**NHS Education for Scotland**

**Transcript of ‘Bereavement support for families after critical illness’**

**NES Bereavement Conference 2021 session recording**

**Speakers**:

* Dr Nazir Lone, Senior Clinical Lecturer in Critical Care, University of Edinburgh / Honorary Consultant in Critical Care, NHS Lothian
* Janine Wilson, Deputy Charge Nurse, Critical Care Unit, NHS Lothian

**Chair**: Nicola Cotter, Head of Scotland Office, General Medical Council

Nicola Cotter (NC): So we’ll just formally open the session and just welcome everyone to this ‘Bereavement Support for Families After Critical Illness’. My name’s Nicola Cotter. I’m the Head of GMC Scotland and I’m a, a member of the NES Bereavement Steering Group so I’m here to sort of Chair the session this afternoon and, and field the questions afterwards. So you’re going to hear two presentations and I’ll introduce both Naz and Janine shortly just to help with the flow of the session, I’ll just do them both together. And after the presentations we’re hoping to have around 15 minutes for questions.

So, first of all, I want to introduce you to, to Naz. So, Naz is a Senior Clinical Lecturer in Critical Care at the University of Edinburgh and a Consultant at the Royal Infirmary of Edinburgh. His programme of research focuses on longer-term outcomes of patients surviving critical care and improving the quality of care for those who become critically ill. He has a particular research interest in epidemiological methods and realising the full potential of healthcare data. And is currently Director of Research for the UK Intensive Care Society and promotes benchmarking and quality in his role as Chair of the Scottish Intensive Care Society Audit Group, Steering Group… Audit Group Steering Group for Public Health Scotland. So welcome, Naz, and thanks for taking your time… the time today to talk to us.

After Naz we’ll then hear from Janine. And Janine is a Deputy Charge Nurse in Critical Care and a Bereavement Nurse Lead in the Royal Infirmary of Edinburgh. She has over 12 years’ experience helping to run and organise a nurse-led bereavement follow-up service while also working clinically on the unit leading a team of nurses. And this year Janine and a team of experts are working on a funded quality improvement project that looks to improve on the current bereavement care experience by families via implementing a bespoke educational programme and working on providing more consistent care. This project is funded by the Scottish Partnership for Palliative Care, Building on the Best grants. So I’m going to hand over now, I think it’s Naz first, to do your presentation, Naz, and then after that we’ll pass over to Janine.

Nazir Lone (NL): Thanks very much, Nicola. And I will start sharing my screen now. Thanks for the introduction, Nicola. There we go, that’s visible now. So the way we’ll divide this session is I will give some context and some background to critical care and end-of-life care and bereavement in critical care, and review some of the evidence base. And then I’ll hand over to Janine who I work with also, we work in the same hospital, the same unit, who’ll be talking about our programme of bereavement support we have in, in our unit.

So just to give you some context. In, in ICUs in Scotland we have roughly about 10,000 people who are admitted every year and unfortunately around 1 in 6 people who are admitted will die. The, the, just for some terminology here, we, we often use critical care and ICU intensive care interchangeably. Critical care encompasses both intensive care and high dependency care and the difference between them is intensive care generally has more types of life support treatments, particularly mechanical ventilation.

So death is common. So 1 in 6 of our patients are dying. And to put that in a bit of context, we, we decided to compare - we published this a few months ago - deaths in intensive care compared with deaths in hospices. And what we found was that around 5% of deaths in Scotland occur in hospices and about, sorry 6% in hospices and about 5% in critical care units. So, so not hugely different. But when you look at that in a slightly different way and look at the number of deaths that are occurring in the beds, the physical beds available, actually critical care is probably the institution in the country which sees the most deaths per, per bed. So something staff are trying to help support families with on a daily basis across the country.

When we look, though, at… in a bit more depth at those deaths, this is looking at different age groups, how commonly people will end up dying in critical care. And you can see on the left-hand side of there, the red line is deaths in critical care, and it goes up to about 1 in 7 deaths. All deaths of people who are aged 20-30 are occurring in critical care units and a far lower number in hospices. And the reason why we’re doing this… we decided to do this comparison is because we view in critical care, hospices as the sort of gold standard way, with ability to provide bereavement care. So many deaths, a significant proportion of deaths in younger age groups, are occurring in critical care. And when you look at the reasons why people are dying, we looked at that too, and it’s… as you might expect, unexpected events such as accidents, trauma, self-harm, suicide as well as emergency operations and infections. So, deaths occurring in critical care are in younger age groups and actually often due to unexpected circumstances and that likely will mean that family members have got a lot more to cope with and deal with when coming to terms with a death.

Other issues in intensive care I think to be aware of, for those who aren’t familiar with the environment, is one of the key things is most patients, particularly patients who die, end up being in a medically-induced coma for most of their stay in ICU. And that means that they’re unable to communicate with family members and importantly, can’t be involved in decision making about the types of treatments that they’re prepared to receive, particularly when some of those treatments can be potentially distressing. So for that reason it’s been, perhaps not surprising then that family members are more likely to experience mental health problems and, and are less able to, to deal with the death. And this study was done a few years ago, just trying to understand how frequent these problems are. So six months after a death in ICU, family members have really quite high levels of depression and post-traumatic stress disorder, about 1 in 3. And around 1 in 3 end up at high risk of complicated grief. And complicated grief is, is something that… a concept to capture when people who are bereaved have really intense emotions still about the death and find it very difficult to come to terms with the death, even many months after a death and, and then can’t get on and live their lives on a day-to-day basis.

So common problems there, it looks like in, in our… the family members of patients we look after, and because there’s such a limited resource for bereavement support, as there is in the community, it’s exactly the same in critical care units, potentially we need to be trying to look at people at higher risk. And hospices do this routinely, my understanding is, to, to, to understand those who might be at higher risk of, of problems when they… when they’re bereaved. And in ICUs there are some specific features there which might flag things which are perhaps not so common in other contexts. So one is a patient dying whilst on a ventilator and intubated. But importantly, in many circumstances in ICU we have to make an active decision when we think that treatments are no longer beneficial and that balance of benefit of burden of treatment is switching to being overly burdensome and move to, to end-of-life care and palliative care and when there’s disagreement with a family, that can potentially cause significant problems for them coming to terms with the death down the line. Also if family members find the communication unsatisfactory, that can lead to increased risk of complicated grief and mental health problems. One thing that’s very protective is when patients are conscious enough to be involved in decision making and they actively decide which treatments they will and will not accept. And family members then presumably are less burdened by what they feel is, is decision making that they’re having to make on behalf of family members.

So that, that means that when we’re looking to make sure we have adequate bereavement support in place, we look to an evidence base in virtually everything else we do in intensive care, we try and make sure it’s subjected to trials and, and suchlike. So these are some things which there is a weak evidence base for as to what could potentially could become components of a bereavement support programme, including sending a sympathy card and offering follow-up meetings. And Janine’s going to talk about these things in more detail. So I, I won’t talk about them more here.

So I think just to finish and summarise, you know, deaths in ICU and critical care are very common and they’re part of our day-to-day roles. We’re obviously trained in being able to, to know the know-how of how to provide technical life support treatments but equally importantly many of us feel the ability to comfort family members, help them come to terms with a death, that’s particularly important because the deaths we see are often unexpected in younger age groups potentially as well and that’s the reason why many of us in critical care are passionate about providing good end-of-life care and bereavement care. So, I will finish there and I will hand over to Janine.

NC: Thanks for that, Naz, and, yes, Janine, if you can share, share your slides now. Thank you.

Janine Wilson (JW): Hi there. So my name is Janine Wilson. I’m a Deputy Charge Nurse in critical care. I’ve worked in critical care for around 13 years and I’ve been leading our bereavement follow-up service in ICU for around six years in the Royal Infirmary in Edinburgh. I’ve always had an interest in end-of-life care and I’ve been an integral part of our team trying to champion improvements in relation to providing excellence in end-of-life care which includes aftercare for families. Today I will be discussing what bereavement care we offer within our unit. Firstly I’ll begin by providing an overview of critical care for those who are unfamiliar with this type of setting. I’ll also discuss how we were impacted during the first wave of the pandemic and how this affected end-of-life care and families who were impacted by this. I’ll then go on to discuss the care and follow-up care we offer families alongside some of the benefits and limitations to providing a nurse-led service. I will put this into context by providing some examples of how we’ve managed to help families who’ve got in touch with us and some of the feedback that we’ve, that we’ve received. Lastly, I’ll touch on our quality improvement project that we’ve been collectively working on during the course of this year.

Our unit is a general, recently up-sized, 42-bedded critical care unit specialising in trauma, neuro and transplant, to name but a few. Around 260 nurses work on our unit in total, all of varying degrees of experience and exposure to some of the unfortunate cases where patients cannot be saved and end up being palliated. End-of-life care is a big and inevitable part of our job which in more recent times has really pushed a lot of our nurses’ resilience and coping mechanisms to the max. Despite this, some comfort can be gained in what we’re able to offer families in the form of our own Bereavement Service which I will discuss in more detail later on.

Just to set the scene a little bit more, critical care can be quite a scary and alien environment for patients and families alike. I’m sure you’ve all seen the media footage recently of critical care units, big, open-plan ward full of various machines and equipment, lines and cables, not to mention all of the associated noises and beeps from monitors. So we do like to give families advance warning of what the unit looks like before they come in to visit their loved ones. Equally, if children are coming in to visit their loved ones, we’ll sit them down with a little book that we have available with a picture of what a bed space looks like to help them prepare. A lot of time will go in to supporting families prior to visiting their loved one on the unit. We will discuss what their loved one might look like - potentially unconscious and, and unable to talk with various tubes and lines attached. The nursing and medical team really work hard to establish a good rapport with families early on so that they can trust us to help not only look after their loved one but help support and reassure them as well. Of key importance is assuring families that the patient is comfortable and pain-free which is our primary goal as clinical professionals.

Prior to the Covid pandemic, some of the key advantages that really benefited both patients and families alike was having an open visiting policy. Equally, nurses and doctors could show their faces, thus be more easily recognisable and empathetic during the delivery of care and during difficult conversations. There were also fewer communication barriers with those that have sensory difficulties. But most importantly, families could come in straight away to be with their loved ones prior and during end-of-life care. The benefits and assurance that this provides families where they’re able to have peace of mind, that they could say what they wanted to say and visually see that their loved one’s comfortable and being looked after well are insurmountable.

During the Covid pandemic, things changed very rapidly on our unit. Despite the internal environment not changing a huge deal, the external environment changed massively. Plastic sheeting barricaded the entry and exit ways to the unit to create what we call a bubble. This bubble helps to prevent cross-infection of Covid to other areas of the unit with the main goal of protecting patients who are otherwise unwell but Covid-free. Staff had to wear essential PPE to help protect themselves and others from cross-contamination. A mask, hat and visor meant that we were almost unrecognisable to each other, never mind the patients, and communication was a lot more difficult due to difficulty hearing with all this gear on. The first wave of the pandemic hit us hard and the team were going on governmental advice to stop visiting for a period of time. At that point the medical team were also trialling different treatments for Covid which contributed to the uncertainty of some of our patients’ prognoses. Many patients who were struggling with Covid were placed on non-invasive ventilation to begin with. This meant that these patients were awake and breathing for themselves with the added help of some extra support with their breathing through a mask or hood placed over their mouth or all the way over their head. Despite medications prescribed for these patients to take the edge off some of their anxieties, I cannot begin to imagine how terrified they would have been and still are. A lot of pressure was placed on nursing and medical staff to keep families updated at home via phone calls. Families were terrified and it was very difficult trying to provide any source of reassurance, especially remotely. Patients were also so sad and upset not being able to see their families. This was such a tough time for everyone involved. Due to lockdown, some very vulnerable family members were left at home alone with no-one to help support them. If and when a patient became acutely unwell and we thought they might die, we had to make very difficult phone calls to families at home to break the news. If end-of-life care was approaching very rapidly, sometimes the nurse would have to be the bearer of bad news. At that point no visiting was allowed even during end-of-life care. Calling family members who were alone at home with no other support to explain that perhaps their partner was dying was probably the hardest thing I and others had ever had to do. It still haunts me to this day. Despite there being next to no comfort at all to be gained from situations like that for all parties involved, our Bereavement Service components came in handy.

As part of our Bereavement Service we offer a few different things. The service has helped provide some comfort and help to families who can go on to experience grief complications associated with experiencing a death in critical care. So we offer memory making in the form of hand prints, hair locks and hearts. During the pandemic, many people in the community across the UK were trying to come up with something that may benefit those who lost family members during Covid. This is where the knitted hearts concept came from which we found to be very thoughtful and touching. The idea was that a heart remained with the patient and one was sent to the family member at home to provide some form of connection during such a hideously tough time. Knitted hearts were sent to us in abundance which was so kind but the decision came to move to glass hearts due to the fear of cross-contamination of Covid. Some families, due to the suddenness of some deaths on the unit, have no recent, tangible memories to hold onto when someone dies. It has proven beneficial to some families to have these provisions offered to them and presented nicely in a little box. This allows families and children the opportunity to have something to cherish and hold onto whenever they wish to revisit their grief. Children’s charities such as Winston’s Wish also recommend memory boxes for children to help them process their grief during the course of their lifetime.

We also provide a booklet with lots of useful information called ‘When Someone Has Died’. This booklet contains information from how to register a death during Covid, what grief symptoms to expect and who to contact for extra support and advice such as GPs and counselling charities. Within this booklet we also include information on our own nurse-led Bereavement Service and how to contact us. We have a dedicated phone number and email address should families wish to discuss any aspect of care or have any questions down the line. This booklet was in existence prior and during Covid but we had it sent out to families’ home address during the lockdown period.

Furthermore, we collect the most suitable family member’s home address to send them a follow-up card 4-6 weeks post death mark. This card is so important as it helps to signpost available bereavement help such as a chat with an experienced nurse or a consultant should there be anything they wish to discuss. The card has a bereavement care label attached to alert families of the content. We certainly do not wish to cause any harm or additional upset. This card generates a significant response, whether it’s just to say thank you for the thoughtful card or a call to organise a chat with one of our bereavement nurses. Without this key prompt which acts as an invitation at such a well-considered time point, many families at home feel like they cannot contact us any more, wrongly assuming that we are too busy and that we may have forgotten about them. Prior to receiving this extra contact from us, we do encourage nurses to spread the word about bereavement follow-up to families so they have, they have the option to decline if they wish. Not every individual case presents itself suitable for follow-up. Some patients present with no significant other or at best, very estranged family members or friends. In situations like these we tend to document and miss out.

Lastly, we’ve also developed a carefully and sensitively worded anonymous survey that aims at capturing feedback on end-of-life care and bereavement care on our unit. This is a completely optional survey sent out at the 3-6 month mark. Data collected is currently being analysed as a way to help influence and guide us in our current practice. Allowing families to express their thoughts and feelings about such a difficult time in their life and providing a suitable platform from which they can do that, whether personally chatting to one of us or anonymously via our survey, can be incredibly beneficial. One of our newer components that we’ve added this year as a result of an ongoing improvement project is the offer of a follow-up call. Again, this is only if the family request this via an invitation sent in their card. So they can email us requesting a call back at a time that suits them and us. The uptake of this offer hasn’t been huge so it might be something we review as we go on.

From what we understand about grief and bereavement following a death in ICU, the setup of our own service maintains an open door policy for families to get in touch via a more professionally organised system. We understand that the suddenness of deaths that can occur in our unit are traumatising for families both pre-Covid and during. The shock and suddenness of what can be described as complex and highly medicalised deaths can mean that families go away and develop questions over time. These questions, unless welcomed, discussed and answered, can lead to complications with the grieving process further down the line. Therefore, we welcome families to get in touch with us should they wish to discuss any aspect of care. This is a nurse-led service supplementary to the generic Bereavement Service within NHS Lothian which is also available to families. Our service, which has proven to help many families over the years, offers the chance to chat to experienced nurses about any aspect of care. If more complex chat or more detailed information is required, then a member of our Bereavement Service will link in with the most suitable consultant and arrange a meeting to ensure that families have all their questions answered. I will discuss examples of commonly-faced scenarios that bereavement BOP deals with in a second, but first let’s just recap on what we feel the benefits and limitations of running such a service are.

So the benefits include families have a more appropriate avenue in which to contact critical care directly. They may go through the wider NHS Bereavement Service but if there’s something specific in relation to the care received in our unit, then families will invariably be transferred back to us. At least this way, families feel like they can contact us directly and via a suitable number and email address. If they were to contact the unit directly, then there could be issues with nurses having to look up details and take a message, not to mention the interruption to clinical care that this would cause. Families can chat to a nurse or consultant without having to explain what they’ve gone through from the very beginning. We’ve inside medical knowledge available and are able to answer questions and put families in touch with the right medical personnel should that be required. With myself leading the service and the experience I have, I’m confidently able to discuss and recommend counselling options or a suitable children’s bereavement charity option should that be required. The wider critical care team, medical and nursing, can rest assured that there’s someone available to pick up on any potential issues, organise meetings and liaise with families or consultants, of course, with the help of our wider network of interested bereavement follow-up nurses. Last but not least, we can help provide the sort of assurance that families are looking for that might not otherwise be able to be gained from chatting to GPs or counsellors.

Limitations include, so my time is limited as I’m a clinical nurse with additional responsibilities including helping manage a team of nurses. Generally I do what I can whilst on shift if there’s time. But if there have been, there have been occasions where I have come in on days off to help facilitate meetings. That said, this type of service only really functions if there’s a lead nurse operating it and delegating jobs so that the workload is shared. Some inconsistencies have occurred with the running of the service. This includes the failure to capture some families’ home address so that we can actually send the card highlighting what’s on offer. Without this some families will go away not realising that our service exists. We’re working on, on improvements just now to correct this issue. Nurses on the floor, given such a high turnaround with new nurses starting all the time, will not immediately know about our service or some of the other components that are on offer such as memory making. Therefore, there may be inconsistencies in terms of the level of support and what’s offered to families during such a crucial period where we only have one opportunity to get things right. Again, as part of a wider improvement project, myself and others have been working on ways to develop an educational package that aims to iron out any inconsistencies.

Now I shall talk about some of the common issues that we encounter and help to resolve for families if and when they do contact us. The most common scenario that we come across and help discuss through include family members completely forgetting what caused the death of their loved one due to shock and trauma, as well as the complexities of illnesses that we deal with. Although our multidisciplinary team in critical care spend a lot of time before and during the course of palliating patients ensuring families have complete trust, acceptance and understanding of the situation, we often hear about family members struggling to remember the timeline of events or the more finer details of what led to the death of their loved one after they leave our unit. These questions cannot be answered by GPs or counsellors so we therefore realise how essential it is to remain accessible to families should they require help with this. We also receive calls from families who wish to chat through things to help alleviate guilt. Guilt is a common feeling that plague family members for a long time. Again, affecting and causing grief complications. Examples of this include family members blaming themselves for not calling an ambulance in time or not providing effective CPR or not recognising the signs of a serious head injury and delaying hospitalisation. These situations are harrowing for family members and our bereavement follow-up nurse representatives. However, because of our in-depth knowledge and experience behind some of these events, we can and we will try to help alleviate and put families’ minds to rest. Family members find it particularly beneficial talking to an experienced critical care nurse who’s already had background knowledge of the event that’s occurred without families having to explain it all again to a stranger. They feel like they can trust us not to judge them and a lot can be gained via active listening and just being kind and empathetic. Of course we’re not trained counsellors. However, we can help families via active listening, providing some emotional support which is what we do and what we’re experienced with anyway during our day-to-day jobs. We will, of course, always advocate the benefits of counselling and will help direct families to engage with one of the many charities that exist out there when they feel ready.

The Covid pandemic has raised a few different issues for families. Visiting restrictions meant for some families that they couldn’t come in to see their family member or not at least until the patient was actively dying by which point the patient may be less alert and uncommunicative. We’ve chatted to family members struggling to come to terms with this and we’ve had to provide a lot of reassurance that their family member died comfortably and not alone, that a nurse would have been present with the patient the whole time. The daughter and son of one family who lost both parents to Covid on our unit within one week got in touch with us to go over a few things. They both mainly wanted reassurance and clarification that we’d done everything we could to help save their parents. Both parents were relatively awake when they died. The daughter who was not allowed into the unit, was not allowed into the unit because she’d not had Covid before was allowed to speak to her mum and dad via a video link. She was effectively watching them die. This has really long-lasting effects on the daughter who at the time lacked assurance that her mum and dad weren’t in any pain. We were able to go through things with her on the phone and reassure her that their comfort was our prime focus. Being able to seek that type of assurance has really benefited family members, particularly during the time when family members were not able to visit. This type of situation has thankfully all changed. This year alone over 35 families with various queries and concerns were in contact with us. Sometimes family members just call to give thanks for the card they received in the post and the exceptional care that their loved one received. I always make sure to pass on compliments and thanks to the wider team. This feedback does engage the team with the ongoing provision of our care.

So, last of all, I just want to touch on our ongoing, ongoing improvement project. We were successful in securing funding as part of the Building on the Best grants from the Scottish Partnership of Palliative Care towards our quality improvement project. The project is led by myself alongside a group of highly specialised individuals, nurses and medics, all named on this slide here. So we set out to improve the quality of bereavement care experienced in critical care over a 12-month period by developing and working on what we already do. We’ve outlined four main objectives. So we’re… number 1: We hope to improve the processes involved in the components of the current bereavement care programme by ironing out any inconsistencies. 2: We look to enhance the programme with the introduction of the telephone follow-up at the request of the family member. Number 3: We’re looking to introduce a bespoke educational programme for nurses to support communication with family members during end-of-life care. And number 4: We’re looking to improve our understanding of bereavement care pathways following on from intensive care via the organisation of a stakeholder engagement event. Once complete we’d like to share our learning across other ICUs in Scotland.

As discussed earlier, we recognise that there were some logistical issues preventing families from hearing about our service. Given the busyness of our unit we were struggling to gather the next of kin address. Identification of bereaved family members eligible and collection of family correspondence details is crucial to facilitate our follow-up service. Initial work identified that we’re not consistently achieving this process, thus affecting the quantity of families who receive a card signposting available care. Compliancy of offered memory-making via a review of nursing documentation was also suboptimal. In short, we’ve successfully managed to work towards improvements with a focus on providing more education, streamlining documentation, delegation of roles, and the biggest of all improvements, the allocation of dedicated time allowed to focus on running this additional service. The funding provided was partially granted to allow two office days a month which has hugely contributed to the success of this objective. Sending correspondence requires time to ensure accuracy of families receiving follow-up and time to respond to families requesting help and advice. We also have included the option of a follow-up call if requested as an additional component which we’re in the midst of trialling.

Our bespoke educational programme also looks to enhance nursing confidence in communication during end-of-life care using a specific framework. This is something we’ve tested with significant positive feedback. Lastly, we wish to expand our knowledge of bereavement care pathways following on from intensive care. An organised stakeholder engagement event with experts in primary and tertiary care sectors will help enhance our knowledge of these pathways and help identify and define the purpose of our bereavement support service as something beneficial in amongst everything else that exists out there. Thank you so much for listening. Are there any questions?

NC: Thanks, Janine. I think, you know, everybody will agree that’s really impressive work and one person actually commented that, that their mum had come to see you a few years ago and the staff were amazing and supportive and she’s still here to tell the tale. So I think that’s, that’s really great to hear I’m sure for you. There’s a couple of logistical questions that were in before and I see there’s some more coming in so we’ll, we’ll, I’ll get to them in a minute. But I think there was a couple of questions around how many staff are involved in the Bereavement Support Service and, and does it operate seven days a week? And, and a similar one about how many staff and hours are allocated on an average week? So really, sort of, some of the logistics I think people are interested in to how it’s run.

JW: So, well I’ve been operating and running it for the last six years and generally I operate a rota system. That’s, kind of, not worked out over the last, kind of, few years or so just because of the busyness of our unit. So it has required me leading it but obviously I can’t do everything at once so I do delegate to those who are part of the Bereavement Service as required, just to avoid them having to come in on days off, etc. So we do have... Our nurses are split into four teams. We have nurse representatives in each of the four teams to, kind of, ensure that we’ve got cover most days of the week basically. So that’s how we tend to operate it. But generally, in terms of sending out cards, I would say it’s generally me that does that just to make sure that we don’t make any mistakes and we do have, obviously, a robust guideline in place just to ensure we’re, kind of, ticking all the boxes correctly and making sure we’re missing out families that have requested not to receive any follow-up.

NC: Thanks, thanks for that, Janine. Another question here and I think this is, this is, you know, certainly something I thought about when I was reading your transcript, was that, you know, it, I think people appreciate it’s been such an intense and difficult time for everybody [inaudible] the workforce, and, and how did you find time for your own debrief and self-care?

JW: Yeah, so certainly having to look after yourself is important. Just working with the team that I work alongside is incredibly helpful. Obviously we, kind of, chat all the time behind the scenes as to, kind of, what’s going on. We’ve been lucky to receive psychological support from the team downstairs. They’ve been up with us, working quite closely with us through the Covid pandemic which I found really helpful. My partner works in critical care as well so that’s also very beneficial for me, and obviously just to have someone that understands, like, some of the stuff that, kind of, goes on in the unit. And actually just having the team of nurses that are interested in bereavement follow-up as well has been so helpful because obviously we can work together and obviously I’ve got a few go-to people that I go to for advice and the consultants have all been really supportive of the follow-up service that we provide now. Probably more so after Covid given that some of the unusual situations that we’ve, kind of, had to deal with. Obviously we, we knew that we had to like, basically pick up on families that were lacking any, kind of, information or, you know, assurance that they... Especially if they weren’t there to, kind of, witness their family member dying.

NC: Thanks, Janine. Sorry, more for you. I have got, I have got a question for you, Naz, in a bit. But I’ll get through these ones first Janine if that’s okay. Something here about your educational package and there’s a question here about, ‘Do you think your educational package would be valuable for other professionals working in critical care units?’

JW: Yeah, absolutely. We’ve linked in actually with a palliative care consultant, Kirsty Boyd, who’s developed a specific framework called the RED MAP Framework, which can… she teaches EC4H communication tools basically which can be applied throughout health care, not just ICU. And this was something that we basically adapted and tweaked to suit ITU scenarios that nurses, kind of, go through. And we trialled this back in September and we received some really good feedback. So we, kind of, basically selected one of many scenarios that nurses can obviously have to go through with family members at different points in, you know, the palliative process. So we basically, kind of, did a webinar where we, kind of, did a mock, kind of, conversation with a family member and how the nurse dealt with that using the framework and that was incredibly beneficial. So we’re hoping to do another one in January. And obviously the feedback and results that we’re getting from the, the survey, pre-webinar and post-webinar, are, kind of, showing that our educational package is beneficial. So it could definitely be rolled out across other ITUs.

NC: Thanks, Janine. I’m going to give you a bit of a break now and I’m, I’m going to come to, come to Naz. And this is actually something that I thought about after, after listening to what you were saying about the impact of family disagreement in decisions around end-of-life care and, and the fact that, you know, that has such an impact on, you know, on their grief journey afterwards. And just wondered if you could say a bit about, you know, the importance of, or how you see the, sort of, anticipatory care planning and how you get that, you know, because quite often, as you, as you suggested, people at that stage are not able to make decisions for themselves. So what, what is important to do and think about?

NL: Yeah, definitely. I think that probably is one of the things, as anticipatory care planning has become a bit more common, that’s very helpful in those discussions. When we have those discussions, perhaps for the majority of the time there hasn’t been anticipatory care planning and often we end up with situations, even when people have a formal power of attorney, they have never actually discussed with the person, how they would view what treatments would be beneficial or even what quality of life they find acceptable, given that in critical care, if people do survive, people can often end up with some sort of impairment as well. So given that, our conversations at the time, when the majority aren’t framed with any knowledge, are very carefully trying to understand what the patient’s view might be of these things, and trying to make sure that family members or friends are not thinking that this is their decision that they’re having to make. I think that’s one of the most important facts we try and emphasise. Maybe, I think it’s perhaps American TV shows, maybe in British TV shows, where it very much seems to be family members have to sign something or making sure they’re not responsible and yet some people frame it as, you know, ‘I don’t want to be the person who’s flipping the switch’, that’s a whole idea as well, so it’s really trying to move away from that and explain the process here is us trying to understand the individual as best we can because they can’t be here in the room with us having this conversation. They’re the person we’d want to have this conversation with really. I think one thing with Covid that’s happened, there’s a lot more awareness of critical care and the consequences of what the ventilator is, that’s something very new, and unfortunately quite a lot of misconceptions as well and real concerns read about and that’s been in the press about people being denied treatments because there aren’t enough to go around. So, that’s never been the situation for us, thankfully, in our unit but it makes the conversations even more challenging then to try and navigate those.

NC: Thanks, thanks very much for that, Naz. I, I know we’re getting short on time now but a couple of, of other questions, Janine, that have come in about, about the work that you do. One about signposting and, and who… somebody asking who you signpost to for, for bereavement follow-up care other than, other than Cruse? And also a question around what staff, do you have a set of staff who are dedicated to children’s area, or is there just, kind of, cross-cover and does that, you know, just thinking about that, childrens’ bereavement services differing from, from adult bereavement services. So I don’t know if you can maybe pick them up, Janine.

JW: Yeah, so the booklet that families receive as well, they go home with this. All families will receive a booklet with a list of all the kind of, support services that exist including obviously Cruse but many, many others. It’s a bit of a minefield out there in terms of how many charities exist out there. So obviously I’ll mention a few of them like Cruse being the main one obviously and I’ll always advocate that they do chat to their GP as well. But sometimes I’ll advise them going just to the NHS Bereavement. There’s like, on the internet there’s like a list of support services there as well. Sometimes it just depends on the type of death that’s occurred. If there’s been a suicide, that type of thing, there are specific dedicated charities that deal with bereavement after that. Children, so there’s not a specific person that deals with it, but it’s kind of me, it’s very kind of, cross-cover. Again, I’ll just be mentioning to the families any local charities that exist like Richmond’s Hope or Winston’s Wish, giving them the option. But usually I just refer back to the booklet they, they received but quite often families do get in touch with us when they receive the card because during all the shock and trauma after their loved one’s died, they forget even having received all that information to begin with. So usually it’s just a case of me reiterating what they’ve already kind of, received or, you know, to kind of double check to see what’s in that book, what might suit them. But there’s a lot of helpful websites out there as well.

NC: Great. Thanks, Janine. And there’s some helpful chat going on that people will be able to have a look at as well that are on the call. I think our time is, is about up so I think we’ll just stop it there because I don’t want us to get cut off mid, mid-speaking. So just really to thank both of you for, for sharing your experiences and, and the information that you have today. And, you know, I’m sure colleagues who have been at the session will, will know where to get you and get in touch if there’s any further questions. And, so, yes thank you and enjoy the rest of the conference, everybody.

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/691484194](https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fvimeo.com%2F691484194&data=05%7C02%7Cbecky.mccoo%40nhs.scot%7C68a7a8da2d014cf7e5de08dc5325f924%7C10efe0bda0304bca809cb5e6745e499a%7C0%7C0%7C638476670045732071%7CUnknown%7CTWFpbGZsb3d8eyJWIjoiMC4wLjAwMDAiLCJQIjoiV2luMzIiLCJBTiI6Ik1haWwiLCJXVCI6Mn0%3D%7C0%7C%7C%7C&sdata=D%2BwLV9xfuLr579WaVYfA2VZ%2FOBfweSDAmpriCdfGuCA%3D&reserved=0)

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

© NHS Education for Scotland 2021. You can copy or reproduce the information in this document for use within NHS Scotland and for non-commercial purposes. Use of this document for commercial purposes is permitted only with the written permission of NES.