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 6: 14 March 2018

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Members present

Dr Caroline Johnson MP (Co-Chair).

Witnesses

- Lindsey Barron, Integrated Children's Commissioner, Luton Council and Luton Clinical Commissioning Group.
- Julie Bayliss, Consultant Nurse Paediatric Palliative Care, Great Ormond Street Hospital Foundation Trust.
- Professor Bernie Carter, Professor of Children's Nursing, Edge Hill University.
- Rachel Cooke, Bereavement Service Manager and Joint Manager, Child Death Helpline, Great Ormond Street Hospital Foundation Trust (representing the Royal College of Nursing).
- Dr Helena Dunbar, Senior Lecturer, School of Nursing and Midwifery, De Montfort University.
- Dr Sue Neilson, School of Nursing, University of Birmingham.

Examination of witnesses

Dr Caroline Johnson MP chaired the session

Dr Caroline Johnson MP:

Perhaps we should go round and do some introductions to start with. Lindsey, can we start with you and go clockwise.

Lindsey Barron:

Hi, my name in Lindsey Barron, I'm an Integrated Commissioner across Luton CCG and Luton Council, with responsibility of complex care, disabilities and palliative care.

Rachel Cooke:

I'm Rachel Cooke and my day job is at Great Ormond Street as Bereavement Service manager but I'm here representing the Royal College of Nursing on behalf of Fiona Smith.

Rachel Cross:

I’m public affairs advisor at the Royal College of Nursing, I’m here with our members as a silent observer.

Julie Bayliss:

I’m Julie Bayliss, I am an RCM member and RSA nurse consultant at the palliative care team in Great Ormond Street at the tertiary centre and I’m here as well to sit in for James.

Dr Caroline Johnson MP:

Are you here as part of your job at Great Ormond Street?

Julie Bayliss:

I’m sort of supporting the RCN because I’m actually a member of the group but also James invited me to come as well to give evidence as well.

Nikki Lancaster:

I’m Nikki Lancaster, I’m a parent.

Sophie Dodgeon:

I’m Sophie Dodgeon, I’m the observer from The Rainbow Trust children’s charity and plus I’m campaigns manager.

Dr Helena Dunbar:

I am Helena Dunbar, I’m a senior lecturer at De Montfort University and lead the children’s undergraduate program there. I’ve also just completed a PhD in children’s health care.

Dr Caroline Johnson MP:

Great. Well done!

Professor Carter:

I am Professor Bernie Carter, I’m from Edge Hill University and among the research that I do focuses on children with complex healthcare needs and fits in with the whole of the inquiry and I’m a children’s nurse.

James Cooper:

I’m James Cooper, I’m public affair and policy manager at Together for Short Lives, and we provide secretariat services to this APPG.

Dr Caroline Johnson MP:

Indeed. Thank you.

Okay, so how we've done this is we've got a list of questions. Essentially, we're going to go through to look at different aspects of it and the way it can work is there's a hot seat goes to Lindsey first if that's okay?

Lindsey Barron:

I've got the short straw here

[Laughter]

Dr Caroline Johnson MP:

You did, yes! Sorry. We'll go through these first but if anyone else wants to chip in then they can.

So we'll start with, in the end of life care choice commitment the government says, I'm going to quote them, 'To support high quality personalised care for children and young people, commissioners and providers of services must prioritise children's palliative care in their strategic planning so that services can work there seamlessly, and advanced care planning can be shared and acted upon'. Do you feel that your council in Luton and your CCG do that?

Lindsey Barron:

Yeah. I've got some notes here so if you don't mind if I just read from them?

Yes, is the short and simple answer to the question. We've got a clearly defined strategy, with agreed pathways for referral at care which has been implemented across the CCG, the local authority and our partner agencies. Our partner agencies include the local hospital, the hospice, community nursing and provider services. We've got an established and integrated multi agencies strategic group that's responsible for driving the palliative care strategy forward. The group is led by myself as an integrated commissioner and includes service needs for children's disability, social care, oncology, paediatric hospital consultants, GP representatives, hospice professionals and our emotional wellbeing provider service that provides a bereavement support. Not all children and young people have advanced care plans but where they do exist they are communicated to and shared with the hospice, the consultant, the GP…

Dr Caroline Johnson MP:

Why don't they all have a care plan?

Lindsey Barron:

They don't always have advanced care plans. It's not always possible to act upon an advanced care plan particularly when the child's health declines really really rapidly and also, we have had some instances where parents have withdrawn consent, so we will have advanced care plans, but we are not always… I think it's really important to say it's not always possible to carry them out to the letter because there will be incidences as I've just mentioned where it's just not possible.

Dr Caroline Johnson MP:

When you say parents withdraw consent, withdraw consent for a non-resuscitation statements?

Lindsey Barron:

For lots of different things. We have had a few cases where parents had a preference for their child to pass away at home but when it came quite close to the time going, they actually said we can't deal with this at home, we would like our child to be moved to the hospice. We've worked really hard to make sure that we can be as flexible as possible at that moment that families need us.

Dr Caroline Johnson MP:

I think it's very difficult to know what anyone could want in that kind of situation.

Lindsey Barron: Some families do not want to engage in the conversation about the care plan because of everything that that means to that family. Some families are not ready to accept the fact that this is an end of life case. Some families do not want to accept that their child is palliative so if they don't have that conversation, you know, they can kind of keep deferring, deferring, deferring… I'm sure you can appreciate that, and that's the feedback from our fabulous GP who works across the community and very close to Keech and the local hospital. It is always our intention to have an ACP but it's not always possible.

Dr Caroline Johnson MP:

How far is the hospice from your patients?

Lindsey Barron:

Geographically?

Dr Caroline Johnson MP:

Yeah.

Lindsey Barron:

At least within… literally on the edge of the town. I guess if you lived the further point away you would be travelling under 10 miles.

Dr Caroline Johnson MP:

It's not difficult for your parents to get there?

Lindsey Barron:

No. No.

Dr Caroline Johnson MP:

Is this typical of what you see elsewhere?

Lindsey Barron:

In what…?

Dr Caroline Johnson MP:

In terms of that you've obviously got great services, is that typical of what's seen elsewhere?

Lindsey Barron:

No, I don't think so. I think nationally, if you look at any national media, even Together for Short Lives reports clearly documents that palliative care is not consistent.

Dr Caroline Johnson MP:

So, some areas are very good, some are less so?

Lindsey Barron:

Yeah.

Dr Helena Dunbar:

Can I just say there that I think that the strategy, certainly within the East Midlands, in terms of clinical commissioning groups, is very focused on adult end of life and the implementation of that really and I think children's palliative care isn't included in that all of most of the time.

Lindsey Barron:

We've certainly got separate strategies. We have one led by our adults' commissioner and we have our own children's strategy. We also have a transition pathway that's in both our strategies, so I think transition is another issue, big issue actually.

Dr Caroline Johnson MP:

Do you think there's any barriers that could prevent you or others from commissioning children's palliative care?

Lindsey Barron:

Yes.

Dr Caroline Johnson MP:

What are they? What would you like to do that you can't?

Lindsey Barron:

I've got a short list actually of the most… in a climate of ever reducing budgets, cost pressures…

Dr Caroline Johnson MP:

Is your budget actually reducing in money?

Lindsey Barron:

For the local authority it's been reducing year on year since austerity. Again, I think much the same as a lot of local authorities.

Dr Caroline Johnson MP:

So, your budget for your palliative care has that changed?

Lindsey Barron:

No, it’s remained the same. It hasn’t increased but it has remained the same.

Dr Caroline Johnson MP:

Okay, so your budget stayed the same.

Lindsey Barron:

Within the CCG, yeah, and then the local authority budgets have been reducing.

Dr Caroline Johnson MP:

But they’ve protected yours?

Lindsey Barron:

No, it’s not protected in any way, shape or form. No.

Dr Caroline Johnson MP:

So, the amount of money that you get to run your service, regardless of what the local authority have or haven’t got to share in terms of their total pie side, your slice of the pie has remained the same amount of money?

Lindsey Barron:

Yes.

Dr Caroline Johnson MP:

Is that the same amount of money in real terms of just the same amount of money in hard cash?

Lindsey Barron:

Hard cash.

Dr Caroline Johnson MP:

Okay, so your budgets are the same. Over what period?

Lindsey Barron:

It hasn’t changed in the last five years.

Dr Caroline Johnson MP:

Okay. If you had extra money what would you spend it on?

Lindsey Barron:

Well, the funding itself is not going to address the issues with capacity at the local hospice. We have one hospice that covers four CCG areas, they have a limited number of beds, their priority clearly is the end of life palliative care symptom control and pain management, so short breaks, respite is right down on the pecking list because they need to focus on what their priority care core offer is and they are trying to meet the needs of Luton, Bedfordshire, Milton Keynes, Hertfordshire and in some places I understand, some part of Buckinghamshire have also been approaching Keech for them to take young people.

Dr Caroline Johnson MP:

So, those children are travelling more than 10 miles, aren't they?

Lindsey Barron:

Yeah, there isn't anywhere else for them to go.

Dr Caroline Johnson MP:

So, within your commissioning group they within currently 10 miles, but other commissioning groups using the same hospice are travelling much further?

Lindsey Barron:

Much, much, much further. Yes. Much further. As I say, there isn't anything else locally. We have Keech Hospice in Bedfordshire, Nascot Lawn in Hertfordshire, Keech in Cambridge but that's an awful long way for families to travel and particularly if their family is in crisis and then you have Oxford, so you're looking at in excess of a 30-40-mile journey.

Dr Helena Dunbar:

In my study, one of my families was travelling 58 miles into the hospice.

Dr Caroline Johnson MP:

In geography I suppose it's like many things isn't it, it's the feature of the number of people living in any geographic area, because fortunately I suppose, children's' palliative care is not as common as adults and so I guess there isn't as many people requiring that sort of care. Have you seen any change in the number of people requiring it?

Lindsey Barron:

I think that one of the issues is the fact that the numbers are relatively small compared to adults, but they're so much more complex than adults and this is where I think it does get a little bit frustrating from my personal experience as a commissioner, just because the numbers are small does not mean to say that their need is not great.

Dr Caroline Johnson MP:

No, but it means the geographical, travel location presumably makes it quite difficult to provide services very close to everybody's house.

Lindsey Barron:

I guess so.

Dr Helena Dunbar:

That goes back to the kinds of models that you're trying to provide in terms of the service isn't it, and there's a difference between having a centralised service in an area or how much an outreach model that you can go out.

Dr Caroline Johnson MP:

My constituency doesn't have a hospital at all actually.

Lindsey Barron:

A hospital or a hospice?

Dr Caroline Johnson MP:

Either. Four hundred and thirty three square miles and I have neither in the area at all and so to some extent that's just a recognition of the population density I guess in the area. So, you think money is a barrier but if the budget went up 10% what would you be able to provide with that?

Lindsey Barron:

I think that's very difficult to say because the issue is when you have such a limited budget you get used to working in quite… You work with your initiative - let's stay that. So we look at how else can we support our families. Recruitment and retention of nurses is another reason why money can be an issue. If we increase our budget by 10% would that necessarily mean that Keech could recruit to that 10%? Probably not so would that be the best way of spending that additional 10%? With commissioning, clearly, you're in a cycle the whole time, you're trying to understand your market, plan what you're going to do and review and deliver, what I would like to see is more joint working. I've tried particularly hard to engage with our neighbours to have a joint strategy approach and discussions around a pool budget approach that… what could we do if we had that kind of agreement? Could we do more? If we could do more, how could we deliver it? Could we increase the care in the community? I have not been able to progress those discussions so that's been a little bit frustrating.

Dr Caroline Johnson MP:

The workforce issues, is that about the difficulty of the job, emotional stresses of the job?

Lindsey Barron:

You would need to ask the employer because I can't answer that question as a commissioner. All I'm aware of is that we have a national shortage of paediatric nurses. My understanding is that historically or paediatric nurses or palliative care nurses don't necessarily stay in that field for particularly long, it maybe that it's just too emotional, too much of a drain, I really don't know, you'd be much better to speak to a practitioner or an employer. I can only give you what I know as a national picture.

Julie Bayliss:

One of the things from the RCN perspective is we know there is roughly about 3,500 paediatric nurse shortage UK wide and…

Dr Caroline Johnson MP:

As part of the health select committee we did a… I recently stepped down from that, but we did a review of nursing workforce and the figures around shortages were very opaque in that respect in as much as we were given the shortage of numbers but then when you looked at the numbers… so I think we were told initially there was a shortage of about 36,000 or 40,000 depending of which people you spoke to, but then when we dug deeper into those statistics what we found was that actually the individual nurses were around and they were employed and doing all but 3,000 of those jobs nationally, so if you say it was 40,000 you could say 36 ½ of those jobs are actually being done by nursing staff working as either locum or bank or something like that, so the individual people seem to be there…

Lindsey Barron:

There’s huge vacancy but If I could use…

Dr Caroline Johnson MP:

… and the word ‘’vacancy again is that the numbers were… the vacancy was to find a job that had been advertised and not filled but some places were putting in adverts for jobs that didn’t exist or that were regularly put in by a trust in case a vacancy came up so there was an advert in, it was quick. Some of it was about desirability rather than necessity. So vacancy is a hugely difficult thing to…

Lindsey Barron:

It is, I agree with you, but also, looking at the competency and the skills of the workforce is key because the vacancy in our heads, as we’re hearing from around the country through the RCN, is it tends to be at the senior level, the leadership - so your band six and up. For example, at GOSH we’ve just taken on 200 junior staff, we’re seeing the impact that that is having. They haven’t got the skills or the resilience or the training behind them to deal with these palliative care cases and complex cases, so the retention of staff is really difficult.

Dr Caroline Johnson MP:

The other thing that the government didn’t have figures on, the reports asked them to provide figures on in the future, the Department of Health, is when the nurses are getting to band six, previously they would have been on the wards providing that senior level support and one of the things I’ve noticed on the ward is that the nurses when they get to that stage now have many other options that would be band seven or band eight pay that are still nursing jobs that are on the wards but work with more sociable hours mid-week, not night hours, and they’ve got practitioner-type roles, [inaudible 20:19] roles, [inaudible 20:20] development nurse, all these things that are more attractive as a role than working night shift for the same money.

Lindsey Barron:

In palliative care it costs to care doesn’t it, it’s that emotional labour and the intensity of it that has a huge impact on the retention of our staff and just basic things like clinical supervision, it’s not there for a lot of staff. Junior staff come in quite eager to join a pathway and we were talking about that the other day, there's not the path like you just suggested for them to remain so they want to stay on the ward in the leadership.

Dr Caroline Johnson MP:

No, that's the point, it seemed to me that we provide insufficient ward to the senior nurse who's providing the ward-based care, we've gone to providing more of a ward in terms of financial and working conditions for the nurse that does the advanced practice but that means we're taking the senior nurses away from ward-based care, not providing that balance of attraction. They didn't have any numbers. I'm not saying that these [bills 21:29] aren't valuable but the Department of Health have no figures on what's...

Lindsey Barron:

That's quite interesting because Health Education England were doing research and we haven't seen this. Fiona relayed to me that they looked at the workforce particularly in children and young people, but they haven't finished that report. That would be really good if we could have that. What did they find? Why didn't they publish it?

Dr Caroline Johnson MP:

I know the nursing work force thing that [inaudible 21:57] [from a simple perspective 21:58], that has recommended that the government provide these sorts of figures so that they can see what's happened to the nurse when he or she has got to band five and decided to go and find a different role. It maybe that the nurses on the ward need to be [uplifted 22:16] from their remuneration to recognise [over speaking 22:20].

Lindsey Barron:

It's about training.

Dr Helena Dunbar:

Absolutely, part of the problem is our undergraduates, student nurses aren't getting the experiences in terms of palliative care because that goes back to a capacity thing and for us at our university, we could train double the amount of cohort that we have but we can't because we haven't got the placement capacity for them so there is nowhere for the nurses to go to get experience and certainly experience in palliative care and the mentors aren't there to mentor them.

Dr Caroline Johnson MP:

Is that a feature of capacity of we've reached saturation point in the system for the ability to train people because there are only so many patients? The same with medical schools [over speaking 23:14].

[group agree, 'No']

Lindsey Barron:

That's not reached saturation or even close to saturation point I don't think personally.

Dr Caroline Johnson MP:

No? So, it’s capacity… if you think there is capacity in the system to put these student nurses somewhere to learn, so how would you develop that capacity?

Dr Helena Dunbar:

Well, it comes back to trying to retain the staff that we have got, and it is band sixes that we don’t have because we need them to mentor our band fives and our student nurses and our apprentices that are coming through, but if you fundamentally aren’t retaining your senior staff, then that’s where part of our issue is really. It goes right back as well in terms of how to care to what’s in the curriculum in terms of the experiences that our student nurses are getting, and what training they’re getting. So, from a children’s perspective, with any of our nursing curriculums we have limited times for the children’s nurses because it’s quite a generic curriculum, so they’re not fundamentally getting the key skills that we would want them to have, from our point of view our hospice in the East Midlands takes four students at a time, two from our university and two from another university. When you’ve got a cohort of 40, you maybe want that experience and two of them get it.

Dr Caroline Johnson MP:

A lot of this is that… is the hospice realistically large enough to put 40 students in without it being [over daunting 24:53]?

Dr Helena Dunbar:

You couldn’t put 40 in at one time, but certainly you could look at that but they’re not really made for that.

Dr Caroline Johnson MP:

How many more could be realistically fit? I mean, if…

Dr Helena Dunbar:

More than two.

Dr Caroline Johnson MP:

I get that, but not as many as 40 but where does that balance lie?

Professor Carter:

I think it’s surely got to come down to what capacity a service has to meet the needs of the patient’s families, for the children and the families so that they don’t compromise that care because that care is just so individualised, it’s so important, it’s so special to families that trying to mentor and support the future people that will be looking after the children and families has to be balanced against that so that you don’t take your eye off that service to families who are so vulnerable and in so much need of a really trusting relationship, that even if they know that the next generation of nurses needs to learn their priority is for their child, their family and a really close trusting relationship with the people within the hospice or the service. It’s a really fine balance everywhere within children’s nursing to make sure that what you’re giving is family centred but also modelling the best possible care that can be given and providing that window into that service, because palliative care is one of many specialities that is difficult for children’s nurses to become exposed to and therefore they think it’s more difficult than actually it is, that it’s more complex and whilst it is complex and difficult and special and wonderful, nurses who become exposed to that can realise that equally it’s rewarding and beautiful and some of the best nursing that you can ever have. Some of your strongest memories can be there but they need the nurses who are delivering the mentoring, the nurses who are delivering the care to children and the student nurses needs high amounts of support and supervision and when you start to build a new workforce you start to take that workforce away from the place where they’re working into places where they need to be taught, so there’s a huge issue of whether or not you’re moving the resources, so it’s like a complicated chess board that if you move people here so that you provide future nurses, we’re starting to rob the places that are where the care is being delivered. Families absolutely understand that, so it’s going to take years to get a workforce that is as good as we want it to be and as good as the children and parents deserve it to be and as supportive as it can be, and Julie’s got lots of things to say and…

Julie Bayliss:

I agree with what you say, I’m just thinking I totally agree. I think it’s about there’s a whole… there are lots of workplace issues, there are issues around retaining nurses within the speciality that actually moving into palliative care it is about training and nurturing them through education and it’s post registration education and it’s working with senior people in that area but it’s actually that balance as Bernie has just said, from actually the requirement at the moment of service delivery and doing that, so you might be a senior nurse doing all the doing but actually also the commitment to train as well and at a time that you need more resources and more workforce to enable you to do that because the nurses are also providing telephone on call, the complex conversations, the medicines management they’re doing, the nurses in these areas are working very much at that sort of high end level doing a lot around seizure management, pain management and these patients are becoming much more complex with the whole move of the way treatments are going, patients are being offered more treatments, there are more options for them all to the good, but it is bringing many more complexities for the workforce. I think it is about having a strategy for all, so you’re training everybody, so it’s making sure that everybody whether you’re a surgical nurse on a ward as a band five has some knowledge and skills around looking after these patients to the specialist where you are actually there for teaching and training. It needs that whole investment all the way through.

Professor Carter:

And at the senior level. Some of the conversations I’ve had with past students and people with considerable experience and considerable skills and great knowledge of palliative care, when they’re working is hospitals the decisions that they’re making and the level of isolation they can feel as a senior experienced nurse away from the support structures that are available within the tertiary centre, you could feel physically and geographically you can be a long way from help and you can be the most senior person there but still… you would be not junior, but there would be lots of other people that were more senior to you and more available of you were working within a similarly sick child or child with particular needs than you would if you were in a tertiary hospital setting.

Dr Caroline Johnson MP:

Do you think that the answer to that then is that we locate further hospice environments on the same campus site as a tertiary centre?

Professor Carter:

I think that's a possibility. One of the things that you need to think about is that all tertiary centres aren't always in fantastically good places and what we have done…

Lindsey Barron:

I don't think it's the location of the hospice that's the issue it's the staff.

Dr Caroline Johnson MP:

Saying they're geographically far and feeling isolated because you don't have access…

Professor Carter:

Not all of them, but some of them are. I think one of the things that we could do is do more talking to parents and more talking to children to find out where they would like services to be placed because traditionally they've been placed in beautiful setting which may or may not be the most perfect… and maybe the setting is not the most perfect place for the delivery of these services. I think we need to not exactly wipe the slate clean, but we need to think about what services the parents and children want and need and how can we bring that map together with the services that are actually available because I think if there were the ability to engage and to swap and to integrate and collaborate more we'd have a more flexible and a stronger and more resilient sector.

Lindsey Barron:

You need nurses without borders, Médecins Sans Frontières.

Dr Caroline Johnson MP:

Who would be then also… if you had a tertiary centre there wouldn't be this, if your children needed to be admitted to the ward for this than and the other and then go back?

Lindsey Barron:

You could do another step up, step down.

Dr Caroline Johnson MP:

Well, in as much as you get children who have been having hospice care and come to the hospital for something to be done and drugs to be given or some treatment or some sort of examination, I'm not talking in the last few hours or days but before that, would presumably be possible for the… if you were co-located for staff to come to you rather than the child having to move?

Professor Carter:

That kind of takes it away from the notion of home is the best place for children to be where it's appropriate for the family. I think most families would prefer the services came to them and Lennon's mum is definitely nodding there… so there is that sense that we need to consider that the child is the centre of the care and the parents and the family. The thing that comes out of every single conversation you ever have with parents is that need to spend as much time as they can with the child as part of their family and the family is generally most a family when they're at home, so I think that has to be catered to, so rather than making people co-locate with tertiary centres we need to think about how our services can be delivered more locally and the community, the home as being the centre of the care because end of life care for the sort of children we're talking about here goes on for a long time rather than just days, it's the lifetime of responsibility and caring and trying to remain a mum as well as the carer of the child. It's a massively difficult balance to make.

Julie Bayliss:

An area maybe we just haven't mentioned yet is community nursing and it comes to your point about being at home and I think that's a real area where there are real workforce issued in our community nursing and is a real deficit and those families that have really excellent supportive community nurses that work alongside the hospice and the tertiary centre work really well, but where there are limited resources from community nurses only working Monday to Friday or Monday to Thursday, eight to four, they're very isolated out of those hours and those families have often said they will ring tertiary centres or they will go to their local hospital, so actually they end up going into local hospitals in the middle of the night because there's no one to come out to them.

Dr Caroline Johnson MP:

Though not all children presumably with palliative care needs would always have a tertiary care centre?

Julie Bayliss:

Yeah, I'd say it varies yeah. There will be a tertiary centre that they're linked to even if it's a difficult travel. Typically, the last thing that a parent will want to do is to take a child out of the home and take them to hospital. They will do everything that they could possibly do to keep that child at home. As soon as they take the child to hospital, however good the staff are there, there's a sense of being out of control, so if it's a pain management matter, they'd much rather a community children's nurse would come in and provide care for them.

Rachel Cooke:

Unfortunately, community children's nurses have been decommissioned in areas, we're hearing that, so the numbers are short and so we can't deliver 24/7 nursing care, or the teams are shrinking.

Dr Caroline Johnson MP:

The government says commissioners should consider how they structure services to ensure that they offer accessible high-quality respite and grievance support, Lindsey, how does your CCG ensure that they've done that?

Lindsey Barron:

We work, as I say, in an integrated way. So, we have a service level agreement with the local authority for the provision of overnight short breaks with other [inaudible 36:05]. We also have a CCG, through a poor budget arrangement contributes for us what's called the contract care service, where contract carers are recruited, and the child or young person will go into that carers home to have a short break within a family setting, so they're not going into a residential unit or hospice, they're going into a carers home and having their care there. We also have…

Dr Caroline Johnson MP:

Do you provide care for the families at home?

Lindsey Barron:

Through the hospice contract they have the community nurses go in and visit, we don’t commission to do care overnight say, but certainly listening to what everyone’s saying here, I’m going to take that back to my powers that be to look at what we can do there to support families outside of those… after five o’clock and before eight AM.

Dr Caroline Johnson MP:

Because one of the things that we got previously was that if a family… if I wanted to go on a night out then I might arrange a babysitter and that for these families it’s very much more challenging, almost impossible to achieve that particularly if you want to go out with your family who are [inaudible 37:30] and so the only solution seems to be a short break where you take the child to a hospice or another place.

Lindsey Barron:

We have three options in Luton. We’ve got a residential inhouse short break unit…

Dr Caroline Johnson MP:

How many days a year do families get?

Lindsey Barron:

That would vary from child to child and it would depend on need, it will depend on preference and it will also depend on capacity of whatever service the family choses. They will probably overall get less through Keech purely because of Keech’s capacity.

Dr Caroline Johnson MP:

What sort of range are you looking at for, what sort of range or average are you looking at?

Lindsey Barron:

What, of stays?

Dr Caroline Johnson MP:

Hmm.

Lindsey Barron:

Within the number of [inaudible 38:24] resource centre which is our inhouse residential unit, I think it works out on average to be… and I’ll have to come back and clarify this for you, I think it works out to be one night in two and a half weeks or one night in four and for the life of me I can’t remember, sorry I’m having a blank moment on that one.

Dr Caroline Johnson MP:

Okay. Do you provide any services where trained people will go out to the home and provide that care, so parents can literally go out for the evening and come back and have the child and do their own thing?

Lindsey Barron:

No. We don't offer a babysitting service, we don't do a childminding service. The options are care within the contract carers home, the hospice or the inhouse and residential, however if the family are known to social care they can get a direct payment and they can then use that direct payment to get their direct payment worker to go into the home to care for their child when they go out, but generally speaking that's not…

Dr Caroline Johnson MP:

Do you have that?

Nikki Lancaster:

We didn't have direct payments, but we qualified for continuing healthcare. I would get a continuing healthcare trained worker who would come and help me at home but because my son had quite complex health needs, he required hours of medical care during the day, two hours of medical care of a night and the only people that were trained to look after him were Keech hospice, me, dad, the continuing healthcare girls and the respite at Nascot Lawn, if me and my partner ever wanted to go out or take our other children away because my son couldn't leave the country or go on holiday or anything, it would be our break at Nascot Lawn would be what we would use. We had a package of 41 nights a year, so we generally used them as one weekend a month from a Friday night to Monday morning once a month, and then we would use five nights in the summer holiday as well and take our daughters away for a holiday. Unfortunately, as everyone around the table will probably know, Nascot Lawn is the only healthcare funded respite centre in Hertfordshire and is threatened with closure.

The CCG withdrew funding in June last year. We started a campaign to try and save it because those children that are using Nascot Lawn are unable to use the other respite centres in Hertfordshire because they have complex medical health needs so there's no nursing in any of the other three respite centres in Hertfordshire. We took it to a judicial review and took it to a second judicial review a couple of weeks ago and won on the grounds that the judge found it was a nursing facility, it was an NHS facility. Unfortunately, it still looks like it's going to close, the CCG still look like they're going to pull the funding and maybe hopefully work together with the LA to put some sort of nursing care into the three other respite facilities but unfortunately for the short term it means that those families that are now under Nascot Lawn have had their respite reduced too, so they're now receiving about a quarter of their package and have been since November last year. They're considering community care in that side of the county you can't fulfil the care packages so one instance that we were discussing before was that there is one family in particular who have a community healthcare package, they're using Nascot Lawn, their son has been very ill and has been in Great Ormond Street, he came home and unfortunately his dad got an infection and had to be admitted to Watford General, the continuing healthcare team couldn't fulfil the community healthcare package, the child then went into Watford General HDU because they couldn't look after him at home, not because he needed to go into HDU, but because there was no one else to look after him, there was no manpower to look after him at home so he took up an HDU bed.

Dr Caroline Johnson MP:

I've definitely seen people bring their children to a hospital on a Friday because they definitely need their respite and they can't find it any other way.

Nikki Lancaster:

That's a last resort for a parent. I would do anything not to step foot in a hospital. It would be a true last resort.

Julie Bayliss:

Parents I think are the absolute unsung heroes and they don't want to be heroes, because every time, however committed the service are and however good we try to make them the parents are constantly absorbing the lack of service. You talk to parents and they are on their third night providing, quote 'Third night of three or four days of providing 24-hour care for their child because the carers can't come or the package has broken down or whatever has happened, and you know that that would not be allowed in a workplace setting, it's allowable and it's almost acceptable and it's almost routine now that parents will just absorb those deficits within the services that we're providing and it's so unfair to the parents because they just cannot… they do it year after year, month after month and we need to know that the service that we're providing is being covered by parents who can't do anything else because they absolutely love their kids and they know that they will just go on until the last minute.

Dr Caroline Johnson MP:

The interesting thing is that when you have a baby and they're in the maternity unit, they're not allowed to take the child home until it's requiring four hourly feeds because three hourly attention is felt to be too much to provide around the clock, and yet you're providing two hourly attention…

Nikki Lancaster:

Well, hourly during the day and two hourly overnight.

Julie Bayliss:

And its vigilance every single minute of the day, the parents are never off duty. Never off duty.

Nikki Lancaster:

You can't take your eyes off them. We couldn't take our eyes of our son, ever. It was constantly…

Professor Carter:

And that's with making toast for the children's breakfast while packing the bag, which is where people like…

Lindsey Barron:

Going to the bathroom.

Professor Carter:

Going to the bath and having a shower. People like Rainbow Trust who provide a brilliant service in terms of the non-clinical care. As I was saying this morning that one of the stories that remains with me from some research I did, was when I asked the mum what does the difference between having a non-clinical support worker make to your life? She said, last week she went and got the jam for tea. We had almost half an hour's conversation about that one tiny [inaudible 45:11] because other children wanted jam for their tea and she knew that should couldn't go and get jam because there was no carer, there was no support and she was kind of trapped in the house, so the worker actually went over, found out what jam the kids wanted, went and got it and that mum was then able to make tea for the kids. It sounds really ridiculous, that's the level of hypervigilance that they had to have for that and the way in which it impacts on every aspect of their lives.

Dr Caroline Johnson MP:

Do you think it's clear who's responsible for commissioning the short breaks?

Lindsey Barron:

No, is my nice quick answer to that.

Dr Caroline Johnson MP:

You don't think the government is clear whose job it is?

Lindsey Barron:

Well, I think… again, my personal observation, there are a lot of legislation about what local authorities must do and clearly where their responsibilities lie and it's all over the Children's Act and the Children and Families Act. It's not as clear when it comes to CCG responsibility and unless I've missed something and if I have shoot me glaringly around CCG responsibility for short breaks, the default position tends to fall with the local authority. The only time I've heard of a successful challenge was the Harringay case, that's the only time I ever heard of a successful about not being a local authorities responsibility to provide the short break and that was where the case was some complex it had to be a qualified nurse who delivered that particular level of care.

Dr Caroline Johnson MP:

So, you think it is clear but it's the local authorities?

Lindsey Barron:

I don't think it's clear, no. I think there's very muddied waters between who is responsible for short breaks. Now, this is why at the CCG we fund the contract care service because it is a local authority short break service but the complexity of the children's needs are such that it falls outside of a local authority responsibility, so our contract carers tend to be ex nurses or care staff who are willing to take whatever training is required to look after that young person's medical needs.

Dr Caroline Johnson MP:

Nurse and the NHCAs?

Lindsey Barron:

Yes, that kind of thing, yeah. I do think we would benefit generally from clearer guidance on where the responsibilities for CCGs fall. I know that if I'm commissioning or looking at a short break request for a child with complex health needs then we generally in Luton, have a pooled budget approach, so a local authority will contribute, and the CCG will contribute and then that way, the local authority are meeting their duty to provide the short break and the CCG are meeting their duty to provide appropriately qualified staff.

Dr Caroline Johnson MP:

How do you decide how to pool that in terms of slice of budget?

Lindsey Barron:

It comes through a section 75 agreement, some for contract care service for example it's pre-agreed between senior management what the contributions will be, but we take an integrated personalised approach as far as individual cases coming through. There are a number of ways that you can slice the pie, you can do a 50/50 split because this is what the need of the child is, the local authority are paying 'X' and the CCG match that payment making sure that payment is sufficient to meet the needs of that particular service. We have had some situations where the level of complexity of the health need is up here, so we've done a 75 contribution and social care have done a 25 but it's not set in stone and we look at each individual case.

Dr Caroline Johnson MP:

Does that mean the parents get nothing while there's a fight about who pays for 'Y'?

Lindsey Barron:

There is never a fight.

Dr Caroline Johnson MP:

No. You always have an easy amicable agreement?

Lindsey Barron:

I'm an integrated commissioner, I argue with myself. I am commissioner for the local authority and I'm commissioner for the CCG.

Dr Caroline Johnson MP:

So, you make the decision and therefore they?

Lindsey Barron:

I don't make that decision and I'm not solely responsible for the decision. There's a panel of professionals.

Dr Caroline Johnson MP:

Because, I do have a constituent whose written to me who's basically caught between a local authority saying it's not their job and the CCG are saying it's not their job and the patient is sat in the middle.

Lindsey Barron:

I've heard that a lot.

Dr Caroline Johnson MP:

But in your area, having an integrated care commissioner which is you, and you've basically taken you on. Do you come under pressure yourself from the local authority and the CCG to act in their… you know, our budget is quite tights, could it be a bit more of the other one?

Lindsey Barron:

We're always under pressure with tight budgets and I don't think it matters whether it's the local authority or the CCG that you're representing, that is the way of the world today but what happens is they'll present a case, or a case will come to panel for consideration and you take into account everything that you know as a commissioner, so what are your legal obligations? Well, by being my local authority commissioner then I know that I've got the Children's and Families Act, the Children's Act etc., and as I say, very hard and fast legislation. From the CCG I look at what the NICE guidelines might be for this particular… there will be lots of different [national 50:55] things that I will take into consideration. We then bring that to panel and discuss it as a panel what's best for this child and family and then we'll get the agreement and then we'll get down to the, are we 50/50 in this split or 60/40. Moving forward, I just want to say we are looking at a resource allocation system that will give us indictive budgets for health and social care and as we move towards a more integrated agenda and certainly with the personalisation agenda, that will give us an indictive budget from which to start putting a package of care together.

Dr Caroline Johnson MP:

So, more recently it's become the Department of Health and Social Care as opposed to the Department of Health when you talk about the personalised budgets. Do you think that will help you in terms of providing the care for patients?

Lindsey Barron:

Yes, it will help providing we have the services out there to deliver the care. Personal budget is only as good as the services that you've got.

Dr Caroline Johnson MP:

The other thing is NHS England children's palliative care funding currency. Tell me about that?

Lindsey Barron:

I can't tell you very much about that because we don't use it.

Dr Caroline Johnson MP:

Why don’t you use it.

Lindsey Barron:

The CCG opted not to participate in the initial pilot, I forget why sorry. So, no, we haven’t looked at the currency and haven’t used the currency. We are working with a very fixed budget and one provider so there’s not been a lot of wiggle room. I also have to say that I have read through the tariff documentation a few times, I personally find it very confusing. I didn’t understand really what it meant so my apologies, but it meant nothing to me.

Dr Caroline Johnson MP:

Okay. Tell me a bit more about the personal budgets. How do you use those?

Lindsey Barron:

In Luton we have two families who wish to have a personal health budget, everybody else has opted to stay with the commissioned provider. Various reasons, some don’t want change, they like the continuity of care that they have currently got and they’re happy with the provider they currently have, and we have some families who financially are not in a position to be able to manage their own budget and set up a bank account and don’t want to use the third party that we have available for that. So, sorry could you go back and say your other question, I’ve forgotten what you said at the beginning?

Dr Caroline Johnson MP:

Have you assessed any of the local health economic benefits of commissioning children’s palliative care? So, by having good palliative care, are you saving money in other areas of the health economy?

Lindsey Barron:

I’ve not even considered that correlation, sorry.

Dr Caroline Johnson MP:

I think they’re looking at in terms of if they’re going to do palliative care are there less admissions to hospital, are there less admissions to intensive care, are… you know…?

Lindsey Barron:

That’s an interesting point, I don’t know if its related…

Dr Caroline Johnson MP:

Are parent’s able to… you know, does it have an effect on the other children’s mental health?

Lindsey Barron:

I was having a chat earlier on and I know this from the conference we’ve done with Together for Short Lives as well, when you have a child where it’s either continuing healthcare needs, complex health… or continuing health care the parent might phone the GP and say, ‘My child has got a cold today', and the response will be, 'You've got open access at the hospital, take them there'. So, I think yes, we could definitely avoid hospital admissions if there was a bit more awareness raising or understanding within the community.

Julie Bayliss:

It's also the children that are still in hospital, who can't come home and are there for many months because there isn't a service out there to provide that service for them or like you said, you go back in for a weekend because you have no other option.

Lindsey Barron:

We have one little on in our area who is in hospital because of a housing issue. There isn't anywhere for that child to go with the equipment. The family remained homeless while they were in hospital looking after their little baby, so I think there's absolutely work to be done about preventing hospital admission.

Professor Carter:

The position is there for the families in terms of every child that's in hospital it puts financial strain on the parents because they've got travel costs…

Lindsey Barron:

Especially the fare in London.

Professor Carter:

… they've got things like car parking costs. It's really expensive to have your child in hospital.

Dr Caroline Johnson MP:

Do any of these places tend to give parents or the admitted children…

Professor Carter:

You can do but…

Lindsey Barron:

Some but not all.

Professor Carter:

Some but not all. Families that have often gone through perhaps being two person earning family to a one person earning family and then the number of times that parents are losing money because if dad is the main earner he might actually not take some of the opportunities. It could be within his job to get promotion, but he needs to be close to home or he can't take those so there's huge economic cost for the family and…

Lindsey Barron:

Especially in parents' self-employed.

Professor Carter:

Absolutely.

Lindsey Barron:

They've got even bigger issues there, if they're self-employed.

Professor Carter:

Certainly, from some work we did with the Department of Health a number of years ago on children's communities, it's was when people were considering or not it was worth our service or not, for one family who kept a diary of the number of times that their child was admitted in the year before they went onto really good experiences with social services, they had… I can't remember exactly, it was something like 20 admissions to hospital over a number of days and then in the year that they had with the community nursing teams they've had one, which was an exceptional… you know, any [inaudible 57:39] could have kept that child out of hospital but there are healthy economic gains that could be achieved, I don't think there's ever been a really concerted effort of looking at that.

Dr Caroline Johnson MP:

And many more other gains.

Professor Carter:

Many more other gains.

Dr Caroline Johnson MP:

You're commissioning these services; how do you hold the providers to account for providing good services?

Lindsey Barron:

We have quarterly contract meetings and we look at their performance and their output, children's outcomes. We also look at quality schedule and anything new that might have come through from say NICE guidelines.

Dr Caroline Johnson MP:

This is the NICE… the quality ambitions for palliative care and end of life care?

Lindsey Barron:

Yeah, we don't literally sit there with it, but everything that we've done is built around that ambition and certainly as far as the hospice is concerned they are very up for delivering that ambition within the restraints that they've got.

Dr Caroline Johnson MP:

What other resources are available to you in terms of your commission? You've got the local authority money and the money from the CCG; do you have money from elsewhere? Do you get charitable money or other sources of income?

Lindsey Barron:

We don’t, as a CCG or a local authority. I think the hospice do, they do their own funding bids.

Dr Caroline Johnson MP:

So, when you commission the hospice service, the hospice receives additional funds that it uses to provide additional services to those that you commission?

Lindsey Barron:

We have a small budget that we use to fund Keech to provide overnight short breaks and that’s in addition to their core services funding that they receive for their symptom management and their pain management. Symptom control, sorry, and pain management.

Dr Caroline Johnson MP:

So, they’re providing the basic levels of care and then on top of that there’s sort of other bits that are provided by charities?

Lindsey Barron:

Yes, that’s my understanding.

Julie Bayliss:

Charities like WellChild have made a massive difference in both raising the profile and raising awareness about the need for children to have… or the right for children to be cared for at home as well as providing WellChild nurses who are either based in the community and linked into hospitals or are based in hospitals and link out to the community who provide services where one of their key roles is to get children home from hospital as quickly as they possibly can and then to develop really strong networks within that child’s community to make sure that any service that is available for that child is actually called in. They are one of the really strong charitable contributions to making life for children with complex healthcare needs better.

Dr Caroline Johnson MP:

Do they work all over the country?

Julie Bayliss:

Yes. They started small and they are growing, and they are [mighty 60:52] and the plan is that they’re charity funded for the first three to four years or something and then the trust picks up that funding which is always a difficult conversation at the end whether the trust will actually commit to that funding but WellChild are very…

Rachel Cook:

It’s like the Macmillan model isn’t it?

Julie Bayliss:

It is.

Dr Caroline Johnson MP:

And you've got more experience obviously.

Julie Bayliss:

Yeah, it is that sort of [pump funding 61:16] a post for three years and then really establishing that within your team which has been a great difference.

Professor Carter:

Yeah, and network across each other, they provide expertise. It's a really strong network of highly expert people.

Julie Bayliss:

And again, the model around education is very good there that actually it is the training, the trainer and then training in the community and again, I think they've got much more of a strategy around education as well that they're trying to take forward because they can see a need for it in the community.

Professor Carter:

Yeah, and they have feisty parents who are at the heart of the campaign. Again, they are supporting parents to be ambassadors and champions for making change and plans that influence government.

Dr Caroline Johnson MP:

I can see that being particularly valuable perhaps in areas like my constituency where it can be 40 miles to the nearest acute trust that provides paediatric care.

Julie Bayliss:

But one nurse won't make a difference; it's about building that infrastructure and that team.

Dr Caroline Johnson MP:

You need a rota.

Julie Bayliss:

Yes, exactly, and that's where things often fall down where you rely on one person in a post and that's where there's that sort of resilience in retaining people and that's where we sometimes fall down.

Dr Caroline Johnson MP:

So, to some extent, you need a rota that by the fact that these numbers then demand that that person provides something else?

Julie Bayliss:

Yes, and it needs to be built in, like you put a WellChild nurse or put any type of nurse in, it needs to be built into a community nursing team or into another sort of structure within that, not just stand alone.

Dr Caroline Johnson MP:

A difficult question Lindsey, if you could recommend one thing that the government or NHS England or other stakeholders could do to help you what would it be? But only one?

Lindsey Barron:

I did an awful lot of work last night I have to say, and I kept changing my answer so I'm going to stick to one and again, this is my personal opinion. Ring fence funding or palliative care. I could have given you a list as long as my arm but it's like, okay if you only want one, if you're going to make me chose one, that's what it is, ring fence funding.

Dr Caroline Johnson MP:

So, the budget that you have at the moment that you get from the local authority that hasn't changed…

Lindsey Barron:

The budget from local authority is the one that has been reducing year on year because we are in a period of austerity and the one from the CCG is the one that hasn't changed in the last five years.

Dr Caroline Johnson MP:

Right, sorry I miss understood that. So, you've got a budget from CCG that just stays the same but the local authority budget that you personally receive as your budget…

Lindsey Barron:

No, it's not my personal budget, it is the social care directors budget. She allocates a set amount towards short breaks for children with palliative care.

Dr Caroline Johnson MP:

And the amount allocated for short breaks for children with palliative care, has that fallen?

Lindsey Barron:

Yes, but so has the delivery. It's fallen because of austerity but it's also fallen because Keech has reduced capacity to be able to deliver because they have such an increasing demand from the other areas. Seven or eight years ago when palliative care numbers were generally smaller and where they were providing services mainly to just Luton and Bedfordshire, we had a fantastic short break service - oh my God, it was all singing all dancing.

Dr Caroline Johnson MP:

So, what you’re saying is that because they’re providing more palliative care services they don’t have enough space within the unit to provide any short breaks?

Lindsey Barron:

Short breaks is now down here on the pecking order because it’s…

Dr Caroline Johnson MP:

So that’s….

Lindsey Barron:

Absolutely, yeah.

Dr Caroline Johnson MP:

So that’s affected the budget because even if the money was there and the budget was the same they still couldn’t provide it?

Lindsey Barron:

Yeah, which is why when you said to me at the beginning, if you gave me another 10% of money, actually it’s not going to make a lot of difference because they’re still going to have the same capacity issues, they still have the same workforce issues, so throwing a little bit of extra money wouldn’t actually solve the situation that we are in at the moment.

Dr Caroline Johnson MP:

Have you got a large increase in the number of children requiring palliative care?

Lindsey Barron:

I suppose the way in which we’re recording has changed. On paper it probably does look like we’ve got a bigger cohort and certainly in the work that was done through Public Health England and Fraser et al, they also predicted quite an increase for Luton in particular in the east of England, much much more higher cases.

Dr Caroline Johnson MP:

So why are children there dying?

Lindsey Barron:

Good question. I’ll ask Public Health England and see what they say.

I would have said it was the opposite way around actually, I would have said they are surviving longer [agreement] rather than more dying. Our numbers are bigger because we’ve seen, say for example, a perfect example would be cystic fibrosis where 10 years ago, 15 years ago their life expectancy was lower, now they’re living well into their 40s and then with medical intervention and technology we’re also seeing our young people live longer so our numbers now… I think when I first wrote strategy the numbers were around the 50 mark, I think that was around 2011/2012 we started that and when I looked at the numbers before Christmas we were close to 90.

But also, we’re not counting some additions. This is a particular bug bear for my strategic group, why are we not counting some of the cardiac conditions, some of our cancers and oncologies? They’re still palliative but they’re not being counted. I think if we started factoring those numbers in we would see an even bigger cohort of children.

Dr Caroline Johnson MP:

So do you think you’re counting the wrong population then?

Lindsey Barron:

No, it’s not us, it’s the guidance we were given from the government that you do not include these, these and these conditions within your palliative care numbers which doesn’t make sense particularly when you’re talking about oncology.

Dr Caroline Johnson MP:

So, you actually wouldn’t necessarily include a child with oncology problem who’s got a high risk of dying in a short period of time, but you might include a child with cystic fibrosis who may have another 30 years?

Lindsey Barron:

No, cystic fibrosis is not included in those numbers, some cardiac conditions are not included in that and also oncology.

Dr Caroline Johnson MP:

Because their life span is likely to be quite long?

Lindsey Barron:

I don’t know why the decision was taken, I would really love to know who made that decision actually and why, but it causes an awful lot of conversation every strategic meeting and we’ve been having strategic meetings for six years plus.

Dr Caroline Johnson MP:

Do you think there should be a more specific definition? The think is, it’s very difficult to…

Lindsey Barron:

Of what?

Dr Caroline Johnson MP:

Of what counts as palliative?

Lindsey Barron:

No, because I think we’ve covered the definition, what I think we’re not doing is counting the children we should be counting to get a true picture of the number of palliative care cases we have.

Dr Helena Dunbar:

And I think York are working on that aren't they, that's the work that [inaudible 68:45] is ongoing and continuing to do, that demographical details, she's continuing to work on that. We have numbers now that we didn't have and data that we didn't have 10-15 years ago.

Lindsey Barron:

Yeah, that's true.

Dr Caroline Johnson MP:

I guess the question I'm asking is if the numbers are going up because the lifespan is that people are living longer…

Lindsey Barron:

Because of medical intervention.

Dr Caroline Johnson MP:

… because of medical intervention, or new treatment or whatever, is there then an argument do you feel, that some children could now be said to be not receiving palliative care because the length of life is now going to be well into adulthood to the point that… no?

Lindsey Barron:

No, we don't take that approach in Luton. If you have a palliative care diagnosis you have a palliative care diagnosis regardless of when… if you're going to pass away tomorrow or next year or 10 years' time. I would not be comfortable saying, 'Actually you're not due to die until 20 whatever, so therefore you can't have services now'. That would not sit well with me ethically, personally or as a commissioner.

Dr Helena Dunbar:

I think what we are seeing is that some hospices are having to look at their entry criteria into the hospice and as you said, the number of short beds that they're now able to provide is reducing because of the complexity of the children that they now need to care for. We have a lot more children now in the community with long term ventilation that we never had years ago, so I think that's what we're seeing in terms of the criteria.

Lindsey Barron:

Within Luton what we do is RAG rate for want of a better word.

Dr Caroline Johnson MP:

You do what, sorry?

Lindsey Barron:

RAG rate it, red, amber, green, although I expect it's more than that because we have four levels. We have the numbers that are in crisis. The numbers that are in remission or non-crisis. The numbers that are close to end of life and then the numbers that are being supported post bereavement because clearly that's the other thing about palliative care, is it’s not a straight line, it’s not a straight trajectory. Children will be really really poorly perhaps one week and then have a period where their health improves and they maintain a steady life for want of a better way, so we try to look at… Keech don’t base it wholly upon that but Keech do look at clearly families that are in crisis, families who’s child has had a rapid decline in health will take a priority over those who are stable and doing quite nicely thank you and not at the point of crisis.

Julie Bayliss:

I was just going to add that there is a growth area around anti-natal and neonatal referrals and that’s what we’re definitely seeing so now actually. We are picking up mothers and meeting them before they have their babies and working with them and going into hospices and working with them and that’s definitely been a growth area that we’ve seen over the last few years and we’ve put a lot of education into that and we can see the referral patterning as well.

Dr Caroline Johnson MP:

Do you do that as part of their decision-making process, or do you come to them after that decision that they make?

Julie Bayliss:

We hopefully through the education try and get into there earlier now and meet with the decision making and with the obstetrician and make it a joint meeting with the mother and father at that time, so yes, as early as you can to allow…

Lindsey Barron:

We have a dedicated neonatal pathway.

Dr Caroline Johnson MP:

So, you meet the mum and you say, if you continue your pregnancy then this is the sort of services you will need?

Julie Bayliss:

The obstetrician would have laid out what they’ve seen on the scan and then they will say we’re going to introduce palliative care at this point and then they talk about labour and what the options are there and if the baby survives the labour the baby could be born stillborn, what would the steps be we might move you to the hospice but there’s some great work where by meeting them there and linking to the hospice they then get bereavement support so there’s some real positive inroads there and if they survive we would do A, B or C and they would go from the ward, they might transition to a hospice, they might want to go home with the baby, so yes, that’s about all those options.

Dr Caroline Johnson MP:

That’s definitely an improvement in…

Julie Bayliss:

But what it comes to, is just to add in to you about the numbers though, it does mean that numbers are growing in that area because we get more referrals which we hadn't have done that before.

Professor Carter:

I think whichever way you count them there's clear evidence that the numbers of [carers 74:03] and children is increasing, the resource that we need to service is increasing and not only are more children surviving early on but they're surviving longer term so we've got more numbers in the system and more numbers in the system for a longer period of time and almost nowhere for the children to go to as they transition from children's services to adult services.

Dr Caroline Johnson MP:

I can see that medical success has created a large number of people in the system for a longer period of time but what's causing a large number of people coming into the system in the first place?

Professor Carter:

They're children who would have died very early on are surviving.

Dr Caroline Johnson MP:

I understand that increased survival and longer survival causes a higher number but what causes a higher number of children to be [inaudible 74:56] in the first place?

Lindsey Barron:

Sorry, I didn't hear that, what causes what?

Dr Caroline Johnson MP:

They are saying the numbers are going up and one of the reasons for them going up is that children are spending a greater time receiving palliative care because they're surviving for longer and I understand that, but what's causing the greater number of children at the beginning?

Professor Carter:

Those children who typically would have died very early on and wouldn't have ever reached palliative care services are surviving. We're now doing interventions early on that means that those children are actually surviving to the point that they can actually be considered for palliative care.

Dr Caroline Johnson MP:

So, the baby that would have received compassionate care on the maternity unit is now getting a bereavement package?

Professor Carter:

Yeah, although they might have spent two days a week in paediatric intensive care and then died actually are surviving and then coming out paediatric intensive care.

Dr Helena Dunbar:

So gestational babies of 23 weeks are now surviving.

Professor Carter:

It’s spreading from the very tiniest youngest most vulnerable baby to the child that was never expected to survive, getting to and being a toddler or a young teenager or a young adult.

Dr Caroline Johnson MP:

The next question is, one of the actions the government has stated it will take to implement it’s end of life care choice commitment is to ensure that we’ve got the right people with the right knowledge and skills to deliver high quality personal care. We’ve talked about some of the challenges haven’t we of the nursing workforce.

Rachel Cook:

It’s just that Fiona stated there was a growing evidence to show that children’s palliative care workforce is limited both in number and available children’s nurses and care assistants and the capacity to provide what we discussed, the care packages that were required. It’s the ongoing education perspective when we look at health education England’s own an impact and reduces the PD budgets for nurses especially women. Doctors get a bit more; doctors and dental get 12% more.

Dr Caroline Johnson MP:

They do but they usually pay a lot more for the same course. If you look at the adverts for the courses they will usually say doctors £400, nurses £300, so there is a reason for that.

Rachel Cook:

But multi-disciplinary when we’re doing that training, just for example, we’re doing [sims 77:30] training of when a child dies now, that is multi-disciplinary and that’s the same cost across the board, but it is difficult to get bums on seats and in universities as well because of the costs. Where you have post grad training, I know it’s been difficult to recruit in some universities for nurses because they just can’t get funding to be able to go on those courses.

Julie Bayliss:

I think it’s being released isn’t it from the workforce because I think that’s the biggest issue at the moment. I just notice it over my years is that actually nurses are…

Lindsey Barron:

I’m really sorry but I’m going to have to go because I’ve got to catch a train to get back for a one o’clock meeting. Is there anything you want to ask before I go?

Dr Caroline Johnson MP:

No, that's brilliant. Thank you.

Lindsey Barron:

If you have any questions, James has my contact details, I'd be really happy to meet.

Dr Caroline Johnson MP:

Because to some extent, this would require nurses and doctors to do courses in their own time at their own expense isn't it, for all aspects of medical?

Sophie Dodgeon:

It's also about… I just wanted to say from an earning perspective, absolutely, we're asked and encouraged by the children's hospital palliative care team to set on a post graduate quality care course which is [inaudible 78:44] releasing funding for people to go on that course and that's a huge issue for us. If you speak to the staff in the palliative care team they want to develop, and I often see who miss these opportunities and perhaps have potential as well because they left because of the career structure and education and development to stay in the post so it's…

Dr Helena Dunbar:

I was just going to say that palliative care is everyone's business really and it's about the fundamentals, making sure that that's available to undergraduates and then building on that and I quite like the model where we have fundamental skills for everyone and then building that because not everybody uses specialist skills, not everybody needs to attend a palliative care course but you need to make sure that the fundamentals of being able to talk to parents, having those communication skills, you're actually understanding, signposting what palliative care is can be done at basic level and if student nurses can do that they can empower parents as well.

Dr Sue Neilson:

I know the NMC standards are going to put end of life on the…

Dr Helena Dunbar:

We hope.

Dr Sue Neilson:

We hope… in that, and I think that's important for under grads as well in the training because if I talk from a personal perspective in that teaching death and dying in that millennial workforce that we have is reacting quite differently to death and dying when I taught it before.

Dr Caroline Johnson MP:

In what way?

Dr Sue Neilson:

In that they are absolutely the fear factor and anxiety around death and dying is a lot more than you'd expect, say for example if I'm a nurse on an oncology ward I would expect I'd be used to seeing a child die but actually the impact that that's having on the workforce is quite huge and I spend a lot of my time doing bespoke training just to support millennial junior work staff.

Dr Caroline Johnson MP:

Why do you think that is? Is that something about?

Dr Sue Neilson?:

Well society, one, we don't talk about death and dying, passed away or gone to the other side, they use all euphemisms.

Dr Caroline Johnson MP:

Has that changed significantly in 20 years?

Dr Sue Neilson?:

I think it has changed hugely. I didn't quite train with Florence Nightingale, but close enough. I think with my training in the 80s we saw a lot more death and they don't see so much death now and I think CSI and silent witness it just puts fear factors in there.

Julie Bayliss:

I think nurses are very fearful also around that and legalities now. Doctors are much more fearful about having this emergency care planning conversations where parents have got parental responsibility and signing documents, you know, all of that around people changing their mind and I think nurses are worried about medications. I think there's much more around that litigation that makes people feel fearful and actually worried about what they're doing so it is around making sure there is the training and support.

Dr Caroline Johnson MP:

That's a big issue at the moment around Dr [inaudible 81:57] case so we have got a [inaudible 82:00] on that because it has been a belief in the past that as long as you did your best and didn't do anything malicious and didn't refuse to come, that you would be fine. Whereas, I think that case has really reset that belief, which is causing a lot of quite understandable fear actually but hopefully the review which publishes next month will be able to help.

Dr Sue Neilson?:

I think education for me is the key, it's just to train the trainer, get them used to that and that they're… this is gaps fed back through the specialist interest group at the Royal College of Nursing, is that around the country it's not just what we experience at Great Ormond Street, it's right across, its education and the need for resilience. I think there would be more resilience if they had the education. It's that double edge isn't it.

Sophie Dodgeon:

I think there's also Helena's point as well about the communication and quality care learning [inaudible 83:04] support the patient and to support families and [inaudible 83:09] for some reason don't feel they are able to sit down and have those conversations because it is general conversations with specialists in the palliative care team are giving and their views are that the ward staff are too busy and they call the palliative care team because they don't have the time to sit…

Dr Caroline Johnson MP:

Do you think the fact that you now have a palliative care specialist means that the people on the ward then feel that they're not as good as the specialist and that they'd be doing a dis-service to the child if they didn't call that specialist and almost that they feel that they're not providing as good a service so if the palliative care specialist is not available they feel they're making do rather than providing the gold standard so that it's almost de skilling the rest of the workforce because it's always done by that team? Diabetes has that issue.

Julie Bayliss:

I think there's also an element that they're not sure also about if they start engaging in a conversation they don't know where the conversation is going to go, will they find themselves out of depth but also if I start that conversation and I know I've got someone who needs some medication in 10 minutes [inaudible 84:14] conversation together with [inaudible 84:15] patient, so I think those… we haven't explored a [inaudible 84:22] that's a [inaudible 84:24] research and that's the sort of background [I come from 84:26] [medication research 84:26] [inaudible 84:27] we start to find those reason why but there's definitely a combination of time and as you say, that fear of what happens if I ask a question [inaudible 84:41].

Professor Carter:

I think it comes back to that junior workforce. I really think they are a junior workforce and again, they've had some education but again, it about building on that education through other means and courses and education around communications skills and that sort of thing.

Sophie Dodgeon:

We had the oncology training didn't we a few years back, the Royal College communication training which was just rolled out to oncology it was [over speaking 85:07] that was three days.

Professor Carter:

That worked really well, yeah.

Sophie Dodgeon:

… the communication so…

Professor Carter:

Advanced communication skills.

Sophie Dodgeon:

… that worked really well but it was just for a very narrow…

Dr Caroline Johnson MP:

So, the thing that you're saying is that you need to obtain… the more senior nurses in the ward they direct their role?

Professor Carter:

That's right but again, I think the resources sometimes actually don't have the more senior posts, they're always only just one more sister or one practice educator across the three or four wards so again, that's why they will call in nurse specialists or practitioners.

Dr Caroline Johnson MP:

One thing I've not understood ever from nursing workforce is that if you're running a rota and you're looking at who's going to be on your nightshift, you'll have a consultant and registrar and [inaudible 85:53] and a junior [inaudible 85:54] or the modern equivalent or something but you can go on a shift and you can find you've got four band fives and you can go on another shift and find you've got four band sixes or even three band sixes and a band of seven. Why is that? There doesn't seem to be the same degree of each shift must contain a balance of nursing skills [over speaking 86:19]?

Professor Carter:

I'm not sure that…

Dr Caroline Johnson MP:

You're laughing now because it's true isn't it?

Professor Carter:

No, I'm not sure that is true, that's why I was laughing actually because I was thinking actually nowadays there are much more, one band six, one band seven who's there on Monday to Friday and then they do a rota for the band sevens to cover the weekends and the sisters sort of do that so actually the senior… the band sixes, the reason why it's been really difficult to retain people is because the band sixes have been so alone that there is just lots of and lots of band fives.

Dr Caroline Johnson MP:

I [inaudible 86:48]. I go in sometimes and I'm surrounded by navy and sometimes I'm surrounded by light blue and I think this is not… this is peculiar.

Professor Carter:

They do electronic rostering and its e-rostering, so you put in your requirement so actually it's why I was thinking it shouldn't happen because you want this level of nurse who can do A, B and C. Can do IVs, can do chemo, can do whatever you want and then you build on that [over speaking 87:13].

It shouldn't happen.

Julie Bayliss:

[inaudible 87:14] dependency, what are the needs within the unit and then you put the right skill mix for shift ideally.

Dr Caroline Johnson MP:

That [over speaking 87:24].

Julie Bayliss:

Yeah, on e-rostrum but whether that's…

Dr Helena Dunbar:

But often we're getting our nurses on the ward who have been fully qualified for a year or two years and they're in charge and they're expected to do everything and look after students and you know.

Julie Bayliss:

That hasn't changed.

Professor Carter:

I think it has changed [inaudible 87:43] going back [inaudible 87:44].

Dr Caroline Johnson MP:

So, you've gone back to [inaudible 87:45], when did you first qualify?

Professor Carter:

I started in 76 and qualified in 1980 and [about 300 years 87:54].

[Laughter]

I wouldn't go back to the old days. I think whatever those deficits are in the system we've got, you know, dealing with amazingly complex cases and I think we have some wonderful band fives who are doing amazing jobs and I think it is difficult. I think it's difficult for anybody to communicate effectively with parents, but I don't think I've ever met a parent who's said a nurse had said something so terrible to them that it made them just back off. The thing that we can't do is just not talk to parents, we have to try and communicate with parents and I think Helena was saying that it is everybody's responsibility because these children will be seen on ENT wards, they'll be seen everywhere within the hospital, so we know that our nurses' junior and senior will be working with them.

I think specialisms within nursing has created some level of separation, it has created a sense that that's the job the palliative care people, that's the job that the pain nurse does, that's the job that the infection control nurse does, and I think that's a role that we have to think everybody has got a responsibly for being as good as they can at the level of competency that they're at to engage with that family. You're not expected to have a massive end of life conversation, but you can actually talk about simple things, you can actually be engaged with parents and children and I think most children's nurses can do that if they’re given the confidence to do that and they get feedback and support on how they’ve done.

Julie Bayliss:

It does come down to that foundation education, something that actually everybody has whether [or where you’re 89:43] working, so it’s core skills, communication and sort of helping them.

Professor Carter:

It’s that feedback. I mean it’s a big push at the moment, it’s separate to this mental health so that we can talk to young people about mental health and there’s a big push at the moment, but you can talk to people that you think are at risk of suicide because people won’t want to say the wrong things but actually saying something is better than saying [over speaking 90:09].

Dr Caroline Johnson MP:

I’m aware of time pressing on so I’m going to with the last question go around for that one… the one thing and we’re only allowed one, if there were one thing that the government, HE or other stakeholders could do to make sure that you have nurses, the skills, knowledge and experience to provide palliative care to children, one thing, what would it be? Education? More money for CPD?

Professor Carter:

Will you come back to me?

Dr Helena Dunbar:

I think yes, we could all say more money but actually I think we need to look at how we deliver things differently and we are waiting for a new curriculum to come out and new standards for education and actually I was talking to Bernie earlier about how ATA should have been in there and yes, palliative care might be on it and how’s that going to look? Is it a little bit that we stick on the end or are we fundamentally going to influence the whole nursing curriculum the whole way through? Follow that patient journey and influence the fundamentals of how to care all the way through that and beyond into CPD.

Professor Carter:

I’ll go for more local support for families, so whatever that is, be it specialist paediatric clinical care team or if it’s community children’s nurses, whichever, and they might be overlapping but that local support to maintain and sustain families.

Dr Caroline Johnson MP:

Local underlined.

Nikki Lancaster:

If I could have picked one thing that I would have liked extra it would have been 24 hour needs nursing.

Dr Caroline Johnson MP:

So, you feel quite alone on the night?

Nikki Lancaster:

Yeah, so nine to five my community nurses were amazing, they would drop anything for me but come five o'clock in the evening you're very alone and it's a huge responsibility, massively overwhelming responsibility keeping a child alive and when it's your child it's even more so and when you're out there on your own and you've got no support it's hard, emotionally hard as well. The decisions, you're making the decisions but if your child was in a hospital setting a consultant would be making those decisions but as a parent you're at home making those decisions.

Dr Caroline Johnson MP:

It must be scary.

Nikki Lancaster:

Yeah, very.

Julie Bayliss:

Mine would be community nursing, I would definitely say that. I would say services and equitably services overall because again, there's just so many differences and I would say invest in training and education, community nurses…

Dr Caroline Johnson MP:

You only get one!

[Laughter]

So, 24-hour community nurses, yeah? Or at least it need to be joined up?

Julie Bayliss:

Yeah, it might not be a community nurse, it might be linked with your hospice and you want to be able to provide that 24/7 with trained community nurses.

Dr Caroline Johnson MP:

Has anyone go anything?

Rachel Cooke:

No, I don't think I've got anything else to say really, do I?

Dr Caroline Johnson MP:

I don't know. No, I'll leave it to the experts.

Rachel Cooke:

Safe, comprehensive 24/7 sustainable service.

Dr Caroline Johnson MP:

It's all about being able to make sure that people aren't left alone overnight.

Professor Carter:

Maybe some of us as professionals have stood in the shoes that the parents wear, but if any of us here could do that we would know why it's so important. They're marvellous and they're brilliant and they are so alone and they are so responsible and they're so tired, they are so tired and anything we can do to actually support that just has massive effects for that mum or that dad, the child who's at the centre of the care that we're delivering and the siblings and to the future of all of those people within that family because as and when that child dies that family continues fractured, fragmented and together or whatever, and that child's support has had an intense affect on that family during the child's life and will continue to have that so the life chances of the siblings are changed and different and the same for the family so whatever we can put in, health economically if that's the most important thing, it will repay in the long-term.

Sophie Dodgeon:

Speaking for the Rainbow Trust, we provide we provide a non-clinical support to families [over speaking 95:25]…

Dr Caroline Johnson MP:

So, what would be your one thing?

Sophie Dodgeon:

The one thing would have to be to be honest, we don't want to ask for more money necessarily because we know there's nothing in the system but it's more access to system funding because we can't access the system funding because we're not clinical, because it's not a clinical service, we are only reliant on small amounts of short breaks funding which [over speaking 95:47].

Dr Caroline Johnson MP:

Basically, increase your break [tier 95:49]?

Sophie Dodgeon:

But also, the criteria for short breaks doesn't necessarily work for our service because we provide quite a wide range of services to people and councils are really looking for particular less of [over speaking 96:00].

Dr Helena Dunbar:

It’s that definition of short breaks, I think we’ve heard that now and families want different things.

Dr Caroline Johnson MP:

And they want their children at home don’t they so I wouldn’t feel comfortable with the idea that if I’m going out for a night out I’ve got to take my child to somebody else’s house to leave them there for three days, so I can have a whole evening out. I’d want someone to come to my house for a few hours.

Dr Helena Dunbar:

How do you get to the hairdressers?

Dr Caroline Johnson MP:

Well, as is probably evident! That’s tricky!

[Laughter]

Thank you ever so much, I think that was very [inaudible 96:35]. The bell will go in six minutes by which time I need to be sort of in my seat.