

## Quality of Life

May 14, 2019

Hello everyone, thank you for joining us today and welcome to the atom Alliance Community Action Network virtual meeting. My name is Kathy Munn, I'm one of the several Atom Alliance team members that are monitoring today's call. Thank you for taking time to join us, we appreciate all you do to improve quality and achieve better health care outcomes for the patients and the communities that we serve.

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The atom Alliance is a five state Alliance composed of three nonprofit healthcare quality improvement consulting companies. We hold contracts with the Center for Medicare & Medicaid Services in which we partner with healthcare providers, stakeholders and beneficiaries to accomplish objectives geared towards meeting the National Quality Strategy aims. Those are better more affordable care and healthier communities. As a part of these efforts, we help eligible clinicians and groups better understand and successfully participate in the Quality Payment Program by offering free technical assistance tools, resources and educational events. We welcome participants from our Alliance states of Alabama, Indiana, Kentucky, Mississippi and Tennessee.

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As I mentioned, I'm Kathy Munn and I'll be facilitating the call today. I'm one of the Quality Improvement Advisors in the state of Alabama. On this slide you'll see other Quality Improvement leads across the atom Alliance. These are your contacts for your particular state, and we are all happy to help you with any questions or technical assistance needs that you may have, so please reach out to any one of us.

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We want everyone to know that during this call you're in a safe environment for sharing without in without any judgment. So, to that end, we would ask that you be fully present and engaged, open minded, collaborative and willing to participate, willing to share successes and challenges, and ready to value each other's experiences.

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Before we begin, I want to review just a few housekeeping items with you. Today's lines are muted during the presentations. However, we do hope that you will join in the conversation if you have a question or a pressing idea that you'd like to share, you can raise your hand by clicking the hand icon next to your name in the GoToWebinar control panel on the right-hand side of your screen. We will unmute your line at the next pause in the presentation. Several of us from atom Alliance will be monitoring the questions area and the GoToMeeting control panel in case you would rather type in your question or comments to be shared with the panelists and

with the audience. Today's call is also being recorded. The recording of the presentation will be available and placed on the canned webpage on the atom Alliance web sheet in approximately a week. The slide deck is available now on the main control section where you can download it at your convenience.

Before we get started, we want to celebrate some of the successes that we've had over the past four years. The atom Alliance would like to thank everyone for participating in our Community Action Network meetings and working with us over the past five years. Our communities will continue to be extremely important in the future as additional work will continue to be conducted at the community level. Beginning in August of 2019, work at the community level will include behavioral health, chronic kidney disease, antibiotic stewardship, reducing the burden of opioid use, reducing admissions, along with additional interventions that will impact the level of care in our communities. We look forward to these great results that we can achieve together as we continue the journey to impact the quality of life and medical care for our Medicare beneficiaries. But as we look forward, I want to also take a moment to look back at some of the things that we've done over the past five years.

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You will see that our collaborative efforts over the past five years have impacted 2.25 million people with Medicare. And of those patients or beneficiaries, over a million live in rural areas. So that's really a huge impact when you think about that five-state region. Our next slide shows that our interventions have helped avoid approximately 41,000 hospital admissions which resulted in 478 million dollars in savings.

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We also helped avoid more than 6,300 hospital readmissions, which also resulted in savings of more than 81 million dollars. As we move forward with our presentation this morning, I would draw your attention to the objectives for today's presentation. At the end of the webinar we hope that attendees will be able to understand the difference between palliative care and curative directed therapy, be able to describe hospice care, understand the types of patients that may be classified as end-of-life, recognize the myths around hospice care, know the benefits of hospice care and be able to discuss symptom management strategies at the end of life. Today's presentation is available in the handouts area of the GoToWebinar control panel, as I mentioned. If you open this during call, it will take time to download. So, I would suggest that you open the document after today's presentation. And finally, your feedback is very important to us as it will help us shape future events. So please complete the five-question post event survey. Again, thank you for joining us, and I'll now turn the presentation over to Cindy Todd who will introduce our speaker for today's web ex, Cindy.

Thank You Kathy, I would like to say good afternoon to everyone. Also, I am a very active member of our atom team which I know I know many of you on the call. So, I have the greatest pleasure of introducing our guest speaker, Dr. Dustin Dillon. Dr. Dillon is the Associate Medical Director of the Adult Palliative Care and Pediatric Team for Hospice, excuse me, Hosparus Health. Dr. Dillon earned his medical degree from the University of Louisville School of

Medicine where he graduated magna cum laude and completed his pediatric residency and fellowship in hospice and palliative medicine at Northwestern University. He is a fellow of the American Academy of Pediatrics and board certified by the American Board of Pediatrics. He joined Hosparus Health in 2017, returning home to his home state of Kentucky with his wife and son. So, welcome Dr. Dillon, we are looking forward to this webinar.

All right, well thank you for having me. Like she said I am originally from Kentucky and so I am a pediatrician by training, but, then it's part of fellowship, I did do some adult hospice and palliative medicine. So, I tell people I'm a little bit of a mutt now when it comes to what I do. So, I do some pediatrics, some adults, some palliative medicine, some hospice. So, it always keeps me on my toes. The first thing I just wanted to briefly mention on, you know, I think the big question is, well what is palliative care and what does that look like as compared to a curative focused plan of care? And it really comes down to what the goals are. And so, you know a curative focus plan of care really is medical team driven and you guys have probably already seen that. You know the patient that has breast cancer that may or may not be metastasized somewhere. The plan of care is really driven by the medical team, because the goal of that is to give that patient as long a life as possible and then hopefully cure that patient. You know the unit of care, like who we're treating, we really do focus on the patient and not so much the family or friends or significant others and things like that.

If you look at what palliative care is, it really just means an extra layer of support for patients. Also, the patient's families or friends or significant others, if they're facing some sort of serious or life limiting illness. And, I think the biggest difference between that, and a curative focused plan of care is that the patient is really steering the ship. You know I tell folks that if their decisions about what they want their life and they want their time to look like is really important for me to know that, so that we can come up with a plan of care together. But they're going to be the ones that always have the ultimate say at the end of the day. And this really is a holistic model, so we don't just focus on the medicine. So, I don't just focus on, you know, the nausea, vomiting, the pain, the agitation, anxiety, but we also focus on the psychosocial issues surrounding serious medical illnesses. We focus on the emotional aspects; we focus on the spiritual aspects, and we really use an interdisciplinary team to do that and treat our patients.

So that brings us, actually, to the first polling question. And it's very simple, so do you know the difference between palliative care and hospice care? You'll see the polling question there. If you would take a moment to select your answer, we'll leave this poll open for about 30 seconds to give everyone a chance to vote and then we'll look at the results. Okay! So, it looks like the vast majority of our audience does know the difference between palliative care and hospice care. So, Dr. Dillon, I'll turn it back over to you.

Awesome, so that's wonderful. So, I think that you guys are ahead of the curve when it comes to the general population in the community and also the general population in the medical field. Cause, I think there's still a lot of confusion around that. So, I'm going to kind of go into a little bit in more depth about what is hospice. So, hospice is really prognosis driven so it's time driven. So, what this is, is essentially palliative care but for patients that have a prognosis of six months or less as determined by their physician. You know the goal of hospice care is really to palliate

symptoms, so to make patients feel better to increase their quality of life and not necessarily to focus on curative aspects of treatment. And, it's also not our goal to either hasten or delay death. So, we really do see death in hospice as a normal part of living, and it's an important part of the lifespan when we come to the end and we really utilize a team approach. So again, not just the medicine, the medical aspect, so there's nurses and physicians, social workers, chaplains, bereavement counselors, CNAs, home health aides. All those are part of the interdisciplinary team. But I will say that hospice is really a small part of the palliative medicine model.

And so, I used this slide and I really, really like this slide. I've given it for a bunch of different presentations, but it really shows how palliative care evolves over time. So, if you look at the patient when they're diagnosed at point A in their disease process, their goals really may be life prolonging therapy. So, let's go back to that breast cancer patient that has localized disease. They get a mastectomy and then they get radiation, followed by chemotherapy, with the goal of prolonging their life. Palliative care still has a role with that patient even upfront at diagnosis, because we may be able to help with things like nausea or pain or anxiety. But as you know over time, some of these patients, their disease progresses. So, let's say that the cancer comes back for that breast cancer patient and now it's metastatic to the bones, the liver and even maybe the brain. So as their goal shifts from a curative focused plan of care it becomes more of a palliative focused plan of care. The role of palliative care support becomes more important and it's really not only until you get down here to where point F is, when you start entering that final six months of life is when they're eligible for hospice care. The other important thing to remember is part of hospice care is that it continues even after death. So as part of the hospice benefit, the Medicare hospice benefit, which we'll talk about. All patient's families and friends get 13 months of bereavement support and grief counseling following death. Again, the hospice philosophy, we really focus on the patient and their family in those final weeks, months, hours, days, whatever it is of life, with our goal of making them as comfortable as possible. But also, just making sure that each day really matters and it's as good as possible.

Again, we recognize that dying is a part of the normal process of living. Well, I'm always careful when I'm talking to patients and families even in our inpatient unit or at home. You know I always say, I never say that's normal, because a lot of times they'll ask me, like we've been noticing this symptom, right. Maybe it's the respiratory pattern is changing and if you just say that that's normal, I think it doesn't really kind of affirm what the family's seeing. And so, I always say that that's normal for the process of dying, because for a lot of our patients and families they may not have ever been around somebody that's dying and so none of this is normal at all.

If you look back at the history of hospice, you can trace it way back to the medieval times. But, Dame Cicely Saunders, she was actually her whole, like, interdisciplinary team in one. So, she was a nurse, a social worker and a chaplain. And she started her own Hospice in London in 1948 and so, or she started taking care of dying folks in 1948, and then founded the first modern hospice at St. Chris's in Britain in 1967. At the same time, I think you guys have all heard of Elizabeth Kubler-Ross's, *On Death and Dying*. So, she's the one that came up with the idea of the different stages of grief and so when she wrote that book in 1969 it started the shift from

folks dying in institutions to hopefully more folks dying at home. And so, the first Hospice was actually started in 1974 in the US. And so, the hospice of Louisville and southern Indiana, which is now Hosparus Health, which is who I work for, it was started in 1978. So, no good deed ever goes unpunished, which I always say, and so 1980 JCAHO wanted to establish standards of care for accreditation for hospices to try to make sure that everybody was doing the best thing for the patients and really following the standard of care.

And then in 1983 is when the Medicare hospice benefit came out and so people always say, well what is the Medicare hospice benefit. Well essentially for patients that have Medicare, they exchange their part A benefit for their hospice benefit. And so, all you need to be able to be eligible for the Medicare hospice benefit, if you're a Medicare patient, is you have to have a prognosis of six months or less as determined by a Medical Director of the hospice or an attending physician. And you also have to have goals of care that align with what a hospice does. So, a patient that is has metastatic prostate cancer that definitely has a prognosis of less than six months, but maybe their goals of care don't necessarily align with hospice. So that maybe they still want to get aggressive disease directed therapy with which means like chemotherapy. And they still want to be admitted to the hospital and they still want to intervene if they're hyponatremic or if they're calcium's low. All that may mean that the patient even though they're eligible from a prognosis standpoint, their goals of care may not necessarily align and so there's these conditions of participation that Medicare put out in 1983 and they've been revised a few times. But it's essentially guidelines that allow us to see which patients really qualify for the Medicare hospice benefit.

So, if you look at the benefit periods, this is really not important too much for folks outside of Medicare or outside of hospice. But just keep in mind there are different benefit periods. They are unlimited in the sense that as long as you have a prognosis of less than six months, you are always eligible for hospice, and the prognosis of six months really is from that day that you are thinking about the patient or talking about the patient. It's never retroactive. And so, what I mean by that is let's say a patient comes on to hospice and we think they have a prognosis of less than six months and they have heart failure. Well let's say that they've been with us and they've already been with us for eight months. So they've already outlived what we thought their life expectancy was. As long as it is from that moment that I'm seeing them or that we're talking about them in team, as long as I think that their prognosis is still less than six months, they can continue to receive their Medicare hospice benefit and remain on hospice service even if they've outlived that six-month prognosis. And you'll see that more commonly in dementia patients or heart failure patients as compared to cancer patients really do tend to usually die in a few weeks to months after coming on to hospice service.

So, what do you get if you're being cared for by a local hospice agency? So, you get all these things I've already kind of talked about that. You get the entire interdisciplinary team and so this is both medical and non-medical personnel.

So, I think we're going to spend the majority of our talk, I'm really talking about who belongs in hospice right, so we want to serve as many patients as possible. Because I really truly think that the goal of hospice is an amazing one, and to really serve patients at home or wherever they're

living, whether that's literally at home or maybe it's in a nursing facility or in an assisted living. So, our goal is to make the amount of time that they have left as good as possible and control their symptoms and really focus on the things that are important to them. And so, in order to do that we really have to figure out, like well, which patients are eligible for hospice, right. Which patients really have a disease that gives them a prognosis of six months or less. So, there are different disease specific criteria both related to cancer patients and non-cancer patients and we'll talk about those. But I'm a really, really big proponent of looking at functional decline. And so, what I mean by that is, like really focus on what the patient is able to do for themselves or not able to do for themselves for lack of a better term. And so, if you look back over the span of the last year, I always ask patients, like tell me what you were doing at this time of year ago. And it always allows me to kind of paint a picture in my mind of how fast this patient is declining. You know if they tell me a year ago that they were still working, they were able to mow their yard, they were doing all of their activities of daily living and now they spend the majority of their time either in bed or in a chair, regardless of their disease process I think that's a pretty compelling argument that they have had disease progression and their disease is getting worse. And so, we're going to talk about some of those things to look for.

So general hospice criteria again, the terminal condition or the prognosis is really determined by the attending physician or the hospice Medical Director. We want to make sure that patients and families are aware that they have a terminal condition. I used to think that whatever patient, if they're receiving hospice, they must know that they had a really serious medical illness and their prognosis is poor. After doing this for a while, I now know that that's not always the case. I'm actually surprised at how many times I go in to see a family at home and the first thing I always ask them is, I know that you guys have had a lot of conversations with your medical team or your primary care provider, tell me what you understand is going on. And it is shocking how many times families have, and patients have very little understanding of where they're at in their disease process. And so, one of the roles that I have is really providing education and helping manage expectations. When you look at criteria that can be applied to any patient to see where they're at on their disease process. So, ongoing disease progression is something important to look at and this is really easy to do if you have, like a cancer patient. You know three months ago; we did scans, and their disease was stable and then just last week we got a CT scan of the abdomen and pelvis and it showed that the ovarian cancer had actually spread. The lymph nodes that used to be stable had now gotten bigger in size and there's now a new mass in the pelvis. So that's pretty easy to talk about disease progression when you have scans.

If you don't have scans, let's say it's a COPD patient or a heart failure patient. One of the things that I always look for is recurrent ER or hospitalizations. And so, you can really look back and say you know two years ago Mr. Smith with his COPD, he was admitted one time in 2017 and then in 2018 he was admitted three times and he had four ER visits for shortness of breath and COPD exacerbation. And now, since the beginning of 2019 he's been admitted to the hospital every month and he's only been home for two weeks total. And so, I think that allows you to understand that Mr. Smith's disease is definitely getting worse based on how many times he's had to go to the hospital.

You could also look at something called a palliative performance scale, or a PPS, and I want to show a slide of that but that's really the hallmark of what I use as a hospice physician and that really just tells me about what the patient is doing functionally. You can look at dependence on ADL's too. So, I will tell you as a pediatrician and thinking about activities of daily living. When I started doing this job it was actually really hard for me because most of my kids that I care for, they're dependent for all of their ADL's because they're children. So really, this was a new way of thinking for me. But really if you think about what patients are doing as far as their feeding, their bathing, their dressing, their toileting, all of those activities of daily living, how dependent are they on somebody or a caregiver to help get those done. And then another big, big hallmark to look at is weight loss of greater than 10% over the last six months. So regardless of what the disease process is, if they're losing weight regardless. I always say that that's a really important thing to think about when you're looking at prognosis.

So, this is that palliative performance scale that I talked about. So, there's five different domains that you can look at and the most important domain is ambulation. And so, this graph is definitely left-sided dominant. So, ambulation is more important than consciousness level because as you can see you can actually be fully conscious all the way down to a PPS of 20% and that's very close to death. And so, if you look at ambulation these patients I said, remember I wanted to look for patients that have a palliative performance scale of 50% or less. These are the patients that mainly sit or lie in bed so, they're in their chair the majority of the day or they're there in bed the majority of the day. And so, this is able to help me when I'm thinking about prognosis for these patients. If you look at disease specific criteria, so, if you think about cancer first, honestly to me this is the easiest. When you're thinking about prognosis, because I can tell you that patients with metastatic solid tumors without disease directed therapy in general have less than six months to live. And so, most of these patients should have a functional status of a PPS of 60% or less. So again, we're entering into that 50% range. They in general shouldn't be fully working full-time if they're in hospice and they should have weight loss or complication of disease. We use also, kind of like the palliative performance scale, we use something called the Karnofsky or the ECOG scale so a Karnofsky score of 40 is equivalent to a PPS 50%. So again, a patient with cancer that spends the majority of their time in the chair or lying down so again they have a palliative performance scale 50% or their Karnofsky score is 40 or that corresponds to an ECOG of three, all of these are basically saying the same thing. You can estimate their prognosis at less than three months. So, a really important question to ask for your cancer patients that you're seeing is how much time do you spend in a chair or lying down? If they say, I spend most of my day in the chair or in bed. That patient is likely entering the final months of their life based on their disease progression. And so, I think that's important to keep in mind.

These other things that I think we forget about how serious they can be also tell us how long patients generally live after being diagnosed with one of these. And so, this is median survival. So, again a patient that has a brain met that tumor is spread to their brain and let's say they are not receiving radiation therapy to the brain, their median survival is usually somewhere between four and eight weeks. Even if they receive radiation the median survival goes only up to 12 to 24 weeks. So really up to six months max, and so brain metastasis is a really, really important thing when you're thinking about cancer prognosis. The same thing is, you know these patients that

have malignant pericardial effusions or malignant pleural effusions, these are all hallmarks that the disease is getting worse and likely the patient is entering the final few months of their life.

Switching gears, a little bit we talked a little bit about cancer disease specific prognostic data. So, if you look at Alzheimer's dementia and there's something called this functional assessment scale or a FAST score. So, if you look down, if you're thinking about advanced dementia or end stage dementia. Where we normally start seeing patients in hospice is when they have a FAST score of seven, which means they should be incontinent of bowel and bladder, because that's a 6D or a 6E, and so really these patients should be incontinent and really don't have the ability to speak more than six words. And again, this only applies for Alzheimer's dementia, this doesn't apply to vascular dementia or Lewy Body dementia or frontal temporal dementia. This is really just specific to Alzheimer's disease.

And so, for patients that we admit to hospice we really look for them to have a fast score of 7A or higher. And if we're, if they let's say they have a 6E, but let's say they're having recurrent fevers, they're losing weight, they've had recurrent aspiration pneumonias, or UTIs or they have stage three or four ulcers, that's all a sign that their disease is getting worse and they're likely entering those final six months. I put this up there, this slide, just because I think it's always interesting to think about. So, if you look at all types of dementia, so not just Alzheimer's, but all types of dementia with patients with end stage dementia that's progressing and they're having trouble swallowing or eating. If you look, once they start having dysphasia or difficulty swallowing almost 40% of these patients are dead within six months. And if you look at, this is always a big one right so, hip fractures, so we know that hip fractures and end-stage dementia, half of those patients are dead in six months. So, if I get called about a patient that they say, well you know Dustin, Miss Smith, she has Alzheimer's disease, she's incontinent of bowel and bladder and she recently just fell and broke her hip and she's not really a good surgical candidate. They elected to just treat it medically and make sure she's comfortable. That patient is definitely eligible for hospice service.

Again, we talked about evidence of a functional decline and some of the things you can look for, so again, a decline in the palliative performance scale. So, the patient that's gone from being in the wheelchair most of the day and being able to get around the facility, to now they're in bed most of the day, that's a big functional decline. Or maybe a patient that's been able to eat by mouth and now they're only taking bites and sips of food, this is a functional decline as well. Unintentional weight loss, we've already talked about. Just in general, patients that have a low BMI, so less than 22, that's a poor prognostic factor and so I always look for that especially in our dementia patients. And you know most of the time they'll say their BMI is like 15 or 16 they're just really, really small and cachectic. Sarcopenia means they're losing muscle mass and so we'll measure upper arm circumference, so the M is mid, the U, upper. A is arm circumference and so, we'll measure that over time. And if you have labs you can always look at an albumin. If it's less than 2.5, that's definitely a marker that they have a poor functional status or nutritional status.

So that brings us to polling question number two, and that is which of these are common misconceptions of hospice care.

You'll see the polling question come up on your screen in just a moment. When it pops up it will ask you to enter your responses to the polling question. There we go. Which of these are common misconceptions of hospice care? You can select one, and then we'll give folks a couple seconds to enter their responses, and then we'll take a look at our results. So please enter your responses and we'll give it a about ten seconds, and we'll come back and see what the audience's response to the polling question is. Okay, Dr. Dillon it looks like we've got some results here. All people in the audience feel like all of the above are common misconceptions of hospice care. I'll turn it back over to you.

Perfect, I'm just going to get right back, so yeah, I think everybody nailed it. So, we hear this all the time, right. So, I was actually just talking to a family yesterday of a little seven-month-old with really bad congenital heart disease that's not really a candidate for surgery. And so, one of the caregivers had mentioned, well I'm afraid of hospice because that once you say that you're going to go into hospice they just give you meds and make sure death comes on really, really soon. So, I wish I could say that I didn't hear this all the time, but I definitely do. These are all common misconceptions, right. So, I just put this up there that some myths and facts about hospice so again, hospice care hastens death. So again, our goal is neither to necessarily prolong life. If we do things that prolong life that's absolutely fine if our goal is making sure the patient is comfortable. So, I always bring this up when it comes talking about antibiotics. So, let's say a patient is still really functional. We think they have a prognosis of months, but they get a UTI and they're having burning and pain when they're going to the restroom. Well, antibiotics, probably for them, that would actually prolong life, but it also helped their symptoms, right. Our goal is, to number one, make sure their symptoms are being managed and so if we can give them an antibiotic, it helps their dysuria, then we're absolutely going to do that, but our goal is never, ever, ever to hasten death.

And so, you know hospice care is only for cancer patients. I will say that in Hosparus Health about a third to a half of our patients have cancer. The rest of our patients have any combination of dementia, COPD, heart failure, renal failure, liver failure. Most of them actually you know, we are in Kentucky and, we do serve southern Indiana, so the majority of our patients actually have a combination of all those together just from years of a pretty hard living and their body has taken a lot.

The other big myth is you know, hospice means giving up. And so, I always hear that a lot too in pediatrics. It'll say, oh this means giving up or this means we're going to lose hope, right. And so, I actually think it's the opposite of giving up, right. So, I always tell patients and families like you've fought whatever disease that you've been dealing with for a long time and you've done an amazing job, and now you're going to fight for something different. And maybe that is fighting to stay at home or fighting to be as comfortable as possible or fighting to spend as much time with your family as possible and making sure that that's good time. And so sometimes it's just about managing expectations. And maybe before, when the patient or family hoped for a cure maybe now, we have to shift what we're hoping for and we can help families explore what their goals and hopes are.

Hospice care again, is only in the last two weeks of life, obviously that's a myth. Again, we want to serve patients for as long as possible. Any patient that has a prognosis of six months or less is absolutely eligible for hospice. But I will just say, nationwide, we all have to do a better job of getting patients into hospice sooner. Because the median length of stay for most hospices, including ours is still only about two weeks to maybe three weeks. And so, patients, if we can identify those folks earlier and get them into hospice earlier, I really think we can even make more of a difference than what we're already making.

And again, hospice care is expensive. It's absolutely a myth so Medicare, Medicaid and pretty much all private insurances have hospice plans that will pay for a hundred percent of charges that are related to the patient's terminal prognosis. So, anything that's related to what's causing them to die in six months should all be covered under the Medicare hospice benefit or the Medicaid hospice benefit, or the Anthem hospice benefit. I will say for you guys, that if you're dealing with private insurances, there are sometimes some nuances that they may have in their hospice policies. That's always good to check prior to utilizing that. So, we just had a patient recently that we admitted at a hospice that private insurance in their insurance plan limited the number of days they could receive hospice to like 500 or something. And so, I still don't think that that patient will be alive for 500 days, but it is something to look into prior to enrolling patients.

So, this study was actually done back a few years ago, and it actually looked at Medicare folks that entered hospice with all these different diagnoses. And, it actually followed them over a span of time, and it looked at patients that had Medicare that did not get hospice with the same diagnosis and it actually compared their survival as far as time goes. And so, it looked at almost 4,500 patients. The majority of these patients had lung cancer. But what we actually found was that the patients that had hospice actually had an increased survival time of 30 days. Now I don't mean to say I don't say this to make it sound like our goal is to make life longer because again we've already talked about that. Our goal is to not necessarily to prolong life nor to hasten death our goal is to focus on palliating symptoms. But in this study actually, patients that had hospice lived a little bit longer, lived a month longer than patients that did not get hospice. I will say that the largest difference in the survival cohorts was with heart failure. Which I get, you know, as you guys probably know if you take care of heart failure patients, trying to predict when they're going to die is really, really, really difficult. But, I do think the notion that patients once they enter hospice die faster is definitely a myth and this is just some data that supports that.

So, now we're going to shift from those are the types of patients that are eligible for hospice, to how you can help identify those patients that are moving towards the end of life. But let's really kind of dive into the symptoms that we focus on at the end of life. So, these are the patients that may only have hours, to days, to weeks to live, right? So what do we do as far as symptom management goes. So, common end of life symptoms, if you actually look at the most common symptom that patients report at the end of life it's actually fatigue, right. And I wish I could say that we had a wonderful medicine that we could use for fatigue and it really made a big difference. But to be quite honest with you, the best way to help manage fatigue is really through education and helping families and patients prioritize what's important to them. If we know that, you know, Mr. Jones with his pancreatic cancer really is only able to stay awake a few hours

during the day, then what do we want those few hours to look like? Do we want it trying to get him a full meal in? Do we want it to be spent with his family or when his grandchildren are visiting? So, it all really goes back to education. But, the second most common symptom at the end of life, and I don't think this is a shock to anybody, is pain, followed by shortness of breath, nausea, vomiting, restlessness and then also oral pharyngeal secretions is the medical term for the death rattle, right. So, the folks, they can't swallow their secretions and you hear it rattling, both in their throat and in their lungs, as they're breathing. It's a really, really common symptom. So, I put it up here the idea of total pain or total dyspnea, which is total shortness of breath. And what I mean by that is that total pain, we know that the person that has pain at the end of life it's not just physical pain right. There are spiritual concerns that contribute to their pain, there are financial concerns, there are emotional concerns, there are psychological concerns and that's why the interdisciplinary team is so, so, so important. Sure, I can write for an opioid, I can write for a patient some morphine to help control their pain. But, morphine doesn't help if it's a young mother that's leaving behind a few children, right. Morphine's not going to help that. So, what can we do as an interdisciplinary team to help that? The same thing with shortness of breath, right, maybe the shortness of breath is because they actually have fluid in their lungs because they have end-stage heart failure. But maybe it's because that they have a lot of concerns about what happens to them after they die. They have a lot of spiritual distress about the afterlife and then that's causing anxiety and causing them to have shortness of breath. Again, I can give them Ativan or some sort of benzodiazepine to help with that anxiety but that's not going to take away their spiritual distress. So, we really need to make sure that we're working together as a team to focus on all those aspects of disease.

I would say if you take home like one big slide from this presentation, I would say this is probably it. When it comes to end-of-life symptoms so education, education, education. I think this is my biggest role as a physician. And honestly, it's the one I enjoy the most. I love sitting down with families and talking to them about, let's talk about the things that you're going to see with your mother over the next you know hours, to days, to maybe weeks and let's talk about the what those changes mean and what they tell us. Right? So, you can definitely see changes in temperature right, you can see fevers, especially in the last few days of life and this is probably because the brain lacks its ability to control the temperature. But also, patients are probably aspirating, having a little bit of an aspiration pneumonitis. We can see changes in their breathing pattern. Right? So, I think if you guys have been around dying patients you'll notice that sometimes they breathe really, really, really shallow and then every few seconds to maybe minutes they'll take a really big deep gasp, and then they'll go back to breathing really shallow, and then they may have pauses which is called apnea. And so that doesn't necessarily mean that their breathing is labored, that it's bothering them. But, it truly does bother the folks that are in the room and so if I can sit down with patients and their families and show them, like this is what I'm seeing and then this is a normal part of the process, this is a normal reflex at the end of life, it really does go a long way. Because as that gets worse over time families are going to say you know what, this is what the doc told us about what to expect. You can also see changes in circulation. So, right as the heart is slowing down the biggest thing you're going to see is, you know, their fingers and toes become dusky or they can become purple. You can see mottling of the skin and that's that kind of lacy appearing rash as the heart slows down. I always tell folks to

look for that over the knees and shins and elbows, kind of over those bony areas. Changes in alertness, as you're dying, as the patient's dying, they just become less alert and there may be moments of clarity that they have with their families. But, those may, those moments that clarity may be few and far between. I tell folks, you know, I'm in our inpatient hospice unit today, I'm going to go see patients here in a few minutes, and I can promise you that one of the things that families always ask me is are they going to wake up, right. Are they going to be able to communicate with us? And the answer to that is, I just I don't know, but if they do like take every single second of that moment and cherish that and tell them all the things that you want them to hear and just be present with them.

Again, the changes in secretions, the death rattle. Again, I always tell families, I'll say you know that's not bothering your mama, that's not bothering your dad or your brother or your son. But I will freely recognize that it bothers everyone else in the room. So, what can we do to help those secretions and we're going to talk about that? So, if you look at pain and trouble breathing, this simple best drug that's always going to be used are going to be opioids right. So, these are things like morphine, like hydromorphone, which is dilaudid, fentanyl, methadone, oxycodone all of these different opioids. And so, people understand that those are used for pain. But honestly in hospice, we use them just as much to treat refractory shortness of breath. So that's why I highlighted both of these in red. So, we don't really know how those medicines work. I can tell you how it does not work is that it doesn't work by suppressing their breathing okay, and I think this is what everybody always worried about. Oh well, you're giving the morphine to suppress their breathing because they're struggling. No, no, it actually works in the brain and it tells the patient that they're not as short of breath as they think they are. And so, we use these, and we just titrate up over time depending on how labored the breathing is or how much pain they're in. I always say you know an addiction versus dependence versus tolerance. Dependence just means that if you stop the drug, that you'll have withdrawal symptoms. And tolerance just means that if, you over time, you need more of the drug to get to this, to get the same effect. So, honestly these are normal processes that would happen with any of us. And this is very much different from addiction, which is a psychological dependence on the drug. It's the patients, the folks that have cravings that will do anything to get the drug that even though they're getting in trouble with it and it's interrupting their life, they will still seek that drug. That's a completely different and separate SU from dependence and tolerance. And so, I think we always just have to keep that in mind so again, I highlighted here that appropriate dosing of opioids does not cause respiratory depression, okay. It actually works in the brain to just tell you that you're not as short of breath as you are, and it relaxes your breathing that way and it will help you relax and not be as labored.

Another thing that I always just want to keep in mind and tell folks is that handheld fans are one of the best things to help treat shortness of breath. So, there's a reflex of a nerve that runs in our face, it's called the trigeminal nerve, and as air blows across your face it actually sends a reflex back to your brain that helps relax your breathing. And so that's why I always have, we always have handheld fans in our rooms. Especially in the inpatient hospice unit and we'll use those fans to blow on the patient especially across their face because this does seem to help that trouble breathing.

Terminal restlessness, as we enter the last few weeks of our life, can definitely pop up and so these are those patients it doesn't seem to be pain; it doesn't seem to be anxiety. But they just cannot get comfortable and it's usually the patients I will watch them as they're kind of bringing them into our inpatient hospice unit, and you can see them they're kind of picking at their covers or they're constantly gripping their covers, or maybe their hands are really gripped or maybe they really look agitated and they're flailing about. So, they just cannot get comfortable.

And it's really, really common to hallucinate too. Hallucinations aren't necessarily bad especially if they're comforting hallucinations. So, we don't just necessarily treat hallucinations just because they're hallucinating. You know if they say I'm seeing my mom and she's telling me that everything's going to be okay, then that's a comforting hallucination. I don't necessarily think we need to treat that. But if they're seeing little kids in the corner and the little kids look disfigured, which is a common thing we actually hear, and I don't really know why. That's really, really distressing to the families, or sorry, to the patients and the families also, so it's our goal to treat that. So, what do, we do to treat those and so really, it's benzodiazepines some things like lorazepam, some nerve medicine or things like antipsychotics. So, things like Haldol, sometimes it takes a combination of both and sometimes it takes a lot of that medicine to help with that. And again, the last day, to weeks of life our preferred agent really is the Ativan. Because those patients, as they're entering the active dying process, we know they're going to be bed bound. We don't have to worry about them being a falls risk. And so, using these medicines while before we would always be worried about it they were you know 88 and still ambulatory like putting somebody on Ativan or lorazepam that's definitely worrisome, right. Because that's been known to cause falls. And so, our goals are just different at the end of life and we're able to use medicines, still judiciously. We still use them at appropriate doses and appropriate intervals, but our ability and our focus is just different once we get to the end of life.

So again, the death rattle, so audible oral pharyngeal secretions, the single best thing that we do to treat this is we get people in the recovery position. So, this is where we get folks on their side. And, this just allows those secretions to drain out the side of the mouth because what's happening is those secretions are just pooling in the back of the throat and if we can just shift those to be not in the back of the throat, that actually takes care of the rattle, right. And so, I'll talk to patients about this in families and we'll get them in a recovery position. If this doesn't help or it doesn't help as much as families would like, one of the things we can definitely try are things called anticholinergic medication. So, these are things like glycopyrrolate, which is called robinul, you've probably heard of that, or hyoscyamine which is called levsin. The other one I put up here is I will frequently especially for folks at home, I will use atropine drops because they can put two drops underneath their tongue to see if that helps with the secretions. It's really, really important to remember that they are actually eye drops. So if you don't tell the families exactly how to use it a lot of them will say, well we put it in their eyes instead of underneath their tongue, which honestly will still work. It can still dry up their secretions, but it will cause their pupils to be very, very dilated, which is pretty troublesome or troubling for a lot of caregivers.

So again, final thoughts please, please, please refer early to whatever local hospice you work with. If you think a patient may be entering the last months of their life go ahead and call and we

can always go out and do an evaluation. And, even if they're not eligible at that time, we can always help you and say these are the things we would look for to tell you that they are eligible for hospice services. And again, if you have symptom management issues that you're having trouble within the hospital, you can always call the local hospice organizations and I promise you the medical directors are always happy to help. And, that happens pretty frequently with us. You know we'll get calls from outside hospitals that are still in our kind of footprint and they'll say hey we got this patient and their pain is really, really difficult to control. This is what they're getting, do you have any thoughts and sometimes it just helps to kind of bounce that off someone else. So, at this point in our last few minutes I'll take any questions that I could answer from the group.

We have no hands raised at this time. But, just a reminder to our attendees today you can click the little hand button on your GoToWebinar control panel and either we can unmute your line or you could also enter a question into the questions area on that same panel. And I'm not seeing any questions still, looks like you covered everything Dr. Dylan.

Yes, I will just say that's a really comprehensive. It's kind of a 30,000-foot overview of hospice. But I do think the important parts are really focusing on the patients that are eligible and trying to identify those as early as possible and then also being able to identify like what are the common symptoms at the end of life that we can help patients and their families and caregivers understand what they're going to see, because I think that's the most important thing. So, thank you guys for having me and then I will turn it over to finish up the discussion.

Oh, Dr. Dylan, thank you so much! This is Cindy again, just to thank you for that very comprehensive presentation and a big thanks to all of our participants for joining the call today. The atom Alliance staff is here to help you. Please contact us if you have any questions about what you just heard or need technical assistance with your improvement initiatives. The evaluation survey will pop up on your screen. It will also be sent within an hour following today's presentation. The survey takes about two minutes and should be easy to complete. We'll be using your responses to tailor future meetings to determine the meeting schedules and the topics, so thank you in advance for this important feedback. We really want to hear from you. Please visit our website at [atomalliance.org](http://atomalliance.org) for additional learning opportunities, review our initiatives, access clinical tools and resources and subscribe to our monthly e-news and please connect with us through your favorite social media channels. Thank you all again once again for joining us and have a great afternoon.