



**Breaking Down Barriers in the Context of
Complex Illness, Uncertainty and Grief**



C. Elizabeth Dougherty, B.S.W, M.S.W, R.S.W

Breaking Down Barriers in the Context of Complex Illness, Uncertainty and Grief

- Demystifying issues related to illness, dying and grief
- Providing compassionate care following the diagnosis of a complex illness, through to end of life and into bereavement
- Promoting access to care within our own practice and across communities
- Resources



Breaking Down Barriers in the Context of Complex Illness, Uncertainty and Grief



"I'm right there in the room, and no one even acknowledges me."



DEMYSTIFYING ISSUES RELATED TO ILLNESS, DYING AND GRIEF



Acute care hospitals focus on short-term episodic care and interventions and treatments aimed at cure, creating an environment where **death is seen as a failure** or where death is *denied*

Bloomer, M, et.al. (2013)
Palliative Medicine



DID YOU KNOW?

Less than one quarter of Canadian general practitioners and family physicians (GP/FPs) and nurses are experienced and comfortable talking about planning for illness and end of life with their patients through advance care plans.

24% of GP/FPs and **32%** of nurses have NO experience and are not comfortable with conversations.

24% of GP/FPs and **18%** of nurses ARE experienced and comfortable with ACP conversations.



52% of GP/FPs and **51%** of nurses have SOME experience but are not very comfortable with conversations.



The Way Forward Initiative
www.hpcintegration.ca



The unpredictable nature of a terminal illness means reversible and irreversible events and declining health are interwoven with periods of stability **patients live with knowing that death will come, but not knowing where or when**

Hutchings, D. (2007)
Palliative & Supportive Care

A Friend's Story. Robert Pope



WHEN DOES DYING BEGIN?

- the moment we are *born*;
- when a fatal condition *begins*;
- when a fatal condition is *recognized* by a physician;
- when a patient is *told* of his/her fatal condition;
- when the patient *realizes* or *accepts* the facts;
- when nothing more can be done to *reverse* the condition or *preserve life*

Encyclopedia of Death. Kastenbaum (1989)



END-OF-LIFE IS A PROCESS

Bereaved carers' accounts of the end of life and the role of healthcare providers (HCPs) in a '**good death**':

- Much of the literature is focused on death itself, implying a *single event*
- The experiences of reaching awareness, good communication and symptom management implies a **process** which takes place in days, weeks, months and even years before death
- These processes contribute to the whole end-of-life experience and where HCPs can have the **greatest impact**

Holdsworth, LM. (2015) Palliative Medicine





Though
commonalities
exist,
responses
to illness, dying,
grief and loss
are unique
to each
Individual



RESPONSES TO ILLNESS, GRIEF & DYING

Based on:

- Stage in life cycle
- Illness history (chronic, recent, advanced)
- Loss history (deaths, identity, mobility, intimacy)
- Trauma history
- Coping style/personality
- Cultural values
- Spirituality and/or religious affiliation
- Presence/absence of support network
- Additional stressors (caregiving for children/parents, financial concerns)

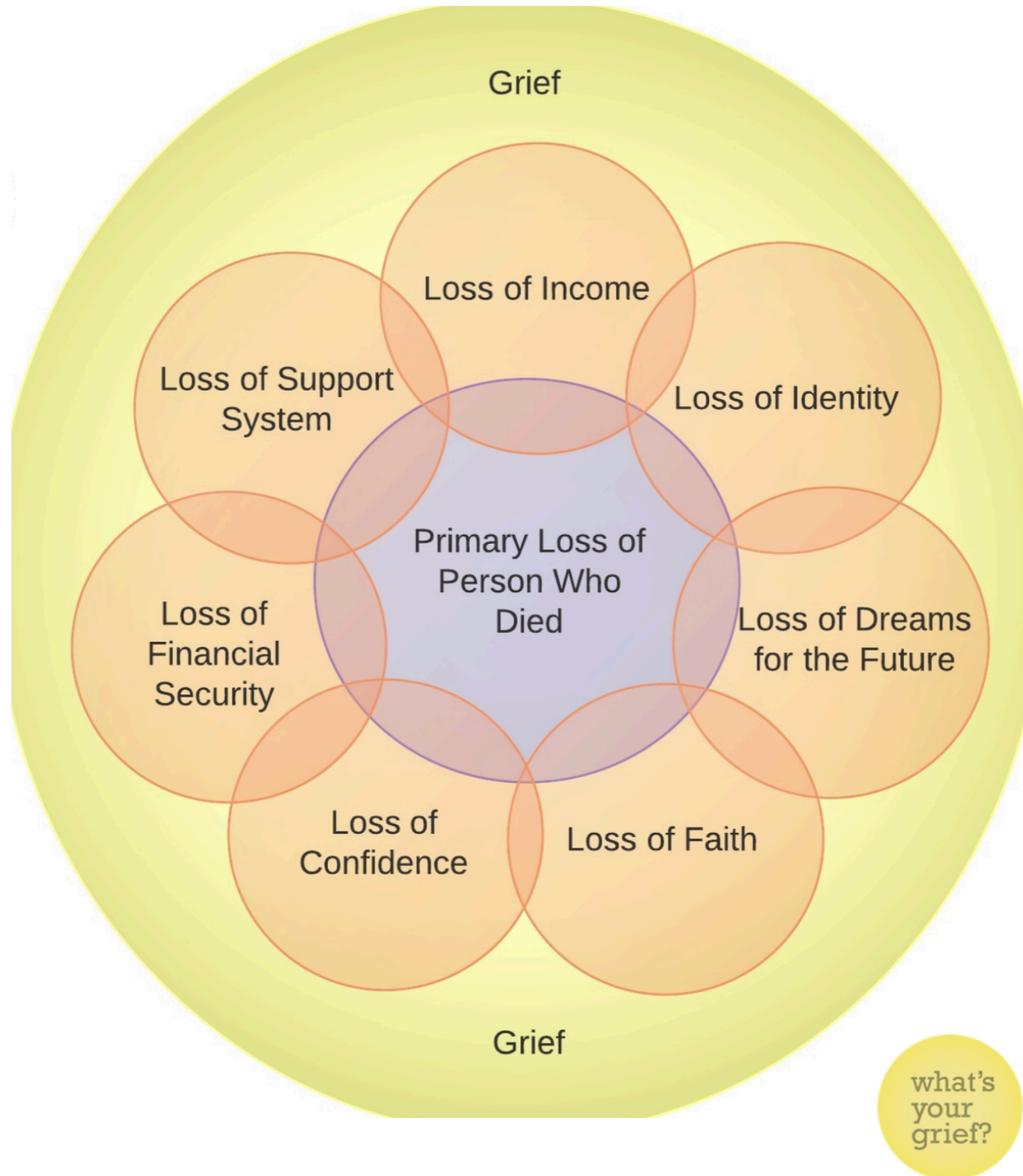


Grief is
a reaction to loss.
We often confuse it as a
reaction to death.
It's really just a very
natural reaction to loss...
when we lose any
significant form of
attachment.
It's the process of
adjusting.

Dr. Kenneth Doka



SECONDARY LOSSES



what's
your
grief?



Grief is not a disorder,
a disease or sign of
weakness.

It is an emotional,
physical and spiritual
necessity, the price you
pay for love.

The only cure for grief
is to grieve.

Dr. Earl Grollman



THE EMOTIONAL EXPERIENCE OF CARE

The *emotional experience* of care was rated *most significant aspect of care* contributing to ability cope by patients and families. In addition to:

- Access to practical help
- Access to specialist knowledge
- Interprofessional communication
- Coordination of resources
- Safe to express positive and negative emotions
- **EOL presents a crisis for the whole family**

Sampson (2014) BMJ Supportive & Palliative Care





HOSPICE PALLIATIVE CARE

- is appropriate for *any* person and/or family living with, or at risk of developing, a life-limiting illness due to *any* diagnosis, with *any* prognosis, *regardless* of age, and at *any* time they have unmet expectations and/or needs, and are prepared to accept care;
- may complement and enhance disease-modifying therapy, or it may become the total focus of care;
- is most effectively delivered by an interdisciplinary *team* who are both knowledgeable and skilled in all aspects of the *caring process* related to their discipline.



HOSPICE PALLIATIVE CARE

- treat *all* active issues and prevent new issues from occurring;
- address physical, psychological, social, spiritual and practical issues, and their associated expectations, needs, hopes and fears;
- prepare for and manage self-determined life closure and the dying process;
- cope with loss and grief during the illness and bereavement.



**PROVIDING COMPASSIONATE CARE:
FOLLOWING DIAGNOSIS OF A COMPLEX
ILLNESS, THROUGH TO END OF LIFE
AND INTO BEREAVEMENT**

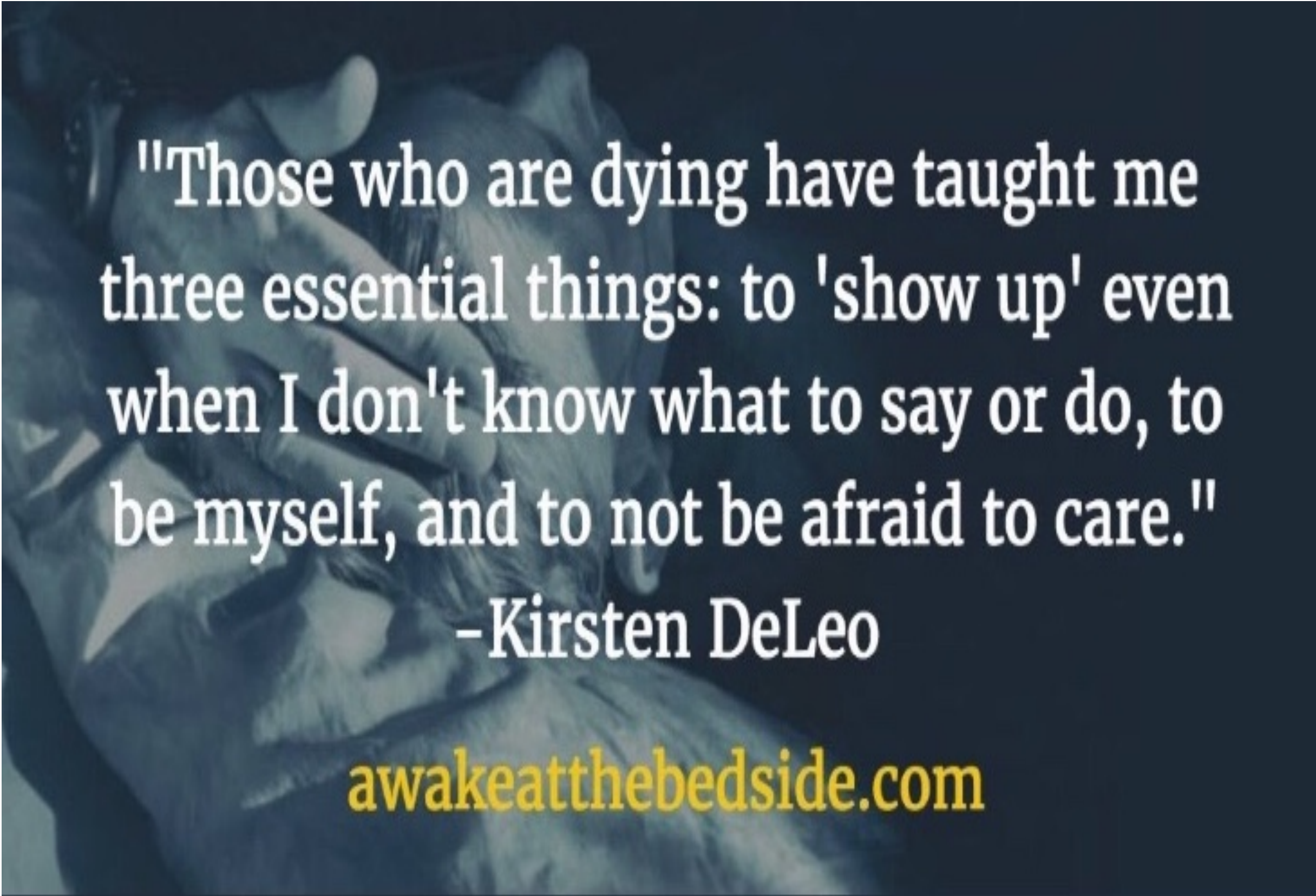


Someone needs to
encourage us not to brush
aside what we feel.
Not to be ashamed of the
love and grief that it arouses
in us.
Not to be afraid of pain.
Someone needs to
encourage us:
that this soft spot in us could
be awakened,
and that to do this would
change our lives.

Pema Chödrön

© C. ELIZABETH DOUGHERTY CONSULTING





"Those who are dying have taught me three essential things: to 'show up' even when I don't know what to say or do, to be myself, and to not be afraid to care."

-Kirsten DeLeo

awakeatthebedside.com



Creativity is not
elective in
healthcare...
Creativity and
doubt are at the
core of our work.

Dr. Rita Charon



I am always
doing what
I cannot do yet,
in order to learn
how to do it.

Vincent Van Gogh



Image: At Eternity's Gate. Vincent Van Gogh

Vulnerability is not
weakness, and that
myth is profoundly
dangerous.
Vulnerability is the
birthplace of
Innovation, Creativity
and Change.

Dr. Brené Brown





Definition:

1. the introduction of something ***new***
2. a new ***idea, method or device***



The most
dangerous phrase
in the language is "we've
always done it this way."

Rear Admiral Grace Hopper

Where the
magic happens

Your
Comfort
Zone



Compassionately
embrace suffering
and step out from
behind the
protection of our
roles.

Frank Ostaseski



EXPLORING MEANING

“What do you understand about...”



EXPLORING MEANING



@nayyirahwaheed



i love listening. it is one of the only spaces where you can be still and moved at the same time.

9/28/17, 8:15 AM



EXPLORING MEANING

Wonder?

“Is there something that you are wondering about?”

Worry?

“Is there something that you are worried about?”

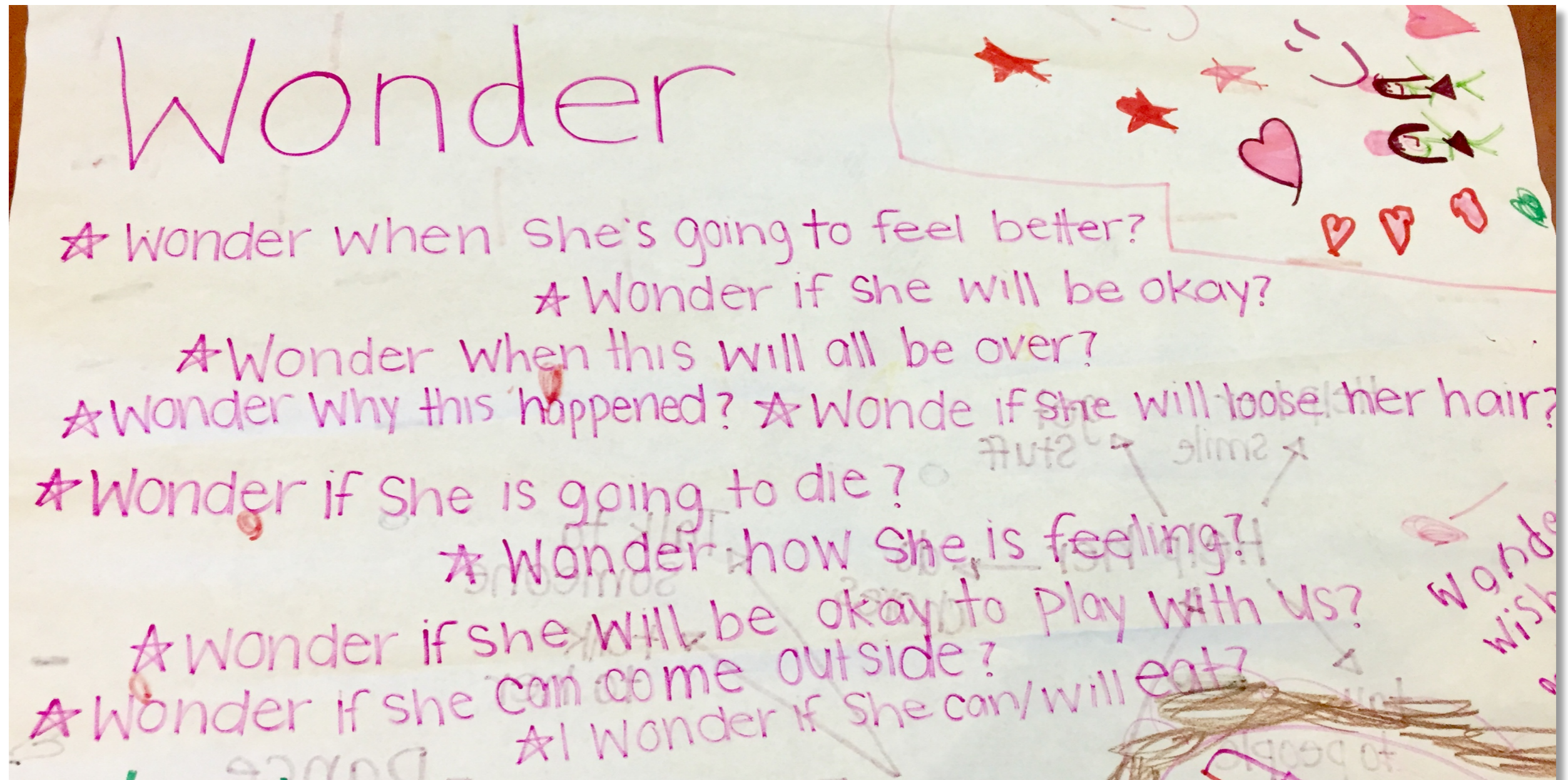
Wish?

“Is there something that you are wishing for?”



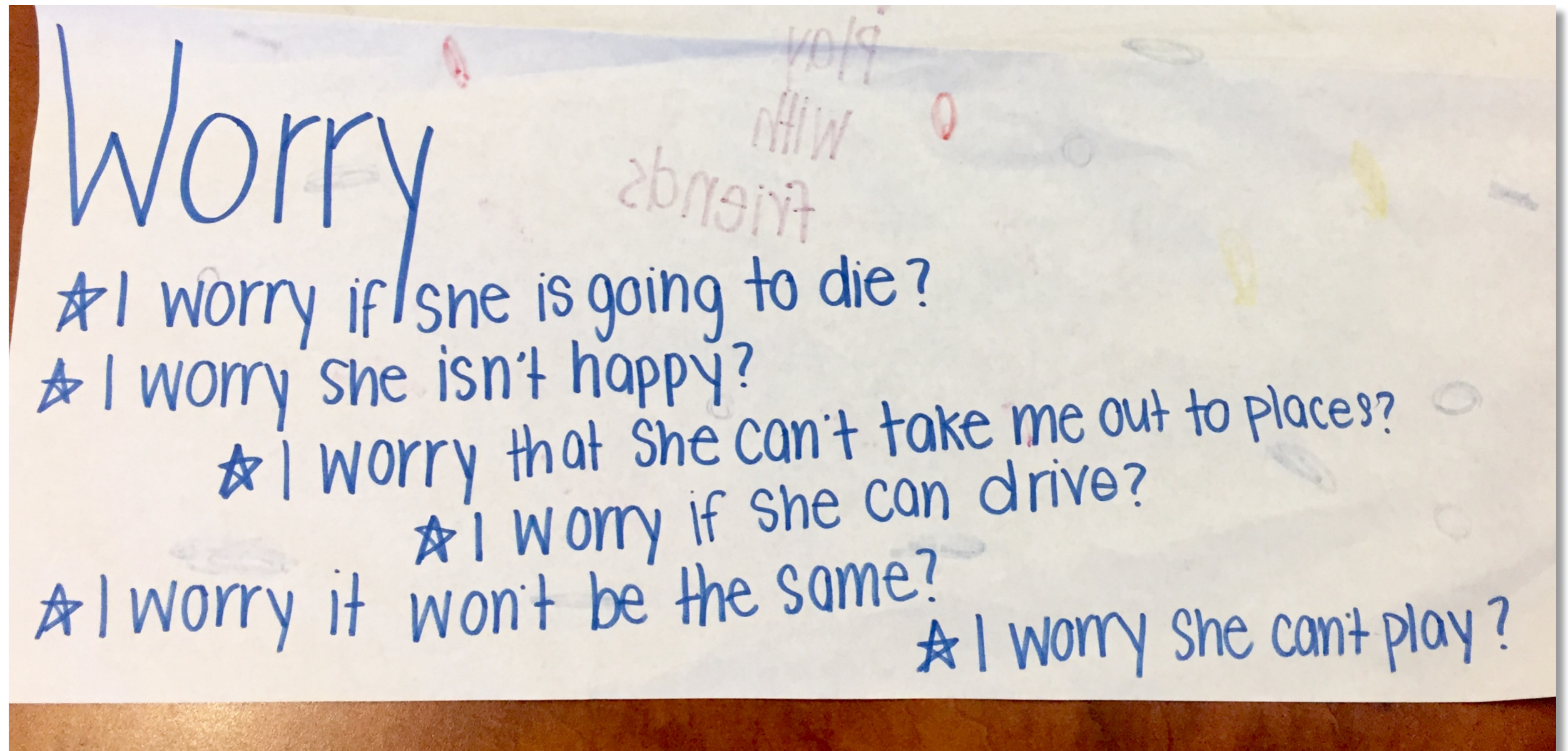
EXPLORING MEANING

WONDER (exploring questions)



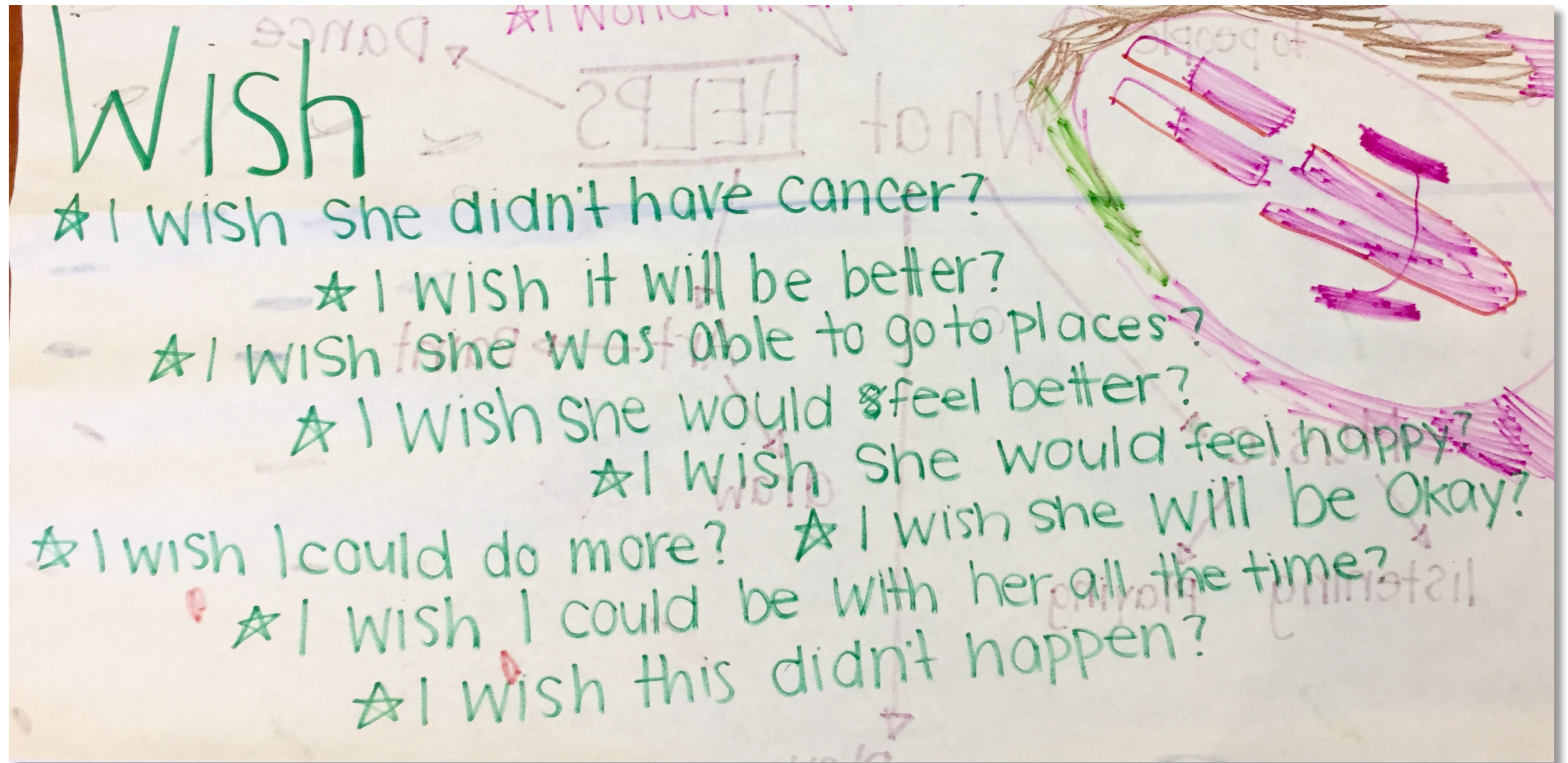
EXPLORING MEANING

WORRY (exploring fears)



EXPLORING MEANING

WISH (exploring hope)



EXPLORING MEANING



LEGBANDY

**We need to start
treating our death
as part of our legacy
instead of the end of it.**

yg2d.com



The “Hug” as a Therapeutic Intervention





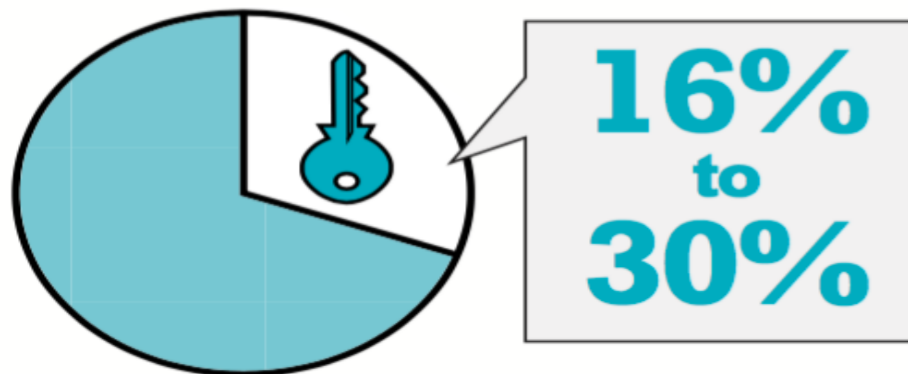
The “Hug” as a Therapeutic Intervention





PROMOTING ACCESS TO CARE WITHIN OUR OWN PRACTICE AND ACROSS COMMUNITIES





Of Canadians who die currently **HAVE ACCESS** to or receive hospice palliative and end-of-life care services – regardless of where they live in Canada. Even fewer receive grief and bereavement services.



STATUTES OF CANADA 2017

CHAPTER 28

An Act providing for the development of a framework on palliative care in Canada

ASSENTED TO

DECEMBER 12, 2017

BILL C-277

SUMMARY

This enactment provides for the development of a framework designed to support improved access for Canadians to palliative care.



SW & SSW Code of Ethics and Standards of Practice



Ontario College of
Social Workers and
Social Service Workers

The scope of practice of **Social Work (SW)** and **Social Service Work (SSW)** includes:

“...the assessment, treatment and evaluation of individual, interpersonal and societal problems through the use of knowledge, skills, interventions and strategies, to assist individuals, dyads, families, groups, organizations and communities to achieve optimum psychosocial and social functioning.”



Creating social work competencies for practice in hospice palliative care

Palliative Medicine

24(1) 79–87

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pmj.sagepub.com



Harvey Bosma *School of Social Work, University of British Columbia, Vancouver, BC, Canada*

Meaghan Johnston *School of Social Work, University of British Columbia, Vancouver, BC, Canada*

Susan Cadell *Lyle S Hallman Faculty of Social Work, Wilfrid Laurier University, Kitchener, ON, Canada*

Wendy Wainwright *Victoria Hospice, Victoria, BC, Canada*

Ngairé Abernethy *Mental Health Services for the Elderly, Brandon Regional Health Authority, Brandon, MB, Canada*

Andrew Feron *Parkwood Hospital, St Joseph's Health Care, London, ON, Canada*

Mary Lou Kelley *School of Social Work & Northern Ontario School of Medicine, Lakehead University, Thunder Bay, ON, Canada*

Fred Nelson *Palliative Care Program, Winnipeg Regional Health Authority, Winnipeg, MB, Canada*

“The profession of social work brings a unique perspective to end-of-life care that reflects and supports the holistic philosophy of HPC. It draws on an ecological approach to problem-solving that considers the multi-dimensional impact of individual, family, and socio-cultural influences in our daily experiences. This approach fits well with the focus of palliative care...”



Canadian Social Work Competencies for Hospice Palliative Care:
A Framework to Guide Education and Practice
at the Generalist and Specialist Levels

2008

Bosma, H, Johnston, M, Cadell S, Wainwright, W,
Abernathy N, Feron, A, Kelley ML, Nelson, F.

http://www.chpca.net/interest_groups/social_workers-counselors/social-work_counsellors_competencies.html

Essential Competencies

- Advocacy
- Assessment
- Care Planning
- Care Delivery
- Community Capacity Building
- Evaluation
- Decision-Making
- Education and Research
- Information Sharing
- Interdisciplinary Team
- Self-Reflective Practice



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- Self-Reflective Practice



Compassionate
community initiatives
and programs
are essential to promote
community-capacity
building, advocacy,
education and
information-sharing,
citizen engagement and
empowerment



COMPASSIONATE COMMUNITY INITIATIVES AS A SOLO-PRACTITIONER



Death Café
is a '*social franchise*'.

It is a free event,
creating a safe space
to normalize conversations
about living and dying,
it can be offered anywhere,
at anytime,
and is accessible
to the public



About the Death Café



- At a Death Cafe people, often strangers, gather to eat, drink and discuss death.
- Death Cafe is open to, and respectful of, people of all communities and belief systems.
- The objective is *'to increase awareness of death with a view to helping people make the most of their (finite) lives'*.
- A Death Cafe is a group directed discussion of death. It is a discussion group, rather than a grief support or counselling session.





COMPASSIONATE COMMUNITY INITIATIVES AS PART OF A COLLECTIVE





Youth desire inclusion and honest information both prior to and following the death of someone close to them.

OUR MISSION

To advocate for educational opportunities and support services that will benefit children and youth who are grieving the dying or the death of someone they care about.

OUR VALUES

- Every child's rights should be respected
- Every child is unique and their response to death is individual
- There should be a broad range of grief support (formal and informal) available to all children and youth
- Grief support strives to give children and youth coping skills and increase their resilience to face life events
- Grief support should be culturally sensitive
- Accurate language is especially important in talking to young people about grief and death
- Communities need to have capacity to support grieving children and youth: education and access to education, tools and services





Centre For Grief and Healing
Bereaved Families Of Ontario-Halton/Peel



Dr. Jay Children's Grief Centre
A home for grieving hearts

Andrea Warnick Consulting

Supporting Grieving Children, Youth, and Adults, through Education and Counselling



C. Elizabeth Dougherty Consulting
Supporting Children, Youth and Adults
Facing Illness, Uncertainty and Loss



The Dorothy Ley Hospice
A COMMUNITY OF SUPPORT & CARE



Children and Youth
GRIEF NETWORK

ChildrenandYouthGriefNetwork.com



HEART HOUSE
H O S P I C E



Light House

Peer Support for Grieving Children, Youth and their Families



Carpenter Hospice



VICTORIA HAGERMAN
CERTIFIED CHILD LIFE SPECIALIST



Acclaim Health




Bethell Hospice



Family Education Centre









Children and Youth
GRIEF NETWORK

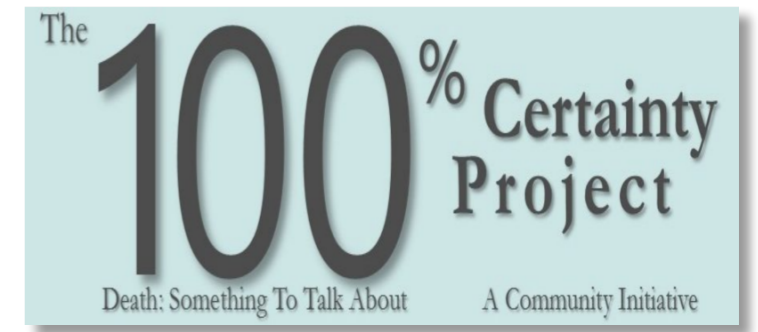
The Children & Youth Grief Network
presents:

**ONTARIO CHILDREN'S GRIEF AWARENESS
FAMILY DAY - OAKVILLE**

Saturday November 4, 2017

A local event acknowledging the National Alliance for Grieving
Children's Awareness Day on November 16, 2017





- a collaborative community effort using books with themes of death, dying, bereavement and loss to spark dialogue amongst citizens with the hope that grassroots efforts begin to build the social fabric we all will need at end-of-life
- the project attempts to de-medicalize the experience of death & dying and engage the general public, community agencies and community activists



Julia Samuel

in conversation with Wendy O'Brien

Thursday, January 18, 2018 at 7pm

Hamilton Room at Hamilton Central Library (55 York Blvd.)
Open to the public Free of charge All welcome

Grief Works

Stories of Life, Death and Surviving



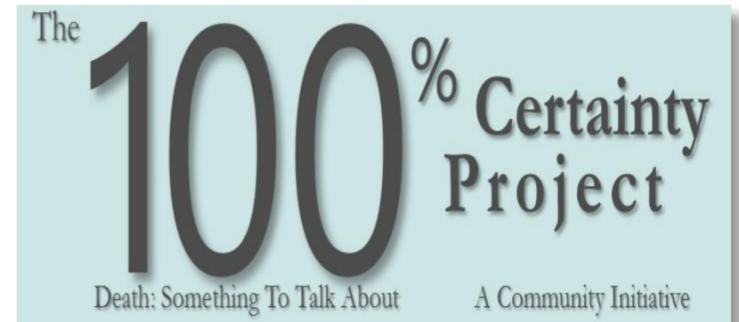
Julia Samuel

"Self-help at its most philosophical, practical and profound."
The Sunday Times

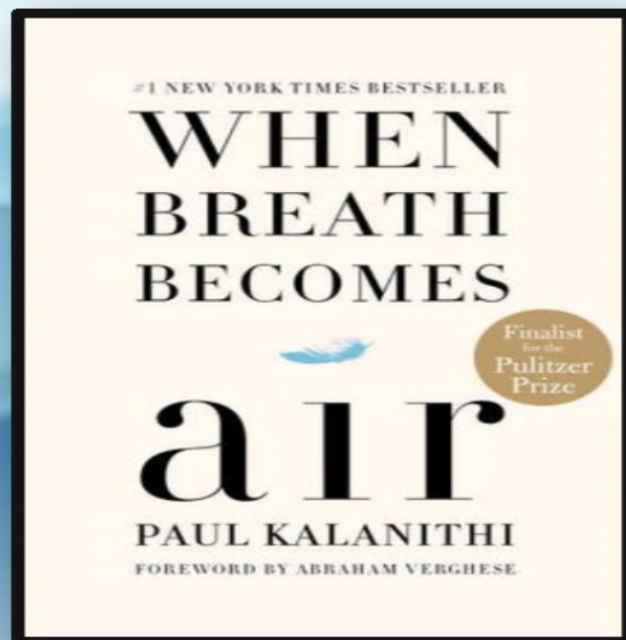
Part of the 100% Certainty Project: Death Something to Talk About – A Community Initiative
For more info: talkaboutdeath100@gmail.com or call Bryan Prince Bookseller @ 905 528-4508



talkaboutdeath.ca



Many healthcare students and providers do not feel prepared to encounter dying and death.



Join us at a free event where we will explore what makes life worth living in the face of death. We will:
 Feature "When Breath Becomes Air," the memoir of Dr. Paul Kalanithi, a young neurosurgeon facing terminal cancer.
 Watch the Ted Talk from his wife, an Internist, Dr. Lucy Kalanithi.
 Participate in a Death Café where we will explore how to make the most of our finite lives.



Registration required.
 Please register at: <https://goo.gl/cdHFWt>

Tuesday, March 27th
5:30-8:00pm

talkaboutdeath.ca

@Ytalkaboutdeath

David Braley Health Sciences Centre Room 2035 — 100 Main Street West
 Series part of the 100% Certainty Project: A Community Initiative



tuesdays with “Morrie”

Join us for wisdom, lessons
and end of life conversations.



tuesday, april 10, 2018

7-8pm @ Dundas Library - 18 Ogilvie St.

“Dialogue about the Wisdom of Aging”

Rabbis Baskin and Cohen, Temple Anshe Sholom



tuesday, april 17, 2018

7-8pm @ Dundas Library - 18 Ogilvie St.

Dr. Christopher Patterson, Geriatrician



tuesday, april 24, 2018

7-8pm @ Dundas Library - 18 Ogilvie St.

“The Journey of Grief, from Diagnosis to Death, and Beyond”

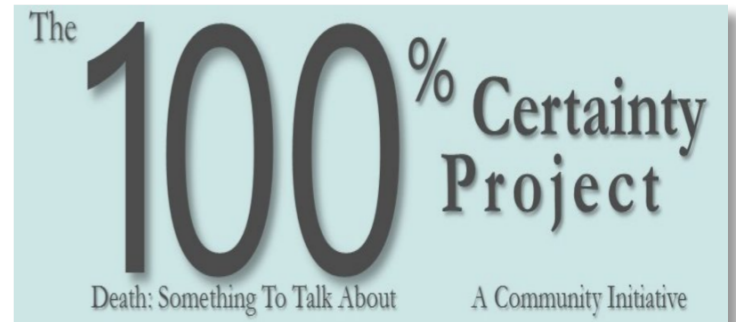
Jackie Storer, Carpenter Hospice

All welcome. Free of charge. Free parking after 6pm.
Part of the 100% Certainty Project: A Community Initiative
talkaboutdeath.ca



FAMILY MEDICINE
Division of Palliative Care

15
Years



The **100%** Certainty Project
Death: Something To Talk About A Community Initiative

EXTREMIS

DOCUMENTARY FILM AND DISCUSSION



talkaboutdeath.ca

Join us for a screening of
the Oscar-nominated
Netflix Original documentary,
EXTREMIS, (24 minutes long)
and a conversation with
palliative care experts

APRIL 18, 2018

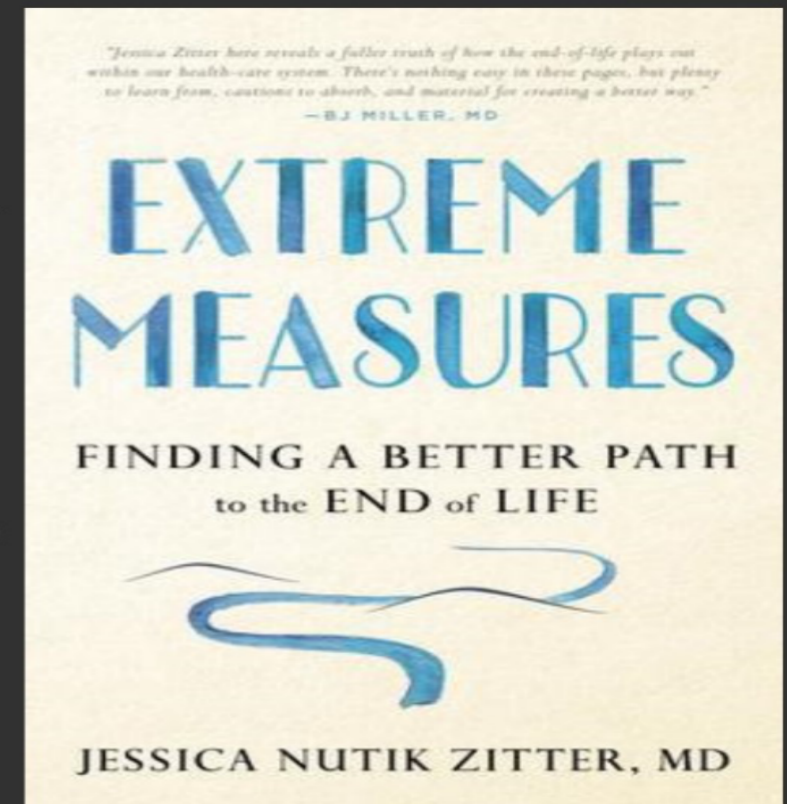
7PM @ DBHSC

100 Main St W., Hamilton, ON

(corner of Bay & Main) ROOM 2032 2nd floor

Free admission All welcome

Register for tickets: <https://goo.gl/JgG3gM>



@Ytalkaboutdeath



FAMILY MEDICINE
Division of Palliative Care



Hamilton
Public Library
FREEDOM TO DISCOVER

BRYAN PRINCE
BOOKSELLER

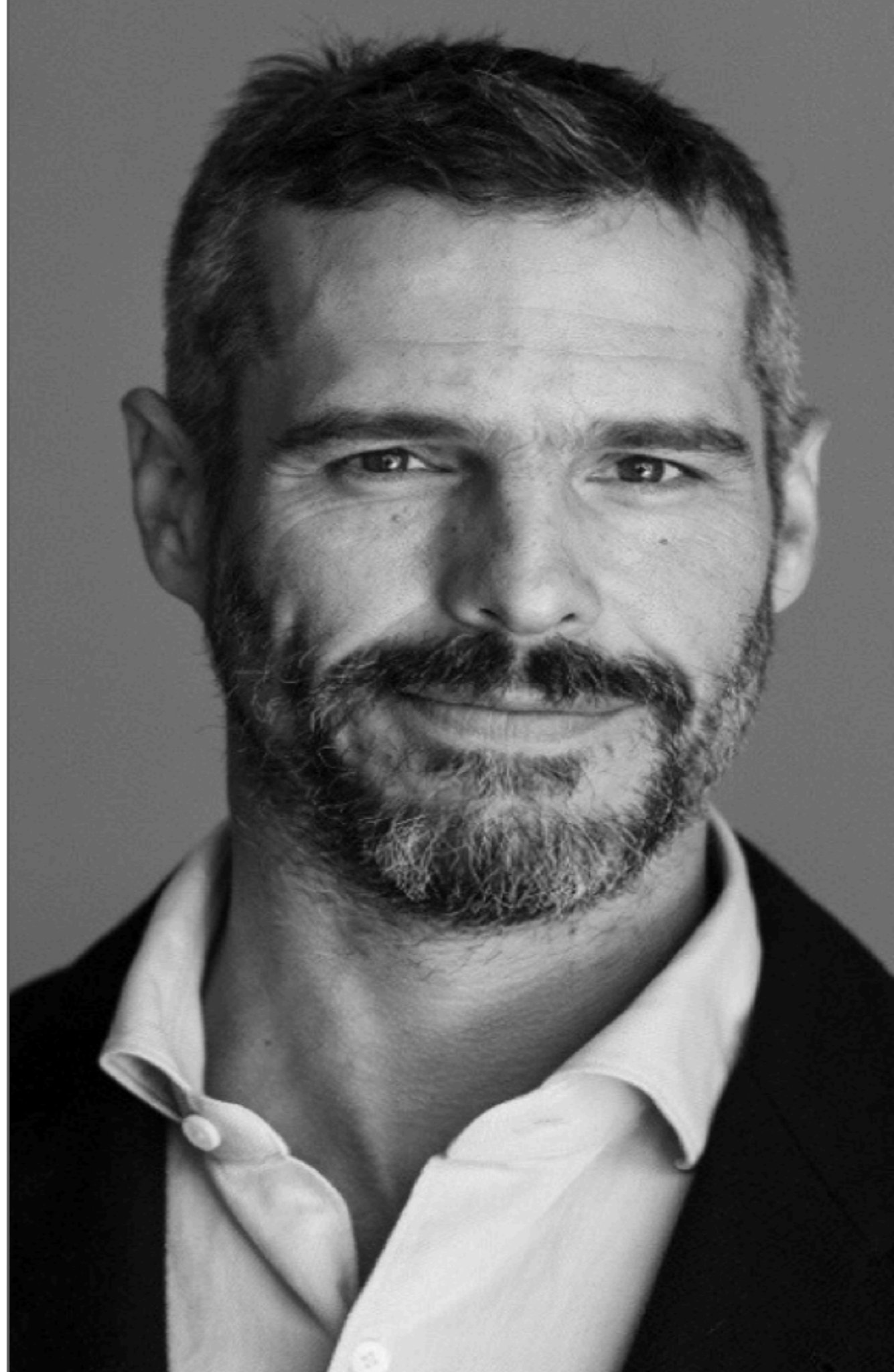


CREATIVE SPACES TO SUPPORT GRIEVING



There's nothing
inherently medical
about dying.
It's much larger
than medicine.
It's purely human.
Part of the mission
is to keep all of this
couched in humanity.

Dr. BJ Miller





The most important questions don't seem to have ready answers. But the questions themselves have a healing power when they are shared. An answer is an invitation to stop thinking about something, to stop wondering. Life has no such stopping places, life is a process whose every event is connected to the moment that just went by. An unanswered question is a fine traveling companion. It sharpens your eye for the road.


Remen, RN. (2006). Kitchen Table Wisdom: Stories That Heal



RESOURCES



RESOURCES



CANADIAN
Virtual Hospice
Information and support on palliative and end-of-life care, loss and grief.



HPCO
Hospice Palliative Care Ontario



Pallium Canada
Palliative Care Education for All Care Providers - Mobilizing Compassionate Communities
Formation sur les soins palliatifs pour tous les soignants - Mobiliser les communautés bienveillantes



Children and Youth
GRIEF NETWORK
ChildrenandYouthGriefNetwork.com



SWHPN Social Work Hospice & Palliative Care Network
swhpn.org



Canadian Hospice Palliative Care Association
Association canadienne de soins palliatifs



RESOURCES

English አማርኛ 粵語 فارسي हिंदी 国語 Tagalog ਪੰਜਾਬੀ Italiano اردو Af Soomaali Search

CANADIAN Virtual Hospice

LivingMyCulture.ca

Culture Topic People

Quality palliative care helps you honour your culture, spirituality and traditions. At LivingMyCulture.ca, people from various cultures share their stories and wisdom about living with serious illness, end of life and grief to support others.

First Nations



Chinese

Inuit



Ethiopian

Métis



Filipino



RESOURCES



✉ Email: info@virtualhospice.ca



MyGrief.ca

Because losing someone is hard

MyGrief.ca helps you to understand and work through your grief.

- Confidential
- Access in the privacy of your own home
- Developed by families and grief experts
- Stories from people who have "been there"
- A resource for professionals



RESOURCES

KidsGrief.ca

Home | Français



Text Size:



About | Resources

Talking with
Kids & teens
about dying
and death



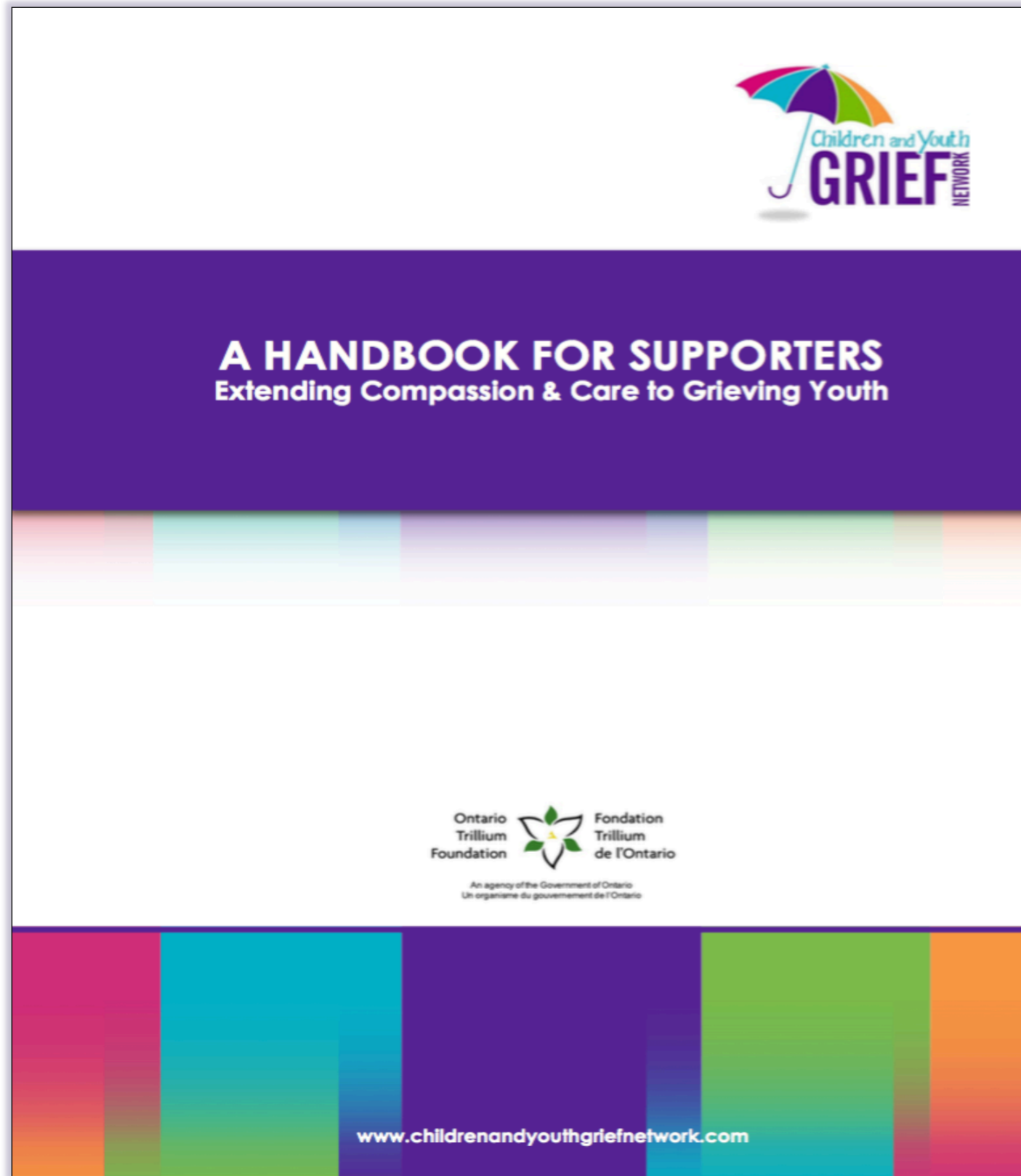
What do I tell the kids? How do I
support them?



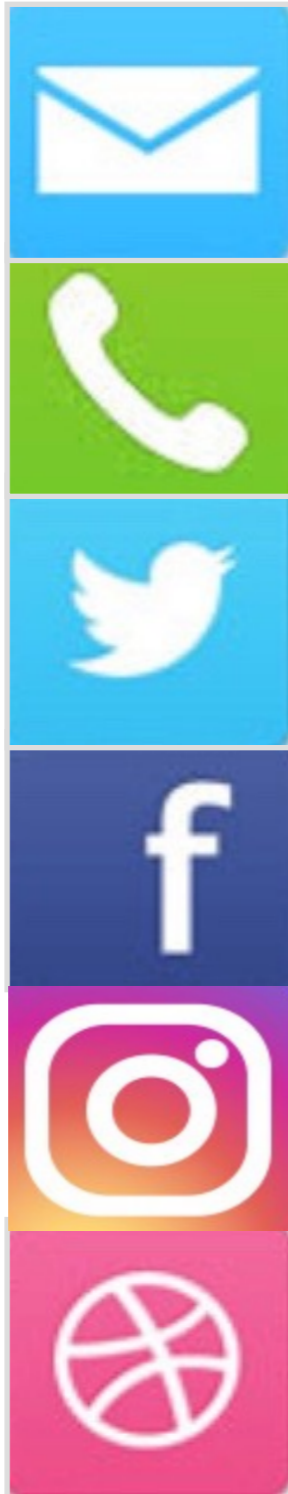
RESOURCES



RESOURCES



C. Elizabeth Dougherty B.S.W, M.S.W, R.S.W



elizabeth@cedoughertyconsulting.org

(647) 633 6805

@CEDoughertyMSW

@C.ElizabethDoughertyConsulting

@celizabethdougherty

cedoughertyconsulting.org

