genuine] and he's capable, I think they slowly, slowly [gave me] more of a free hand. So I just started taking him out of the box, putting the mask on him and keeping him out for a bit. That kind of stuff. Slowly, slowly. In terms of development, mentally, physically, apart from the lungs, obviously, he was just... not just a normal little boy, but he was more than that. He was just unbelievable. And that motivated me even more. Like sometimes, if you think a child’s poorly, they've got mental issues or physically they're weak, there's only limited things you can do, but with him he encouraged me to try push the boundaries, “go further, Dad”.

Can you imagine? I remember that day when we start taking him out of the cot on and I said to them, “look, this mask thing, we're stuck here when I take him out. Can you extend this oxygen tubing?” [They said] all right, that's a good idea. So by the end of it, he had the oxygen tube 10 metres long, can you imagine that? He was up and down the corridors in the ward. And riding a bike of all things, up and down the corridor with oxygen tubing [and] a mask on. Oh my God. The first time when I got the oxygen tube and stuff and I took him out of the room, out the door. And he looked down the corridor. And when I saw his face - because all he had seen was this room, that was his life, that was his world, wasn't it? I took him out. But as soon as I took him out, he just looked up.

You could see right down the corridor, people walking around and suddenly, the world had just expanded. [His reaction was] what on Earth is this? What is this, Dad? That for me was like, wow - we need more of this.

> **And it was snowing outside and I thought, you know what, let me just take him out. He went out and saw this white stuff on his hand.**

So like I said, the consultant, he gave me a kind of… I mean they generally won't even allow you to take them out of the cot, never mind do all these things with him. I got the physios involved, I got them to give me some equipment, get him a bouncer because he was laid down. He was six to seven months and even though there's nothing wrong with him, he just didn't have the balance or anything. So we got him one of those bouncers and made him stand in there and [he would be] jumping to strengthen his legs and he would be sat up, we got a special seat for him. He could just sit nice and properly and then we ended up getting in pushchairs and prams and… Oh my God, when I took him out the corridor and he was like, “Oh my God”. It was just unbelievable. And then slowly I started taking him out of the ward with oxygen cylinders and stuff, and a nurse came with us. It was winter. And it was snowing outside and I thought, you know what, let me just take him out. He went out and saw this white stuff on his hand. But anyway, the thing is, he was up for it. If I was pushing things, there was a reason behind it because it was him who was spurring me on.

When I saw a spark in his eyes, when I saw a spark in his face and when his face lit up, that was enough for me to just keep pushing more and more and more.

So, then I started looking at things on how to make him more comfortable in the cot, so I had a chat with the nurses, they got medical physics department involved and we designed a tent for him. A full-blown tent. We pumped oxygen into there, so when he's in there, he could sit up, he could play around, and he'd have toys in there and it's just like a tent over him. It's see-through. Obviously, it was very technical because of the oxygen and carbon dioxide build up, so everything has to be so you have carbon dioxide monitors in there, oxygen monitors in there. I was so glad, all my life, I've been thinking "what on earth did I do chemistry for?" Even when I graduated, I didn't go into that side of things. But maybe this was the reason, because I had to have that analytical thought process, the logical thinking so that I know the process and everything. [Chemistry] gave me that, those skills, and for me to understand him better, what he's going through. It was tough. But it was it was a challenge, you see. We got the tent made and that improved his quality of life more. Then obviously there was talk about - because obviously we won't get anywhere in terms of treatment - there was talk about lung transplants and whatnot.

He was only about two, two and a bit when the conversation about the transplant started. There's only two places in in the UK, Great Ormond Street and Newcastle Freeman Hospital that dealt with paediatric lung transplants. The main consultant says there's two places, it's up to you, do what you want to do. And I said, just send me to both.

I said I want to go check both places out. I don't want to just take Ibrahim with me with oxygen on, it was like a military operation. So, I went down to Newcastle myself. I spent a night there chatting with the doctors, staff. And I checked it out, looked around and thought “OK, sounds good”. And then then I went to Great Ormond Street in London and checked them guys out, spoke to them. Obviously Great Ormond Street is Great Ormond Street and I think “this is it”. Though it was difficult for us, it was further [to get] there, it was more expensive, because it's going to be a long-term thing now, isn't it? But I just felt more comfortable in London and so I thought, you know, we’ll just go with that. We started having these conversations.

[I said to the medical physics staff] now we need to think about something portable, so [when] we end up in a different hospital, we can have this kind of set up [with the oxygen tent] where we can just fix something on. So we made another tent, we got to London and obviously ambulance doctors were with us. And it wasn't just like us taking him. These doctors in London, they've read his files, he's two years old by now. So they must have been reading all this stuff, and in their in their minds, they had the picture of some child, of somebody really poorly. Literally if there’s oxygen interruption for like 10 seconds, he’ll go blue straight away. Within a few seconds, he couldn't survive. That was the most scary thing of all. That’s why some of the staff [were] so scared that to take him out if something happens to him. It was so intense, 24/7 looking after him. So the staff themselves were almost a bit nervous.

But for me it was different because he's my son and I can start pushing things. Somebody had to be with him 24/7 just in case and a few times things did happen and there were a few accidents. We talked about him going up and down on the bike, in the corridors and stuff. And there's one time when, I don’t know if someone accidentally stood on [the tube] or it got trapped somewhere, but when the pressure goes, it just pops off, so he's down the corridor and the oxygen's come off and we weren't there. This is early in the morning. Obviously, he just literally... he collapsed. He was blue straight away, and obviously all the ward started panicking but they realised [it was the] oxygen, they got a cylinder of oxygen, and they got him back. We went in and everybody's crying at the ward, all the nurses, as soon as they have seen us come through the door. I'm like, “calm down, is everything OK? Is Ibrahim OK?” He’s absolutely fine but they're crying their eyes out.

[Ibrahim] didn't know any different [from the life he was living]. For him, it was more like “this is what it is, this is life”. And since I got involved with him, every day was an excitement. It wasn't like he was like, “oh, I'm stuck like that”. He was never depressed. Never in his life he was depressed, you know? Never did he ever in his whole life he complain, “Dad, why me?” He wasn't like that.

So we got to London. Like I said, they had their own conception of what kind of child he is going to be. We’re in London setting something up. I carried everything [Ibrahim needed] with me and told them “Look, I need this, I need this, I need this”. I took my [oxygen] tube and I got there.

> **And I'm thinking, he's only two. He's only just over two and we don't know what's actually wrong with him. We haven't got a prognosis. He hasn't been diagnosed with anything.**

Slapped the tube in, pulled the tents out and they gave us a bed. There's four beds. And there's other patients, their parents. Soon as I pulled this big, massive duffle bag out, everyone is looking [and thinking] “what's this guy on?” And it's just a contraption. It's not even like a medical professional kit or anything. It's just pieces of metal sticking out from this side. I've got my spanners with me and everybody's looking and thinking, “what on Earth is this? What's going on?” But anyway, because he likes to go on the bike and stuff, I got the bike for him. The whole team of transplant consultants and psychologists and whatnot, everybody turns up and they walked straight past us, and they go into the bay and Mum was sat there and she said “he's just with his dad. He's just out there.” And they looked as if to say, “Are you sure?” They looked back like down the corridor, and they still didn’t... because they were expecting a child to be, I don't know, maybe underweight, someone really poorly, can't move or whatever because they heard about how much oxygen he needs and he's gastrotomy fed. And she's like, “no, no, that's him that on the bike, him”. They all looked at each other like, “him? Him?” They were so shocked, they started [saying] “we’ve come to see Ibrahim, the chap from Bradford, from Yorkshire?”

We had the meeting with them to do the assessments and whatnot and the thing was, because of how good he looked, they're like, “I don't think we should go down the transplant side of things”. So I said OK, that's absolutely no problem at all. This after we spent a few days there now. They've assessed us as a family. There’s supposed to be this meeting at the end of the [assessment] and the discussion was going to take place. But a couple of them who came beforehand sat with me and they said we want to give you a little heads-up that we don't think we're going to go for the transplant. And I'm not here to make a decision anyway. I'm just here to understand the process and what it involved. I need to look into all this myself and all this kind of stuff.

I call my wife [and said] “that's alright, we got what we needed anyway”. So I think tomorrow we'll be going back [home]. We've got this late meeting in the evening anyway, so we'll go to that and that'll be the last of it. But because of the little chat I had with a couple of them beforehand, we got chatting about other things as well, about us as a family rather than just about Ibrahim. Then I explained how difficult it is. I had to give up my career, what pressures [we were under] and [how] you can't be in on your own with him, because you need to go to the loo, you literally haven't even got that time to leave him for a bit. And suddenly, it was a different kind of… and I'm thinking that just a couple of hours ago, me and you were having a completely different conversation. But there [in that later conversation] something changed basically. And so, I have all these questions in my head. And I'm thinking, he's only two. He's only just over two and we don't know what's actually wrong with him. We haven't got a prognosis.

He hasn't been diagnosed with anything. I had this simple question. I say "look, say we go through with the transplant. The risk in itself, just the surgery, I'm going to put all that to the side. Can you tell me, when he's got a new set of lungs, will the same things not happen again, because obviously you don't know what's causing it? And [what if] we go through all this and then at the end of it, we end up with the same situation and then we've got another thing to deal with on top of that…" So I said I need an answer for that, otherwise, it's difficult for me. And they're all like "well, that's the thing we can't really say, but we really think that he would benefit from a transplant". So the conversation was more of them trying to say that their advice was that it's the best thing for him that he needed. He's the perfect candidate now for this. So then obviously I'm questioning about other things. How come you know? I felt bad about the doctor a little bit because he wasn't supposed to come and tell me [that they weren't going to recommend a transplant]. I said, "look, I'm sorry, but I'm a bit confused because of the conversation we had before". And they said, "the thing is, after having looked at every single thing, we think that he is the perfect candidate for it". So, I said "look, OK, we'll think about it".

So we came back, and it was to and fro, basically, [with] all this stuff at Bradford hospital, which is still continuing like normal. Every day we're going in, all this kind of stuff, and I'm trying to make things better for him and all that kind of stuff. At the same time, all this is going on. The thing is I couldn't… the questions I had, there was no answers for them, and I couldn't move past it. They even got psychologists involved to have a chat with me and to understand what's going on.

I think at the end the [psychologists'] report [said] that the thing is [that] he goes into too much depth. He goes into too much detail. But for me, I have to understand everything. If I don't understand it, I'm not going to make a decision about my son's life-or-death decision without me understanding everything I need to understand about it.

We lived with extended family at that time. I'm one of seven. I'm one of the eldest. I have lot of responsibility. All these guys are younger than me, you know. Mum passed away when I was 16, so there was that responsibility as well. And my dad, having lost a wife, he had his own situation. So there was all that responsibility. It wasn't just my wife and my kids.

From my understanding, [there] was a bit of a kind of push [from the doctors], "Go for it. Go for it. Go for it". But I decided not to, and I said to them "because you can't answer these questions about his medical [issues], what's causing these kind of things and the same thing might happen again and we don't know. And you're telling me that, at the same time, the life expectancy after transplant is low, five to six years on average. Literally what you're asking me to do is, just to make my life easier for myself, you want me to stamp him with an expiry date." I said "that's why I cannot make this decision and I'd rather suffer.

I'd rather go through whatever it is I need to go through, but if there's a remote, slight, 0.001% chance that a year down the line, two years down the line, someone can say, ‘I've got it, this is what's wrong with him, this is the medicine for him, this is we can do for him’... Because if I go through what you're asking me to go through, if someone finds out what's wrong with him, I can't do nothing because it's an irreversible process, isn't it?” So it’s basically an expiry date, isn't it? I said “even if it takes me how long it takes and if it gives him a chance to have a normal life at the end of it, I'm willing to sacrifice... I mean, I've already sacrificed quite a lot, but I'm willing to go all the way.” I have no issues in that sense. I don't care if I have to stay with him at night, I gave him my life for him. He was about two years old [at this point]. But they were saying to me it was a risk because he was already on like 50, 60, 70, 80% oxygen. So, if he got poorly or a chest infection or anything else, there was not much room to play about with.

At the same time, I was always looking to push him forward without harm, so I wanted to get him home. I said “look, I just want to get him home now, because on the medical side, there isn't much going on. So it's just about you guys looking after him on the ward and stuff and if I can manage him at home myself, if I can it prove to you and everything, I'd rather do that.” So then there was this whole thing, meetings and meetings about sending Ibrahim home, can you imagine the care that he needs, how people were scared to touch him at times, with his oxygen requirements and everything?

So I start looking up all the oxygen setups at home and what happens and [it took] six months of planning. We first started bringing him home just for a couple of hours from the hospital, but via ambulance [with the] doctors with us, nursing staff, they would stay with him in the house for a couple of hours and then we take him back. So this carried on for a little while. And then the doctor started staying behind and just the [nursing] staff would come. And then by the end, I was confident. I wasn't scared of doing certain things and handling things and taking responsibility. So two to three hours became four to five hours, [and] after a while [it] became a full day. So we get up in the morning quickly, early as we can, [and go] straight to hospital get him ready and pick him up. By this time, I've been taking him in my own car.

The normal oxygen cylinders you see in hospitals, for Ibby, that lasted only 20 minutes. So when I say [it was a] military operation, I'm not just saying that; everything had to be calculated in terms of how long will it take to get home? Something might happen on the way, so you have to calculate every single thing.

He was just short of his third birthday [when he could live at home permanently]. We're still at the family house at that time. I set up a room for him and everything, electrical equipment and socket, sectors, maybe like you could say a hospital room [was]. So we got all that sorted, we brought him home and then we spent the first night at home. He wasn't discharged from hospital, but it was just like, we've done the days, now let's do a night. Let's see how it goes.

So, we got all the oxygen equipment and everything fitted in. And we've got another tent for home, all that. So it was so exciting, him being at home for the first night. It was wonderful. We had a beautiful night. Everything went smooth, even though we had two nurses and a doctor sat all night with us. I couldn't sleep. I was there sat with him there enjoying, you know… my son’s upstairs in his bedroom, for goodness’ sake! It spurred me on [to keep] going and going and going. So at the end we managed to get him home. I think [to myself] “I need to start looking to move in a place of our own”.

We got oxygen tubing from [the house] to the end of the gate and from the back garden, so he was free. He had his oxygen on and he could go out. Mentally he was sharp. He was on the ball; he was full of beans.

We always had the Community Team when the home thing started. They would come in pretty much every day; two to three hours a day and they would do about two nights. Now that we are home, we could settle but just to give us some respite, we used to get two nights of cover so we could just relax. During the day, the Community Team come to play with him and all that kind of stuff. We had that all the way through. And I mean in terms of support, I was so involved, I was his social worker, I was his dietician, I did his gastrostomy stuff every, I changed that myself. The consultant was so confident that whatever I asked for, even when [Ibrahim] was poorly, he's like “you can keep him at home, if it was anybody else, you'd have to be in hospital”. They trusted me so much and he knew how involved I was.

I didn't want him to be [taken to hospital] every time because he was so complex in terms of his oxygen requirements and everything else, it took so long to prepare [his first discharge].

They [the hospital staff] knew him from day one, more or less. Even now, they come to the house. The doctor was here just about four weeks ago, just to see how we are. The thing is with Ibrahim, even though he was my son, he wasn't just my son. He was all theirs, he was all theirs as well. They would do anything for him, you know? It was like they treated him like their own child, basically. They have photos of him in the ward, even now if you go to the office, they have photos of him.

I got another bed made for home. It was like a bunk bed, but I've got Perspex put on all the sides [for his] oxygen, with tight, sliding doors on it. It was like a fire engine from the outside, but inside he had his own cabin. I had to put a camera in there. Oxygen saturation things. Carbon monoxide... People used to come just to have a look at the bed, what these guys have done for him.

Everything with Ibrahim, everything about him was unique. You couldn't open up a book and say, "right this child suffers from this, he needs this, this, this and this, this equipment and that equipment." It wasn't like that with Ibrahim. Everything had to be bespoke. There was nothing like [what he needed because of his oxygen requirements] on the market so I just made it. I made it myself. For him the innovation that we had to do and what we have to come up with and the bed that we've made for him, and you know... it was just, my God, it was just unbelievable stuff, seriously.

What I'm saying to you is that, that child, he just brought out the best in you.

For me the thing was, going through what we're going through with Ibrahim, I could have been depressed. What I'm saying to you is that, that child, he just brought out the best in you.

By this time, he's now six or seven years old. I left out the story about him going to school, a mainstream school, even to a mainstream nursery. You can imagine, I had him in a mainstream nursery?

I came a point when I started paying less attention to all [the finer details of Ibrahim's oxygen needs and equipment], but obviously I didn't want to take any risks. But whatever I could do, I started taking things in my own hands. My thing was I wanted to push him as far as I could without having a major intervention like the transplant for example, because, like I said the transplant was the end. That's it. There's no hope for him, expiry date five years, four years depending on how it works out for him. He could be lucky. He might be unlucky. He might not even make it through the transfer process. There's all these things [to consider]. I wanted to stretch it and only take that decision when I've got no other choice, when I know that, if I don't do this, that he might not have long to live. It was so difficult managing him, taking him out with oxygen, hospital appointments, cars full of oxygen and everything. It was a lot, but we didn't think of it. We got so used to it and it was a routine.

When he was, he was six and a half, seven years old, he got poorly. I mean, there was a lot of these [incidents] in between as well [where] we ended up in hospital a week, two weeks. But we'd only take him in only when [we had to], there's no point disturbing him. He was loving it at home, and he didn't like going back to hospital, why would you? With the medical teams, we have this understanding as well, because they trusted us, and they trust me, and they knew that I wouldn't just keep him if I knew that he needed to be in hospital. So we'd only take him when we thought that he needs a good treatment for something, a lengthy treatment, antibiotics, or IVs or whatever it is. Then there came time when he got so poorly, so poorly that, to be honest, even taking him to hospital wasn't even… there is nothing they can do for him apart from just putting him back on oxygen and keeping him in a bed and observing him. They can't give him any medicine. They can't give him anything to him. He can have antibiotics, he can have them at home as well, but that's the most they going to do. But it's just a matter of a bit of reassurance sometimes.

It became more difficult for us to take him into [hospital] because he wanted to stay here. Because even when you go to hospital, there was nothing much going on. There was nothing much we could do for him. It was just down to him. He could have the medicines. He could have the antibiotics. But what else? What else can anybody do? It was often just keeping giving him oxygen and we can give him oxygen at home anyway. Why mentally distress him as well? On top of his? I got trained up with a lot of medical procedures and stuff.

I didn't want to take him in for petty things into hospital, like his button needs changing. I got confident, I got signed up with competencies and stuff, I just did everything. At the same time, I don't take anything [away] from the medical side because they did everything. They did every single thing, whatever they could do. They bent their backs and whatever they could do for us in medicines and whatnot, [they did]. I have no complaints in terms of his medical care. But it was just the situation demanded something with... in my view it was better if he's at home.

So this time, he’s six or seven years old. This is when he got poorly, within a few days, he's breathing really heavy and he's like in his 80s now [in terms of oxygen saturation]. I did get him checked out at hospital as well. But there's no point of being in hospital and keeping him in overnight. So we have him at home, and I'm sat with him in his room. He's in his oxygen bed and everything. But his sats are dropping and soon as he closes his eyes, his sats start plummeting even more, down to the 60s. But by this time, obviously Ibrahim was a superhuman. He was a superhuman. I took him out of the bed and we both sat on the floor and I'm looking at his sats and as soon as his eyes are [closing], because he's so tired... He can't stay awake. And I'm just sat there with him, thinking that was it. It's already been a couple of nights. I don't want to wake him up [but] do you wake him up? Can you imagine spending a whole night like that with him?

I spent the night with him, and I pray to God. Every breath he took, I thought this was literally his last. Mum was sleeping in the other room.

I didn't wake her up even though I knew that this could be his last [moment]. But I couldn’t even leave him for a second just to go tell anybody. Really what should have happened was I should have been on the phone. I should have had ambulances outside. But it wasn't [like that] because nobody could do nothing. What can anybody do? He's on 100% oxygen. They can't give 110%, 200% oxygen. You can only give 100% oxygen. His sats are still not [going up] so what's the point? If this is his last, whatever it is, let him be calm, let him be nice, easy. But somehow, we got through the night. Somehow, we got through the night. And I [did] a lot of praying. Even the prayers weren’t “Allah please save him”. It wasn't that. It was “you know what is best for him”. What's the point in me being selfish to want him alive, [only] for him to suffer? I'm conscious of that as well. And these doctors and professionals [were] telling me he needs a transplant, but I've taken the responsibility not to do that. Everything lies on my… it's down to me [if] something happens to him because I didn't go for the transplant. [It would be like] “we told you so, you could have another five years”, not that anybody said that to me. But [I’m thinking] “have I made the right choice for my son or not?” It's a big decision I've taken in my head. It's too much for a parent or for any individual. But I mean, God gave me this, you know, he gave me this power or whatever it is to go through this and make these decisions and think [things] through and still be calm about things.

But we got through that night. And I said “look, now is the time to have a conversation about the transplant”. Because I don't know how we got through that night.

Because looking at all the numbers, looking at all the sats and numbers and I've got monitors, I've got everything in front of me, I'm looking at his heart rate; I'm looking at his oxygen saturation. I'm looking at all the numbers and the numbers were telling me “Listen, mate, this is it, this is it, this is it”. And like I said, I've got this chemistry background as well. You follow numbers. I mean, there's always hope as well because you’re a human being. But if you're like a logical kind of person… I couldn't believe he made it through the night.

I said to [my wife] “forget everything else, we need to make a decision now”. That's where we are right now because he made it through last night. But I don't think he's got it in him that if we go through a similar situation again, he’s going to make it through. So we got on the phone straightaway in the morning. I said “look, I need to restart this conversation about the transplant so can you start arranging [things]?” and we ended up back in London. I had a chat with them, assessments, and this and that. And they're wary of me. The doctors sat down with me and said, “you’ve got to make the decision [and you’ve] got to stick [with it]”. I understood that we have to go for the transplant now. I didn't want to gamble, that would be too much for me to make a decision and say no [to the transplant], then something happens. That would have been a bit too much for me. So I said, “based on the facts, based on numbers and everything, we need to [do it]”. After long deliberation I said “yes” to them and they were like “alright, OK”, but then they kept on [saying] “are you sure? Are you sure?” I'm like “yeah, I am”. I understand it. I understand looking at everything that has to be done, leaving the emotions to one side but just looking at it from a scientific or analytical [point of view].

We got told in terms of preparation, we had a bag with all his stuff, with our stuff, for whenever we need that, because the call can come anytime. The phone call can come anytime, anytime of the day it doesn’t matter whether it's a bank holiday, whether it's holidays, you have to be ready within half an hour. It's a live organ, isn't it? Oh my God, I mean there's so much stuff I had to wrestle with. Because the lungs have to come from somewhere. It's not like someone’s going to take something off the shelf. People come and are chatting [and saying] he is on the transplant list now, that's good, we just pray that it happens quickly. “Hey, hey, calm down”, I said. What do you mean? I said, “don't you dare even say that”. They're saying this from a well-meaning view, but for me, what I'm thinking about is for him to have that transplant some other little boy, somewhere in the world has to lose his life. Can you imagine? That was another reason why the transplant was such a big thing for me. There was so much stuff to it, the background of it and I would just say “please don't say that, please don't make a prayer that it happens quick because what you're doing is, really for it to happen, [it] means you want someone to die.” Not that that's what they were thinking, but that's my problem. [There are] all these different angles and it just drives me nuts sometimes. But that's my process, I have to go through every single thing before I make a decision. I mean, because it's such an important thing.

It was in 2013 Ibrahim had this transplant. That was after a three-year wait. So [we had] three years of having a bag ready and expecting a phone call anytime. We didn’t go out of town, didn't go too far, I didn't do anything. And then after three years, there's a few things I had to address abroad, in Pakistan. My dad was in Pakistan, and I thought [I might take] a week in Pakistan.

And guess what happens as soon as I fly to Pakistan? Two days later, we get a phone call from London. Oh my God, can you imagine that? And I'm the main person who deals with everything. My wife is ringing me in Pakistan. I said, “just go for it and I'll be there”. I go to the airport and [in] my last conversation with Ibrahim and Mum, she says they're just about to take him in now and I was just about to board the flight. An eight-hour flight. Can you imagine? My phone’s off. Nothing. I don't know what's going on, but when I land, I don't know what to expect. And I was so scared when I landed in London. I was so scared to switch my phone on. It's a big procedure, isn't it? Going for a lung transplant. But anyway, it was OK, we got through all that stuff. But before the transplant and after transplant, that is a completely different challenge. It was completely different.

So, we got rid of the oxygen and all that kind of stuff. [Despite] all the research that I had done into the transplant and coming to that decision, in a way, we were kind of forced into making that decision because of his situation. But it was a completely different, different challenge, and different because it was at Great Ormond Street, you know? Me and Ibby, we used to travel to London every week, every week we were on the M1. All these journeys were difficult. But looking back now, I'm just glad that me and Ibby, [we had] five or six hours driving, spending the night, two nights, three nights whatever it is and driving all the way back. Just the two of us. Just talking about whatever, that was lovely. But it got a bit difficult because of the medications and immunosuppressants.

And I mean obviously [with] medications, there's always side effects, so they started affecting his kidneys and other things and there’s a lot of doing and froing and a lot of different challenges and it did become difficult for us.

And then he went back to school. He did everything as normal as he could from 2013 onwards. The first year was difficult anyway because every week we were in London, every week, up and down, up, and down. It was almost [like] that's all we did, because by the time you get back home, you were ready to go back again. It was almost a full year of that kind of stuff. But can you imagine Ibrahim being stuck on oxygen and not being able to do anything? Every time I went out, we had all this planning and everything. I remember the first few weeks. We spent about a month in London after his transplant. And, oh my God, the doctors were shocked at him. He was one of the only people that went through that transplant and two, three days later, he was up walking about. My boy, he was something, you know. So for me it was good because I thought “everything’s going good, everything's fine”. You know, better than expectations. But it was just a lot of challenges afterwards.

We had a good couple of years and then we have ups and downs, like you always do. We had a good few years and then, in 2018, that's when he got really poorly again, and we ended up in London again. I think we spent at least eight, nine, ten months in hospital, just me and him in in London. And, after that, that's when I kind of realised that everything's catching up now. Because he had been about five years from his transplant as well, and expectancy afterwards is [about five years].

That's when we first got introduced to the palliative care side and that was in London Great Ormond Street.

Mentally for me, looking at all the numbers and everything, everything is going in the wrong direction now. We reached the peak and now, slowly, kidney function’s going down, down, down. Every time he got poorly; it took something away from him. It took something out, you know. And I could see that.

I don't remember having any [conversation with staff about it] because it was so obvious. I mean, we must have had this conversation, but I think they knew as well – “we have to explain to him this was going on” - I knew the decline had started. I remember having conversations with my wife a few times. And I said, “look, we've probably got about two years with him”. Understanding all the results and the procedures and everything, I could see it clear as day. It was completely different now, compared to before, even though I knew this from day one, because they told me he wouldn’t make it past six months. But it wasn't like before [when] was this challenge and he spurred me on to do all this and that. Now I could see that doesn't matter how hard I try; it doesn't matter what I do. Doesn't matter. There's nothing anybody can do now apart from just adjust his medications. Try something new. If this doesn't work, maybe try something else. That's when we first got introduced to the palliative care side and that was in London Great Ormond Street. That was in 2018, just the initial conversations kind of started as well. He was about 15 or 16.

I don't think he wanted to go down that [road]. I mean, he understood everything. But he didn't want that to affect him in any way. I remember the doctor having conversations with me, [he said] we could offer this, and we can offer this and we can talk to him and I said, “look, no, no, no, no, you don't know him that well”. Even though he was 16, 17, 18, in some ways he was beyond [that age] in terms of understanding. But in other ways, he was still like a 12, 13-year-old boy, emotionally and stuff. I remember, he was nine when he had the transplant. When he had the transplant, when the oxygen came off, one of the things I noticed about him was that because he was free, all the things that little toddlers do, [putting their] head in the cupboards and that kind of stuff, he was doing that early exploring that kids do. [Getting a] piece of paper, little scissors, and that kind of stuff, making a mess everywhere, going out and opening another door somewhere else. That kind of stuff. We used to laugh as well, like “look what he's doing now! I've just cleaned!” I said, “look, he's going through that phase. He's missed that phase. Just let him do whatever he wants.” What I'm saying is in some ways, in understanding and everything, he was beyond even like normal kids in that sense. But when it came to other things, he was like a little [child], and it was just amazing. It was just amazing.

I had a chat with a couple of the staff and nurses [about palliative care] and they were like “whatever you need, we're here for this. We can do this. We can do that.” But Ibby was different. Ibby wasn't one of those where he'd wanted to explore these kinds of things, where this is a reality. Initially the before the transplant we got introduced to the children’s hospice and we went there.

That's the only place we could go because of oxygen and everything. So that came back on the cards. Because after the transplant, because it was OK, we didn't need any of that. So that came back on, and he was like, “no, no, no, no”. Because he knew what that was all about, the hospice kind of thing and it's like, “I don't want to go, Dad”. I said look, it's like a holiday, you don't have to stay there or anything. You could just do that for a day out or even as a family, we can go. “No, Dad. No, Dad, I don't want to.” And then one time, he said “I don't want to because I'm not like them [the other patients]”. Because he was fully there, wasn't he? And when he saw people in wheelchairs and this kind of thing that didn't make him feel normal, because he wanted to feel normal… That's one of the reasons why, even in terms of schooling, he went to a mainstream school. He didn't go to a specialist school or anything, even though his requirements were like… even the nursing staff, they were scared to touch him at times. That's the kind of person he was. He loved his family. Loved his extended family. Parties at home was his thing, getting everybody together.

So all it was [was] hospital appointments and hospital appointments. Oh my God. Every week you'd have two. You know, he's got bloods in the morning… there was a transplant side, the side in Bradford. There was London looking after him. There was Leeds, then there was the kidney side getting involved now. So, there was the kidney issues going on then, in 2018 while we were in hospital, he developed IBD as well. He had some bowel issues and was in a lot of pain. But all that kind of settled down and we used to travel to London for just one IV especially, the particular IV that he used to have.

Can you imagine travelling over to a London hospital just for that? It was every two weeks just for that, and then all the appointments in between for other things. But it's what we did, it's just life. It wasn't like, “oh, no, not this again”. That was my job, that's how I saw it. I never had to fight with him, he was so good in that sense.

Then of course the other thing was obviously COVID hit after that, soon after [the conversations about palliative care]. So then we became isolated. Can you imagine COVID for us, with him around? Oh my God. You know, what we had to do and whatnot? But in between, this is now where the IBD had kind of settled down, lungs were what they were. After the transplant [lung function was] like 80%, 70%, whatever. And by this time, you know, we were down to like 30%. Kidneys came down to about 30%. And then through that year I could see now the kidneys were fluctuating up and down. There's all this talk about dialysis and all that kind of stuff. In the back of my mind, I knew, I don't think we're going to… for anybody else looking at [Ibrahim] they couldn't see any change in him, they could think he's still the same. I mean, he got little bloated at the end because of the kidneys and stuff but nobody could actually see it. But I knew it and sometimes you got hurt from it. I found it difficult, my wife as well because it just changes the whole atmosphere of the thing. Maybe it was selfish of me, but I just tried to do things which I thought would benefit [him]

At the same time, he’s going towards 18. And because of the dialysis - that might be on the cards - now the question is he's moving into adult [services]. So now all this, all this stuff started about the transition from children’s to adults.

[Part of me thought] “listen, don't bother. What's the point?” That's how I felt. But then obviously, I still have to go in and then we have to meet the teams. And that got a bit difficult for him because all these teams.... paediatrics we knew from day one. [Now] the staff are going to start changing. And that got a bit difficult for us because we got introduced to the new kidney specialist that handled services in Bradford. And then we got referred to Manchester. So, we used to go to London and then because it was a transition, now all the care has been transferred to Manchester. There's a whole new team, new people. He just took it in his stride. [His attitude was] “Dad, if you think this is what we have to do, let's [do it]”. He was so good in that way.

So it became [a case of] trying to sort teams out, who's going to look after him here, and then there's so many different disciplines as well because he was looked after by so many different [teams] and it became a bit of a... because the transplant side is going to be Manchester; the kidney side now had to be fast-tracked. The kidney specialist was in Bradford, a wonderful, wonderful, wonderful chap. It got messed up because his kidneys [were] the main issue at this moment that had to be transitioned quickly.

For some services we're with the adults, for some things were [with children’s]. And it's hard for them to communicate with each other. I had to deal with all that, keeping everybody on the same page. It was just what we did.

We got back to Bradford after 2018 and like I said [we got] through COVID and whatnot. And then the palliative care team and local team, they kind of got in touch as well. And [the palliative care coordinator] had moved on to the palliative care team; before then she used to be with the community care team. So she knew us from [before]. The thing is, because I kind of did everything, he didn't have a social worker because I did all that for him. Anything for the school, anything for the doctor, I was there, I gave [up] my career for him. There was a lot of “have you got a social worker? Do you want to? Do you know?” I said, I don't know if I need one. I said “look, these are the things I do”.

So palliative care, they got involved. My contact was [the community coordinator] and she was always doing a phone call [asking] “what can we do? How can we help you? How can we help you there?” But it wasn't full-on, like what people might expect. There were some things like, because his mobility got affected now, he was getting out of breath and his kidneys and his legs were hurting at times. So, I say, “look, I think he could benefit from electric scooter and a wheelchair and all that kind of stuff”. So they help me with that, but it was a long process. This was 2020. We went for assessment. It took a long time to get everything sorted. They said that he definitely needs a scooter, at school he could benefit from this. We have to wait for funding. And I thought, forget all this. My younger brother came and he says, “forget that”, so we just went out and bought one for him. And we went out and I bought a new wheelchair for him. Because you realise, he ain't got time. [If there are] summers he can enjoy, whatever he can, do it. Let's just do it.

> **You can imagine being in hospital during COVID lockdowns and whatnot.**

They [the palliative care team] were there for me. I don't think I used them too much because of everything that I had to go through, and it took a while and I didn't have a while. The positive involvement [from the team] was limited to that, but [the palliative care coordinator] would always ring, pop down and ask “how are you doing? How's this? How's that?” She's the one who sorted the assessments you need to get in touch with and so on, so that was there. I don't know what else palliative care... what else there is that could have been done. Plus, because I think everybody knew about us as a family, that [we] can deal with things and they know that when [we] need something, [we] will ask - they were there, but kind of not, you know what I mean?

Ibrahim was becoming more and more tired. Everything had become a bit of a mission for him at times. And then last year... he got a little bit poorly in the beginning of the year. We spent a couple of weeks in the hospital. You can imagine being in hospital during COVID lockdowns and whatnot. In 2021, I think it was, we ended up in hospital for about six weeks and we've gone to the ward and you've got locked up in the room and I couldn't get out. Once you were in, there was no swapping between mum and dad. No cigarette breaks, no nothing. Food’s being given to you inside the room. So we experienced all that kind of stuff as well. That's when he got poorly, that took quite a bit away from him.

I realised that it's time, you know. He recovered but [he was] not back to his [previous self]. We carried on with life, he carried on. We still did what we did. Lockdowns were over. We start going out again. And we started doing things. I never thought once that something could happen this year, something could happen in a few months. It wasn't like that.

It was a May bank holiday and he planned a trip, he planned it all. We went to Lincoln to a motorhome site. He rang his aunties, all of them. I've got seven brothers and sisters. He rang everyone, each one of them. He said “You got three days’ bank holiday weekend. I want everybody to come. I don't care, I want everyone.” And you know what? He just dragged us all out. And he wasn't well. He wasn't well at all because nights got harder with him. Nights got difficult; we were up most of the night. He was breathing heavy at times, and he was on oxygen again. But he wanted to go. Obviously, me, I [was] doing all the research again and I mean, what kind of hospitals are there and how far [they are], and all this, and I thought, you know what, it's a gamble. It's a risk. In any other situation I never, never would have done this, but you're [Ibrahim is] saying it, let's just do it. And we went.

We got there that Friday; a Friday evening and he's loving it and he’s playing with his cousins and everything. And come nighttime… my God, it was me and him. And he started having problems. He couldn't breathe. He was awake all night. He was literally struggling to breathe. And I'm like, “listen, we're going”. There's no point in taking you to these hospitals here, nobody knows you, it's only an hour and a half drive back home. “No Dad, no Dad, I'm not going; I'm not going.

Everybody's here, everybody. I'm not going.” I swear, all night I was up with him. He didn't sleep, I didn't sleep, and I said to myself, we're going to get through this night and in the morning we're going home. [But in the morning] he's up and he said “Dad I'm not going. I'm not going”. I said, “alright, let's spend a few hours. Let's see how things are”, but during the day he will be fine, he'll be back to his normal self. At night he was like a different person. So he made me spend the whole Saturday there. “No, Dad just one more night. We'll see what happens tonight.” He made me stay the second night as well - again, same thing. No sleep. Not just no sleep, but a struggle. Every few minutes, [he was asking] “Dad, what time is it?” I look at the time and I said, “half 12”. “Dad, can I just stay on your chest for a bit?” I said “yeah, yeah”. So, you know, we're just there, hugging. And he asks the time again. I say “son, it's 1:30”; “Dad, is that it? Is it only 1:30 yet?” He wants the sun to come up and he wants to get out. He didn't sleep all night again. We got up again in the morning, same thing again. [He is saying] “I don't want to go”. We spend Sunday night there as well. Monday, we came home, had about two hours, we dressed, [and we] took him straight to hospital.

Just before this, the palliative care for the children’s hospice, we had a few meetings with them, during COVID and whatnot. [Ibrahim] didn't want nothing to do with it, to be honest with you. He didn't want anything to do with them. Plus, the doctors and the staff were a bit different. We hadn't met them before, so we had a couple of visits from them all. [They explained] “this is what we can do. These are the kind of services that we can offer”. But it seems so far away at that time. You know, it was like, well, we’re doing OK. So, towards the end, they got involved.

Ibby got poorly and, I swear to you, even then, I didn't realise that he's only got three weeks left. Even then, I didn't realise. And I remember having a chat with the doctor, because I could see that he’s not well, but I was still thinking six months, eight months, you know; he’s going to come back home, or we may have a difficult time at home now, but he's going to be at home; we’ve got more time with him yet. I remember asking the doctor specially, I said “just tell me one thing. Are we going to make it home from this day in hospital? Are we going to make it home?” That's all I want to know because I'm not ready to give up on him yet. I'm not ready. I'm not, because he just took us out [on holiday]. I mean, I know how difficult the nights were and everything, but we're doing all this, enjoying ourselves, his aunties and uncles were there. Everybody's like “wow, Ibby”, and now two days later, you're telling me that things are not looking good.

I said, “look, I know things aren't good. I can see that. But I need to know, all I need to know, is that we're going to make it home”. Basically, I wanted to have a little summer with him. And at least a bit more time with him because he’s just been walking, talking, having fun and how can he just go? You know, he can't just go. But that was the only stay in hospital. We did manage to come home for little breaks because any time he could get if he can manage, he [would say] “let's go home, Dad. Let's go home, Dad.” So, he'd come home for a few hours and then go back again and that kind of stuff. And that became more and more difficult towards the end and there came a point that he himself said “Dad”, and I said, “son, let's go. We've got everything sorted. I've asked the doctors and everything, we can go home now, for a bit”.

“No Dad, I don't think. I don't think... Let's, let's just stay here. Let's let everybody just come here and stay instead.” I kind of realised that even he knows.

The hospice team got involved. But towards the end I didn't understand what they could do for me, or what they could do for him. I mean, there was talk, there's all these conversations like “we could set everything up at the hospice for him and he could have all the end-of-life care” and that kind of stuff and, or home, or hospital or whatever. And to be honest when it came to that point, I didn't understand how he could benefit. Not that he wouldn't - it is a benefit - but it's not something that we needed at that time. And now I'm thinking, if it's only a matter of weeks, or months, or whatever, I want to let him do what he's happy with [and] he's happy with being at home. Whatever it is, we'll try to set it up. But as things kind of moved on, it became more clearer and clearer that... I don't think we're going to make it home now.

There's even a process where we started everything in terms of making something set up at home and ordered the bed. We asked “Ibby, what kind of bed do you want?” [He said] “I don't, I don't”. Because two years, three years ago my stepmum had passed away. And he remembers because before she passed, she had cancer. Suddenly, liver cancer, we only found out [when she had] only twelve weeks. So, he saw the process where she got a hospital bed set up at home; and then she didn't survive much longer after that. And he even said it to me. I said, “look, Ibby, we’ll get all this set up.” And he said “no, no, no, I don't want any of that. I don't want any of that.

You're going to set up the bed for me and then you're just going to wait for me to die". When he said that, I just…

The doctors from palliative care kept coming in but that became even more difficult for him because they didn't know him that well. Even though I tried to explain to them, because they started seeing him like he was an adult, because he's nearly 18 now. [They said] "Oh, no, we need to. He needs to understand." And I said "he understands everything. You just leave everything to me." But it's a few times we had this. They have the conversation with him and he's just like, "I don't want to, I don't want to". And in fact, it came to a point where this particular doctor, she was a bit pushy. I think he felt it, and even I felt it to an extent, [she would ask Ibrahim] "What would you think?" Or very difficult questions. He didn't need it at that time. He didn't want any of that. He just he wanted the family around.

So that became a bit of a thing for me as well because the doctors from the medical team side, they had to hand everything over to the palliative side. They had to do, because they were the ones who were prescribing the morphines and whatever else it was now. They have to be involved, but it became a bit difficult for me. It was too much, that kind of like "him", that we have to speak to "him", we have to go through "him". And I'm like, "no, no, no, no". I said, "you don't know him". He's like "no, have you talked to my dad? Speak to my dad". They tried to see him at hospital a few times and pop in and he's like, "no, I'm not [seeing them]". One time when they did come to see him, I went [to hospital] and they were already there, in the room with him. And as soon as I walked in, he looked at me like "I've told you, Dad, why [are they here]?"

I said, “look, I'm sorry, we're finishing right here. Whatever it is, I don't know. You've talked about whatever it is, but we're finishing it right here.” Even when we finished, they were still there for like another 10 minutes, we [the staff and I] were having a conversation separately, and he looks up at me after 10 minutes like that “Dad, you said we were finished.” I was chatting with them outside and so that's the kind of the involvement in terms of the palliative care that we had.

But every person is an individual, circumstances are unique. And you know, with Ibrahim, he was completely different. There was no set plan [with him]. Everything had to be bespoke for him and his life was like that. The kind of stuff that we did, and we went through and these London trips and all this, it was so specific. So somebody else coming in last minute and trying to say “this is what we’re doing” … They've got their procedures, haven't they?

[The paediatric palliative care coordinator] for example, our local palliative care team, they knew him, they knew us, so they understood. They know “let's speak to [Dad], he can speak to Ibby”. But it was no hard questions, that kind of stuff in front of him. You know, like, end of life stuff. Whereas these [other] guys say “Ibby, we can take you to the children’s hospice”. What does he care about the children’s hospice? These people, they've got a job to do, and they do a fantastic job. But in my experience - it's not having a go at anybody or anything - but what I'm saying that sometimes it became a bit of like, as soon as they want to have a chat, or they want to come in, we thought “oh, no, not this again”.

> **They've known him since he was a baby and they'll come and take breaks in Ibby's room.**

For someone to come in last minute - even though they had visited us a couple of times, but COVID made it more difficult - it's harder to build that relationship.

From day one, Ibrahim was never interested in all that kind of stuff [end-of-life care] because he was happy the way he was at home, as a family. Wherever you know, hospital appointments, whatever, the teams that we had around him, he was happy with all that. And he had already taken on board these new teams like Manchester, the kidney team. These were new teams and even during the stay in hospital from the respiratory side, we got moved on to the adult ward for a little while as well. But that's because of certain things the paediatrics couldn't do, in terms of CPAP and all that kind of stuff. We got a little bit messed about there in the sense that, suddenly, towards the end, we have to be pushed into - can you imagine? - an adult ward is completely different to a paediatric ward. We spent three days there. The guy who's going to come sort out the CPAP, he's not here for the weekend, so we're just there and they're not like the kind of staff that would come in and [say] “oh, how are you doing, Ibby?” You know, have a little joke, and laugh. They just start doing their job right? “You need this changing. You need that changing.” Ibby’s used to the older staff and nurses.

They've known him since he was a baby and they'll come and take breaks in Ibby's room. Or when it's their break time, they're coming to see Ibby instead. That's the kind of staff he's used to, and suddenly we ended up on that ward.

I said to [Ibrahim's usual doctor] "if there's anything I need to learn about these machines, I'll do it. I'll spend the night and I'll learn everything on these". But, I said, we need to get back to where we need to be. These are the words I used: "we need to come back home" [i.e.: to the children's ward]. That's our home. We need to come back there. We need and we want to be back home. And because we had some experience with it - because in the beginning, before the transplant we used CPAP, it's not rocket science, these home machines, we're not talking about the hospital set up. What's there to learn about them? It's a few settings here and there and I said [to the doctor] "all I need is for somebody to tell me what the settings need to be. But whatever they need to do, you just tell me what the specialists have said, and I'll just change [the settings as required]". At the end, we ended up back on the ward with the machine and if anybody needed something to do with [the machines], it's like "where's [Ibrahim's dad]? Need to call him". Then I would go in. It was just full-on because that's the way he liked it. That's the way it was.

This is towards the end now, [he had only his] last few days left now.

So, there's all this stuff going on and because he was on the CPAP, his carbon dioxide was building up and stuff and we could see him slipping away. And it got down to like, you know... he might not make it through the night. Then the palliative care [got more involved].

This is when [Ibrahim's usual doctor] kind of apologised as well, he says "look, I'm sorry but this is the way things are, because when it comes to this stage, we have to step back, and we have to let these lot [palliative care] do what [they need to]".

One time he's there and I say "Ibby, son, you're the strongest person that I know. All you've been through, no one else could have stood that." So, I said "I need you to try this one last time. I need you to try a bit harder, let's get through this". And he looked up to me, he says "Dad, you know me. I always try". He said, "I always try, Dad". And I said, "son, you always do, but you know you've got to". He said "Dad, I'm trying. Dad, I'm trying". He paused and then he says, "but this time my body's not letting me". He recognised it; he said, "my body won't let me". He said "Dad, I'm trying, I'm trying", you know, "I'm trying. My body is not letting me". That's what he says to me. That was the night before the doctor said to me that he's not going to make it through the night. I stayed up with him all night. It was OK. Sats were fine, everything was fine with him. Come morning, he's up again. I said to the doctors, "whatever plan you put in place before, forget everything, scrap it all. He's not ready to give up. So, let's just restart everything". I said, "I want treatment". As soon as [Ibrahim's usual doctor] came in, I said "I need a meeting with you straightaway". I said, "we agreed a couple of days ago that we're going to cut this, we're going to stop this, we're going to stop that". I said, "I don't care, let's start, restart [treatment]." I said, "if it means he has to go on dialysis, let's go on dialysis". Everybody's like, "yeah, whatever you want, whatever you want". But it wasn't to be. He made me realise, "Dad, what are you giving up for?" Suddenly, he made me realise again, he's not giving up. I'm like, why should I give up?

There was all sorts of things about his mask. When shall we take it off? You know, “we're going to do this, and we need to you know”. They kept calling me in and [saying] “we are going to have to take his mask off at some point”. There's loads of other things as well but at this moment I just can't… that’s the kind of thing that stuck to me. Because that's a difficult one - do you want to take it off? Shall we take it off? When are we going to take it off? “When”, “are you going to”, all these questions. I'm like, how can I? It's impossible, because you said to me, he's not going to make it past the night [but the] next day, he's up, not just made it through that night. He was unbelievable, that kid, you know, the next day he was up. Even the last day he was going to the toilet, with a bit of assistance, but he was walking to the toilet. He didn't want to use a commode. He'd walk to the toilet. But there were all these different difficult questions. “We need to do this. We need to do this. We have to do this. We have to do it.” And I looked at [Ibrahim’s usual doctor] and I said “you know what? I've been listening to [the other doctor], but I think I'm done now.

This is the plan they've put in place.” I said “they've put a plan in place. Let me explain to you what my plan is now. This is what I'm going to do. This is how I’m feeling it needs to be done.” And you know what, he just looked back, and he says “I'm absolutely fine [with that]. I know what you're saying, and I agree with you. I can't say nothing because they [the palliative staff] have got to, you know… so whatever you want to do, I'll back you with whatever it is that you want.” So it was kind of left. I mean, there was a lot of things that they wanted, but I was like “no”.

At the end, he just slipped away, he didn’t even... Can you imagine that? Can you imagine? Having to take a mask off whilst he's still alive? For me it was like, I understand the logic of it and everything, but I even thought to myself, if I take the mask off, I might end up messing myself up, because I'm thinking “I'm the one who took the mask off. That's why he died”. They're trying to help me through this [but] it had to happen as a family, as Mum, Dad, whatever, it had to be done that way and I didn't want anybody else to take his mask off. If anybody, I'm going to do it, nobody [else]. Like I said, they have their procedure, and they have to do their certain things that they’re used to doing and they were just following [that]. But we weren’t about that. We weren’t about that; Ibby was something else. Everything, all his life, had to be particular and his own way of doing things and our way of doing things. By the end, he didn't give anybody a chance. I still remember, I was sat next to him. We all sat there, and he just opened his eyes up. I was in his room, mum was on the left and the kids were on hand, a few of the extended family as well. And he just kind of looked up and just looked at me straight into my eyes like that. And I'm looking at him. He looked at me and I could see the shine go from his eyes. That was it. He was gone.

Even someone who has gone through a similar kind of situation, in terms of losing somebody, even that's not the same. They have their own circumstances. [Ibrahim] was completely unique, his story is completely unique. That kid, he never gave up. He never, ever, ever, gave up. Not once. Towards the end he says to me, “Dad, I think I'm going”, about two or three days before. “Son, we don't know that” I said, “that's up to God”. He was a fighter, he always fought, he always fought.

In terms of the palliative side of things, they were there. They were helpful in certain things, but my experience… it's not like there was anything wrong, but it wasn't tailored for us. It wasn't. Maybe it's just the way we were, because of the way I was. Because of the way I took charge of everything all the time. That's the kind of person I was, being there, liaising with all the different [people]. And this was just another one of those things. And at this moment in time - can you imagine? - I've been doing that for 18 years. Why in the last couple of days, or weeks, am I going to let someone else take over? It's not going to happen. I mean, I'm willing to work [with services], but it has to be on our terms. It has to be the way we feel.

That hospital, it's a home for us. We know the staff; we had no issues. And believe me, the experience that we had of that stay in hospital, [it was] amazing. Absolutely amazing. I can never do justice to the staff, to the doctors, to every person, even the janitors knew him. Can you imagine? I remember back in the days when they first put in the little TVs and stuff, they used to send these engineers to service them every morning when we were in hospital. Every time someone came to our room, they told me that they'll be like two of them, three of them. They're laughing and giggling and I say, "what's going on?" and he says, "in the morning when we come, everybody meets up and there's a fight who's going to go to the ward because of Ibby". That's the impact he had on [people].

Towards the end, we had the massive room. Opposite the room, there's a bay area, so there's about three cubicles and staff. There's a computer desk and everything on the other side. You know what they did for us? They gave us the whole corridor.

Not just for [us] and [our] family, for [our] extended family. As soon as anybody came into the ward, all they had to say was "Ibby". The doors would fly open, whether there's five of them, whether it's eight or nine of them. Someone would escort them. They'd come in and the staff would say "there's some more guests that are here, we put them to that side for you, whenever you feel free". So we had this whole corridor to ourselves. All the family, we spent two nights on the ward. My brothers, my sisters, his mum's sisters. They were from Birmingham.

We're not just Muslims, we're pretty religious in terms of everything that we had to do, whether [it's] prayers, everything, we did in the open. Obviously, they knew us from beginning as well. So there's absolutely nothing I could say that, in terms of our religious side, that we felt a bit [uncomfortable]. No, no, no. Because, for us, they're [the hospital staff are] our family. They knew us, we knew them. For them to just give us the whole area at the back of the hospital, where we could really... and not just that, trolleys full of teas, chocolates, biscuits, sandwiches, and as soon as they go, [they were] refilled. I have the utmost, utmost respect, seriously, and like I said, I don't just see them as staff. I see them as my family, and that's why they still come. They still visit. They ring me. They message me.

We spent three days, that last three days, three nights, we spent with [Ibrahim] and at times we were praying out loud and stuff. I didn't feel that I had to watch myself or anything. They were so good. And because they knew me in the sense of what I was like, when they would come to change his dressing or someone would give him some medicine, or whatever, it's like "are we OK to do this?" It was pretty much in my hands.

The last few days that we did spend with him at the hospital, in terms of the support and the care and the warmth and the sympathy, empathy, whatever, it was more than my expectations. It was more than my expectations and like I said, for the rest of my life, those guys, all of them, I'm not just talking about the doctors or the nurses, I'm talking about the clerical staff, the janitors, everybody you know - I can never repay them. Really, I could never repay them.

I don't think I can say that enough [bereavement support] hasn't been offered. [The paediatric palliative care coordinator] has been in touch. She even helped me out with a few things because I found it difficult afterwards letting the authorities know, because he was on DLA. We were on income support. We were on housing benefit, and we came out and suddenly “poof, boom”, gone. For me to just get through to them, to tell them; I was in half an hour of queues, and I didn't have the patience, I just was so angry at times. But I phoned [the coordinator] up and I said “look, please, just come down, can you just deal with this side of things?” So, God bless her, she came down and I said we need to tell these guys this, this, this, and this. She'd sit there and go onto the queues and queues. She'd be there waiting hours and then, “oh we’ve got through now, right come here now, we got through”. But I felt that that system could have been a lot better. That service. There has to be better. It was ridiculous. We were going through having lost Ibby and everything and then the income support stopped, because income support stopped the disability stopped, because the disability stopped the housing benefits stop, everything.

> **It was hard for me, because I had to explain to them again why the circumstances had changed.**

And I can't deal with this right now. I can't deal with this right now and either, somebody deal with it, or give us some buffer at least. And getting [the coordinator] to do it, she can only ring them, I still have to talk to them. I still have to explain to them. It was hard for me, because I had to explain to them again why the circumstances had changed. I have to go through the whole story again. And then I'm ringing the other department and I've to wait another 45 minutes, an hour, then get through to somebody saying, “good morning, are you having a good day…”. And the thing is housing benefits, housing departments, are different [and] separate to income support. [So they say] “I'm sorry you'll have to ring them. This is their number. We can't deal with that.” It was just ridiculous for me, I'm like, what on Earth is this? Then I have to go and put a new application in for universal credit. And having to do all that while I’m… whilst I don't know what date, what time it is, I don't know what day it is.

So that's been a difficult journey and in terms of support, [the palliative care coordinator] always said “if you need anything, I can make you a referral [to bereavement support]” but you know, it's difficult. If you ask me right now, or if you send me a message [asking] “how are you?”, what am I going to say to you? There's millions of things going on inside, it's not just one thing.

Suddenly I'm dealing with the death of my son, but then suddenly I'm finding myself in a position where, financially, I can't even keep the roof on top of my head. I can't pay bills. We had a Motability car. They were good that they gave me extra month; they said you can keep it one extra month. Suddenly I haven't got a car, the car's gone, everything's gone. All those practical things you know, and it's not like I'm going to get a job tomorrow. It's been a year [since Ibrahim died].

I don't admit to certain things as well. Even my wife complains, [she says] "you don't talk. You don't say anything". But a lot of times, there's certain things that I can't... there's things that you don't need to worry about which is my responsibility; if I start talking to you lot [family] about this and that, then you'll get worried about that stuff [and] what's the point? I am who I am. It's my responsibility, and I'm dealing with it, but sometimes what I realised is, to be honest with you, that sometimes you have to play the system as well. I've realised that maybe I could benefit from [more support for myself]. I think there needs to be a bit more emphasis on the fact that, even though everybody is saying they're OK, they could do with the chat. Or it could be in an open setting where they can gather. So we can let some things off our chest.

With universal credit, the stress you have to go through... One thing is when you go in there and there's a 19-year-old, 20-year-old, 21-year-old sat there in front of you, and they're supposed to be your coach. This little kid is going to be my coach. And I come out of there more angry. But you have to go every two weeks just to show your face, playing the system because we're not ready for all this stuff [since we lost Ibrahim].

We're not ready for this, even though it's been a year and at times I'm surprised how long it's taken me to get over this. And I still haven't got over it because I was thinking to myself, I knew from day one [Ibrahim’s life is] limited. But it's hit me so hard. It's hit me so hard that I can't sleep, I can't eat. I’ve lost about 11kg since last year. [If I were] playing the system, I should have just gone to the doctor and said “listen mate, I'm depressed. I'm this. I'm that”. And, I mean, my wife’s probably worse. I don't want to admit that I'm weak mentally, that I can't deal with it, or I'm stressed. But looking at everything, I'm going through all these difficult times and it's so stressful and everything. I should have just gone to the doctor just to get signed off by him, or just to get them off my back [but] I'm a person where… we’re people who do things the right way. And the whole thing I've learned is doing the things right way in the system, it's not [always] the right way for you. You have to think about playing the system.

Which, I might do now because my wife is really stressed out and she can't deal with it anymore. I said to her, “make yourself an appointment for the doctor now and just explain to him how you are mentally”, which is true. We're not eating, we’re not sleeping. “Just go there and be honest with them. Let's see what they say.” And I think maybe now, maybe we do need to talk to somebody, actually, to be honest. We've tried [by] ourselves. And we're doing ok. We’re trying to as a family, we're trying to stick together and do things. I mean, it's not been easy, and we've had issues. Me and my wife had issues because every little thing makes [us sad]. My tolerance levels [have been affected]. I'm a really easy-going, [but] now, you make a little mistake in front of me and I'm like, “wait, what on Earth?”

My friends have noticed it; my family's noticed it. My siblings have noticed it. I feel like my kids are walking on eggshells around me sometimes, because they just don't know when Dad might just, you know... but it's just that it's all the stress. So that's where we are at the moment.

Sometimes you feel weak, and I'd like to think of myself as not being a weak person, but because I’ve gone through whatever I've gone through with my son and everything... I've got two kids. They need me and I was saying the other day, I was chatting with [someone] and they said, “be honest with me, if you could, what would you want to do, what do you feel like?” And I swear, I said to him, “look, if it was up to me right now, if I have nothing else to worry about, nothing else, I'd get a backpack on and I just get a little hut in the mountains somewhere, or whatever”. I'm completely burnt out. Sometimes I feel I haven't got anything left in me to give. In terms of patience, I've got nothing left. But I've got to carry on.

[Sometimes people say to me that] once you get back into your routine, everything starts [again]. What routine? Ibrahim was my routine for 18 years. I gave up everything for him. He was everything. I've got no routine to go back to. [When] someone experiences something like this, they take a month off, they take two months. They might take six months off and then slowly, slowly, they'll get back into work and start transitioning back into this and that. [But] he was my everything. He was my day and night; he was my job. That was my routine. There's nothing I can go back into to make me feel I can slowly get into things again.

It's completely new and it's all stacked against you. Because I'm in my late forties, even though I've got a degree, even though I've got all this experience, what they see is a person who's been out of work for the last 18 years, even though during that time, I've been part of trusts, I've been doing volunteer work. I've been a vice president of this local organisation; I've helped set up youth clubs because that's the person I was, I'm out and about and all this, and it's only when Ibby got poorly, and I was stuck at home… And even at home, I need more than that. I have to see people, have to interact with people. I have to do things. I have to try and make things better. For everybody, you know. But nobody sees any of that.

All they see is 18 years he's been a carer. A carer could be anything. Someone could be a carer who looks after somebody two or three days a week for a few hours. They're classed as a carer, aren't they? But can you imagine comparing that carer and me as a carer? [The word carer] doesn't do justice to me, so when I send off an application, the last thing I want to do is go to an interview and give them my life story about my son. But I have to be able to explain my thinking without having to go into the… without having to use that as a… Whatever skill I say I've got, I have to try to convey that using the last few years, [but] the last few years, that experience doesn't matter [from a potential employer's perspective]. Over-qualification comes into it [too]. I had a meeting just last week and there's people sat around me, some of them can't even speak English, some of them they've not got GCSEs. I'm trying to sit with them and they're going through all this "how to how to do a CV". "What is a CV?" I'm like, oh my God, can you imagine I'm going to waste time on this?

I'm not after a job to be honest; I'm looking to kick start a career, not a job. If I want a job, I can get a job tomorrow. I said [to the job coach] I'm looking for some training opportunities. The problem is they're looking for young people. But then I have to go to these things [at the Job Centre].

When things are blowing up around you, I need to pay my gas bill, or when the insurance is due and you know, suddenly the MOT’s due and you’ve got to fork out £320, your mind’s filled up. What time are you going to take [for yourself]? Even when you take time out, my mind is like 100 miles per hour. That's why I can't sleep all night.