RCPE Casenotes: Past & Present Podcast - Palliative Care Transcript

Narrated and curated by Dr Daisy Cunynghame, heritage manager and librarian at the Royal College of Physicians of Edinburgh.

[introductory music]

Welcome to the Royal College of Physicians of Edinburgh's Casenotes podcast. Over the next few months we're going to delve into the different physician branches or specialties.

Just to start off with, what is a physician? Most people know what a GP is, and what a surgeon is, but not everyone knows exactly what a physician does. Well the formal description is specialists in internal medicine, so diseases and complaints that happen inside your body.

And even if that sounds unfamiliar, you have almost certainly heard of a lot of the areas that this covers, like cardiology, diabetes, allergies, palliative care, infectious disease and neurology. These are all branches of medicine, or specialties, that physicians are responsible for.

In each coming episode of Casenotes we will pick one of these specialties and delve into its history, looking at its development over hundreds of years, and some of the interesting stories and cases from the past. We'll also talk to a current physician working in that area, to find out what it is like to be working as a specialist physician in the twenty-first century.

[musical interlude]

In this episode of our Casenotes podcast we're going to talk about palliative medicine. We'll start by looking at some of the key moments in the history of palliative care, and then we'll talk to a specialist working in the field in the twenty-first century.

Palliative medicine was formally recognised as a medical specialty in the UK in 1987. But end of life care did not begin there, and for hundreds of years before that physicians had been thinking about, and writing about, the need to make sure that for those for who cure or recovery was

impossible, their care was as pain free and as minimally distressing as possible.

So we'll start in the early nineteenth century. Dr Carl Marx presented his thesis titled *De Euthanasia Medica* in 1826. He began his thesis by asking what can be done to make the passing from life "gentle and bearable" and he then laid out 3 principles: the first is foresight – the watchful attendance of doctors and nurses to ensure the patient's comfort; second is the avoidance of suffering – focusing on easing or eliminating pain with medication; third is the pursuit of higher comfort to relieve agitation, fear and despair. Marx said doctors,

"With no shining ray of hope remaining, consider it their more lofty duty to lay peaceful rest a life they can no longer save. Accordingly, they will extend their energy and their affection, they will follow each successive turn of events, they will apply palliative whenever they can, and with an all-caring heart they will put themselves in readiness for the great event, so that the last breath of passing may be light and not dreadful to those left behind."

Half a century later, in 1887, William Munk published *Euthanasia, or Medical Treatment in Aid of an Easy Death*. He was using the word euthanasia in its classic sense – helping patients die a comfortable death. He claimed that the moment of death is not as painful as it is often feared to be. Munk believed suffering is not necessarily a part of the act of dying, but often caused by circumstances that can be changed. He recommended opium to relieve pain and anxiety, saying "It must be administered in such doses as will appease suffering, and in this respect we are to be governed solely by the effect and the relief afforded".

Moving into the early twentieth century, Alfred Worcester, Professor of Hygiene at Harvard, published *The Care of the Aged, the Dying and the Dead* in 1935. This was during the early days of the hospice movement in North America. Worcester outlined what medical students should be taught, saying that "the indispensable qualifications of the physician", "tact and courtesy, sympathy and devotion…in the practice of our art it often matters little what medicine is given, but matters much that we give ourselves with our pills."

Hospices have existed, in one form or another, for over a thousand years. The word hospice has the same root as hospital, hotel and hostel. All these terms for a long time were fairly interchangeable and into the nineteenth century a building called a hospital could still mean a residential institution for a boarding school or a home for incurable patients, rather than what we think of a hospital as being in the twenty-first century. And similarly a hospice could mean a place for treatment and cure rather than a home for the terminally ill. So we can't always go based on the words that are used, we have to look at what they actually meant.

The 'hospice movement' as we think of hospices today began with Dame Cicely Saunders. She founded St Christopher's Hospice in 1967 and she brought together, for the first time, terminally ill patients and staff who were committed to discover and then teach the best ways of caring for them. She encouraged studies in many aspects of pain control, including a comparison between orally given morphine and diamorphine. This was at the time when it was generally accepted that strong opioids were only effective when injected and addiction was inevitable if they were given regularly. Her leaflet entitled "Drugs commonly used at St Christopher's Hospice" evolved into the *Oxford Textbook of Palliative Medicine*.

Saunders taught internationally and was the author of over eighty-five publications. She received honours from many countries including twenty-five honorary degrees. In the next few years following Saunders' work many more hospices were opened and increasing numbers of physicians began to specialise in palliative care. In 1987 the UK made palliative medicine a subspecialty, the first country in the world to do so.

Dr Derek Doyle, Fellow of the Royal College of Physicians of Edinburgh, is another key figure in the history of palliative medicine. He worked in a hospice in Scotland and lectured at Edinburgh University, helping to establish the new specialty of palliative medicine. He went on to establish the first hospice in Scotland, St Columba's Hospice, in 1977. Doyle has written or edited many books including the prestigious *Oxford Textbook of Palliative Medicine*. We're going to hear a short clip from Doyle, recorded almost twenty years ago, about the establishment of palliative medicine. The audio quality isn't amazing, but hopefully you'll forgive us because [of] the fascination of hearing first-hand

insights he brings to the subject of the development of palliative medicine.

Derek: I feel very strongly, though, that palliative medicine had an identity of its own, which is no credit to it, but I think it had some unique features, and as I've often said to audiences, and we are not a unique feature, I don't think it is us that's unique, we were just ordinary people that were taught to care. But I think the unique thing is that we live in a society where loss and death is, loss in any form, is something to be avoided. I mean, loss and deformity never did anybody any good, because of an interest in history I think that [unintelligible] is quite true. I don't want people to be [unintelligible], or deformed, or harmed in any way, but in fact history shows that a lot of the people that were contributors to society, to the world, who in fact had chronic illness or deformity or deafness or whatever, and God forbid that we should wish that upon them, but having loss doesn't necessarily mean disaster, and yet I think we live in a society which is, thinks that anything to do with loss is a disastrous thing. Palliative medicine says it's not.

https://www.youtube.com/watch?v=Pppx5JxinIY

[musical interlude]

That was Dr Derek Doyle, speaking during an interview in 2006. But now to hear from one of the College's current specialists. At the end of 2021, I spoke to Dr Jeena Ackroyd about her experiences working in palliative medicine.

Daisy: So thank you so much for joining us today, Jeena. So could you just start by telling us a little bit about who you are, what your specialty is and where you work?

Jeena: Thanks Daisy, my name is Jeena Ackroyd. I'm a consultant in palliative medicine based in Calderdale in West Yorkshire. I've been a consultant for over thirteen years now.

Daisy: So how would you define palliative care and the work that you do?

Jeena: Well, I could probably talk all day on that subject, but palliative care or palliative medicine is very much about looking after patients who have an illness, when there's no longer, I guess, a cure. So they have a life-limiting illness, and what we do is not just focus on the illness, but look at the patient as a whole. It can sometimes be deemed as a 'palette of care' in a way, because we do so many different things. I think the important thing for me is that it's very much about the patient themselves, not the illness, but how they deal with it. They may have physical problems but they may also have psychological or social concerns, and it may also be how they are with their family and how other relationships affect them as well.

Daisy: So is there anything that would surprise people about palliative care or anything that people might not know about how this process works and what you do?

Jeena: Obviously it's still a, it is a recognised medical specialty and I think sometimes people assume in palliative care there's a lot of hand holding and drinking cups of tea and it's very much a sort of, sort of a very gentle kind of softly softly specialty. But actually it can be extremely challenging and remain quite medical, in that patients often have quite complex symptoms or complex needs, but actually we often get referred or involved with cases because other treating teams are struggling. So in a way it's kind of an extra layer of expertise, I think.

Daisy: Thank you very much. Yes, definitely a pretty varied experience. So what drew you first to the specialty of palliative care? Why did you decide this was going to be your focus?

Jeena: Good question, I think as a junior doctor, so I did my MRCP training, which was essentially getting a taste of different specialties, so towards the end in my, sort of, final, I think in my third year, I started doing haematology and then I was due to do respiratory, and actually when I did haematology, what I really liked was patients were often on the wards for quite a long period of time, and what I noticed was the nursing staff seemed to get to know the patients really well, whereas as a doctor I was just kind of going in and doing the interventions or the treatments or the investigations and then dipping out again, and I kind of missed sort of having that connection sometimes with the patient. So it just made me think actually which specialties could I potentially get to

know the patient as a whole, and not just look after a particular aspect of them, but look after everything that's important to them. And that drew me to oncology, so I then actually chose to do oncology after haematology, and there I got a flavour, because at that point there was a visiting palliative care consultant who would come and review patients, and that's when I thought, actually, I'd really like to do this specialty.

Daisy: Thank you very much. So you may not be old enough to be able to answer the next question, but I'm interested in how palliative care has changed over the course of your career. Have you seen any significant changes, do you think, or not?

Jeena: I'd love to know how old you think I am Daisy, I'm quite old! I think what has been, I guess, interesting is where, when I first started doing it the majority of patients were cancer patients, and I think as you get older you start feeling like the patients are getting younger, and I think it does feel that we're getting younger patients now, maybe in their twenties and thirties who are struggling, who are, you know, dying and they need our specialism. So I think that's probably what I've noticed. I think with advances in treatments, particularly in oncology, people are living longer, and that's fantastic, but it sometimes also brings more complexity to their illness and more difficult symptoms, and also they're then living with that uncertainty, of living with cancer potentially as well, so I think we are sort of seeing different trends. We're also seeing people who are living longer, so we're getting to know them more, rather than just being people that are potentially just with us for the last few months of their life, we're seeing people who might live longer than that, maybe a year or so, which is quite different to when I first started. And also what we're potentially looking at now is maybe more transitional patients, these are patients who have got illnesses that maybe would have died in childhood who are now living into their adulthood, who potentially might need adult palliative care services too.

Daisy: So I guess, you know, following on from, you know, what changes you've seen to date, do you have any thoughts on how you think palliative care treatment is going to change in the future, you know, ten years or even more kind of down the line, where things are going?

Jeena: I think I'd like to be, and I envisage that palliative care's going to be much more integrated with other specialties, so in a way patients will

be aware of us much earlier on in their disease journey, rather than waiting so we don't come at the last minute, when people are hitting a crisis and time is getting short, we're able to build those relationships earlier because people are understanding that actually, they have a life-limiting illness, they might be living longer but they may have complexity within that illness that needs managing from a palliative care perspective. So I think that's where I can see our role being much more integrated with other specialties, rather than just an add-on at the end.

Daisy: No that makes a lot of sense. So you know with everything that you've said about some of the challenges in your work, but obviously also what you like about it, there may be people listening to this who are thinking about a career in medicine or who are medical students. Do you have any advice on if they are potentially interested in palliative care, how you get into that work or what's the best approach?

Jeena: I think it's always useful, I mean as a, when I was thinking about doing medicine I actually did volunteer in a hospice, so I had a bit of experience in understanding what palliative care was about. People obviously may be touched by palliative care through their personal life as well, so may have experienced it in that way as well, but I do think a lot of it is about resilience and understanding the challenge of working with, and making a difference to, people who ultimately are not going to get better, cause I think sometimes people will view palliative care as, well, how can you do that specialty? No one gets better, everyone's doing to die, how do you carry on as a, you know, as a physician? And I've never viewed it like that because I feel it's still just as important to make a difference to someone, even if I can't, for example, fix their broken leg or, you know, take away something with a medicine, I can help their symptoms, I can help explain some of their worries and thoughts, and in a way I think it's the best of both worlds because I get to be a doctor and do some of the medical stuff – examine patients, pick up signs and symptoms – but I also get to know the person, so it's the different layers that I like about this specialty.

Daisy: No thank you, I mean that's really interesting and yes, I think it's good to get some advice from somebody who knows about how to make that step. So we've talked about the present and the future, so I kind of wanted to go back round and talk about the past a bit. So earlier on in the podcast I talked about the history of palliative care, and I'm

interested in if there are any moments in the history of palliative care, or any people that you found interesting or that have influenced you in any way. So I'm not just talking about, sort of, ancient Greece and Rome, but also kind of, you know, people maybe who are alive now. But yes, are there any sort of standout moments from the past of palliative care that you think about?

Jeena: I mean, the name that everyone knows is Dame Cicely Saunders, cause she was the one who brought in the hospice movement, and it was then sort of recognised as a specialty in itself. I think the person at the moment that has been really great for me, particularly from a palliative care perspective, has been Dr Kathryn Mannix, who has written a few books, *With the End in Mind*, and her new book is called *Listen*. I could listen to her voice forever, so if anyone gets the chance, she's done a lovely podcast for the BBC, "In my honest opinion", where she talks about, it's so eloquently, about the last few moments of dying, and this has really helped actually, any doctor who has to deal with dying patients, explain it to families, because often they find that quite distressing. So what I was liked about it was that she made it normal, she normalised it, because death is the one certainty in life, so to speak – we shouldn't be afraid of it, and actually if you know it's going to happen we can make such a difference, and it is about being open and honest and listening and having those really difficult conversations, because I think sometimes we worry about having those conversations, and actually they're not always as bad as you think. These are kind of the themes that Kathryn talks about, that I think have been so useful, and she's also tied it in, I think, there's been an actor recently, Greg Wise, who has talked quite openly about how he looked after his sister, when she died recently, so I think it is about being open and talking about it. We shouldn't feel, you know, kind of embarrassed to say I'm a palliative care doctor, I'm a physician, because I think there's always this assumption, oooh, don't talk about it because we don't talk about dying.

Daisy: Well thank you, I think that's probably the stereotype that I had in my head that, you know, if you were at a dinner party or something and you say that you work in palliative care then, you know, everyone goes quiet, I don't know if that's how it works.

Jeena: It does, it just everything goes quiet. I'd be better saying I worked in a shop or something, but yeah.

Daisy: Yeah, it's difficult to know exactly what the follow-up is to that. So yeah, the next question I'm going to ask is probably a bit tricky, potentially a bit tricky for palliative care, but I'm asking every sort of medical specialty. Is there one object, one tool that you would think of as associated with your specialty or that you really rely on in your work?

Jeena: Ah, in that respect I would say it, oooh, I was going to say it's sort of about about listening with your ears, listening to the patient, because sometimes I think, I feel in myself I haven't really done anything for the patient, but it is that I've just listened, I've kind of understood what their worries are, and sometimes that can make a huge difference. OK, yes I do have a stethoscope, and I do use other medical equipment, but I think it's just being that presence. I, you know, it's weird because I think people think, well palliative care consultants have got all the time in the world, you know, they spend hours seeing patients, but I probably would view myself as being one of the most impatient people ever, but when I'm with a patient I ensure that I, that's what I'm doing at that time, I'm there for that patient, and I think that's a big thing for me is my ears, listening to what they're saying.

Daisy: So we're recording this in December 2021 and so there is a question or a topic that we can't really avoid bringing up, which is the coronavirus pandemic. So how has that, or has that impacted on your work, and what sorts of changes have you seen as a result of the pandemic?

Jeena: I think for myself and particularly my specialist nurses, throughout the pandemic they have continued to see patients face-to-face. Referrals have continued because patients have needed them and we have just continued to see patients as we can. So, what they've noticed is it's been harder, particularly in the community, where other services have not been as face-to-face, so they've often had to be the eyes and the ears of say, the primary care team, so the GPs, who will then do a video consultation while they're with the patient, so it's been a very different way of working for them, but also quite highly pressurised way of working, because suddenly they're almost being a doctor and a nurse and a physio and everyone else who isn't able to be there at the

time. I think personally I have struggled with, at one point I was trying to avoid my patients coming into hospital to see me in clinic if they didn't need to, so I was doing a lot more video or phone consultations, but a lot of my patients really struggled with doing video, and on the phone I just felt personally I couldn't get a good picture, so I was doing more home visits, if I hadn't met a patient before, because I feel it's important to sort of build that rapport to do a face-to-face consultation, but that's because that's my group of patients. I think for certain specialties virtual consultations can work really well, I think in palliative care you just have to pick and choose, but there's definitely a group of patients where it's harder to do that, so I think that's where I've noticed the real difference. And also patients are asking now, can I come and see you? So actually they miss that human contact as well.

Daisy: And do you think, and I know that this is sort of impossible to predict, because, you know, it's a pandemic, but do you think that, you know, there will be long-term changes or differences as a result of COVID, you know, in a year's time or two years' time, will the way you do things in terms of, you know, more virtual, sort of, meetings and so on, do you think that will continue?

Jeena: I think it's been fantastic with regard to MDTs, so for instance I used to have to travel every week, either to Leeds or to Huddersfield, where my, the other part of the hospital is, for a weekly clinical review meeting, which we now do virtually, and it's been fantastic just thinking of the amount of time I was travelling every day in the car, that I can now do it, quite efficiently, on Teams or Zoom, it's brilliant. So I think that will stay. You know, if we don't all have to go to a neighbouring region, and we can all meet on Teams or Zoom, it makes a huge difference. I think for me I think it probably will depend on the patients, some patients are happy with phone calls or videos, but a lot of patients actually do want to be seen and want to come in and are happy to be seen, happy to come in, so it may be around patient choice, or saying actually I saw you last time, if things are stable I'm happy to do a phone follow-up, or I haven't seen you for a bit, actually it would be really useful to see you. I think having that flexibility in medicine is probably really helpful.

Daisy: Thank you so much Jeena for joining us, that's been fantastic. It's a really fascinating insight and it's great to dispel a few of the myths or stereotypes surrounding palliative care, so thank you very much.

Jeena: OK, thank you.

[musical interlude]

For our case study we're going to look at the case of James Young Simpson. Simpson is one of the most well-known medical names in Edinburgh's history. He was one of the founders of modern obstetrics and gynaecology and is probably best known for his contribution to obstetrics through his discovery of chloroform as an anaesthetic to be administered to women during labour.

Simpson was born in Bathgate in 1811. He held the position of Professor of Midwifery at the University of Edinburgh for over thirty years. He was very progressive for his time – not only concerning himself with reducing women's pain during labour, but he was a supporter of women trying to enter the medical profession and he was a vocal opponent of slavery. In 1850, Simpson became President of the Royal College of Physicians of Edinburgh. But what we're really going to talk about now is the end of his life.

During Simpson's last illness, his nephew, Robert Simpson, spent many hours at his bedside and kept a diary, which gives a touching account of the last two months of Simpson's life. The whereabouts of this diary had been unknown for over a hundred and thirty years. It was discovered in 2006, amongst a bundle of miscellaneous books handed in by an anonymous donor to the Shelter charity shop in Stockbridge, Edinburgh. The manager, recognising its possible importance, contacted our College's library, and it now forms a valuable part of our historic collections.

The diary outlines the onset of Simpson's illness, visits from his family and friends, what books he liked to be read to him, and near the end, describes how his elder brother sat through the night cradling him in his arms. "It was most touching to see the elder brother – 14 years older than the younger, and who watched his progress with such fond affection – watching by the death bed. "Oh Sandy, Sandy," uncle repeatedly said showing he knew who was beside him." The final entry reads: "I moistened his lips, and while the others came in his spirit passed away. No struggle – no pain."

Simpson's contribution to medicine made him one of the most famous men of his time, receiving honours from all over the world. The day of his funeral was declared a day of public mourning in Edinburgh. Many shops and businesses closed, and two thousand people followed his hearse through the streets lined by over thirty thousand mourners.

[musical interlude]

Since we put this podcast together, I'm very sorry to say that Dr Derek Doyle, one of the people featured in this podcast, has passed away.

[musical interlude]

Thank you for listening to this Casenotes podcast. If you'd like to find out more about the work we do you can visit our website at https://rcpe.ac.uk/heritage. You can also find us on Twitter @RCPEHeritage. And we have a JustGiving page – https://www.justgiving.com/campaign/rcpeheritage – linked to on our website if you'd like to support our work and help to fund future podcasts. Thank you.