Last days of life podcast – transcript

Helping patients navigate the last days of life in the community can be a significant challenge for primary healthcare professionals. General practices will often have their own policies and practices relating to end of life care, reflecting the unique settings, demographics and resource constraints under which they operate.

In 2023, bpac[nz] published a **series of resources** with the support of Te Aho o Te Kahu, Cancer Control Agency, reviewing the essential components and considerations required to provide quality end of life care in the community. In support of this work, a peer group discussion was also released, intended as a prompt for general practices to reflect on their approach to care delivery, and consider opportunities for improvement depending on their particular circumstances.

The following transcript involves a conversation with several experts who champion efforts to improve the standard of end of life care within New Zealand. This resource expands on many of the key points that will likely arise during peer group discussions or during self-reflection of practice, adding another layer of perspective when considering how improvements could be made.

For the audio and interactive transcript version please see our website:
bpac.org.nz/2024/ldol.aspx

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Podcast transcript

Welcome, introductions and background information

Adrian Patterson (00:00):
Welcome everyone, and thanks for agreeing to take part in our discussion today around caring for patients in their last days of life. Specifically focusing on how this can be done in a primary care or a community setting. I guess we'll kick things off with a quick round of introductions before touching on the specifics of today's meeting. So I'll start. I'm Adrian Patterson. I'm a senior medical writer here at bpac^{nz}. I've got a background in biomedical science and I've been employed at BPAC for about five or six years now. I'm involved in the general research we do, pulling together clinical insights and recommendations into our tailored resources, which are targeted at a New Zealand primary care audience.

Sharyn Willis (00:42):
So I'm Sharyn Willis. I'm a GP. Been a GP for about 30 years now, but I've also worked for BPAC for the last, around 17 years. Basically because part-time GP was easier to cope with than full-time, but I still do the mix of some clinical days plus some days here at BPAC. So I help develop the resources, provide clinical input as needed and try and keep it grounded so that what I'm doing in my clinical days comes through and reflects in the resources that we develop. I feel it's a good mix of roles and really enjoy doing it.

Vicki Telford (01:19):
I'm Vicki Telford. I work at Nurse Maude in the palliative care team and I've been involved in implementing an end of life care plan in Canterbury since 2009, specifically into aged residential care, but some input into district nursing as well. So that's my primary role.

Kate Grandy (01:40):
I'm Kate Grundy. I'm a palliative medicine physician based in Christchurch. I've worked alongside Vicki for quite a number of years, and I was chair of the palliative care council at the time that the Liverpool care pathway was disestablished and we created the Te Ara Whakapiri programme. And so I kind of have been involved from the get go and obviously in my role in palliative medicine, which is really in the acute environment. So between Vicki and I, we kind of cover all the bases, not so much general practice, which is why the whole BPAC thing has been such a great innovation and a great opportunity for us as we have to get GPs onboard. Understanding and working collaboratively in this kind of unified space - to get everybody on the same page so that we're talking honestly and openly and collaboratively as health professionals, but with the patient and the whānau to help make sure that those end of life days and hours are as good as they can be.

Helen Atkinson (02:42):
I'm Helen Atkinson. I'm a GP and hospice medical officer and I'm currently working part-time at Harbour Hospice here in Auckland. And my role is split. I do some work with the clinical team in the IPU in the community and then I also have a role with the POI team, which works directly with the community supporting general practices and aged residential care. And my involvement with the BPAC resources came from my role with ANZSPM, so the Australia New Zealand Society for Palliative Medicine. And I use that role, I'm a committee member, to advocate for the creation of resources for the use in primary care. So this has been a bit of a dream come true really to see this realised that we've got this amazing resource that we can now share with all of our community palliative care providers.

Adrian (03:30):
Right. Well excellent. Thank you so much everyone. It sounds like we've got a great collection of people here today with some diverse perspectives on what is such an important topic. Before we launch into the specifics of today's discussion, I'll just quickly give a bit of background as to its context for our audience. So last year BPAC delivered a series of education resources around navigating the last days of life in a community setting. This was made with the support of the Cancer Control Agency and we were lucky enough to get insights to help its development from the panel of experts that are in front of you now. As Kate mentioned, our work

was largely informed by the principles covered in the Te Ara Whakapiri resource, which was published by the Ministry of Health in 2017 and later updated. And this aimed to provide a uniquely New Zealand perspective for guiding best practice during the last days of life.

Adrian (04:21):
It covered sort of all the essential components and considerations that it takes to provide quality and consistent care regardless of the setting. And the intent, I guess, of the BPAC resource was to provide a primary care perspective on this conversation. As we know that hospitals and hospices aren't necessarily the only places where people spend their final days and a significant number of people end up passing away in the community, whether it be in a residential aged care facility or in their own home. So navigating these last days of life in the community can be a real challenge for primary healthcare professionals as these situations unfold in such diverse ways. And it's really important to get things right both for the individual's sake but also for their whānau. So in support of the resources we released, we also produced a peer group discussion to help prompt our audience in reflecting upon their clinical practice in this context and to perhaps think about ways in which it might be improved. This resource involved two sets of questions. One was more generally focusing on the overarching principles of care and the other one was focusing on the specifics of symptom management. So the purpose of the meeting today is for experts to provide a little bit more of their insights to inform these discussions. I guess with that in mind, I'll now hand over to my colleague Sharyn, who's going to lead us through some questions with the experts addressing some of these overarching themes of care.

The role of general practice in supporting patients during the last days of life

Sharyn (05:51):
Thanks Adrian. Okay, I guess just to probably set the scene, if we start off with just generally some thoughts about how do you see the role of general practice in caring for people who are spending their last days of life at home? Is it becoming more common for this to happen? Are GPs themselves becoming the prime carers for some families? I know as a part-time GP, I find it a little bit difficult because of my lack of continuity. That's the one downfall of being part-time and that for that reason, it's not something I do very often. And generally my colleagues in my practice where I work who are there more on a full-time basis, tend to be the ones who take the lead role in caring for these people.

Helen (06:37):
Yeah, so I mean obviously working in general practice, I think I see being able to die at home and have normal dying at home as being central to working around what people want. Home isn't always the right place for people to die. Sometimes it's entirely appropriate to die in hospital or in a hospice, but if you want to die at home, then we want to support you to do that as best we can. And I think that's why this new resource is so important. And I really love the title of it, the Navigating Concept, because it really is a journey that requires many moving parts and often there are many transitions in this period, so it's not unusual for somebody to transition from hospital to home or to hospice to home and then back again to those environments in their last days of life.

Helen (07:23):
So I think we need to be able to provide the right care to the right patient at the right time. And so I think general practice is really well placed to do that. It just depends on which area of New Zealand you live in and the equity of access to those resources. I live in urban Auckland, so I am incredibly fortunate that I have access to all kinds of resources to enable people to die at home if they want to, including out of hours community hospice services, our district nurses, our ambulance service is amazing in supporting us. So I think people often do want to die at home, but they have to be given the confidence that that's an option. And that role starts in general practice when you are talking to somebody that you trust, like your GP or your nurse practitioner about "where do I want to do this?" It's having the confidence to offer it as an option as well and say to people "it's okay". And then to walk them through that process and walk alongside them.

Challenges associated with delivering community-based care

Sharyn (08:19):
So you mentioned there are different areas of the country; obviously the resources and access are quite different throughout the country. And rural practices I think also struggle with this a wee bit in terms of just having people on the ground to be there to help.

Kate (08:33):
I mean, I think interestingly, rural GPs are more inclined to support people with home dying. It's different around the country, the ability of GPs to support home visits. And I think that's kind of the elephant in the room. You can't look after somebody at home without visiting at the home. You cannot, and therefore if you don't do it, you cannot do end of life care. And I think we should stop pretending that you can do it by magic. You can support your palliative care nurses, your district nurses, ARC nurses, but you actually have to be prepared to physically go and see someone. And Helen will speak to this, but I don't even know that GPs have anything like adequate remuneration for what is taken to look after people at the end of life. And I think we should be leveraging off this work; if we genuinely want this to happen, we genuinely need to find a way to make this do-able for GPs. I don't think that it's" the GPs don't want to do it", I just don't know that they can afford to do it within their work.

Sharyn (09:44):
I know that certainly where we are we do home visits, but we are one of only a small number of practices that do home visits. When I first started in general practice home visits were you just something you did every single day. I'd spend my lunchtime visiting people. But it's become something, as you say, Kate, the cost of doing so and the cost not only in financial terms but in time constraints are the big problems that we face. And at the moment, obviously general practice is under stress and a lot of people are struggling to just do their normal clinical hours and their paperwork and just get through the day. So adding in that extra layer of trying to provide a really good service to someone who's dying at home might just be impossible because it's very time rich, isn't it? It's not something you can rush. So perhaps Helen, if you could just give some insight there, it would be great.

Helen (10:42):
Yeah, I couldn't agree more. I think general practice kind of is widely accepted to be in crisis across the country currently in terms of our resources being spread so thinly and a standard day in general practice is very much like being on the front lines. So carving out the time to go on a home visit is the first part. And then of course the remuneration for it is completely separate. In the practice that I've worked in, in Orewa in Auckland, I've worked with some phenomenal colleagues that give so much of their personal time on weekends before surgery starts, when surgery finishes. Most of these colleagues are similar to myself. They have young families at home and this time is given freely and as much as they possibly can. It really is quite inspiring, but that work is not remunerated. It is all in their personal time and goodwill can only go so far.

Helen (11:36):
And the population we have here in Orewa is elderly. We have a lot of people that want to die at home and in the community. So that can be a huge burden to the practitioner wanting to provide the best care to these families. Some of the GPs in the practice I've worked with in Orewa have been there for 30 years. You know, they've delivered the children of some of the people that are dying and they want to be able to provide the care, but the system at the moment doesn't support us to do that.

Kate (12:00):
No, and I feel really conflicted in my career. I've done a lot of advocating for dying not being the remit of just specialists. Helen used the perfect language that most normal dying doesn't need to be in a facility looked after by specialists. It is normal, it is part of what society must do and society is supported primarily by GP teams in the community setting, but without a single bit of extra support and remuneration. That's the bit that I feel bad about, that in doing this as general practices become more and more squeezed, there's less and less opportunity for that to happen. I think that we should use our collective strength to highlight this, that if this is genuinely what we want to do, and to keep "normal dying" and people who want to die in the community, that we have to look at how that's provided. And it just isn't at the moment.

Vicki (13:09):
If I can just put in a little bit about aged residential care, given that's home for some people and the GP input that's provided into aged residential care, what I'm seeing increasingly happening, and going forward I think this is probably what is going to happen, is we are seeing many more nurse practitioners in that role. And I would imagine in 10 years time, most facilities will be not having a lot of GP input, but probably nurse practitioner and the bigger organisations are actually paying their staff to be trained in that area. So it's recognising the problems we do have in supply of GP input across the board really. So again, that's not person's home, it's aged residential care I'm referring to.

Sharyn (14:00):
Yeah, it's a huge problem, isn't it? And I don't know the answer. It would be great if we could put some leverage on somewhere, but, sometimes you just feel so powerless and you don't know how to make change. I have my own experience of what happens here with our PHO, how there is a small amount of funds available for palliative care, but that's not without its problems because there's a limited amount and you need to register at a certain time. You need to make sure you've talked to people about it, what the financial implications of that are for them. But then the dilemmas are "hmm, well when do I register them?", "How do I know how long they're going to be in this space?".

Kate (14:43):
And almost always people are referred way too late so the families get none of the benefit or it's because of this agonising "if we do it too early, we're going to run out". One of the benefits of creating a resource like this is that it's something that's given to GPs that can then say "are there GPs out there that want to work with us at trying to improve end of life care in general for general practice". It kind of draws out the champions that are all there, and I think that it's an opportunity to harness some of those champions. One of the things that would be included is to look at how we can get in the ear of Te Whatu Ora to actually have some consistency about GP subsidies. We're all doing a broadly similar type of thing and that we should share advice and wisdom around the timing of getting those subsidies and how that's done.

Kate (15:41):
Because I think that individual GPs or individual GP practices will have a culture of the way that they do it and some young GPs will be terrified of applying for it because someone's going to jump down heavily on them if they use it too much for one patient. And I just think that's so counterproductive, I just wonder whether there is an opportunity to leverage off some other work that we can do. Maybe that's a supplementary part of it "how do GPs apply for the subsidies that are required" and "what is the utilisation of those at the moment", you know, "how are people finding it?" Are GPs in fact surveyed about their usage of end of life subsidies? Because you really can't do it without the time to do it. And I think that the whole issue of nurse practitioners is really important because for nurse practitioners end of life dying in aged care is complicated a lot of the time. And I think many of the nurse practitioners are really stressed and about it and trying to work in partnership, particularly with nurse practitioners who may not have prescribed many of the drugs and certainly weren't prescribed the doses that we sometimes need.

Helen (16:54):
Can I just add that - because I think this discussion around kind of finances and funding is absolutely crucial and I know we're going to go on to discuss other aspects - we're wanting to support normal dying at home and the PHO funding locally for me is roughly around $700 if I apply for it, for me to support normal dying at home in the community. If somebody has assisted dying, the government provides thousands of dollars of funding for this and this is a separate discussion on a different point, but I think we really need to hold this comparison to the light with this wonderful resource we've created to say "look GPs, let's support you to do this in the community. Let's support normal dying if this is what people choose". But if you choose assisted dying, where is the equity there? that there's thousands (and it is thousands) of dollars of funding available for the treatment that that patient chooses, which is absolutely fine, but if you choose to die at home normally where is the same support? It's heartbreaking for me.

Improving policies around communication

Kate (17:54):
A little example: we've got a GP who actually does really good end of life care, but a family member rang to say "my son, who I'm looking after at home, adult son is dying and I'll be needing the GP to do home visits". And the receptionist said "she doesn't do home visits, period". So that's the mantra. I've had to feed that back to that GP to say "your receptionist is including palliative patients in that global decision that the practice has made that we don't have the capacity to do home visits". I mean that's an internal thing, but I know that happens in other places. And ultimately she's gone to another GP who does a billion home visits all in her own time because she just can't help herself. And that's just kind of siphoning patients away to these small numbers of GPs, just as Helen says, who go the extra mile for nothing.

Sharyn (18:51):
That's a really interesting point about what the receptionist says to people when they call. And, again, every practice will have a different way of dealing with it. We have a system; we are relatively small practice with several part-time staff, and we try to keep our communication really as good as we can. We have regular meetings where we try and identify people, you know "I've got this person who's high needs and if they ring, they really do need a time, you need to tell me if they're requesting something". So we try and keep that communication really clear and we actually flag just under the alert system on the PMS that those people are high needs. And so that raises a flag for the receptionist to know "oh, okay, something's going on with this person".

Kate (19:32):
You think there is anything that could be created in a sense for practices and GPs for things like you've talked about, Sharyn, about identifying your palliative patients within your practice that might make it easier for the receptionist and for the nurses? Sometimes people are so caught up in the horrors and sadness and difficulties of looking after a dying person, they suddenly realise they've run out of medicines, and they get the receptionist and they say "it's three days before you can get before you can get that". I mean, I get that, but you are going to be dead in three days! You can't wait three days for your morphine.

Adrian (20:05):
Well, I guess that's where this peer group discussion's probably going to be quite good for practices to come together and sort of establish those internal processes and think what sort of barriers they have to current delivery of care and what can they do better?

Helen (20:21):
The GP college in the UK did a wonderful piece of work called the Daffodil Standards. It's a protocol to go through to look at how you can make your practice as friendly as possible for patients who have palliative needs. And it's exactly things like that: how you flag in the notes, how you highlight them to colleagues. That's a really good thing to have a look at. It's a really beautiful piece of work.

Considerations when forming a care plan

Sharyn (20:42):
We might just take it right back to, again, a general question about how you go about forming a care plan for a patient in their last days of life. This might be a bit of a rundown on some of the principles that are in the guiding document, but just pulling out what are the key aspects that should be considered?

Helen (21:03):
I think I can probably start off. Because we're particularly talking about normal dying in the community, general practitioners are perfectly placed to start this discussion and to guide a family through it. Often we will have multiple members of the family enrolled under us, or at least in the practice. And so we are familiar with people. And when it comes to the goals of care discussion, I think one of the things that colleagues often struggle with is when you look at Te Ara Whakapiri and it asks specifically about spirituality, which is a

concept that sometimes seems alien to us, when you try to kind of solidify it into specific questions to cover and actually, it's all about what brings meaning to your life. And GPs know this. We know about your wife that you've been married to for 50 years and your grandchildren, we know about your cat that's precious to you or your garden that really matters to you.

Helen (21:53):
And so I think for me, at the base of every care plan that I form, it's about the person that you are. And it's about knowing those things that make you, you. And those questions become easier the more you ask them. But there's some really good resources out there for kicking off those questions if you're less familiar with them. The Serious Illness Conversation Guide created by the HQSC has got some really nice patient tested language around things that bring meaning to your life. And then there's a newer resource Whenua ki te whenua that HQSC have just released as well around advanced care planning and the way that questions are formed in that are really beautiful, really natural, "what makes your days meaningful?" "How do you feel about facing the future?" "If time was short, what would your priorities be?" Really getting to the nub of what matters to you. That's where I start with the goals of care discussion: "what's important to you as a person?"

Vicki (22:53):
I guess it's really about these timely conversations, isn't it? If we've done it in a meaningful way, maybe months out, when we are recognising deterioration, when it gets to the last hours and days of life, normally we will know what is important to that person. And when we are using Te Ara Whakapiri, we've got a documentation and we've got something that's looking big picture. As I often teach, we are great at doing all the physical things, but what about the spiritual? What about the emotional? What about the psychological? All of those things are so vital to ensure the last hours and days of life are great for the person dying and the family.

Sharyn (23:35):
Just being able to listen. And also it comes down to time, not having the families or the patient think that they're being rushed through, and given time to think about an answer and consider, particularly in an older person who often takes more time to formulate their thoughts and to say them in a way that they're happy with. So just being able to listen is a huge skill, I think. And the more years you spend as a GP, probably the easier that becomes. But yeah, it's a key skill.

Kate (24:06):
The other thing that I think is part of the reassurance that needs to be given as people come to terms with a different goal of care is that it's not about doing less. It's about doing different things and about concentrating on more useful things. People tend to equate treatment with "curative or active treatment" rather than "what is required". So I think sometimes our language is really pivotal because if we just talk about the whole bunch of stuff we're not going to do, rather than the things that we are going to do, then it's not surprising that patients don't want it or are fearful of it. So that's another part of why the shared goal of care stuff is so important.

Navigating conversations with patients and families/whānau and resolving conflict

Sharyn (24:54):
Just when you're discussing these goals of care and involvement of family and things, do you ever have issues with conflict within the families where someone might have very strong views about certain aspects of dying, or not dying, and how those things can be incorporated and resolved or worked through with families. Any tips there that you could offer?,

Kate (25:21):
Talking, listening. The main thing, as you said, finding out where people are at and trying to put the patient at the centre. We always get there in the end by listening, by bringing people together. There are some families where, if their family's been dysfunctional its whole existence, you're not going to solve it in their last days of life. But if you put the patient at the centre and they're your focus, generally people are angry because they've

been treated badly or they've had bad experiences. So genuinely interested in what those experiences are and acknowledge them, put them behind us and focus on the here and now with that individual patient is the best way of stopping just living in the grievance. You've got to put that away to concentrate on the patient that you're looking after. So that's how I do it.

Vicki (26:06):
Also, I think it is similar to the previous discussion we've just had. If we can have timely conversations with families recognising deterioration, et cetera. So there's no huge surprises. Of course there'll be sudden death and other things; that happens. But if we can have those conversations in a timely manner in the last hours and days of life, if people are prepared what to expect when the dying time happens, it does make a difference to families. Huge difference.

Helen (26:35):
I think there are two things that I pull out of that. So first is the workup to it that we've been talking about, having the conversations in a timely fashion. And that for me starts years before the dying. It starts with us normalising dying in our conversations with family and whānau all the time in general practice. Kathryn Mannix, who's a spectacular palliative care physician from the UK who's published books and has done wonderful talks and if you have a look on YouTube, there's some wonderful things she's done. She advocates very much for normalising dying within our community so that death comes as much less of a shock. And so there's lots of work to be done generally in our communities with that. And that's a little bit of a side passion of mine. But specifically to answer your question about the disharmony within families, when there are complex dynamics, one of the things I see, particularly in the community, obviously myself as the general practitioner, exactly as Kate said, you want to draw everybody together and have a conversation.

Helen (27:33):
But that often means carving out time for a family meeting, which cannot be done in 15 minutes, cannot be done in 30 minutes. Getting everybody together is one aspect of that. But the other is the peripheral staff, everybody else that's involved in this. So this is the receptionist taking the call from the really distressed family member, the practice nurse, who then has to navigate this, the staff that we see in our aged residential care facilities who are front facing family members day in, day out, you know, getting sometimes the frustration, the sadness, all of this. The HCAs who sit with the patients every day seeing the frustrations of the family. I think it's a real team effort and to acknowledge that when there is disharmony, the whole team feels it. The key is communication within the team and with the family.

Using syringe drivers

Sharyn (28:25):
So just to load on top of that, when we're thinking about all that the family and the person are dealing with, we then come down to some of the nitty gritty aspects of the medicines. We're just going to go there for a bit. So you've got a family who's already grieving and working this through, and then what we're asking them to do is maybe administer medicine. How do you work that into your conversations and how does that usually go?

Helen (28:51):
From my perspective, working in general practice, it's hopefully like as Vicki and Kate have said, "this is something we have been to before". Because the last thing you want to do in what may be perceived as a crisis moment for the family, when we finally realize that somebody's dying, but hopefully it's not a crisis moment because we have prepared for this and we've talked about normal dying, it's that family members will often be very willing to provide care at home, but they have to feel supported. And that support is around education, around administering medication support, to know if something goes wrong in the middle of the night, if we're using a syringe driver and it starts beeping, if you're not sure which medicine to give at what time, directions are given very clearly and everything is left in the home. But it comes down to the support in my experience that you can provide. There will be some families that do not want to administer medicines at home and that's entirely appropriate and their choice. But what we need to do is

when people want to do this, we have to provide support and it's that peripheral support that people need that that isn't always available across New Zealand. It certainly is here where I work in Auckland, but there'll be areas of New Zealand where it will be incredibly hard to access out of hours support to make that feel safe for families to have somebody to die at home.

Sharyn (30:09):
And I think it's, as you say, providing that support. It's then helping GPs and nurse practitioners practice nurses know the ins and outs of the drugs and how they're administered. And one of the basics of that is "How do you get a syringe driver?" How do you chart the doses for it? What are the ways you mix things up?" It's getting familiar with those things yourself so that you can then teach someone else and support someone else to use that. "What do you do when it beeps? Is it blocked? Are there some sort of troubleshooting things you can think about? What's a good way, or what's your process of trying to educate and get upskilled in the use of syringe drivers?" - Any good tips there?

Helen (30:49):
I think that in terms of the use of a syringe driver for most general practitioners, it won't be something that you do regularly. It will be something that when it comes around you need to do it. And that is when you phone a friend, if you do not know.

Kate (31:03):
For us, Healthpathways is where all that information is, and GPs can find that information there. The problem is that it's sometimes hard isn't it? An unfamiliar thing. It's all right saying "it's on Healthpathways", but actually every patient's a wee bit different. It's inherently tricky. Generally phoning a friend is the most useful thing in the moment rather than just doing it on your own. And the times when we see weird things like the opioid naive person and getting stuck on a syringe drug with a hundred milligrams of morphine has usually happened because the GP was like "Oh I don't know what to do, I'll just give them a nice big dose and they'll all be fine" without talking to anybody. If you are really genuinely not all that sure what you're doing, you need to talk to somebody and hopefully that's what hospices are for, isn't it? Getting advice about that.

Helen (31:55):
I couldn't agree more. A lot of practices will have some GPs that are particularly confident with palliative care. And so I would talk about deferring to a colleague who might be able to help. Healthpathways is an invaluable resource. I think the resources we've got in the guideline, in the navigating last days of life, is really clear about where to start with medication doses. But if you're really not sure, it's about making the call to somebody who's going to help you. And then it comes down to the practicalities of "do you even know which local pharmacy can prepare a syringe driver?" In Auckland we use prefilled syringes. There's only a handful of pharmacies that are available to do that in office hours and then only one that can do it out of hours. So just those practicalities of getting familiar with who stocks what and who can do what is really helpful to have that at the top of your head so that five o'clock on a Friday when you want to support somebody in their normal dying when you're doing it in your own time, that you know where to go for those things.

Helen (32:55):
And that, that would be a really useful thing for the practice to have, is to know which pharmacies can provide those things.

Vicki (33:00):
Back to families and managing medications in their own home. I'm part of a small working group that's been working on a diary for families for subcutaneous medications at home with a record plus also instructions, et cetera. And it's based on work from caring at home in Australia. So we haven't reinvented the wheel and it's just about ready to go to Hospice New Zealand; it will sit there, but it will be a really great resource for families. It'll be a reassuring thing about how to give, when to give, why you're giving.

The place of complementary and alternative medicines

Sharyn (33:36):
Just diverting off a little bit into talking about medicines, thinking about requests that we get for perhaps complimentary or alternative medicines or treatments that might be accessed in those last days of life. Any thoughts on that? The big one of course at the moment is we get requests for medicinal cannabis and a lot of us are still quite "green" with that and learning to negotiate that sphere as well. No pun intended. Any thoughts about that?

Kate (34:10):
You're not going to stop people from accessing those kinds of things to be honest. It's having an open mind, but if people think that a little bit of cannabis oil is going to do what a syringe drug with morphine is going to do, then I think it's just like accepting it. The need for patients and families to access alternative or complimentary medications is the same at the end of life as it is everywhere else. It's people's choice and we shouldn't shut our minds to it. And we know that a lot of complimentary therapies are absolutely essential at the end of life. It's just part of that. You don't want them whizzing them into a surgery to get vitamin C infusion when they're on their deathbed. But I mean most other things I would say, you know, "whatever floats your boat".

Sharyn (34:59):
Yeah. If you believe it's going to work, it will probably work. That sort of thing.

Kate (35:03):
Exactly. And if you ban people, or give them the fear of death that "they shouldn't rub this bit of blah-dee-blah on their blah-dee-blah", then I don't know. What do you think Helen? I mean how often does it come up for you?

Helen (35:15):
Frequently. Very frequently. Specifically with medical cannabis, I think initially the feeling was that you could use it and it didn't really interact with our medicines. We know now that cannabinoids do interact with opioids to some degree. So from a kind of a medicine safety perspective, I encourage families to be really open with me about whatever they are using and that's about setting up the relationship so they feel comfortable sharing that. And it's just so that I bear it in mind with my prescribing. Because we know that cannabinoids do interact with opioids to some degree. So it is just having that in mind. It doesn't change what I'm going to do, but it just helps me guide the rest of my management decisions. And with regards to other complimentary therapies that Kate kind of mentioned, aside from medical cannabis, things like massage, acupuncture, these things can be incredibly beneficial as long as we don't see any inherent harm. And that's where your responsibility as a medical practitioner comes in. But end of life will often present you with brand new situations that you have never encountered, which is one of the things I love about palliative care and general practice, is that you see something new all the time. And it's just about having an open mind. And as long as there's no safety concerns, then we should absolutely be advocating for people to have the treatment they want.

Kate (36:32):
And sometimes actually even suggesting, you know "I don't know whether you've thought about it, but some massage" and then by saying that they go "oh we have been doing a bit of that and we've been doing a bit of this". So just by you kind of raising it, they're incredible enablers because they're very personal and , you know, you have very little control in a lot of things when you're looking after someone who's dying. So to be able to take the initiative and do something that feels right for you that's not been dictated to you or prescribed to you by this health practitioner actually is quite empowering for patients.

Helen (37:12):
Yeah.

Non-pharmacological management strategies

Sharyn (37:13):
Yeah, I think that's a good point. And I think those non-pharmacological aspects as well come into that. So you mentioned massage, but not underestimating the simple things like someone holding your hand, a breath of fresh air on the face from an open window, a view, some music. Yeah. So those things in my experience are important. You guys might have some other views on those things and how you might incorporate those. Or is it just having a discussion again with the family and not forgetting about those smaller things?

Helen (37:47):
That's one of the joys of home visiting. So being in somebody's home, is that they have their favorite music readily available. You know, their books, their pets, the other things that really matter to them. Quite often in the aged residential care setting, when we're doing a shared goals of care discussion and there's a particular section around spirituality, then that's often where I take the opportunity to talk specifically about when you are dying, what are the things that are important to you so your family don't then have to try and think of these for you. And people will often say to you "I want this music or I want to be in this spot". If we can, we've talked about all this kind of planning in a timely manner. It's really nice to have those ahead of time planned by the individual themself and then supported by their family.

Sharyn (38:34):
So that comes back to your point about having those conversations early and trying to preempt the things so that in a crisis situation or if things are moving quicker than you expect that you're not scrambling then to try and find those things and so it becomes a smoother, calmer time for everyone involved. That's pretty vital.

Vicki (38:57):
The holistic guidelines that come with Te Ara Whakapiri, they're incredibly valuable especially in aged care. So for the HCAs who aren't going to administer the medications, what are you going to do to make this time better? And so it makes them think about what you were talking about Helen, you know, like a fan, open a window, change a position, put some music on and what have you. An incredibly valuable resource

Transitioning between home and secondary care (if required)

Sharyn (39:24):
That might just help us lead into perhaps another thought about when things aren't going so well. So you were talking earlier, Kate, about it's perfectly reasonable if someone then goes from home to hospital or to hospice or whatever. What are some of those crisis points that you might see? I mean, they're not a crisis if you've anticipated it. I guess other ways you can think about looking out for sort of signals that things are not going so well.

Kate (39:51):
I think the biggest issue is that people say they want to do something but they've never done it before. They actually don't know what it's going to entail. And then something crops up out of the blue. I think we have a great resource in New Zealand, which is Hato Hone St John, Wellington free ambulance, letting families know that they can ring the ambulance if they get scared. Because you don't want to be outlining every single complication that could ever happen. It's about providing a net of support and giving families permission to call them in if they need them. That would probably be my advice.

Adrian (40:32):
Yeah. And part of the resource that we delivered, we also produced an ambulance management summary sheet. So we felt that that was probably quite a good resource just to prompt those things so that families aren't put on the spot. Having to think "what do we do now?", "What do we say to the ambulance if we do have to call?"

Kate (40:53):
We don't use that so much in Canterbury because we try to use what's called the acute plan, which goes on health Connect South. Although I know some places use those ambulance plans really efficiently and that allows the goal of care to be communicated down the line. The ED for example, because that's where everything falls down as well. They turn up in ED and everybody goes rushing off and doing stuff when actually what they just need to do is be providing that calm and supportive environment, which is focused on comfortable dying rather than doing stuff.

Helen (41:31):
I think anything that can happen will happen sometimes. But you know, one of the core pillars of general practice is safety netting. We are incredibly comfortable with setting up a plan and saying if anything changes come back to me. But this comes back to equity again, the out of hours provision of support. I can say that really confidently here. I know that rural colleagues don't have that amount of backup, in many areas of our country, which is incredibly sad for me. So yeah, I think GPs are really confident in setting the boundaries around when you do need to ask for help, but it just depends on where you live as to what that help might be.

Sharyn (42:11):
We did make the point in some of the resources that documentation of things is vitally important. And it was actually brought home to me the other day when a friend was telling me about a situation they were involved with where it wasn't a palliative patient, but it was someone who basically had a major heart attack at home, but had already had a discussion about end of life and what their wishes were and did not want active treatment. But because there was nothing there on the spot for the ambulance crew to read or to have, they basically felt their responsibility was to try and do as best they can for their patient. But it became a distressing situation for the whole family and the wife in particular. So it did bring home to me that it's really important to document all of this and have everything sitting right with the patient.

Kate (43:00):
People do expect that those things are joined up even though systems don't do a very good job of doing that. So it does take an effort to do that.

Sharyn (43:09):
Yeah, I mean ideally if we had a comprehensive single health record for everyone, it would be wonderful. But until we get that down the track, that communication between everyone who are involved in the care is vitally important. So after hours care, hospice, hospital.

Kate (43:28):
That's the kind of thing that we would put on an acute plan, a very brief acute plan. So if that was, you know, "Mr. Bloggs does not want any type of active treatment". He hasn't done an advanced care plan, but one of the things that is asked for is "do you have patient permission?" So you tick that box and you can write that all in. So it's just taking the time to do it.

Sharyn (43:47):
I know we are rapidly running out of time, but any key areas that you think that would be worth just talking about in terms of problems that you could give our audience help with anticipating? Things that could be done better?

Explaining and managing "death rattle"

Helen (44:01):
I think we probably all have quite a long list of our pet things. But if I can start with, the management of death rattle, which is one of my least favourite phrases in the whole world. But when I take community calls, when I'm working at hospice and I take community calls from GP colleagues, it is often that there is somebody who is dying at home who has what they describe to me as a death rattle, which is incredibly distressing to the family when somebody is quite deeply unconscious and close to dying. And I think that it's just a symptom

that's been misinterpreted for a very long time in the community. It's a symptom of us not seeing normal dying in the home. And as Kate said, and I think Vicki said, people will often want to support family members to die at home, but they've never done it before.

Helen (44:53):
They've never seen it before. Or if they have, they've seen it before and it's not gone particularly well. And so just being able to explain to people that it's just upper respiratory tract secretions; it's a tiny bit of fluid that you can hear when somebody is deeply unconscious, which is actually incredibly reassuring because it means that somebody isn't in any discomfort. And it's a phrase again, I'm going to quote Kathryn Mannix, who's the British physician who's done a lot of work on this in her book. She has a beautiful passage. I think it's the best thing I've ever read actually on how to describe death rattle. And saying that, when she hears this sound and now when I hear this sound, it's incredibly reassuring to me. Families are mortified by it, but when I hear it, it tells me somebody's deeply unconscious and comfortable.

Helen (45:40):
And that's the language that we need to be using with patients and whānau around this and that once you've developed these secretions, there's a temptation to administer medication to dry up secretions. And none of the medicines that we give actually remove the secretions you have. They prevent further secretions from forming. And the medicine most as of as a familiar with is hyoscine butylbromide or Buscopan. And that actually my first line management is, and I document this if I'm ever charting hyoscine, is that I say first line management is family education and repositioning. And then only, it is incredibly rare in my clinical practice that I use Buscopan actually, because a lot of the time I find that it doesn't really help and that it really is around repositioning and education and that that is really what we need to be focusing on.

Sharyn (46:30):
That's an excellent point. Vicki and Kate, any particular concerns that you'd like to talk about?

Vicki (46:39):
I think in my role, I see a lot of situations where staff are uncomfortable having conversations and palliative care is maybe foreign to the nurses. They're not trained in it and so on and so forth. So it's about getting people talking the language really, and not beating around the bush. You know, it's about that honesty, taking people with you and feeling comfortable in having that conversation. Doesn't come easily for some people. I agree totally with Helen. I mean, gurgly breathing is such a horrible thing for people. They think until we reassure them, the families and staff indeed, that actually this isn't a distressing thing for the person. Pain management I think is managed pretty well. And that's really the easiest thing in some ways because it's very quantifiable. It's the bigger picture thing that I think we sometimes miss out on. The spiritual, the emotional, the cultural. It's those things. And that's why I love Te Ara Whakapiri. It's making those things be addressed.

Helen (47:45):
You are absolutely right about the communication, just being able to say the actual words. And you'll notice Sharyn, that both Kate, Victoria and I have all said the word dying an awful lot and that's because it's the word, I don't think we use it often enough. And we say lots of things like, you know "oh they've deteriorated significantly" or "things have changed a lot" and families need to hear the words. And what they need to hear is this person is sick enough to die. We need to be really brave within ourselves because whenever we're discussing dying, it brings us close to our own mortality. It brings up all kinds of emotions in ourselves and until we kind of wrestle with those a little bit and get comfortable with it and manage our own demons around that, I don't think we can really move forward.

Helen (48:33):
When I was at medical school, I had half a day of teaching on palliative care. When I arrived on the wards, I had no idea how to look after somebody who was dying because all my training had been about keeping somebody alive and dying was a catastrophic failure. And it took years of on-the-job clinical practice and working fortunately with wonderful hospices and nurses and people who supported me to, to redefine my

understanding of dying. And we've got to do that first within ourselves as practitioners. We've got to get comfortable with using the words and getting close to it because I certainly wasn't trained to do that. And I don't think many people have been.

Opioid prescribing decisions

Adrian (49:14):
I just had one last medicine specific question. Opioids are obviously very important for care of patients in the last days of life. They've got a good therapeutic benefit. They're also associated with some downsides as well. So like nausea and vomiting or respiratory depression. How should GPs go about troubleshooting those negative sides of the opioids and thinking about those sort of decisions?

Helen (49:41):
So it's about familiarity. It's about making sure that you're happy with any of the medicines we prescribe and there'll be some things that you prescribe more frequently and perhaps opioids aren't the case for you. The University of Otago is now running a wonderful online module on the prescribing of opioids in primary care. And that's an amazing resource for getting yourself really confident with the prescribing of these medicines. But baseline kind of quick troubleshooting things, the top things that kind of come into my mind are usually if I am starting a syringe driver in the community with morphine in it, I will usually put a small dose of haloperidol alongside it for anti-nausea. It's pretty much standard practice. And that would usually be, in my experience, one milligram. That's where I would start, unless I were using the haloperidol for something else like delirium, then you may have higher doses.

Helen (50:33):
We often see on people's allergies, allergy to morphine vomiting. And that's because somebody's had nausea with them; they're not allergic to the morphine, they just need an appropriate antiemetic charting. In my experience, respiratory depression isn't usually an issue. We see breathing pattern changes at the end of life that are entirely normal. And if appropriate titration of the opioid has been done in the way that's described in the guideline in the last days of life resources we've got, and in Te Ara Whakapiri, then it's vanishingly rare that I see respiratory depression as an issue at the end of life. In fact, I can't remember the last time I saw it in the community.

Care after death: bereavement support for families

Helen (51:13):
Just one final thing and it's just about care after death in the community. We manage to achieve normal dying at home supported by the primary care team. One of the gaps that I then see is bereavement support for families.

Helen (51:28):
So as the GP I will usually see the bereaved family in an appointment that they have to pay for to come and see me. And then they may need further support that I'm not trained or qualified to provide. And that's only provided by charities or by accessing something that they have to pay for. So private psychological support. If you die under specialist palliative care, under the hospice, then you have access to their counseling services. And again, it comes back to what Kate was saying where saying to patients, "you should be able to die at home", the burden of this is being given to general practice to manage with no additional resources. And then if you do die at home, your family who have provided the care to you, who've administered your subcutaneous medicines, perhaps sat alongside you with those gurgly respiratory noises, there's then no support left for them. And I think that's just a big hole that we need to address at some point and acknowledge that it's the primary care team that usually bear that burden. It's the pharmacists when they turn up to hand back their medicines in. It's the receptionists who see all of that emotion. And I think that's just something as well that I want to make sure we've acknowledged, that there's still work to be done there as well.

Adrian (52:40):
Emphasising that the care journey doesn't end with the patient dying. It carries on to support the family.

Helen (52:46):
Yeah.

Vicki (52:47):
It also emphasises the inequity of service provision because I know here in Canterbury that Pegasus provides free counseling for five sessions or something. So that's Canterbury, why isn't that national? You know, I mean, I don't have the answer.

Sharyn (53:03):
Okay. I think that's been a fantastic discussion. It's been wide ranging and really interesting just to get some of those things out in the open and let GPs start to talk about them and maybe in the ideal world, put some pressure on the system to change.

Adrian (53:21):
Yeah, I just want to thank everyone for coming together today. It's been, from my perspective, such a great discussion and we've covered so many different things and highlighted so many challenges. But I think as we've all emphasised, these are really good things for the peer groups to be thinking about and sort of troubleshooting and coming up with their own plans and being more communicative with other colleagues or other health professionals or who might be able to help them too. It's been really great.

Being a champion for change

Kate (53:51):
If there are GPs that do want to reach out, because it's an area that they're really passionate about and they want to get involved, I'm happy for people to contact me and we want people to feel as if they've got somewhere that they can take their ideas, particularly if it's around some of these horrible long standings sticking points. There's so many things, as Helen pointed out, there's so many areas that GPs are struggling with, but there will be some GPs, many GPs, like Helen, whose tippy-toppiest area of interest is end of life care and palliative care. And if those people can come together to try and champion some changes, then that has to be worth supporting. I know that myself and others in specialist palliative care would help if we could.

Sharyn (54:42):
That's a lovely offer. Thank you. We've just used up all our time, so thank you again for all your assistance and your wonderful conversation that's given me some things to think about as well. So thank you very much.

Kate (54:58):
No problem. Have a great day.

Sharyn (54:59):
Okay, thank you.

Adrian (55:01):
Have a good day. See you later. Bye.

Further resources recommended or noted during the discussion

- Australia New Zealand Society for Palliative Medicine (ANZSPM)
  - **https://www.anzspm.org.au/**
- Caring at home
  - Australian-based resources for both health professionals and families **https://www.caringathomeproject.com.au/Family-Carer-Resources/Standard-Resources**
- Daffodil standards for end of life care
  - Evidence-based approach to optimising the provision and delivery of end of life care in the United Kingdom **https://www.rcgp.org.uk/learning-resources/daffodil-standards/useful-resources**
- Dr Kathryn Mannix (Palliative Care Physician from the United Kingdom)
  - TED talks and other videos available on Youtube. For example: "What Happens As We Die?" **https://www.youtube.com/watch?v=v9f6twy70iM&ab_channel=TED**
  - With the End in Mind – Dying, Death and Wisdom in an Age of Denial (2017) **https://www.harpercollins.co.nz/9780008210915/with-the-end-in-mind/**
- HealthPathways
  - Specific information regarding prescribing for syringe drivers (see local HealthPathways)
- Health Quality and Safety Commission (HQSC) resources
  - Serious Illness Conversation Guide for structuring discussions around what is most important to patients **https://www.hqsc.govt.nz/assets/Our-work/Advance-care-planning/ACP-info-for-clinicians/Publications-resources/Aotearoa-Serious-Illness-Conversation-Guide-Oct-2019.pdf**
  - Whenua ki te whenua Advance care planning guide (information for families about advance care planning using kaupapa Māori processes, available in English and te reo Māori) **https://www.myacp.org.nz/whenua-ki-te-whenua** and **https://www.hqsc.govt.nz/news/whenua-ki-te-whenua-advance-care-planning-guide-for-whanau-launched/**
- Hospice New Zealand
  - New Zealand-based resources for families **https://www.hospice.org.nz/resources/a-guide-for-carers/**
- Te Ara Whakapiri: Principles and guidance for the last days of life
  - Resource published by the Ministry of Health (Manatū Hauora) outlining essential components and considerations required to promote quality end of life care for all adults in New Zealand, regardless of the setting **https://www.tewhatuora.govt.nz/publications/te-ara-whakapiri-principles-and-guidance-for-the-last-days-of-life**
- University of Otago
  - Palliative Care Opioids module (2024) aimed at primary and secondary care prescribers who provide palliative care in New Zealand. This is a ten-week course, involving two hours of online course work per week, as well as four care-based learning and assessment sessions (over Zoom). The cost associated with this course is $400 for medical professionals and $200 for non-medical professionals. **https://www.otago.ac.nz/continuingeducation#:~:text=Palliative%20Care%20Opioids%20module%20(2024)**

Please contact us (**editor@bpac.org.nz**) if you want to connect with any of our speakers

Glossary

ANZSPM = Australia New Zealand Society for Palliative Medicine
ARC = Aged Residential Care
bpac^{nz} ("BPAC") = Best Practice Advocacy Centre
HCA = Healthcare wwAssistant
HQSC = Health Quality & Safety Commission
IPU = Inpatient Unit
POI = Palliative Outcomes Initiative
Te Ara Whakapiri = The unifying path (a resource published by the Ministry of Health detailing essential principles and guidance for care during the last days of life, regardless of the setting)