

OLDER AGE AND END OF LIFE

INTRODUCTION

As the charity Age UK points out, poor health in later life is not inevitable and is not irreversible (Age UK, 2019). We live in an era in which society is getting older, and healthy ageing is a policy goal and a call to action for many. Nevertheless, as a whole we are more reliant on health and care services as we age, more likely to receive a cancer diagnosis and more likely to live with long-term conditions. The majority of people over 85 are living with three or more conditions. Many older people live in loneliness and social isolation, which can harm their physical and mental well-being. COVID-19 has tragically highlighted the increased susceptibility of older people to certain infectious diseases.

The ways in which health and care services are organised do not always reflect the fact that older people are often the main users. As discussed in Chapter 4, the NHS tends to organise care reactively around single condition pathways, and is weaker at delivering proactive, person-centred care that coordinates different services around the patient. We have noted the importance, reflected in numerous policy documents and research reports, of joined-up care for patients throughout the course of life, particularly as services are provided by so many different health and care organisations, and with varying funding arrangements. At no stage is coordinated care more vital than in older age and at the end of life. This is not only because of the complexity of health and care arrangements, but also because many of the carers are also older and may be vulnerable themselves.

Older people are particularly affected by the under-provision of primary and community services, the underfunding of social care and

patchy support for family carers. There is often poor coordination between NHS and social care – the problem of delayed discharge from hospital being the classic example. The NHS frequently struggles to respond to the needs of people with dementia (which features in a number of the stories in this chapter) and with frailty – both conditions which become more likely with age. Ageism is widely prevalent, according to the World Health Organization, which is harmful to the health of older people and can have an adverse effect on their access to services (WHO, 2015).

Scandals of poor care, for example at the Mid Staffordshire NHS Foundation Trust (Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013), have highlighted failures to respect older people’s basic dignity in hospital, and there are perennial concerns about the quality and sustainability of care in residential homes.

We have chosen to include stories about living with and looking after someone with dementia here rather than earlier as it is mainly – although not always – a disease of older age. Around 850,000 people in the UK live with dementia, including one in six people over the age of 80, with the number expected to increase to over 1 million by 2025 (NHS, 2020). Dementia is therefore becoming a critically important issue, in terms of the high personal and social costs related to the disease (Oliver, 2015).

Everyone should be able to expect services and support that work for them at the end of life, such as access to good palliative care and pain management, emotional and spiritual support, and respect for their personal choices and dignity. For many, hospice care is seen as the gold standard. It has been a policy goal in recent years to enable people to die in a place of their choosing, but the broader goal of enabling a “good death” remains a challenge for the NHS. In the UK, the Liverpool Care Pathway was seen by many as a humane and minimally invasive way of caring for people close to death, but for others it was viewed as the pathway to euthanasia, and it was scrapped (Nasim, 2014). The judgement about when to stop trying to save someone’s life and start enabling them to die with dignity is not always straightforward.

THE STORIES

In Chapter 1 (Section 2, p. 4), we offer a description of patient-centred care, in general, as:

- Understanding and valuing what matters to patients
- Seeing the whole person

- Respecting people's rights and autonomy
- Being customer focussed

There are five stories in this chapter. **Robert** is in his 80s and has a heart condition and also stomach and joint problems. He became involved with patient participation in the NHS after retirement. **Rabiya** cares for her mum, who has dementia and doesn't speak English well. **James** (whom we have already met in Chapter 2, Story 2) looked after his mother for ten years after her diagnosis of dementia until she died. **Sheila** cares for her husband who has dementia and has battled to get a diagnosis and care in place. **Kauri's** dad died recently of pancreatic cancer. She narrates many episodes of excellent care and support.

Story 21: Robert

Robert is in his 80s and has a heart condition and also stomach and joint problems. He became involved with patient participation in the NHS after retirement. He is concerned about fragmentation and communication problems in the NHS, as well as difficulties in getting an appointment with the GP, and he also notes a lack of clarity about the role of the district nurse. He describes good experiences of being treated in an NHS hospital as well as being an NHS patient in a private hospital.

Robert: You have to go back to, believe it or not, 1943, when I was foolish enough to put in my mouth a metal wheel, it had spokes in the middle, and it perforated my bowel, and I was in hospital for the better part of ten months then ...

I've got a wound from that and it is bloated now. I have to go twice a week as a minimum to see a community nurse to have it dressed. And I see a consultant about the stomach wound. On one occasion the consultant said, can I see your wound? And I said, well, you will have to have a nurse to do the wound back again – so he didn't see it. He didn't bother. It would be the best part of ... well, three hours, shall we say, driving there and driving back and waiting. Quite honestly, I think it's a waste of time going to see him. I think it can be done by phone just as easily.

And another thing: he said, if, in other circumstances – by that time I'd been diagnosed with a heart problem – if you didn't have the heart problem, we'd probably operate on it. Well, I'm not certain whether I want an operation because at the age of 83 or 82, or whatever I was at

that time, I would have felt that, well, I don't particularly want to volunteer for a further operation at my age. I'm prepared to put up with this ... I have had to vastly change my clothes because none will fit me; but he said, sorry, we will consider an operation now. But we didn't really discuss any more, I didn't want to, in fairness to him. But there should have been some liaison between him and the heart person. They're in their own silo doing their own thing.

So, with the knees and the hips, have they all been done in a private hospital, as an NHS patient?

R: No. The last operation that I had the second time here was at the local NHS hospital, and apart from not having a room on my own, one with my own television and everything else, the service was equally as good as it was at the private hospital.

I did feel that the physios there, they felt they've made it because they've got to a private hospital, and the service was more along the lines of a chat rather than just dealing with the professional bits.

As concerns the practice, I've probably seen about twenty community nurses in these three and a half years. I don't think, when people are referred, they seem to understand the role of the community nurse. There's an expectation ... if you live round here, they expect a good service. And the demands that are put on the practice here are, in some respects, quite unreasonable. And I think it should be explained why they're not having home visits. The concept of community nursing, I would suggest, is not understood as well as it should be.

I'm going off a little bit my experience as a patient, but I can't divorce the two totally. The patient participation group [at the GP practice] that I chair, last year we initiated a rolling together of all the agencies round here. Now, what we have got round here is a tremendous lot of agencies. You know, if there's an area in the whole of Great Britain with better facilities, lead me to it, because I think it's very good. But integration ...

What do the patients say about how easy is it to get an appointment?

R: It's awful. You're on the phone for ages trying to get through ... and they'll give you a menu of options of numbers to press, and you don't fit into it, necessarily. You're not certain – was it 3 you wanted or 4?

And getting an appointment, the communication in our surgery is awful. There's a lot of reliance on the Internet, but everyone doesn't have Internet ... particularly elderly people. The practice manager seems overwhelmed, but having said that, it does need someone to

be able to stand back and ask: what is going on here? Everything is done in a rush and not thought through ... for example, I was asked to book a non-urgent appointment with the doctor. I went in the morning to see the nurse, for my routine, twice a week, dressing, and when I went to reception to book the doctor's appointment, she said, you have to ring first thing in the morning. Well, but I'm there. I'm there.

You were in the surgery, and they said you have to ring?

R: Yes, I was in the surgery. There's a lack of communication between the practice reception head, and the counter itself. Communication is very important.

Now, as far as the practice pharmacist is concerned, I've had an email exchange about it. The difficulty there is that you get Pharmacist X, who is in situ, but then he goes away for a fortnight, and there's a locum. Now, the locum isn't as well qualified as the first one. As a patient, you go to the pharmacist expecting the service you got on the first occasion from the first person, but can't get the same because of depth of knowledge, or whatever it is, from the second. That's a problem ...

You must have got to know the GPs pretty well at the practice, not just because of your own health conditions, but also as chair of the PPG [patients participation group]: what is their response to the fact – because they're in charge; it's their practice – that it's so hard to get through, it's a struggle to get an appointment, and when you're in the surgery, you're told to ring; you're not allowed to actually make an appointment while you're there?

R: Being honest, I don't know, I haven't discussed it with them. Probably in the last year I've seen four different ones, but – wrongly or rightly – I haven't felt it appropriate to intrude on their time for, in a surgery appointment. And they don't come to PPG meetings.

Story 22: Rabiya

Rabiya cares for her mum, who has early-onset dementia and doesn't speak English well. The process of getting a diagnosis was protracted and placed a huge strain on Rabiya, as a young mother herself, and on her family. There were then big barriers in securing any kind of social care support. As a Muslim Asian woman, Rabiya relates multiple experiences of discrimination, and, in marked contrast, an episode of real kindness from a physiotherapist.

Rabiya: It started probably about four years ago, and at that time I worked in the NHS in mental health services. My mum had been suffering from clinical depression for a long time so I was a young carer from a very, very young age. I noticed, maybe because of me working in mental health services, that this wasn't her usual way of being; this wasn't depression. We noticed a few times that she'd been a bit forgetful: she was used to cooking for large families, we come from a very large Asian family, and she'd nearly burnt the kitchen down twice. The first time it happened we put it down as probably an accident. The second time we were a bit concerned.

My sister lives right next door to my mum and we are six children so we float in and out, but she was quite independent and I think, in Asian families, there's no such thing as living on your own because family flow in and out all the time. One of us is always staying over, but at that time I would class her as independent.

There was another occasion where she didn't realise she was putting water into hot oil ... We went to the doctor's and they said, monitor it, basically. I don't think they were taking it very seriously. She was 56. Very young for dementia. Anyway, things started getting worse. She was locking herself out of the home. Luckily we live in a village-y area so the shopkeepers knew her and we had a few relatives nearby who if they saw her wandering around would telephone us, so we knew it was getting a bit serious.

It was very difficult to get a diagnosis. It took two years. All the tests were done in English. And at first it was, well, you can't translate for your mum because you're a relative. I knew about NHS policies and procedures so I said, okay, let's bring a translator in. It took ages to organise a translator, a day where I could take time off work and Mum could be available and a translator could be available. Mum had started to withdraw at this point because of everything that was going on, and I said, she won't communicate with a stranger. I mean, it takes a lot of effort to even get her into the appointment. So we tried a couple of times with the translator. It just didn't work.

So this went back and forth for a long time and we just couldn't get a diagnosis. At one point I said, why don't you have the translator there who could listen to what I'm translating to Mum because she will respond to me, but I was still not allowed to translate. Eventually it got to a point where I unfortunately had to be quite assertive. I don't like to be aggressive or assertive but I was getting really frustrated. I was really concerned about Mum. I've got a sister working in law, one in the police. I'm the only one working in the healthcare system so they were looking to me to get support for Mum. I work in the system and I couldn't navigate it. How frustrating is that?

Eventually we found a consultant who was willing to take us a little bit seriously. He was Asian so he could understand where I was coming from. I felt like he understood me better and it wasn't like I was fighting the system to get a diagnosis for Mum. We eventually did and the diagnosis, through tests, was done. She didn't just have Alzheimer's, she also had vascular dementia, and she was given the medication of memantine, which she is still on now. My frustration with the system is Mum could have been on that two years ago. It wasn't just because of the translation, it was also because they were unwilling to accept that she could have dementia at such a young age.

Now whilst this was going on I was basically doing an assessment at home constantly. It put an enormous amount of pressure on myself, on my family. I had a young child at the time as well. It was very, very stressful. I felt not heard by the system and I feel like sometimes – and I work in the system so I understand it – the system doesn't listen to the people who are doing the care. Well, maybe that was a one-off. Oh, well, we can't diagnose her if she can't speak English. All of these things are something wrong with the system rather than something wrong with my mum. She should be able to get her care. So I think that's a massive health inequality there.

Our GP, I've known him since we moved to the area in 1998. Even to this day our relationship is, I would say, quite strained because he was not willing to listen to me and I had to bypass him and he did not take that well. My GP was very resistant to diagnose, but instead of trying to seek another way to deal with the problem, they just said, we can't do the test. I felt that it was too complicated and he didn't want to deal with it because it wasn't a straightforward process.

I did put a formal complaint against the GP and I feel it's unfair that I was put in that position. I feel it's unfair that I had to complain about him and take it to all levels to get care for Mum; it's an unnecessary additional stress. That's not even including the emotional stress and the state of us when we did get that diagnosis and we knew there was something wrong with Mum. To this day I don't think I fully emotionally processed that I'm slowly losing my mum every day because I'm just on caring mode whenever I'm with her because the system isn't very supportive of allowing me that space to do that because I don't get help from the system. I feel like I'm fighting the system regularly. All the time.

Is your mum still living in her own home?

R: Yes, my brothers had to move in. The consultant who made the diagnosis was excellent. He said, we don't know how soon it will be that

she'll lose capacity to consent, so I advise you to get legal-appointed status. Through his guidance I got legal power of attorney for health and finances, so out of our family, I'm the one that does all the care arrangements. Me and my younger sister, who lives next door, do her personal care and my brothers do the shopping, feeding and other stuff. Because of our cultural upbringing, my mum would not allow my brothers to support her with her personal care.

I felt more comfortable talking to the hospital consultant who was Asian, saying to him, yes, we are in the home all the time with Mum, you know what it's like with Asian families, this is how we are. We've noticed the change, and it wasn't that I had to prove myself. He just accepted it whilst with the GP, who is white, I felt like constantly I had to prove, when did it happen? Suddenly because I can't put a date, time and log of when it happened he's like, well, did it really happen? He started questioning me. I was the one that was interrogated. It was unnecessary. It put more stress on me.

The hospital consultant was very helpful. He said, one thing you might want to consider is what impact this might have on her physical state and whether you guys can support. We all work full-time so we all had to manage the care around our jobs. He said, you might want to seek support from social services. Even though I work in the healthcare system I didn't know enough about the social care at that time, so I rang all the relevant numbers. It took ages for someone to come out and do an assessment, months.

Eventually I had to go back to the GP and ask them to refer to the social services because we couldn't do a direct referral, for whatever reason. I think I might have even gone back to the consultant and asked him to write a letter and he was very supportive. When the social worker came over, she was a lovely lady, I still can remember her face. She went through the social care assessment and she asked who was supporting the care and I said, well, right now we all are but we wanted to see what was available. I'm really worried, especially about the touch point during the day when we're all at work, whether she'd be all right at home alone and I'm a bit concerned about that. So they said, well, we can provide carers to come in and do some touch points. I was like, oh, right, okay, so Mum doesn't speak English so it would have to be someone that can communicate in Bengali because, especially with her dementia, she gets withdrawn really, really quickly, and they said, we can't guarantee that.

I was like, oh, okay, right, well, I don't think that's going to work then because she will feel very afraid and she might react towards that. I said, okay, can you make sure it's going to be a woman? She said, no, we can't guarantee that either. I said, well, my mum is a survivor of domestic

violence. My dad was very, very physically violent towards her so if you're telling me that a random person – they said, they can't even be consistent with who arrives – so you're saying a random person, who could be a bloke, could arrive at her home, let himself in, that's just not going to work. It's going to put her in such a state. She doesn't even let her sons as men come near her.

There followed a conversation about Rabiya's mum's earlier life.

R: My dad moved abroad to Bangladesh. At the point he left was when I was in secondary school and that's when Mum got diagnosed with clinical depression. It all deteriorated then. My younger brother and sister were still at home, so I was caring for them and caring for Mum at the same time.

Basically Mum got diagnosed with clinical depression and that was it. She was just on tablets. To be honest, thinking back now, I am surprised that no further questions were asked, especially when there were three children at home under the age of 16 – I was 14. Mum was on her own by then, and my older three siblings had already left home by then.

So your mum's had a really hard life, hasn't she?

R: Yes, and with that comes all the kind of cultural kind of expectations of women as well. So the way my mum's been brought up, it's been the woman who feeds and looks after the family, et cetera. There is a deference to men. I mean, that is the reality whether I accept it or not, whether I agree with it or not, that is the reality, so there are certain things my mum would not ask her sons to do, even though they would be willing to. When I realised we couldn't get any carer support, and the social worker was very direct about it, and I'd prefer her to be direct about it, but once again, I was quite frustrated with the system because I thought, to be honest, if we're talking truly about individualising person-centred care, you basically are saying: a) my mum couldn't get a diagnosis for a number of years and b) now you're saying she can't get care because the system is not set up to support her in that sense. And there was no personal budget option.

Rabiya goes on to talk about caring for her mum after the diagnosis of dementia.

R: At that time also caring for Mum was getting quite intensive. I was getting through quite a difficult period because my siblings were at the

point where they were not willing to accept the diagnosis, so I was doing the majority of the care. It was having an impact on going to work. It was having an impact on spending quality time with my daughter. It was having an impact on my health as well.

At that time, the new carer's assessment started coming through. So someone came out from the local authority and I said, well, it's quite horrific, to be honest, I feel like, as a carer, I know it's my responsibility to look after Mum, but I feel like how can the system expect me to work, pay taxes, look after my own home, look after Mum's home and pay the bills – that's just a practical aspect. I have a young child, I'm a single parent and manage all that and then look after Mum to a level where she can have a good quality of life herself. It's very contradictory and it's not supportive at all. Bless her, again the lady was very, very nice, and she was like, yes, that sounds really hard, okay, thank you very much, and off they went. They did direct me to the carers' centre but all the activities happen during the day when I'm at work. And, to be honest, I think sometimes when you're at that state you just want to be able to vent, just venting is quite therapeutic.

Around about that point, two years ago, we had a family meeting, and I just said, you guys are just going to have to pull your socks up, and that's when my brothers said, right, we will move in with Mum so we can be there all the time.

And my brothers started picking up the medication. They've been taking her to the standard appointments. It's become quite tick-boxy. I got a letter through the other day saying, your mum's due her annual dementia check. So I took time off work to take Mum in to do this five-minute dementia check which does nothing. It's just a tick-box. What I really needed, the last time I went to the GP, was a referral to the physiotherapy team because Mum needed a new walking stick and a referral to the incontinence team.

I can't go direct to either of these services. I have to go through a referral from the GP. So I need to take time off work, go to the GP ...

It's a pain because the care gets delayed further because the GP doesn't have the appointment when I'm available. I'm not available all the time because I work. If my siblings go in, the GP doesn't give them what they need. I have to go in and then I have to be quite directive and say, okay, Dr So-and-So, useless appointment, wasted your time, I just need a referral. That's exactly what I want. I don't want to talk about anything, just do a referral. Then he makes a referral. It gets clogged in the system. The incontinence referral letter got lost. It took another three weeks ...

It got to a point where I was in tears, one day when I was talking to the incontinence team administrator, and I said, I can't do this anymore, forget it. I will just buy Mum whatever she needs. I just need you to tell me based on her previous assessment what. I think the lady felt really sorry for me and she said, don't worry, we've done a previous assessment on her about two years ago ... So they provided me with the pads but again, I felt like I had to not navigate the system, I had to go underhand again. Similar to the diagnosis, I had to literally beg or cry or get something done.

Have you got an example where the system has actually worked?

R: Trying to get an appointment to physiotherapy was hell, but last week, on Thursday, I took Mum to the physiotherapy appointment in a new care centre and again, whenever it's a new place, Mum is really jittery. Two appointments had been booked before but she was not in a good state. I couldn't get her out. The other thing about appointments with services – let me just quickly say this so I don't forget – if you cancel an appointment they get really arsey with you but I say to them, when my mum has dementia if I know she's in a poor mental health state, there's no point in me bringing her to the appointment because she will not engage. She won't even get in the car for me.

Sometimes I say, do you do home visits, because you coming into that space I can manage it because it's a familiar surrounding, I can calm her down, I can talk her ... because she's deteriorated over the past four years so sometimes depending on her state in the morning, she'll act quite childlike and sometimes she'll be completely fine. They don't. So I said, fine, so I eventually made it to the physiotherapist and her name is Lily. I won't forget her name because she was such an amazing person.

When she asked me the questions and I said, I can't answer that because she's got dementia so I need you to consider her physical as well as her mental state, Lily got it just like that. She said, I have worked with dementia patients before, I understand. So when Lily said, how mobile is she, has her mobility deteriorated, and I said, it depends on her mental state. Some days she just won't move at all so her mobility will be zero. Other days, if it's a bright sunny day and she's in a good mood I can get her to walk a little bit longer and can get her to move around. She's got osteoporosis and arthritis as well, quite bad and during winter periods it gets worse.

She's in a lot of pain and Lily just got it. I didn't have to justify what I was saying. She just understood. She just listened to me and she said,

I understand. I remember she got a walking stick out and it was one of those hospital walking sticks, the grey ones, and my mum looked at it and she said, I'm not having that old woman stick. She was obviously saying it in Bengali to me. I was like, oh, gosh, how can I say to Lily that she doesn't want that stick? I'm really sorry, Lily, I know this is going to sound really childish but her previous stick was black, can she get a black stick? Lily was like, oh, yes, I just was recommending this one because she can use it on either hand. I completely understand, yes, no worries. If she thinks it's an old woman's stick, that's completely understandable ... and she was just so supportive.

She just understood without challenging me about everything, which I feel like a lot of healthcare professionals do, to be honest. She just went and got the black stick. Mum then was quite happy with that and she responded well, so when Lily was doing some of the exercises with her she was laughing along with Mum, engaging with her. Mum didn't understand what she was saying but Mum could tell from her body language she was being supportive and she just responded really well and it put me at ease as well. I said, do we need to come for another appointment? She said, not unless you need to. If you need to, just contact the physiotherapy team direct. You don't need to come through the GP. I was like, that's great, that's so fantastic, and she said, if you need any advice or something, just give me a bell and we can have a chat over the phone if you don't want to bring your mum in. I just thought that was just really good.

I've not had to contact Lily again, but I feel like, if I do, I've got her name, number ... it's very rare through my mum's healthcare journey that I can pinpoint individuals that have been really supportive. The consultant is number one and Lily is probably number two.

To what extent do you think it is about your mum's ethnic background, the fact she doesn't speak English and your ethnic background, or to what extent do you think it's the kind of hopelessness of the system that is just not joined up?

R: I think attitudes and behaviours are very, very important. My husband is white. My husband is a lovely white, middle-class, very posh-speaking Oxford-educated A&E doctor. The way people respond to him and the way they respond to me is different. I was prepared to go into that physiotherapy appointment already on guard and it was beautiful just to feel that I didn't have to be on guard and all it took was Lily to introduce herself and she goes, how are you doing? I was like, oh, how am I doing? Do you mean, Mum? She goes, no, how are you doing? I was like, oh, right, I'm a bit exhausted, I had to take this day off again. This is the

third time I've tried to get her out. She just listened to me and then when she started to ask me the questions she was truly listening.

I felt like the system isn't set up to be inclusive in the services it provides to its diverse communities. I think there's almost a tightrope, being, do people think I play the race card all the time or is the system institutionally racist? People like my mum do not have access to the healthcare that people who are white will have access to because of the blockers in the system. So if we're not actively doing something to remove those barriers, we are enforcing the racist behaviour of the system.

Sometimes I go to appointments with Mum in my work clothes with my NHS lanyard on because I think I will be taken more seriously. Isn't that sad? Isn't it sad that I need to perform my professional role in order to get the care for my mum? But I do, and I feel I do because I know I'll get a better response.

One of the things that we've spoken about as a family is, what are we going to do as Mum gets older? Now in our culture, this is going to sound harsh, we don't put people in homes. We look after our elderly. Western society isn't set up to support family members. In Bangladesh the entire village will look after. It's a community thing.

Now, thankfully, Mum's got six kids. I think about all those people that don't have families and what will happen with them. There's at least four of us that can support Mum on a day-to-day basis and that's what we've just accepted that that's the way it's going to be. We've accepted that we probably won't get any support from the state that can support Mum, and we've accepted that as she gets older, we will need to rearrange our lives to make sure that we can look after her. Of course that puts strain on the relationships because, for example, I could not move away. So if I decided to get a job in Scotland I can't. We have to coordinate how we take holidays.

I think there is an assumption made that because Mum comes from an Asian background, she'll have family to look after her.

The conversation then turned to support from the GP practice.

R: If you were to ask me, is there anyone that I feel like I've connected with in the healthcare system that really sees Mum as an individual or has taken responsibility about supporting me in her care, I would say no.

She's borderline diabetic, so about every six months I need to go and have her bloods checked. She also has low blood pressure so sometimes if her blood levels are not right she passes out and she also has a rotary tear. So every six months she needs to go and have some steroid

injections. It's very difficult when it feels like you are having to navigate five or six different services at any one given time and every one of them feels like there's a problem with it. Now, it's not always the healthcare professional themselves, but getting to the healthcare professional can be a problem.

Story 23: James

We first met James in Chapter 2 when he related his experiences of becoming a dad, and how he and his partner fared during childbirth and afterwards. Before that, James looked after his mother for ten years after her diagnosis of dementia until she died. He set up a carers' support group in his local area because he found there wasn't much help and support. This enabled James and his mum to enjoy outings and holidays. After his mum had a spell in hospital which made her largely bedbound, the local health and social care agencies very efficiently arranged home care support. The care provider didn't always provide the level of care that had been commissioned and James had to push to get that put right. There were a couple of episodes towards the end of his mum's life which stand out for James which are a reminder about the need to plan ahead.

James: My dad had died when I was 17. He'd had cancer, so that was quite tough. My sister was 15. Mum was still young. She really loved my dad and she didn't want to meet anyone else because the time she had with him was really special. She didn't have that need to meet anyone else.

And then we started noticing things. The same month that my mum was diagnosed with Alzheimer's and dementia, my employer asked me to relocate down south. I thought, I can't really do that, she's in her hour of need, so I'll take redundancy. That was probably ten or eleven years ago now. I was 42 then. She didn't want to go in a care home, so I said, I'll do as much as I can to prevent that.

My sister said that she couldn't be a carer, it's not her nature. You save for a rainy day and it started drizzling a bit so I thought, right, it's payback time. She looked after me fantastically well as a little lad, great mother, I couldn't hope for a better mum, I need to look after her.

When she became incontinent, and as she deteriorated, she needed me there all the time. So, I rented out my house and moved in with Mum. My sister was at work. I got weekends off occasionally, so she would look after her ...

It worked quite well. My sister did things like bathing her and I did everything else. I maintained her dignity. She became incontinent, but I could still manage to maintain her dignity, believe it or not. It was only until the last six months of her life, when she was in bed all the time. I felt I couldn't do that. There were things I couldn't do as a son for my mum, really. That's my mum.

She was 64 when she was diagnosed. I was absolutely astonished at how poorly she'd performed in a simple memory test. It was a real eye-opener for me when she couldn't draw the numbers around a face of a clock. It was a wake-up call, really because you just think some of these things are because she's getting a bit older.

When she was diagnosed, I was disappointed with the service she got from the NHS. It was a case of, right, there's your diagnosis, you've got mixed dementia, Alzheimer's and vascular dementia, here's some tablets, come back in twelve months, and that's it. This is a massive, life-changing thing for her and for her family. We didn't know what to expect. So I whizzed up to the library to get all the books I can on dementia and Alzheimer's. All the books I could get were clinical. Where's the help about how we help her to live?

We just cracked on with it. Mum was doing okay. Then she started falling out of bed a lot. You'd just hear a massive crash during the night, she'd be on the floor. Then she became quite challenging and we had to look out for help from somewhere. Then we became aware of the carers' centre. The support there was excellent. There was a carer's assessment as well, which was great. On the back of that, we were referred to occupational therapists and they got the council to come out and fix a fantastic bit of kit. Just on the wall, and it had like an infrared beam round her bed, so that if ever she put her leg over it, an alarm would go off and it would prevent her from hurting herself by falling out of bed. You could just run and help her.

Alzheimer's Society was there as a support group. The thing about that was you were not allowed to take the person you cared for – it was only for carers – so what do you do with the person that you care for? Also, we weren't allowed to bring the cared-for person with you to the Christmas dinner, which everyone was devastated by. So, I thought, this isn't right. Everything's about risk and you couldn't do anything with the person with dementia.

We thought, right, we need something better than this. So, we set up a charitable group and we'll work round these risks. We took everyone out for a Christmas meal. That was eight years ago now and it really took off. We had good support from the older people's psychologist at the local specialist mental health service. She had a real passion to create a

group like this for years. There's no staff, there's no employees, it's all goodwill. We take people on holiday once a year. It's fab. Mum loved that. It doesn't matter if you embarrass yourself because everyone's in the same ...

The conversation then turned to support from the GP practice.

J: I was worried about power of attorney and her capacity and also her health. The GP just said, I haven't got time for that, your appointment is only ten minutes. That was all. So, he wasn't very helpful at all.

At the time, it was a case of, well you've got your diagnosis, just get on with it, really. There was no support whatever. It was only towards the end of her life, when she was on the end-of-life pathway, where the GP got more actively involved. In fact, the GPs were very good. They'd come out frequently because she got infections and things like that.

But in that ten-year time, she was hardly ever at the GP, which I suppose, physically, she was okay. But she had trouble with incontinence. That was a real difficult time. She was doubly incontinent, ultimately, but initially it was just urine that she was incontinent. A gap there was no one tells you how long you should keep a pad on or what it looks like when it's full. Then you think, well, we're not getting enough pads here to cope with her needs. Then it's a case of, well, we only supply that many. So, it's like, right, what are we doing wrong here? So, in the end, the NHS would supply so many pads a week and we just went out and bought whatever we needed.

I did think the education side to the carer could be a lot better on managing incontinence for her. Another thing that was a problem was your bin gets full very quickly. You have to apply to the council for another bin and people don't tell you about these things.

What happened with the support, it came in dribs and drabs. You had the falls team who came in when she fell. That was a real harrowing time, when she'd fall and hurt herself, because her spatial awareness deteriorated as she went along. For example, if you had a change in the carpet somewhere, she would freeze and you'd have to show her that you can actually make that step onto that different carpet. Or even on the pavement. I remember taking her somewhere for a meal and there was a shadow on the floor in the pavement, at night-time, and she thought it was a hole ... she was petrified of taking that step.

She fell and she had a fracture on her wrist. That was awful for her 'cause she lost her ability to use a knife and fork then. These little aids that came in, like a commode, it wasn't really joined up, there wasn't

like a plan. It was just like, if something happened, you had to think, who do I ask about this, who do I go to?

I could live off my savings, basically, so it didn't really matter. But I did feel a bit aggrieved that this is a chunk of my life that I'm giving Mum. She deserves it. But you do think, oh, gosh, what will I do after this? On a bit of a scrapheap, sort of thing. So, it's a worry. And I had cabin fever big time. You go from quite a demanding job to that and it's like, oh my goodness.

I thought, I'll volunteer for the NHS so that when people have just received a diagnosis of dementia, me as a carer and the psychiatric nurse will have an informal chat with them to tell them what's available, for about an hour, to an hour and a half. I produced a checklist of everything to discuss with them, like power of attorney, support groups, the carers' centre, benefits, and all the rest of it. We did that for some years.

Something that was really sad for Mum, she soon formed pressure ulcers on her hips when she was at home and I do think that could have been avoided. They got to category-4 pressure ulcers and they were really bad. Eventually, they got a special mattress for her. I thought, there's no way will they ever heal up. I mean, fair play to the district nurses, they perfectly healed. They were absolutely amazing what they did with her. But if that could have been avoided, it would have saved the NHS so much time, effort. So, the preventative side, maybe they could have given her a mattress straightaway, or told me, look, you need to think about getting this mattress because she's at risk of this.

I felt like I'd let her down there because this had happened and they could have prevented that. You think of the time and effort for those district nurses to come and do that for months and months.

In the August, she had cellulitis in her leg, which meant she had to go into hospital and they put her on antibiotics. She's in there for probably about six or eight weeks. I was there every day with her. She couldn't really talk much, and the food would come, the plate in front of her, and then she was left to do it. So, I had to go in and feed her, every mealtime.

I stayed with her all day and then my sister would go after she'd been to work, for an hour. That's when they said, look, she can't mobilise now, she's going to go home and stay in her bed, basically. So, she had a hospital bed at home with a mattress that moved to prevent her getting pressure ulcers. Then she got a package of care.

What was excellent was when she was discharged from hospital, everything worked fantastically well in terms of the staff at the hospital. The council's social workers arranged that package of care so quickly and so

well and got the bed in there, got a care company who would come out ... 'cause she had to be moved for her pressure ulcers as well – four times a day, I think it was. They'd come in four times a day, move her, change her dressings, et cetera. She lasted another six months.

Then one day, she was very ill. I got up in the morning, she was obviously in distress and she'd been sick, like coffee grounds or something like that, 999. Then it's a case of, right, she's on a DNR [do not resuscitate order] anyway, which she agreed she wanted? But they did anyway take her to A&E, they were fab. They couldn't even take any blood 'cause her blood pressure was so low and ... beepers going off all over the place. She came through again, and she got home and then lasted another three months at home.

So, what difference did it make to you and your sister when you found that the care was so well organised between the hospital and social care?

J: The healthcare professional and the social worker met with me and my sister in the hospital together. While Mum was in there, the social worker had done a lot of fact-finding about our situation. Then on the actual day of discharge we met there and talked about what's going to happen. Everything that they said would happen, happened. I was amazed. It was just like, wow, this is so good. We'd had nothing before. We can actually go out, and things like that, and not worry about Mum, she's going to be all right.

Although it was fantastic at the start, what we soon found ... She was commissioned to have two carers, first thing in the morning, lunchtime, about five o'clock, and then ten o'clock at night. Frequently, you'd find either only one carer would turn up ... there should be two people to move her safely ... or there might be no one turn up. That's when I thought, someone's paying for this and we're not getting the service that we've been expecting here. So, a few times I marched off to the care provider and said, well, this is not on.

The ladies who were providing the care was fantastic, they were rushed off their feet, they always did a great job, we got to know them well. It was just poor management or not enough staff, basically, at the care provider. But when you keep banging on about it to them, she got what she was entitled to, but only because I kept going on. If you were a carer who hasn't got that time or capacity to do that, you could be walked all over.

Can I ask about – if it's not too hard and difficult – what it was like in the last few days of her life?

J: The district nurses started coming in a bit more frequently. For Mum, it was the same, playing music for her, talking to her. At the end I used to give her fluids by a syringe, to keep her lips moistened all the time 'cause they were very dry. Food, she would just have anything that was full of sugar, basically. Her swallow wasn't very good. So everything had to be thickened. Then it was just keeping her hydrated and with some amount of food. But the last three days or so, that wasn't important. The nurses said, don't worry about that. What is important is about keeping her comfortable. There were all these drugs prescribed that were sat in a cupboard waiting and they had to be checked every now and again. At the end she was put on a syringe drive with morphine. Literally, that was in the morning and then she passed away by two o'clock.

One thing I would have done differently is for me and my sister to sit down and discuss what we both wanted for her death. Because I made the assumption that my sister would want to be there with Mum when it finally happened, wrongly, and she didn't want to do that. I was on the phone to her, saying, look, this is it, you've got to get here as quick as you can. Of course, she starts crying. I was thinking, gosh, you've got to get here, I don't want you to miss her and the chance to say goodbye. Whereas I didn't know that she was happy with how we'd left it. If we'd have had that discussion, I wouldn't have been in as much of a flap at the time.

Story 24: Sheila

Sheila cares for her husband, who has dementia. She describes the battle to get a diagnosis and care in place with little support from the GP. They used her husband's private medical insurance to access medical consultant advice and monitoring.

Sheila: He is 85 ... he has been diagnosed with dementia, probably Alzheimer's, and now secondarily with Parkinson's disease ... he's been diagnosed more than ten years. When we first went to the GP he clearly felt I was worrying unnecessarily and that the concerns I was expressing were normal for a then 74-, 75-year-old as in forgetfulness, and reluctance to get engaged with the activities that he used to perform quite comfortably. So I got nowhere with that, so I had to invent another symptom.

I gave new life to previous symptoms that Brian had had. He had problems with his heart, he had atrial fibrillation and he hadn't had any episodes for a few years, but I felt that this was another route into further

exploration. So I took him back to the doctor and said I was concerned that he was having increasing heart problems and wondered if there was something could be done. It was at that point that he was sent off for testing and he was diagnosed.

Later on there was a crisis in which he fell over and dislocated his shoulder. At that point we ended up within the radar of social services and at that point I was aware that there were resources I could tap into. Everything that I've discovered, I've discovered on my own. I didn't know who the gatekeepers were, the signposters. I now am aware that there are useful people but I often discovered them fairly randomly: an article in the local paper offering some sort of carers' support ... coffee meeting, for instance ... which I attended and then found there were other resources that I could access via a very efficient carers' forum. It's all been really random.

I became aware of things like memory clinics, which I understand is a sort of euphemism for a general one-stop shop, which I heard about and I thought would be quite useful to go and check that out. I did think it was good as a one-stop shop because you saw a nurse, a physio, an OT [occupational therapist], who all gave you the big picture. I thought it was jolly useful. But logistically it was a nightmare. The local hospital were having repairs done at the time. I had to drop B off in his wheelchair at the entrance and then drive for ages to park. By the time I got back, somebody had moved Brian. So we didn't do it again. The logistics were too much. But it was, you know, I thought there was potential. But we did have a private consultant who met some of the broader needs or certainly was more able to signpost.

Is it the same GP that you've had all this time?

S: We changed the practice only a couple of years ago when we moved to a new location. Brian had had that previous GP for some years. I think I could say we had no support from the GP. Brian was very fit and healthy; we rarely needed to see them again. Having got ourselves into the system and found a very good private consultant, we were then a bit out of the loop. I can't remember really going back to the GP after that, although I did get an amazing letter at one point from the practice asking me to rate the support that I was being offered by the practice in relation to being a carer for my husband ... I had to reply to that: no support, what support?

However, the new practice then made a new appointment. Something like patient coordinator, who came visiting us at home, spent an hour with us filling in the form, and I felt she had a great potential

to be very useful and certainly it felt that this would be a very useful channel for me. I have actually used her a couple of times. I phoned her up when I needed advice, information, help, and although didn't have the answer then, was very prompt in getting back to me ... I felt there finally was someone who I could just ring up and ask for support. Yes.

Story 25: Kauri

Kauri's dad died recently of pancreatic cancer. There had been some delay in getting a diagnosis, which was finally made after a second visit to A&E. Kauri goes on to narrate many episodes of excellent care and support given by the hospital and the GP, including a three-month hospital stay and end-of-life care supported by district nurses, visiting hospice staff and GP. The main challenge for Kauri as the prime carer was managing the differing demands of the wider family during this difficult time.

Kauri: In March last year, my dad was diagnosed with pancreatic cancer. He had been suffering with symptoms from October, mostly to do with sickness, nausea, and that had got progressively worse. He did go to see the GP in October, because he was complaining of pain in his back. They did an ultrasound, there was nothing obvious showing. He just thought that he was on his feet quite a lot. He was a picture framer, so he was very active in terms of this job, and he just thought that he was wearing the wrong footwear, and it was getting cold so he just put his back pain down to a few other related issues. The sickness got worse, so we got to a point where after eating he would have to go and be sick because he just couldn't keep the food down. The period of time between sickness got shorter and shorter. He went for a number of tests as an outpatient in December and January and they didn't show anything untoward. On 15 February he was very ill and was being sick a lot during the day and my younger brother decided that it was just ridiculous: he needed to go to A&E. He'd actually been to A&E two weeks before and they hadn't found anything and had suggested that he just carried on with the tests that had been arranged through an outpatient appointment.

So Dad went into hospital on 15 February, and he stayed in hospital for three months. It took a month to diagnose, and that was because of the position of the tumour. The endoscopy and the colonoscopy showed nothing. The initial CT scan didn't show a great deal, so a biopsy was done, but because the area was so inflamed the results of the first biopsy

weren't very clear at all. So we had to wait and completely clear the stomach so that a second biopsy could be done. All through this time Dad wasn't eating. So from 15 February he wasn't eating at all. He was drinking a little bit but no food was being consumed. It was a very scary time for him. He was not used to being in hospital at all. He had run his own business for thirty-seven years and was very used to being in his shop, in his little community, very well respected, very well liked. So to go from that to being in a hospital bed was just a complete shock to the system. It was a complete shock to all of us as well.

He was 68 at the time. It turned our lives upside down as well. I was very fortunate that I could work from home and be very flexible in terms of what I did and take time off. My younger brother took time off from his job as well and started picking up bits and pieces at the shop, because we'd still got a pipeline of customer work.

And most of our customers are very understanding. They still have pieces of work that they want to give us, gifts or something, so we needed to keep on top of that, so myself and my younger brother did that. Mum was just very concerned about what was going on. The care overall that he was receiving was good, but it was very frustrating because we didn't know what was happening. I took it on myself to be the point person for the family and the consultants. I would go to the hospital on a daily basis outside of visiting hours so that I could see the consultant and be there when the consultant did their rounds with Dad.

Dad was very clear that he wanted somebody to be with him, and the consultants got to know us quite well because literally the minute visiting time started I was there and I was there throughout, and when Dad was first admitted he was on a gastro ward, and I think visiting was something like twelve till seven, so it was for the majority of the day. I just asked, can we come in and talk to the consultants? And they said yes. They were very accommodating in that respect, and Dad was in a bay of four, so he wasn't in a side room or anything. But we were still very aware that there were other patients around, so after the consultant had done their rounds we'd have a little chat and then we'd go off and get a coffee or something and Dad would have a little snooze, because he wasn't sleeping very well. We weren't there as a permanent fixture, but we did make a point of being at the hospital at about nine, 9:30 every day in the morning, so that we could catch consultants.

It made a huge difference for Dad. It really reassured him. My dad speaks English, he understands English very well. But it just helped him knowing that there was somebody else there listening. And I would always make a point of making sure that Dad had understood what the consultants were saying. The consultants would talk to Dad, and if they

talked to me I would direct them to talk to Dad, because I'm just there as a secondary, I'm just there to listen. I would always make sure that Dad understood and had the opportunity to ask any questions, so it didn't become a conversation with me as his daughter; it was still a conversation with Dad as the patient, I was just there to help and support him. We'd have a little think beforehand if there were results of a test that we didn't understand or something, and we'd have a little chat beforehand and we'd write down some questions. So I constantly carried a notebook around with me, and encouraged Dad to write down questions when they came to his mind as well so he didn't forget them.

I probably know most of the consultant gastroenterologists at the hospital now, and they were all very accommodating, very helpful. One in particular who did the biopsies, who came to tell Dad the results of the second biopsy, was very interested in Dad's care, to the point that he wasn't the consultant on ward that week but he still came with the consultant who was looking after the ward to give Dad the results of the biopsy, because he also wanted to get to the bottom of it. At first they thought it was a treatable cancer, but once they did the second biopsy they understood that it was pancreatic. They didn't tell us the stage at the time, but then I spoke to the clinical director who was on ward rounds the week that we found out Dad's diagnosis, and he was very direct with me and basically said stage three, nearly stage four, you're looking at three to six months. So in terms of sharing a message with me they were very direct, probably because they knew I could handle it. They were still direct with Dad. When we had the diagnosis – I will never forget that. Mum, my aunt, me and Dad, in the cubicle with the curtain drawn, so, interestingly, not in a separate room. Other patients could hear. And we were devastated, obviously. At that point I think I just had to put the diagnosis to one side because I'd got family really annoying me to be honest.

Wider family asking constant questions. I've got an aunt and uncle in the States who are clinicians and they were constantly asking to speak to the consultants here and I was saying no, because they're not oncologists. My uncle's a GP who specialises in diabetes, and my aunt's a diabetes nurse, so – sorry, no. There's probably a lot of relationships in my wider family that won't be the same, won't be as open, won't be as engaging, because I was very clear from the start that any conversations about Dad's care included Dad. So there were no side conversations with the consultants and anybody else who might have a medical interest or background or experience. Because, as far as I'm concerned, Dad's the patient, this is happening to Dad, it's not happening to anybody else, so if that conversation doesn't include Dad, then it's not happening.

And how was your mum, as the other very close person to your dad, with that approach that you took?

K: My youngest brother and my mum were completely supportive. My other brother less so. He had his own agendas. He took it upon himself to communicate to the wider family when we didn't even know what was going on, so we weren't ready to share information, whereas he was the first one to pick up the phone. And that continued.

Our family is practising Sikh. There's a very large Sikh community in XXX. Really helpfully, some of the nurses speak a little bit of Punjabi to be able to converse with their patients. That was really nice for Dad to hear. There was one male nurse in particular on one of the surgical wards that Dad was on and he would converse in Punjabi, and Dad would teach him correct pronunciations. There were other Sikh patients on the ward that would get to know Dad, and actually Dad was able to converse with them when their English might have not been so good. So he was there to help translate ...

The hospital knew that I was always the one there to help them with any questions about Dad. They also knew that if I asked any questions they were genuine questions, and I was collating information and trying to get answers. He had two stomach bypasses. Dad's main concern was that he couldn't eat, and so – regardless of anything else – he wanted to be able to eat. So the consultant agreed to do a stomach bypass. That basically replumbed through into the stomach so that they bypassed where the tumour was.

Unfortunately the first bypass didn't work as well. So only five weeks after the first operation Dad had a second more complicated bypass. And then two days after that he haemorrhaged. I'm convinced that it was partly due to the stress of having wider family come and visit. Dad always put other people first. So family would come and visit and his main concern would be, so what are you going to eat tonight? Make sure you eat, don't leave without us feeding you. They'd come to visit him and he would be more concerned about making sure that as a family we were hospitable and looking after them.

I have an aunt and uncle who live in Kent; they're very unsteady on their feet. They insisted on coming and visiting but would not let me know in advance. So on the day that he haemorrhaged they turned up, and we'd told people that he was undergoing surgery. He's two days after having a second major stomach operation, he's not up to visitors. He got so, so upset. He sat down with my aunt, she was in tears, he was in tears, and he said, look, this is not right, you can pick up the phone and talk to me, you do not have to come and see me, this is not helping. And that evening he haemorrhaged.

We rushed back to the hospital. The ward wouldn't let us in. They knew that we were there. One of the nurses, she was just doing her job, but she could have probably been a little bit more empathetic. And we could hear him. We could hear him being ill, and I was trying to ring the ward to find out what was going on as we were driving, and the ward telephone had been given, coincidentally, to the man in the next bed as my dad. A patient answered the ward phone. This is probably at about 9:30 at night. Bless him, he said, oh, I'm really sorry, the ward staff are dealing with an emergency so they're a little bit stretched. I said, yes, I think that emergency is my dad.

We probably waited outside the ward window for about an hour. They let Mum in first, then they let me and my younger brother in, and every five minutes or so Dad was throwing up blood. It was awful. The trust instigated their major haemorrhage procedure. One of the nurses on the ward was very young and afterwards she said that this was the first time she'd ever been involved in anything so serious. It seemed like it took forever for the on-call gastroenterologist to appear, and it was somebody we'd never seen, and she was umm-ing and ah-ing and Dad was like, you need to do something, I'm in a lot of pain here. Some useless junior doctor appeared to take blood from Dad to work out what his blood group was, and in the meantime Dad's saying, I'm AB positive, I'm AB positive. Because they decided at that point he needed a transfusion.

And all of this – it's probably like eleven o'clock at night – the rest of the patients in the ward are trying to sleep but there's all this commotion going on. And they can hear everything. So Dad's not moved to a side room or somewhere a bit quieter, this is all on a bay with probably five or six patients. Dad ended up going in for an emergency procedure. He had eight units of blood that evening. He went to ICU. It was probably the longest evening of our lives. We literally stayed at the hospital all night-long whilst he was in surgery, and then waiting for him to be taken into ICU. Luckily he was transferred out of ICU back onto the surgical ward into a side room the following day. Only two weeks after that he was discharged home, after a three-month stay. He went in on 15 February, he came out on 15 May.

In general, the consultants were very accommodating with our requests, which personally was very helpful. So I didn't have any battles. The nurses, in the week, during the day, absolutely fantastic in terms of the number of nurses available and the response time if Dad needed something. At night and at the weekends Dad would say that he could tell that they were doing their absolute best, but they were stretched.

There were some nurses that Dad liked more than others. Dad celebrated his birthday on the gastro ward on 16 March, and all the nurses organised a cake for Dad and they signed a card and they sung happy birthday to him. We were so touched. It was such a wonderfully generous thing to do. We've got a picture of all the nurses with Dad.

And he really put the effort into building that relationship with the people that looked after him.

Kauri then talked about when her dad came home after the three-month stay in hospital.

K: He was referred to a hospice for palliative care. They are absolutely fantastic. We were assigned a palliative care nurse that came to start with on a weekly basis, and she was as concerned about us as a family as she was with Dad and his care, and she made it very clear that she was there to look after all of us and support all of us. Mum and Dad's GP was very engaged as well. Mum and Dad have been at that GP practice for thirty-four years, got a really good relationship. The lead GP for palliative care was very frustrated that it had taken so long to diagnose the problem, and she made the extra effort to come and see Dad on a regular basis at home and to make sure that he was okay.

We got the impression from all of the team at the hospice, as well as the GP, that they genuinely cared about Dad and us. So between Mum and I, we looked after Dad at home. So Dad was mobile. He decided that he was going to stay in our spare room because that was nearer the bathroom for him and it meant that he would get a good night's sleep and Mum would get a good night's sleep in her room as well. So we moved a few things around and got Dad comfortable in there, and he was very self-sufficient to start with.

I took it upon myself with my youngest brother and my mum to devise a little chart of food, and we would between us manage what Dad ate, and we would try lots of different things. Some things he liked, some things he didn't. So we did whatever we could to try and encourage him to eat. And it wasn't helped by family asking questions like, do you feel hungry, so what's it like not having eaten, and clearly ridiculous questions. Some of my family have zero tact. All the time we're managing Dad coming home, we're still having to deal with the wider family who are saying he should be having chemo, and have you looked at this treatment and have you looked at that treatment. And at that time he wasn't strong enough for chemo.

We had an oncologist appointment for the end of May because they wanted to wait until Dad had fully recovered from surgery before

considering options. And at that point Dad was offered a very low dose of chemo and then had an infection which meant a return to hospital.

During all of this my younger brother had proposed to his girlfriend, and they decided to bring the wedding forward to July. So whilst we were planning an Indian wedding in three weeks, we also had to deal with the fact that Dad was back in hospital again for the third time. He wasn't eating as well by now, so my ideal of six very small meals throughout the day was becoming more like three or four because Dad was sleeping a lot. We felt very guilty waking him up to give him food.

But he fully enjoyed my brother's wedding. It was in a Sikh temple. We'd arranged for a little side room, we'd taken a foldout bed, a duvet, a heater. It was in the middle of July but the weather wasn't fantastic. Dad didn't need any of that. He drew on all of the love in the room to get him through the day, and he was as proud as punch to see his youngest son get married ...

He started to have bouts of very low blood pressure, and that caused him to black out, and that was very scary for us. And all of the time we are still looking after him at home, Mum and I and my youngest brother. We are getting more support from hospice. So the palliative nurse is probably coming twice a week now. The GPs may be coming on a more regular basis to help alleviate symptoms and trying different things like increasing pain relief. So Dad's not on morphine or anything at this point. He's still on a combination of paracetamol and co-codamol, but we're just changing the combination slightly. But the dips in low blood pressure are starting to concern us. And he is sleeping a lot more. We persuaded him to have a hospital bed because it's more comfortable for him. He's very reluctant, but we persuaded him that that's the right thing to do. So that suddenly arrived without much notice, so there was lots of moving of furniture. But he's a lot more comfortable.

Two days after my brother's wedding the GP and palliative nurse did a joint visit, and they talked to us about anticipatory medicines. So in the event that sickness might be uncontrollable or Dad gets really agitated there are four particular medicines that can be just kept at home and administered by syringe by the district nurses. They're there if they're needed. So we had the conversation about that and those were requested. Our local pharmacist is also a family friend. They literally are in the next shop to Dad's shop, so they come and tell my youngest brother, who's now running Dad's business for him, about these and help him understand the point at which they might be needed. So we're getting a lot of really helpful advice.

First week of August, Dad has a fall in the bathroom because of the low blood pressure, and it knocks his confidence, so he's not venturing

downstairs at all now. He wants to stay upstairs. And we're trying to encourage him as much as possible. He loved his walks in the garden. Mum and Dad have got a really nice garden. But he was having none of it. He wanted to stay upstairs.

Coming up to the August bank holiday, Dad's not coming downstairs now. He's had a couple more falls, and he's sleeping a lot more. Hospice are providing a night-sitting service, which is fantastic, because Mum is now sleeping in the same room as Dad and had been probably since about the middle of July, just so that she's nearby if he needs anything. And she refuses to let me share that burden with her.

It's probably three or four times a week, depending on the need of others that they're looking after as well. And the night-sitters are so caring and kind. Yet again Dad is making sure that they're okay. There was one evening in particular and this lovely sitter turned up and Dad said, oh, we've got a chair in the corner, nice comfy chair, you make sure you're comfortable, would you like a tea or coffee, we've got some doughnuts downstairs, would you like a doughnut? And we're like, who's looking after who here? That was just Dad. He just wanted to make sure that everybody else was looked after.

It was around August bank holiday that we decided actually that we might need the anticipatory medicines. The first injection just completely wipes him out for nearly forty-eight hours.

My dad was one of eight, and my mum's one of four. We've had a few visitors over the bank holiday and they've seen how poorly Dad is, and actually he's getting worse. And my aunt in the States wants to Facetime to see Dad. My dad has never liked Facetime. This request comes through my aunt in Solihull. I say no to her, and she says, well, we'll see what your brothers and your mum and dad think. I said, fine, have the conversation. And this was before the GP comes to visit. The GP comes to visit and we have a private conversation with her, myself, my brother and Mum, and we tell her how stressful it is. At this point there's lots of family round constantly and it's very difficult to focus on Dad. My other brother isn't helping. He is taking daily calls from my aunt and uncle in the States and insisting that they speak to Dad and waking Dad up when he's asleep and it's just not helping in the slightest.

The GP said, well, would you like me to go downstairs and talk to them? So the GP comes downstairs and she has a very blunt conversation with some of the family who were there that basically goes along the lines of: these are the last days of his life, this is the time where his immediate family should be spending that valuable time with him. She talks about this Facetime request and says that's utter nonsense. She says that immediate family are going to need a lot of support so the best

thing you can do is support, and she points to me and my brother and his wife, support these three and his wife who's upstairs in a very upset state because we don't know what the next few days are going to bring. And actually it was very brave of her to do that, but also because she was the GP, she was independent, she was professional, that message carried authority ...

So he's now got a syringe driver and that's administering morphine and other medication to him, and the nurses are coming and monitoring that. As we get to 31 August it's my mum and dad's forty-fourth wedding anniversary. It's a Saturday. We had lots of people in the day, and it's probably about eight o'clock. We've had a night-sitter the night before. They're very good at handing over to the district nurses as well, so they document everything in the yellow folder that's kept in Dad's room, but they also talk to each other as well. So that's fantastic because when somebody arrives you don't have to go over everything.

The evening district nurse comes and my brother and his wife go upstairs and are with Dad whilst she's just making him comfortable, and she says that she's not sure that she'll see us tomorrow because she's not sure that Dad will make it. And we just sit by Dad. The night-sitter comes in and she can see that it's very near the end. And Dad passes away about quarter past eleven that night. On his wedding anniversary. Surrounded by his family and all of our love and all that positivity to take him where he's going to.

The night that Dad passes, the night-sitter's fantastic: she phones the district nurses, they come in and remove the syringe driver, and then she makes Dad comfortable and just makes him look really presentable, and then gives us a little bit of time. She calls the 111 service, because we're in the middle of the night now, and we have to wait for a doctor to come and certify the death. So whilst we're waiting we've got some time to spend with Dad, and that was really important for us to do.

Then myself and my two brothers went to see the GP on Monday because the family GP had seen him within fourteen days, so we need that GP to sign the documentation. Unfortunately she's on holiday that day so we see somebody else. But actually that's quite smooth, and all the registration is absolutely fine. The district nurse who came on the Saturday evening and said, I don't think I'll see you, comes the day after to collect the paperwork, the yellow folder, because actually that's the NHS's property, and she's very sympathetic. It was actually quite nice to see her to thank her and all of her team.

We do have to wait for the hospital bed to be collected, and that seems to take an age. And I don't mind that so much, but my sister-in-law doesn't like the fact that that bed is in the room. She doesn't like it

at all. But I can deal with that, I'm fine with that. There is a lot of phoning people, and this is where my practical head switches on and I'm doing all of this. In the meantime we have a lot of family come to visit us. The process of grieving is quite interesting in that it's now an open house, so people can literally turn up whenever they like to pay their respects. In one way that's open, but in another way it gives us no privacy at all. So for two solid weeks until Dad's funeral we have people, night in, night out, and my mum is exhausted, and there is no chance for a lie-in for her. There's no chance of any time for her at all to process what's happened, to even start to grieve, because culturally it's the norm. It's what happens.

And there were other bizarre rituals that are done, some of which I understand, others of which have no logic or rationale in terms of explanation, so I question them, and I get told that this is just how it is. Well, that's not good enough for me. Well, it's still going to happen because that's how it is. This isn't my mother saying it, this is other people saying that.

For example, because my father has passed away, after the crematorium service we go back to the temple and there is this little ceremony where my brother is given a turban as a way of acknowledging that he is now head of the household, and with that comes the responsibility of looking after the family. Well, he doesn't deserve that, quite frankly. And I question why it's given to the eldest son, not the eldest child. Well, you're a girl, what are you going to do with a turban? Well then, let's not do the ceremony. No, no, we've got to do it. Well, what would happen if you had no male siblings? Well, you wouldn't do it. Well then, let's not do it. No, no, it's got to be done. So this nonsense ceremony is done which means nothing to me or my younger brother.

OLDER AGE AND END OF LIFE: REFLECTIONS AND RESPONSES TO THESE STORIES

Immediate questions

1. Why is it important to take account of family circumstances in organising complex care for older people?
2. What may have been the reasons for some of the different responses of the statutory agencies to Rabiya's and James's situation – both of whom were looking after mothers with dementia?

3. How important do you think was the role that Kauri played in collaborating with healthcare professionals to organise her dad's care?
4. "Sometimes I go to appointments with Mum in my work clothes with my NHS lanyard on because I think I will be taken more seriously." Why does Rabiya think that is necessary?
5. James is disappointed with the dismissive way in which his mother's diagnosis is delivered. "It was a case of, right, there's your diagnosis ... come back in twelve months, and that's it." What would a better response have looked like?

Strategic questions

1. What does Rabiya's story tell us about the intersection between racism and ageism in the NHS?
2. These stories have several examples of people "battling" the system to get better care for their loved ones. What are the wider implications of a system that needs to be "battled"?
3. What part can health and social care agencies play in managing family tensions and differences during serious illness and at the end of life?
4. These stories contain a number of examples of really good care and professional practice. What makes them good?

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