Speaker 1 (00:02):

Hi everyone. And welcome to this episode of ask a DAPA doula. My name is Susan O'Brien. Thank you so much for being here. Today's episode is pain management at the end of life. And I'm gonna share with you that as a former hospice and oncology nurse pain management, especially home hospice area of care is done by the family. So the hospice nurse comes in, she assesses the patient. They, the doctor then obviously based on those recommendations will, will have prescribed medication and regimens, but it's up to the family for the most part to give an administer that medication. And I'm gonna share with you right here right now that this is one of the most feared areas of care for the family and one that is greatly missed. So we're gonna cover pain management at the end of life today. And again, please always ask your questions during this.

Speaker 1 (01:00):

We'll get back to you on it. This is a very important pod cast. And again, something that I have found from my experience over decades, working with end of life is the single most feared and missed area of care by the caregiver. And we don't want that to be so why? Because if people are not comfortable giving medications and they don't give them, then people are suffering at the end of life. And of course we don't want that. So welcome to pain management at the end of life. And why I say it's pain management at the end of life. This podcast is because that's as very specific area and we need to know the difference between pain management, when people have chronic illnesses or acute illnesses in their lifetime. And the difference with that at the end of life, very, very different. So we're gonna cover that.

Speaker 1 (01:49):

The first thing that I wanna share with you is that there's two different types of pain. So there's two different types of pain, which are sematic pain, which is the, you know, ma mostly what we know is called sematic pain. And that is something that we really think about when we have pain for the most part. And it's something, again, that the management would be a narcotic medicine like a morphine or in that family that would make that pain, um, manageable diminish. That's how they would treat it somatic pain, but there's enough type of pain and that is nerve pain. And it, you can put as much narcotic into the mix and it won't touch that pain. It needs a very specific medication to handle nerve pathways, and this gets missed a lot. So again, the most common type of pain is somatic pain that a narcotic medicine would address, but there are those and many that come out with an end of life that has either solely nerve pain or in addition to somatic pain has nerve pain.

Speaker 1 (03:01):

So let me give you an example. I'm gonna share a story with you from one of my beautiful patients that you know, you fall in love with your patients all the time. It's such an honor to be invited into this space and it's such an important space to get right for families. So I came in as a hospice nurse, um, this be beautiful woman who had lung cancer diagnosis, terminal diagnosis on hospice care with lung cancer. And I came in to meet her for the first time and I'm smiling. Cause I just adore this family and this person, and she had pain that was really high. So she had an eight out of 10 on a pain scale, which will go over how you assess and how you wanna keep what the benchmark is for pain management. But 10 being the maximum pain you could possibly be, be in.

Speaker 1 (03:47):

She was saying she was in an eight and she was already on a lot of narcotic medicine. Well, here's the thing. Her pain was in her head. Okay. And she had the lung cancer. So not, would you think that there's

gonna be an association with pain in the head? Although lung cancer can metastasize the cancer to brain cancer, but that's not what was happening here. She was early in her presentation and it was unrelated to her lung cancer, as you can imagine, but she had just incredible levels of pain in her head. And she would say it's like burning. It's like a stabbing. It's like a stabbing all the time. And they kept prescribing narcotic medicine. Whoever was on the case, doctors kept prescribing. She said she had pain, high levels of pain. They just were prescribing narcotic medicine. Well, her pain in her head was a nerve of pain.

Speaker 1 (04:41):

And after really thorough assessment and talking to her, she had been diagnosed and had shingles months prior, which is a affects the nerves, the, the sheath of the nerves, like very, very painful. They say like fire a like stabbing pain, like, um, just fire, like that's kind of the way it is. So she needed medicine that would react to the nerve pathways, which narcotic will not do will not do. You can give as much as it you want, which is a dangerous thing as you are probably well aware of. And it won't touch the actual nerve pain. It will make people sleepy probably eventually, but that fiery stabbing pain needs a medicine called Gabapentin also known as Neurotin. So here's what I wanna share with you after doing that assessment as a nurse and after bringing that to the medical directors awareness, they ordered her Gabapentin right on the recommendation.

Speaker 1 (05:42):

And within, you know, 24 to 48 hours, this woman started to feel better. She got her life back where she was. So we always wanna strive for the highest quality every single day. She got that pain under control. She got the quality of her life back daily. She was able to watch her soap operas. That's what she loved to do. Eat tuna fish sandwiches and drink milk. That's what she loved at lunchtime don't judge. We're not here to judge. We're here to support people where they are in their, again, highest quality of daily living. But you can imagine that if you have a pain eight out of 10, constantly with a stabbing, that's all you're gonna think about. That's all that's gonna consume your every day, not to mention just pure torture. So very important to know that there's two different types of pains. Again, the nerve pain is not as common, but it's common with chemotherapy can lead to side effect of nerve damage, different other disease processes.

Speaker 1 (06:38):

But here's the thing that I always wanna share with you treat the symptoms. So if somebody share with them, if they're having pain and you wanna always ask, what does it feel like? Is it adult pain? Is it a intermittent pain? It is a pounding pain. It is a fiery pain. So nerve pain typically will, will go on the feet and the head. Um, so again, that will give you another clue of somebody saying, oh, I have like burning my feet or burning. That can be from diabetes and different chemotherapy. You wanna make sure you're asking the questions of what type of pain and also assessing the outcome of what pain medicine is is prescribed. So I'm gonna give you some tools today to assess that. So the first thing I want you to know is that there's two different type of pain, somatic pain, and nerve pain, and both of them need different treatments.

Speaker 1 (07:30):

The next thing that I wanna share with you is that my rule of thumb, and this is probably a really good Pearl, is that if somebody is going home on home, hospice is being admitted to hospice is to have the comfort kit from hospice within that home within the 24 hour period. Why? Because at two o'clock in

the morning, if you need something for pain or breathing issues and you don't have it in, it's gonna seem like an eternity. So we know that we have somebody that has an end of life diagnosis. It's not somebody who's going to have a spontaneous recovery or get better. We know there's gonna be a decline. We just don't know what rate they're gonna decline and things can happen very quickly. So I wanna share with you that my rule of thumb as a giver, as a hospice nurse, as a, just a caregiver of anyone, is that if somebody is admitted to hospice care, I want that comfort kit within that home, within the 24 hours of their admission, have the hospice nurse actually go over the medications with the care.

Speaker 1 (08:40):

So the first thing that I'm gonna advise you to do is pick one person in the family that will be in charge of administering the medications. Why? Cuz there's always one person that's usually the most comfortable within that space. And when you have people that are uncomfortable here, not that anyone is ever trying to do anything wrong. It's just human nature. They're going to hesitate. They're going to avoid because they don't wanna do it wrong. So let we know that end of life is really hard on everyone, right? Everyone in the family is touched by the end of life. And all people are probably having different experiences. Don't put the pressure on somebody who's uncomfortable with medications to be the person responsible for giving the medications. Let's talk about this as a family who is the most comfortable. Okay? I am. Okay, great. Let's take, have you designated as that person, that's gonna give dad his medications and let the hospice nurse, when he or she comes to the house, teach you how to do that.

Speaker 1 (09:45):

And why do I say that? Because again, this gets missed all the time. The comfort kit gets delivered to the house. It gets put in the refrigerator. Why not? Because it needs to be refrigerated, but because, and people need to find it. When people, you know, in the middle of the night, somebody's having pain, they call the on-call hospice team. They will usually say again, go to the refrigerator and get the comfort kit out. So that's where they can find it. This is really important. This is not the time to try to out how to administer medication. When somebody is screaming in pain or somebody is having air hunger, this is gonna get missed. This is unfair. And we wanna practice it multiple times to get comfortable with it, right? It's like a drill. Once you go over it, the brain starts to build pathways towards that.

Speaker 1 (10:34):

It starts to become more comfort. Bullet starts to become more. Second nature. You can explore a little bit more. So my recommendation to you is to pick the one designated person and then have the hospice nurse. When they're on their weekly visits, come open that kit up, have the caregiver draw up the medicine, make, let them touch it, let them see what it's like, because cuz that's gonna allow them when they need to do it to be that much more at ease with it, knowledgeable with it. Um, and this is all critically important. So have the hospice nurse reteach that not just once, several times pick one person that you designate to give the medication. What is the rule of thumb about medication management? Is that on a pain scale of one to 10? That's usually how it's assessed one being no pain, 10 being the most pain that somebody could possibly be in because pain is subjective.

Speaker 1 (11:32):

You want that pain to be at a four or below, kept at a four or below. And here's the key when pain is going up when pain somebody's having pain and it's starting to go up, we know what that feels like, right? You've gotta cut it off before it gets too high. It's just the way that the body works and you've

gotta stop that pain on its incline or control it because if it gets too high, it's gonna be almost impossible to bring down. So many of my patients lovingly beautiful going through all of this really feel loss of control. And I understand what that feel like. It just must be really difficult again, to be in that space, especially in the shock phase. And one of the things they can control is whether or not they take medication. And so one of the things that I have found is that people will hold off on taking medication because that's one of the only things they have a choice in until they really need it.

Speaker 1 (12:38):

And what happens is they're like, no, I don't want it. I don't want my medication. And then that pain is at a seven or an eight and they say, okay, gimme the medication. And guess what? It won't work. It won't work. So if that pain is too high, it'll take forever for it. Come back down. So you've got to have really good assessment and management on an ongoing basis. And when that pain me level is going up, you wanna cut it off. You wanna administer that medication to keep it at a four or below. And this is something that is subjective. So you're gonna be asking your mom, your dad, whoever this is, what is your pain level? And let's just say, mom says, you know, it's, it's a four and it's it keeps going up. Well, you know that that's a good time to administer a dosage based on the prescription.

Speaker 1 (13:27):

Then about 45 minutes later, 30 to 45 minutes later, you're gonna go ask her, what number is it now? And hopefully she says, it's a three it's coming down because you always wanna be having great assessment and symptom management. You can't take medicine out of somebody. And many people will resist taking pain medicine cause they don't wanna be knocked out. Totally understand that. And we don't want people to be knocked out. That's not what this is for. It's for not removing the pain completely, but it's for keeping it at a manageable level where they can have quality to their every day. So instead of it being an eight, it can be a two or three. So we know it's there. It's not completely gone, but it's not consuming my every thought. And it's not preventing me from having visits with family or watching my soap operas or whatever somebody wants to do.

Speaker 1 (14:20):

That is really important. And that's gonna take ongoing assessment rule of thumb. You can't take medicine out of somebody. So always there should be a little increment added. This is again by medical practitioners that are gonna prescribe it another little bit till you get to that therapy space. And what is a therapeutic space, a number four or below now, why do we need to keep assessing somebody? I want you to keep asking your mom every single day, how is her pain? What level is it? Because pain changes because tumors grow because things in the body change. And so we always wanna strive for the highest quality every single day for that person so that they can enjoy the Yankees game or whatever it is that they wanna do. This is important because at the end of life, we know we have an end of life diagnosis.

Speaker 1 (15:09):

We know that usually there's going to, to be increases in pain and changes that are going on in the body and we wanna be ahead of it. So we wanna be assessing that the doctor doesn't know this unless we're told, unless we tell them unless we're assessing it. So very important is caregivers because you're the one that's spending the most time with your loved one. So you'll know mom, you know, you just don't seem right. Are you having a lot of pain? Yeah, but I took my pain medicine, but all of a sudden it's not working anymore that the doctor needs to know that the hospice nurse needs to know so that they can

change the prescribed amount. All right. Third thing that I wanna share with you is to keep a log book, keep a book next to the bed. Why? Because we forget, right?

Speaker 1 (15:54):

We in all best intention, we wanna remember, you know, when the last medication was given what the, the level of pain was before that was administered. And then what was the level of pain? 45 minutes after to assess how well it's working. That's a really good thing. And it means that anyone including the high nurse can come in, go to that log book and see the whole week of how things were. This is really, really good protocol, good rule of thumb. It allows you to at a glance, be able to see, are there changes? Are there patterns what's happening here? And it also will help the nurse when she comes in. Um, the fourth thing is to keep a log book and keep track of bowel movements. And yes, is this an uncomfortable topic for people? You know, probably. And I'm sorry, but it's a very important one.

Speaker 1 (16:43):

We're doing this all out of love. We're doing this all out of really good care for your loved one. So narcotics are known to be constipating. So do kind of quiet down the pain, but they also quiet down this stimulation of our gastrointestinal tract and our ability to have, um, regular bowel movement. So you wanna be ahead of that. Now I've had many patients who have refused to take pain meds just because they don't wanna be constipated. That's how bad it is. So this is really important to make sure that you keep track. People should have bowel movements every one to two days, it's about comfort. It also can turn into a crisis situation. If they are constipated and blocked for an extended period of time, there should be a stool, softener and a laxative on the medication and administration page. This is again something that the medical team should have already done.

Speaker 1 (17:39):

They usually do, but you wanna make sure that not only is it part of that regimen, but need to know when to give it. So if mom skips a day and she has an have of bowel movement, then that laxative should be given if it's not already in a, um, prescribed dosing on a regular basis. So make sure that you're keeping a log and a tab of bowel movements as well. When people have narcotic medicine, make sure that there is something on a column on the side of bowel movements when, and they were the size, the consistency, all of that's gonna be really helpful for again, quality of life care, but also that the nurse can come in and see at glance what's happening from the week, okay. Have sublingual pain medicine in the home. And that's what that comfort kit. So the comfort kit from hospice will have what you call sublingual pain medicine.

Speaker 1 (18:32):

What is sublingual? It means that it can be given to somebody underneath the tongue in the side of the cheek, that they don't have to have the ability to swallow. And why is this critically important? Because there is inevitably always going to be a day when that person is not able to swallow. That is not the time. That means they're headed into their transition phase. That is not the time. It's never gonna work out this way to try and get a sublingual pain medicine. I had a, I was subbing for a hospice nurse. She was a very new young hospice nurse. It was not, you know, that anyone was trying to do anything wrong. And I was subbing for her patients for the day. And I came in and this man had just gone into the head of his transition phase. He was awake, but he couldn't swallow.

Speaker 1 (19:22):

And he had no sublingual medication in the home only pill form pain meds. And he was R RTH in pain and sublingual medicine that is narcotic form is very difficult to get from. You have a specific pharmacy. It needs to come to, it is not something that is readily available and it will seem forever. And it will be forever that you have somebody that's driving in pain that you can't control. So again, that rule of doula givers, Pearl, to have the comfort kit within the home with the medicines within 24 hours, I don't even care if somebody has never had a pain history or a breathing history. You want those medicines in the home because inevitably if it happens and most times it does, you wanna make sure that you have them there. So the sibling will medicines are wonderful because this is going to allow you to provide that pain management with somebody who can't swallow and or when they're in a deep sleep coma.

Speaker 1 (20:22):

Okay? So you have everything that you need, so you wanna make sure. And just so you know, the medication that is usually given is the sublingual form of more morphine, liquid morphine, which is known as ROL. And it also hears a doula givers, Pearl, it's one of the best medications for breathing issues. So if somebody is having breathing issues or air hunger at the end of life, which comes up with many disease processes, is that a small amount of Mo liquid morphine known as Resinol, which will all be prescribed for you from the doctor has a great effect for allowing people to breathe easier. And it works very quickly. So it's a fat, what you call a fast acting. It works quick and it leaves quick. So it's really wonderful. Don't let the word morphine get you scared and prevent you from being able to be that great caregiver with the knowledge to administer medications.

Speaker 1 (21:18):

It is nothing to be scared of. It's your best friend at the end of life? Liquid morphine is your best friend at the of life. Okay. Um, so again, you wanna understand the pain scale and you know, that pain is subjective. So where I might have a tolerable pain at four, somebody might, a four might be a lot for them, but you always want the rule of thumb to be a four or below keeping it a four below. We don't want pain to completely disappear. We just want it to not be something that is causing, you know, every second of every day to be suffering and not be able to have any quality to the day. So pain scale one to 10, and then I want to share with you today. And this is a very important moment of our, a topic. I wanna talk to you about pain management at the end of life and addiction.

Speaker 1 (22:16):

So there are so many misconceptions around this space and we really wanna clear them up because when we don't have the knowledge, then people are left without having their pain managed at the end of life suffering. And I know that you don't want that. So let's talk about two different things. Number one, some people will say, well, we don't wanna give them pain medicine because we don't want them to become addicted to the medicine. So we know that there's so much news about addiction and, and talk about it. And yes, it's a real significant problem, but we also want to breathe for a moment and ground, okay? Because this is not a scenario when addiction occurs. There's two things from my understanding. One is that there's a predisposition to addiction within that person's body chemistry. The second is when people take recreational, um, medication to get euphoria where there isn't any pain, the body starts to then want that and crave that.

Speaker 1 (23:23):

So it starts to, yes, it starts to say, wait a minute, that felt so good. We were having such a great time am feeling wonderful. Ooh, I want that again. So now there is something that's created, but what I just

shared with you is it's because there's no pain there and it was just pure euphoria. So those are two reasons why people suffer and get addicted to medications. Number one, again, they might have a predisposition within their chemistry of their body. Number two is that they're using it recreationally when there's no pain to be controlled and it's just pure euphoria. So there's new pathways being made in the body that say, wait, I want the, again, I want that again. So those are the two reasons. So at end of life, those are not present. The neither one is present. So well, maybe the first one might be, so we're gonna cover addiction in a minute, but, but it's not present.

Speaker 1 (24:19):

People have pain. And that's why there's pain medicine prescribed and won't get addicted. If the caregiver is knowledgeable and comfortable and is assessing again on keeping that pain at a four or below, I wanna share with you right here today that this loved one is going to have their end of life. They're either going to have it being comfortable and having their pain managed or suffering and having a lot of pain. They're going to have their end of life. It's not gonna prevent them from having it. It's not gonna, Hasen the end of life. It's a question of them either being comfortable in this last phase of their life or being in pain and suffering in this last phase. So this is something I wanna support you in understanding and how to do really well. Cause I know that you want your loved one to be as comfortable as possible. So let's talk about the first one. Let's talk about pain administration at the end of life, with somebody who has a history of addiction.

Speaker 1 (25:24):

We know that there's so much that goes on with patients and families. It's it's, first of all, it's a medical condition, a medical condition addiction, and we should not have judgment and have compassion for people that being said. I know that there's so many avenues that families and people with addiction go through that have so much and pain and all of the things that go along with it. So I know how sensitive this area is, but if somebody has had a past history with addiction and they're at the end of life, should we withhold pain medication?

Speaker 1 (26:04):

Of course not. Of course not. You wanna make sure there's somebody who's managing that medicine. That's not just out there. If that person is awake and able to, um, access medication themselves, it should be kept in a locked box. Hospice will provide a locked box for any, um, families that have addiction. Either people in the home with addiction or the person has addiction. So it would be very controlled. I think that the fear is that they're going to reactivate their addiction or, you know, you know, maybe start behaving like you're used to the past years that they were addicted. And all of the things that go with that that are very, very intense and heavy, but they're at the end of life now. So that's not gonna happen. It's again, a question of being present, being loving and being the caregiver and helping them to be as comfortable as possible within this end of life, part of their journey.

Speaker 1 (27:02):

It's not gonna mean that they're gonna be out in the streets trying to get more medicine. This is an end of life. This is very different. So I know how many layers of pain and triggers that this can bring up, but let's, let's go back for a minute and let's really try and get grounded in having no judgment addiction, which is a medical condition, a condition. I know that it has so many layers to it, but at the core of it, let's try not to judge people, but let's also support in this moment and take a breath of what the truth is here and how very important it is to somebody that we love at the end of life, no matter what their past

has been. So if there is an addiction history, you can have a locked box. You have somebody that is the person again, that is comfortable with administering that medication.

Speaker 1 (27:59):

But please don't think that this should be with help from somebody who as a past, uh, addiction history, because they're at the end of life. And they like everyone else deserves to have the most comfortable pain well managed at the end of life. Breathing well managed at the end of life. Everyone deserves that. So again, talk to your hospice team and let them support you in this. But please don't withhold medication from people who have a past addiction history, okay. Pain management at the end of life is one of the most important educations that we can give out. There are two types of pain, somatic pain, which is your most common, which used with narcotic as treatment. And then you have nerve pain, which again, would need a medication like Gabapentin. Um, also known as Neurotin. And that is a stabbing fiery type of pain.

Speaker 1 (28:57):

Having one person designated to be the person that administers that's comfortable with the pain medicine, having the hospice nurse come and let that person practice and draw it up right in front of them so that they can get used to what that looks like. The dosing, how you do it, get com really comfortable with that. Having a pain log book at the side of the bed note, noting what number the pain level was at before pain medicine was administered. And what was the outcome about four minutes later, keeping track of bowel movements, right alongside with pain management. Knowing that again, constipation is a side effect of narcotic pain medicine and understanding the importance of treating pain at the end of life. We just don't want people to withhold medication and it happens all of the time because they just don't feel comfortable in this space. We wanna educate you and the time to do that is well before we ever get there, just like everything at else.

Speaker 1 (30:02):

This was pain management at the end of life. My name is Susan O'Brien. Please leave a comment or a question below. I'll make sure to answer it. The other thing that is just a fun fact within all of this is that most hospices will have an indicator on the comfort kit color coding. So you might have the liquid morphine with a plastic bag around it with a purple dot. And why do they have colored dots on the medications? Because this is how feared medications are for caregivers. Is that when that call comes into the hospice at two in the morning that my loved one's in pain, I don't know what to do. And they go go, literally walk you to the refrigerator to get the comfort kit. And they will literally say, find the purple dot and why do we actually break it down into such simplistic measures is because it's that fear and when we're fearful common sense and just, it's very hard to learn any, anything. So we'll literally say get the purple dot, read what that is, and then to administer it. That is not the time to learn how to do this. The time is now. All right, everyone, please leave me a comment or a question and I will answer them. And I wanna thank you so so much for being here again. This is Susan O'Brien on ask a death doula, have a great day, and I'll see you in the next episode.