>> Keith Dow: Welcome to our training on Reframing Hope at the End of Life. I'm Keith Dow, Manager of Organizational and Spiritual life with Karis Disability Services. I have brown hair, graying beard, wearing glasses, middle-aged, and I'm wearing a gray cardigan with a collared shirt underneath.

>> Sarah McKenny: And I'm Sarah McKenny. I'm the Spiritual Support Coordinator for Stone Belt Arc, and serve the South Central Indiana area. I am middle-aged woman, dark hair, dark brown hair, with some gray streaks at the temples, and I am wearing a denim blue shirt today.

>> Keith Dow: Supporting someone through the final weeks or months of their life can be intimidating and overwhelming at times, but it's also deeply meaningful. And so our hope with this training is that you're equipped so that those days can be filled with memory-making moments, rather than being caught up in managing the practical realities around someone's anticipated death. Now getting to this place requires a combination of a helpful support philosophy or approach, and practical tools. Ideally, the important questions have been answered long before someone's death is imminent, and so this video training provides examples of how to support someone well using actual situations and offering helpful resources. Before we get there though, let's – let's talk about death. So a couple of months ago I met with someone supported by Karis Disability Services. We were going to talk about grief and loss. Let's call her Ang. She's a late middle-aged Asian woman who isn't afraid to stare directly at you, and talking to her reflects this approach. She has an uncomfortable habit of frequently talking about people who have died. Actually at our most recent annual general meeting, she started just listing the names of her friends who had died. And her directness, most of the time, is a gift. She reminds us of the people who have shaped who we are even after they're gone. David Kennedy is a longtime supportive care counselor and hospice coordinator, and he says that we're a death denying and death defying culture. Despite death being inevitable, we often avoid talking about it at all costs. So when I sat down with Ang to work through some of her thoughts and feelings around grief, I thought we were starting with small talk: "what are you going to do today," she asked. Then she went on "Sit around and talk about dead people." That's actually exactly what I was going to do. And later in the conversation, she wisely observed, death is a part of life. We live and then we die. It's refreshing, her approach to talking about death, and the people that she's cared about who have died. These are simple and somewhat blunt, but truthful observations, and I think we could all learn from Ang's death directness.

>> Sarah McKenny: And so today throughout the talk, you're going to hear a lot about death. And we're going to use words like death, dying, died, which culturally, we're not super used to. We're instead used to kind of word games, different euphemisms, phrases, words, such as passed away, kicked the bucket, lost, pushing up daisies. But these phrases are very confusing and have lots of other types of meaning. And also, it's avoiding these real easy to understand words like died, death, and dying. These phrases can also be really confusing for people who are especially literal thinkers. Such phrases like "gone up the grand staircase" can be very confusing when somebody's trying to describe or understand death. A few years ago, I was working with a gentleman who hadn't been up the stairs in a house for probably about two decades. There was a real fear of going up the stairs. We didn't know why, we – nobody had really known the story. But he was clearly afraid of going upstairs. So one day we talked, and I learned more about what was behind that fear. This is when he told me that a couple years ago or several years ago, his grandmother went up the grand staircase. And so he was afraid of going up the stairs thinking that he would never come back. It was confusing. But death, dying, and died, those words are much easier to understand and far less confusing.

>> Keith Dow: Atul Gawande is the author of "Being Mortal: Medicine and What Matters Most in the End" and he's a physician. But he pushes back against this desire we sometimes have to preserve hope at all costs. And so as somebody nears the end of their life, they and often we tend to cling to this kind of hopeful fantasy that they're going to fully recover, and be able to live the way that they did before. And doctors and medical professionals often don't help us to manage expectations well. They don't want to be the bearers of bad news, and are sometimes overconfident in the power of medicine and healthcare themselves. And so in this book, Gawande writes "Again and again, I have seen the damage we do in medicine when we fail to acknowledge that the power of medicine is finite and always will be. We've been wrong about what our job is in medicine. We think our job is to ensure health and survival, but really it is larger than that. It's to enable well-being. And well-being is about the reasons one wishes to be alive." And so we come back to this idea of hope. What does hope really look like at the end of life? Not a hope that we can prolong this life indefinitely, or even that we can return to a previous degree of health or wellness. This is more of a spiritual meaning making hope. What does the person live for? What makes them come alive? Who are the people who are important to them? And what do they enjoy and hope to do in their remaining days and hours? Many people have religious communities or faith that helps to sustain them, often a faith and community that help guide and comfort them through their last days. And so reframing hope, to me, means how do we honor a person, their wishes, and their identity as part of their family, faith, and community right through the end of their life. Let's hear from Sarah and Keegan about how they supported their friend Sandy at the end of her life.

>> Keegan: Hi, I'm Keegan. Of course I have no hair. I have glasses, and I'm wearing this Carhartt or whatever you want to call – kind of call it kind of cream colored jacket.

>> Sarah McKenny: Thank you so a few years ago or about a year ago your housemate, Sandy, lived out her final years and went through the dying process at your house. Can you tell everyone a little bit about that whole time with Sandy in the days leading up to her death, and the time that you spent together?

>> Keegan: The time before Sandy's death, I got to know her because I used to work in the workshop with her. And when I moved to Miller House, which is where I'm at – am right now, I got to know Sandy a little bit more. But the few – fast few days as she was going through the dying process, I sat by her bedside and supported her. And I even sang Amazing Grace for her. And she asked me to sing Amazing Grace at her celebration of life. So I got up there and I sang for her. Of course I couldn't help but crying almost at the end of it. But it was an amazing thing to get to know such an wonderful woman.

>> Sarah McKenny: And how was that – so you spent almost every night, almost every evening for two weeks, you would go into her bedroom and you'd sing Amazing Grace. How was that experience for you to be able to support her in that way?

>> Keegan: The experience to support her – my experience to support her in that way was an amazing experience to ever go through. A sad – it was a sad experience, but – but between all that, it was still amazing.

>> Sarah McKenny: Thank you Keegan. So some of what we're going to talk about now is the terms that you might hear a lot and different options of care. As Keegan described, his housemate Sandy chose to die at home with hospice support. And this is at the time during the end of life stage or even approaching end of life stage, there's a lot of different terms, and it can be kind of hard to understand or know what the differences between all of those options – all those care options actually mean. So I'm going to start with assisted living. So assisted living facility and/or communities. So these are spaces where somebody is – primarily the goal is for independent living. They may need some supports with like bathing or dressing or grooming, but there is more – still some independent living options in that – in those types of care facilities, with assisted living facility. The medical needs are not as high at this stage, and there's a lot of focus on still building relationships and getting out and connecting with people and doing some fun activities. Then the next stage might be that of a nursing home. So a nursing home is – and not everybody may choose this, so these are different choices that you may choose based on your care needs. Somebody else may choose a nursing home when their medical needs – get to be higher and they need additional support and are not so independent. They may need more medical support, support walking such as mobility issues. Maybe the person has Alzheimer's or dementia, and so that is that – the more care needs – more active care needs, and a little less independence in that space. Some people may also choose Palliative care. So Palliative care is a commonly misunderstood support care option. This does not necessarily mean that the person is at their end of life stage. Palliative care can mean that the medical treatment – the medical needs are getting so great, so big, that it's hard to organize. So somebody may have a lot of doctor's appointments. They may have a lot of medications. They may have surgeries or just lots of physicians telling them that they need to do this, this, and this. You may choose Palliative care to help kind of organize that or structure that, especially focusing on maybe what your wants are. So maybe somebody really wants to decrease their pills. Quality of life for them is less pills. So the Palliative care team can kind of sort through and talk with the different doctors to prioritize and give you less pills while also meeting your other treatment needs and wants. So they can kind of do the heavy lifting and the organization for that for you. With Palliative care you can still have medical intervention. So medical intervention means you're still getting active treatment, maybe surgeries, maybe you're on an IV – that's what we mean by medical intervention. You may hit the point where you don't – you no longer want medical intervention. Maybe your illness or your disease or just old age, your body, has hit the point where it is – it's dying, it's in the end of life stage. You may choose hospice at this point. You may – and with hospice, you're choosing to not have that active medical treatment anymore, meaning you're not having those surgeries or IV. Instead, hospice will focus more on pain management and helping you stay comfortable. With hospice, you have added supports like psychologists, social workers, chaplains, nurses, and so you have a kind of another wraparound team to help you with that. Now when you're on hospice you have an estimated 6 months to live. Now you may still end up living a year or two, and I've even known people to be on hospice for three years. But the – based on your diagnosis, it is an estimated 6 months to live. So this really is at the end of life process, that's more of this choice – is really for your end of life choice – your end of life stages. So hopefully that helps to maybe better understand what some of a person's options might be, and the differences, and maybe when you might choose different supports. Now another way to do this or also to help somebody with the planning is this Thinking Ahead Workbook. So a Thinking Ahead Workbook was originally created in Texas, and then California redid it, and now the state of Indiana has redone it again. The Thinking Ahead – we will actually share it with you on our website, the AAIDDreligion.org website. And this workbook really helps to help walk you – walk through what your options are, thinking about what you might want, and then actually making those plans. So for some examples, you may choose to die at home. You may choose to die at a nursing home. Or you may choose to die with hospice, at a hospice house, or at hospice at your home. Lots of different options. You may – it also helps you think about what you want done with your body after you die, so do you want to be buried or cremated? What do those terms even mean? It's all in there. And then even what do you want done with your stuff after? Do you want to donate it to a friend? Do you want some money to go to somebody else? And then also it walks you through, even during that end of life stage, what are those wishes? How do you want to be cared for? Do you want friends to come visit you? Do you want to – you know, is that important to you? So it has a spot even to talk about what quality of care even looks like for you. The whole workbook is in plain language, so it's really easy to understand, and there's even pictures. So it helps you better understand really what your choices are so that you can make those decisions. And finally, it even talks about medical care. What type of medical care do you want? Do you want to do active treatment and IVs to continue to help you and support you in being alive? Or do you want to focus on pain medications and just focusing on kind of living a quality life the rest – you know, in in the rest of the time that you have as you die? This book is also really good and has been used for people who have Alzheimer's or dementia, who again, need that simple language. The thinking ahead workbook is also a great way to actually bring hope into that space of planning your end of life stages. As Keegan was talking about his friend Sandy, I was reminded that Sandy really experienced hope as she did this end of life planning workbook. She felt a sense of control as she – during a time that you don't have much control, and she was able to make decisions on how – on the care that she had while she was dying. She was also able to, like Keegan said, tell everybody that at her celebration of life, she wanted Keegan to sing Amazing Grace. And even in – as she died, it was in her plan that she wanted Keegan to sit by her bedside and sing to her. It was a – provided a great sense of hope that these decisions were going to be carried out, and that she had control in a time that she doesn't really have much control. And finally, i provided her a sense of hope – one of the things that she did not want was she did not want to be a burden on others. And so having this plan really helped her feel like she was taking all of the planning, all of the potential burdens of planning away from people. Even though she wasn't a burden, it made her feel better knowing that she could do as much work and control over the planning as possible to relieve any of that stress or burden from others.

>> Keith Dow: Thanks Sarah and Keegan. I think you've really helped capture how the approach can be combined with tools and resources, and then together it really does help kind of reframe hope for people. Everybody's journey in those last days is going to look different, right? And what we do needs to look different. But we do have some great tools to use in order to help us walk that journey, to ask the right questions, and find out what's really important to people. And I think too often when we think of hope at the end of life, it's – it can be more like a fantasy, it can be more like a denial of what's happening. Celebrating life doesn't just need to happen at the end of somebody's life or after somebody has died, but before. What does that look like in those weeks and months leading up to someone's passing away? And even what does that look like now? So when you think of the people that you support, how do we start that – how do we start that celebration now? And I think that really captures the sense of hope that we're we're working towards here. And so Sarah has a few different ideas on how we can prepare and, again, make this more tangible.

>> Sarah McKenny: Yeah, so – if you are a part of a service provider, I highly recommend having your service provider create an end of life task force. And in that task force, you can, you know, discuss and plan and then develop a plan for your service provider. This provides a little bit of guidance in a situation that is – can be stressful and filled with grief and emotion for the clients but also for the staff as well. So you can – in that task force you can plan and develop grief trainings for your DSPs so that they know more about grief and can support individuals through the grieving process. You might also in your task force develop an end of life training, so that people know what to expect. What does the – what does the dying process actually look like? Again, that can reduce some trauma that the DSPs, but also the individuals that you support, may experience through that process. And finally you might also do kind of what we did today and learn more about Palliative care, hospice, active treatment, again, so that everybody really better understands what the options are and kind of come alongside people as they make those decisions.

>> Keith Dow: And we hope you'll use whatever parts of this training are helpful to you, if it's even just that one part on explaining the differences between the types of end of life care, feel free to use that. Feel free to use Sarah and Keegan's story about Sandy. Whatever it is that's going to be helpful for you and your team as you process this, please do, because we know that this is – it's tricky work, it can be difficult at times, it can be challenging, it can really require a lot of us. It asks for empathy and advocacy. It's also such an honor to help make people's final days meaningful. And we hope that this session has been helpful for you as you help people reframe hope and experience it richly and fully at the end of their life.