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 1: 7 February 2018

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Members present

Dr Caroline Johnson MP MP (Co-Chair) and Catherine McKinnell MP (Co-Chair)

Witnesses

Lucy Watts MBE

Examination of witnesses

Dr Caroline Johnson MP and Catherine McKinnell MP co-chaired the session

Catherine McKinnell MP: Thank you so much for being here and thanks also for all the panel and witnesses for being here as well. And I thought maybe if I introduce myself. I am the MP for Newcastle North and the co-chair of this APPG.

Dr Caroline Johnson MP: I am Dr Caroline Johnson MP and I am the other co-chair of this APPG and also a consultant paediatrician.

Catherine McKinnell MP: And, if you would like to introduce yourself Lucy.

…

Lucy Watts MBE: I’m Lucy Watts MBE, I'm 24 and I have a life limiting condition and Molly sits beside me as my assistant dog.

Catherine McKinnell MP: Are you happy for us to get started then obviously, then, when Junior arrives we can break and do a little introduction as well and also, as already explained I will be leaving so don’t think I’m rude when I sneak out.

So, Lucy, I don’t know if you want to just say something, if you’ve got anything you particularly want to say or if you are happy for me to just ask specific questions? If we start with how professionals. Do you feel that they have had honest discussions with you about your condition, the fact that it's life limiting and, or life threatening, and how well do you feel those conversations have been conducted?

Lucy Watts MBE:

So initially we didn't realise my condition was going to shorten my lifespan and I think for a long time people kind of skirted around that conversation and it got to a kind of, came to a head and they kind of sat me down, and I mean my consultant sat me down, he sat on a bed next to me in the hospital and he just told me. but in a very compassionate way and he did explain it in a lot of detail. He talked to my mum as well, obviously my mums heavily involved but also my hospice nurse from the J’s Hospice. She’s had so many honest conversations with me over the years you know, there's no kind of things off-limits, so you know she doesn't lead the conversation, she lets me lead the conversation, she just kind of guides it so we've always had very open and honest discussions and I think that's reflected with all of our professionals we do, we are open and honest on both sides.

Dr Caroline Johnson MP:

So, when you say you didn’t realise to start with, was that the professionals didn’t realise it was the condition you had, didn’t realise that it was life threatening or that you or your family didn’t realise?

Lucy Watts MBE:

So, basically, I was born without health. I had health problems, but they went undiagnosed through my childhood, so I got on with my life despite everything that was going on and I got to the age of 14 and became disabled and I got diagnosed with the condition called Ehlers-Danlos, which is not life-limiting it's not life-threatening and it's not progressive. My condition has progressed and it will shorten my lifespan and that's when we kind of realised there's something else going on and that's when they kind of sat me down and said look we don't actually expect you to live another five years but I'm still here, but I think that conversation itself sounds like a very bold statement to say, but it was done in such a way that he was kind of saying to us, you know, it is going to shorten Lucy's life span, it is going to you know, get worse, and my mum kind of said, well you know, how long have we got, and he said I wouldn't expect you to see five years but it was just the way he said it, he was so supportive, it was just he spent a lot of time with us just talking to us, just spending that time with us, letting us talk and I actually think that was a lot better because a lot of results come in, they gave a diagnosis, they walk out, whereas he actually spent that time answering our questions going through everything and that was really powerful. Same as my hospice nurse, she's always been upfront and honest with me, you know she had conversations with me when we thought my life was going to end any time, we've had conversations where you know, I think there's a treatment or something that might help and actually we found out it's not, she’s always been there, those conversations are always very compassionate and very kind but they're always very honest and I think I value honesty above anything else. I’d rather know what I was dealing with than someone to say something to make me feel better I just sooner know the worst-case scenario and be able to deal with that.

Dr Caroline Johnson MP:

So, have you been supported to develop like a personalised care plan and based on what your preferences are and how you will be looked after?

Lucy Watts MBE:

Yes, so the hospice have done a lot of conversation, I've had care plans from my social services but the kind of more holistic care plan came from the hospice. We had a very in-depth conversation, we talked about you know, where I wanted to be, what I wanted done, what I would and wouldn't want to happen so I haven't actually put anything in place yet, because I haven't made that decision, but those discussions are down on paper and they know what my wishes are, they know where I want to be, they know where I want to be cared for, they know who I want to be care for by, and actually those conversations and that care plan are very reflective of me, and actually what we did is, she wrote everything down for me and then sent the care plan to me to read through so that I could make sure it was my words so it wasn't just that she listened to me and wrote it down, she then sent it to me so that I could check back and kind of go through it and make sure it was exactly what I wanted it to be.

Dr Caroline Johnson MP:

So is this care plan for now and on a continuing basis or have you also discussed end of life care plan and what you want to happen and how you want that to happen? Is that something that you have discussed as well? When you said you haven't quite decided, is that where you are at?

Lucy Watts MBE:

So basically I've got the general life care plan and that's got kind of a statement of my life as it is now, but the end-of-life planning, I've got my preferred priorities of care, so where I want to be cared for and who by and I've got preferred place of death so if I do plan to end my life where I want to be, I am on the local end-of-life register so that if anything does suddenly deteriorate then it's flagged up that we've got kind of the generalised care plan, that kind of changes over time. We've got this end-of-life plan that I think has been changed a couple of times but actually although I have my own advance directive and decided that actually I don't want this or I don't want that, actually my wishes and where I want to be and where I want to be cared for are written down.

Dr Caroline Johnson MP:

Does that make a big difference for you that that is in place?

Lucy Watts MBE:

It does, it's peace of mind more than anything I know that wherever I go whatever I do, you know if you phone for an ambulance and it's a life-threatening situation then perhaps I don't want to be in hospital, we've got this document to show them. If you know I go to a consultation or something like that I've got care plan to refer back to that actually says, you know, this is what I want, this is where I want to be, this is who I want to be cared by, and actually that's really important, and I think it comes back to peace of mind. I know that whatever happens that care plan is there so everyone will know my wishes.

Dr Caroline Johnson MP:

Do you think they are respected in terms of your needs and your wishes and respected and reflected in the care you receive in practice?

Lucy Watts MBE:

Yes, I mean I've had to fight for a lot of the care packages, things like that so it has been a battle, but in terms of actually having the care plan it's really useful because it's all in one place and actually you can share the same care plan to any kind of professional you encounter. You can send it to the continuing health care team or social services or a consultant or if you're going to be admitted to hospital you can send it to them so everyone, so actually it's kind of like everyone knows where they stand. I've had to fight for my wishes, I won't deny that. We have had to fight at times and there's been times where they've wanted to put me in hospital, I've not wanted to be there, but actually we've always been able to come to a mutual agreement for example if I need antibiotics, if I can stay at home or have them at home, so actually I'm home rather than hospital and it's actually I think it's more of a conversation starter so I can actually say that these are my wishes what can we do and then together we can actually work out a reasonable and agreement on both terms.

Dr Caroline Johnson MP:

Can I ask how old you are?

Lucy Watts MBE:

I'm 24

Dr Caroline Johnson MP:

Do you think it’s known as adults that that’s easier because you are able to have more autonomy than what you would like to have than when you are a child?

Lucy Watts MBE:

I think so, I think it's probably easier because I can speak for myself because I make my own decisions whereas obviously as a child my mum was making my decisions and actually you know transition to adulthood was a horrendous time for me, you know it was horrible, but actually it's given me a lot and it's giving me that autonomy, and you know, I always say you know what, my mum is still a part of all my appointments, all my meetings, everything, but it's me that makes the decisions and I value that autonomy and the fact that I'm respected for what I say. I think in paediatrics they don't always take the young person seriously because they think all the parents got the overriding decision but actually I would be believing you should involve children from as early as possible in their care and their decisions, because then for me, I didn't get involved in my decisions and I've got to transition to adult and it was a sudden, you know, leap into the unknown for me, but again I still got mum with me but it's me that makes all the decisions and I'm respected for that and actually I'm listened to and actually what I say is valued.

Dr Caroline Johnson MP:

Do you think, are there professionals that have the skills and the knowledge, in the event, that you know, it shouldn’t always be you that has to advocate for your care that sometimes you have trust the professionals too? Do you think that there is that connection between the health and social care system that it's joined up enough and that we've got professionals that can also meet your wishes even if you're not the person advocating for them all the time.

Lucy Watts MBE:

I mean there is a big disconnect I will say between health and social and even down to between inpatient and outpatient treatment, so actually it's quite hard to get a seamless transition between all these different places but I think things are joined up better than they were that's when I first transitioned in 2011 but it is hard. I've got my mum who can advocate for me if I can't speak for myself and that is really important, but actually my professionals are very good at stepping up to that role, they know what I want, they know what my life wishes are, what I want to do with my life and actually I go to my appointments with my professionals and they’ll say to me, what do you want out of this appointment, and I'll say my part, and they'll say, well we want this out of this appointment and then we sit there and we work out how to achieve all of these goals, and it's a team effort, so actually they understand me implicitly, but also the hospice, my hospice nurse has always been a fantastic advocate. She’s come to meetings, she's liaised on my behalf, so actually I've got me as a first port of call, my mum, the hospice, but any of my professionals are fantastic at being the advocate when they need to be.

Dr Caroline Johnson MP:

If there could be one thing that could be improved, do you or from your experience that would make a difference for other people as well, that the Government could do, what would that be?

Lucy Watts MBE:

I’d say make funding less of a postcode lottery because it really is who you are, where you live, what you have in that area when I'm very fortunate we have the adult hospice, the hospice at home service so we have that support but actually you know, we didn't find out about that through the professionals we found about that through Googling, and actually there's no kind of communication, but also it's just that postcode lottery. Then my CCG don't fund the hospice, they never have done, so they’ve had to do my care for free, obviously that's not sustainable and the CCG are quite happy for the hospice to step up when I need them but they are not happy to them fund them for what they give. So, it’s a postcode lottery.

Dr Caroline Johnson MP:

Do you get any social care funding through the local authority?

Lucy Watts MBE:

No I'm fully health funded under continuing health care so it's all NHS funding, but you know they're not interested in funding at this, I think someone saw it as it's a bit expensive for what it is. I think that's their words. I don't think they understand really what that hospice is, it's not just the hands-on care, is that liaising, that advocating, that support having someone at the end of the phone 24/7 that you can talk to, having that backup you know if we were in a crisis situation you can phone the hospice and someone will talk us through it, they'll make phone calls, they'll do this, they’ll do that, so we've also got that backup because otherwise it's home or hospital but you've got home hospital, hospice hasn’t got a building their our backup plan.

Dr Caroline Johnson MP:

Did you have a particular professional that co-ordinates the care?

Lucy Watts MBE:

This is always an issue I see one of my consults as my main consultant but actually they don't do a lot of organising so I don't have a key worker. The hospice used to fill that role but as they’ve got busier and obviously the funding situations, they can't be to the same degree as they were when I was 17 and they were smaller, so actually it’s us, you know it's us that's coordinating everything when I think it's exhausting actually.

Dr Caroline Johnson MP:

When you were a child in the paediatric department, did you have a specific person coordinating your care there.

Lucy Watts MBE:

Not really, I had my general paediatrician but no one really coordinated the care that was down to my mum and we did have the district nurses and we had a social worker but again it was all this fragmented kind of support, so they do so much but not do everything, so much we've never had a land key worker that could coordinate my care it's always been myself or my mum.

Dr Caroline Johnson MP:

I find that, I did some research on this more than a decade ago and find it really disappointing to hear that you felt that you haven’t had a single, usual consultant in charge of coordinating all of that and certainly, I don’t know whereabouts in the country you live but in some arears that’s clearly happening, and some arears it’s not and it should be happening.

Lucy Watts MBE:

I mean I’ve got a fantastic team but it’s us that’s going between them. When I go to an appointment I take letters from everyone else because you can’t rely on them being sent to them, it’s exhausting it’s constant fighting.

Dr Caroline Johnson MP:

You are clearly very able individual, very strong, not everybody is in that situation.

Lucy Watts MBE:

I feel very lucky to have that support.

Dr Caroline Johnson MP:

I’m quite interested as well in that experience you had in transitioning between the child and an adult, in health terms, you said that it was a very difficult time and obviously it’s a difficult time in many ways, but for you obviously it was a particularly challenging times for your care. What could be done to make that transition better?

Lucy Watts MBE:

So I went to see my paediatrician a week of my sixteenth birthday, he said, I’m discharging you, so I had no adult team, no adult consultant, no nothing to move on to. I was on tube feeding and was quite medically unstable at the time as well so I literally had nothing, so we went from you know, being having the children's ward, having the paediatrician and having this kind of network around us of paediatric professionals to then nothing. I had a district nurse follow on us into the adult services but no consultant to oversee my care so actually we fought to the first 18 months to two years to get a team of consultants and that was us, that was looking up, finding out you know, asking for referral, there just wasn’t any continuity and another thing for me is, I went from one admission on a children's ward, my mum was allowed to stay with me 24/7 you know the very different ethos in children services and then the next mission I was on an adult ward with 5 dementia patients, there was no TV, there was no distractions no internet signal, no nothing. You know a 17-year-old that never did experience an adult ward before it was terrifying, and actually I found the staff didn't understand why I wasn't just a little adult if that makes sense, I was a young adult, but they just thought I was the same as everyone else and actually I needed support and it was the first time I was making life-or-death decisions on my own and that was it was terrifying Then my mum wasn't allowed to be there except her visiting time so I was completely alone making decisions on my own without that support and without understanding. No one cut me any slack, if I wasn't sure no one kind of treated me with anything, not saying I wanted anyone to mollycoddle me but just to be more gentle, more supportive, to actually say Do you need someone to sit with you Lucy whilst a consultant is here, do you want your mum to come and sit with you while we talk to you? There was none of that.

Dr Caroline Johnson MP:

And if you thought that was something that would happen, what sort of age do you think that would happen because young people are, we hear on the news that in one respect they want to be treated as adults earlier and in the other respect they want to be allowed to have support for longer? What do you think is right? What do you think the right sort of age would be?

Lucy Watts MBE:

I mean cut a 16 to 19 but I think I mean in other countries now some children's will stay up to 25. I think sometimes having that option would be nice but I think the biggest thing for me is not necessarily the age of when someone transitions but when they're ready developmentally appropriate, when they've been supported, when they've had that education - you know from age 12-13 involving them in their care, teaching them about their condition, helping them to make decisions, you know, maybe see professional on their own for once and actually accept it's not necessarily the actual age but the actual amount of preparation they've had and the development at the appropriate age. Actually it's really important because I was bright articulate but was not ready because I hadn't been prepared and if I'd been prepared it would've been far, far less scary.

Junior Jimoh

Sadly, it was not possible for the APPG to record and transcribe Junior's oral evidence. However the following notes summarise his contribution:

- Junior is 25 years old and has had a tracheostomy for six years.
- Junior's life-limiting condition resulted from being physically attacked when he was younger. His condition was recognised after he began to lose his voice and feel tired on a regular basis.
- Professionals did not know what was causing his symptoms. They were open and honest in trying figure out what was causing them.
- Junior was supported in developing care plan. However, professionals caring for him are not following it. They send random carers to his house without telling him. Nurses have been sent to him in the past who have not had the skills to care for his tracheotomy.
- The professionals caring for Junior began to discuss an end of life care plan with him, but this has not been completed.
- Junior does not feel that his needs and wishes are respected by the professionals who care for him.
- His care agency provides him with "random carers" who Junior is not comfortable with. They fall asleep when they should be watching him. This frightens Junior. He feels uncomfortable around carers he does not already know.
- Junior feels that no one tells him anything. He has to fight for himself.
- Two consultants are in charge of Junior's care – there is supposed to be just one.

- Some staff don't interact with him and make assumptions about his condition.

- Junior said that the government could make sure that professionals and services respect his wishes. He said that he is not asking for much, just for people to get to know him before they start to care for him.

- Junior sees his consultants just once a year. He has infections up to five times a year, when he needs to see his GP. He is not confident that his consultants really know what is happening.

- He feels that his situation has recently got worse. This has affected his mental health. He has received care and support for this, but it has been inconsistent.

- In his own words, Junior is “fed-up, because I'm not seeing a change.”