Bereavement Program Guidelines and Resources

Debi Arterburn, LPN, Senior CommUnity Care
Tom Smith, LCSW, Senior Community Care
David Wensel, DO, MidlandCare PACE
Since comprehensive care is provided to PACE participants, those participants who need end-of-life care will receive the appropriate medical, pharmaceutical, and psychosocial services through the PACE organization.
NPA Palliative and End-of-Life Care Workgroup History

- **<2014**
  - Presentations Interest
  - NPA Collaborations

- **2015**
  - 5 members PCC Survey Conference

- **2016**
  - 30 members Definitions Guidelines 10 Modules Conference

- **2017**
  - 50 Members P.M. Boot Camp ACP Survey Conference

- **2018**
  - 60 Members Bereavement ACP Resource Table
How to Access Resources

- NPA members
- NPA Website
  - Member Resources
  - Participant Care Resources

http://www.npaonline.org/member-resources/participant-care-resources
Resource Table
How to become a member

NPA Contact:
Mia Phifer
Vice President, Quality
National PACE Association
MiaP@npaonline.org
Bereavement Program Guidelines and Resources: Objectives

1. Increase understanding of the purpose and goals of the NPA PC/EOL workgroup.

2. Learn about the bereavement program guidelines and resources available to PACE organizations.

3. Be able to access bereavement program guidelines and resources.
Components of a Bereavement Program

- Grief Assessments
- Follow-up after death
- Grief recognition spaces in Day Center
- Ritual
- Communication
- Education
- Documentation
- Resources
To give PACE organizations suggestions and guidance on how to structure and provide bereavement program services.
Grief Assessments: Definition

- Assessing participants and grieving families to ensure that appropriate bereavement services are provided through the continuum of care from enrollment through the year following the death of the participant.
Grief Assessments

• Adult Attitude to Grief Scale

• Bereavement Risk Assessment Tool (BRAT)

• Caregiver Questionnaire

• Complicated Grief Assessment
Bereavement Assessment Timeline

Intake

Participant and Family

6 m
1 yr
6 m
2 yr

Death

Family

13 month Mailing Program

1 3 6 9 11 13
Follow-up After Death: Definition

• Providing services and interventions to support loved ones after the death of a participant.
Follow-up After Death: components

• Home visits
  o Presence
  o Comfort
  o Education
  o Assessment
Follow-up After Death: components

• Condolence cards
  o who, why, when

• Thank you cards
  o who, why, when
Follow-up After Death: components

- Support calls
  - who, why, when

- Support visits
  - who, why, when

- Grief Groups
  - who, why, when
Follow-up After Death: Mailing Program
Bereavement Assessment Timeline

Intake

- 6 m
- 1 yr
- 6 m
- 2 yr

Death

13 month Mailing Program

- 1
- 3
- 6
- 9
- 11
- 13

COS

Participant and Family

Family
A place for participants and staff to honor and celebrate the lives of participants who have died.
Recognition Spaces in Day Center

• Celebration of Life/Memorial Table
Recognition Spaces in Day Center

- Annual scroll of names from previous year

- Celebration of Life Alcove
Recognition Spaces in Day Center

- Memory Tree
Ritual

- Services and rituals to help participants, families, and staff process grief.
Ritual: Celebration of Life Service
Ritual: Annual Ritual
Ritual: Annual Ritual
Ritual: Annual Ritual
Ritual: Annual Staff Ritual
Ritual: Holiday Season
Ritual: Stones
Communication

• Communication within the participants circle of care as well as organizationally is essential to a bereavement program.

THE SINGLE BIGGEST PROBLEM IN COMMUNICATION

IS THE ILLUSION IT HAS TAKEN PLACE

- GEORGE BERNARD SHAW
Addressing confidentiality

Knock Knock!
-Who's there?
HIPAA!
-HIPAA who?
I can't tell you that.
• Staff is better able to provide care and process their own grief when quality communication occurs throughout the dying process.
Communication: Staff

- When a Participant starts receiving EOL care
- Major Changes
- Actively dying
- At time of death
Communication: Staff

- PACE celebration of life service
- Community service
- Annual memory service
• Participants in PACE programs often become very close.

• When possible and when permission has been given, information regarding the death of a participant should be shared in a timely manner.
Communication: Participants

- Actively dying
- At time of death
- PACE Celebration of Life Service
- Community Service
- Annual memory service
Communication with family members is of the utmost importance during the bereavement process.

Families need to know about bereavement program services available and that they are welcomed at PACE services.
Communication: Family

- PACE celebration of Life service
- Annual memory service
- Phone calls
- Face-to-face
- Condolence and “thinking of you” cards
Education

• Education regarding bereavement topics and services should be provided to staff, participants and families.
Education

• Staff
  o All-staff
  o Staff meetings

• Participants
  o Regular intervals
  o Adult education sessions
  o Voluntary workshops

• Family
  o Family education presented as needed
Definition: Documentation should effectively capture the essence of related conversations and actions taken as part of the bereavement process.

• Who: responsible party
• What: guideline
• Where: drop downs in EMR
• When: always
Resource List
Speaker Contact Information

Debi Arterburn, LPN, Senior CommUnity Care
darterburn@voa.org

Tom Smith, LCSW, Senior Community Care
thosmith@voa.org

David Wensel, DO, MidlandCare PACE
dwensel@midlandcc.org