**NHS Education for Scotland**

**Transcript of ‘Palliative Care Patients with Children: Supporting the Family’**

**NES Bereavement Conference 2021 session recording**

**Speakers**:

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* Dr Catriona Macpherson, Children & Families Practitioner, Fife Specialist Palliative Care, NHS Fife

**Facilitator**: Dr Ruth Isherwood, Consultant in Palliative Medicine, NHS Tayside

Ruth Isherwood (RI): Good morning, everybody. I can see that people are joining promptly again and I hope you've managed to get a break. Thank you for joining this session - Supporting Palliative Care Patients and their Children. My name is Ruth Isherwood, I'm a Consultant in Palliative Medicine in NHS Tayside and I have the great pleasure of chairing this session. Our speakers for this session are Catriona Macpherson and Donna Hastings and they are here to share with us a wealth of experience. Donna is the Child and Families Lead at St Columba's Hospice Care in Edinburgh. She's a Practitioner, Childhood Grief Therapist and Play Specialist and is an active member of many of the key bereavement groups. Catriona has over 25 years' experience of supporting patients to prepare themselves and their children for parental serious illness, dying, death and bereavement. She works in NHS Fife and collaborates widely with colleagues in order to provide both clinical services and education. I can see people are already introducing themselves in the chat function, which is lovely. We use the chat function for any questions, we'll keep those to the end and I will ask those on your behalf after we've heard from our speakers. So, Donna and Catriona, thank you very much.

Catriona Macpherson (CM): Thank you very much, Ruth. And hello, everybody, even though we can't see any of you. I guess this session is a, is a plea for reminding us all about a very kind of family systems approach in, in healthcare and social care. I think COVID gave that a bit of a panelling, really, because there were so many decisions that had to be taken around patient safety- well, everybody's safety, but there was a move towards the slightly more patient-focus, I think, and this is our opportunity to really make sure that doesn't stick. It's also a session about starting to think about bereavement long before their death and preferably as early as possible. And early intervention being a big part of what specialist palliative care is about. This is just a reminder about the fact that for all of us who are involved in this kind of care, we are concurrently working with individuals, couples... families, extended families. There's been quite a drive for the concept of patient-centred care, but really it's, it’s family-centred care that, that matters. And I think that's been very loud and clear in the earlier sessions. And, of course, all the individuals within a family may not be on the same page or have the same understanding or the same expectations, which can make our, our work much more challenging... and also time-consuming, which I think is another thing that, that sometimes worries people. I've just popped in this... reference really from Allan Kellehear's recent work which is his plea, I guess, to remind us to see families as the unit of care. But also to think about advance care planning as being about what matters most to people and to be less focused on some of the technical tasks that go around thinking about advance care planning. It is a plea to think about living with dying... and, and the social ecology of care. To think about personal health, if you like, in the, the local context and the family context of our patients. The priorities and the values, particularly the values, I think, of a person's lived experience are a big part of, I guess, what we're trying to focus on. And what matters to them in their own world. And, and it's bringing that world into the care package that we're trying to put together and the thinking around what everyone needs.

I think we have a challenge as NHS staff. We now have the United Nations' Charter for the Rights of Children and obviously all of the children's rights that are enshrined in that Charter, which has been adopted by Scotland, are relevant to delivering care to a dying parent. But thinking quite carefully about the impact of that on children and their right to have some understanding of that is something that, that we need to start grappling with. Of course, however, we also have to work with our own codes of conduct which require us not to be giving information to anybody in a family without patient's consent. And that can create quite a challenge. You know, the right to confidentiality and privacy and the right, as was mentioned earlier, to prepare for grieving and to grieve. And I think all eyes are on Sweden just now because they are a bit ahead of us in terms of the way that they're enacting this type of policy and the kind of difficulties it's creating for them. So there's some interesting literature on that if you're interested in it.

The next slide looks at some of the evidence around why parents, understandably, want to avoid going into detail with their children and want to kind of hang off from giving too much information. The fears that they have about frightening their children or not getting it right or taking away hope, feeling themselves that they don't have the skills or the knowledge to do it, the fact that we're increasingly understanding that patients with dependants are more likely to choose life-prolonging treatment over quality of life. The drive to have as long as possible with your children. There's lots of worries about what they will miss out on and the quality of parenting that their children are going to receive when they're no longer there. And I wonder if we might put in the, the first poll at this point.

The poll that we were wanting you to answer was 'My biggest worry about talking to parents about talking to their children about incurable illness is:'. If you could have a look at that poll and have a think about the kind of things that you find most difficult about talking to parents or bringing up the subject of, of talking to their children prior to parental death. The, the reason we chose those items on the poll were because these are the things that, that we struggle with, even with quite a lot of experience of doing it. And, the business about where to send them for tailored advice, I think, is, is a wider issue that needs to be addressed. But I think our personal concerns about how to manage what to say and giving the wrong advice are, are an issue as well.

I guess this slide is really just to try to give a little bit of context about some of the background things that I think are important. We know that, for example, that the, the wellbeing of the surviving parent, or the person who's going to be the surviving parent or surviving carer is the most important determinant in terms of how well children do afterwards and that's, that’s been replicated in a number of studies. So it is obviously very important that we're starting to work with parents as early as possible. I think that parents have, themselves, adults themselves have to, have to get their head kind of around it and have to be able almost to say to themselves, "This thing is going to happen" or "it might happen" and to be able to really kind of acknowledge it internally before any of us are in a position to start thinking about how to speak to children. And that's why we run an early-intervention clinic, trying to get parents in at, at advance diagnosis or at a point of recurrence, as early as possible to start having these conversations. However, it's the case that many parents don't, don’t want their children to be told anything, don't want to be given information and so sometimes we are left in a position where we have to respect that and we have to maintain those wishes.

I think, also, the idea that adjustment is a lifelong process for children is really important for parents to get their head round, this is not something we rush at with counselling in the first few weeks and then that's it, sorted, it's a very long-term process, as I hardly need tell most of the people who are here. But I think that the systems haven't quite addressed that or come to terms with that fact. I also think that parents are the key people in terms of making sure that all of the... that social ecology of care, all of the people around the child are using the language that they want to be used and that everybody's kind of on the same page, saying the same kind of things to give consistency to their children.

The next slide is around what we know matters to children, which coincides with the previous slide that the best person to help the child is not a counsellor or a professional, it is the, the person who will be doing the caring, so that has to be the key individual. We know, obviously, that emotional developmental stage and understanding is very important and experience of, of bereavement generally, and I think it will be very interesting to review our understandings of that in light of COVID. Circumstances of death have been covered this morning quite a lot and that idea of children being present and being around and being part of the dying process is something that most specialist palliative care units have spent some considerable time juggling and tackling over the last couple of years. And, and lots of practical advice which goes around that long-term need for support and the ways of children expressing their grief, which is something that Donna is about to talk about now.

Donna Hastings (DH): Thanks, Catriona. So, what do we know that children need? They need information at a level that they can understand, they need the opportunity to be able to ask questions. And one of the most important things that we can do is to remove the sole responsibility to talk about the grief from them, we should provide opportunities, but it's about… having a conversation with them to let them know that you're available to speak to them and that you are going to check in with them now and again, you know, every few days, about if there is any questions they have or how they're feeling about things. Because by doing that, we're letting them know that we're available to them, but it also saves them from having to gather up all their strength to be able to come and say, "Can I ask this?" or, "I need to speak to you about this”, because a lot of children, when that onus of responsibility is on them, it's much harder for them to reach out than it is for us to reach in. So just by checking out with them every now and again and letting them know that we're going to do that can be a real support to them, and a way of checking in with them how they're doing. It's absolutely imperative that we get the message to children that it's okay to share all of their feelings, that, you know, when this event is happening, that it's okay to, to be sad or upset or confused or worried or angry, but it's also okay to be happy. And, you know, there are real messages in there about... you know, about how we, we give children information to let them know that, that we're doing okay ourselves, you know, as, as carers of children who are, are facing a bereavement or when they are bereaved. So, for a parent who, you know, will go into a bedroom to cry, they are, you know, that's okay as an adult because we, we know that that works for us, but actually what we're showing to children is that if we are sad and we want to cry, that we go into the bedroom and close the door and do that alone. So, actually, you know, being able to cry and share emotions in front of them is absolutely vital to them being able to know about how it's okay to share their, their feelings about all of this that's going on and get support from one another whilst reassuring them that you're okay, you're just, you know, really sad or upset about the, the situation that's happening or you're sad because somebody has died.

Most children don't need experts. Statistically, it's about a third of children that will need that kind of support. But, like everybody, they just need opportunities to be heard and to be understood. And, often, childhood grief can be overlooked, you know, as time has passed from a death and people don't relate a, a child's behaviour necessarily to a bereavement that they've maybe experienced and it's, it’s really helpful that we are mindful to keep in mind that, actually, a child can grieve for the rest of their lives and that they will revisit their grief at, at different development and significant points in their, their childhood into adulthood.

And, for children, they need to know about what the illness is or you know, what the disease is, you know, if it's cancer, that we're actually using that word and we're explaining what it is and making the distinction between you know, something like COVID, and it will just help children with their understanding and to be clear for them and save any confusion. It can also be really helpful for children to know that they can't make adults get cancer. It can be very often one of the things that children worry about, that something they have done has made their person get cancer and that they're going to be responsible for them dying.

So, these are just some resources that when children have a significant person who has an incurable illness, that they might be able to access some of these resources. So, things like ‘The Secret C’ or ‘When Mummy or Daddy has Cancer’. There are websites like riprap when a parent has cancer and the app that you can see is called recordmenow and it's a digital legacy. And, actually, often when children are bereaved in childhood, what they can seek as they get older is questions about "what was the person like, you know, before I was born", even. "What were they like when they were growing up?", you know, "Where did they go to school?" "Who were their best friends?" "What kind of mischief did they get up to?" "Am I like them?" And, actually, the, the app recordmenow is an opportunity for someone to go through and tell that life story so that it's there as a legacy for children... as they grow with their grief through childhood and it's there right into adulthood.

So, how do children and young people respond when they're facing either the death of someone significant or when they are bereaved? We know that very young children, pre-school age, might be more clingy to the parent. They will worry that something might happen to somebody else. Some children might ignore the death or respond with a puzzled detachment that they're maybe unable to grasp that absence for, for several months and, and think that the person is elsewhere. And, of course, it's been really difficult… added to this during the pandemic, because for many children, they've been unable to see a person if they've been ill, if they've been cared for in hospital. You know, in hospice, children are, and have been able to visit when it's been a parent who has the incurable illness, but in hospitals we know that you know, children weren't allowed to visit. And so, not being able to see the person for a long period of time and then that person dies can really impact children's understanding of the, the fact that somebody has died and that they're not just being cared for elsewhere.

And they also might ask the same or similar questions repeatedly and need the information told time and time again. Some children of this age might show no apparent grief as long as they have that secure relationship with their surviving parent because, you know, if life is otherwise little changed, if they're having their needs all met and supported. But, of course, they can be impacted by how other people are grieving around them and how their care of them is happening. And children of this age will tend to associate death with what they know already. It can be really important for families at this age, though, to know that there are still resources that we can use that can benefit children as they grow, again, through childhood because it's not necessarily at the time that it might be important, but it will be later on when they are thinking about, you know, what life would be like if that person was still here, if they hadn't died. And again, what they might've had in common with that person and also grieve that loss of memory and relationship. So, there are things that we can do, like... you know... the recordmenow app or an ‘All about me’ book that is from the parent telling the child all about their life or if there's photographs of the parent with the child in the photograph, to not only have the, the photograph and the story of it so that the child's able to see themselves with that person when they're older, but if they're able to keep the piece of clothing the parent has on in the picture, then the, the child will be able to look at the photograph and see themselves being cuddled by Daddy or Mummy and then have that physical kind of connection with the piece of clothing they were wearing and it can be a real comfort. So, although children of this age might not be necessarily... really impacted by this age and would look like they're able to manage their grief, it might well be much later on that they would need support and that those kind of resources can be really helpful.

So, children five to eight, by this age, most children will begin to understand the finality of death. But, again, dependant on the child and their development, it might be that they can still be a bit confused about thinking that it's magic and equate it with things like cartoons, like people can die and come back again. Often children can see it as a punishment for something that they've done wrong and can think that it's their fault and they can experience guilt. And so, age-appropriate explanations and concrete words can help support children's understanding during this age.

Again, just some additional resources. The Childhood Bereavement Network postcards that children can check things off and give to teachers to let them know when somebody is seriously ill or there is ones when children are bereaved and it gives them that additional support in school, you know, if they're needing just some time out of the, the class or a bit of additional support with homework. The, the teddy bears that you see, and lots of you might be familiar with these, but they're big and small and the idea is that the small bear represents the child and the larger bear represents the adult and then they, they swap, so the child ends up with the large bear that represents the parent or their adult caregiver and the adult will have the baby bear as a representation of their child. And for children, this can be a real, real comfort... for a long time after somebody has died and, you know, they will carry it with them knowing that this is their bear that was from their adult and that their adult has their bear with them when they've had their funeral.

Children eight to 12, by this age, they will fully understand the, the finality, that somebody cannot come alive again and we might see their responses to death as some prolonged crying, they might be withdrawn, you know, want to stop going to extra-curricular activities or being with friends and we might see their eating and sleep disrupted. But, of course, we can see those through different ages and stages, not just necessarily at this age. And real questioning about what happens when you die and a real worry as well about who might look after them and what happens if something happens to their other parent. And lots of structure and reassurance and boundaries will hold children at this age.

And, along with the, the other resources, again, you might be familiar with ‘The Invisible String’, but it can be really helpful for children to know that, you know, even when they can't physically be with somebody anymore, that they have a connection because they are connected and, and carry people in their hearts. And one of the lovely things we can do with this activity is to read the story with children and then have them on a piece of paper, draw themselves in the middle and then around them, have them think about who their invisible strings are connected to so that they know what supports they have around them as well.

And then, as we move on to adolescence, in this age group, there's more of a social pressure to almost be "more adult", often fulfilling parental roles and looking after younger siblings and that sense of responsibility that you know "I have to step up and look after the rest of the family now". The peer group may be unable to offer support. You know, some young people will be able to talk to their friends, but often will feel like nobody quite understands what it's, it’s like for them and they can feel very different from their peers because they, they haven't had a parent that's died or they, they don't understand what their grief is like. They can often try to protect the adults around them because they're aware that they are grieving too and so they put a hold on what their own needs are to try and look after the adults around them. For young people, they can often... it can be a time of risk-taking, you know, almost "what's the point?", really taking chances they, they otherwise wouldn't. And for a lot of young people, this study at the bottom by Nicola Turner talked about young people taking an active role in shaping family communication and what she was saying was that you know, we have to be considered when we are giving young people information. So if young people are, you know, taking on a caring role in their family and it's their parent that is dying, that we, we should check out with them what information they are ready to hear and not just assume that they should get every single piece of information. It's about a conversation with saying "We have this information" and, you know, "Are you ready to hear it? Do you want to hear it?" And, where at all possible, that conversation should happen with their parent or adult caregiver. Catriona?

CM: Hi. I think we just wanted to do a little bit of work around how we... support children and parents. I think there's a lot of, of work that goes on in hospices, but that's also replicated in hospitals. And the idea, around the idea of a partnership with parents and our role being to work with them, which is largely around helping them to articulate their questions and concerns about their children, but also to start doing, I suppose, a bit of coaching around language. I think we do a lot of work on helping with the kind of day-to-day visiting and the running of the family while someone might be in hospice or hospital. Parents often need a bit of help to work out what should change and what should stay the same in terms of regimes and structures. And in the before times, before COVID, we often used to have you know, hundreds of family visiting and trying to help... parents to see that children needed one-to-one time with the patient, parent, without everybody else butting in, it was really important. That actually has become much easier to achieve now because of... you know, large numbers of extended family not necessarily being able to come in to visit and the focus being much more on, on children and key individuals.

As Donna mentioned earlier, you know, most children don't need direct counselling, they do need support within their own networks though and a big part of my role, certainly, is liaising with every school of every child that, that we have using our service to ensure that they're fully aware of what's going on. That's obviously with parental consent, but most parents are more than happy for that to happen because it ensures that background level of support for their kids. And some of you will be aware about the series of studies that have come out of North America from Eliza Park's group which have been incredibly helpful looking at what parents are looking for and what they need and this idea of how to help the surviving parent keep bonds alive between the child and the person that's died, the parent that's died, is a big part of the work and, as I'm sure, a lot of you who are working in bereavement are already doing.

We just thought we would put something in about the partnership and how that works. And the, the conversation around giving of information to children happening as early as possible. I've mentioned about the early-intervention clinic, which, anecdotally, I think has made a huge difference to what happens at the actual end-of-life phase because people have already embarked upon dealing with some of the most difficult emotions around the process. But this, this business of trying to give staged information and to help parents to, to stage the information at the right time and point in time is a big concern for them. And we tend to kind of try and suggest that you know, they stick to, we stick to where we are today, which is of course very much what we do with adult patients as well. But also that parents know how their children are going to respond, they understand the dynamics, sibling dynamics for example in the family, and how to do sharing and information, sharing of information with their children, whether to treat all their children as a kind of a job lot or whether they need to do, have different times with different children at different developmental stages within the family. So, parents have already got a huge skillset about how to manage their own children, our job is to try and support that and give them greater confidence in tackling some new language, some language that they're not familiar with using themselves.

This is just, just really to make the point that a lot of people that are here today will be well-versed in the giving of bad news and the, the reinforcing of bad news. And the same principles exactly work for working with, with parents to prepare their children. And I often find when I start this process around trying to talk through "here's one approach", they will immediately say, "Oh yeah, that's exactly what my doctor does" or, "that's exactly what the specialist oncology nurse does”. So that's starting with where are you already, what are you already thinking, what have you been wondering about? And then what the bits of information are that the child needs to know. What has happened, what's happening now and what will happen, probably in a very short-term way, in the future?

And kids will often come up with some very unexpected questions around, you know, well "Mum's gonna be in hospital, who's gonna make my tea?" they'll ask Dad, who's you know perfectly capable of making the tea. But it's a very... they're very concrete in their thinking and they're looking for practical support around understanding the changes to their daily life. And always allowing children to ask questions is an important message to get across to parents because they sometimes just don't think of that... "Have you got any questions for Mum or Dad?".

I think the idea that we need to repeat this information to children is something that we need to remember with adults as well because they also only take in a small... we know from many studies that adults take in a small percentage of what we tell them in terms of bad news and children are exactly the same. Other stresses that might be going on in their life, and certainly it's been a very stressful two years for most children and certainly young people, has an impact on what we can take in and what we can understand.

I think there are some basic emotional needs that parents are very able to understand with a bit of support. So, that telling children, "You'll not be left on your own to cope with this, we're going to do this together, we're going to be a team". And the very, what seems bleeding obvious to us, but isn't necessarily to children, that nobody's choosing this, it's not a voluntary state, it's something that adults don't have control over and children are used to adults fixing everything and, of course, that's precisely why adults find it so difficult to, to face some of this stuff, because they can't fix it, the kind of powerlessness that we're all in together with it. I think the other thing is that parents often don't realise that children will immediately, egocentrically, as is their duty, start to think about what maybe they've done to make the situation worse. A lot of kids now know that there's a relationship between cancer and stress so there's the worry that they've caused stress and they've made things worse. So it being very important for parents to be able to you know directly say, "This was not caused by anything that you did, this is not your fault and it's not your responsibility to make it better. We need to work together on looking after each other." But you know, particularly for the oldest sibling in a family, they often feel responsible for their younger siblings.

One of the questions I get asked an awful lot is when to say things. I use the 'how many sleeps' rule. There's evidence base for this whatsoever, it's just something that I kind of made up over the years. Parents know how many sleeps into the future their children can fully anticipate and that gives us a bit of a guide. Some quite young children are able to manage six or seven days and as we approach the Santa season, the 'how many sleeps' thing is, is something that you know, most families are kind of dealing with. But it's really about trying to help parents to say, "We can just stick with where we are today, we don't need to be going into the future because we actually don't know the answers." And the reality is, with my team I often joke, I think we worked out we have something like 600 years’ experience between our big team, but we're wrong 50% of the time about when things are going to happen. So we don't know when things are exactly going to happen, we need to stick with where we are just now.

I think a lot of you will know about this stuff about talking about "dead" and using the word "dead", "dying" and "dead" and not "passed away" or "being like sleep" or "lost", but using concrete language is really important. I think that might be something that's a bit more evident following COVID, that you know the word "death" is perhaps a bit more used than it was before. I think we're still frightened to use it with children, but I think it's very important that we do and that we explain what it means in these very concrete terms. And there are some very helpful resources around language. There's lots to help us to, to help parents feel a bit more confident about this.

Immediately after the death, families need a lot of practical help around decision making and that, you know, whether they would… whether the viewing of the body and the saying goodbye to the body is important part of that family's culture or something they want to consider. But how much we model and normalise that I think is really important... and family being able to have full discussions around what is the right thing to do. I'm conscious of the time. I think funerals, which have been discussed this morning... I think we're much more aware than when I started about 25 years ago, children often didn't attend funerals. I think that's different now and I think we're much more able to offer child-centred funerals. And to think around how to prepare children. Crematoriums, for example, are still doing visits where children who've had a parent who has died, are able to go to visit the... the facility and kind of… at least so it's familiar on the day of the funeral.

I just wanted to bring something in about high complexity because I think that this family group that we're talking about have a lot of trauma in their history for natural. There's a high rate of ACEs within this patient group. Consistently, 20-25% of my case load have themselves been parentally bereaved as children and they have experience of that. And consistently, over 60% have one or more ACEs in their, in their history. So we're looking at a group of people who've already got a high level of trauma before we even start and that is why work needs to start as early as possible.

My go-to place when I'm really stuck, and I get stuck quite often, is that honesty and openness are not the same thing, and most parents will get that. It is really important that we're honest with our children, most parents don't want to lie to their children. That does not mean to say you have to be completely open. So, for families that are really struggling with talking to their children, at the very minimum we can get to... you know, "Mum and Dad are having to deal with a difficult thing to do with Mum or Dad's illness and when we're ready we will talk that through with you." So there's an acknowledgement that there's something going on in the family that children will be able to see and feel, but we're not quite ready to talk about it. And that's sometimes a good starting point when, when you're getting really stuck with, with families, just acknowledging that. I just want to finish with the, the importance of, of modelling and being with, which I think is one of the most significant things that, that happen in hospice and hospital. That, that giving words for what you're doing, speaking through what's happening as you work with the family. That helps parents to feel more confident about doing the same thing with their children. So that, I think we often feel that we're not doing very much or we're not helping and we don't notice how important our modelling is as we are, as we be with, hang out with, spend time with the families that we're working with. Thank you very much.

RI: Thank you both, that was an excellent presentation, really enjoyable session. There was of comments and support and networking happening in the chat function, which was really good to see. A question, please, around how to unblock communication when children aren't talking to adults because they're trying to protect their adults.

CM: Well, I, I think one of the things that adults can do is to just say that. "I'm worried that you're not talking to me because you think it's going to make me too upset. And I might get upset or I will get upset, but that is okay." So it's kind of just calling it, I think. Of course, not all parents are able for that, but it's helping them to see that it might not be catastrophic just to say it. I don't know if that's helpful or what you're looking for.

DH: I think when you voice it with them, you know, they might not be where they're ready to talk about it and that's also okay, but in having a conversation to say that, you know, "I am just going to check out with you now and again and when you are ready, I am here." And remind them that they, they can ask, but that you will check it out because for, for different children and where they are and, and just their development and their responses, they just might not be, be quite there yet and that's okay.

RI: And there was another question around the role of play therapy before we finish.

DH: So, I mean, for children and young people, having play in front of them is a way for them to be able to process and work through what their, their lived experience is. And often, you know, for children, they can't verbalise and find the words and it will often come through their play. And so, having lots of different play and activities around to give them opportunities for that is just a different way of helping them process and express the situation for them.

RI: Okay. Thank you, that's really helpful. So, I think we've come to the end of the session. So thank you very much to both Catriona and Donna for what was a really insightful and helpful presentation. Just a reminder to please visit the posters which are available on the left-hand tabs and I hope you all enjoy the rest of the conference. Thank you for coming to this session. Bye.

DH: Thanks, everyone.

CM: Thank you.

The film was produced in November 2021 and can be found at [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk/) or <https://vimeo.com/677737244>

For more information visit [www.sad.scot.nhs.uk](http://www.sad.scot.nhs.uk/) or contact [SupportAroundDeath@nes.scot.nhs.uk](mailto:SupportAroundDeath@nes.scot.nhs.uk)

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