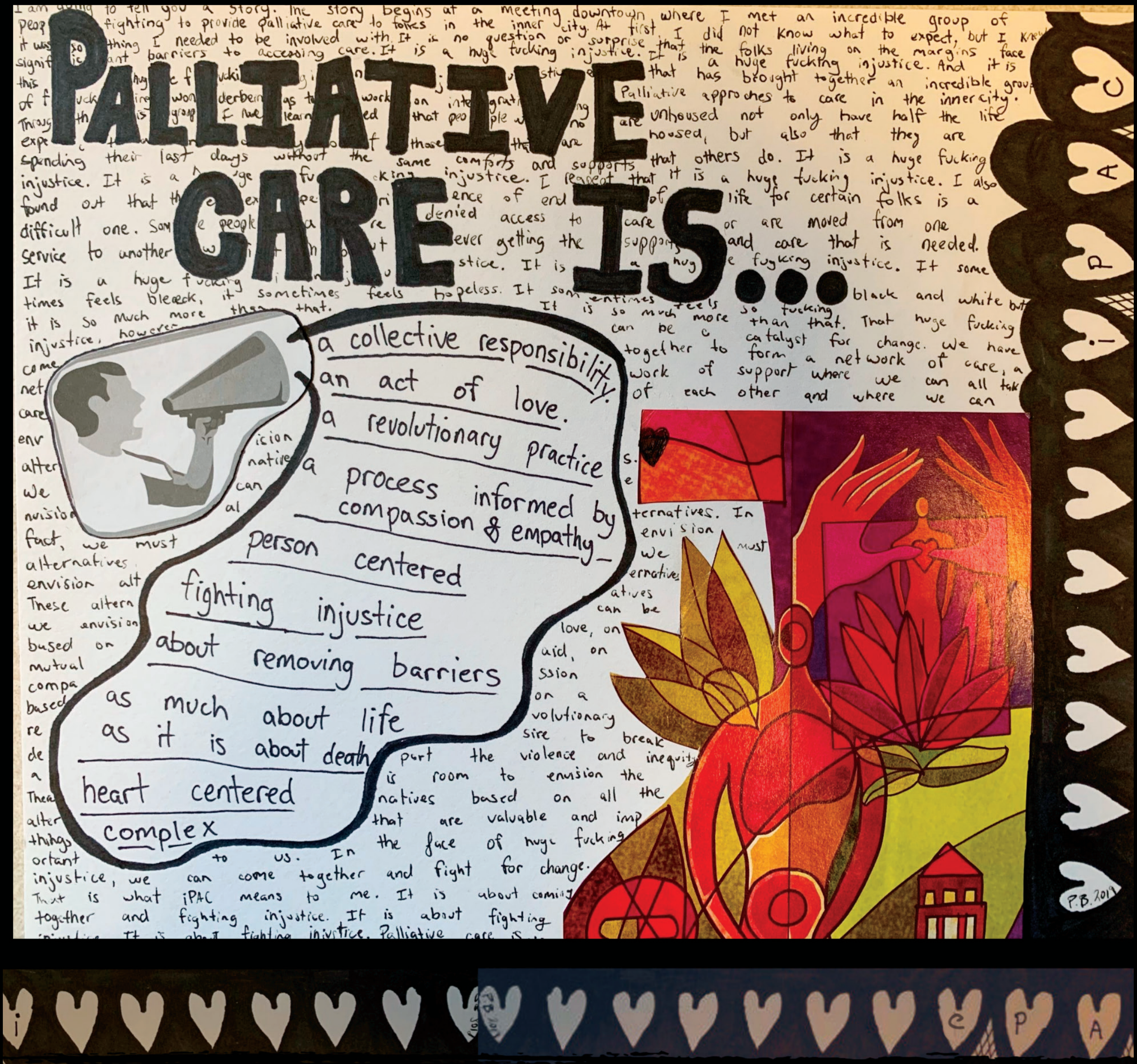

A collective response to death, dying, and grief in the inner city

Palliative Care Is....

A Collective Response to Death, Dying, and Grief in the Inner City

To access the online guide:

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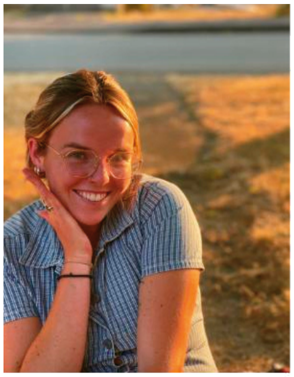
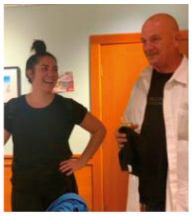
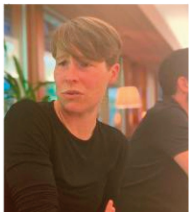
island health

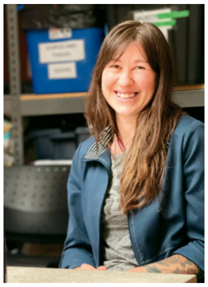
Table of Contents


CULTIVATING HOPE
why
CONNECTION
Breaking the cycle of disconnect









This guide is dedicated to Paige Phillips, a fierce leader, advocate, and mother whose contributions to our collective work cannot be understated. Paige joined our inner city action team in 2017 mobilizing experiential knowledge to relieve suffering and improve care for her friends, family, and community. She will forever be remembered for her fighting spirit and deep love inspiring hope in all of us. So many more people will get the care they need and deserve because Paige lived.

Where we are at

'Meet people where they're at' is something we say a lot in inner city settings. This phrase and its many meanings connect to a harm reduction approach and can guide our work, and our relationships and engagement with one another. But to meet people where they are at, we need to also understand where *we* are at. We think that naming the harm that necessitates a harm reduction approach is a good place to start.

While this guide begins to take apart mainstream understandings of how and where care, dying, and death occurs, it is rooted in Western knowledge, and we recognize how much further we need to go. We preface this guide with a recognition that this work is needed because of the ongoing colonial legacy embedded in Canada's systems and institutions of power. We can't talk about inequity and a palliative approach to care without talking about how our historical and ongoing racist policies and practices have driven early and unjust deaths—especially for Indigenous Peoples.

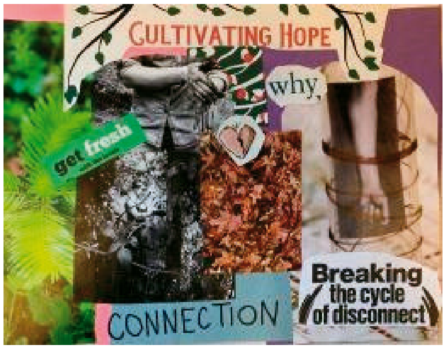
We call for greater support for culturally safe(*r*) care and humility in our inner city and palliative care organizations. When we talk about improving mainstream health and social systems, we must listen to Indigenous people who tell us that Canada's systems will never be healthy nor truly safe. Going forward, we commit to being part of the changes needed in challenging the dominance of Western knowledge systems and holding up Indigenous ways of being and knowing in care, life, dying, and death.

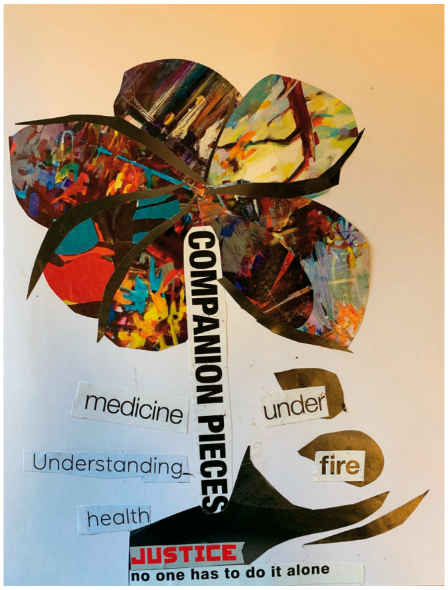
Beginning in colonial minds Canadian laws and the criminal justice system were created to protect the rights of white landowners and justify their violence. Whether protecting white womanhood or maintaining segregated neighbourhoods criminal ‘justice’ has been used as a tool against poor and racialized bodies. Our current drug toxicity and criminalization crisis is rooted in this war.

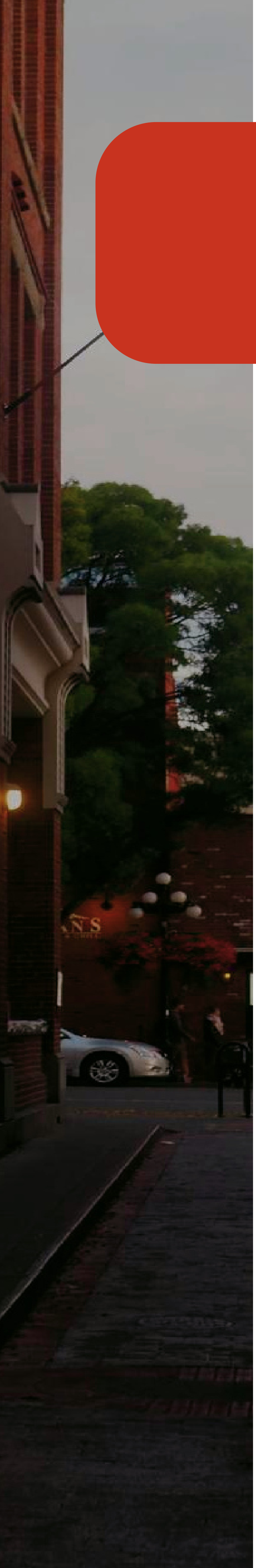
While this guide offers approaches that can mitigate the harms of criminalization, it does not address the roots. As we attend to those who could benefit from a palliative approach to care, we must also work to change the systems that sustain preventable deaths.

The issues discussed in this guide are not new to those who have experienced disability-based discrimination throughout their lives. Whether we are talking about medical system trauma, care needs and approaches, or the body, we see our work as disability justice. This lens is crucial because of how we are all, eventually and inevitably, harmed by ableism. We need a radical transformation of how we see ‘care’ and ‘help’ and this shift needs to prioritize the knowledge of those who have experienced structural harm and whose voices, and bodies, have been historically erased.

We also need to name the gendered aspect of this care work. Going above and beyond the call of duty, cultivating relationships, and caring for people should be valued as important work deserving of a decent wage and respect. As we call out the lack of recognition and support that inner city workers receive, we can see ourselves in solidarity with others in gendered work.







01

Welcome

Death and dying is all around us in the inner city. Drug poisoning, discrimination, racism, and other inequities drive unjust, unsupported, and preventable deaths. High rates of serious illness like cancers and organ failure are made worse by barriers to care and support. Inner city workers often fill gaps in complex systems that people need but can't get access to.

Our goal here is to make showing up for death and dying a greater and more valued part of inner city work – one that is acknowledged, supported, and less distressing for people who are experiencing and witnessing it. While a palliative approach to care does not solve the systemic issues or bring people back, it can be 'just' care in the face of injustice. We hope this guide helps you reflect on the work you're already doing, gives you some new tools to navigate the complexity and uncertainty of it all, and shows you the transformative potential of a palliative approach to care.

What's in this chapter?

When death is all around us

People who face poverty, homelessness, racialization, criminalization, and stigma are at greater risk of poor health outcomes and early death. Because of historical and ongoing barriers to health care and conditions that contribute to good health (e.g., safe housing, adequate income, nutritious food, social connection), the people you work with are more likely to develop chronic health conditions and not be diagnosed with or treated for them. The people you support may die from the progression of these health issues or experience more sudden deaths from toxic drugs or violence against them.

The reality of working in the inner city is that death and dying are all around us but rarely talked about or planned for.

Every year, the government reports mortality rates from official public health crises but the deaths from poverty, racism, discrimination, and criminalization remain underreported and unknown. The preventable deaths we witness in our communities are numbing in their sheer volume yet they represent people we know, people we support, and our friends, and family. There is no way to process this loss and the years of government inaction has left workers, friends, and family members distressed and unsupported.

Death can be distressing regardless but the common lack of conversation and preparation around it can add stress and complications. Friends and workers are often left out of communication, decision making, and opportunities to ask questions about what happens to the people they care about. Past and ongoing experiences with death and dying can prompt rage, numbness, sickness, fatigue, flashbacks, and pain.

So why do we even want to think about it anyways?

A palliative approach to care can be a tool for advocacy to get people the things they need.

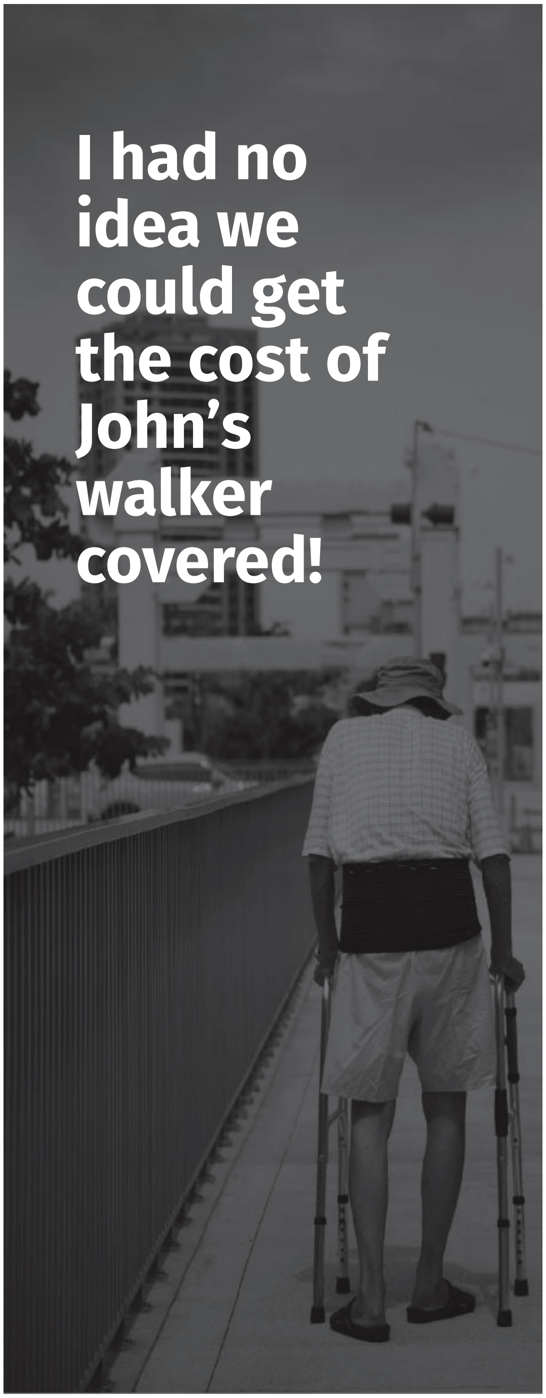
A palliative approach is good care

When we think of palliative care, we often think about hospices and hospitals where people go to die. While palliative care can be a service, a palliative approach to care is not a place or thing. This approach can help anyone, but it can be especially helpful when people learn they have a serious health condition that may get worse like severe lung disease, organ failure, or advanced cancer. Applied early rather than just at the end-of-life, this approach prioritizes improving quality of life, preventing needless suffering, and can even help people live longer.

A palliative approach is good care. A palliative approach focuses on mind, body, and spirit, paying particular attention to managing pain and other symptoms (e.g., nausea, shortness of breath) that may come with a person's health and living conditions. In addition to what you're already doing for people you work with, using a palliative approach can get people access to things that can not only maintain, but improve, their quality of life.

A palliative approach to care is driven by the person's priorities and wishes. It is not about 'fixing' or 'curing', but about pursuing quality of life in the way that the person defines it.

Talking about what matters and getting a sense of what to expect can mean less unplanned hospitalizations, better pain and symptom management, and better deaths, as people providing care are aware of the person's wishes and can therefore act on them.

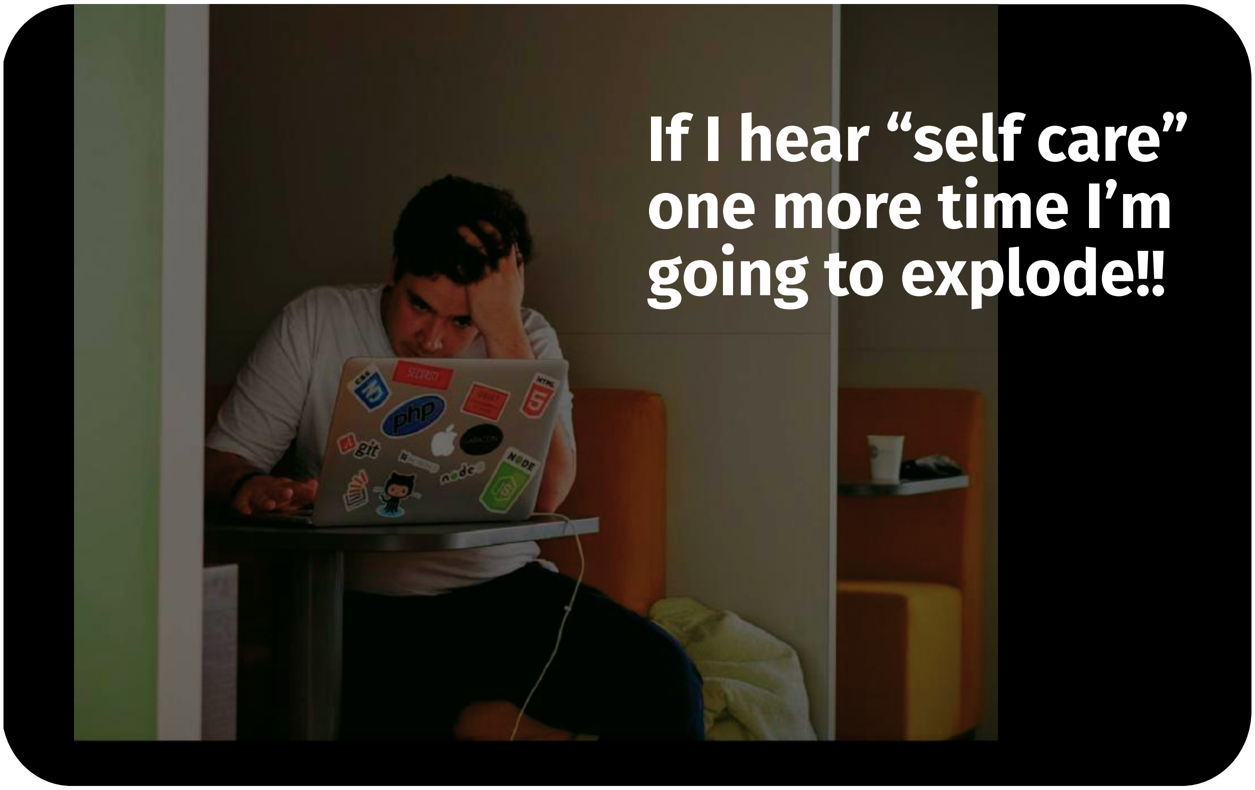


I had no idea we could get the cost of John's walker covered!

A palliative approach can happen anywhere

Palliative care is often seen as outside the realm of inner city work but the consequences of unexpected deaths fall on friends, family, and workers. A palliative approach recognizes that death is a normal part of life and must be attended to in all settings.

There are a range of experiences and responses in the face of dying and death, grief, and loss. So much of what is called bad boundaries, trauma, and burnout in inner city work is in fact, responses to injustice, grief, and loss. Rather than blaming workers, we need a collective response.



If I hear “self care” one more time I’m going to explode!!

So much of what is called bad boundaries, trauma, and burnout in inner city work is in fact, responses to injustice, grief, and loss.

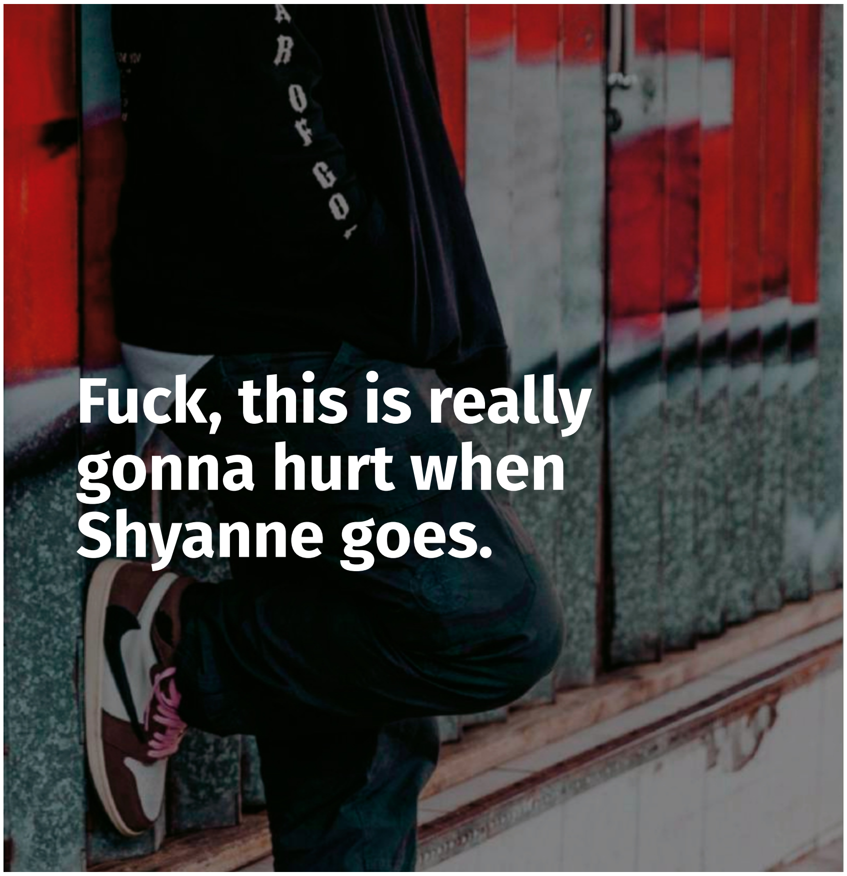
You are part of a palliative approach to care

Health care is often focused on the individual in need of care but living and dying through a palliative lens recognizes that a person’s friends, family (however that's defined), and community are central to their living and dying experiences.

A palliative approach seeks to reduce suffering by putting the person and their supporters at the centre of the health and social care relationship. This approach encourages people and their support networks to be active participants in care and support plans.

Inner city workers are an important part of supporting people who are dying. You are likely paid to support people, but may also work outside your paid hours, scope, or role to do so. These important yet sometimes complex roles deserve recognition and support.

A palliative approach to care can mean less suffering for both the person experiencing it and those witnessing it.



Guiding principles of a palliative approach to care

Death and dying is primarily a social (not medical) experience.

Physically, death and dying is the body shutting down, but death and dying occur in a context of social experiences and relationships with others. This means that our relationships with our families, communities, and cultures are an important part of care at the end-of-life.

Whole person care that starts with the person's priorities.

A palliative approach involves attending to the whole person including their physical, mental, emotional, social, and spiritual needs. This approach starts with determining what a person's priorities are rather than making assumptions about what they want or putting our own values/beliefs on them.

Attention to the social determinants of health is critical to enhancing quality of life as people are dying.

We know that having access to good quality housing, food, income, and networks of support can help people live well until they die. Yet, access to these social determinants of health is not equal. In the face of inequity, attending to and addressing these determinants of health is critical when meeting people's palliative needs.

The care of people who are dying is a collective responsibility.

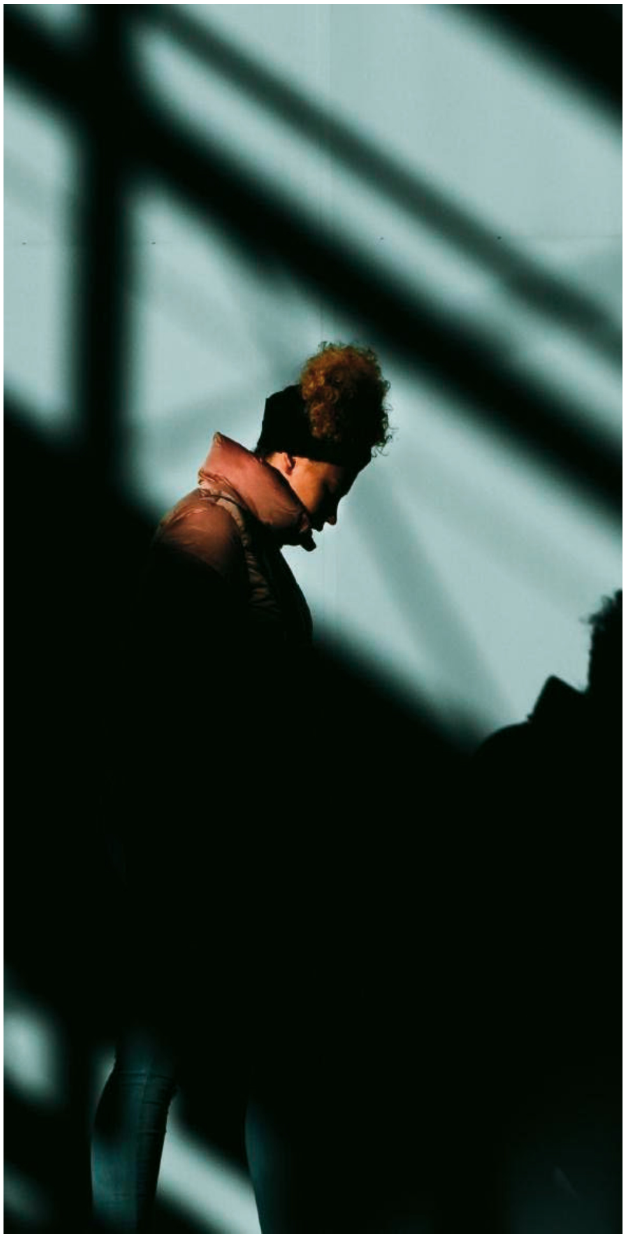
Ensuring that someone lives their best quality of life until they die requires the entire care team to work together- friends, family (however that's defined), volunteers, workers, health care providers, and anyone that the person deems as important to them. The way we care for and honour people says a lot about the health of our communities.

Enabling people to benefit from a palliative approach to care is social justice in the context of injustice.

Life in the face of inequities is unjust for people who experience it and those who witness it. Reducing this suffering by prioritizing the needs of the people and their families and ensuring access to quality care at the end-of-life is 'just' care in the face of injustice.

It has never been more clear that health and health care access are not created equally.

About this guide



This guide is rooted in workers' knowledge and experiences of witnessing unjust and undignified deaths. Through a collaborative research process, a collective need was identified to create resources by and for workers who are supporting people living and dying in contexts of inequity. This guide contains insights developed from research and ongoing collaboration between inner city workers (e.g., housing/shelter, outreach, peer, etc.), researchers, and palliative care providers (see page 88).

In our collaborative work as inner city workers, palliative care practitioners, and researchers, we have found many benefits to opening up the conversation about death and dying in inner city settings. However, this guide may be relevant beyond inner city settings and in other places where people are facing challenges when trying to access care and support for serious illness.

Inner city workers are an important part of supporting people who are dying and we deserve support too.

Using this guide

In an environment where workers are constantly being asked to do more with less support, we see a palliative approach to care as an orientation to the work rather than another "task" to add on. This guide should not be used to teach workers how to "do" palliative care, but to support workers in what they are already doing. If this resource is shared, we hope it's shared by workers who see this as valuable to their context rather than as a top-down teaching tool.

As you read through this guide, we hope you reflect on what fits for you and what doesn't. Feel free to read the whole thing or parts at a time taking away what is useful to you and your work.

Using this guide to navigate a palliative approach in your work

See Chapter 2	Recognize how a palliative approach may **align** with the work you are already doing.
See Chapter 3	Identifying people who could **benefit** from a palliative approach to care could lead to more availability of resources and benefits including income and housing options.
See Chapter 4	**Conversations** about wishes, hopes, and fears around serious illness and dying can be relieving to people experiencing it and the people who are supporting them.
See Chapter 5	**Planning** takes the guess work out of what the person you're supporting wants. It can be relieving to operate and make decisions in line with a person's stated wishes.
See Chapter 6	When you know what someone wants, people who specialize in palliative care including in pain and symptom management and other ways to **relieve suffering** can be brought in to help support.
See Chapter 6	A palliative approach works from a **shared care** philosophy. When you are not navigating support and decision-making alone and you can draw on a larger team, the burden you feel can lift.
See Chapter 7	A palliative approach **recognizes the support needs** of caregivers. When you can talk about the realities of your work without the risk of being labeled 'broken or bad' workers, there is potential to understand distress as a compassionate response to inequity and suffering.
See Chapter 7	Ritual and **collective care** following death is a key focus in palliative care. Collective responses to death can honour and humanize the people who died and the communities they are a part of, and be a way to push back against systemic injustice.

Key takeaways

Death and dying is all around in the inner city, but it's rarely expected, talked about, or planned for. The injustice from stigma, racism, and lack of access to care compounds distress associated with death and dying.

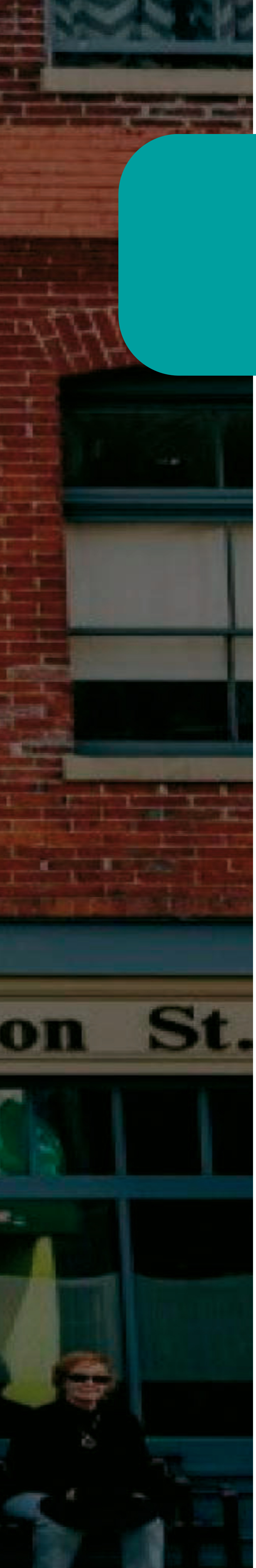
Social support is essential to a palliative approach to care. This approach can happen anywhere and especially in the social care spaces of community and inner city organizations.

A palliative approach can be a tool for advocacy to get you and the people you serve the things you both need. It can mean improved quality of life and less suffering for those experiencing and witnessing serious illness in the context of inequities.

Inner city workers may be the first or only point of contact for someone who is in need of a palliative approach to care. You may be juggling multiple roles as a worker, friend, or chosen family member, which can be challenging to navigate.

Much of what is called bad boundaries, trauma, and burnout can in fact be understood as normal responses to injustice, grief, and loss.

This is not a resource to teach you how to become a medical worker or ask you to do more, but to acknowledge and support the work you're already doing.



02

A Palliative Approach to Care In The Inner City

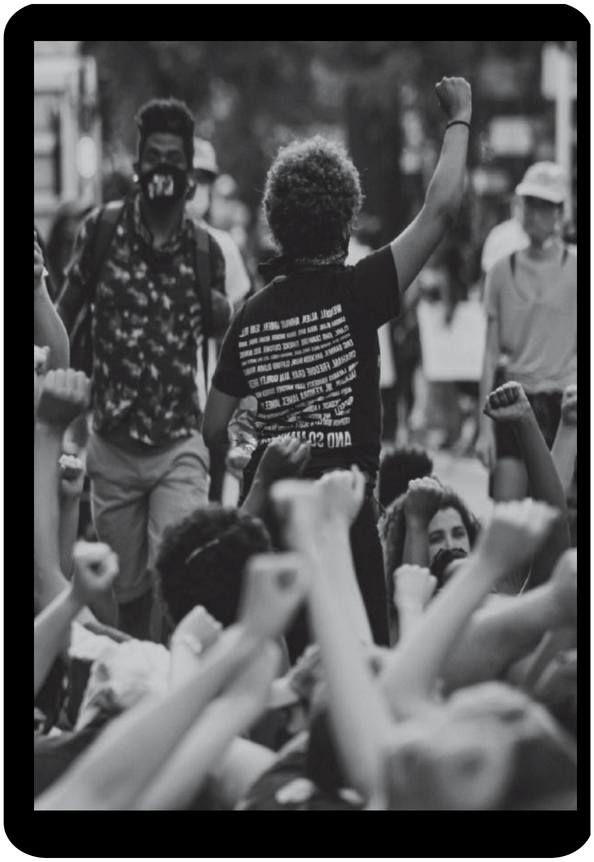
After reading **Chapter 1,** we hope you can see how a palliative approach to care may benefit you and the people you work with. In this chapter, we discuss the roots of palliative care. We also talk about how a palliative approach to care can align with other approaches you may already be using in your work that centre the person, their friends, family, and community. We go into common signs of declining health and how to recognize someone who might benefit from a palliative approach to care in **Chapter 3.**

What's in this chapter?

Palliative care, activism, and advocacy

Palliative care has always been about advocacy. Modern palliative care emerged in the 1960s as a grassroots activist movement, pushing back against a medical system focused on treatment and cure. Palliative care practitioners saw that people living with conditions that weren't curable or those who were dying were marginalized and dismissed. Rather than seeing illness and death as a failure, a palliative approach to care focuses on the relief of suffering and quality of life until death.

Rooted in community, a palliative approach to care is about ensuring a good quality of life at end-of-life while pushing back against policies and practices that cause early, unsupported, and unjust deaths.



Inner city work often involves witnessing and advocating against social and systemic injustices. It involves using approaches that differ from the ones used in mainstream settings. The people you're supporting may be sick and dying because of accessibility barriers around early diagnosis and treatment from the health system. Or because they can't get access to safe housing, enough income to live, good nutrition, or social supports. The people you see may be suffering at the hands of a system full of barriers, stigma, and limited choices.

Where workers fit into a palliative approach to care

The health care system often assumes that people have family caregivers available to provide care and support but this isn’t always the case. The people you are supporting could have strong networks, or they may be quite socially isolated. They may be disconnected or estranged from their biological family. The family members that are involved in the person's life– biological, chosen, or otherwise – may have competing priorities and not be able to provide the care they’d like to.

You may be in a situation where you’re the primary support for someone or you may share that support with a team. You may be one of the few people around at someone’s end-of-life stage, and this vital role might not be recognized or supported. Care and support for people with serious illness can be more complicated if you fill both family-like and worker roles. No matter your role, you are likely in a position of meeting people's support needs. In this kind of role, your tasks can look like fulfilling both practical needs, like housing, food, and emotional support, or health needs and support work which can look like regular and casual conversations pertaining to someone's health status and plans.

While medical support is an important part of palliative care, most death and dying work is social.

Community care is health care

In a palliative approach to care, the focus is on the person, their caregivers, and the community that surrounds them. A palliative approach to care understands that we need to take the contexts where care happens and not just the care itself into consideration.

This means that by providing social, physical, emotional, and spiritual support to people with serious illness, you are part of that circle of care.

How a palliative approach aligns with the work you already do

Because we can never fully know someone's world, we need to ask what people need. This is central to inner city work and fundamental to approaches used by workers like person-centred care, harm reduction, trauma and violence-informed care, and cultural humility. Like these approaches, a palliative approach to care starts with the priorities of the person and their chosen supporters rather than the system's priorities.

A palliative approach to care, like harm reduction, involves communities caring for one another. Communities have always known how to look after each other. However, when care is medicalized - or brought under the control of medical institutions - something is lost.

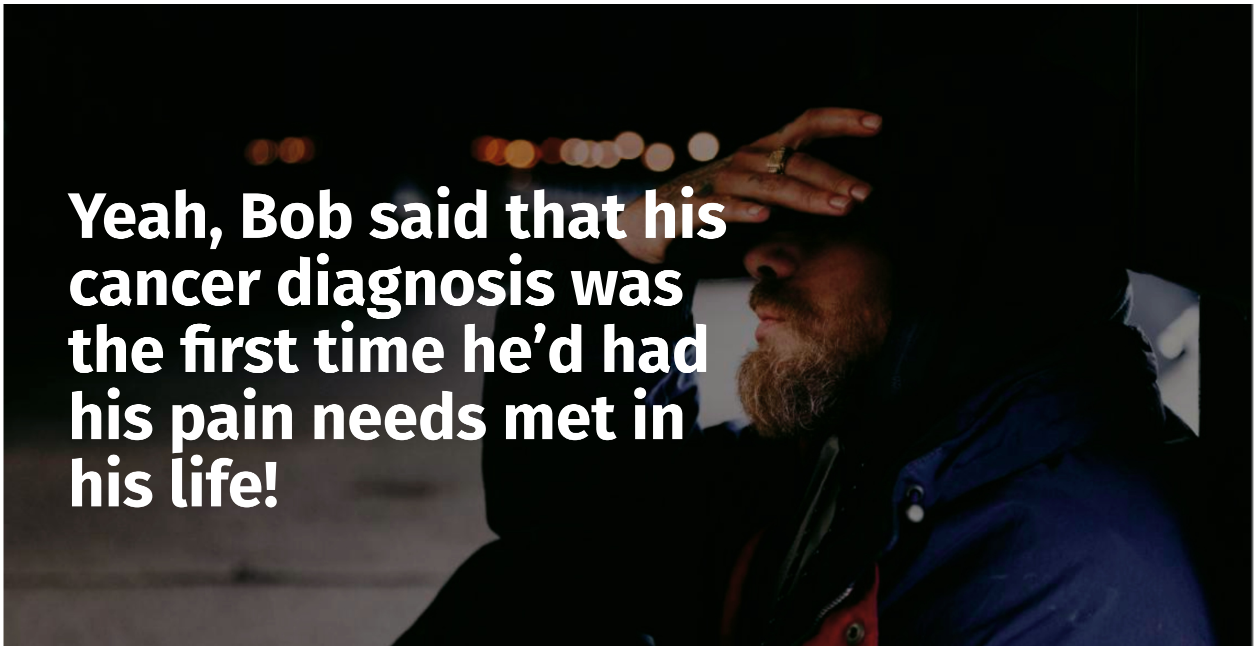
Just as harm reduction is more than providing sterile supplies, palliative care is more than pain and symptom management. A palliative approach to care can happen anywhere and be used by anyone. While pain and symptom expertise may be needed, many aspects of palliative care are social. This care can include knowing a person well enough to be able to discuss their priorities, desires, goals, and decisions with them. This is something you are likely already doing in your work.

A palliative approach to care is an attempt to increase personal and relational autonomy, comfort, and dignity while decreasing the trauma associated with accessing health care and support that many people who experience marginalization face. A palliative approach can look like policies and practices that support people to die in the places they call home, surrounded by their friends, family, and community. It can look like attending to a person's cultural and spiritual needs alongside their physical and emotional ones. It can include policies and practices to support chosen family and workers in the care of people at end-of-life, and tend to grief and loss needs after someone dies.

Rather than avoiding or stigmatizing substance use, pain and symptom management is a key pillar of palliative care. Focusing on people's quality of life, their pain, and symptoms means understanding and learning about a person's pain (physical, psychological, and spiritual/existential) and figuring out the most effective ways for treating the pain and symptoms associated with their serious illness.

A palliative approach to care shares harm reduction's principles of **non-judgement, self-determination, and autonomy,** but adds a focus on death, dying, grief, and loss. Good palliative care practitioners take these insights into consideration because it means that their strategies for managing pain will be more successful.

People who use substances often know a lot about their body, how substances operate, and have preferences for some drugs over others.



Yeah, Bob said that his cancer diagnosis was the first time he'd had his pain needs met in his life!

A palliative approach to care can align with other practices you use in your work such as person-centred care, trauma and violence-informed care, and/or cultural humility. This approach can benefit more than just people who are dying as it attends to the whole person, asks instead of assumes what a person needs, and plans and prepares for the future.

With this focus, a palliative approach may support your work with people who are going through life transitions such as hospitalizations, incarceration, a new disability or brain injury, or those who are experiencing grief and loss. A palliative approach may help you in your own life to think through your own role in relation to death and dying and to help make sense of grief and loss.

A palliative approach doesn't erase systemic injustice or the ongoing inequities around access to health and social care. However, workers have shared how applying this lens to their work helps to understand and improve what they're already doing.

Adapted from: EQUIP. (2022). Equip Health Care: Research to Improve Health Equity. https://equiphealthcare.ca/

Key takeaways

Rather than seeing illness and death as a failure, a palliative approach to care focuses on the relief of suffering and quality of life until death.

Rooted in community, a palliative approach is not only about ensuring a good quality of life at end-of-life, but about pushing back against policies and practices that cause early, unsupported, and unjust deaths.

By providing social, physical, emotional, and spiritual support to people with serious illness, you are an important part of people's support network.

Care and support for people with serious illness may be more complicated if you fill both a family-like and worker role.

While medical support is an important part of palliative care, most death and dying work is social.

A palliative approach to care shares principles with a harm reduction approach including non-judgement, self- determination, and autonomy, but adds a focus on death, dying, grief, and loss.

A palliative approach to care focuses on planning for the future. It engages with discussions and the documentation of wishes for life with serious illness, death, and the post- death stage.

03

Benefits Of A Palliative Approach To Care

In **Chapters 1** and **2**, you learned about a palliative approach to care and how it can align with the work you're already doing. There is often no way to predict how a person's illness will progress or when they will die and this is especially true in the context of life-limiting conditions like homelessness, poverty, racism, and discrimination. There are, however, signs and patterns that we can watch out for. The purpose is not to diagnose or 'know' what's going on with a person, but to help us include more people in the benefits of a palliative approach to care.

What's in this chapter?

Figuring out who could benefit from a palliative approach

People who work in palliative care have developed a "**surprise question**" to identify people who could benefit from a palliative approach: 'Would you be surprised if the person you're supporting died within 6 months?' But people who live and work in the inner city don't always find this question helpful. They report that **while death is often unexpected, it's not often a 'surprise'**.

The people you work with can sometimes be in and out of hospital for various reasons that are often unpredictable. Whether it be an infection at risk of becoming septic, a wound that needs care, or a mental health crisis, it can be difficult to know what the outcome of the visit will be. Sometimes people stabilize and return back to where they were living without any extended impact on their daily life. Sometimes, though, people get so sick – sick enough to die.

For instance, while a housed and well-resourced person with an infection could access some antibiotics and cure their infection in sanitary conditions, people who don't have safe and sanitary places to live don't always have that luxury. As a result, infections and wounds can become chronic and can lead to death.

It can be hard to figure out if someone might benefit from a palliative approach if you don't have access to their medical records. They might not be aware that they have a serious or life-limiting condition like advanced cancer or kidney, liver, or lung disease because of barriers they face in accessing health care and specialist services. So, **how could you know when people might benefit from a palliative approach to care?**

Preventable and treatable conditions may become life threatening in the context of poverty and homelessness.

Common signs of declining health

The person can’t move around as well or as quickly as they used to

Did the person used to easily walk a couple of blocks to get a meal and now is having difficulty? Were they able to climb a flight of stairs but are now having trouble? Are they falling or having frequent accidents? Are they having trouble bathing, getting dressed, or going to the bathroom by themselves? Are they asking you for help with things that they used to be able to do independently?

The person looks like they are losing weight

Do you notice that the person’s clothes fit differently and seem loose? Do their dentures no longer fit? Do they look like they are losing weight even though they are eating the same amount? Are they eating less than they used to or don’t seem to have much of an appetite?

The person isn’t visiting with friends as much or doing the things they used to enjoy

Do you notice the person is spending more time where they sleep than they used to? Do you see them withdrawing from social activities that they used to enjoy? Do you see them hanging out with friends less than before?

The person is having pain, shortness of breath or other symptoms that make everyday living hard

Do you notice that the person seems uncomfortable when they are moving or their facial expression makes you think they might be in pain? Are they telling you they are uncomfortable or that they have pain that is preventing them from doing the things they usually do? Has their substance use changed (e.g., using more/ using less)? Are they running out of breath or breathing more heavily even when they are sitting down? Do you notice that their belly is swollen or their pants are getting tight?

The person is more muddled in their thinking or you notice changes in their memory

Do you notice the person saying the same thing or asking the same questions over and over? Are they getting lost in familiar places? Are they having difficulty following instructions or becoming confused about who you are or what time of the day it is?

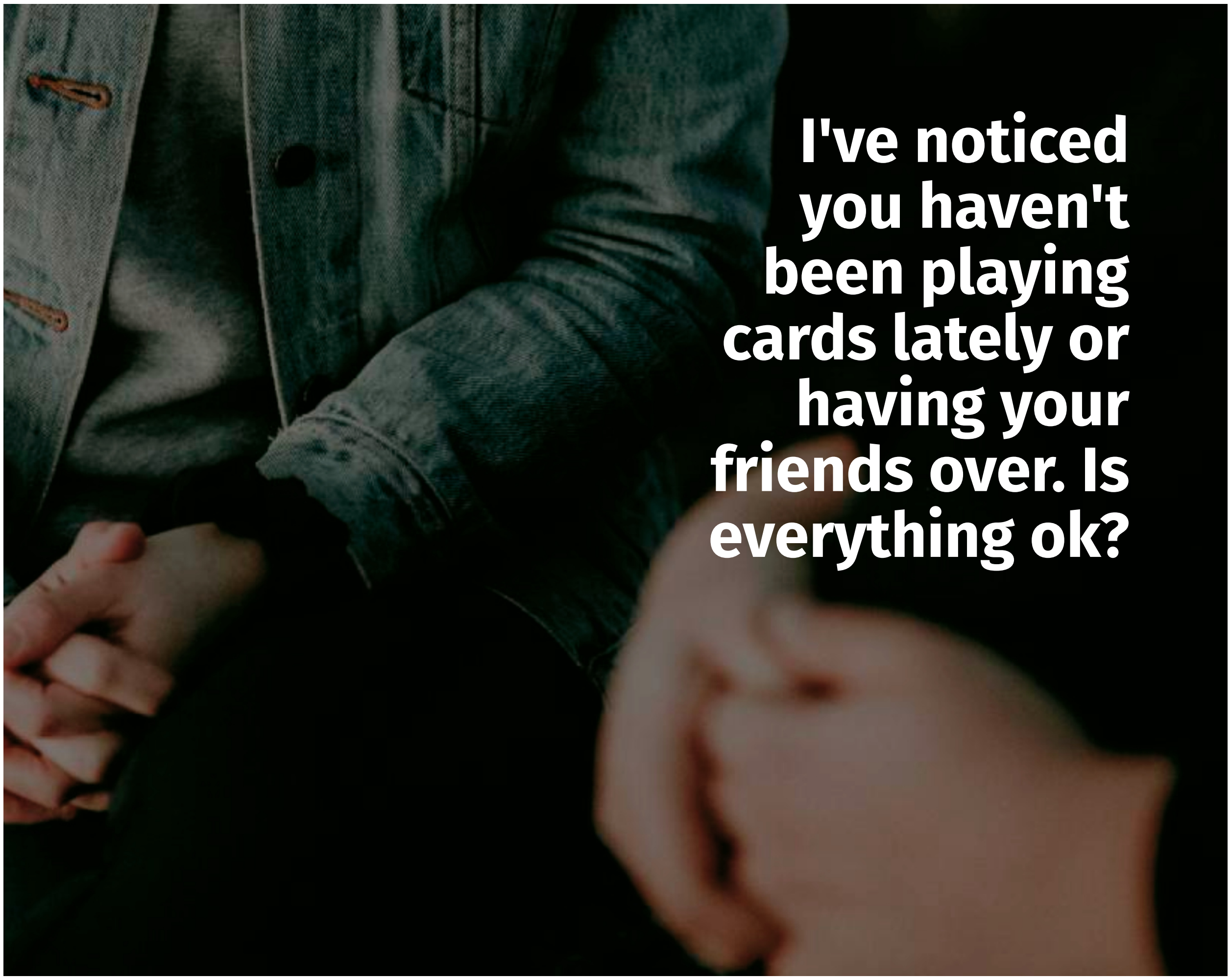
Everyone forgets things from time to time but there is a difference between changes in memory due to age from those changes that make it hard to live day-to- day. Memory problems can also be seen in younger ages, especially for people who have been heavy drinkers.

The person has more frequent hospitalizations or trips to the emergency room

Has the person been hospitalized more than a couple of times in the last six months? Are they needing to go to emergency more because of health issues? When they come back from the hospital, do you notice that they don’t “bounce back” as well? Are you thinking they are too unwell to live in the building you work at because they have more care needs than your organization can provide?

Any of these common signs of declining health could be due to a condition that is treatable. They could also mean that the person has a condition that may get worse over time like kidney, heart or liver disease, cancer, or an infection that is difficult to treat. Trust your gut when it comes to seeing the signs listed above and suspecting something might be wrong! It could help someone get a prompt diagnosis, which can increase the options for effective treatments.

Even if the person you are working with doesn't have palliative needs, talking with them and getting their permission to bring your observations forward to someone they trust or the person's health care provider is important. This can get them the help they may need.



Understanding how different illnesses progress

Another way to identify people who could benefit from a palliative approach to care is to observe patterns of change over time. While there is no perfect way to predict how a person's illness will progress or to know exactly when someone is going to die, there are common patterns that we see as a person gets sicker. Being aware of these patterns can give us more clues on how to best support people.

In health care, patterns of decline can be drawn and are often called illness trajectories.

There are four common illness trajectories:

1. Sudden Death
2. Steady Decline
3. Roller Coaster Decline
4. Slow Decline

01
Sudden Death

02
Steady Decline

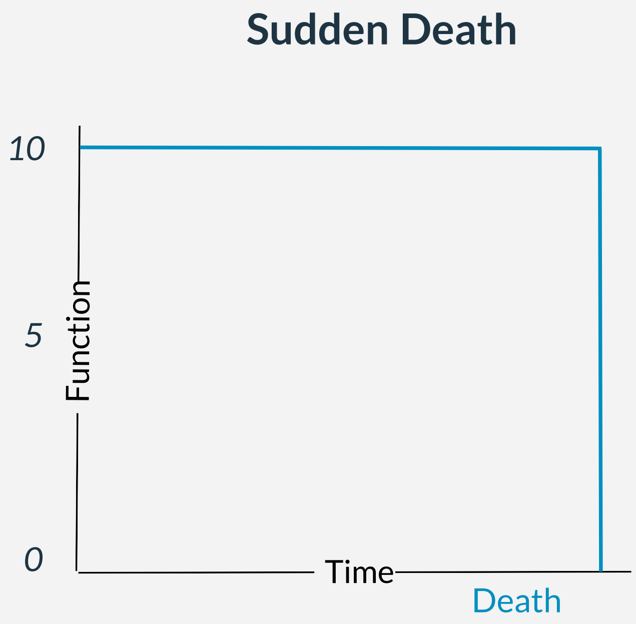
03
Roller Coaster Decline

04
Slow Decline

Adapted from: Lynn, J. (2005). Living long in fragile health: The new demographics shape end of life care. In Improving end of life care: Why has it been so difficult? *Hastings Center Report Special Report*, *35*(6), S14-S18.

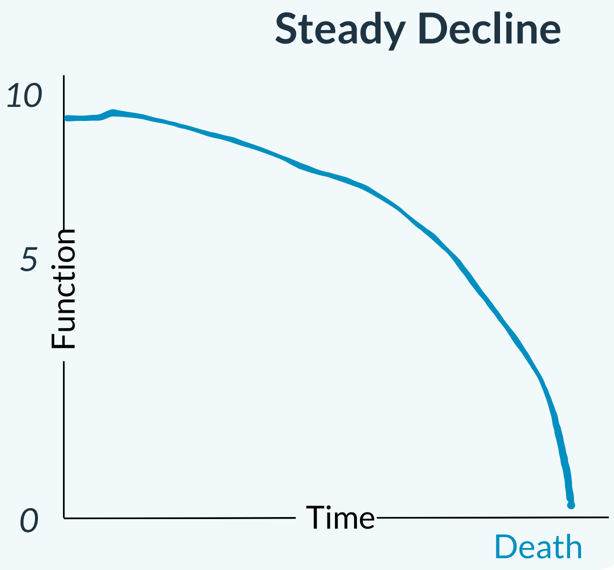
1. Sudden Death

When we think of sudden death we often think of accidents, heart attacks, suicides or major strokes. Sudden death, like death due to drug overdose, can also occur as our communities struggle with the injustices associated with a toxic drug supply. Whatever the cause of the sudden death, it is an experience that can be unexpected, unsettling, and traumatic for family, friends, and workers, especially when the death is unjust and preventable. Working through the grief of losing someone who has died in this manner can be distressing. **Chapter 7** provides a bit more information about working with loss and grief in contexts of injustice.

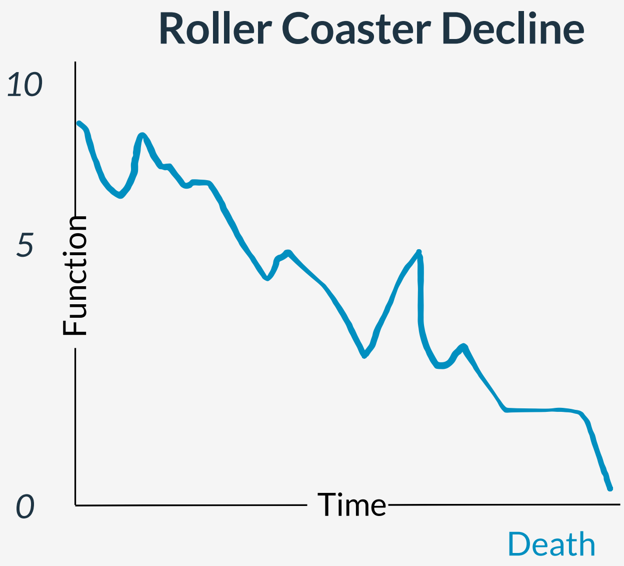


2. Steady Decline

A steady decline in health due to a disease is often seen in people who have cancer. For most people with cancer, they can remain relatively healthy and strong for a long time, even years, depending on the kind of cancer that they have. Diseases like cancer are made worse by living in dire poverty or when people are sleeping in rough or unstable living situations. People who don't have access to nutrition or income and have few support networks are likely to decline and die earlier because these social determinants of health are not met.



3. Roller Coaster Decline



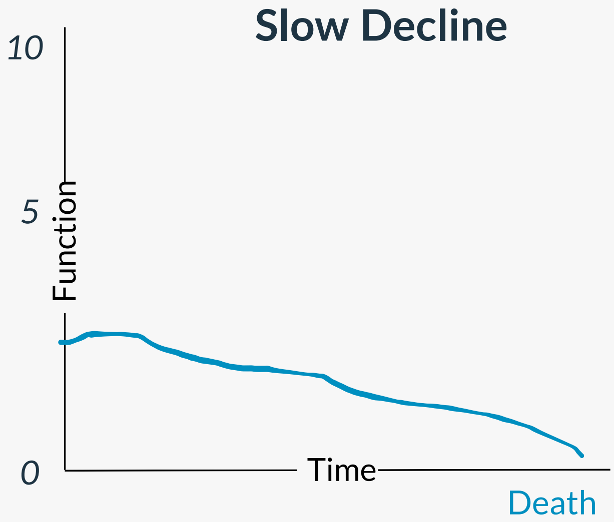
The roller coaster decline is one commonly seen in people who have chronic illnesses like liver, lung, or kidney disease. This trajectory is described as a roller coaster because usually people experience up and down periods of being sick and being well. It is not unusual to see people experiencing this form of decline get into a health crisis, like having trouble breathing because of their lung disease or because they got the flu. They may end up going to the hospital, getting treated, and discharged back to where they were living.

As illnesses progress, however, getting back to where they were before the health crisis becomes harder and harder. That is how many (but not all) chronic illnesses work. Over the years, a person's health slowly starts to decline. The person may go back and forth between feeling well and unwell for years. But, these repeated periods of decline will eventually lead to death.

It is challenging to tell when people who experience a roller coaster decline are going to die. Up to half of the people with advanced chronic illness will not know that the week before they are going to die is the last week of their life. Sometimes regular hospitalizations can become the 'norm' and people don't take hospitalizations seriously or as a sign of decline. Understanding the roller coaster trajectory, or any of the common patterns of decline, can help you to plan and support people. Planning for periods of illness and wellness could help people to stay in community longer or even prevent them from losing their housing. This information can also be used to communicate what you are seeing related to the person's health to a health care team.

4. Slow Decline

When we consider slow decline, we often think of older adults coming to the natural end of their life. This decline is often more subtle and occurs over several years. Typically, a slow decline is seen in older people with illnesses like dementia, Parkinson's disease, or increased frailty. In the context of inequities, however, slow decline might look different.



For example, if you consider that being chronically unhoused lowers life expectancy by around 30 years, slow decline may occur at a much earlier age and over the course of a couple of years rather than several. Changes in a person's mental capacity, like confusion, memory loss, or poor balance, or the person is complaining of changes in their vision, are associated with a slow decline.

Are there people you think might benefit from a palliative approach to care?

Advocating for a palliative approach to care

You probably have trusting relationships and know a lot about the people you support. Often, you are the person who has built trusting relationships with them. While being a medical or health care expert isn't necessarily your role, you have a lot to teach the health care team about what you are seeing. Sharing this knowledge is important in developing good plans to ensure that a person's needs are met in a way that is **respectful, dignified, and person-centred.**

Sometimes health care providers don't understand the social context of people's lives. They don't think about the fact that people with wounds, infections, or other acute illnesses could actually benefit from a palliative approach to care. Your **social knowledge** is an important part of understanding how to support someone in their illness or dying experience. It is important because you have the understanding of the life-limiting effects of poverty and homelessness, and how complicated the systems that grant medical care and other resources are for some people to navigate.

Early identification of people who could benefit from a palliative approach is one way to get people the care they need and deserve. In fact, in some instances, being identified as on a "palliative trajectory" opens up a whole basket of services and supports that people often can't access otherwise (e.g., food, nutritional supplements, pain medication, housing) that could greatly enhance their **quality of life**.

Early identification of people who could benefit from a palliative approach is one way to get people the care they need.

> So Donna was in the hospital for a couple of weeks and we almost had to give her room to someone else.
>
> But the medication adjustments in hospital helped with her shortness of breath and she was well enough to come back home. I’m really glad she is able to stay!

Advocating for a palliative approach to care can also look like talking with someone's health provider if you have their permission. Maybe you have a palliative care team that works in your city and you could call them to describe what you’re seeing and ask what they think. Maybe you could engage the person in further conversations about what’s going on for them and their hopes and wishes for the future (see **Chapter 4**).

Key takeaways

Preventable and treatable conditions may become life threatening in the context of poverty, homelessness, racism, and discrimination.

Sometimes health care providers don’t understand the social context of people’s lives, so your social knowledge is an important part of understanding how to support someone in their illness or dying experience.

While there is no perfect way to predict how a person’s illness will progress or to tell exactly when someone is going to die, there are common patterns that we see as a person’s illness progresses. Being aware of these patterns can give us more clues on how to best support people.

Being recognized as on a **“palliative trajectory”** can open up a whole basket of services and supports that people can’t always easily access (e.g., food, nutritional supplements, pain medication, housing) that could greatly enhance their quality of life.

Early identification of people who could benefit from a palliative approach is one way to get people the care they need and deserve.

04

How To Talk About Hard Things

In **Chapter 3**, we discussed signs and patterns that might tell us a person's health is declining or their illness is progressing. In this chapter, we share some ideas for picking up on these cues and “leaning in” to difficult conversations. We encourage reflection on your own role, including the barriers that you might experience in supporting someone with serious illness. A palliative approach to care starts by asking what a person wants. They could want more support or not want anything to change about the support you provide. Conversations are important because they can lead to planning for life and death with serious illness, which we will talk about more in **Chapter 5.**

What's in this chapter?

Connecting the dots: From noticing to talking about it

Earlier in this guide, we discussed the importance of knowing your role in relation to the person you're supporting. Just because someone wants you to be part of their heath and/or dying experience, doesn't mean you're in a position to be. Just because you want to support someone doesn't mean that your organization will allow it, and it also doesn't mean the person wants your support. Sometimes there are policies in place that prevent care at the end-of-life from happening. Reflecting on your role and potential barriers to supporting someone is important, but equally important is thinking about how you CAN support someone, if they want it, and what form that support can take.

In **Chapter 3**, we discussed how you might identify someone who could benefit from a palliative approach to care. This knowing is especially dependent on the relationship between yourself and the person you're supporting.

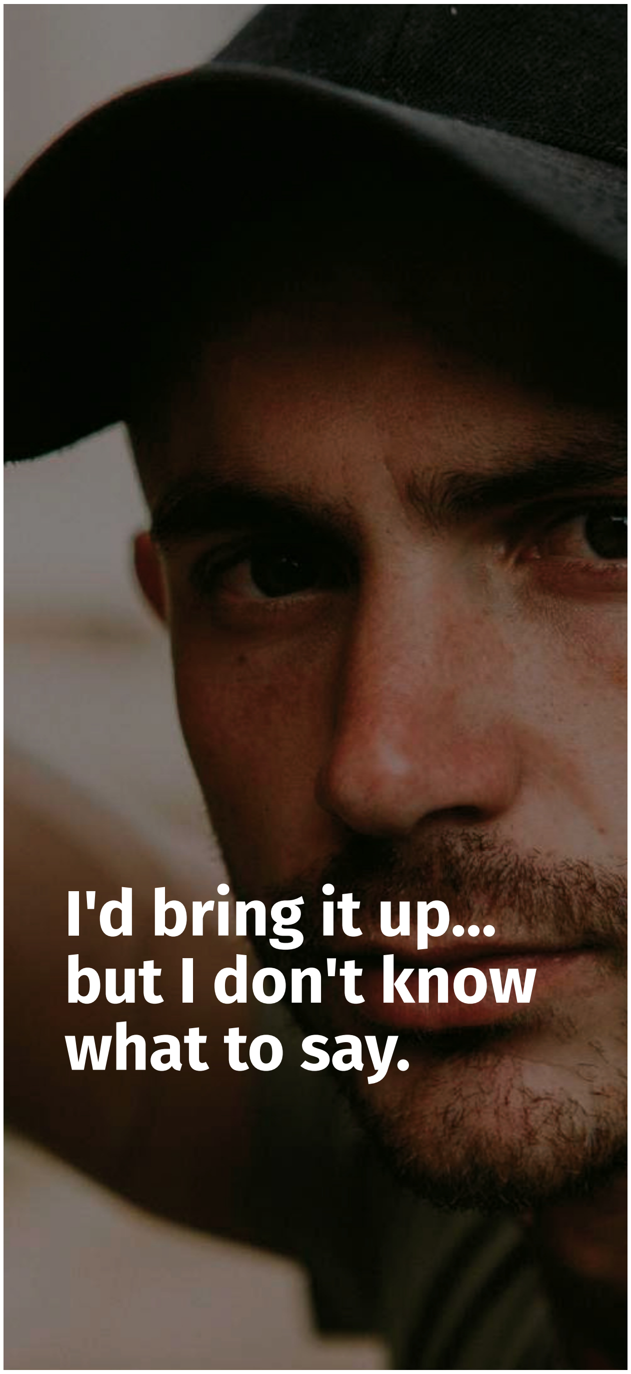
A person could tell you they were diagnosed with a serious condition like advanced cancer, lung disease, or organ failure. Maybe you learn that they've been in and out of hospital for medical treatments. Perhaps you've noticed that a 'regular' isn't coming into your facility as much. Maybe they look rougher every time you see them. Or maybe you just don't see them at all anymore.

Conversation is a way to connect the dots between the work you're already doing and a palliative approach to care. One of the central pieces of a palliative approach to care is working from a place of the person's wants, needs, and priorities. How would you know what those are? **You gotta talk about it.**

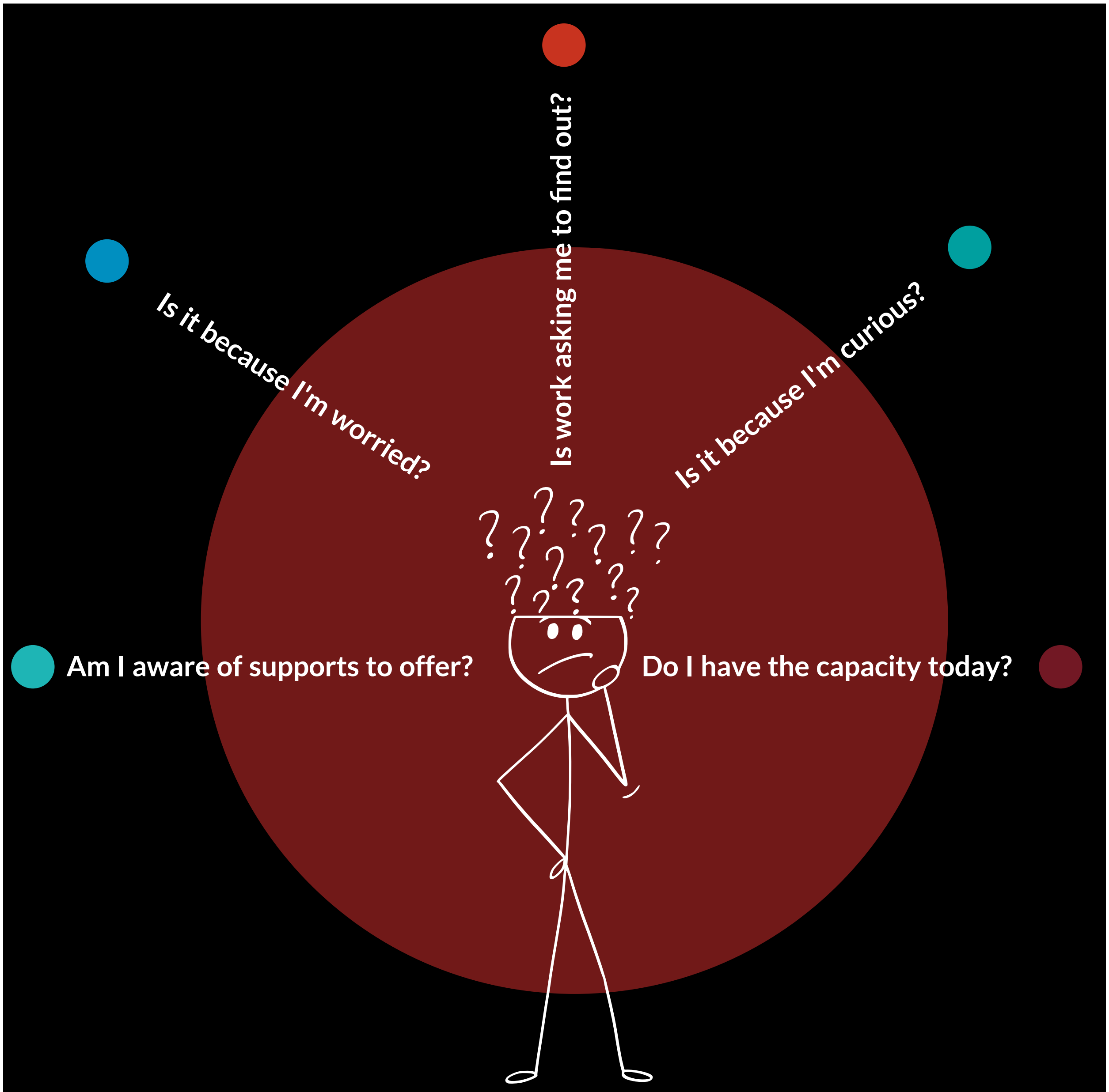
Reflecting on my role

It can be intimidating to have a conversation with someone about their potential support needs. You might not know what to say. You could be worried about triggering them. You could be worried that asking a person what they want or need will create expectations that you can't meet. The goal is not to convince people to do things a certain way or do what you think is best for them, but to determine what a person wants and how you can support that.

Before asking people to share information about their health, it's important to consider our own role and the extent to which we can keep this information private and in line with the person's wishes and priorities. If you don't feel like you're the right person to have these conversations, are there people you can bring in to support the person and yourself?


I'd bring it up... but I don't know what to say.

Before going into the conversation, take a moment and reflect on why you want to have the conversation with the person now. For example, you could ask yourself questions like these:



This exercise isn't about having the right answer; it is about reflecting on your answer in this moment.

How to have hard conversations

You might see people often enough to notice when things are changing for them– mentally, physically, or spiritually.

You may be in a good position to have conversations with people about their health, wishes, and priorities for the future. Workers are often consistent in the life of people on the street, and can therefore notice when things are changing for people – mentally, physically, or spiritually. You are practiced in the art of meeting people where they're at, asking (rather than telling) people what they need, and being ok with the answer even if it's not what you expect. In line with harm reduction approaches to care, a palliative approach to care stresses the importance of choice, autonomy, and dignity.

Acknowledging these fears and worries, the reality is that you might be the first person who has talked openly with someone about their diagnosis or health status. The person you're supporting may never have been asked if they have an understanding of what's going on for them, how they feel, or what their priorities are with regards to their health. A palliative approach to care is about listening, noticing, and attending to what people are doing and saying. You are likely already doing this or well equipped to do it!

Workers know, first-hand, the ability for people to survive against the odds. You may normally speak with encouraging and hopeful words in the face of adversity. However, sometimes encouragement can have the opposite effect, shutting people down from speaking their truth and saying what they need. Like all skills, it takes practice to listen for these natural prompts. It can feel difficult at first to "lean in" to hard conversations, but it gets better with time and practice. It can feel relieving to both you and the people you're serving to put concerns and worries out on the table. Starting these conversations allows the planning process to start, which is important for understanding and meeting people's needs and wishes around their future care.

Once you feel like the trust, relationships, and conditions are right to have supportive conversations, you could explore what a person's worries and concerns are. Making space for people to talk about their thoughts about what's happening to them, including their fears, anxieties, and hopes for the future is important in a palliative approach to care.

How to have hard conversations

Pick up on natural prompts and respond with openness.

Use open-ended statements that invite further exploration.

Yeah, I've noticed you've been losing weight too. Do you know why that might be happening?

Find the right time and space

Ask when would be a good time to talk.

Hey, I know you have an appointment to run off to, but check in with me when you get back!

Explore what they're noticing and their concerns

Ask if health changes are a concern for them or tell them what you are noticing.

You've had a rough go these last couple months. Are you noticing any changes in yourself or your body since you came out of hospital?

Ask if/how they would like their concerns shared

Ask if it's ok to share your/their concerns with others who might be able to help.

Would you like me to come with you to your appointment or help you prepare?

Help people to think through their support needs

Clarify what you're hearing and explore your/their ideas for more support.

How did you feel about that appointment? Do you want me to help you get more information about what you heard there?

How to have hard conversations

Pick up on natural prompts and respond with openness

We've found the best way into supportive conversations is to pick up on the natural things that people are saying to you. Rather than responding with close-ended statements that shut a conversation down (e.g., can be answered with a 'yes' or a 'no'), you can respond with open-ended statements that invite people to further explore their thoughts.

Find the right time and space

If natural prompts aren't presenting themselves, find a time and space that would be comfortable for the person you're supporting. It might not be the best time to talk when a person is running out of the door or is distracted with other things. Asking the person when a good time for them would be creates an opportunity to set up a chat for later.

Ask if/how they would like their concerns shared

You could begin by asking them about the changes they are noticing in themselves or tell them what you've been noticing. You could ask if what they're noticing is concerning for them. The person you're supporting may have just done a long stint in the hospital and are fearful of future hospitalizations because of previous judgment and stigma they've experienced there. Asking about how things could look different in the future could give clues into people's wishes, hopes, and needs for today.

Explore if they've noticed anything and if they're concerned

Sharing concerns might lead them to see a health care provider. You could support someone to prepare for an appointment by writing down their concerns and what they hope to find out. You could ask them if it's ok to share your/their concerns with others who might be able to help. If your job allows it offer to go to the appointment with them if that is what they want or look for an outreach worker or street nurse who could accompany them.

Help people to think through their support needs

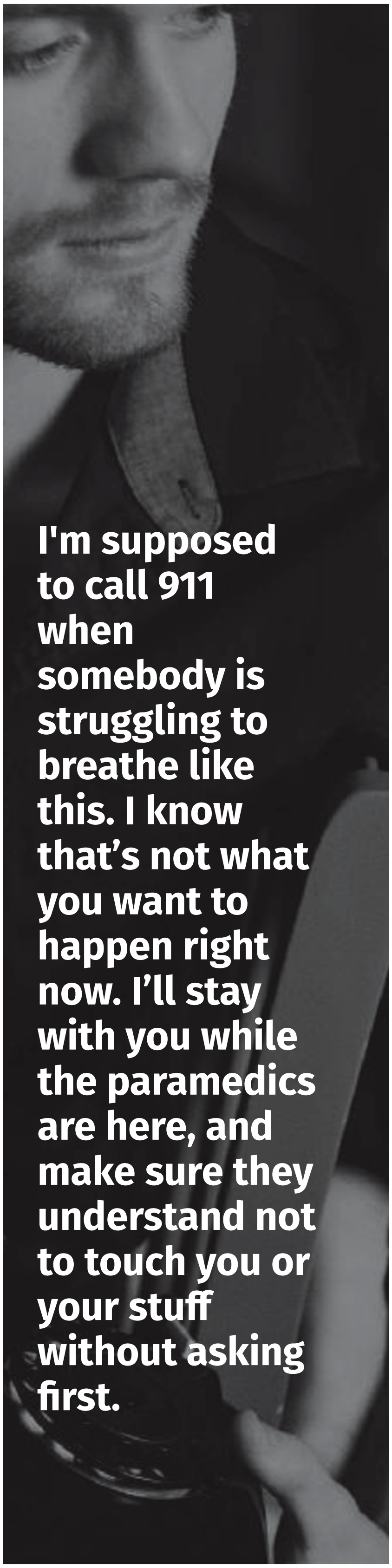
Exploring a person's concerns doesn't have to lead to them expressing their needs. However, through the process of conversation, people might tell you what they need and you might start to get ideas for how you could support them.

When a person doesn't want your support

It’s important to know that there are reasons that a person may NOT want to share information about their health with you. They may worry that they will face consequences if they tell you the truth. For instance, if they’re living in a building that requires them to be physically ‘able’ to live there, decline may lead to eviction. Perhaps they are worried about showing their vulnerability. The person you’re supporting may have others in their life who they open up to. Non-engagement is always an option because a palliative approach is not about saving people.

Some people will choose not to acknowledge that they are living with a serious illness or close to death, preferring to continue receiving the same level of support they have been getting. They may decide not to engage in conversations around death and dying and even want to decrease the support they’re getting from you or others. They may avoid making decisions related to their end-of-life and after death period with few modifications to accommodate their changing health.

When people don't make these decisions ahead of time, the healthcare system will have a process in place to determine what should be done at crucial decision-making moments. Some people want to avoid thinking about these moments and prefer to have others make those decisions for them, which is okay too. If this is the case, support them as you normally would: don’t force conversations on people, and be straightforward when you need to be.



I'm supposed to call 911 when somebody is struggling to breathe like this. I know that’s not what you want to happen right now. I’ll stay with you while the paramedics are here, and make sure they understand not to touch you or your stuff without asking first.

Key takeaways

Reflecting on your role and potential barriers to supporting someone is important, but equally important is thinking about how you CAN support someone, and what form that support can take.

Conversation is a way to connect the dots between the work you're already doing and a palliative approach to care. Simply talking about the things you are noticing about someone you support (e.g., changes in behaviour, appearance, or diagnosis) can be a starting point for a palliative approach to care.

A palliative approach to care starts with asking the person what they want, and being ok with the answer, even through it's not what you expect or think is best.

Before asking people to share information about their health, it's important to consider your own role, motivations, and capacity to support someone.

Sometimes people won't want your support. The goal is not to convince people to do things a certain way or do what you think is best for people, but to determine what a person wants and how best to support that.

05

Planning For The Future

In **Chapter 4,** we talked about how to pick up on the things people are saying to you and what you're noticing so you can "lean in" to **difficult conversations**. If you're the right person to do this, these conversations can lead to people identifying their care and support needs. In this chapter, we talk more about the planning process, including who a person considers their family and friends and who a person would want to make decisions for them. We introduce the option of **Advance Care Planning** and offer examples about how it may benefit the people you're working with. In **Chapter 6,** we talk about how making plans can lead to offering support in the ways that a person defines it.

What's in this chapter?

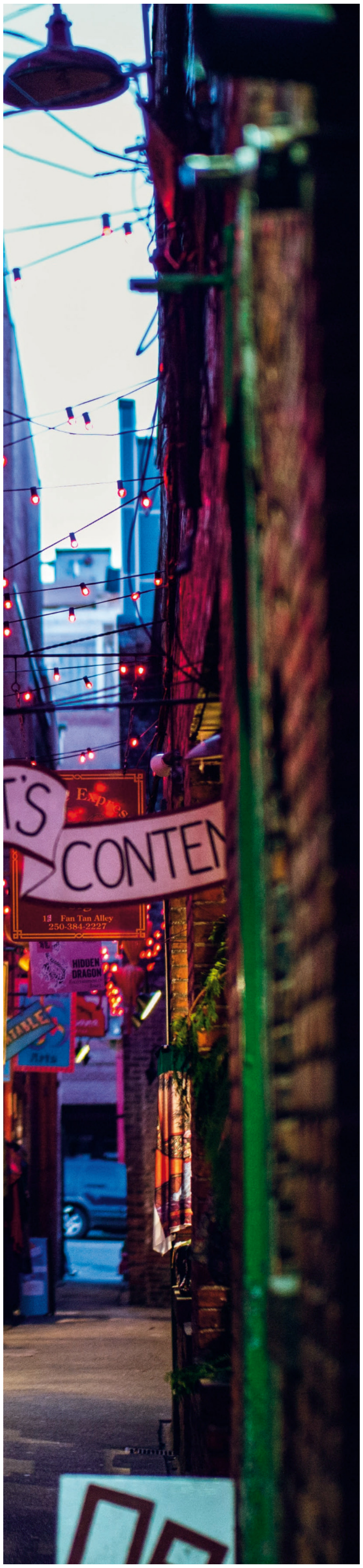
Why thinking and talking about death can help

There's no denying that witnessing sudden, unjust, and unsupported deaths is distressing to the entire community, including yourself and your coworkers. The injustice associated with preventable deaths or deaths that result from racism, stigma, and unmet needs compound the heartache. A palliative approach to care can't bring people back, but it can help alleviate the pain surrounding death and dying that's caused by not knowing what a person wants, not being able to meet their wishes, and witnessing suffering.

I was one of the people that would not go to a hospital. No matter what.

"I was one of the people that would not go to a hospital no matter what. A lot of the people I know did not want to go there when they were really sick, and they didn't want to die in a hospital because of, you know, how would they get treated. So when this advance care planning came up, I found out that you had a choice, you could die at home with, you know, with your friends or family or whoever. You don't have to be in the hospital. And so with this, we have a choice. We can choose, if, when that does happen. If we want to, you know, be in the hospital or be with our family, friends, whoever that may be. That's why this document is really beneficial. You can decide if you want to be cremated, and where your stuff is going to go, because before we didn't have a say."

—Peer Worker



Much of inner city work is responding to immediate crises and acute health issues. Planning for the future can seem far off, unhelpful, and difficult to do. But as you build relationships, you are learning about what people want and don't want, who they trust, and their interests. You are likely already having conversations that could be considered planning for the future, but this information often stays with you and is rarely documented. Not to say that you're responsible for knowing everything a person wants, but some of the things people tell you might become really important and useful when they get sick and can't speak for themselves.

Documenting the things people want can be an advocacy tool to instruct the health care system on how to care for a person in a way that's in line with their personal wishes. It can direct you to other people and resources you could bring in to support. You may learn, for instance, that a person holds spiritual views or has cultural protocols that are important to their care and quality of life.

Also, planning can ease distress for both the people needing and providing care. Like we discussed in **Chapter 4**, conversations about what a person wants for their future can build on the things they are saying to you now. Bad experiences in hospital, like the ones in the opening quote, could prompt people to think about what happens if they get sick again and require medical care. You might hear things like:

- "I'd rather die then end up in hospital again"
- "I'm not allowed to smoke in hospital, I'm not going there."
- "This is Jim, my best friend. He knows me better than anyone else in the whole world."

The circle of care

The health care system – especially at the end-of-life – relies on a person's family members to do a lot of the care work. However, familial relationships can be complicated. The people you are supporting may have family who are active in their life or they may be estranged from them. They may be living "away from home" displaced from their home lands and communities. They may have street families or chosen families who they support and rely on with varying abilities to provide support for serious illness. You may be in a family-like role, doing your best to fill systemic and familial gaps.

A palliative approach to care focuses on the person and their family and/or support network, however that's defined. A good place to start is finding out who a person considers in their support network. If you're part of that network, it can be helpful to see who else is there with you. This **eco-map tool** gives a good visual representation to assist recognizing someone's support network. The tool suggests you put the supported person in the middle and then draw lines between those who aid them – this could be people, teams, or organizations.

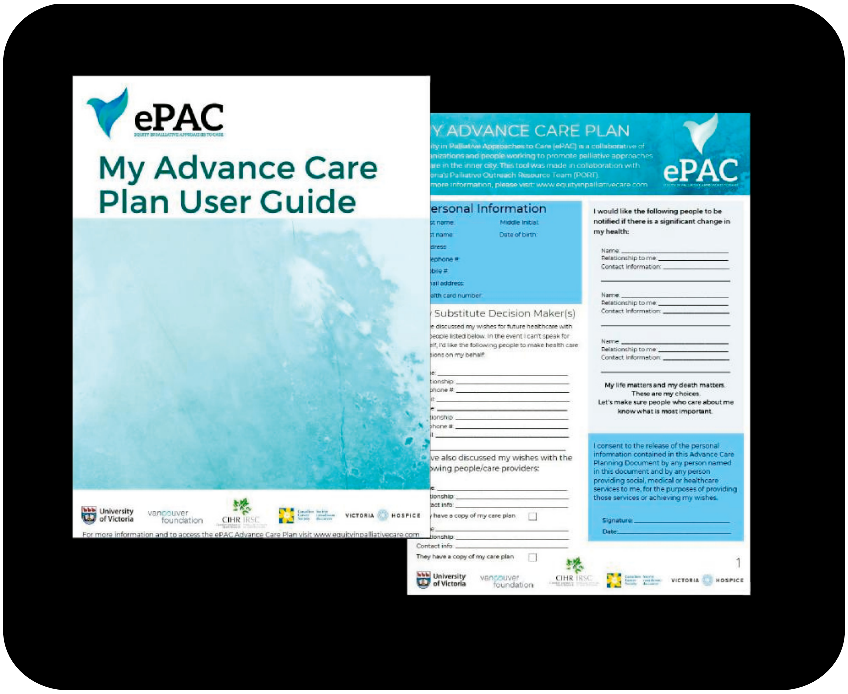
Adapted from: Kennedy, P, Hudson, B.F, Shulman, C. & Brophy, N (2018). Ecomap Tool. A toolkit for supporting homeless people with advanced ill health. https://www.homelesspalliativecare.com/

Advance care planning

In 2020, our collaborative released an **Advance Care Plan (ACP)** tool, guide and wallet card. We created these resources after workers and street families reported witnessing people they cared about ending up in health care settings without their personal wishes documented and, commonly, without the ability to speak for themselves. These resources are based on the questions that workers and street family members were being asked in the hospital.

Conversations to talk about and plan for care, sickness, death, and dying are part of what's called **Advance Care Planning.** Advance care planning is thinking, talking, and writing about what's most important to us. This can happen anywhere and at any time. However, diagnosis with a serious illness can make people think more about who they would want to make decisions for them if they couldn't speak for themselves, what their values for care are, and other considerations before and after death. It is easier to have these conversations before people get too sick so they have time to think about what they would want and are able to easily express themselves.

People might want help documenting their wishes or they might want to do it alone.



ePAC
EQUITY IN PALLIATIVE APPROACHES TO CARE

My Advance Care Plan User Guide

University of Victoria
vancouver foundation
CIHR IRSC
VICTORIA HOSPICE

For more information and to access the ePAC Advance Care Plan visit www.equityinpalliativecare.com

Y ADVANCE CARE PLAN

ity in Palliative Approaches to Care (ePAC) is a collaborative of
anizations and people working to promote palliative approaches
are in the inner city. This tool was made in collaboration with
oria's Palliative Outreach Resource Team (PORT).
more information, please visit: www.equityinpalliativecare.com

ePAC

ersonal Information

st name: Middle Initial:
st name: Date of birth:
dress:
ephone #:
bile #:
nail address:
alth card number:

Substitute Decision Maker(s)

e discussed my wishes for future healthcare with
people listed below. In the event I can't speak for
elf, I'd like the following people to make health care
sions on my behalf:

e: __________
tionship: __________
phone #: __________
il: __________
e: __________
tionship: __________
phone #: __________
il: __________

ve also discussed my wishes with the
owing people/care providers:

e: __________
tionship: __________
act info: __________
y have a copy of my care plan ☐
e: __________
tionship: __________
Contact info: __________
They have a copy of my care plan ☐

I would like the following people to be notified if there is a significant change in my health:

Name: __________
Relationship to me: __________
Contact Information: __________

Name: __________
Relationship to me: __________
Contact Information: __________

Name: __________
Relationship to me: __________
Contact Information: __________

My life matters and my death matters.
These are my choices.
Let's make sure people who care about me know what is most important.

I consent to the release of the personal information contained in this Advance Care Planning Document by any person named in this document and by any person providing social, medical or healthcare services to me, for the purposes of providing those services or achieving my wishes.

Signature: __________
Date: __________

1

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Health care decision making

Understanding who a person trusts to carry out their wishes is especially important when it comes to health care decision making. If the person you're supporting has an accident or gets sick or loses the ability to communicate, their friends, family and medical practitioners can look to their advance care plan for answers. A person who makes a decision on someone else's behalf is called a **Substitute or Surrogate Decision Maker (SDM).**

If no decision maker is named then the health care system tries to find someone. Health care providers rely on a list of people to call that prioritizes biologically or legally connected family members as decision makers. If there's no one to take on this role, a government agency will often step in. As a result, chosen family can get left out. If you're supporting someone who wants their friend or family member to be legally named as their substitute decision maker then there are some forms to fill out. There are different forms depending on what province, territory, or country you're in. For instance, in British Columbia these are called **Representation Agreements.**

A person who makes a decision on someone else's behalf is called a substitute decision maker (SDM).

Jonah

During an intake into transitional housing, Jonah filled out an **Advance Care Plan (ACP)** with his housing worker. A few months later, he had an accident and wound up in hospital in a coma. While going through his wallet to look for ID, the hospital social worker found the ACP card saying that Jonah had an ACP in the community. They called his housing provider who faxed over the ACP and called the people that Jonah had named in his ACP – who he wanted notified if his health changed significantly. Jonah's friends showed up at the hospital and because they had copies of the ACP, were able to support him in line with his wishes. For instance, Jonah had written that he wanted to listen to rock and so his friends set up a radio for him. The transitional housing staff kept his belongings safe and secure while he was in hospital and felt good that they knew who to reach out to. Jonah recovered and moved back into transitional housing feeling good that his friends were notified, his belongings were kept safe and secure, and that the hospital staff listened to his wishes.

What if the person you're supporting wants **you** to make decisions for them? Your decision to do this can depend on your comfort level, relationship with the person, employer policies, or health care decision making legislation. For instance, some places don't allow you to be a decision maker if you're being paid to provide care or support. As a reminder, you can always be helpful in this process (i.e., pointing health care providers to a person's **advance care plan**) without being the one making the final decision.

A person's beliefs, values, and wishes form the basis of **Goals of Care** conversations with health care providers (e.g., doctors or nurse practitioners). These decisions determine what treatments and interventions are best for people as they progress in their illness. For instance, a person who knows they are dying may choose to have **"comfort measures,"** meaning they want to die naturally and not have treatments that would keep them alive longer but with a questionable **quality of life** (e.g., having a tube inserted in your mouth to help you breathe).

Allen asked me to make decisions for him when he went in the hospital. What do I say? What does that even mean?

Jessica

Jessica has had bad experiences in hospital and said her and her friends are not listened to or respected there. She had friends who died in hospital without anyone being told they were there and she didn't want that to happen to her. She decided to bring her friends together to do advance care planning. They talked about who they would want to be part of their care if they were sick, their fears about sickness and dying, and what they would want to happen to their belongings and pets if they couldn't look after them anymore. Over a couple of weeks, she wrote down her thoughts on an **Advance Care Plan (ACP)** and shared a copy with her trusted friends. Jessica gave a copy to her doctor and asked them to put it on her medical record. Talking about and writing these things down gave Jessica a sense of relief and power knowing that the medical system has access to her wishes and will take them seriously.

Planning for death

While death is often all around in the inner city, most people don't think about death until it's right in front of them. While planning for death can help the friends, families, and organizations surrounding an individual know what to do, death in the inner city is often unexpected. If someone dies suddenly and without a plan, responding or witnessing the response by your co-workers, ambulance, police, and coroner services can be devastating.

As death is often a time of crisis and high emotion, if possible, it can be helpful to plan for dying and death before it happens. Having conversations and planning can help to support people to stay in community longer than they would ever be able to. The measure of success is doing our best to provide care and support in line with a person's wishes. You could consider asking yourself: In the case that the person I'm supporting dies, is there a plan in place? Does my organization have policies around what to do? Do I know who to call or what to do?

The person you're supporting may have wishes for their body, pets, and belongings, yet never had the chance to write them down. Perhaps you're working at a site that holds people's belongings or is responsible for clearing out a person's room when they go to hospital. Are there opportunities to ask people what they would want done with their stuff if something happens to them? Knowing what a person wants for their life and death is a keystone of a palliative approach to care.

Thinking ahead not only helps to prevent crisis, but allows you to provide support by asking about and writing down, what their wishes are.

The ePAC ACP tool prompts people to think about and discuss who they would leave pets with, whether they would want their organs donated, if/how they would like to be memorialized, and whether they would like cremation or burial. A person you're working with won't necessarily have wishes about these things or they may have more to say!

All of these things and more can be contained in a person's will. A will is a legal document that says what a person wants done with their property after they die. Property includes things like belongings, bank accounts, and vehicles. If the person has significant assets – money or land - it might be useful to connect with a lawyer.

Making a will valid is different depending on where you live. However, having something written down is often better than nothing at all and that's why we created a section in our simplified **Advance Care Plan** for people to add in their wishes pertaining to:

Belongings

Who would the person you're supporting like to leave their belongings to? It's helpful if people can be as specific as possible, describing the item and providing people's full names, chosen names, and contact information. If they wish to leave everything to one or two people, this can also be indicated.

Pets

Who would people like to leave their pets to and how would they want them cared for?

Memorial

How would they like to be memorialized? Do they want a party or just a small group to gather in their honour? Do they want an obituary published and a donation in their name?

Organ Donation

Would the person you're supporting like to be an organ donor?

Cremation or Burial

Is there a place they would like to be buried? If they chose cremation, do they want someone to receive their ashes?

Key takeaways

You are likely already having conversations that could be considered planning for the future with the people you support. Conversations about what a person wants can build from the things they are saying to you now.

Some of the things people tell you might become really important when they get sick and can't speak for themselves. Documenting their wants can be an advocacy tool to direct the health care system on how to act in line with a person's wishes.

Advance care planning conversations can be done anywhere and at any time and are often ongoing conversations.

There are provincial and federal resources that can help planning and decision making that are specific to where you live.

Planning can ease distress for both the people needing care and those providing it.

06

Getting More Support

In **Chapter 5**, we talked about how conversations with people about what they want (e.g., advance care planning) could lead to better experiences in life and death. A palliative approach to care sees value in all kinds of support for a person, their support network, and broader community. In this chapter, we talk about support in the realm of serious illness, dying, and death including how the support you're already providing is included in a palliative approach to care. We highlight some things to think about when caring for someone who is getting sicker and talk about access to formal health, home care, and palliative care services. You also might be in need of care. This is something we talk more about in **Chapter 7.**

What's in this chapter?

The work you’re already doing is a palliative approach

Most of what makes us sick is not related to genetics, choices, or behaviours but, instead, to the conditions in which we live. The **Social Determinants of Health (SDoH)** refer to the factors outside of biology and lifestyle choices that determine and impact our health. In your role you are already doing a lot to meet people’s SDoH needs, whether that be getting people access to health care or meals. Social support becomes even more important in the context of inequities and at the end-of-life stage.

A palliative approach to care seeks to reduce suffering and improve quality of life. Neither of these things can happen without attending to people's social needs. For instance, a person may have a great doctor who will prescribe them medications to control their pain and symptoms, but if they have no way to get to the appointment then this doesn't matter. Access barriers can cause great suffering and reduce quality of life.

You may be very familiar with a person’s support needs. However, when people get sick or diagnosed with a serious illness, their needs may start to change. They may have more trouble getting around and need to find accessible housing. They may be struggling with side effects from meds or require a specialized diet. Someone who used to be able to do their banking on their own may now need support to do so.

Depending on where you live, there are often additional income benefits that become available when a person is at the end-stages of their serious illness. These palliative benefits may cover costs of medication, medical supplies, and equipment needed as a person gets sicker. You may want to look into what benefits are available to people with serious illness where you live. Most require an assessment from a doctor or nurse practitioner, so this is where it’s helpful for a person to have a health care provider in their circle of care.

A palliative approach to care attends to the social determinants of health.

Strengthening family & community support

In **Chapter 5,** we suggested finding out who the person you're supporting considers part of their family and community. From there, could you explore how they want people involved in their care? In the ePAC ACP tool, there is a section to write who the person would want contacted if their health changes and who they might want to make decisions for them if they can't speak for themselves. Maybe there are few or no family or friends in the picture and you're the sole supporter. In this case, assessing your support needs is important – more on this in **Chapter 7.**

Just as government benefits are available for people with serious illness, family members (and those "like family") may also be eligible for benefits. **Caregiver Benefits** can include compensation and/or leave for someone who has reduced their work hours to care for someone with serious illness.

Support for serious illness can look different for everyone. Here are some things to think about:

- What support are you already offering the person?
- How do you anticipate their support needs changing?
- Are there **palliative benefits** available to the person living with serious or life-limiting illness where you live?
- What is the eligibility criteria and how can they be accessed?

One thing to think about is how the person's family and supporters may be prevented from being a part of their care. If a person is living in their private home, they might be able to have a family member stay overnight. Yet, if they are living in a shelter or supportive housing, guest policies might prevent their family or friends from staying with them or even visiting. If people are living far away from their family or territory, income and transportation barriers may stand in the way of care provision. Reflecting on these barriers to care with people needing care, your colleagues and organizational leaders, can result in actions to better include people's chosen supporters in their circle of care. For instance, can exceptions be made to guest policies? Can policies shift to facilitate care from friends and family? Are there income or transportation subsidies available to enable caregiving supports?

Surrounding the person and their family is their community. Knowing the places and people that are important to a person can help you know how best to support them as they get sicker. Say a person can no longer get out and about — are there people who could be notified so that they could come visit them in home or hospital?

Family, friends, and community support: Some things to think about

What friends and family are most important to the person? How do they want those people to be part of their care? Are there ways they DON'T want people involved?

Are there government benefits available for family and friends who are caring?

Are there barriers to the person's friends and family being able to support them? Are there workarounds to enable their chosen supporters to provide care?

Are there others that the person sees as part of their community? What kind of involvement of these community members does the person want?

Are you part of the circle of care? What kinds of support needs do you have in supporting the person with serious illness? More on this in **Chapter 7.**

Would you like some help filling out that benefit form?

Is there information you want shared with your girlfriend or sister? When would you want this information shared? Anything you would like to keep private?

I know you spend a lot of time at the drop in. Is there anyone there you'd want to come visit you in the hospital?

Getting support from health care providers

People often need a lot of care as illness progresses and it's almost impossible for 1 or 2 people to meet all those needs alone. As a holistic and team-based approach, a palliative approach to care includes inner city workers, health care practitioners, specialists, families, friends, and communities. After all, death and dying is a collective responsibility.

If you're worried about the person's weight loss, pain, ability to look after themselves or are noticing other signs of declining health, you could encourage the person to make an appointment with a health care provider. You could offer to make the appointment or, if able, take them to a clinic if they want to go. There are lots of reasons why people wouldn't want to access medical care. You could explore these reasons with them and try to come up with a plan together that would get them the attention they need.

As discussed in **Chapter 3**, health and palliative care providers may not understand the impact of inequities on health outcomes for treatable conditions. For example, it is more likely for an infection or wound to become chronic and deadly if someone is sleeping rough. Or, cases of treatable cancer are sometimes dismissed due to stigmas of "drug-seeking" until it is too late. So the knowledge you have about the person's living conditions and their housing, sanitation, and other important information can be really helpful to the health care team. Sharing your knowledge — with the person's consent of course — is a way you can advocate for the person you're supporting. Helping people prepare and taking notes at appointments can also be helpful. Workers can be essential advocates to help someone walk away from their appointments with a clearer understanding of their condition by asking clarifying questions and writing instructions down.

Maybe you can help with negotiating and problem solving with healthcare providers who don't recognize the barriers to care people experience.

Health care providers are often an important part of the circle of support for someone with serious illness. You can support them by helping to explain the context, being clear about your role and where you can/can't support, and asking the health team to consider options to increase access (e.g., home visits). Your awareness of options and resources, coupled with your knowledge of the person's reality, leaves you well positioned to advocate for creative solutions that may not be obvious to others.

> **I know you want to see Kat three times per week for wound care, but they have a hard time getting to appointments and can't afford the transport. Is there someone who could see them in the drop in? We have a private office here that could be used.**

Getting support from health care providers: Some things to think about

Does the person you're supporting have a regular doctor or nurse? If not, are there trusted health care providers you could encourage the person to contact, if this is their wish?

Is there information about the person's condition, context, and barriers to care that could be shared, with consent, with health care providers to aid in care planning?

Are there things you or your organization already do or can offer to help the person access health care or reduce barriers to care?

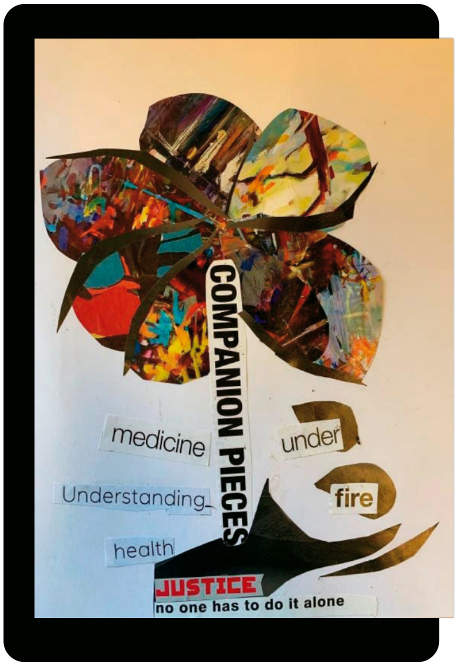
Are there ways you could assist the person with their appointments (e.g., arranging them, getting there, taking notes?)

Palliative care services

If the person you're working with needs extra support, consider talking with your manager or supervisor about what home care and palliative care services might be available. Depending on where a person lives, there may be services that specialize in palliative care that operate out of a hospice or an end-of-life/palliative program in their local health care system. Typically, people involved in delivery of palliative care services include doctors, nurses, social workers, occupational therapists (OT), physical therapists (PT), home support workers, spiritual care practitioners, counsellors and others. While this guide talks about applying a palliative approach to care further upstream, most palliative care services require people to be close to the end of their lives to access care.

Providers who are specialized in palliative care can help people you're supporting with:

- Managing their pain and symptoms - they know how pain works in the body and have good strategies (and drugs) to meet people's needs
- Getting people access to treatments and health care
- Talking about what's important to them as their illness progresses
- Advocating for their needs in the healthcare system
- Understanding and addressing loss and grief
- Attending to spiritual issues (e.g., existential, religious) and rituals that might be important to them as they progress in their illness
- Dealing with complex family dynamics
- Planning for death and after death



When there are barriers to support

Palliative care organizations and providers may not have had experiences of caring for people experiencing health and social inequities. They might be afraid or have stigmatizing attitudes and judgements. Because of policies, assumptions, and/or beliefs, health care workers might be concerned about risk and be reluctant to get involved.

Even though some people working in palliative care might have fears and judgements, they hopefully share a common commitment with you. Engaging with palliative care providers early can ensure that people who are on a dying trajectory get the best care possible.

A strategy for reducing barriers to palliative care has been the development of mobile palliative care teams. For instance, in Canada, there are several palliative care teams with doctors, nurses, social workers, and outreach workers/navigators that meet people where they're at when providing care at the end-of-life. Other communities have developed specialized hospices for the homeless.

The people you're supporting may have had poor experiences with health care providers and may have no reason to expect the care they receive to improve as they decline. They may worry about allowing health care providers into their homes. They may have busy schedules that don't work with the support and options that home care offers. Sometimes, starting small and finding a supportive person or two can start relationship building between palliative care practitioners, your colleagues, and the people you're supporting. This can have a lasting effect in breaking down barriers on a small scale and improving access to care.

People experiencing poverty, homelessness, racialization, and stigma have identified major barriers to health and palliative care services.

> **I’ve always had good experiences with Lorraine, the nurse on the palliative outreach team. I’m going to give her a shout and see what she thinks.**

Getting access to extra support: Some things to think about

Are there home care or palliative care services available where you live? What is the eligibility criteria? What criteria could pose a barrier to the person you’re working with?

Are there supportive health or palliative care practitioners who could help to reduce barriers to care?

If you aren’t in a position to support the person, who can?

Are there specialized palliative teams for people facing homelessness, poverty, and other barriers near you that you could reach out to?

Are there opportunities to sensitize health and palliative care practitioners to the contexts in which you work to help improve their understanding (e.g., joint visits with clients, presentations, community dialogues, etc.)?

Support after death: What to expect

Experiences of death and dying are going to look really different depending on where the person is living, their wishes, and the support available. Depending on the context of the death or plans in place, a person's body may be taken away to the hospital or to a funeral after they die. The person responsible for their estate, called an executor or administrator, will take care of their legal and financial affairs. This role may be taken over by the government if the person hasn't named anyone for these roles or if no one else is found. If they have a will, this person or organization will be responsible for following the person's wishes. If they don't have a will, the process can be much more complicated and is different depending on where you live. You may or may not be involved in this process. Something to think about is how much you want to be involved in after-death support. This can change depending on the relationship you have with the person.

Dying at home is often held up as an ideal in society, yet it is really hard to do. Death at home takes an immense amount of support for those who are well housed and resourced let alone those facing health and social inequities. The people you are supporting may want to die at home surrounded by their friends and community and this is a great goal. It is important to recognize that as a person declines and needs more support, death at home or in community may not be an option. And this should not be seen as a failure.

Skeet said that even though there was bad blood, he really wanted his family back home to come to his funeral.

Support needs after death: Some things to think about

How involved do you want to be, or are allowed to be, in after death support?

What are your strategies for sharing news about death in your workplace?

Would you know what to do if someone died suddenly at work? Is there a plan in place? Does your organization have policies around death in the workplace?

Do you know where to find the person's important people to notify them of the death? Is this part of your job/role?

Key takeaways

Always start by asking if the person wants you to be involved in their care. Support is defined by the person.

Social support is palliative support. Supporting people with access to shelter/housing, food and meals, and income and disability supports may be something that you're already doing and these are essential to a palliative approach to care.

Additional government resources may be available to the person with serious illness and the people who are caring for them.

To supplement the care being provided by friends and family, there may be opportunities for a referral to home care nursing or support workers.

07

Grief And Resistance

In this guide, we've talked about how a palliative approach to care may benefit the people you support and how it might be relevant to the work you're already doing. Workers are often providing direct support for people with serious illness and are an important part of their surrounding community. Just as death is all around, so too is grief. Grief is a normal response to loss, but it can be complicated. There aren't enough outlets, time, and attention designated to work-related grief and its impacts in inner city settings. Workers say they experience distress from working in inequitable systems. However, the common responses to this systemic distress are often individualized management strategies such as boundary setting and self-care. This can be confusing because understanding grief as our fault and responsibility hides the role of systemic harm while leaving us isolated and alone in it. It feels complicated.

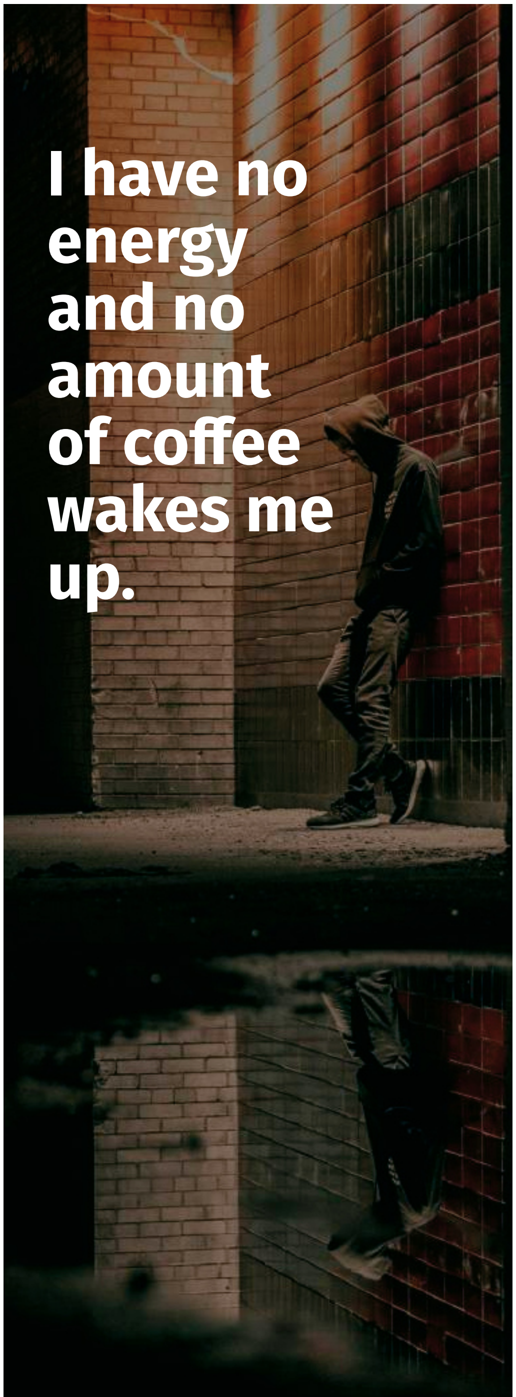
What's in this chapter?

We experience loss when we lose something or someone we value. This chapter pulls from a long history of social and political advocacy challenging the idea that some people matter less because they aren’t deemed valuable. Instead of carrying on as if nothing has happened, grieving interrupts business-as-usual and it marks the significance of what we have lost. Our grief has the potential to connect us to each other. Here, we discuss things that have helped us based on our experiences of grief as it connects to our work. By talking about grief in this chapter, we hope to expand the supports, interventions, and meanings we make about our grief and work.

What is grief?

Many people living and working in the street community are suffering a relentless flood of loss as their family, friends, and clients die unjust and premature deaths. In the type of work you do, you may hear a lot about burnout, feelings of powerlessness, compassion fatigue, or vicarious trauma but you may not hear a lot about grief, loss, and bereavement. Having an understanding of what grief is – and our relationship to it – is an important part of the work. In order to respond to grief, we need to be able to recognize it, and grief can be hard to see or identify. Grief is often understood as an emotion that happens after a death or loss, but grief may be something we always carry with us.

Grief and bereavement are deeply personal and they look different for everyone. You could feel sadness, regret, anger, frustration, or you could feel nothing at all. Grief can impact you physically from increased inflammation to lowered immune response. You could be getting sick all the time or be experiencing chronic pain. You could have trouble sleeping and feel exhausted. There could be impacts in other areas of your life, including your family or relationships. You might find yourself doing more, like taking more shifts and going “above and beyond” to try to meet people’s needs and distract yourself. Unsupported and unrecognized loss can have huge health, social, and economic implications for the grieving such as higher rates of depression, heart issues, income loss, trauma, substance use, and even premature death.



I have no energy and no amount of coffee wakes me up.

Grief is the word used for our responses to loss. Bereavement is a word that refers to a state of loss. You might ‘experience’ grief, but you may ‘also’ be bereaved.

Grief: It's complicated

The illicit drug poisoning crisis and other systemic injustices have caused many of us to be caught in a cycle of mourning and rage for years. Grief is hard enough, but can be made even more difficult when death is an injustice; work is unsupported, unrecognized, and morally distressing; relational complexity blurs the lines between personal and professional; grief is individualized; and grief is identified as a problem instead of a normal reaction to loss. We explore these issues more below.

When death is an injustice

Grief is complex, especially when the deaths are unjust. Many of the people you are supporting aren't dying because they've reached old age. Some people are dying because we live in an inequitable world and the systems are failing them.

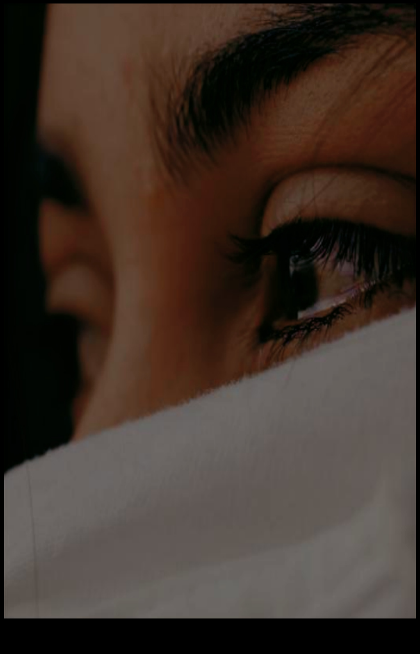
Historically and presently, colonization, racism, criminalization, and discrimination fuels early deaths. There is constant death because of the drug poisoning crisis that disproportionately impacts poor and racialized drug users. Witnessing these unjust, unexpected, and unplanned deaths compounds the distress and pain of losing someone. The people you're supporting may have been denied access to prevention and treatment. Each death compounds the last because the injustice remains.

The persistent injustice, lack of dignity, frustration, anger, and helplessness about it ALL can be overwhelming, especially when there is a lack of access to supports. Many inner city workers have said that the distress they feel isn't caused by the work itself — it is from the distress of coming up against systemic barriers with little power to affect change. Or from witnessing people being left behind as a result of government inaction. It's from being told to do more with fewer resources. It's from not being able to talk openly and honestly about challenges in the work. Or it's from not being listened to.

Unsupported, unrecognized, and morally distressing work

Grief is complicated by the role and scope of inner city work. Workers report not being prepared to face the amount of death and dying they see in their work. Despite being all around, death and dying work is often seen as separate from poverty, homelessness, harm reduction, substance use, or mental health services. The focus of the work is often on keeping people alive rather than preparing and planning for the end-of-life. While feeling unprepared and unsupported, workers are often put in positions to fill the gaps in health and palliative care services. You might feel left holding the responsibility for meeting someone's support needs and that's a heavy place to hold alone or with a few colleagues.

They were here yesterday and today they're gone. I heard they died in hospital. I wish I could have said goodbye.



When death and dying happens, it is often sudden and we feel unprepared. Workers try to make do with the things they can offer, but it often doesn't feel like enough or like justice. You may be warned about the health and financial consequences of obtaining an injury by doing tasks that aren't covered by workers compensation, but there are no alternatives offered. You might worry about someone being evicted or sent to hospital against their stated wishes, so you go beyond your scope to provide them care. Sometimes people's access to support depends on you or others bending the rules and figuring out the workaround.

Death is sometimes right in your face, but more often the people you support are taken away to hospitals and hospice units to die. People who live and work in the community report a lack of closure when the people they've been attending to are suddenly moved into these settings. You may not know what happened to the person you care about, be unable to get information, and may have not had the chance to say goodbye.

Relational complexity blurs the lines

Grief is made even more complex by the nature of your support role. You might have a strictly worker role or you might be more like a friend or family member. They may be a ‘client’ at work, then a member of your community when you go home. It may be hard to untangle the grief from individual loss (e.g., wondering whether you did enough) and the grief from people dying all around (e.g., knowing that it shouldn’t be this way). At some point in your life, you may have been warned about burn out, vicarious trauma, or compassion fatigue, and told that ensuring “good boundaries” is a way to prevent these things from happening to you. But **talking about distress as a consequence of bad boundaries hides systemic issues as well as the relationships you have, or had, with people.**

Boundaries are often thought of as black and white, rigid, and fixed. But boundaries are complicated and exist in grey areas within constantly shifting situations. Inner city work has a lot of variation, including in the amount of structure and flexibility you have to do your job. You likely have to make daily decisions about your approach, role, and scope. What you can give to others may change day-to-day as well. There isn’t often guidance or encouragement around developing flexible ways of working with people that prioritize your relationships with them.

Jan wants me to name me her as her substitute decision maker. What do I do with that?

Individualizing our grief: Responsibility and isolation

Organizational attitudes of grief are embedded in workplace environments through its culture, policies, and practices. Organizations may unknowingly make the grief worse by framing acts of care as poor boundaries or a lack of professionalism. Effects of grief such as anger, illness, and extending the role/scope of the work can be used against workers. When the problem is framed as bad self-care or poor boundaries, then the solution is left up to you. Viewing distress as somehow separate from its social and structural root causes can isolate workers in their individual grief.

Like boundaries, when people talk about self-care, it can feel like blame. Promoting self-care as a response to the moral distress of systemic inequities can leave workers feeling isolated, disconnected, and ashamed for struggling. Also, suggestions for self-care almost always cost money (e.g., yoga fees, gym memberships) or time and energy (e.g., special meal preparation, meditation). Sometimes counselling sessions are offered, but these are often limited or you need to attend them outside of your work hours. This is hard to justify or prioritize, especially if an issue you're struggling with is created by your workplace's policies and practices.

Viewing distress as somehow separate from its social and structural root causes can isolate workers in their individual grief.

The years of ongoing public health crises have strained the capacities of many inner city services – never enough resources and never enough time. Organizations are often unprepared and unable to support the grief of their workers, even when they really want to. You may be given a phone number to call or a few counselling sessions you can access, but these strategies might not feel like enough.

Grief is a normal reaction to loss

While the conventional places for grief and bereavement support, such as counselling or support groups, can be vital for connection and healing, these resources are not always desired, relevant, or available to you and the people you support. Work hours, caregiving, and other responsibilities may prevent you from attending the sessions or groups you want to. When you do go, they can feel unsupportive.

It can feel wrong to seek support from a counsellor who doesn't understand the environment you work in. You might feel like you are shocking them by even sharing what happens in your day. Even where support for grief is available, opening up the space for grief can come with consequences to your job. What happens when you can't afford to miss work to grieve? Is paid leave for grieving an option at your workplace? What if being a 'good worker' relies on you ‘sucking it up’ and stuffing your grief? What happens if showing your grief marks you as a bad worker or leaves you feeling worse?

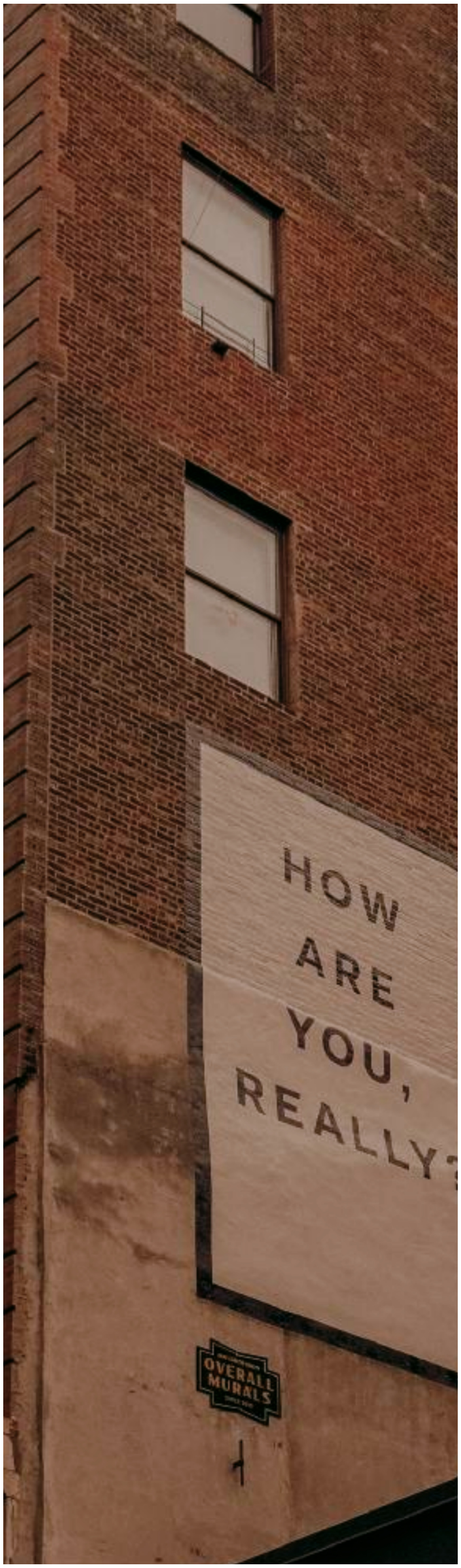
I really don't want to open up this can of worms.

Naming and responding to grief

The job of supporting ourselves through the harms of working in inequitable systems is just not able to be done alone. We need more than our individual efforts if we want to resist the distress often experienced in our workplaces. We are stronger when we treat care as a collective responsibility rather than something we must carry alone.

Doing grief together rather than alone can be healing. Although it is true that grief is deeply personal, seeing yourself as part of a larger, collective experience of grieving can expand options for support and connection. If we think about how experiences of grief are connected by the work, there is an opportunity to see grief as something that is shared. Recognizing collective grieving also opens opportunities for solidarity amongst workers and the people they support.

If we think about the main causes of unjust and early death in the inner city, grief responses should include changing the systems that cause these deaths.



There’s no simple solution to grief, but these are some points workers have shared with us and reported as being helpful:

Finding your people

The type of support almost seems less important than who you do it with. Whether it is in a grief support group, your roller derby team, or community activism, there is a lot of power in ‘finding your people.’

I’m not crying, you’re crying

Doing grief together doesn’t need to be labelled as ‘grief support’ at all. There can be a kind of ‘side-door’ that opens when we aren’t trying to manage or fix the pain. This kind of support happens when people just ‘get it,’ through having shared experiences or context into your situation. Knowing you aren’t alone in your experiences can help, whether talking about grief or not.

Benefit of preparing

There’s no one way to fully prepare for death and dying, but it helps if we have a plan for what to do when it comes. Palliative approaches to care discussed in this guide can support workers to know how to work in line with the expressed wishes of the individual, minimizing moral distress felt after death.

Memorial spaces at work

While reminders of people who have died aren’t great for everyone, having a discrete space where people can share a memory or sign a banner can support remembrance. It is important that people have a choice about whether or not they engage with spaces like this.

Getting people support helps

Because so much distress is about people living and dying in unjust circumstances, identifying people who could benefit from a palliative approach to care, supporting them to get the things they need, and bringing in others (if wanted), can help workers share the load and burden, and prevent them from feeling like they’re not doing enough.

Collective debriefing

Collective debriefing after deaths can help prevent workers from feeling like they're going through the loss or carrying a burden alone. Workers have shared that grief is made worse by feeling like they didn’t do enough. Insights from good and bad experiences of death/dying can be used to inform future planning.

Public mourning: Grief and resistance

Publicly mourning the people we have lost is a way to respond to our grief collectively. When some people's lives are treated as disposable, openly grieving together can be a radical act. Pushing back against this idea of disposability means we can challenge the expectation that it is more professional or better for our health to carry on with business-as-usual.

Public mourning is a way to witness and support each other through our shared pain. When we join together and acknowledge the significance of our losses, we demonstrate how to be in relationship with each other and remember we aren't alone. These shared spaces are important to care work, to communities, and to our wellness, because connecting to others is vital to knowing how to grieve. It shows everyone, including ourselves, that our distress matters, we matter, people matter.

It doesn't always have to be formal, like in funerals or wakes, but can exist in forms like activism and spontaneous memorials. Banners or walls where people can write the names of their loved ones, public art displays, gatherings, or protests to fight against unjust deaths are all examples of ways to be with our people in collective grief.

Traditional territory of the Lekwungen peoples, and the Songhees, Esquimalt, and W̱SÁNEĆ First Nations

National Day of Action on the Overdose Crisis. April 16, 2019.

Key takeaways

Grief and grieving are political acts in the context of inequity.

Grief is the word used for our responses to loss. Bereavement is a word that refers to a state of loss.

Community care expands ‘how do I take care of myself?’ into ‘how do we take care of each other?

Public mourning is a way to witness and support each other through our shared pain when we join together and acknowledge the significance of our losses.

Viewing distress as separate from its social and structural roots can isolate workers in their individual grief.

Grief is enmeshed with the resistance of caring for people not seen as grievable by society.

Grief shows us we aren’t singular and can be a way to connect us to each ther.

The End is the Beginning

We have reached the end of this guide but we hope that this is the beginning of something larger. Our goal in creating this resource was to help shift the conversation around death and dying in inner city settings and show different ways of thinking about and approaching it. We wanted to highlight the importance of the 'social' in care, looking at how people's communities, environments, conditions, and access to resources shape their life and death experiences. We wanted to recognize that people living and working in the inner city - in shelter, housing, outreach, support, and peer roles - play a very big part in the circle of care. We wanted to acknowledge that this work is difficult and that distress is compounded by organizational and societal responses to grief and loss. And finally, we wanted to expand imaginations around what a palliative approach to care can offer outside medical and health care spaces.

Recognizing that many people reading this guide are already attending to physical, mental, emotional, and spiritual needs of others, we offered some practical ways to shift your orientation towards a palliative approach to care. Identifying people who could benefit from a palliative approach could open up access to resources and benefits such as income and housing options. Conversations that are already occurring with people you support could be documented as part of an advance care planning process. Collaborating to figure out how to support someone in their future needs could result in less distressing experiences for the person and their supporters. Thinking about how organizations could not only support someone to live, but also age and die in place (if this is their wish) could mean less suffering at an individual, organizational, and broader community level.

We recognize that shifting towards a palliative approach to care does not solve the systemic and structural issues that are causing unjust, early, and preventable deaths. We have much work to do in realizing a society free of violence and harm. However, we see radical possibility in a palliative approach to care.

Asking what people want and orienting care around their wishes and priorities challenges health and social care systems that claim to know what is best. A palliative approach to care is a model that can be applied early, where it has the most impact and where people do not have to be dying to get good quality care. Our collective care and grief shows that people are not disposable and are deserving of care, love, community, good lives, and good deaths.

Going forward, as we work to create ways to make this guide as useful and impactful as possible, we want to hear from you! Please visit our website to let us know what stood out for you and your ideas for applying the information to your work and life.

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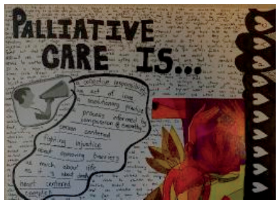
Further Reading



The content in this guide is based on our team's collective research and contains findings and insights developed through ongoing dialogue and analysis with inner city workers (e.g., housing/shelter, outreach, peer, etc.), palliative care providers, and decision makers involved in our collaborative work.

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