TRANSCRIPT:
Grief Offerings: (End of) Life Wishes
Etzali Hernández, Emilia Beatriz and Sandra Alland

[0:00:00]

[♫ "grief offerings theme music" - electronic cymbal vibrates softly, slow xylophone-like notes play individually, gently echoing ♫]

[0:00:12]

FREYA: Hi this is Freya from the committee at Rhubaba.

Grief Offerings: (End of) Life Wishes is an audio and transcribed conversation interspersed with poems. There are downloadable transcripts as PDF and docx, and a downloadable list of references. You can find links to these, and to other related resources by visiting the Rhubaba website at R. H. U. B. A. B. A. Dot org.

Grief Offerings is part of the Care, Resistance … Joy! programme of workshops, podcasts and commissions by artists and facilitators invited to consider structures of care, power and community whilst centring joyful acts of resistance and methods of living well. The projects aim to provide a space for respite, reflection and community: informed by Queer-Ecology and Decolonial thought, as well as legacies of collective action.

Content notes for the conversation include: death, dying, eugenics, suicide, racism, ableism, classism and institutionalisation.

EMILIA: Hi, I'm Emilia Beatriz.

SAN: I'm Sandra Alland. People call me San.

ETZALI: I'm Etzali Hernández.

[0:01:27]

EMILIA: Emilia speaking. This audio transmission begins with an online conversation between the three of us on third of September 2022. We used the theme of 'end of life wishes' as a starting point to share ways we want to care, mourn, live and resist in the current climate, with a focus on mental health and disability justice.

Our chat continues work we're doing with our friends and communities, as well as public conversations. For example, San and Etzali's zine, "*Sore Loser*", and their podcast on queer disabled grief and memorialisation.

We will take breaks from our discussion to share a poem from each of us, plus readings from other Scotland-based poets whose work supports and holds us in difficult times. We're grateful to have poetic 'grief offerings' from Nat Raha, Jeda Pearl and Andrés N. Ordorica. The sound has been lovingly mixed and mastered by Claude Nouk.

[0:02:31]

ETZALI: Etzali speaking. Before we begin, we want to honour and name some of our recently lost kin. Raquel, Bob, Callie, Beldina, Ryan, Jenny, Danny, Susan, RM, Nila, Filomeno, Alice, Grace, Eréndira, Shaun, Vanessa y Lesvia.

SAN: San speaking. We invite you to receive this audio transmission from a place where you feel held. Feel free to pause at any point.

ETZALI: Take the time you need. Thank you for sharing this space with us.

[♫ twinkling piano ♫; transition into Zoom conversation]

[0:03:24]

SAN: We are all smiling. Although Etzali looks slightly pensive. [Etzali giggles]

ETZALI: I thought there was something else coming after that, so I was, like, waiting.

EMILIA: Did anyone have a point they wanted to start with , or...?

[0:03:43]

SAN: I guess any conversation about 'end of life' in this current moment – I mean, always, but especially in this current moment – for disabled people needs to acknowledge what 'life' entails.

And I think currently we're living in an extra-eugenicist moment. In that eugenics has been present; it's never gone away. But the pandemic has brought out a sort of enabling of overtly stating such things, I think. And it's played out in a really disastrous way for disabled people. So that it's been made very clear by governments, and by our peers in many cases, that our lives are valued less.

And this is, of course, compounded by, you know, racism. Which is tied to… You can't separate ableism and racism and eugenics; they're all tied together. And of course, also classism.

[0:05:04]

And so, when we talk about 'dying well,' it's hard to get to that before we talk about 'living well,' and being given the tools to live well. So, when we have a culture where… we're at this point where it's okay that so many disabled people have been... have died from COVID and been killed, essentially, because there's been so much irresponsible behaviour from governments and also from the public…

Then how do we… How do we get to a point where we talk about how we can die well? And when is the time to die? What people consider unbearable, like a time that they would want their life to end, is often based in ableism as well.

[0:05:55]

EMILIA: I think that's a really important place to start and an important frame to hold any conversation about end of life. Given that, where do we start?

What I was interested in looking at these 'end of life' wishes prompts, was it was assuming that people have not had to write something like that before. Potentially, maybe not. And it made me think about the kinds of 'advanced directives' as they're called, which is to say, writing down instruction, or imagining something for the future, about a situation, and writing requests or demands or desires.

The main place where I've encountered that is to do with friends who require care on a day-to-day basis, and/or friends and community, and myself, who require care on an occasional basis, based on crisis states or states where something fluctuates into another.

[0:07:06]

And, um, what I like about the kinds of care maps or crisis maps that I've seen before that's different from this thing about 'end of life' is it has a space to describe and self-define how we are when we're well. As well as a space to start to define and self-describe how we are when we're not well. And then… wishes. A space to write and talk about our wishes in each of those spaces.

So it's actually… There's this less separation of, oh, actually, the end of your life is the first time when you might need to write down your wishes. Or your dreams or your desires, or requests within community about how we want to be treated.

ETZALI: Mm-hm. [agrees]

SAN: Etzali, did you want to say anything on that?

ETZALI: I'm slow today.

SAN: Okay.

[0:08:03]

ETZALI: No, I'm just thinking about what you were mentioning about the context or the historical contexts we are in at this moment. And then what Emi was mentioning about having a choice of how you want your life to end.

And, how... I guess 'irony' is not the right word. But the like, of which of those things can come together, just now. Because, if we think about what San was mentioning, on how COVID is affecting a lot of disabled people, then you don't get a choice on how you want your life to end at this moment in time. Because that has been taken away from you.

And then like, if we go out of this time, of this historical context, to before that. Then, the question is... It's not a question, I guess, actually. But I'm thinking, disabled people have never had a choice. You know?

So, then I'm starting to maybe reflect or… [sighs] Like, it's weighing on me; the fact that nothing has changed.

SAN: Hmm. Yes.

ETZALI: There's this... I don't know if it's like we are presented with this idea of the living will. But as you were mentioning, Emi, it's for people who have a choice or who think that they are going to die of an old age, for example. Whether I think that the reality of life when you are disabled is that that can happen at any given time. So… it feels like this is like a long-term plan.

[0:10:03]

SAN: And this is probably something that disabled people do think about more, as Emilia was saying. You know, we make plans while we're still alive, for our care, for when we have times when we can't support ourselves. Whether we're interdependent with people always or whether there are certain times. And that a living will can sort of encompass this for disabled people.

Etzali, you and I talked about the need to think about what we want after we die. We need to talk about what we want while we're alive. And when we might not be well enough to express what we want.

It's always, as you say, Etzali, been important for disabled people, BIPOC, trans people specifically, queer people. And we can be controlled by our families, and by others – which is something we talked about when we talked about death.

[0:11:03]

Basically, if you don't make a plan, then your blood family is given all of the power to make choices for you. You may have a lovely family, but even a lovely family is likely to have internalised ableism, and ideas around what is 'liveable' are very scary.

If decisions about your well-being are made by your family and doctors, as opposed to what your wishes are, then we end up in situations like we have had during this pandemic where disabled people have Do Not Resuscitate orders put onto their files by their doctors, without any consultation.

And in that case, even if you have a living will, where is it accessed? How is it accessed if you're in the hospital with COVID and your family can't come in? But yes, making our plans very well known, I think is really important. There's an assumption around what people's ideas of 'suffering' are that's really, really ableist.

[0:12:08]

SAN: Now we'll hear a poem from Etzali Hernández.

[Etzali reads the poem in English and Spanish, without translation]

in the middle of dos mundos

looking out of the window
viendo las nubes bailar
the flowers singing with the wind,
el sol jugando con el agua.

Mountains and hills surround us
vigilando sigilosamente cada movimiento
wondering if this would be the time
en el que aceptaremos el poder de nuestres antepasades.

Blood that runs through us
y que marca cada luna llena.
Blood that bleeds out of our ancestors
y que destruye y construye nuestra cosmovisión.

Everything around us is ready for the awakening
nuestres hijes están destinades a vivir libres
of the yoke of white cis hetero patriarchal capitalism
su futuro es su territorio!

[0:13:05]

EMILIA: Hi, I'm Emilia Beatriz.

ETZALI: Hi, I'm Etzali Hernández.

SAN: I'm Sandra Alland.

[♫ "grief offerings theme music"♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

SAN: There's a lot of issues going on right now with eugenicist plans. Like in Canada. I don't know how aware both of you are of M-A-I-D 'MAID', Medical Assistance In Dying. And I mean, I suppose this whole conversation's gonna have a large content note, but it's around assisted suicide or assisted dying. Which most non-disabled people think, 'Oh well, I

would like that option.' And even a lot of disabled people think about choosing how they want to die. But those sorts of things are already available to most of us through palliative care and through having a care plan. And what MAiD is… [sighs] It's basically a culling of disabled people that was passed in Canada and has been incrementally made worse during the pandemic.

It was first of all around the idea of if you had a terminal illness, which is something most people can wrap their heads around. It soon became that was no longer a requirement; to have a terminal illness. It could be anything to do with pain or 'suffering'. And as of March of next year, it will include mental health as the sole reason, mental ill-health, and including young people.

[0:14:49]

So, whereas in every other circumstance besides disabled people, we would be trying to save people from suicide, disabled people are being offered this as a solution to their problems. And where it becomes especially evil is that it's classed and it's racialised. And so it's mainly affecting Indigenous and Black populations, and impoverished populations. There's no accessible housing. And a large number of people who are 'choosing' – and I say that with quotation marks – MAID are openly stating they're choosing it because they cannot afford to live. Because they can't find a place to live.

These are not the kinds of end of life plans we want happening. The issues with them are many, but a lot of it is about… A family member can decide this for you. One doctor can decide this for you. They've gotten rid of a lot of the safeguards that were originally there. And Scotland wants to do this, The Green Party! [laughs sadly] The Scottish Greens. And I think a lot of people see it as a forward-thinking kind of thing, and it's... If you talk to most disabled people and organisations, they'll strongly disagree.

EMILIA: That's really chilling.

SAN: Yeah.

EMILIA: And it really illustrates very clearly, like, worlds that we do imagine… The language and the practice of that can be appropriated in this way, where it disregards that in order to live in that way that we want, we need to have means to survive day-to-day. Whether that's housing, health care, education and all the rest.

And yeah, that's really scary, that there's just this really harmful gutting of the conditions of life that would then make the ways of deciding around our death to be an empowering one. Thank you for sharing that, too. I didn't know anything about that particular context.

[0:16:54]

ETZALI: And I think we are back to where we started, right? Like, who has the choice to… in any way? Because, I guess in a way, the example that San is giving is like they are being given a choice, right? But is it really a choice? In that context when your material reality has been… Like, how can you make a choice? You can't.

SAN: Yeah, it's literally been presented as a cost-saving measure. But this is the kind of slippery slope we end up on, right? And why it's important, as Emilia was talking about, to really… To fight for all of these things, especially home care, because that's been decimated everywhere, including in Scotland. For better housing, for increased benefits. And for working within our communities to make sure these things don't happen.

[0:17:55]

ETZALI: And now, Andrés Ordorica will share his poem, "Division and Subtraction". [Andrés reads the poem]

[Division and Subtraction]

I was never good at maths beyond adding
and subtracting. Don't get me started on matrices
or indivisible numbers, integers, I know not of.
But I can count up all the ways I feel scared
and subtract each ounce of hope I'm losing.
I hear inflation and experience depreciation,
I worry about how long this can go on,
at what point we can no longer add
any more struggles to our lives.

But then I walk atop humid grass, floral perfumes
in the air, people smiling from all this beauty
and I think, no, wait, I know my heart is infinite
and so, I promise to never let them divide me
from hope, promise to never let them take our joy.

[♫ "grief offerings theme music" ♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

[0:19:30]

SAN: Emilia, you had mentioned, I think, 'The Five Wishes', the sort of United States living will and... It's like a living will plus a health care power of attorney. Although you're talking more in a community way as well, of making plans with community. And I think in the UK, it's called lasting power of attorney. In Scotland, again, it goes back to just power of attorney. You can appoint several people. They can be family, friends, and solicitors, to look after your finances as well.

Going through those wishes that you were talking about, I think it kind of lays out things around palliative care, whether you choose to have that at home, in the hospital, in a hospice. And who you want to care for you.

[laughs uneasily] Who you have agreements with, to care for you. And... what you want. What you like to eat!

I thought it might be interesting, because I was trying to imagine being a person listening to us... [Etzali laughs] To think of maybe naming what The Five Wishes are that you were speaking about. It might be useful because it kind of gives a framing for people who wanna think about this stuff, I guess?

[0:20:48]

EMILIA: Someone want to read them out, or should we take turns?

SAN: We could take turns.

EMILIA: I'll start. From the Wikipedia, it says… The Five Wishes starts with Wish One, 'The person or persons I want to make care decisions for me when I cannot.'

SAN: And the second one; 'The kind of medical treatment I want or don't want.'

ETZALI: And then Wish Three, which is 'How comfortable I want to be. This relates about comfort care, like pain management and personal grooming, bathing, or hospice care, or other options.'

EMILIA: Sorry, I didn't see that there was more information under each one.

SAN: Oh, is there? [laughs] I thought that came from Etzali's brain! [both laugh]

[0:21:46]

EMILIA: Number four is, 'How I want people to treat me. This section speaks to your personal matters such as whether you'd like to be at home.'

SAN: Right, yeah. For that one, for number four, one thing that immediately made me think of was… The kinds of preparations that trans people and non-binary people and queer people often have to make if going into hospital, or into any kind of care, about how you want to be spoken about

and referred to. Things to do with names and pronouns and… relationships. That's something that could be helpful to write down, even if it seems obvious.

And Wish Five was, 'What I want my loved ones to know. This section deals with matters of forgiveness.' I find that interesting. 'How you wish to be remembered, and final wishes regarding funeral or memorial plans.' Personally, I think if you're going to get to forgiveness, maybe… Maybe before is a good time, I don't know! [laughing] It's usually more of a conversation, I dunno. I get it. I get it. But...

[0:23:11]

EMILIA: Besides wanting to say, like, we don't… We're not… like, um…

SAN: Advocating the Five Wishes, yeah.

EMILIA: [laughs] But it also… It reminded me of, I was reading a biography of James Baldwin and there was this moment that stuck with me. It's a story about a conversation that James Baldwin had with one of their students. A close friend to theirs had passed away without having communicated to anyone that he was very sick.

SAN: Hmm.

EMILIA: And James Baldwin's friend was quite disturbed by that and said, "Please promise me you wouldn't ever keep something like that from me. What if there was important things left unsaid?" And James Baldwin said, "They are not," he says. "They are not unsaid at all." And he smiled and took her hand, but he did not promise.

That struck me because it was, you know… Our wishes for things and also our wishes to NOT. To live the way that we want to live, we wouldn't leave things like working on forgiveness until this very, this like, faraway moment.

SAN: A-ha.

EMILIA: What does it mean about practising modes of repair in our day-to-day, and not leaving those for some other time?

[0:24:31]

SAN: Yeah, I agree. Although I'm trying to see it from a perspective of like, if it's something that… if it's a sudden change in life, I might not be prepared yet to... to work on a particular relationship. But I might have it in my mind that I want to, at some point. And then something interferes, whether it be health or death.

So I can see circumstances where that's, you know, something, for me, that that could be valid. But overall, I think, yeah, there's this weird idea that we wait until we're on our deathbeds to be like, "That time that...." [laughs uncomfortably]. You know? [Emilia laughs.] I don't know, it's just… Yeah. I think… [sighs]

[0:25:17]

There's also something very Christian about this framing in a way to me because there was also... You didn't read it out, but there was something about prayer. I was glad you didn't read it out, but now I'm gonna say it. Because, I mean, prayer doesn't have to be Christian, but the feelings of this to me just kind of come off a little bit as if they were maybe formed in that way originally? Maybe I'm wrong.

But… I think it is actually important to mention prayer being allowed. But I think Christian prayer is always assumed to be allowed and there's often like, you know, chapels… And people expect that as a reality, but other forms of religion are not necessarily welcomed into hospitals and other spaces.

[0:26:04]

EMILIA: It is important that section number 4 is, like, it's about how we would like people to gather. Or like what process or ritual or custom would we like to be happening.

SAN: Now we'll hear a poem from Jeda Pearl. [Jeda reads the poem.]

Sparklers
After Barbara Crooker

I want to scorch your names
on the cold cosmos
with indelible forever fireworks
capture your outlines
from that first-flush of love caught
in the gritty black and white
as you stride, defiant – gleeful –
into your poemed future
hand in hand, past the spits, stares and shouts

I want to sear your names
that created mine
but I only have this one sparkler
fizzling out faster than expected
as I beg it to last just a moment longer
to stay
stay
stay

then he leans in with love –
your grandson
and they swell with delight
your grandchildren
so I take all of us in

and 'it's okay' I say to you in my mind
'we'll be okay – look
we're managing'
to celebrate with sparkles of joy
and love, to worry, or disagree
but make up fast
because we know our sparklers
will die out
unexpectedly
or as expected but far too soon
leaving a hot ember
that still burns

[♫ "grief offerings theme music" ♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

[0:28:45]

SAN: I don't know if you wanted to talk, Emilia, about how you came to The Five Wishes?

EMILIA: So, I first heard about it because my mom filled it out and sent it to me, and has opened a conversation around her wishes for her end of life. What has struck me is that it is a conversation about how we want to live.

San, when you were talking before about the different times that we might find these kinds of tools useful, and the different moments that we might be interdependent with one another to lesser or higher degrees… And I think, for me, I'm drawn to this kind of framework for having a conversation because I feel that we are already always interdependent and relying on each other in so many ways. And that a lot of how Western, so-called, culture seems to act is to deny the ways that we are interdependent, or to invisibilise the ways that we're already caring for each other and having the

kind of entangled web of… looking out for each other and creating access for each other.

[0:29:53]

And so then, something like this, asks these very specific questions around a point in our life where we might be needing others in a way that we haven't needed others previously... I think the details in some of that for me, were quite moving in terms of thinking about how we want to live in general.

So, when my mom sent this, 'The Five Wishes' to me, she spoke about the lighting. She didn't want to be in any circumstance living under fluorescent lighting. And this is a choice that my mom has made in her life. And suddenly she's having to tell other people, "I need you to... this is a really important thing for me." And she says something about the way that she braids her hair and on which side the hair is braided, and a very particular kind of touch that she likes on her hand and not on other parts of her body.

[0:30:45]

And so what was really interesting for me was to get to learn these things about my mom, and be invited into a world, not only about the demands and the desires around power, and the law and the healthcare system and the moments where we might be encountering the state or the institution, but also in these moments of the specificities of care, and the ways that she viscerally described her desires for being cared for. I wonder if the people around me know the things that I like, or I know how to articulate the ways that I want to be cared for now, already! As well as in different moments that I might experience in the future.

[0:31:36]

SAN: It's beautiful.

ETZALI: It's an interesting thing to think about, especially when you were saying, "Do I know the ways in which I want to be cared for?" I think a lot of times, we

don't know. I have often conversations with my counsellor about, like… They will ask me at the start of each session, "How are you?" And I'm always like, "I'm okay." And they're like, "Hm…"

And then there are some days when I'm like, "Actually no, I was lying, I'm not okay." But like, it's having that self-awareness as well of like, or acceptance, about how you are feeling and what your needs are. And I think sometimes that's a very hard thing to know how to express. Because you cannot express what you don't know.

So, how do you find ways in which this can be shared with others? And also an understanding that what I need now is not what I'm gonna need tomorrow. So, like, allowing a space for these things to be flexible and to change, and to have that understanding among ourselves too.

[0:33:02]

SAN: It does come back to what you said before though, too, Etzali, about choice. I think it's really important for us to become aware of where wants and choice intersect or don't intersect in the current climate. And historically.

I can't help thinking about my friends in the hospital, and how… even though they may very clearly know what they want, and they have expressed that to people, they're put in a room with as many as nine other people, in a situation where they're left without proper care of the most basic kinds. Never mind what they want. I think by naming what we want, we can perhaps move into finding ways to make that happen, in a more concrete way, maybe? But… [sighs] It's really difficult right now because I could… I could write all of this down and agree it with people, but I'm not so sure that it would happen that way.

As the NHS is decimated, these kinds of things probably become less and less possible. Which is where, you know, you get this gap that opens up and something like MAID comes in. Or something like excessive DNRs come in

because suddenly there's no one to do this work. You know? And that's what's been happening with homecare for a lot of disabled people. And we're seeing a return to institutionalisation as well. Which is really horrifying when, you know, people have only… [sighs] recently declared a sort of end to institutionalisation, on a massive scale anyway.

But I do think there is an incredible power in articulating… Like, that story you told about your mother is so moving, Emilia. And so important. Like it's so specific. Because even if you're in a situation where there's a lot of problems, if you can braid her hair in that specific way, that is something huge to hold on to.

ETZALI: Without wanting to sound like a white hippie person [Etzali and San laugh]. I'm thinking like what you were saying about the power of saying… the power of articulating our wishes. And the way in which those things can construct part of our reality. Probably, but not probably… not in a material way.

Because we cannot change sometimes those things without supporting each other. Like, individually, we cannot make those material realities change. But, like, in an individual way, knowing what you want, what you need, what you desire, can make a shift on those realities and help, at least in a way, to how you connect with others to then change the material reality you are living.

SAN: This seems like a good moment and listen to a poem from Nat Raha.

[0:36:40]

NAT: Hello. My name is Nat Raha. I'm a poet based in Edinburgh. I'm gonna read two poems that were written for the poet Callie Gardner, who died suddenly in the summer of 2021 in Glasgow.

I wrote these poems whilst… I guess feeling bereft of a conversation that I'd had with Callie that began when we became poet friends in 2015. And, in the knowledge that in losing a friend who's also a writer, the meaning of

what they've written shifts but continues to unfold after their passing. And being aware that I can still hear Callie's voice when I read their work.

And in this process also of reading their work and of getting deeper, the meaning of the work continuing to unfold and emerge in the readings that we – and I mean, like a 'we' of poets and other readers, and people who care about poetry – are getting as we continue to read and engage with their work.

[These next two poems have aspects of concrete poetry, a form of poetry where the words and sometimes individual letters are arranged to create images that deepen the meaning of the text.]

[Visual description of 'elegy for callie gardner' – shape-shifting cloud-like text groupings slide to the right margin of the page, then stretch out, contracting and expanding like a wave…but also a bird?]

[Nat reads poem]

elegy for callie gardner

ok , so if the natural sciences
skewed
on the installation of their world
,
our gravities exert like
the moon in relation , legs

exquisite to this north
grove is a groove on enjambment ,
the music we pull/ed from the dictionary
paper knitting lines into friends, flutter
over wrought-gates
,, we make
kin w/ diasporic arbours
quiet calling your poems
, let their
intimations vibrate, seep sonics into cones

ɯ but the(ir) garden calls time, en-
closing around us, non
-natives whisked from ground
the logic of conservation
after the asphyxiation of the earth

– that's how all conversations go now. let's
meet on our bikes, worn hearts, speed off isolation
as bells usher,
heron lands high, young, looksout
knows the depth of the basin where
i home among eiders – no, lock us in with
our fauna, anxiety, poems
, the heterosexuals tying themselves up

& even
in endless day, still
harmonics beautiful gorging
& then ground aflame, grouse felled
by gun, in the
nowhere we sow flowers unbeknownst
bereft in grievous summer , of
gossip of the south
-side, the state of soil & libraries

& half of the moon still spinning

eyes attend brightest nights in bloom—
for a few hours we forget our work, move to life
among worms, birds—

eighteenth august 2021

[Nat reads another poem. She reads the first part as truncated un-words.]

[Visual description of next poem. Sprawling strands of single letters extend downward through a three-line fragment of sentence soil; like melting water flowing down tree roots. Then staggered poem lines are layered like sediment bedrock.]

countersonnet for callie *("gratia growth" / while the redwoods talk among themselves)*

e o b
g t h je
in c
o t
d i
n fication of paper , slow accelerant
u day's breathing / to pace poetics as
arboreal study
b tu
k a n
n w i
o l n
w i g
s n l
g g e i
r c a n
a h a v t

v r t e o
i r e u s
t s e s
y h o t
t i n a
o s
s h l
e l l , o w b l
i nk

extends winter into a couple of hundred years
or how long it takes to have really
arrived
grove is in the heart
to spite
institutional loggerheads / clear-cutting
four-hundred-fifty poets down a day in monoculture

con/serving the nation in a singularity / *abused*
in
silence

skull
ar/rest
in a grief-wave, floored-out ¾
speaking 'cross the breeze
, clawn in dappled cerulean / polarised
like the streaks of social life ,,
exilic care splayed
, woven in the cut
poetry mycorrhizal an antidote dilute

but doesn't reach. spine lax to bark the lines left

eighth of july, twenty twenty-two

[♫ "grief offerings theme music" ♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

[0:42:07]

EMILIA: I'm gonna pop in the chat the care crisis directive. It's posted on the FireWeed Collectives website. They post resources online, around the intersection of Healing Justice and DisabilityJustice, and they have this care directive, which is a PDF. And I thought maybe it's interesting to read them out, just to maybe offer different kinds of frameworks that are used and how we might think about them… Some different ways of structuring these kinds of conversations.

SAN: I'm also thinking immediately of Mia Mingus and a lot of work around, um, 'pods,' and community care and interconnectedness. But let's look at this Icarus. Where do you want to read from? "Crisis response suggestions", that part?

EMILIA: No, where it says 'Sample Advance Directives'. I think in the top left corner. It was what I thought of when I read The Five Wishes and I was interested in how they were similar and not similar.

So, this is a "Sample Advance Directive" published by the Icarus Project, and this one is referenced to someone called Mary Ellen Copeland. It's for context of mental health crisis. And it starts with, 'When I am feeling well, I am...' And then it says 'describe yourself when you are feeling well.'

SAN: Then it says, 'The following symptoms indicate that I am no longer able to make decisions for myself, that I am no longer able to be responsible for myself or to make appropriate decisions.'

ETZALI: Next one says, 'When I clearly have some of the above symptoms, I want the following people to make decisions for me, see that I get appropriate treatment, and to give me care and support.'

EMILIA: And then it says, 'I do not want the following people involved in any way in my care or treatment. List the names and optionally say why you do not want them involved.'

[0:44:11]

SAN: We talked about that a bit before, Etzali, in terms of funerals and things. And I think it's very important. And then there's things about medications; 'preferred, acceptable, unacceptable'. And treatments; 'acceptable and unacceptable.'

ETZALI: 'Options about Home, Community Care or Respite options. Preferred treatment facilities and why. Unacceptable and acceptable treatment facilities and why.'

EMILIA: And then there's separate spaces to respond about 'What I want from my supporters when I'm experiencing these symptoms.' And 'What I do not want from my supporters when I'm experiencing these symptoms.'

SAN: 'What I want my supporters to do if I'm a danger to myself or others'. And 'Things I need others to do for me and who I want to do it.'

ETZALI: 'How I want disagreements between my supporters settled.'

EMILIA: Interesting.

ETZALI: And, 'Things I can do for myself.'

[0:45:20]

SAN: And then there's, 'I give permission, or I do not, give permission for my supporters to talk with each other about my symptoms and make plans on how to assist me.' And 'Indicators that supporters no longer need to use this plan are...' I think there's a lot of important space for nuance in there.

ETZALI: Mm-hm. [agrees]

SAN: And for the things that happen that we imagine will never happen, well, some people imagine will never happen, around disagreements and what people think is best, and that sort of thing.

ETZALI: I think I like that about this one because the other one feels in a way, kind of rose tinted glasses, Is that the expression? [giggles] And this one feels more grounded in things that are already difficult to talk about or to bring up. And it feels… There's things about this one that, to me personally, feel more empowering. Like about who I want or not to be involved.

I think maybe it's the way in which the questions are framed, or the prompts are framed. That, and how I want disagreements between my supporters settled. That is a huge thing, because even when we have a plan, everybody can execute that plan in a very different way. So, I think that always brings tensions. And how do you… Because obviously if you are not in a place where you can help to bridge those disagreements, how are those disagreements get settled, so that you can get what you need?

[0:47:19]

EMILIA: And here, another grief offering in the form of a poem.

SAN: San Alland here, on a different day. A rainy day in Glasgow's east end. I'm going to read a poem from my collection *Naturally Speaking*, which was published by Toronto's espresso in 2012. The book is me collaborating, and messing with, dictation software 'Dragon' or 'Naturally Speaking'. Reading to it in languages it didn't understand. Or laughing, crying into my microphone to see what it would type based on its programming and its studying of my documents.

This poem is the final poem from the collection. It's called "epilogue: tears". [San reads the poem]

[epilogue: tears]
to the who you are not
like she
one of the gang

this and the good-looking loan

pick a victim, little bullet.
in the middle and back

pick a bone on another earth, like London

the recent cuts a a a a a a a a a a a a a a a a

[In the final line of the poem, the individual 'a' sounds are pronounced 'ah', like a soft 'a'. San varies their emotion and rhythm as they read the 'ah's, evoking pain or weeping]

[♫ "grief offerings theme music" ♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

[0:48:54]

EMILIA: I think I like the bit about self-identifying. 'The Five Wishes' is around end of life, which presumably is something that people experience once. [laughter] You're making a face, San!

SAN: No, I just… [laughs]

ETZALI: One will hope that one only dies once, but you never know!

EMILIA: But there's something about…! You know, it's–it's the language that's used... that I think it's like this thing of 'end of life'. It's like, when does that start and for who? And what does that mean for different people? And the way that people with different experiences might identify these moments, as well. I felt that the 'end of life' one has this potential to do that and to have these conversations, but doesn't quite give us the nuance of questions that would encourage that conversation to happen.

[0:49:48]

SAN: Yeah, it feels a lot more like a non-disabled or non-ill kind of framing. Whereas this, this is very specific. And obviously specifically very very important around mental health because of how mental health support is non-existent, and often violent, in these islands and globally. So, having this kind of plan is very, very important. And for those of us who are fortunate enough to have people we can make these plans with.

I suppose that's something that has kind of been at the back of my mind for some of this conversation, though, too, is the: What about the people who don't have people? And that's a really hard and maybe different discussion…

ETZALI: Yeah.

SAN: But there's a lot of isolation amongst ill and disabled people. Not everyone has disabled community. And it's really tough to try to advocate. Because we can advocate for the people we know and love, right? But that's usually a thing that happens fairly naturally. With work, but, you know? But what

about these other people that don't have that kind of network? It's just something to think about. I don't have any answers.

[0:51:17]

EMILIA: Yes. It's something that we should protect and advocate for, you know?.

SAN: Yeah, wouldn't it be great if all health care was like this? [Emilia laughs] Or any health care? Because so much of it is carceral, right? And that's what this kind of directive directly fights against. You know, making sure that you don't end up in situations where you're taken to places or treatments that you don't want.

EMILIA: I guess it also brought up the question for me of when we can't be present. How it might be harder to be in the same place, for example, or be in the same room. There's been big losses around the possibility to grieve and mourn together in the ways that we have before. So I guess it made me think about what additional questions would we need that would address the current condition?

[0:52:14]

SAN: I was just gonna say... I don't think we've said the word 'grief'. And then you said it, like it was psychically the moment! We have talked about it, but like not with the actual language of loss and grief, which I find...

Because we think of grief, often, as associated with death and dying. But I think also, as we've all expressed, the grief right now is like this overwhelming grief of that; of, of mass death and disablement. But also, disconnection from each other, and from the spaces that we knew. And for disabled and ill people who are isolating still or shielding, it's, I think, a really massive daily grief that [sighs] is very, very huge.

And a lot of the issues that we've raised have been getting worse during this time, but there's less support. Disabled people have historically been hidden away. And that's happening again. And that is a huge grief.

ETZALI: And on that, for me, irony is not lost. And the fact that the pandemic has caused, or has increased, the number of people who are disabled.

ETZALI: So...and I think I talked about this with both of you, like about the amount of collective grief and trauma that we are all experiencing, and that is not talked about. But that is there. And it obviously has an effect in the ways in which we relate to each other. And the ways in which we also behave in our communities.

SAN: Mm-hm. [agrees]

EMILIA: Yeah, and I think that's also the 'why' of… why are we talking about this. Because in that landscape, to be present with the grief and the ongoing grief and the anticipatory grief, I think is about holding and making a space for ourselves, with others, advocating for others elsewhere, to be able to be with the question of grief.

I think that's, for me,... how I understood it as an offering. That's how I received it when I was sent it from my mom is, 'Oh this is a space that's being made to sit with this and I want to be here. And I want to see where it goes.' So yeah, thank you, also for... I feel that we're doing that here.

[0:55:24]

ETZALI: Time to listen to Emilia's poem contribution.

EMILIA: Emilia here. This poem is called "Una busqueda / digging for roots (after conversation with Denise Ferreira da Silva)". It is read by Ángela, my mother. The final lines from this poem are a quote and nod to Erica Mena's poem "El Problema con Los Infinitivos".

[Ángela reads the poem in English and Spanish, without translation]

Una busqueda / digging for roots (after conversation with Denise)

Entangle
To enfold, as in accomplice,
As in multiply,
As in 'one, as one together with'

Or to weave
abuela's braids
ceiba seeds
or water on the wind

Of embrace,
as in care and/as reciprocal debt

Of incrimination,
as in misbehaving particles.

barrunto

Of earth
earthen
barrio

As in *blas*,
barro, mud, clay

Of *baros*,
the residual matter de otro tiempo

of broch y basura
the matter of the dead.

Of bright, or brown?

Horizon, barranco, mound,

Or maybe of *bher*
de cargar, to bring forth

monte
iceberg
burial

Or the entierro of the atmosphere;
Of the *'always filled, always infinite space'*
between here and there

[♫ "grief offerings theme music" ♫]
[Emilia's voice echoes] You're listening to grief offerings, an audio transmission.

[0:57:49]

SAN: I think conversations around all of these things need to happen more. And yeah, I thank you for bringing this grief offering to me. And also sharing that particular story. It was very hopeful, to think about those small moments. We

often kind of think, "Oh, I want it to be kind of like this." But the specificity is what really struck me about what you shared from your mother. Especially when your world is restricted by a lot of different things. To have those specific joys, those little moments is really, it's really beautiful.

I want to know if you're going to do this? Are we going to do this in community? Is this something that...I mean you don't have to answer if you don't want to. But, you know, is this something you're thinking of doing for your lives?

ETZALI: Maybe that's a good question to finish. I think we can answer that or not. [Emilia and Etzali laugh]

SAN: That was to the 'big' you. As opposed to just you two. Yeah, yeah.

[0:59:03]

ETZALI: But yeah, the 'big you' can answer later when this gets released. There was something I wanted to say and I forgot. Oh yeah, on the grief offering. If there's something I think that I'm really grateful and that I have learned from you both is like, to actually have, or create, a space for these conversations to happen.

And, like, to sit here and talk about these things. Simply that, I think, for me, that in itself is an offering. I'm probably thinking of the… 'What do I… what do I wish?' I think for me, I'm so wrapped up into being just now here that I haven't put time to think about what could happen. Which is another part of a conversation, right? Like... reckon with your own mortality, or accepting that you are gonna die sooner or later. One wishes for the later [laughs]. But we do not know.

[1:00:22]

SAN: Yeah, and creating supportive structures in our communities where we have support towards thinking about that, I guess. And towards thinking

about living well. How we're going to manage that against all the odds. And having plans!

Like, what do we do in X scenario? Because if you wait for that scenario to arrive, it may be quite difficult to be in touch. How do we stay in touch if people can't afford to be, even less than before, afford to be online, afford to pay their electricity, these sorts of things. What plans do we have for analogue communication, maybe? I think of Leah Lakshmi Piepzna-Samarasinha and *Care Work* and other works they've written.

But as Etzali says, yeah, we're in the moment because there's so many things. We've gotta pay the bills. We've gotta get on with each week, each day, each hour as it comes and finding time to make plans, I think especially for ourselves is I think, you know, it takes... You have to say I care about my well-being enough that I'm going to put aside time to spell out these things. And I think many of us can do this for other people, but we don't allow it for ourselves.

[1:01:53]

EMILIA: We had originally talked about doing that during this time, actually. One thing I remembered from that conversation was that, you know, it might be interesting to share with each other because we're part of each other's lives and part of each other's care communities, but yet we might not be the people on the list.

Etzali said, 'No offence.' [laughter]. And I was like, Yes, I'm here for that and I want that too. And I want, you know, the being able to bring these conversations to the different kind of parts of our intimacies or communities that are less intimate.

[1:02:26]

And we are very good at caring for each other. And I think disabled people and a lot of other people that have to name their needs in order to not face, or in order to resist certain kinds of violences, get better at naming

their needs on a day to day basis. And, like, that becomes sort of part of our integral kind of space. But yeah, to be able to zoom out and plan and think in this way.

It reminds me a little bit of speculative fiction, and two writers who I admire, adrienne maree brown and Walidah Imarisha, who talk about how science fiction is organising and 'all organising is science fiction.' And this particular kind of, like, dreaming space into the future as a form of organising ourselves for the worlds that we want to make. I would like to write about these things and chat about them very specifically. To those details ... to the joyful details with you both, and with others.

ETZALI: Mm-hm. [agrees]

SAN: I'm here for it.

[1:03:31]

ETZALI: I think when I say, like, 'No offence', I'm just thinking about, like, 'Why did I say that?' [San laughs] I'm not…I don't want to justify myself, but I think there's something about also knowing your own limitations about what you can offer to others.

I think in the back of my mind I was thinking about my own limitations and providing care for others. And like being like, 'I love you, but maybe I can't care for you.' [laughs] And I have to accept that. And I have to be very honest and upfront about that with you, as well. Because I cannot offer you what you are requiring on me in that moment, maybe? But it might be different in another time. Which is where we were talking earlier about, like, the flexibility of being able to, 'Not today but maybe tomorrow.' [Etza giggles]

[1:04:31]

SAN: Also, it is really tough because, as disabled and chronically ill people, we are often the ones doing this work for each other. And in some ways we are

the most equipped. In other ways we are the least equipped and have the least energy. And not as many easy tools as some other people would have. So, it is really important, as you say, Etzali, to be really aware of what we can commit, you know. And that can change and fluctuate, of course. But, care work is a lot of work. And I wish more non-disabled people were involved in positive ways in care work. And hopefully that will happen.

[silence]

SAN: We're blowing kisses at each other [laughter] in a private moment I just ruined [all laugh]. With my constant need to audio describe.

EMILIA: Thank you for audio describing.

[1:05:41]

EMILIA: Thank you to all of our poet contributors. To our communities and everyone we have referenced. To Claude and Freya and Rhubaba for making this happen. Thank you for sharing this time with us.

[Emilia's voice echoes] This has been Grief Offerings, an audio transmission.

[♫ "grief offerings theme music" plays, fades out. ♫]

[♫ Etzali's sweet playful sing-song voice echoes ♫] 'Emi, San & Etza show.'

[1:06:25 end]