

Episode: *Ethics Talk: How Poetry Can Enhance Ethical Inquiry*

Guest: Jake Young, PhD, MFA, MPH

Host: Tim Hoff

Transcript: Cheryl Green

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[mellow theme music]

[00:00:06] TIM HOFF: Welcome to a special episode of *Ethics Talk*. I'm your host, Tim Hoff. Art can be a tool for ethical inquiry. Creative works—visual art, music, poetry, etc—can illustrate alternative perspectives on health care experiences. They can prompt reflection, sharpen relational skills, and help identify and explore key ethics themes. On this episode, we're talking with Dr Jake Young, poet and senior policy analyst in the Council on Ethical and Judicial Affairs at the American Medical Association. He's here to discuss his poem, "*A Rare Bone Disease*." Jake, thank you so much for being here. [music fades]

DR JAKE YOUNG: Thanks so much for having me.

[00:01:03] HOFF: Can we start with a reading of the poem that we're going to be discussing today?

YOUNG: Absolutely. I'd be happy to. "*A Rare Bone Disease*."

Some bones bloom beneath skin, lilac
or rosemary, swollen buds
split open; and yet, this growth
stunts limbs, too, even as bone
grows like wax flowing
down the sides of a candle,
a slow guttering. No one is sure
why; but the pain is real,
the gasp of a rose expanding
within a hip, ankle, or arm,
so intense you cannot look upon it.

And you think you're alone;
the only one with flowing bones,
until you meet someone else
with a bouquet hidden inside them,
petals peeling outwards from shins
or fingers or spine, bones bursting
with calcified blossoms. How beautiful
to find another who understands
the pain that blooms within you

and feel you're not suffering alone
every morning when you wake.

[00:02:24] HOFF: Beautiful. Thank you for sharing that. Although we might've already gotten hints from the content and the title of this particular piece, can you highlight for us the key ethics themes or health concepts that this poem explores?

YOUNG: Absolutely. Well, as the title suggests, this poem is about having a rare bone disease. I was born with a condition called melorheostosis, which affects about one in a million people. The disorder is characterized by hyperostosis, where the cortical bone thickens more than it should, affecting both bone and soft tissue growth and development. And on X-rays, the appearance of melorheostosis is often described as looking like a candle with melted wax flowing down the sides. And in my case, about half of the bones below my right knee are affected. And so, it can be scary and isolating to suffer from a rare disease. There are often so many unknowns and so few people to commiserate with who have shared experiences and can understand your situation.

I was around 21 when I learned about the Melorheostosis Association, an organization that's dedicated to promoting awareness and finding the cause, treatment, and cure for melorheostosis. And they have a biannual conference that brings together melorheostosis patients, their families, and experts in the field, which I attended that year. And I was just really surprised by how moved I was to finally meet other people who suffered from the same disease as me for the first time. I didn't realize how lonely I had felt until that moment, when I was able to meet people and talk with them about our shared experiences of living with this rare disease.

[00:04:15] HOFF: Hmm. You've already sort of responded to this next question, but what about this poem do you think might be of interest for readers and listeners who are interested in arts and health humanities specifically?

YOUNG: I think the arts are hugely important, not only for self-expression, but also for self-discovery. The act of engaging with art is hugely transformative. By creating art, we give form to chaos, find a means to express the inexpressible, and allow ourselves to contemplate and reframe past experiences. When we encounter a work of art, we allow ourselves to engage in reflection, empathy, and contemplation. And so, what I hope readers and listeners take away from this poem is the sense that they are not alone, that there's wonder and beauty that exists even when we're in pain, and that no matter how isolated we feel, that loneliness and separation is actually something shared, felt by other people, even though we may have never met them, but who nonetheless understand what we're going through.

[00:05:20] HOFF: Mm. You've described that this poem has blossomed, to borrow a phrase—

YOUNG: [delighted chuckle]

HOFF: —in part, from meeting people with similar experiences to yours. Can you talk a little bit more about the process of creating this work?

YOUNG: Absolutely, absolutely. I wrote an early draft of this poem in my hotel room the first night I attended the Melorheostosis Association conference. I just remember feeling overwhelmed by meeting other people for the first time who have the same bone disease as me. How much joy and relief I felt at being able to talk about my past treatments and pain, worries. How satisfying it was to not have to explain what the disease was, and also, just how much sadness and empathy I felt for those who suffer from the disease far worse than I do. The poem then kind of sat in my notebook for about a month or two before I typed it up, and I revised it several more times before I felt that it was finished. Now, some poems take a lot of work, but this one started off further along than most. It mainly just needed to be cut down a little bit. Some of the images needed to be made more clear. And once I was satisfied with it, I added it to the manuscript I was working on at the time, which ended up turning into my second book of poetry, *All I Wanted*.

[00:06:36] HOFF: Is that process, that reflective response to strong emotional experiences, a common way that you work and that poems come to you, or is that unique to this one?

YOUNG: I think it can be. It's not that every poem comes to me quite as finished as this one did and might not be driven by an emotional response that was as clear as this one. Often, I will have a more general emotion, a more general image that I sit with and hold onto for a while. And as it starts coalescing, almost like a grain of sand in an oyster that slowly gets turned into a pearl, when I finally feel that it's polished enough, I can sit down and try to turn it into a poem. So this kind of almost took that process and sped it up. It was a little more intensified than most, but it's not necessarily uncommon either.

[00:07:38] HOFF: Mm, mm-hmm. And I imagine that the process of going from that grain of sand to the sort of finished pearl requires, at least sometimes, the use of techniques and poetic devices that we might be interested in hearing about. So, can you talk about that side of things?

YOUNG: I'm happy to. So this poem is written in two stanzas of 11 lines each. The first stanza focuses on the physical effects of the disease. The start of the second stanza marks the beginning of a turn in the poem, where the tone shifts, and a subject is finally introduced with the line "and you think you're alone." The poem shifts focus here, turning away from the focus on the disease to instead explore the effects of community and feeling recognized and seen.

The whole poem also plays with language to show how beauty and pain are so often entangled. The deformed bones are described as blooming flowers, yet these flowers aren't without thorns as they swell inside, causing pain that is invisible to others. Yet, like the image of bones blooming, finding oneself a member of a community, of discovering people who have a shared experience and understanding of what you are going through, finding out that you are not alone is itself a kind of blooming, a kind of beauty, even when it's a community born from pain, and perhaps even more so then. And lastly, this is somewhat of a concrete poem. a poem that, by its very image seems to suggest something, since the shape of the stanzas—flat on the left margin and

jagged on the right—in some ways suggests the image of a smooth bone on one side, and then on the other one affected by melorheostosis.

[00:09:29] HOFF: And to see the formatting of this poem and to read it again, there will be a link in the show notes and on the web page on our website, journalofethics.org where viewers can see that.

But to wrap up, which poets and poems might you recommend for our ethics and health humanities audiences who might want to read more of this kind of thing?

YOUNG: I always love this kind of question. There's so many recommendations that I'd like to make, but three that come to my mind are Ada Limón's book, *The Carrying*. Ada Limón is the current US Poet Laureate. She was appointed in 2022, and her term was renewed for another two years last year. *The Carrying* is her fifth book of poems, and it's just a beautiful collection that explores love, fertility, desire, and so much more. Another favorite collection is *Magical Negro* by Morgan Parker. *Magical Negro* won the 2019 National Book Critics Circle Award. It's just a fabulous collection. Delves into Black womanhood and touches on individual and collective trauma, loneliness, grief, but also focuses on finding ways to celebrate and triumph. And the last recommendation I'll leave you with is *Life on Mars* by Tracy K Smith, who won the Pulitzer Prize for poetry in 2012 for the collection. The book's center of gravity is the death of her father, who worked on the Hubble Space Telescope, though the poems span from moments of personal grief to pop culture, the cosmos, and beyond. [theme music returns]

[00:11:19] HOFF: Jake, thank you so much for being here and for sharing your work with us.

YOUNG: My pleasure. Thank you.

HOFF: That's all for this episode of *Ethics Talk*. Thanks to Dr Young for joining us. Music was by Blue Dot Sessions. To read our full June 2025 issue on embodiment in arts practice, visit our site, JournalOfEthics.org. We'll be back soon with more *Ethics Talk*. Talk to you then.