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 3: 21 February 2018

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Members present

Catherine McKinnell MP (Co-Chair), Christine Jardine MP and David Linden MP.

Witnesses

- Dr Sat Jassal (Medical Director, Rainbows Hospice for Children and Young People)
- Francis Edwards (Palliative Care Liaison Nurse, University Hospitals Bristol NHS Foundation Trust)
- Julie Potts (Diana Service Palliative Care Lead Nurse, Leicestershire Partnership NHS Trust)
- Dr Fauzia Paize (Consultant Neonatologist, Liverpool Women's NHS Foundation Trust).

Examination of witnesses

Catherine McKinnell MP chaired the session

Catherine McKinnell MP:

Good morning, everyone. Thanks so much, everyone, for being here. I'm loving the layout of the room. Whilst we're waiting – Caroline is on her way – we could perhaps just go round the room and introduce ourselves, just say who we are, so that everybody knows who everybody else is. I'm Catherine McKinnell MP. I'm the co-chair of this All-Party Parliamentary Group. I was elected in 2010, so I'm an MP from Newcastle.

David Linden MP:

My name's David Linden MP. I'm the Member of Parliament for Glasgow East. I'm a member of the APPG and I was elected just in June last year.

Shaun Walsh:

My name's Shaun Walsh. I'm Director of Policy for Together for Short Lives. We provide secretariat for this all-party group.

Francis Edwards:

My name is Francis Edwards and I'm the lead nurse for Children's Palliative Care Group and Support Services at Bristol Children's Hospital.

Dr Sat Jassal:

I'm Dr Sat Jassal. I'm a man who has lots of different hats. One of those is I'm a general practitioner. I'm the Medical Director at Rainbow Children's Hospice. I also sit on the CCG board in Leicestershire as Child Health lead. I also work for NHS England as the GP lead for what was the old East Midlands for Palliative Care.

Catherine McKinnell MP:

Are you wearing all of those hats today?

Dr Sat Jassal:

Only the ones you want me to.

Julie Potts:

I'm Julie Potts. I'm one of the Diana nurses in Leicester. I was originally a community children's nurse but have been in the service for 20 years. I have a passion for palliative care and now I'm the lead for palliative care for the service. I'm part of the East Midlands palliative care group as well.

Dr Fauzia Paize:

I'm Dr Fauzia Paize. I'm a consultant neonatologist so my main day job is the bells and whistles of intensive care. I'm also a bereaved mum myself and I think from that I've developed an interest in baby loss and palliative care.

Catherine McKinnell MP:

Thank you so much, everybody, for making the time to come here this morning. I know this is a really important issue for all of us, which is why we're here. Our first panel, we're going to structure this so that we ask the same questions, because this is obviously a continuous inquiry over a number of weeks. We're trying to get some consistency in the questions we're asking. If it seems a little bit structured, that's why, but obviously you feel free to talk about what you think is important in terms of the answers that you give. You don't have to answer all the questions. If you've got something to add to what somebody else has said, by all means add it but don't feel like you have to, because there'll be plenty of opportunity to share your experiences and give your opinions so that we can make the best of this inquiry. This is really to add to the report that this group is going to make. We're going to make findings from all the evidence that we've taken from all the different people that we're speaking to and we're going to make recommendations as well, coming out of it. Your time today is really valuable and will, with all good speed, feed into a very valuable report that will hopefully make lives better for those involved in this field. I'll just start with the first question. Whoever would like to answer first, feel free. Do you and your colleagues have an honest discussion with children and their families about their conditions, the fact that they are life-limiting or life-threatening, and if so, how well do you feel these conversations are conducted? Who would like to start? Julie?

Julie Potts:

I’ve had quite a lot of involvement over the last few years in post working with professionals related to developing emergency healthcare plans. On the family experience, a lot of families don’t have early discussions, maybe because they’ve got lots of different consultants involved. It may be because perhaps the professionals aren’t sure how to approach it with the families, and very much when we’re doing the emergency healthcare plans I’ve found that it’s very varied with what skills the doctors and nurses have in how they relay the information. Sometimes there’s lots of medical jargon the families don’t quite understand. They’ll talk about resuscitation and different levels that the family don’t really know what they’re signing up for. I think that the conversations aren’t necessarily always open and honest because the families aren’t quite on the same page as the doctors and they don’t understand what they’re saying. A lot of families have said through their journey they’ve not had those open conversations early enough. I think if we’re talking about life-limiting, life-threatening conditions, it’s a difficult conversation to have, so sometimes it’s not broached with the families when it should be.

Catherine McKinnell MP:

Does anyone else have anything to add to that? It sounds like it’s very much dependent upon the individuals concerned, the doctors concerned, and whether or not that’s part of their skills set, to be able to communicate difficult conversations.

Dr Sat Jassal:

I think that’s certainly one of the key elements. There are a number of things to consider as well. One is that you have to approach the discussion at an appropriate stage of the child’s journey. A lot of the children that we look after may be life-limited but they’re not dying at that point in time, and the continual discussion about death doesn’t always sit well with them and their families. It’s one of these things where the conversation has to be had at an appropriate time in a sensitive manner, and those things are so dependent on the individual child and what their conditions are, where they are with their journey and where the family is as well. You do have to have a degree of sensitivity to how to approach it.

Francis Edwards:

I’ll also add to that and agree with what people have said is that working in the acute sector I think there a lot of professionals who don’t have that skill set, and that makes it very very difficult. Also they have a place where they always feel there’s something more that they can do for the child and so they offer families those different choices which then makes it very difficult for a family to engage in that. I think, as a mother, you’d want to do everything you can for your child, and if you keep being offered something, you’re going to go for that. I do think some professionals have a real difficulty with parallel planning and thinking about that. For us in Bristol, it’s important for us to make sure the families have the opportunity to have that discussion if they choose to have it, but also we like to change the conversation around to have a conversation about what we are going to do, rather than what we’re not going to do. Sometimes those conversations seem to be very negative and it’s about resuscitation and those kinds of things, but actually thinking about what we are going to do puts a completely different spin on the conversation and turns it into a positive conversation rather than a negative conversation.

Catherine McKinnell MP:

That leads helpfully into the next question I was going to ask, which was: Is your approach to actually sit down with the child and with the family to make a personalised care plan, and to what extent are those available to the family, and to what extent are they held by the doctors? How does that work in practice?

Dr Fauzia Paize:

Just touching on the previous question, I work in neonatal intensive care and the majority of child death happens in the first 28 days of life, so we see a lot of death and we see a lot of parallel planning needing to be made. I do agree that we all need to be better at making those parallel plans available at 24 weeks. We give intensive care for that baby but we also need to talk about the baby might die fairly early on in that process. We involve parents every day on our ward rounds and I think the majority of units do that too, so we're always involved in the plans for their baby. What we don't do well enough is to try to discuss with them the possibility of what's going to happen if things don't go well and how we're going to manage that. We don't always write that down long enough so that people know that we've communicated that to each other.

Catherine McKinnell MP:

What's your experience of personalised care plans?

Francis Edwards:

We have a very positive experience if the family wish to engage in that conversation. Once you've got that engagement, we all talk to the family, be it parents and the child, depending on the age of the child and their ability, wanting to join in that conversation, and we'll formulate what we call a wishes document, an advanced care plan by another name, and once that's done, it's not a legal document, it's not set in stone. It's a fluid document, it can be changing all the time, so it's important it gets that review. Where we are in the Southwest, we cover the whole of the Southwest, South Wales, so all those care plans are shared electronically to all the people that are involved in that child's care. It's the responsibility of the person that updates that document then to share it back with all those contacts, so you've got a live document. So if a child comes into the Children's Hospital in Bristol, I will get an alert on my computer to say this child has come in and they've got a wishes document, so that we can go and see that.

Catherine McKinnell MP:

But that's not a national...

Dr Fauzia Paize:

No, that's a local best practice. That's what should happen elsewhere in the country but it doesn't and there are inequalities.

Catherine McKinnell MP:

That's really helpful to understand. Just from a purely IT perspective, is that a document that's on a shared platform that you can all access or does it have to be physically circulated?

Francis Edwards:

It's circulated electronically because you've got different providers, so if the child's under the care of the local hospice, we'll send an electronic copy to them.

Catherine McKinnell MP:

So it relies on the individual and your support systems to make those updates.

Francis Edwards:

But the main person who's carrying that document is the family.

Catherine McKinnell MP:

OK, so the family is the coordinator, effectively.

Francis Edwards:

Absolutely, and when they come into hospital, the first question they should be asked: 'Are these still your wishes?' because they may well have changed, for whatever reason.

Catherine McKinnell MP:

Do you find that works? Is that the correct portfolio?

Dr Sat Jassal:

It's a live document. You have to really consider it a living document. It changes as the parents' wishes change. Having the conversation is not difficult, to be perfectly honest, with parents. Parents actually welcome that discussion. Changing the document isn't difficult. Sharing the document takes up time and work. There's been quite a lot of work that's been done by Bee Wee on the national level, who's Palliative Care Lead with NHS England around how do we share information electronically. There's big issues there around computer systems all talking to each other and the fact that they don't talk to each other, and currently the shared care records systems is something that has been used more extensively within the adult world. The difficulties occur in that we prepare very complex detailed plans for children and young adults but once they transition into the adult world, the adult world lives in a world of DNAR. You either have one or you don't have one. They don't go into the complexities. As more and more children are living longer and transitioning, we're starting to see these discussions having to be had with different units about the fact that actually it's not whether you just resuscitate or not. There's more complexity to the wishes of the family and the child or the young adult.

Julie Potts:

I think the education around emergency healthcare plans, advanced care plans, isn't there. Depending on if you've got somebody passionate within your organisation to promote the plans and arrange to educate the people on them, then you explain to the families very differently. Over the years they used to be called end-of-life plans many many years ago, which is wrong. They're not just for end-of-life care. Obviously we talk to each other and professionals explain to the families what these plans are, and if they're explained as if there is a way of trying to make the families make decisions about whether their child should have resuscitation or not, they're going to run away from it. We've found that a lot of families didn't want plans. They've had really bad experiences of how it's been explained to them, and I definitely think that's because of lack of education. Within my role, I'm an advocate for the plans. Since the specialist role was put in place, we've gone from 200% increase in plans over the last 18 months because we've educated the doctors, we've highlighted the need to have them, we've explained to families that if your child was going to have an emergency situation where you need to call an ambulance or go to A&E or go to Admissions, would you want that team to have a little bit more information about your child? So that's the starting block and I've not come across a family yet that hasn't said, 'Yes, that would be really helpful, because we have to explain every time we go in.' If you can start on that process, and actually work with the doctors that's leading on it, the conversation can be a lot better and more open-minded to the family. Families that thought they were going to be written off have ended up with plans that say, 'We want everything,' but it gives details, it explains about the family's understanding of where they're at. The families aren't unrealistic most of the time about where their child's at and the child is potentially life-limiting, but a lot of families still want choices and options in care. The families that we've developed plans with have all been really positive and hang onto their plans and take it round with them. We've also had really good feedback from ambulance services to say that that information is exactly what we need when we go into a family's home. We've also had feedback from Accident & Emergency saying, 'Why on earth wouldn't somebody have thought of these plans earlier?' They say they see the same children coming in and out without any plan, so hopefully, with more education, more plans will be developed and children won't be having inappropriate escalation of treatment, but I don't think we're there yet, in Leicester anyway.

Dr Sat Jassal:

The other group of people who find these plans very helpful are intensivists because the type of children that we look after are very vulnerable. They go off very quickly, they get rushed in and then the doctors have to make a judgement decision: 'Do we ventilate this child? Do we take them up to the intensive care unit?' The difficulty is knowing what the child was like before and what the wishes were. Without those, the default position is then to ventilate. Now, if you ventilate those children, actually it's not always appropriate to ventilate them because you then can't get them off the ventilator. I'm afraid that if you walked around the paediatric intensive care units around the country quite a few of those beds are filled with children who are ventilated. We could have a very interesting ethical discussion about how appropriate it is to leave a child ventilated in that situation, and are you actually being kind or not in those situations? There's a health resource issue as well because it takes six months to take those children who are ventilated off an intensive care unit, so those beds are blocked for other ill children. It costs approximately £100,000 per year to keep a ventilated child at home in terms of care packages that you have to bring together. Actually, a simple thing like an advanced care plan, where the wishes of the family, the child, can be taken into account doesn't just have benefits for the child and family but has a benefit for the health sector and the state in a major way.

Francis Edwards:

To start off with, Julie makes some really good points there, and I think there is a big thing around education and about professionals distinguishing between palliative care and end-of-life care. The two of them get morphed into one and that changes the attitude of the conversation. I think there needs to be a national conversation around what we mean by children's palliative care. I think that's really really important if we're to make any progress. Just taking the point that Sat's just made, we have to ask the question: 'Who is this plan for?' Is it for the professionals or is it for the family? I think there's a bit of work that's been going on nationally about trying to create a document that can be used all over the country. That's come to a place where it's actually massive because the intensivists want this kind of information, the palliative care want this information and you end up with this massive document. So who is this plan for? Is it for the family or is it for the convenience of the professionals?

Julie Potts:

There this thing about, not so much the education side of it, but the problem we have sometimes I feel that we fight to get a plan for the children and it feels like we're trying to get families to sign up for something too early in their condition. We have difficulty with the different doctors that lead on the care, so you might have a child that's got potentially a community paediatrician and they may have been in and out of intensive care so the doctor involved there. Respiratory doctors are virtually always involved because children generally go down the respiratory route but they may also have a neurology oncology doctor, so we struggle to actually find a doctor that's willing to lead on it. It tends to go towards the respiratory doctors because children generally go down the respiratory route if they're poorly and then end up in intensive care, but the respiratory doctors don't always feel it's their place because they're not the lead doctor. If there was a palliative care consultant available to guide professionals, maybe that would form a link when there's lots of different consultants involved.

Catherine McKinnell MP:

Francis, you made a differentiation there between palliative care and end-of-life care, that we need a national conversation about it. My next question was going to be, now that we've talked about getting those care plans in place, actually you do need to have a conversation with the parents about end-of-life choices. How does that conversation happen? What steps do you take? How do you determine at what point you are moving from one to the other? You said we need to have a national conversation about the difference, is there a way of exploring that here?

Francis Edwards:

So we will have the conversation by the bedside with the family, a newly diagnosed family, and we're talking about palliative care, we'd be talking about living rather than dying, and making the most of those moments and the time that they have got, and that's really really important. Again, it's the positive kind of approach to it. But then having the conversation about, 'Well, actually, if this happens, what would you like to happen?' and then developing that over a period of time. If a child's admitted acutely into an intensive care unit, it's not right to have that kind of conversation. You'd be having a 'do not resuscitate' conversation, and then if the child survives that episode of care, translating that into a more advanced care plan. I think it's about having a conversation about what enables that to happen. I'll tell you the story of a family whose child kept getting recurrent infections, recurrently going into hospital. They've got an advanced care plan and they decided they didn't want to go anymore and they were at home, Mum and Dad and their daughter, and their child got another chest infection and they wanted to stay at home, they wanted to stay at home and then they panicked and they called an ambulance. The ambulance knew that they'd got an advanced care plan, so the ambulance turned up to the house and said to the family, 'Right, what would you like to do? What would you like us to do?' They said, 'We'd like to go to hospital.' They said, 'OK.' So they put the child and the mum in the back of the ambulance and dad followed behind in the car. The child died on the way to hospital. The ambulance pulled over, got Dad into the back of the ambulance where he could spend some time with his child and then the ambulance crew said to them, 'What would you like to do now?' and they said, 'We'd like to go home.' They said, 'Fine,' so they turned the ambulance around and took the child home. If the child hadn't got that documentation, that thought, they would have continued to hospital. It would have been an unexpected death. There would have been a post-mortem, all kinds of things would have happened. It's about what it enables to happen, rather than what it doesn't. So it's a positive kind of approach that we need to be having to this. I was at the event where the mother who launched the book.

Julie Potts:

Sasha.

Francis Edwards:

At that event, she made that very good point about more families need to understand what palliative care is. Actually, more professionals also need to understand what palliative care is.

Catherine McKinnell MP:

From your experience, is it always the case that families want to be in that decision-making role?

Dr Fauzia Paize:

Yes, absolutely.

Francis Edwards:

They want a decision-making role but they don't want to be the main decision-makers.

Catherine McKinnell MP:

They don't want to trust the health professionals to make those decisions.

Dr Fauzia Paize:

It's teamwork, isn't it. It's a collaboration between yourselves and the families. We need to make these plans, we need to make these decisions. From my point of view they don't always lead those discussion because, for me, we've known the babies as long as the parents have, so we've known the parents who've taken them home and looked after these children at home for a long time and then are accessing the services, but you make those plans. We tend to leave more of those discussions about moving towards end-of-life care when intensive care isn't the right thing for babies, but you're doing it in partnership with the families. You should always be doing it in partnership with the families.

Dr Sat Jassal:

You have to be slightly careful here because it's not 100 per cent. Sometimes it's frightening for parents to make those tough calls. It's very difficult for a parent.

Dr Fauzia Paize:

But they should be involved.

Catherine McKinnell MP:

That is the question I ask which was not: Should they always be involved? It was: Should they be in the driving seat in the sense that the ambulance in that case is saying, 'What would you like to do?' and I think sometimes, I imagine, as a parent, you aren't necessarily seeing it as clearly as a medical professional is. You might be terribly distressed and it's a very difficult position to be in to have to make life and death decisions and choices, and that's what I was getting at, not that you would ever exclude a parent from that decision-making process.

Julie Potts:

I think it sometimes takes it away from the parent that they've not got that responsibility because a doctor agrees with them where they're at. I definitely think it empowers the family to then make that decision because obviously that plan would have said, 'This child does not need to go into hospital if they suddenly die. They could go to a hospice. The family potentially would like to choose that option to stay at home.' It gives them more options and we're really open with them that if a child dies that the coroner will need to be involved and the police will need to be involved if it's quite sudden and they haven't got a plan and they've not seen their doctor for a while. When the ambulance is called or the doctor arrives, they will contact the Coroner and say, 'Where do we go, what do you want to do?' They'll take the history and then the coroner will support whatever decision they want to make but it still enables families to stay at home. I think it actually enables families to have more options. The other thing in terms of palliative care, when we bring the plans in, what we tend to do is we've got a system at the moment that we look at the children we look after and we go with the [inaudible 0:27:20] for whether the child's stable, unstable, deteriorating or dying. We'll look at those children and the odd palliative care child will have episodes where they're acutely unwell, so they'll get chest infections, and you find that they start to have those infections perhaps more frequently at the beginning when they're quite young and vulnerable, or they have them along the journey. So they have this up and down process. What I start to do is have those conversations with the family at that point and say, 'As your child is quite vulnerable at times and may need to access services, this may be a time to look at a plan so that everybody's aware of what their wishes are and the doctor's medical opinion is.' It just helps to start. It could be a full plan and I think it's easy for families then, when it's starting towards the end-of-life care, to actually start looking at the plan again and say, 'Actually, is that care appropriate now? Is that in their best interests? Will that prolong life or cause them more discomfort?' A plan starting from the beginning, say with an oncology child, where everybody's been trying to fight for their care and trying to keep them alive with every single treatment going and just that last bit of chemo might help when we know that the end result is that the child is palliative and will eventually die, those poor families then have those discussions all of a sudden all in one go, whereas I think we could have had those discussions to say, 'Your child is palliative, he's got a palliative oncology condition, let's write a plan for if they become suddenly unwell, so that when later on it gets to that stage, it's an easier conversation to approach because they know the form already and they've been having it.'

Catherine McKinnell MP:

So what steps do you take to move into that space of talking about end-of-life care? Do you have a protocol?

Dr Fauzia Paize:

Common sense.

Dr Sat Jassal:

There's no protocol. You just look at the child, you look at the family and you have that discussion. Call it clinical skills, call it common sense, we just tend to pick up those discussions.

Catherine McKinnell MP:

But do you think that's happening correctly in all cases?

Dr Fauzia Paize:

I don't think there's enough parallel planning happens, there's not enough conversations that start early enough. A big part of my work is antenatal care, because palliative care can start in the antenatal period with something detected on scans, and we need to make plan A, B and C for what's going to happen for them. The best clinical situation is the baby's going to be born, ranging from they're going to die in the delivery room and sometimes in our care those conversations don't happen early enough so they can happen maybe at 30 weeks if the woman's gone into pre-term labour. I'm sure that's [inaudible 0:30:15] paediatric palliative care as well, that the conversations... Everyone loves to be proved wrong if you're planning for end-of-life care but they don't die, that's fine, but it's to actually make that plan in the first place and talk about it, about what's going to happen and what's important to that family at the time when they reach end-of-life care.

Julie Potts:

We've got a few families I know that we've shared with them at Rainbow's Hospice as well where the children have been in NNU, the family have been told that the child will die, that they've got a very short prognosis and they're given options about going home or going to Rainbow's Hospice, so they have an emergency healthcare plan written, which is what we all need really to prevent us from having to resuscitate, and then there's a big back pedal then if the child starts feeding or starts doing a little bit better than expected. I've got a lovely letter from a family that I'll give to you that had that. She said that for the next few months, as her child started to do better, he is going to have profound disabilities, he is still palliative, but she found it was a bit of a wait and see now. You've still got your plan for 'do not resuscitate', and she felt that the services didn't all kick in place for her because there was still this wait and see from the neonatal side of things. I think it's really important that everybody parallel plans. You've got to be certain with the families, haven't you, that...

Dr Fauzia Paize:

No, I don't think you do. I think you need to hedge your bets on absolutely everything.

Catherine McKinnell MP:

You've got to plan for the worst, effectively, and then for the best. Would that be a fair assessment?

Dr Fauzia Paize:

Yeah.

Dr Sat Jassal:

Essentially, children are not small adults. Adults, when they die, I can pretty much predict the timescale, and they follow a trajectory that goes downwards. It might go up and down but you can work out with some simple formulas. If they're deteriorating within months, they'll die within months. If they're deteriorating within weeks, they'll die within weeks. If they're deteriorating within days, they'll die within days. That's the simple adult formula. Children, well, in some situations you may get lucky and be able to work it out, but they don't tend to do that. In my mind, it's a much more painful process for the parents to go through. I have, over the last 25 years, said to a number of parents, ‘I’m sorry, but your child’s going to pass away,’ and they look absolutely dreadful and they’ve got no colour and three days later the child’s smiling at me and another two days later the family are going home with the child. We say this is the death of a thousand lashes because for the parents, emotionally, they’ve gone through the grief process that they’re going to lose their child and the child recovers, but they’re going to be back. They’re back in a few months, a few weeks to go through the whole thing again and again and again. It’s actually emotionally incredibly exhausting for the parents to go through that. This particularly happens to the neuro degenerative-type conditions but it can happen with a lot of other conditions. With hypoxic ischemic encephalopathy, which is what Fauzia will see lots of, these are children who’ve been brain damaged at birth. They’re incredibly vulnerable for the first few weeks of life, so you can lose them then, but if they survive, and they shouldn’t survive, because no adult could survive what they’re going through, then they can carry on, and then they go into this stage of disability, and the neonatologists are better at keeping them alive through that first phase, so we’re getting more children going through the disability phase now, but it’s so unpredictable. You cannot work out which child will go through which process, and that causes tensions between specialists and the parents, because the parents have been told that your child’s going to die and they don’t. It’s a very uncertain thing to work out what will happen with a child.

Francis Edwards:

At the heart of that also is about trying to manage family’s expectations. The key to it is the working relationship you have with that family on that journey.

Catherine McKinnell MP:

How do you always ensure the best wishes of the child? You’ve talked a lot about the plan being is it for the medical specialist team, is it for the family? You talk a lot about the family. I appreciate they’re tiny babies but ultimately is it not the child who should always be at the centre of that decision making? Obviously it is but how do you make sure?

Francis Edwards:

I think they are, and they’re always there as their best interests. We might have a meeting with the family and the child can’t communicate, but as professionals we’ll be talking about the best interests of that child. I think it’s for us to hold that because the parents might not necessarily hold that because they might want surgery or they might want their child to go on a ventilator, but we have to think about the best interests. We bring that into the agreement.

Catherine McKinnell MP:

How do you ensure that at any stage?

Dr Sat Jassal:

I think the first thing to say, I would suggest, is that the majority of parents know their own children and they make the right decisions. I have children, I like to feel that when they were little I made the decisions and I would do anything for my children. I think anybody who’s got children would feel that. I would say that, yes, you do hear the cases that go to court, but they’re the exceptions to the rule. Mostly, we just discuss and negotiate with the family. As soon as a young adult is able to communicate with us, then we listen to what they say. If you’ve got an eight year old or a nine year old, you know that they’re also going to be looking at their mum. They want to know from mum or dad what to do, so it does tend to be that we communicate when we can and we do listen to what the child’s got to say. The majority of parents know what they feel is right for their child. The times that we get conflict is very emotionally difficult and intensive and then we do need the courts to help us, but they’re not happening all the time. They happen more often, but not all the time.

David Linden MP:

Have you had examples where the child has a very different view from the parent, and how do you resolve that at that point?

Dr Sat Jassal:

I had a young child who had a malignant melanoma, that’s skin cancer. It had spread. He was about 11 or 12. He came to the hospice and he fought us every step of the way in terms of pain relief for himself. All he wanted to do was just go home. He didn’t want any more treatment, he was fed up with everything. He wasn’t depressed but these were his wishes. You have to assess whether they’ve got depression. At the end of the day, all we could do in that situation was discuss with the parents that this is the child’s wishes and both the parents and ourselves decided that if this is his wish, and he’d made it quite clear, then all we could do is to let him go home. He didn’t want lots of people around him. He didn’t want the medical teams, he didn’t want nurses, he didn’t want anyone. He just wanted to be left alone, and actually that’s how he died. He died very peacefully in his own home and he didn’t have a lot of people around, just his family. So at quite a young age he knew what he wanted to do, and I think it was our duty then, even though we felt we wanted to do more for him, we felt we could do a lot more for him, but those were his wishes. We did our best in that situation to adhere to his wishes.

Francis Edwards:

I just want to go back to the best interests thing as well with a live example, where the child hasn’t got a voice. Just recently a child came to us who’d had a massive out of hospital cardiac arrest. Mum said he died then but he hadn’t died and they were very keen to end it. They thought we should end. As a palliative care team we were there advocating for that child’s best interests and saying, ‘What he needs now is some time.’ That came across to the parents as a very negative kind of thing. Three weeks later the dad stopped me on the stairs and said, ‘I was very sorry about the way that I behaved when you came to see us but now we can see that,’ and now they’ve got a child who has survived and is different and who they’re now happy to take home. That’s not unusual. We’ve had three of those in the last 18 months. For the palliative care team to be advocating for, promoting life, we have to work on both sides of that.

Julie Potts:

I think we do have barriers with professionals and families making decisions. From my experience, the main barrier is the religious beliefs of the families and the belief that you continue treatment at all costs, or appear to be withholding treatment. I think it’s having those conversations with the family in a delicate manner. Eventually, the child will deteriorate and decisions may change. I think most families wouldn’t want to see their child suffer. Sometimes it’s how it’s put to them that you’re not actually withdrawing treatment; you’re actually giving treatment that’s most appropriate for your child. I definitely think there are quite a few children that end up in intensive care ventilated over and over again because the families aren’t willing to agree with the doctors, and maybe there’s a worry about... There’s been lots of court cases, hasn’t there, recently. I don’t know if that causes doctors to not make, or be firm about, the decision that’s right for the child. I do worry that sometimes that is not happening and that children are going back in and out of intensive care when we all know that they shouldn’t be. It’s difficult.

Dr Fauzia Paize:

Trust and building relationships is really important, to be able to trust the medical teams that you're working together to keep the child in the centre is really important.

David Linden MP:

You mentioned the sensitive issues around putting together people from different religious backgrounds. Is there any central guidance issued from Government or training given about that? That is obviously a very sensitive area.

Julie Potts:

They all do lots of education around different beliefs of families.

David Linden MP:

Is that something you've got to go out and do yourself?

Julie Potts:

We do. I don't think we've got any central. We've got a multi-cultural link worker within our team that guides us on different stuff and that really helps us but I know not all teams have got that.

Dr Sat Jassal:

There was a wonderful piece of work done by Acorns Hospice which looked at different faiths and how they look at death and dying and treatment. I wrote a chapter for a textbook on how different faiths perceive things, the difficulties, you might say. The Muslim faith perceives this but within the Muslim faith you have different levels, and within Judaism they also have a belief of continuing to treat at all costs. One has to be careful not to generalise. However, there are key issues that occur where there's community pressure on families to go for treatment at all costs, even when the parents feel that they don't wish to. We've written some beautiful care plans for families and, 'We'll do this and we'll do that,' and as soon as the child heads into that journey or they get poorly, they don't just keep the child at home, they don't trigger the Diana teams, they don't trigger the community support teams; they dial 999, ambulance, even though they've said they don't want to do that and they go straight into hospital and the child dies in the A&E department. I'm afraid that those are some of the facts that we see. You can do everything, you can have everything laid out but the last-minute social pressure, cultural pressures have an effect.

Julie Potts:

We have got children with those wishes still with emergency healthcare plans that actually identify that if the child is deteriorating and it's felt at the time that it's not in the child's best interests to continue treatment, that the parents and the medical team will make that decision at the time and their own doctors will support the decision made. I think there's ways of actually wording it so that it supports the family in their want to progress with treatment but also gives the emergency services the ability to know the family's... The families aren't naive. They know that their child is deteriorating but just want to know that their best interests... We've got quite a few families that have perhaps died in Accident & Emergency with plans and the staff have been guided afterwards and found the plan useful to know where the family are at. There's still a place for that plan for those children.

Dr Sat Jassal:

One of the key significant improvements that I've seen recently has been around how the Coroner looks at certain types of deaths within religious faiths. So within the Muslim faith, when the child dies you really want to try and get the paperwork done then at the mosque before sunset. This is culturally very important to people. We now have systems in place where the Registrar of Births and Deaths will fast-track the paperwork. You can phone the Coroner even at a weekend. They have special phone numbers for us to call. They'll take the details, rubber-stamp the paperwork through to allow that to happen. This has been a significant improvement for that cultural group and has been a great benefit to them. So there have been some positive changes and, of course, within the care planning you put that into the system because not everybody knows what the phone numbers are for these different people.

Christine Jardine MP:

Just going back to something you said earlier that struck me as being very important, as part of the system, when you come to the point where you have to discuss these decisions with the parents, presumably you have to go to some lengths to make sure that the people who have known the child the longest, and have been most involved, are there, if nothing else as reassurance for the parents, those people who understood are involved. Presumably that's all built into the system as well.

Francis Edwards:

And have a core team around them. You're right to say that is important. There's an example from just this week where a family have been under the care of the oncology team for many years and our team hadn't been involved with that family. The child is suddenly in intensive care and the family just turned round one morning and said, 'Please can we see the palliative care team?' They'd come to a decision then so there were new people coming into that.

Christine Jardine MP:

So they made the decision themselves when the time was right?

Francis Edwards:

Yes, but it is being flexible, working with them and being available.

Dr Sat Jassal:

There's been a sea change in attitude, particularly in the last ten to 15 years amongst healthcare professionals from where palliative care, when we first started, people said, 'What is it?' They had no idea. Now it's entered mainstream, paediatricians talk about it, they understand about it within specialities. That may not sound impressive in your world, but in our world any change like that is a phenomenal change in consultant thinking. They now will talk directly to use, which never used to happen.

Francis Edwards:

I want to add to that because, for me, this is a big issue. I think that if we have to see children's palliative care as everybody's business, it's everybody's core business working in the health service, working with families, and we need to move away from this idea of specialism, because that just disempowers, and we need to be empowering the person by the bedside to be able to deliver that care, the community nurse working in the home to deliver that care. It shouldn't be seen as a specialist team. That can actually do it a disservice.

Julie Potts:

I'd agree with that but I also think there needs to be people in lead posts.

Francis Edwards:

Absolutely.

Julie Potts:

My role actually embeds palliative care. Originally they said my role shouldn't exist because the care should be embedded but if you've not actually got somebody overlooking and looking at emergency healthcare plans, looking at the training, looking at the packs the staff need for going on call when the child's ill... So I totally agree.

Francis Edwards:

I totally agree with that as well. The way that we work in our team, we're an empowering team. Just recently we worked with one of the wards that had never had a child death. It was going to happen at some stage and we worked with that team and they managed that beautifully, but they did it, we didn't do it. We empowered them to be able to deliver that care because they were the team that knew the family. That's where the family wanted to be.

Dr Sat Jassal:

This is such an important point from your view of the care plan. Care plan is not something that should be written by the likes of me. It should be written, as you've quite rightly said, by the team who's looking after the child. That team is not a palliative care team, necessarily. It can be any team and it should be the team that knows the child the best and the family the best, because, quite frankly, they have the insights that are needed. It is so difficult for me to go in when I have to and ask to write a care plan for a child when I've only just met them because then I don't have that sense or feel. I can do it but it takes a lot longer.

Julie Potts:

But that often does happen, doesn't it, because we go to Sat to say, 'We are struggling to get a doctor to lead on this,' and then we'll ask. With good community paediatricians recently they weren't doing any plans, but now, what the hospital have been asking for is a discussion with the other consultants. That's when I find it works best. The community team, if they're known to the child, will speak to the various consultants involved with ourselves and then we'll go with the families and even go to the family home with that one doctor that knows everybody's views and they have that conversation with the key people involved, and it's a much nicer environment to do it in the family's home with doctors that they know, than a meeting like this. I've been to meetings like this where everybody's sitting round and we've got people [s.I. scribing 0:48:58] while we're doing it. It's really not an appropriate way round but it's the education on how to go round it.

Catherine McKinnell MP:

We’ve talked a lot about the hospital and the medical team and your moving it out into the community paediatricians, but another aspect to this is the social care services as well, where there may be a social care support package in place to support the family at home. From your perspective, is there adequate, joined-up working in respect of health and social care? If not, are there any thoughts on we might improve that? What’s your experience?

Dr Sat Jassal:

I was told to behave.

Catherine McKinnell MP:

No, you don’t have to behave. I would rather hear what you think if that’s something that needs to come out of this process, then it will.

Dr Sat Jassal:

The standard answer is that we all work together very effectively. The reality is that the level of cuts that the Government have made to county councils has absolutely crippled social care. Parents fight tooth and nail for every little thing that they need. From a commissioning point of view, commissioners are absolutely broke. Even providing simple things is becoming incredibly difficult. The truth is that actually parents constantly battle for everything. We know it’s not easy, and, yes, a lot of parents get this name that they’re always complaining, they always want things, but they have to do it. It’s the only way they can get anything. It’s not because social services aren’t wanting to help. They just don’t have the resources. It’s not that the NHS doesn’t want to help. They don’t have the resources. I’m afraid this one’s on your side of the fence. You need to start to look at what you’re actually doing politically. Not hearing from the people who are at the top saying how wonderful everything is, but actually, on the ground, because it ain’t wonderful. It’s absolutely dire.

Catherine McKinnell MP:

I guess putting that back, I know what the situation is in my local area in terms of the level of funding cuts to the local authority, and I know that one of the casualties of that is always social care, and it’s hugely challenging. What would be really helpful to understand is what the practical implications are of that for you as medical practitioners, if there are any. I see it from the social care side from constituents that come to talk to me about their own battles, as you say, to try and get what they need. It would be useful to understand from you as medical practitioners whether you’re having to extend your reach further in, where you’re able to. I know that the NHS are picking up some of those pieces where social care can’t meet it any more. How does that work in practice?

Francis Edwards:

We’re finding that more and more children are spending longer and longer in hospital when they could be in another location. I think that’s the rub of it. I agree with what Sat said but I’d like to add another spin to that. In 2005 I was asked to go to Dublin to give a talk. I called that talk The Big English Mistake, which they loved, but the mistake is the total lack of coordination. What we need to have is we need to have better coordination of the services that we’ve got and we need people to be working together. Strong local networks are part of the answer to the issues that we face at the moment. There’s some good examples of local networks, the West Midlands being one, but they’re very few and far between. We need to focus on that and make sure the hospice sector, social services, NHS are all working together in partnership and not being precious about it, because some preciousness does come into this. Different teams think they're not going to work with anybody else. We need to get over that. For me it's about the total lack of coordination of the resources that we have got.

Catherine McKinnell MP:

Who do you think is taking the lead on that?

Francis Edwards:

I don't think anybody is. Nobody is.

Dr Fauzia Paize:

That's one of the issues that people say and then things fall down the crack in the middle unless the family are able to have that difficult role in amongst everything else.

Francis Edwards:

We've got a mother at the moment whose had surgery on Monday. She's got a very dependent child. She can't now lift for six weeks. That child is going to spend most of the next six weeks in hospital because they haven't got a community care package. That's the wrong place for that child to be.

Dr Sat Jassal:

Better Care Together – did you have that? Better Care Together was a big thing. Now we're into another big thing, which is looking at approaching it a different way. We're all meant to be working together, so working through the CCG we've been told all work together. Social services, we've had so many meetings within our organisation or with social services but when shove comes to push nobody's got any money to give up, nobody moves any money out and all the sectors are being cut back. You can have a lot of nice talk about it but the brutal reality is that when it comes to it, when it comes to us as commissioners – I said I had various hats on – we have to protect the limited resources we have and focus on what are the priorities. For example, social services, their priority is child protection so a large amount of their resources will go down that route. As the cuts are taking effect, they're going to mandatory what they have to do and these extra bells and whistles on... It's what they call them, bells and whistles. The same is happening within the commissioning groups. We don't have any money to give out for anything else. When it comes to the cutbacks, you have to look to see what you're going to cut back on. The net result is always the same. There's somebody stuck in a hospital bed and it's actually costing more but nobody sees it that way.

Catherine McKinnell MP:

Sorry, but we're going to have to move on to the next panel. This has been really really helpful.

Francis Edwards:

People in Bristol have sat around a local table for ten years and have got nowhere because they take this kind of 'it's all a problem', rather than 'is there another way of going about this?' We've just brought a new group of people together and added a different approach to that and now we've come up with a model of actually trying to coordinate those different local services. It’s taking an appreciative inquiry approach to that rather than a problem-solving approach to that and that’s what we need. We need some fresh thinking and we need a new model.

Julie Potts:

I just wanted to really quickly say there’s one thing we’ve not covered is in adult services there’s adults that are dying, at end of life, where you’ve got specific services set up for end of life – specialist nurses, lots of doctors and training available. Within children’s, because it’s perceived as small numbers, there isn’t the same level of need. You don’t need a nursing service constantly to provide end-of-life care because we’re not always on call. So we’ll do the core level of care for all the children and then when we get a child end-of-life care, first of all we feel it’s a battle to set the on-call up and make sure that everything’s in place because the hospital aren’t aware of what we need in the community and the anticipatory medication, the parallel planning, the step-ups and things. You’ve got our nursing team and physios that are doing their day job, with all the other children they’re looking after, and then they get a child for end-of-life care. The nurses that actually do the day job are providing the on-call at night. In adult it’s district nurses. They have a nursing service that provide night care, so I could be working all day today and then I’m also on call and then could be called out for quite a period in the night. Because it’s small numbers we haven’t got the... I feel there needs to be some money ring-fenced so that when you do get a child for palliative care, it doesn’t just go to the money for the family to have decision tools and funding for them to have a bit of respite, but actually to provide nurses, to increase the nurses to be able to accommodate the out-of-hours care as well. We say about giving families choices but the choice is that they are going to do the care for their child at home with a nurse visiting to set up care or to actually visit them when their child’s condition deteriorates. Because of the goodness in our hearts and the care that we have for our families, we provide family choice and that’s because of the care and dedication of the team, not because there’s resources and things set in place.

Dr Fauzia Paize:

I know we need to finish but I don’t think we do offer enough choice in location of end-of-life care. Partly, for me, it’s the set-up of our transport services. They don’t necessarily lend itself to be able to provide end-of-life care outside of a neonatal unit for when babies that are dying.

Julie Potts:

Weekends, bank holidays, out of hours.

Dr Fauzia Paize:

Yes, it’s emergency services only.

Catherine McKinnell MP:

So the other aspect of that as well is hospice and hospice care and I know that we’re going to hear from the next panel from three different hospices. Is there anything else you’d finally like to add?

Dr Sat Jassal:

Just to say thank you for giving us the opportunity to talk to you.

Catherine McKinnell MP:

Can I say thank you because your time is so valuable and we totally appreciate you giving up your valuable time to come and do this. I said at the beginning, and I really mean it, that that valuable time will be used to make some valuable contributions to actually improving services. We've heard a lot of really amazing practice and we're also hearing stories where it's not working quite so well. Hopefully, where things are going well we can then share that nationally, and then where things need to improve, I think the message about the social care funding is a very powerful one as well. We can use this to try and get the resources that we need and to make sure that that care is joined up at every level and everywhere around the country. I think we do have a real patchwork of success stories and where it's not working quite so well, so thank you so much.

Francis Edwards:

I do also think that the CQC have a role to play in this, and I think that that's not fit for purpose at the moment around children's end-of-life care. They're using an adult model of inspection which doesn't work for children.

Catherine McKinnell MP:

OK, that's helpful, thank you.

Julie Potts:

Do you mind if I give you these? I've got three families that knew I was coming that have given me feedback and then also I see they've also filled in the questions as well.

Catherine McKinnell MP:

Thanks so much. Really appreciate it.