

The All-Party Parliamentary Group for Children Who Need Palliative Care

Oral evidence: how the government is meeting its commitment to choice for babies, children and young people who need palliative care

Session 2: 7 February 2018

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Members present

Dr Caroline Johnson MP (Co-Chair)

Witnesses

Doug Morris, Stephanie Nimmo, Carly Hadman and Paul Hadman

Examination of witnesses

Dr Caroline Johnson MP chaired the session

Dr Caroline Johnson MP:

Moving on to the second panel of people that have come to talk to us today. Thank you for coming and taking the time out of your busy schedules to come in this morning. I wondered if perhaps you could start by introducing yourselves? Just explain a little bit about yourselves please. Go left to right.

Doug Morris:

My name is Doug Morris. I'm a parent carer. I have a son who is 17 with spinal muscular atrophy. I'm also a trustee of Together for Short Lives.

Paul Hadman:

I'm Paul Hadman. We lost a daughter last year to Batten disease. She was six and a half. We've got a little boy who is four.

Dr Caroline Johnson MP:

Fit and healthy?

Carly Hadman:

He is, yeah. We had him tested. Our daughter was diagnosed when George was six weeks old. She got poorly when she was three and a half. We had George tested because it's a genetic disease that you don't show any symptoms until you're three. We had George tested - he's a carrier, but he won't be affected by that.

Stephanie Nimmo:

I'm Stephanie Nimmo. I'm a bereaved parent. My daughter Daisy died a year ago last week and she was 12. She was my youngest daughter. I had four children and they were seven, five and two when Daisy was born. She had Costello syndrome, which is a rare genetic disease caused by completely sporadic gene mutation, but she unfortunately had a very rare form of it. The doctors believe there was something else going on. She had complete intestinal failure and was 24/7 TPN-dependent and she died of sepsis in Great Ormond Street last year, which we were anticipating, but it's still a shock. Unfortunately, a year before Daisy died, my husband died of stage 4 cancer, so I was on my own caring for Daisy and my other three children for a year before she died. Now, after she's died I'm on my own.

Dr Caroline Johnson MP:

I'm so sorry.

Stephanie Nimmo:

It is what it is. It's the reality, yeah.

Dr Caroline Johnson MP:

Thank you for the introductions. What I want to do is essentially go through some of the very similar questions to those which we went through with the young people just now, just to get different perspectives on essentially what are the same questions. I think the easiest, rather than going through each of you in turn is if I ask a question and then if you want to chip in on that particular question. The first question is about whether professionals have been having honest discussions with you about the life-limiting nature of your child's condition and how you feel those conversations were handled by the professionals that you met.

Carly Hadman:

We had two main professionals involved in our daughter's care. We had a neurologist at the Evelina. She is the Batten disease specialist. It's an incredibly rare disease. It's five children diagnosed each year, so for a doctor to have heard of it, let alone see a patient, is really rare. We had Dr Williams and then we had our local hospital paediatrician. The issues that we had is that Dr Williams had had lots of experience, she knew that the life expectancy is 5-12 for children with Batten disease. She was quite honest with us. She said, 'It could be any day now, we just don't know.' Our local paediatrician – there was another little boy who's still with us. He's 12. He was of the opinion of he's managed to get one patient to 12, he'll get our daughter to 12. We had one side saying, 'Any day now,' another doctor saying, 'You've got at least another six years to go.' That made things quite difficult for us, because we were trying to get things in line with Dr Williams, so that we were prepared for it to be today or tomorrow, and then we had the pushback from the hospital saying, 'You're thinking about things too soon. You don't need to worry about things just yet.' They were both giving their honest opinions, but they differed greatly.

Dr Caroline Johnson MP:

I've looked after children with Batten disease in the past and it is a horrific condition to experience. There's no doubt about it. Lifespan is quite variable. In my experience – I don't know whether you had a similar experience – is the children come in and you don't know whether they're going to survive a particular remission or not, and then they go home. To some extent, there's an unpredictability there and it's a shame that they weren't more – flexible is the wrong word, but they were so definite in their prognosis, rather than more

variable. Did you find that that made your life and your family's life more difficult than if you had been given a wider prognosis? If somebody had said to you, 'We don't know, but it could be in this range.' Would that have been easier than dealing with two conflicts, do you think?

Carly Hadman:

I think it would have been a lot easier if they were on the same page. Our hospice nurse was our main supporter and she would come to the Peterborough with us and she would hear the doctor saying, 'You've got quite a few years to go.' Fortunately, she came with us down to London one time as well and listened to Dr Williams say there is a big range. It could be today, it could be six years. She heard what we was hearing, so she worked behind the scenes with Dr Williams to get us a big box of end-of-life drugs at home so we were prepared.

Dr Caroline Johnson MP:

Where is it you live?

Carly Hadman:

Peterborough.

Dr Caroline Johnson MP:

I've probably met your daughter. Who is your paediatrician?

Carly Hadman:

It's Dr Brown.

Dr Caroline Johnson MP:

Yes, so I've probably met your daughter actually. Because I was a consultant paediatrician at Peterborough.

Carly Hadman:

Oh, okay.

Dr Caroline Johnson MP:

I may have met her at some point. Anybody else have any comments?

Stephanie Nimmo:

My daughter's condition, it's not necessarily associated with being terminal, Costello syndrome. It's like any syndrome. There's a whole load of variables. I'm in touch with some families in the US where people live to adulthood and actually to about their 40s. The doctors, when Daisy was born, because she was born very prematurely, all they could say was, 'She seems to be pretty poorly. We know nothing about this syndrome. We haven't come across a child with it before.' There's a 1 in 1.25 million risk of having a child with Costello syndrome. They said, 'We don't know if she'll live to her first birthday,' and then we just kept hearing, 'She probably won't make adulthood,' as more and more was happening, but there was absolutely no timeframe. What was very clear to us was Daisy wasn't following the traditional pattern of Costello syndrome from what people knew, again, with it being rare.

While children, it's not associated with being degenerative, Daisy was clearly on a degenerative path. We were in completely a black hole. What I really appreciated from day one, Daisy's neonatologist, she was very open and honest. What was very good, she was a woman the same sort of age as me, same age children. She was just back from maternity leave, so we formed a real bond. She stayed with Daisy till she died as her named consultant. She was very upfront and said, 'I just don't know,' but what she was very good at was making sure that we had the services. She wasn't able to give us any information on Daisy's lifespan, but she found out and I really appreciated that she was honest and said she didn't know, and then I also appreciated what she did do. Things like, when Daisy was in the neonatal unit, she asked me who our favourite GP was in the local practice. Who did we have the best relationship with? She said, 'because you're going to need a really good relationship with your GP.' Daisy was in for eight weeks and she made regular weekly updates to our GP, so that when we came out, he was absolutely up to speed with everything.

Dr Caroline Johnson MP:

That's very good.

Stephanie Nimmo:

Yeah, really good. I would recommend any consultant to do that, to keep that link going with the community.

Dr Caroline Johnson MP:

I wouldn't say that that's something which would be routine practice.

Stephanie Nimmo:

No, I think it was because of this particular individual, and because she was another mum, same age as me, and she just was able to put herself in my shoes. She was the one that also referred us to the hospice. Although all we knew was that Daisy had a life-limiting condition, by six months, Daisy was being supported by the hospice, which was just an incredible lifeline, because we had no extended family and four very young children. One of whom, we didn't know if she would die next week, next year, or live till adulthood and being like the previous speakers having to negotiate adult services. We were really in a black hole.

Doug Morris:

Our experience was similar, but different I suppose in the long run. We got our diagnosis at 11 months for SMA and the neurologist at the time said, 'I'm not sure.' There's different types of SMA – type 1, 2, 3 – and he wasn't sure if he was a 1 or a 2. He said, this was in October, 'Come back in February and we'll see.' With hindsight, I think what he was thinking, is Ben going to get through the winter?

Dr Caroline Johnson MP:

If he does, it would be more likely to be type 2.

Doug Morris:

If he doesn't, he'll be type 1, if he does, he'll be type 2. In that time, we started to build up a great relationship with our paediatrician. We had specialist care from the neurologist, trying to wind up all of the relevant people in the right direction. Then the paediatrician at a local

level was giving us emotional support. In those early years, I'm not sure that we recognised that we were building up a package of palliative care. The term has never been used in any of our conversations, even for 17 years, but it's there. In that first two years, when I look back -- and I have counted -- we had 217 meetings, assessments, reviews of one sort or another, just to get a grip of what needs to be done to manage this little package that we had. When we went back in the February, the neurologist had said, 'Right, Ben's a survivor. We need to plan.' Everything kicked off after that. We didn't get involved in hospices until he was five, because of course, as parents we can do everything we need to do. We don't need help. That was our job, until somebody says, 'Actually, you need help.'

Dr Caroline Johnson MP:

Okay, thank you. Let's talk about personalised care plans. Do you feel that you were supported in helping with your children's care plan, ensuring that it was suitable for you and your family?

Stephanie Nimmo:

I think, again, because of the absolute unpredictability of my daughter's condition, she kept moving the goalposts, so it was really difficult to make care plans and it really fell on me to constantly shout. We would have stages where, at one point, she did a year in Great Ormond Street, she bounced between Great Ormond Street and our local hospital. We thought she was stable before she went in and when she came out she was out on TPN. Then the care plan had to change, because it had to become more medicalised and we had to have more health support. Then, we would try and get in place some sort of regular routine, nurses to take her to school, and then she would be back in hospital. There didn't seem to be the agility among the services to respond to Daisy's ever-changing needs. They were constantly playing catch up and me constantly shouting and on my knees, so if I wasn't the person I was, I don't think Daisy would have had the support that she got. I also strongly believe that Daisy lived as long as she did because she was born where she was. We live in South West London, so we had access to an amazing hospice who fought for us. We also had access to Great Ormond Street and she was referred to palliative services at the age of seven. Our palliative consultant fought for her as well and would come to meetings. Without those two things in place and parents who were just constantly working. I gave up a really successful career, because there was no way I could work and look after Daisy, not when you're a year in hospital. Had we not had all those things in place, I'm not sure if she would have lived as long as she did, and had the quality of life that she did, which was the absolute most crucial thing. Although she was deteriorating, and every year, it would appear new things would happen, like she would develop epilepsy, bladder failure -- it was one thing after another -- we still were able to support her wishes which were to try and get to school as much as possible, be with her friends, be a little girl, and spend time with her siblings. Obviously, with her father dying, that became even harder, but we made it happen. It was hard, it was really, really hard.

Dr Caroline Johnson MP:

It's a slightly aside topic, but do your children now get good support?

Stephanie Nimmo:

No, we are suffering from the ripple effect of living in anticipatory grief. My youngest son was two when Daisy was born and lived his whole life knowing that his sister wasn't going to be with him forever, and then to have that curveball of his dad dying as well. We are allegedly under CAMHS, but CAMHS cannot give the level of support my son needs. They are great at treating and streeting. We get support from the hospice, but for my soon, it's always too

close, it's too raw to go back to the hospice at the moment. I'm having to pay for psychotherapy support for him. That's why I used to keep fighting and fighting for the support for Daisy and to enable her to go to school and for me to have nights of sleep, which I think is a human right. I used to say, and my social workers would absolutely remember this, 'My children have one chance of childhood.' Not just Daisy, Daisy has one chance of however long or short it is, but also, my other three are as severely impacted as the child with the life-limiting condition. It's a whole family and I think the system just tends to look at the child and not the knock-on effects. It was only when my husband was diagnosed, and he was stage 4 on diagnosis, that suddenly it was all systems go and we got a big care package. They did try and say to me, 'We will take Daisy into care,' which was just horrific. It's like, we'll take that problem out, so you can look after your husband. Then when my husband died, I spent the year after he died, which was the last year I had with Daisy, fighting to maintain that care package, because I had review after review where I was basically told, 'That was an emergency package while your husband was ill.' The implication being, now he's dead, you don't need that care because you don't have to look after him as well now. Again, without our palliative consultant, she fought and fought and was on the phone to the CCG constantly saying, 'You cannot do this to this family.' Even after Daisy died, she phoned up the CCG and said, 'Do you know that the last year that this woman had with her daughter was spent fighting to maintain a care package?' Which was a really good care package, because it enabled me to have a break. It was what should be, it shouldn't have just been put in place as an emergency. It should have been what I should have had and what other families should have.

Dr Caroline Johnson MP:

I'm sorry to hear this. You're incredible.

Carly Hadman:

We were given a care package. Not through social care, we had issues with the social worker. She turned up one day and then we didn't see her for a year and then she sent somebody else who said, 'What's wrong with your daughter?' So, we had to repeat it all over again. She said, 'We'll get you some help,' and then went away, we didn't hear from her. Six months later, they sent another lady who said, 'What's wrong with your daughter? Oh yes, we need to get her some care.' We basically gave up on having a social worker. When Effie – six months before she died she had a seizure. She was in hospital for about three weeks. They still couldn't stop it, so we took her home, and at that point, the health specialist got us our care package. They approved two overnights per week through an agency, but the agency couldn't find anybody with the right skills to help with Effie. They found somebody that could do one night every other week, but they couldn't find an extra person. At one point they did send us a lady. They said, 'Chat to this lady, see what you think. She's ready to start.' She'd been working in an old people's home as a carer and I said, 'Do you have any experience with children?' 'No.' 'Any experience of seeing a seizure before?' Effie had a seizure every couple of minutes. She'd never seen a seizure before. She'd never tube fed a child who was having 52 doses of medicine through a tube every day, some through the night. She'd never used a tube before. Effie would be suctioned so she could breathe maybe three or four times a night. She'd never suctioned before. They were sending somebody that really couldn't look after Effie at all, so we just had to plod on, just do it ourselves. We had a three-year-old to look after, so we weren't getting any sleep, and having to look after a child 24/7 with Effie's needs. I don't feel we were supported. In terms of help at home, we weren't supported at all.

Dr Caroline Johnson MP:

Okay. How was it for you?

Doug Morris:

We've got four care plans.

Dr Caroline Johnson MP:

Okay! Are you following any of them?

Doug Morris:

One for home, for our continuing care service. One for school and one for the community, when he goes on short breaks and working with social care. One in our hospice. If we put them all together to create a super care plan, it would be brilliant, but of course, we can't do that because health must have theirs, education must have theirs, and that's disappointing. We've been involved in writing all four of them and I just got great at cut and pasting, because I'm just giving them exactly the same information and just popping it into the forms. That's if you can get an electronic form off them. 'Can't do that. Data sharing.' Data sharing can get in the way, not only when you're working with one service, but across services. It is used as a vehicle to act as a barrier, rather than an enabler sometimes. Absolutely recognise Data Protection Act, etc, but sometimes that can be a challenge.

Dr Caroline Johnson MP:

Now people have migrated on to this NHS.net email, that shouldn't be the case. Prior to that, there was this reluctance to email unsecure documents on an insecure line. Now with NHS.net providing a secure email for the health professionals, it shouldn't be a barrier to sharing information in a way that it perhaps was even as much as a year or two years ago.

Doug Morris:

I think we can look at a utopian world of data sharing, certainly in local authorities and CCGs.

Stephanie Nimmo:

That's just the NHS side.

Doug Morris:

They do work on disparate systems. The STP process, where they're trying to bring those sort of technological challenges onto one platform is taking time and within the NHS England mandate and the STP work, the five-year plan to overcome those technological difficulties, it will help, but when you're sharing it outside of the network with public email addresses, that is sometimes a challenge that people feel unable to do. As we're moving into transition, getting adult services to engage in this is equally challenging. Just re-echoing what you were saying about social care and health working together. The way they should dovetail with our cohort is challenging. I think sometimes social care working under section 17 in the Children Act, look at our kids and go, 'This is health,' they pass it on to the CCG or whatever and say, 'We don't know what to do with this.' There are some elements of what they should be providing. Equally, things like short breaks that CCGs could be commissioning in a better way through hospices and other sources are saying, 'Oh, it's short breaks, that's nothing to do with us,' under the Chronic Illnesses Act. You ask yourself – you're stuck in the middle trying to say, 'We need something. Why don't you just create a joint commissioning strategy

and deliver us what we need? Talk to each other.' That is often the challenge. We're the ones stuck in the middle having to deal with it.

Stephanie Nimmo:

Yeah, coordinate it.

Dr Caroline Johnson MP:

How much is the short breaks a challenge? One of the things that's very clear is that if you want to go out for the evening and you have a child who is fit and well, then you can get a babysitter to look after them very easily. Much, much, much more challenging if your child has complex needs. The short breaks should be there to support you in that, but I've seen people...

Stephanie Nimmo:

I hate the term short breaks even, because it implies the wrong thing. It should be called regular funded respite. Guaranteed. Short breaks sounds like it's a treat, but actually, I think all of us would agree, having a full night's sleep is not a treat. That is something that I constantly say it's a human right.

Doug Morris:

It's a luxury.

Stephanie Nimmo:

When we did have nurses in, my husband and I weren't allowed to leave the house, because of Daisy's TPN. The other problem – I think you alluded to it as well – is that you can have a short break package or a respite package, but then you don't necessarily have the staff to fill it.

Carly Hadman:

That's only funded a carer, not a nurse.

Stephanie Nimmo:

That makes me so angry. That was what happened to me. A child with a Hickman line on 24/7 TPN, who needs all her drugs given via infusion, cannot be cared for by a carer. A child that's having seizures constantly cannot be cared for by a carer that needs class A drugs, and yet, that's what happens. That's how they try and cut costs. They can say, 'We are giving you X number of hours,' however, it's the quality of the care that you need. We had to have IV-trained nurses and, as we know, there's a shortage of IV-trained nurses. Daisy often just didn't go to school, because if I couldn't go to school because I have one of my other kids off, because I would have to be her one-to-one, she didn't go to school. Yeah, that's how they try and get around it to cut costs is carers. You can't sleep, because you have to get up to administer ketamine in the middle of the night, or morphine, or set up an IV-infusion. They're a waste of space. They might as well go downstairs and load your dishwasher for you or something, rather than trying to care for your child. Not a waste of space, but in terms of the needs of the child.

Carly Hadman:

They can help with bed changes.

Stephanie Nimmo:

Yeah, that's about it. Or the fun stuff, like reading a story, or playtime and you do all the rubbish stuff.

Carly Hadman:

Yeah, make you miss that.

Dr Caroline Johnson MP:

What about the flexibility of those hours? I've heard people say to me, 'We get the respite time, but actually, it's got to be this particular week and that isn't the weekend of my brother's wedding,' or a big family event or whatever, which is actually when the family would like to be able to have some respite care to go to that. I've also seen over time, genuinely children have been admitted to hospital on a Friday evening and I've said to the nurses, 'What have they come in with?' Essentially, they might have got a bit of a cold, but some of it is actually about the family have got a big event and there's just no other childcare available. I understand completely why that would happen, but to me, it's a failure of the system that hasn't provided for that care. Would you agree with that?

Stephanie Nimmo:

Absolutely. What I've found, I used to complain about this, is that I could get respite care during the week and during school term time, but if I needed something during the children's school holidays, it was so hard. When you've got other children in school. Or weekends. Weekends are so hard. I used to look forward to Monday. I would have, in the end, in the last two years of Daisy's life, I had guaranteed two nights a week at the Children's Trust in Tadworth. That was funded by the CCG. That was because my husband was ill. That was a Monday and Tuesday. My other kids were in school. I had to take Daisy to one of my husband's oncology appointments, because I had no one to care for her. It was a really important appointment and I needed to be there because he needed me there as well taking notes. That's where it becomes really, really serious. Again, I think it's a balance of limited availability of the appropriately trained staff to deliver respite, and then the joined-up thinking between CCGs and social services to understand what the family needs and surrounding the family and providing a package that is relevant and responsive to their needs.

Dr Caroline Johnson MP:

We talked a little bit about sharing professionals. The other question is about whether you feel you've got someone that was coordinating, somebody that was in charge. Did you feel that you had one specific medical professional or one specific consultant that was overall in charge and you knew who that was?

Doug Morris:

Yeah, I think we've been led by two. That is the neurologist and the neurology service, which when we are having specialist appointments, specialist reviews in Oxford John Radcliffe, they have brought together respiratory, physio, gastrostomy, all the various components just to ensure that there is a coordinated leadership from the specialist perspective. In the

community, paediatricians led it and certainly, the early years, I think most of the services deferred to our paediatrician and wanted her view.

Dr Caroline Johnson MP:

So, yours has been relatively well led?

Doug Morris:

Yeah, I think it was and the paediatrician was well respected as well. Not just in respect of us, but within the community. We had a good lead. There were times when social care or education needed to step up to the plate and she did the pushing, if you like, so we were comfortable with that and that has been transferred to a new paediatrician because she then decided to retire and go skiing. Inconsiderate I know. He's taken over the mantle. As we're discussing transition now, I fear that that is going to get lost. We will start to see disparate specialist processes. Respiratory, neurology, orthopaedics start to create different channels in our normal life, or Ben's normal life, and I'd like to echo a little bit of what Lucy said, in that she's having to take over a lot of her own management, and that's something Ben's got to do at the age of 18. He's echoed his lack of interest in trying to do that, thank you very much indeed, and he's going to leave it to me. That's where we have to encourage and support agencies to not just at the tick of the clock all of a sudden switch over to Ben. Part of the process has been that we've had to ensure that people will refer to us until Ben says he's ready. I've had acknowledgement from everybody on that and I'm probably pretty certain that not very many people would be able to manage and achieve that goal, because they will be pushed by services and led by services, rather than me being a strong advocate, as I'm sure others have been too. You have to be a strong advocate, otherwise there is this sense, and I hear it from other parents, you get pushed around.

Dr Caroline Johnson MP:

How much have they started to prepare Ben for the transition?

Doug Morris:

We started planning and talking about it two and a half years ago. I hate surprises, so what we started doing is trying to understand what we were looking forward to, what we were looking into, what we've got now, what are the likely scenarios as Ben moves forward. By doing the groundwork and planning over the last two years, literally last week we had an adult continuing healthcare assessment and there was a pile of information that has reinforced everything that we get in paediatric services delivered and transferring that, to what extent we don't know yet, into continuing healthcare in adult services. His need won't change, because his needs are what he needs. What support we get, don't know yet. What I've always found fascinating is that with all the best will in the world, assessors come to speak to us, take down all the details, and they'll say, 'Thank you very much indeed, we'll take all that away and then we'll present it to a panel of commissioners who will decide.' Those commissioners have never met Ben. I find that incredible. I was just thinking about it at the back of the room. You can almost liken it to the generals leading the battle in the First World War, 10 miles from the front. It's not surprising things goes wrong. Commissioners need to get closer to parents like us and understand what we have to deal with before they can really make the right commissioning decisions. Not on an individual basis but at a wider level too.

Dr Caroline Johnson MP:

How do you feel that they prepare you for it? As well as the child learning to be prepared for making their own decisions, a parent who has been a powerful advocate, it's almost a full-time job for years and years, has to also...

Doug Morris:

We've got to let go. Absolutely right, yeah.

Dr Caroline Johnson MP:

... let go. How do you feel that the transition actually acknowledges that and helps to prepare the parent for allowing that to happen?

Doug Morris:

I've not read anything. You can fill a library with what's been written on transition. I've not seen anything that says, 'and this is what we're going to do to let the parents down.' In the planning process that I've been through so far, I probably went through that epiphany about 12 months ago. It dawned on me that while I created spreadsheets and documents and everything for what needed to be done and I was thinking, what am I going to do? I'm not going to be needed. That's when you start to think, well, okay, what am I going to do? You have to learn to let go, which is probably the right thing to do for Ben, but to what extent? And Ben has to take over.

Stephanie Nimmo:

Ben's cognitively able, isn't he?

Doug Morris:

Ben is mentally well.

Stephanie Nimmo:

He's got normal cognition. He's not got a learning disability.

Doug Morris:

Yeah, he's got a physical.

Stephanie Nimmo:

If Daisy had reached and her cohort – Daisy's peers, when they reached transition, they've got a learning disability. The job never ends with parents.

Doug Morris:

Quite.

Stephanie Nimmo:

I know parents who are parenting adults in their 40s. It's one thing when the young person – so, Lucy and Junior were able to stand here and talk about their specific experience. Daisy

couldn't have done that at that age and she would still need a parent. People with a learning disability still need people to advocate. There's assumptions made with transition that the young person will then take on speaking for themselves, but then there's this whole... and a lot of genetic diseases are associated with a learning disability as well.

Doug Morris:

When you go through the domains on continuing healthcare, there is cognitive ability within there and that is assessed, and whether or not you're subject to the Mental Capacity Act, but there is also this presumption, to a greater or lesser degree – rightly or wrongly, I don't know – that parents can actually follow. That shouldn't necessarily be the case.

Stephanie Nimmo:

Look at my situation. One of the parents died and what certainly happened to me when Daisy was alive, I was told by the social worker, in a meeting, because her care was so complex. I could not leave her in the hospital. Even in Great Ormond Street. When she was in intensive care, end of life, I had to catheterise her Mitrofanoff, because they so rarely have kids in with a catheterised Mitrofanoff.

Dr Caroline Johnson MP:

Really?

Stephanie Nimmo:

Yeah, because she had a particularly difficult one, as always. The social worker said, 'If anything happened to you, Steph, or if you needed to go and care for your children or something happened, we don't know what we would do with Daisy, because we couldn't just put her into the children's ward.' The hospice – sometimes she could not have a respite stay at the hospice because they didn't have enough trained staff, because if Daisy was in, they couldn't take her trach vent out, for example. It was Daisy or one of the complex, you couldn't have two complex children. It's almost like the more complex your child is, the more they've got going on, the less there is available to support you, because it's more expensive and there's more training needed.

Carly Hadman:

That's so much pressure on you.

Stephanie Nimmo:

Huge pressure. It was a huge pressure just to stay alive! Just basically, that was it. Talking about coordination of care – the care that she needed, so things like the specialist IVs, putting up TPN, catheterising the Mitrofanoff, dealing with seizures. She was dual-sensory impaired, so I used sign language to communicate to her. It all fell on me. There was nobody else. As I mentioned, our neonatologist, that was only because of personalities. She stayed with us and remained Daisy's coordinating local paediatrician, although she was a neonatologist, because she had the common sense to see that nobody else would just get it. She would do things like write letters that would go in to A&E, because we didn't have open access to the ward. We always went through A&E. We could never go to a GP. Everything went through A&E, even if Daisy had – well, Daisy didn't just have a cough. Everything had to be IV. Everything, just a rash that needed cream, always through A&E. There was a note that our neonatologist wrote that stayed in A&E that basically said, 'If Daisy's mum thinks Daisy is stable enough, then I trust her judgement.' That was because we worked and

collaborated together. From the tertiary hospital point of view, it was really only when Daisy was referred to hospital palliative care services that I felt I had someone else coordinating and advocating who could then coordinate the tertiary services in GOS, because as you know, they're all very, very specialist. Everyone operates very much in a silo. There's no general people. It was palliative that began that really began that joined-up thinking and then began that liaison back to the community. I don't know how much of that was actually their role and how much of that was, someone needs to sort this out and someone needs to take some pressure off Steph having to do all of this, as well as liaising with schools and social care.

Dr Caroline Johnson MP:

My understanding is there should always be somebody, but which consultant you choose, to some extent, depends on the child's condition. To some extent, depends on, like you say, the personality of the parent and who they gel with really. Everybody's different. Do you think the people that were caring for your child had the right skills and the right knowledge to be able to do so? We've heard about Junior and his [trach care 43:24] and sometimes not getting nurses that had the right skills. How did you feel about that?

Carly Hadman:

In terms of at home?

Dr Caroline Johnson MP:

At home, in the hospital, both.

Carly Hadman:

We absolutely can't fault Peterborough Hospital. It was amazing. Everything about it, the staff to the synergies.

Paul Hadman:

I think with having the other child in that hospital as well, they've had that experience. They were very, very different children, but similar. They knew they had to ask us where we were and what we would do. Yeah, they understood.

Dr Caroline Johnson MP:

They shouldn't be talking about one child with another child's parents.

Paul Hadman:

No, no, it wasn't like that. When we walked in the door and we said, 'She's got Batten disease,' because she was diagnosed in Leicester, because we lived in Leicester at the time, and then we moved. They always took the disease a little bit more... We've spoken to doctors where they've Googled, because they'd never heard of it. Having that little bit of knowledge, they've had a child in front of them, helped us a lot.

Dr Caroline Johnson MP:

I would say most paediatric places I've worked have had at least one child with that condition.

Carly Hadman:

In Leicester, they hadn't, and whenever we went into Leicester – it's normally the seizures that go along with the disease – we saw one doctor in the assessment unit go on to Google.

Stephanie Nimmo:

I'd see that all the time. I'd see Costello syndrome brought up in the nurses' station and they'd be Googling, and of course, every child is different. They may have diagnosis, but how that manifests is different and so they would look and think, oh yeah, look, there's young people in America in their 30s doing Saturday jobs and living semi-independently, but that is one absolute extreme and then we have other extremes. There's information out there, but it's the child. They're a child with the genetics of their parents that could be non-Batten disease, Costello syndrome, SMA, that could be other things, and that's what they now believe with Daisy. She's in the 10,000 Genomes Project, looking at potentially there's a mitochondrial thing going on with her. That double whammy.

Doug Morris:

Just thinking back to those early days when nobody had heard of SMA, it was almost a standard phrase with the books under my arm saying to people, the first time I've met an OT or a physio or a respiratory this, that and the other, 'Have you come across SMA before?' As much as they were saying, 'No,' their view was, it didn't matter because they were looking at their discipline, but because they were looking at their discipline, they weren't looking at the holistic view. This is why you say, 'Well, how many services do you deal with?' 'Oh, I've only got 50.' Like a competition. How many can you go for? You almost feel like you should be dealing with one and certainly, the coordination that we have in children's services, if I were to be hit by a bus today, then I wouldn't be worried looking down thinking I've got children's services to pull together to make something happen. In 10 months' time, I'm not sure the services would come together to work to deliver a package to support Ben, because they don't communicate. There isn't a keyworker necessarily to pull that together as yet.

Dr Caroline Johnson MP:

You think the children's services are good, but you're concerned about what's going to be happen?

Doug Morris:

Absolutely, yeah.

Stephanie Nimmo:

That was my biggest fear. That Daisy would live to be 18. It's just awful and she had deteriorated so much and was in so much pain, that it was clearly her time. In some ways, there was almost a sense of I'm so glad we didn't have to go through transition, because the intestinal failure team at Great Ormond Street, although she was 12, had started having initial conversations with St Mark's, the adults intestinal failure team, because they said she's so complex. If she is going to defy the odds as she keeps doing, then we better start reaching out now. I'm not the only parent that feels like that. As you know as a doctor, medical science is incredible because children that shouldn't have survived are surviving. Daisy had 12 amazing years and when you think about all the things that were going on with her on top of Costello syndrome, with her increased risk of cancer, she had cardiomyopathy, so many things, and yet she had a good quality of life and that was thanks to medical science. What's not happened is the community support services have not caught up with

the ever-prolonged lives of our young people. It's heart-breaking to see, and particularly then when you see things like Douglas House being closed down. Douglas House is the hospice for young adults once they are no longer 18. I can't remember where Douglas House is. It's in the Midlands. It was recently announced this week. It's one of only two specialist services. That's what worried me. The hospice was a lifeline. I live in London. My family lived in Wales. My in-laws lived in Scotland. That was it. I had friends who also had kids who just helped out. It was the hospice that was my lifeline. Over the years, I saw the number of days that we were able to access the hospice depleted, because they had a bigger and bigger caseload. When we first started at Shooting Star Chase, we had 18 days a year respite and then Daisy's last year we had 12. That's not even funded by social services, that's just free bonus nights. If we hadn't had our social services package that's all I would have got, 12 nights. That's to do things like take my daughter for uni open days, to go to CAMHS appointments with my son, let alone have a holiday or anything. We couldn't have holidays with Daisy. She wasn't fit to fly in the end, I couldn't do anything. My biggest fear was if she had got to the age of growing out of hospice services and over 18, what would we have done? Where would we have gone? I'd never have been able to go back to work. I've only just been able to go back to work. How would we financially have survived? Everything. There were so many ramifications of Daisy living – it was just a blessing that Daisy lived as long as she did, but the fighting and the support, that was hard and that's taken its toll. It's taken its toll on me. It's taken its toll on my kids. Clearly, I can't say that my husband wouldn't have had cancer anyway, but maybe we'd have picked up his symptoms earlier if we weren't spending our time living on adrenaline all the time and fighting for things.

Doug Morris:

When you think about hospices. Whilst we get support in the home through a continuing healthcare package, our hospice is Helen House in Oxford and it's been a great source of support for the last 12 years. To go there, home from home, etc. Our plan was to move to Douglas House. You've probably heard in the press recently that that's going to be closing down. That would have been a great adolescent young person's place to go for respite. Reasonably, I've sent off an email to social care and health to say, 'Okay, that was the plan, it's part of transition. What do we do now? What residential support is available?' I haven't heard anything yet and I Ben – just thinking about today – last night and I said, 'Given the opportunity for either end of life or any other respite support, would you prefer to stay at home, go to hospital, or go to the local adult hospice?' He didn't quite say, I wouldn't want to be seen dead in an adult hospice, but he was absolutely dead set on not going to that adult hospice in Swindon and he's devastated that Douglas House is closing.

Dr Caroline Johnson MP:

What choices did you feel you had about palliative care, the end-of-life care, and were they respected at the time it happened or was it not possible to respect them at the time?

Carly Hadman:

We spent a lot of time with each going through what happens. We had a choice of hospice, home or hospital. Each were brilliant. They went through exactly what happens. Regarding where Effie will be taken in each situation and how each situation would work. We chose home as our first option and then hospice the second, hospital as third. As it happens, with the unpredictability of patterns, I was at home with her, just the two of us, Paul was at work over an hour away, and she stopped breathing. That wasn't planned. We did have a DNR in place and in theory, we'd chosen to be at home with the DNR, but we hadn't thought that it would be just me on my own, so I did call Paul and said, 'You need to say goodbye.' You were saying goodbye to Effie over the phone, and I thought, no, this isn't what we want, so then I did start to resuscitate, and we called an ambulance. We did go to hospital and then

she did survive. She had two weeks in hospital. After the first week, her gut failed. There was no option to go anywhere else. The machine that she used to breathe could only be used in hospital, we couldn't take it home. She would die in the ambulance on the way home. The hospice was over an hour away. We don't want her to be on the A14 in a lay-by, so we felt that we had to be in hospital, but I think that was the best option for us in the end, even though it wasn't in our plan. Her needs would change by the hour. The syringe driver could be increased, whereas I don't think we would have had that care at home if we'd have been there. She was doing all sorts of strange things. Her eyes bubbled and the dehydration and things that we weren't expecting to see, so being in hospital, we had doctors on hand that could come straight in and do whatever we needed. Even though it wasn't our first choice, we did get the best care possible at the very end.

Stephanie Nimmo:

We were really fortunate. As I said, we were referred to the hospice from six months and had had some very open conversations because of the unpredictability of Daisy's condition. Then when she clearly was in a deteriorating pathway, we were referred to the hospital hospice services. Again, it was really difficult to know, because there were so many factors at play. Daisy had cardiomyopathy, so she could have had a sudden catastrophic cardiac event; or she could have developed cancer, because she had a significantly increased risk of tumours; or sepsis, and she had multiple, multiple episodes of sepsis. In my mind, I had always thought, she's probably going to die in the hospital, but I wanted her to be able to come back to the hospice in some way. In fact, when she did die, she deteriorated and was on a vent in Great Ormond Street, and I asked if we could have a compassionate extubation at home. It would have been possible if it wasn't for the fact her heart was then going into failure.

Again, the same situation, the doctor said she could die in an ambulance in the centre of London. So, because we'd had very open conversations. We had an advance care directive and we'd always said we will know when the time is right and, in a way, Daisy kind of guided us that this was her time. We switched everything off in Great Ormond Street and the palliative nurse was with me, because I was on my own and I'd had that opportunity to build a good relationship with that team. They got to know Daisy and got to understand her wishes, but then what was incredible, and so healing for my children as well, was that I then said, 'I want to take her home now because I promised I'd take her home.' Our community hospice nurse set up a cold blanket in her bedroom and the palliative team at Great Ormond Street liaised with the undertaker and the hospice team and they brought her home, so my children were with her at the end as well. We went home and then Daisy was brought home and we had her back at home. We took all the machines off and she was just a little girl. After one night at home, where we just felt we'd reclaimed her, we took her to the hospice and spent time there, and that was the most important thing. Although she wasn't alive when we brought her home, I felt I'd honoured her wishes by bringing her home. I've subsequently found out that cold blankets aren't something that are a standard option. I heard that last week a child died in Great Ormond Street and a cold blanket wasn't available at their hospice and they were told, 'If you want your child home, they need to be embalmed.' A five-year-old child, it's just horrific, the thought of that. Again, that's why I say we were so lucky that we live where we do, that we're under the hospice that we're under, and that we have Great Ormond Street. We had an incredible, long-term relationship with palliative. Although Daisy's death, while predictable, was also unpredictable, because we didn't know when or how, I still felt despite everything I gave her a good death. Although it was pretty horrific the last 24 hours, it was still a good death and it was planned, and we'd discussed, and nothing really was a surprise. We'd gone through all the various scenarios, but then we were able to actually feel that we were able to reclaim her and take ownership again by bringing her home. As I say, I know that not every hospital has a paediatric palliative team, that not every hospice is able to offer a cold blanket, that the option of coming home if your child has died

in the hospital is not always an option. The cold room at the hospice, there was already a child in there, but again, because of the cold blanket, we were able to set it up in one of the bedrooms in the hospice and Daisy was able to just be there. The post-death phase is so crucial for the family, as part of going through and getting your head around and coming to terms with the bereavement. Again, if we hadn't been under the hospice, where would we have gone? What would we have done? The thought of my daughter going in to a mortuary and me not being able to spend time with her. Her elder sister not being able to paint her nails and put on make-up and dress her in her favourite dress. I don't think I'd be able to sit here and talk to you today if I hadn't had such a positive experience of letting my daughter go and being prepared to let my daughter go.

Dr Caroline Johnson MP:

Wow. Very moving story. The final question, because I'm aware of the time, is that if the government could do one thing to help, what would it be?

Doug Morris:

I think it's making sure that through the NHS England mandate that STPs and joint commissioning recognises the need for – the children's palliative care agenda is put on their agenda. I read through 'Our commitment to you for end of life care' and the comments that start on page 39 on what the commitments are. What I drew from that is that they're all pointing towards adult end-of-life care, dementia, cancer care. Children's cancer care seems to drop off the map and I think that there needs to be a bigger push through NHS England to ensure CCGs are paying proper attention to the children's palliative care agenda. Not only support in holistic care, but through the hospice movement and other sources, pulling together in a sensible way. Another example of that is, where it's not happening, I was in a meeting in Swindon recently and a guy was presenting their data strategy for the next five years. They're going to be doing a fantastic exercise where they're going to be sharing their CSR with the CCG, with social care, and with the local hospice. It was the local adult hospice. I pulled the chap up and I said, 'Excuse me, and what are you doing about contacting children's hospices for palliative care for children?' He said, 'We're not looking at that, because there aren't enough of them.'

Dr Caroline Johnson MP:

Okay. Thank you for that. Mr and Mrs Hadman.

Carly Hadman:

I think personal care at home, there needs to be proper funding for the right type of carers. Nurses rather than healthcare assistants. In time as well, the initial 10 hours a week that we had, it took us over a year to get that, even though it was promised, and they did say, 'Employ somebody and we'll pay you back,' which we couldn't just employ somebody, and we didn't have the means to pay ourselves. Who's going to work for us as a carer and be paid in a year's time when we get funding? So, I think the right level of care and the time. The other thing is, our four-year-old needs counselling. He's been left – I think it's post traumatic stress he has. It looks like asthma attacks, but he doesn't have asthma. He's worried that the angels are going to come down at night and take him away like they took his sister away, because that's his reality, so he does need some proper support. We've been told that once he goes to school, that's when the NHS can step in and give him counselling. Same with our hospice. They said, 'When he turns five, we can offer counselling.' We have found a local charity that has a play therapist there to see once a week, but I don't think that's enough to cover his needs.

Dr Caroline Johnson MP:

And he's three now, is he?

Carly Hadman:

He's turned four.

Dr Caroline Johnson MP:

Just turned four.

Carly Hadman:

Yeah.

Paul Hadman:

Just to add that I thought, certainly with Effie, her needs changed very rapidly. It was almost all go when she needs, I don't know, whatever it may be, a new chair, 'Okay, we'll get you an appointment,' and that would be how many weeks down the line?

Carly Hadman:

Three months maybe.

Paul Hadman:

Yeah, and then they come out, assess it, and she'd already changed from the initial conversation and booking the appointment. Then by the time the chair turned up, changed again. You're chasing your tail all the while and we were constantly on the phone trying to gee people up and making sure.

Carly Hadman:

Trying to get [inaudible 1:04:32].

Paul Hadman:

Yeah, if you're lucky. But I don't know whether there needs to be almost two tracks. Whether that's right or wrong, I don't know, but certainly, with Effie's changing needs very rapidly, I'm guessing other children are maybe not changing needs as quickly as Effie did.

Dr Caroline Johnson MP:

Not keeping up.

Paul Hadman:

Whether there needs to be two tracks, I don't know.

Dr Caroline Johnson MP:

Fast track?

Paul Hadman:

Yeah, whether that's fair or not, I don't know, but certainly, that was a big problem. People just could not keep up with her. All the services could not keep up with her.

Stephanie Nimmo:

Literally, the day after Daisy died, I had a phone call to say that we've now had the go ahead to install some hoists in your house and I'd waited two years. This child was 12 and I was lifting and carrying her. It was the day after she died that I eventually had the sign off on the OT. That's why I spend a lot with an osteopath. I would say that early intervention with paediatric palliative care services is vital, so investment in that is absolutely crucial. The hospice support was incredibly vital and that was at no cost to our CCG or social services, but they leaned very heavily on voluntary services to support us and it shouldn't be like that. The voluntary services should be the icing on a well-formed cake of support underneath and that's just not there, so it's starting at the basis to have that foundation of good support and then voluntary services wrapping around. Commissioning voluntary services, not just relying on them constantly to give their services for free, because much as the statutory services are creaking at the seams, so are the voluntary services. Seeing hospices close down is just not acceptable, absolutely not, and I just really feel that there should be some more guaranteed funding given to hospices if services are going to rely on them so heavily.

Carly Hadman:

Our care coordinator was from our hospice. She was our hospice specialist nurse. She coordinated all of Effie's care. She was the one on the phone to the paediatrician, the neurologist, the chemist.

Stephanie Nimmo:

Our CCG didn't pay our hospice any money, so in some areas they would commission outreach services, but ours that was just voluntary.

Doug Morris:

There is the sense that they're getting away with it.

Stephanie Nimmo:

Yes, yeah.

Doug Morris:

The CCGs are getting away with not funding possibly what they should be doing as statutory service.

Stephanie Nimmo:

Our community nursing team only works nine till five, if we're lucky, five days a week. They're the ones that were supposed to support me and supposed to do continuing care plans, etc. Of course, when the child has got a life-limiting condition, they're always ill on a Friday evening. Always. And we went to A&E. That's just not acceptable. We need to have more community-based paediatric palliative care specialists, because children with life-limiting conditions are living longer. They're coming out of the neonatal unit and surviving and we are not supporting the families and the children and they deserve, however long or

short that childhood, they deserve a childhood. It's about enabling them to have a childhood, not be patients, but Daisy to go to school and have fun. For me to look back and think, she had a childhood, despite everything.

Dr Caroline Johnson MP:

I just wanted to say thank you for coming today and telling us about your experiences. They're very moving experiences. And to say that we will take your points forward into a report, bringing it all together what you said, and making what we believe the recommendations should be for the government to move forward. Some of these problems are about people talking to each other, which isn't necessarily something government can direct, but we'll look at what the government can do to help people who are going through the sort of experiences that you've had. Thank you for coming.