Hospice Yukon

Friendship during a Health Crisis

How to show up in ways that help

Inside this issue:

Our health care system is changing all the time, and improvements to health care mean that sometimes we truly don't know how a scary diagnosis will turn out. It can be hard to know what to say and how to help when a friend or family member is coping with a health challenge.

With a range of possible outcomes and illness trajectories, it can feel awkward to talk openly about the possibility of death, and to offer practical support that helps people "get their affairs in order." Many of us have little or no experience with preparing for end of life, or with the many practical challenges in making the most of living well during a health crisis.

In this issue you'll find a range of ideas for questions that can be supportive, and resources and tools to help with many different practical needs.

Planning for health changes and end-of-life is something we are wise to do in ongoing ways throughout our lives, by talking with our friends and family about our wishes and what brings us the most joy in living.

Advance Care Planning for our health needs is part of it, and organizing our legal situation with a will, an enduring power of attorney, and making sure that it is clear who we want to speak for us when we can no longer make decisions for ourselves.

For many of us, this planning doesn't happen until a crisis provokes it. But in learning how to help a friend, you may learn lots that is helpful for your own living and dying.

One popular myth is that palliative care is for people who are in the last stages of a terminal illness. In fact, a palliative care team can be a wonderful resource for people who are ill and get better. The article on page 3 helps explain why.

One of our Hospice Yukon volunteers has written an article about how to normalize conversations about end of life, by inviting friends to talk about "Death over Dinner." Around the world, there are now online and in-person "death cafés" to help explore difficult topics in supportive ways.

There are online apps that can organize friends and family who want to help during a health crisis. We explore apps to coordinate communications, meals, transportation help, fundraising, photos and memories, practical tasks like dog-walking and lawn care, childcare, prescriptions and more.

Sometimes we just don't know what to say when a friend or work colleague is sick or grieving. Check page 4 for tips on what NOT to say and how to listen in compassionate ways.

If you're suddenly taking on a new role as a caregiver, we hope this publication empowers you to know that self-care, respite time and finding people to support your own questions and grief will help you take care of yourself as you take care of others.

You're not alone. ♥

Death over Dinner

by Joan Turner

Death and dying used to be, and still can be, challenging and difficult subjects for conversation.

My friends, fellow Hospice volunteers and I have shared some wonderful dinner table talks about all kinds of topics related to end of life.

“Death over Dinner” is an international movement and you can find out more at www.deathoverdinner.org

As a Yukoner, I love helping make “death conversations” feel normal, an everyday part of living my life.

We’re all going to die, although we rarely talk about it.

Often we manage to ignore it until someone close to us is ill. And at that point it can feel even more awkward to know what to do or say.

Here’s what I do – it’s simple.

I invite a few friends for dinner.

I send out a few questions by email; conversation starters. Sometimes I invite participants to bring a poem, a passage, or a book that resonates or is meaningful for them.

Usually our conversations are so rich that we don’t get through very many questions! Here are some that we’ve used as prompts:

What was your first real-life experience with death?

Are you afraid of death? If so, what do you fear?

Does death feel like an end or a doorway?

Can we know, without dying, what dying feels like?

Imagine your ideal death. Where are you? What is happening?

How do you want to be remembered?

What do you want to leave behind?

What have you created or done to remember a loved one?

Of course, there are many more questions and stories that could be shared.

And these conversations don’t have to happen over dinner… we can plan for a walk and talk or meet over coffee.

It’s always fulfilling and heartwarming.

Joan Turner is a long-time volunteer at Hospice Yukon

ADVANCE CARE PLANNING:

the basics

Think about your values and wishes for future health and personal care

Share your wishes with others

Decide who will speak for you if you can’t speak for yourself

ADVANCE DIRECTIVE is the legal form that describes your health care wishes and your Health Proxy .

HEALTH PROXY means the person who can make health decisions when you can’t speak for yourself .

ENDURING POWER OF ATTORNEY is someone who can legally make decisions about your financial and other needs when you can’t speak for yourself.

A WILL is a legal document that describes what you want done with your belongings after you die.

An EXECUTOR is the person who can make financial and other decisions once you have died, according to the terms of your will.

I'm not dying - why palliative care?

There's a common belief that palliative care is just for people in the final stages of a terminal illness. In fact, a palliative care team can be a wonderful resource for people who are ill and get better.

Palliative care is ***not*** just for the final days or months of life. It is a holistic approach that includes excellent pain and symptom management, caregiver support, spiritual care, bereavement support and more. Studies show that people receiving palliative care actually live longer than those who don't receive it.

The World Health Organization's definition of palliative care has evolved such that the recipient's illness is no longer required to be deemed incurable. Palliative care is now described as an approach to life-limiting illness, and "applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life." This modern definition aims to include patients for whom a cure may be possible.

In simple terms, palliative care can include many aspects, including psychological, spiritual and social support, advance care planning, music and art therapy, recreation therapy, physiotherapy or respiratory therapy and many more services.

A palliative care approach helps patients and loved ones prepare for the worst (death) but still allows hope for the best (recovery/cure). By including palliative care soon after diagnosis, the pathway of care includes both disease management and palliative care so that patients may recover, and if they don't, their remaining time is well-lived and their loved ones are supported in the grieving process.

Adapted from www.canadianvirtualhospice.ca "The Bow Tie Model of 21st Century Palliative Care"

A palliative care team can help patients
live life to the fullest
throughout the trajectory of their illness.

Palliative Care
Resource Team

We provide support to Yukon families coping with life-limiting illness.

Email: palliativecare@yukon.ca
Phone: 867-667-9380
See: https://yukon.ca/palliative-care for more resources

Yukon

Each person's body is unique and there are no firm timelines.

Understanding the common illness trajectories can help us prepare.

A palliative care team can help.

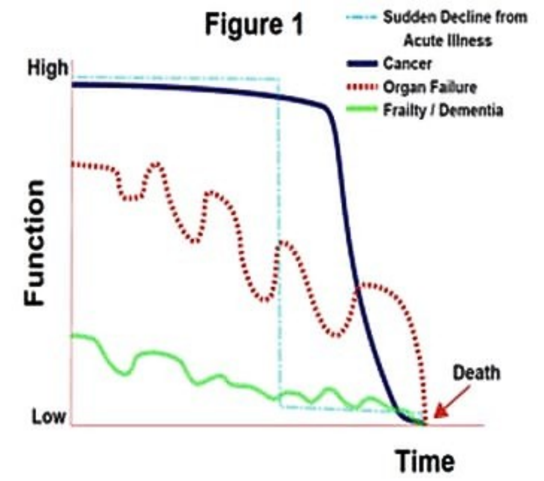


Figure 1

Awkward is Normal

It’s uncomfortable – we can’t fix their pain. Feeling unsure is part of a genuine, empathetic response.

Don’t say nothing… it’s worse to ignore the loss.

There’s no perfect thing to say.

Some things to avoid:
Don’t try to find a silver lining (avoid anything starting with ‘at least’).

Don’t give advice. Avoid any “you should“ opinion (get more sleep, have a cry, eat well) .

Don’t try to make sense of it (don’t say ‘everything happens for a reason’, etc).

Things to focus on:
Tend to your own grief. Showing up in a helpful way includes managing our own feelings.

Listening is often more helpful than thoughtful words.

Offer concrete, specific forms of help, rather than saying ‘let me know if you need anything’ or ‘I’m here if you need me,’ .

Ask them if you can lighten their load at work, organize a meal train, arrange child care or house cleaning, etc. They may not accept the first time (or at all) but the offer can mean a lot.

When your friend is grieving

Do's	Don'ts
Do Say "I can't imagine how you feel"	**Don't Say** "I know how you feel"
Do Say "I don't know what to say"	**Don't Say** "You just have to be strong"
Do Say "What happened?"	**Don't Say** "You'll be fine in time"
Do Say "I can't imagine how heartbreaking that must have been for you"	**Don't Say** "It was just a dog, cat, bird etc. "

Someone who is grieving just wants to be heard. Don't try and fix them, just listen to them

Allow all emotions to be expressed, without judgement, criticism, or analysis.

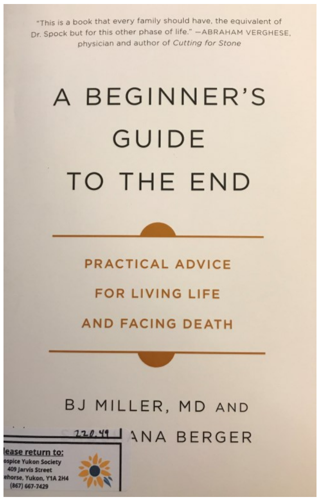
Do listen with your heart, not your head.

adapted from

www.griefrecoverymethod.com

A Beginner's Guide to the End

Book Review by Heather Finton



"This is a book that every family should have, the equivalent of Dr. Spock but for this other phase of life." —ABRAHAM VERGHESE, physician and author of *Cutting for Stone*

A BEGINNER'S
GUIDE
TO THE END

PRACTICAL ADVICE
FOR LIVING LIFE
AND FACING DEATH

BJ MILLER, MD AND
ANA BERGER

220.49
lease return to:
ospice Yukon Society
409 Jarvis Street
ehorse, Yukon, Y1A 2H4
(867) 667-7429

A Beginner's Guide to the End: Practical Advice for Living Life and Facing Death is an excellent resource for all of us.

It's particularly helpful for people who have received a challenging diagnosis, and their caregivers and friends.

Written by BJ Miller, MD and Shoshana Berger, the book covers a very diverse range of topics in plain language. Clear pictures, stories and short chapter summaries make this a book that can be flipped through, browsed, absorbed in available moments.

The material moves from advance care planning questions (*yes, this means you and me*) through diagnosis and treatment, all kinds of impacts on daily life (*yes, there's a sex chapter*), and practical issues from home medical equipment to burial choices.

Canadian readers must be cautious about some of the details. Written from a U.S. perspective, the information on Medicaid, health insurance, tax law, caregiver benefits and physician-assisted death (called Medical Assistance in Dying or MAID in Canada) does not apply, but these topic areas and suggestions can be good starting points.

Miller is a hospice and palliative medicine physician who thinks deeply about how to create a dignified, graceful end of life for his patients. His TED talks are worth watching, and his personal experience as a young adult receiving medical care fuels his understanding of the need for patients and families to speak and advocate for their own needs.

His encouragement and caring are conveyed throughout the book.

The chapters are arranged in five main sections.

Planning Ahead covers sorting through physical clutter, "cleaning up" emotional relationships, identifying values and priorities, practical paperwork for health choices and wills, legacy ideas and financial arrangements.

Dealing with Illness is about reactions to a diagnosis, illness trajectories, good questions for "taking stock" of your own needs, questions for doctors, making decisions, telling others, impacts on relationships and many practical tips for coping.

Help Along the Way describes hospital "hacks," palliative care, when to hire help, how to involve others, care for the caregiver, talking to children, and detailed advice about symptom management.

When Death is Close outlines a range of end of life choices, burial and cremation options, and what to expect in the final weeks and days.

After is a useful chapter about the first 24 hours after a death, grief and mourning, writing obituaries and eulogies, celebrations and memorials, and executor obligations in the first year.

There is also a very comprehensive Resources section with dozens of helpful websites.

This "guide to the end" has been described as a book for every family.

In the same way that we prepare for a baby's arrival with "What to Expect" resources, this book is a good companion or travel guide on our journeys with illness and death.

It's available in our Hospice Yukon library.

Heather Finton is the Communications Coordinator at Hospice Yukon

"Caring for myself is not self-indulgence, it is self-preservation."

- Audre Lorde, author of Cancer Journals

Supporting A Friend with Cancer

Adapted from https://www.letsfcancer.com/guide/supporting-a-friend/

THINGS TO KEEP IN MIND
When it comes to supporting your friend, you know them best. Every friendship is unique, so do what feels right for your relationship.

Keep it simple
The little things are often the most meaningful. Just calling your friend or watching a movie with them can mean the world when they're going through it.

Prepare yourself
Try to process your own feelings before talking to your friend. They're going through enough already, they don't need to take on the burden of receiving your feelings too.

They're not *just* a patient
Your friend is still the same person they've always been. Don't forget to talk to them about all the interests and passions you share, as well as talking to them about cancer if they want to.

Ask questions
Avoid commenting on appearance (don't say "you look good" - they may feel different than what you see). Pause and turn your opinions into questions.

Learn about their cancer
You don't need to be an expert, but doing a little background research on their cancer allows you to spend your time talking about other things and not just having them regurgitate facts. But remember that every experience is unique.

Consider their perspective
While you should never assume you know what they're going through, consider what your friend might need and things you can do to help. This will make you more empathetic when you talk to them.

Support the primary caregiver
Both people with cancer and their caregivers need a strong support system. Help make sure their caregiver gets support too.

The Ring Theory

Adapted from an article by Susan Silk and Barry Goldman

Draw a circle. In it, put the name of the person at the center of the trauma. In the next ring put the name of the next person most intimately affected. Repeat. Parents and children before more distant relatives. Intimate friends in smaller rings, other friends in larger ones.

The person in the center ring can say anything they want to anyone. They can complain and curse the heavens and say, "Life is unfair" and "Why me?"

Everyone else can say those things too, but only to people in larger rings.

When you are talking to a person in a ring smaller than yours, the goal is to help. Listening is often more helpful than talking.

If you want to scream or cry, that's fine. It's a perfectly normal response. Just do it to someone in a bigger ring.

Comfort IN, dump OUT.

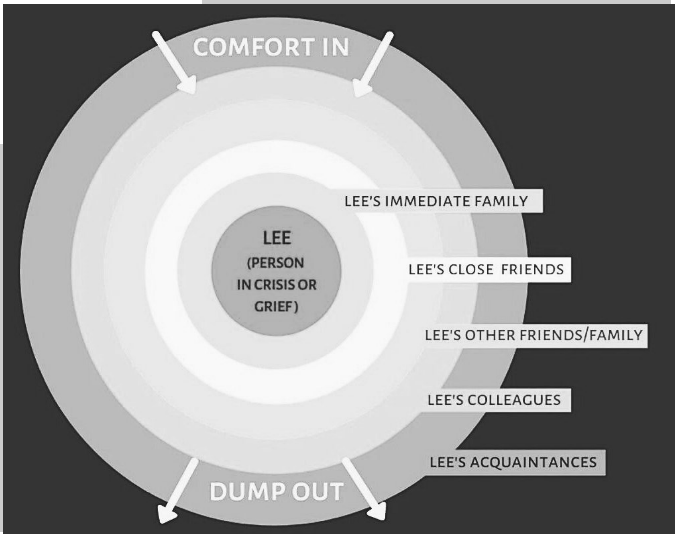
COMFORT IN

DUMP OUT

→

Ring Theory image

by Annie Reneau



Apps & Online Resources

Writing about online resources in a printed publication when the tech world is changing rapidly means that there may be even better resources emerging all the time.

We want to highlight some of the tools for caregivers that can help coordinate the involvement of friends, family and other care providers.

The websites mentioned here are all free to use, although some of them offer additional paid services. They have a range of privacy options for different features so that you can share some information publicly, some with all invited members of a private community, and some with just a handful of people.

Meals
There’s something instinctive about wanting to help others eat well in a challenging time. But it can be overwhelming for a family to receive a pile of meals at once. The “Meal Train” app can help families be clear about their own food needs (frozen, fresh, vegan, day and time, where to leave it, etc), and even provide links for gift cards or take-out pizza. Friends sign up for specific dates to provide some certainty.

Meal Train accounts can be linked to other apps like Caring Bridge and Go Fund Me. Other calendar platforms can be used to coordinate meals as well.

Communications Updates
Sitting at a bedside, it can feel daunting to keep friends up-to-date on the latest news about a health crisis. Those well-meaning phone calls, emails and texts can be stressful. Instead, there are apps to help funnel communications through one update point. Popular options including Caring Bridge, Care Flash and Caring Village, among others. They have calendars and other features as well.

Transportation and Errands
Your friend may be struggling to get to medical appointments or do basic shopping. They may be secretly worrying about a borrowed lawn mower or an overdue tax return. Using an online communications tool can help clarify what tasks need doing and when, and can mobilize friends and neighbours to take on the small steps that make a huge difference.

Some families and friends are already set up with Google docs, calendars, and task functions. It may be that these tools are easiest to incorporate into your new needs for sharing information.

Using an online tool is also a great way to spread the word about your friend’s expressed wishes. Maybe you can’t do what they need doing, but can help spread the word to find someone who can.

Medical Info & Prescriptions
Sometimes there are several people involved as caregivers, including family, friends and professionals. Coordinating medication refills and making sure that they receive the right dose on time can be supported by the medication features on apps like Caring Bridge.

Stories, Photos and Memories
Your friend may feel unwell, but you can help brighten their day and lift the spirits of other caregivers when you share photos or memories of time with them. These can be shared on the apps listed above.

You may also want to ask them for their permission to help sort photo albums or digital photos, as a way of spending meaningful and helpful time together. You might even want to create a poster collage with good memories that can be displayed near the bed. Sites like Kudoboard, Canva or Shutterfly can help.

There are many wonderful conversation-starter websites, with inspiration for asking questions about what memories and values are most important to your friend. Check out the Story Corps “great questions” or the free Ethical Will template at Everplans for ideas on learning more about what is most important to your friend.

Childcare & Pet Care
When life goes sideways, it takes a community to keep going. An online scheduling tool can help coordinate who is taking care of the little ones who can’t take care of themselves.

Household & Garden help
When we’re sick, things get messy. It can be hard to ask for help, and even embarrassing. As a friend, you can be specific about what you notice and offer to do. Remember that your friend gets to choose. It may be that the clutter you want to help with is not actually a priority for them, and they don’t want that help. But if you don’t offer, they can’t choose. And if they want help, an online scheduler makes it clear about who’s doing what.

Hired & volunteer help
The online Yukon Helpers Network may have ideas for filling gaps. If your friend is in BC, check out the helpers on Tuktu to lend a hand when you can’t.

Fundraising
If your friend has to travel for medical appointments, or has to pause their work life, the financial impact can be very challenging and stressful. Caring Bridge has partnered with GoFund Me to integrate crowdfunding so that your community can help raise what’s needed.

Remember, your friend and their primary caregivers get to choose who and how they want to involve other people. You might feel the urge to conduct a successful social media campaign while your friend just wants to keep their situation private, with tight control on who knows what. This is their right.

When there is so much beyond their control, it is important to respect their choices.

It can be a relief, though, to let technology help streamline the many ways that people can share the load.

Hospice Yukon

Programs and Services

Living with Loss - An Introduction to Healthy Grieving
Gain a better understanding of the grief journey in this online education session. Offered four times per year.

Counselling
One-on-one counselling support for those who are dying or grieving, and their loved ones.

Grief Support Groups
We offer a variety of groups to help grieving people find support and connection with others who are also experiencing loss.
Visit our website for upcoming offerings.

Healing Touch
A relaxing energy therapy that supports holistic health.
Volunteers trained in Healing Touch use gentle touch to clear and balance your energy system.

Lending Library & Kids Corner
Our extensive library of books and resource material is open to the general public.

Professional Support
Support, education and resources for professionals and caregivers.

All of our programs and services are provided free of charge.
Tel. 867-667-7429 info@hospiceyukon.net

www.hospiceyukon.net

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Please visit us online at ***hospiceyukon.net***