

# **Anticipatory Grief: Families Facing Death, A Challenge to the Family System**

**MyNHPCO Bereavement Community Chat**  
**April 2022**

*Panelists:*  
NHPCO Bereavement Steering Committee

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# MyNHPCO: Where do I find it, and what is it?

- Visit: <http://my.nhpc.org/home> and use your NHPCO email and password.
- A collaboration of 15 discipline-specific professional communities and issue-based communities.
- Interdisciplinary-focused
- MyNHPCO contains on-line resources, forums and networking will help you grow professionally, find new solutions, contribute to the field, and elevate the national profile of your program.

# MyNHPCO



PROFESSIONAL  
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DISCUSSION  
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BLOG

# Please contact us...



...if you have questions about membership,



...if you have topics you would like us to discuss,



...if you would like to become a community committee member, and



...stay connected at the Bereavement Professional MyNHPCO Community!

# Housekeeping

- We call this hour a 'chat' for a reason
- Feel free to type in your questions in the chat feature on the side of your screen
- We want everyone to share their experiences
- We will offer suggestions but welcome everyone's participation and input
- You may introduce your self in the CHAT.
- Let's get started!

Christine Longaker writes in **Facing Death and Finding Hope**:

*Usually, neither the dying nor their families fully understand the physical and emotional processes they are going through in facing death.*

*In experiencing the dying process of a loved one,  
family members may feel as though they themselves are dying.*

*They do not realize that their conflicting emotions, anticipatory grief, feelings of helplessness, anxiety, frustration, and guilt are perfectly normal.*

*They lack the validation and support that they desperately need  
during this extremely difficult time.*

***'Dying' is sometimes a harder process for the loved ones  
than it is for the person facing death .***

# Poll: What is your background?

Social Work, MSW, LCSW

Marriage and Family Therapist, MFT, LMFT

MS Counseling, LPC

Master of Divinity, Mdiv, Pastoral Counseling

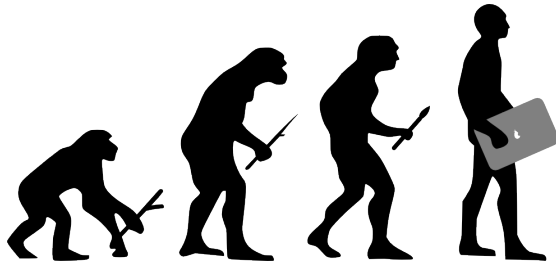
D Min

PhD/PsyD

CT/FT

Other

# Anticipatory Grief/Anticipatory Mourning Evolution



- 1944 Erich Lindemann: Individuals anticipating a loss could experience grief reactions.
- 1971 Fulton & Fulton; 1980 Fulton & Gottesman: Anticipatory Grief as a more common reaction as illnesses were more prolonged.
- 2000 Rando: Anticipatory Grief (a reaction) is a misnomer, yet useful. Redefines anticipatory grief as **Anticipatory Mourning** referring to the reactions experienced also the intrapsychic and interpsychic processes that one uses to **adapt** to and **cope** with life-limiting illness. The **patient**, **family members** and even **professional caregivers** may experience these losses as the patient continues to decline.

*Counseling Individuals with Life Threatening Illness, 2<sup>nd</sup> Ed., 2014-Ken Doka*



**All families operate according to certain fundamental rules**

The action of any one part of the system will have an effect on the system as a whole.



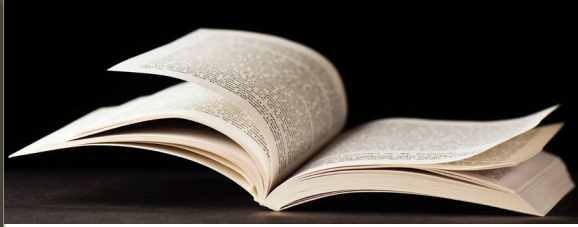
**A primary goal of all family systems is to maintain a homeostatic balance that ensures a reasonable degree of function and comfort for everyone.**



**The delicate emotional balance of the family is threatened by a terminal diagnosis.**

**Terminal illness affects ALL members of the family.**





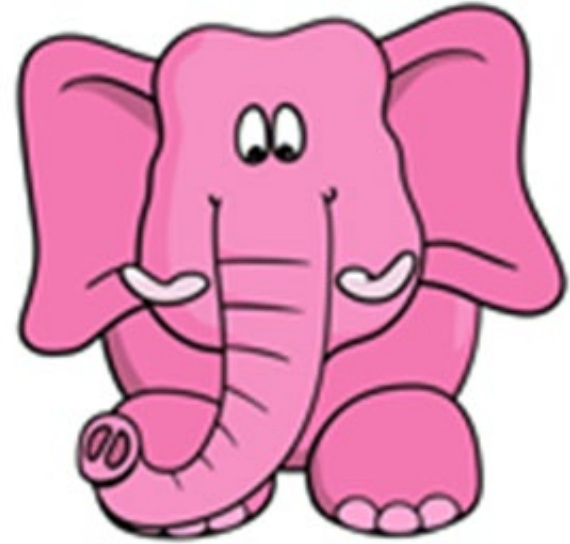
Families that cope most effectively are  
**OPEN** in their discussions

## Expression and Tolerance of Feelings: Open vs Closed

**CLOSED** families provide excuses  
and make comments that allow and encourage other  
family members to remain quiet.

*Grief Counseling and Grief Therapy, 5<sup>th</sup> Edition, 2018. Chapter 8: Grief and Family System ,  
J. William Worden*





## Secrets and the family system.

Secretly hiding an illness can upset the emotional balance in a family system.



**The family in the present is also a powerful representation of its history across previous generations.**

**Legacy** may be the **unspoken belief** that **survival** in the face of tragedy and loss was of **greater importance than expressions of love and affection.**

The **death of a loved one is so painful** that it is **better to avoid love or at least the demonstrative expression of love.**

**Warmth and affection** can be **replaced by bickering and antagonism.**  
**Negative interaction** becomes a **covert manifestation of intimacy and caring.**

**Self  
Reflection:  
Chat  
?**

**How did your FOO  
discuss illness and death?**

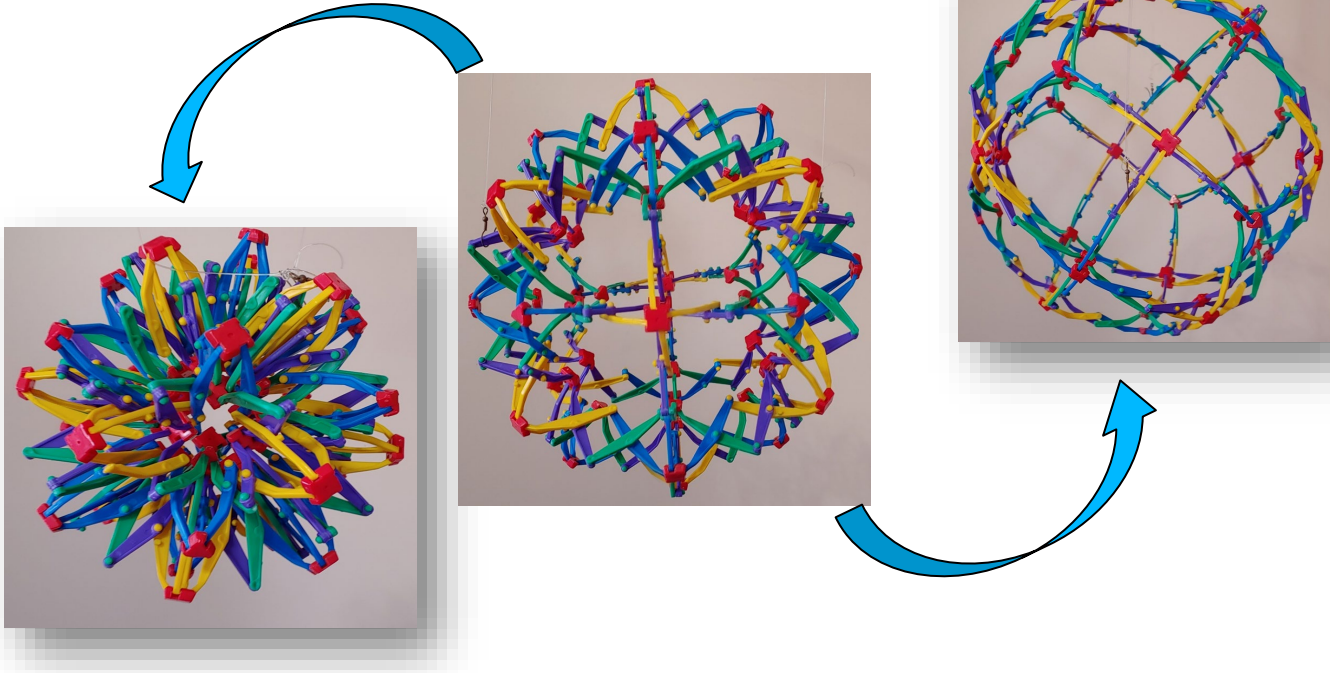
Discussion is difficult. Resist acknowledging the gravity of the illness and fail to comply with treatment regimens. CLOSED-

Use of humor in facing illness and death head on-Extremely OPEN



# *The push/pull of the family life cycle.*

Family of Origin



# Centripetal

**Family is pulling inward.**

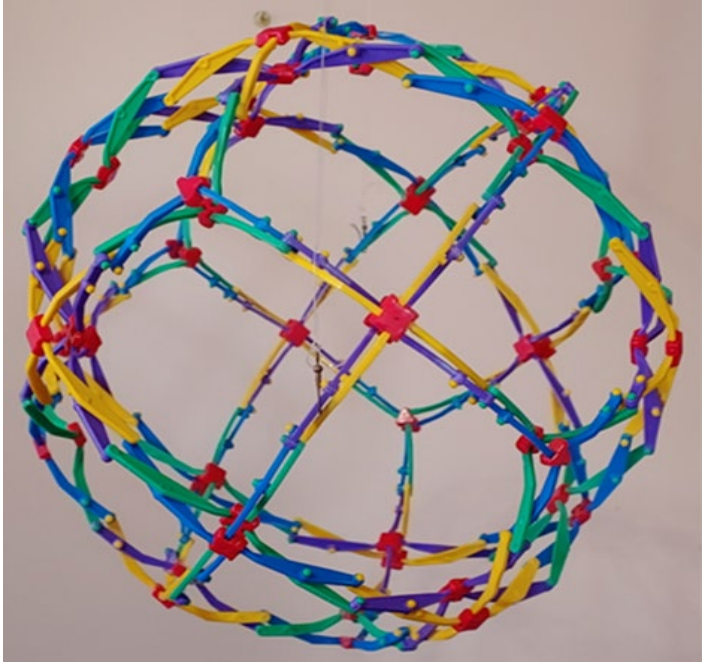
A “Crisis in the family” produces a powerful centripetal force.

Families have a natural tendency to draw together at times of difficulties, often blocking the entrance of outsiders which is frequently not in the family’s best interests.





# Centrifugal



Life cycle tasks that push members away from the family of origin. Normal Examples: latter adolescence, “launching”.

Other: Illness/Death avoidance; Fear



# PHASES OF FAMILY ADAPTATION

*Families Facing Death, A Guide for Healthcare Professionals and Volunteers, 1998: Elliot Rosen*

Four emotional responses of the family to the crisis of prospective loss:

1. **Disorganization**-high
2. **Anxiety**-higher
3. **Emotional liability** is seen in anger and hostility looking for scapegoats to blame for the fate they must accept. (stupid doctors, insensitive nurses, patient blame)
4. **Turning inward** (centripetal) cuts family from sources of support and making it impossible for family members to share fear and sadness.

Will be dramatically different at various phases  
in the family's adjustment to the illness.



### **3 PHASES of a family's progress in response to a fatal illness:**

- Not time-limited
- Nor directly correlated with the physical course of the illness.

**1. The preparatory phase:** beginning when symptoms first appear and continuing through the initial diagnosis.

**The most characteristic responses in the earliest phase of life-threatening illness are fear and denial.**

The family's response will depend on two other factors, which are not related to the patient's physical condition:

- 1. The structure of the family system before the illness:**  
openness, level of function and the role played by the patient in that system.
- 2. The family's perception of the course of the illness:**  
which may not be synonymous with the reality of its physical course.



2. **The middle phase:** can be quite lengthy, when the family lives with the reality and caretaking tasks of the fatal illness.

***Because fatal illness can also be progressive and/ or chronic the second phase can be quite long.(Think Alzheimer's, Huntington's Disease, etc.)***



3. **The final stage:** when the family accepts the imminent death and concludes the process of saying farewell.

***Powerful emotions may resurface with the harsh and now-Immediate reality of the loss.***

***Remember Christine Longaker:***

***'Dying' is sometimes a harder process for the loved ones than it is for the person facing death .***

## Resources this BC uses pre-death:

- **Anticipatory Grief packet** in the Start of Care Packet
- **EBI**-Early Bereavement Intervention for complicated grief and/or complicated situations.

Services begin with an “**Anticipatory Grief**” handout located in the Start of Care packet:

Includes:

- Anticipatory Grief:  
Grieving your loved one while they are still living-Cover sheet(color paper)
- Personalized letter introducing AG handout.
- Processes that are a part of the anticipatory grief and mourning page\*
- Grieving Before A Death: Understanding Anticipatory Grief, Things to Remember When Dealing with Anticipatory Grief page. (Adapted from Understanding Grief/Understanding Grief: Litsa Williams, Whatsyourgrief.com)\*

<https://whatsyourgrief.com/anticipatory-grief/>

## **\*Processes that are a part of anticipatory grief and mourning**

Anticipatory grieving is a valuable opportunity for individuals as well as families.

Anticipatory Grief Allows for:

- Absorbing the reality of the loss gradually over time.
- Finishing unfinished business with the dying person (i.e., expressing feelings, and resolving past conflicts, saying good-bye)
- Making restitution for past transgressions in the relationship by devoting oneself to good caregiving.
- Family members or others gradually assuming the responsibilities of the dying person.
- Redefining the family roles in relationship to the dying person (i.e., a dependent wife becomes head of the family)

# **\*Grieving Before A Death: Understanding Anticipatory Grief**

Things to Remember When Dealing with Anticipatory Grief [whatsyourgrief.com](https://whatsyourgrief.com)

- **Accept that anticipatory grief is normal.**
- **Acknowledge your losses.**
- **Connect with others.**
- **Remember that anticipatory grief doesn't mean you are giving up**
- **Reflect on the remaining time.**
- **Communicate**
- **Take care of yourself.**
- **Take advantage of your support system**
- **Say yes to counseling!**
- **Relief is normal.**
- **Don't assume**

# EBI-Early Bereavement Introduction Intention & Purpose

## Intention:

- EBI **is not** associated with the “Act of Dying”, instead with the process of healing.
- BC gets to know the deceased through the lens of the one(s) grieving.
- SW”s role **is not** duplicated.



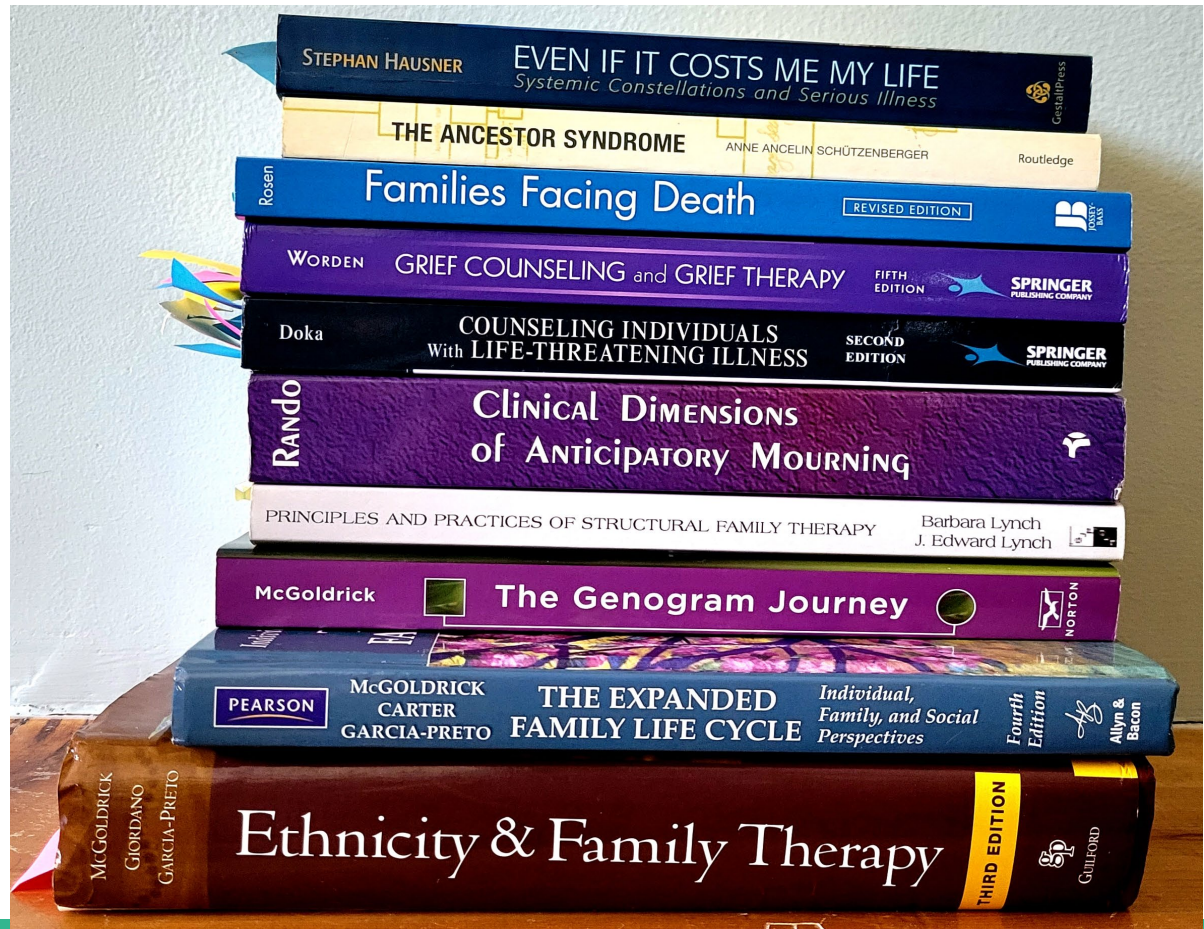
## Purpose:

- BC **support** SW via collaboration, providing literature, coloring books, etc.
- EBI for **complicated grief**, and/or **complicated situations** where it makes sense to make the introduction to the BC earlier to ensure strong continuity of care. (High risk concerns: recent loss, multiple losses, mental health issues, children having difficulty, etc.)
  - Assess
  - Determine Need
- PRN offer a co-led MSW and BC family meeting when other numerous complicating factors are present. Anticipatory grief is acknowledged and validated, families are given a road map as to what to expect in the days ahead and encourage them to share any questions or concerns.

# EBI-Early Bereavement Introduction Case Conf. Template

- **Date:**
- **Patient Name:**
- **Team Members**
- **SN:**
- **SW:**
- **SC:**
- **BC:**
- **VC:**
- **Other:**
- **Primary Bereaved Name/Relationship:**
- **Challenge:**
- **Plan:**

# Just a few Resources:



Panel  
Comments  
&  
Sharing.....



