

# Support for *Young Caregivers & Grieving Youth*

## A Toolkit for K-12 Teachers & Counselors



**CSU** The California  
State University  
**Institute for Palliative Care**  
AT CALIFORNIA STATE UNIVERSITY SAN MARCOS



  
California State University  
SAN MARCOS

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# Support for Young Caregivers and Grieving Youth: A Toolkit for K-12 Teachers and Counselors

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## Foreword

Many people have the idea that childhood is a care-free time of life, a time when the focus is on learning new things, building relationships, and experiencing many “firsts.” However, for a large number of young people in the United States, childhood is also marked by caring for ill or impaired family members or grieving the loss of a loved one. Recent trends in grandparent-led families, parental disabilities due to physical/mental impairments, and substance use/abuse have meant that many young people are providing much-needed assistance to family members. However, they are providing this care while “hidden” from the general population. Few people in the US acknowledge the work young people do, every day, to support their loved ones. Teachers and school counselors are among those individuals who deal with the challenges and outcomes of young caregiving and grief when working with their students. These professionals are in the unique position of being able to educate and serve as a resource for these young people. They can’t be expected to do this alone. Our core belief that teachers and counselors need more support for the work they do with young people who are suffering due to family illness or death. This belief served as the impetus for creating this toolkit.

We have developed the *Support for Young Caregivers and Grieving Youth: A Toolkit for K-12 Teachers and Counselors* to provide the resources education professionals need at their fingertips. Developed by three CSUSM Psychology Professors and two K-12 teachers, we drew on our collective expertise to design a toolkit that provides key information in an easy-to-find format, perfect for using during the brief times in the school day when no students are present (e.g., prep periods, before/after school).

The *Toolkit* is divided into 7 modules:

1. Grief
2. Young Caregivers
3. Health and Illness
4. Helping Students and Managing Classroom Behaviors
5. Additional Support for Teachers and Counselors
6. Resources
7. References

The modules contain brief descriptions of key issues (e.g., the stages of grief, types of treatments for serious illness) so teachers/counselors can get a snapshot of the kinds of issues their students are facing. The modules contain resources and

references for the teachers and counselors to use to access additional information. Additionally, some materials are included for use in the classroom (e.g., I wish my teacher knew....). The *Toolkit* also addresses the impact that our students' stress has on educators, and how to adopt practices that help us to deal with stress and lead to positive outcomes.

Fundamental assumptions incorporated into this *Toolkit* are (1) that we need to provide teachers and counselors with resources, and (2) we need to keep students in the classroom and focused on learning. It is clear that we can't expect teachers and counselors to be able to address all mental health needs of students, but we can help them to have key resources that are easily accessible so they'll be able to refer students who need more help. By having access to this information and resources, teachers and counselors will be able to support children and adolescents in the classroom so that they can learn and be proactive so that absences and time-off-task are reduced.

This *Toolkit* is an important resource for educators. We are all on the "front-line" when tragedy or significant challenges take place in our students' lives. We are also often at a loss as to what we can do when these stressors do arise. The *Toolkit* provides some actions that can be taken to help students to cope and to help teachers and counselors support learning, even when their students are hurting. Ironically, students are not really looking for teachers/counselors to "fix" what is wrong in their lives. They just want to be heard. They want to be acknowledged. As professionals, we want to feel like we can answer this call. This *Toolkit* is intended to do just that.

**Sharon B. Hamill, PhD**

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## About The Authors



**Sharon B. Hamill, PhD**, is a Professor of Developmental Psychology and Faculty Director for the CSU Institute for Palliative Care at California State University San Marcos. Dr. Hamill's research focuses on young caregivers: adolescents and young adults assisting adult family members who suffer from Alzheimer's and other diseases.

Specifically, she explores how these early caregiving experiences contribute to the development of young people's personal and social responsibility and the impacts on their physical health. Dr. Hamill has served family caregivers through her work with the Because I Care Community Fair, the Elizabeth Hospice, and the Alzheimer's Association. She is currently working with local schools on the Youth Resiliency Project. She co-authored and served as the Program Director for the Child and Adolescent Development major offered at CSUSM. Dr. Hamill is the recipient of the 2015-2016 Harry E. Brakebill Distinguished Professor Award for excellence in teaching, research, and service at CSUSM.



**Emily Merryweather, M.A., NCC**, is a research clinician whose area of specialization is clinical counseling with interests in palliative care, trauma-informed care, end-of-life at emerging stages of development, intergenerational meaning-based activities, and self-compassion in caregiving. She is currently part of a research and therapy team at the

University of California, San Diego, studying positive therapeutic outcomes for palliative care patients. Professor Merryweather is a consultant for the CSU Institute for Palliative Care at CSUSM and a lecturer at CSUSM teaching Positive Psychology, Evidence-Based Practice, Abnormal Psychology, History of Psychology and Introduction to Psychology, and leads mindfulness workshops. She is also actively involved in the Academic Senate, committee work, and a mentorship program for disadvantaged students at CSUSM.



**Lissa Lim, PhD** is a bilingual (Spanish & English) psychologist who specializes in working with people struggling with depression and people affected by sexual violence. She has worked in various clinical settings including university counseling centers, a community mental health center, a rape crisis center, and a women's center. In private

practice she has worked with individuals, couples, and groups. She also has extensive experience supporting adults dealing with grief and bereavement in individual

therapy. Dr. Lim has also taught psychology at various universities and colleges across the nation, including Southern Illinois University Carbondale, Santiago Canyon College, and California State University San Marcos. Currently, Dr. Lim is a therapist at California State University San Marcos's Counseling Center.



**Sarah Myers, MEd**, has been a classroom teacher since 2011. She began her career teaching high school students in the Watts/Compton area where she was exposed to many students from a wide range of family environments. This included teenagers caring for family members and those suffering from the grief of losing family members or friends.

She is now employed at a charter school in Menifee and although the environment is very different from her earliest years in teaching, the students are still faced with the same hardships and challenges. Sarah notes that although she can't stop the pain students experience, her hope is that this toolkit can provide teachers with helpful ways to build resiliency, comfort, and a little bit of understanding for students in their classrooms.



**Jennifer Hamby, EdD**, has been a teacher in the Oceanside Unified School District since 1988 and experience spans every grade from K-8. She is currently teaching 1<sup>st</sup> grade at Palmquist Elementary. As a self-proclaimed “struggling reader,” Dr. Hamby’s passion is teaching children to love reading. This led her to obtain her doctorate in literacy.

Dr. Hamby has lost students to illness and death and she sees the need to have the tools/skills available to help teachers and students navigate through difficult times. She believes we need to teach students to be resilient.

## Acknowledgements

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Chris Knutson, RN [Module 3: Facilities that Provide Health Care Outside of the Home]

Colleen Moss, PhD [Module 6: Expressive Arts Activities]

We would also like to acknowledge our graphic designers and copy editors for the *Toolkit*: Lisa Lipsey, Shannon Honour, Jillian Dunn, and Donna Heard. Their creativity has helped us to design a toolkit that will be highly useful for education professionals as they provide much-needed support to their students.

Finally, we'd like to thank our very dedicated student assistants on this project: Madeline Rayón, Irene Totten and Ivette Villagomez. They spent many hours checking references, researching resources and supporting the editing process. We greatly appreciate the contributions they made to the project.

**Sharon B. Hamill, PhD; Emily Merryweather, MA, NCC;  
Lissa Lim, PhD; Sarah Myers, MEd; and Jennifer Hamby, EdD**



# *An Overview of the Toolkit*

The *Toolkit* is divided into 7 modules. The first 5 contain information on the following topics:

1. Grief
2. Young Caregivers
3. Health and Illness
4. Helping Students and Managing Classroom Behaviors
5. Additional Support for Teachers and Counselors

Each Module is tabbed so it can be located quickly and includes:

- A brief statement to ground the reader in the topic
- Information about key issues and terms.
- A resources section; all of the resources relevant for the module are listed here in alphabetical order.
- A Reference section which contains all of the sources used to write the module.

*Module 6: Resources* contains a full description of each resource described in the *Toolkit* by alphabetical order. Readers just need to find the resource they want in the module, then flip to Module 6 to get a full description and contact information if they choose to investigate the resource further. We have included local (San Diego) and national resources and, in some cases, materials we've created for use in the classroom or counselor's office.

*Module 7: References* contains all of the information sources we used to write the *Toolkit*. Whereas specific references by topic are provided within Modules one through five, Module Seven combines all of the references across modules and lists them alphabetically.

We encourage teachers and counselors to use the ancillary materials we've created as they see fit and they may be reproduced for use with K-12 students (without the need to request additional permission).

We hope that this *Toolkit* will provide you with the tools you need to work with students who are suffering because of caregiving responsibilities or the loss of a loved one. We also welcome comments and suggestions on the *Toolkit* as we are always looking for ways to improve it. Thank you for your support of our children and adolescents!

**Sharon B. Hamill, PhD; Emily Merryweather, MA, NCC;  
Lissa Lim, PhD; Sarah Myers, MEd; and Jennifer Hamby, EdD**

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## Grief

*The best way to support your students' grief is to gain an understanding of grief yourself by considering what your students may be experiencing and why. It can also be helpful to talk with your students about the stages of grief to help them identify and understand their own experiences. Talking about the various emotions that are commonly experienced can validate and normalize your students' feelings, and help them heal.*

### What is Grief?

Grief is individual and deeply personal but it is also a universal human experience that draws us to connect with other people during times of sadness. People often confuse the terms “bereavement,” “grief,” and “mourning.” These terms are all related but have different meanings:

**Bereavement** – The period of time after which a person has lost a loved one when grief and mourning occur.

**Grief** – Our internal, emotional experiences related to the loss of a loved one.

**Mourning** – The outward or public expression of our grief. This can include death rituals and burials, cultural expressions of loss such as Dia de Los Muertos in the Hispanic Culture, a Mass of the Celebration of Life for Catholics, sitting Shiva for Jewish mourners, or burying the body of our loved ones facing Mecca in the Muslim religion.

Grief is neither simple nor easy as it is complicated and always changing. While the experience of grief will lessen over time, it will never end entirely. Memories often flood our senses when we see, hear or smell something that reminds us of our loved one, especially around meaningful times of the year (e.g., anniversaries, birthdays, holidays), and various milestones in life (e.g., graduations, when children are born, when relationships end). While these can be upsetting and intrusive in early grief, they can become a sense of comfort and positive reminders of loved ones over time.

Throughout the grieving process, grief can manifest itself in physical, emotional, and behavioral reactions. The circumstances of the loss and the social support available are important factors that affect how individuals will experience their

grief. Some common emotional expressions during the grief process may include denial, emotional outbursts, feeling numb, or being fearful, anxious, and confused. Physical manifestations of grief can include difficulty sleeping, changes in appetite, and regression (e.g., returning to thumb sucking or using baby talk). During a period of grief people may also find themselves thinking a lot about the person who has passed and the relationship they shared. This is a normal part of processing and making sense of loss and the impact the loss has on the world.

### Stages of Grief and Loss

Many people have been exposed to Elisabeth Kubler-Ross' Stage Theory of Grief and Loss. She described grief as occurring in five stages:

1. **Denial** - difficulty accepting the loss
2. **Anger** - feelings of irritability, anger or rage, as well as thoughts about the unfairness of the loss
3. **Bargaining** - trying to make deals or negotiate with health care providers or their higher power to delay or prevent the loss
4. **Depression** - sadness, depression, and despair over their loss
5. **Acceptance** - a calm acceptance in which they recognize that their life has been changed by their loss

Many people exposed to these ideas believe that they will experience this sequence of stages as they cope with their own losses. However, research revealed that most people do not experience grief as a series of progressive stages. Rather, current clinicians recognize that grief is a highly personal and unique experience for all of us and varies by person, culture, and type of loss.

### New Perspectives on Grief and Loss

William Worden (1982; 1991; 2009) has provided a useful way to think about grief and mourning as a series of four tasks as described in his **TEAR** model:

1. **T**o accept the reality of the death
2. **E**xperience the pain of the loss
3. **A**djunct to a new life without the lost person
4. **R**einvest in the new reality

This model does not assume that a grieving person will move through each task in an orderly manner; rather, individuals choose when they move to the different tasks and will deal with each task in their own way. For most people this is likely to be a cyclical process where the various tasks are revisited over time. There are many different emotions to work through and there is no timeline for completing the tasks. This perspective recognizes that there is no “right” way to grieve. Every person’s grieving process is unique.

### **Common Grief Reactions May Include:**

- loss of interest in activities one used to enjoy
- difficulty feeling pleasure
- sleeping too much or too little
- eating too much or too little
- gaining or losing weight
- loss of energy, overall fatigue, being easily fatigued
- loss of motivation
- difficulty concentrating
- difficulty making decisions
- feelings of meaninglessness, hopelessness
- thoughts about death and mortality

It is important to note that these characteristics are also signs of depression and should be discussed with the student’s parents and the school health care provider if they persist for longer than two weeks.

### **Developmental Stages and Grief**

In addition to common stages of grief, a child’s stage of development from pre-school to adolescence is important to consider during the grieving process. This chart of stages is meant to be used as a general guideline. The chart outlines the developmental tasks associated with grief, the typical ways that grief is expressed, and possible interventions you might try for each developmental age group.

|  | Developmental Task   | Grief Expression  | Interventions   |
|--|--|---|---|
| <p>Early Grades<br/>5-9 Years Old<br/>K-3rd Grade</p>      | <ul style="list-style-type: none"> <li>Gaining a sense of self</li> <li>Exploring fantasy, play and social interactions</li> <li>Identity</li> <li>Communication skills</li> </ul> | <ul style="list-style-type: none"> <li>Death can be seen as reversible like in fairytales</li> <li>Repeated wishing or “what ifs” for return of the loved one</li> <li>Questions of “how?” or “why?”</li> <li>Regression to an earlier stage of development</li> <li>Change of sleep or eating patterns</li> <li>Aggressive play</li> </ul> | <ul style="list-style-type: none"> <li>Answer questions as they come up, keeping responses gentle but also simple and direct to minimize stress and confusion</li> <li>Creative play, sand tray</li> <li>Drawing or painting</li> <li>Crafts-make a poster or card</li> <li>Puppets for role-play</li> <li>Stories</li> </ul> |
| <p>Middle Grades<br/>9-13 Years Old<br/>4th-7th Grade</p>  | <ul style="list-style-type: none"> <li>Building self-confidence</li> <li>Socialization</li> <li>Concrete thinking</li> </ul>   | <ul style="list-style-type: none"> <li>The concept of death is seen as final and as punishment</li> <li>Curiosity about loss, with interest in details</li> <li>Change in sleeping or eating patterns</li> <li>Withdrawal from friends and family</li> </ul>  | <ul style="list-style-type: none"> <li>Empathetic listening</li> <li>Answering questions honestly and as directly as possible</li> <li>Encourage naming of feelings and body sensations associated with grief</li> <li>Creative art projects to honor loss (poem, picture or box for special mementos)</li> </ul>             |
| <p>Adolescence<br/>13-18 Years Old<br/>8th -12th Grade</p> | <ul style="list-style-type: none"> <li>Advanced problem solving</li> <li>Abstract thinking</li> </ul>  | <ul style="list-style-type: none"> <li>Questioning of life after death</li> <li>Sadness, denial and regression</li> <li>Seeking social support outside family</li> <li>Risk taking behaviors</li> </ul>   | <ul style="list-style-type: none"> <li>Encourage support networks, friends, older relatives, close family friends</li> <li>Actively listen, reflect back</li> <li>Offer choices and involvement in loss process</li> <li>Self-expression through art or music</li> </ul>  |



## Grief Across Cultures

Whereas the experience of loss is universal, people of different cultures and religions may respond to death in unique ways and may have culturally specific mourning practices. Knowing how to support a student in ways that are culturally sensitive is an important way of honoring the student's ethnic and religious identities.

Teachers/Counselors who are not familiar with their student's unique culture may feel unsure of how to best support their students and may hesitate to offer their support due to fear of offending the student or disrespecting the student's family. If this is how you feel, be gentle with yourself; know that as long as you are thoughtful, sensitive, and respectful, the support you and other students offer can still be meaningful and supportive to the family.

This section is intended to give you a guide to help you support students of diverse cultural and religious backgrounds. It has information about how to be culturally sensitive, offers tips for gaining important cultural information, and identifies common traditional practices of the most common ethnic and religious groups in San Diego County, California.

The following charts of cultures and religions (one culture or religion is discussed per page), as well as the practices described, are not exhaustive. There may be cultural and religious practices that are important to some families that are not listed here. The practices described may also vary due to our melting pot culture in the United States, or varying level of orthodoxy within a religion. Use the practices listed as a guide or starting point, while keeping in mind that every family is unique.

| Cultural Group           | Common Bereavement Practices & Rituals  | How this May Affect Your Student in Class  |
|--------------------------|---|--|
| Asian/<br>Asian-American | <ul style="list-style-type: none"> <li>• Loved ones are discouraged from having outward expressions of grief, instead stoic attitudes are preferred</li> <li>• Older family members are generally responsible for organizing the funeral</li> <li>• An open casket is often used to allow the elders to offer respect to the deceased</li> <li>• Family and friends gather after the funeral for a meal to show respect for the spirit of the deceased</li> <li>• A shrine is often made with picture of the deceased and items they liked, along with incense or candles</li> <li>• There are also many 3-day celebrations that honor the dead in many Asian cultures. These celebrations often involve visiting the tombs or hometown of the deceased, lighting incense and candles, and making a feast for the family</li> </ul> | <ul style="list-style-type: none"> <li>• Students may not express their grief in class, or ask you for help, even if they are experiencing grief and need support</li> <li>• Family members are discouraged from disobeying an elder's decision, so if funeral ceremonies are arranged during class, the student must attend and miss class. This could create more stress for students because many Asian families also strongly value high academic achievement</li> <li>• Students may have reactions to seeing a cadaver and may have reactions about it during class time</li> <li>• Students who want to honor the deceased may carry pictures of the deceased and may show it to classmates</li> <li>• Students who participate in the 3-day celebrations in which they travel to tombs/homes of the deceased may have to take time off school and may have less time to for homework, which can create more stress for them</li> </ul> |

| Cultural Group                     | Common Bereavement Practices & Rituals  | How this may affect your student in class  |
|------------------------------------|---|--|
| <p>Black/<br/>African-American</p> | <ul style="list-style-type: none"> <li>• Loved ones are encouraged to show grief with physical and emotional responses (e.g., falling to the ground, crying)</li> <li>• Family and friends gather at the house of the deceased to offer support and share in grief</li> <li>• Many people play and sing songs during a wake to honor the personality of the deceased and celebrate their return to God</li> <li>• A lot of families have strong ties to their faith and their church, and thus attending religious processions are very important</li> <li>• Some communities mourn through celebration by dressing in white to visually represent hope and honor resurrection. Other African communities mourn by wearing red or black</li> <li>• African-Americans may believe that the spirits of those who have passed live in the memories and thoughts of the living</li> </ul> | <ul style="list-style-type: none"> <li>• Students may express grief in the classroom. This may manifest as crying, shaking, or falling</li> <li>• Students may want to be at home, rather than at school, where there are lots of friends and family offering support. This may make it more difficult for students to concentrate in class</li> <li>• Students may miss class or homework to attend religious processions, especially if they were close to the person who has passed away, or if they have close ties to the church</li> <li>• Some students may wear white, red, or black as a sign of their mourning</li> <li>• Some students may report experiencing (hearing or seeing) the spirit of the deceased, and may communicate with the spirits at school. This should not be confused with hallucinations when they are normal aspects of the student's culture</li> </ul> |

| Cultural Group  | How People Mourn or Honor the Deceased  | How this May Affect Your Student in Class  |
|-----------------|---|--|
| Latin@/Hispanic | <ul style="list-style-type: none"> <li>• Expressions of grief are encouraged, especially for loved ones</li> <li>• Family members are encouraged, and sometimes expected, to participate in the commemoration of the deceased</li> <li>• Catholic families and friends only say the rosary together for several consecutive nights (between 9-40 nights) following the death. These prayers often take place at the home of the deceased or of their family</li> <li>• Family and friends spend a lot of time together after a death occurs. There are often visitors on a daily basis for several days or weeks after a funeral</li> <li>• Survivors honor the deceased by making promises or commitments that are taken very seriously</li> <li>• People from Mexico celebrate el Día de los Muertos (Day of the Dead) on Oct 31<sup>st</sup> - Nov 2<sup>nd</sup>. This is a holiday in which the deceased are celebrated by making the deceased's favorite foods, playing their favorite music, and creating altars for them</li> </ul> | <ul style="list-style-type: none"> <li>• Students may openly express feeling of grief in class. This may manifest as sadness, crying, or isolation</li> <li>• Students who were involved in the commemoration of the deceased may have reactions to seeing or being close to a cadaver, and may express these reactions in class</li> <li>• Catholic students who participate in the rosary ritual or who live in the home where the ritual is being practiced, may not have a quite space or as much time to do their homework</li> <li>• Students may be more committed to their family than to school after the passing of a family member. This may lead them to miss class or assignments to focus on supporting their family</li> <li>• If visitors stay until the late evening this could also disrupt the student's sleep and they may be more tired in class</li> <li>• Students that celebrate the Day of the Dead will likely have some representation of decorated skulls with them during the day of the dead celebrations</li> </ul> |

| Ethnic Group                        | How People Mourn or Honor the Deceased  | How this May Affect Your Student in Class   |
|-------------------------------------|---|---|
| <p>White/<br/>European-American</p> | <ul style="list-style-type: none"> <li>• Following an announcement (newspaper or community bulletin) of death, friends and family may gather at the home of the deceased or family member to support and share in grief. Community members often bring in food for the event and for family</li> <li>• Some rituals include a visitation at the funeral home, a funeral procession around the deceased home and community, a church service, a graveside service and a luncheon for members of family and community</li> <li>• Funeral services tend to be subdued</li> <li>• Dark clothing (often black) tends to be worn during ceremonial services</li> <li>• Older women may wear a short veil while in mourning</li> </ul> | <ul style="list-style-type: none"> <li>• If friends and family gather at the student's home, they may not have a quiet space or time to focus on homework</li> <li>• Student may have to miss several days from school to attend funeral and burial ceremonies</li> <li>• Students may not show their feelings of grief in class</li> <li>• Students may wear dark clothing and be more subdued during class</li> </ul> |

| Religious Group | How People Mourn or Honor the Deceased   | How this May Affect Your Student in Class   |
|-----------------|--|---|
| Buddhist        | <ul style="list-style-type: none"> <li>• Buddhists view death as a natural part of life</li> <li>• Attachments are discouraged because they are seen as the cause of suffering, and thus mourning periods may be relatively short</li> <li>• Buddhists believe in reincarnation meaning that a person will be reborn again after death into new life</li> <li>• The state of mind of the person as they die is very important because it affects their state of rebirth, so families will try to make death as peaceful and happy as possible. Some will wish happiness to the deceased to help their rebirth</li> <li>• Ceremonies are simple and sometimes held at crematorium chapels</li> <li>• Some Buddhists believe in a higher power, but others do not</li> </ul> | <ul style="list-style-type: none"> <li>• Students may appear to be less negatively affected by the death of a loved one. Younger children may not yet understand reincarnation or the risk of attachment and may not understand their family's re-actions, and may ask you to explain</li> <li>• Younger children may talk about their family member's reincarnation in class with other classmates</li> <li>• Students may appear peaceful and happy around the time of the death of a loved one. Other students may not understand and may ask questions about this</li> <li>• Students may begin to ask more questions about death and dying during this time, and may go to you for more information</li> </ul> |

| Religious Group | How People Mourn or Honor the Deceased   | How this May Affect Your Student in Class   |
|-----------------|--|---|
| Catholic        | <ul style="list-style-type: none"> <li>• Families pray with the sick and dedicate mass (church service) to those who are suffering</li> <li>• The sick person may be given “Last Rites” (also called Extreme Unction or Anointing of the Sick) where he/she is anointed with oil. This can happen when they are alive (preferred) or after they have passed.</li> <li>• After someone passes away, there is often a wake and a burial ceremony that follow specific religious guidelines</li> <li>• Prayers at church are sometimes dedicated to the deceased and the surviving family</li> <li>• Dedicating a service or lighting a candle in remembrance to the deceased and their family</li> <li>• Catholics believe that the spirit of people who have followed God’s will go to purgatory after death. God will then decide whether the soul goes to Heaven or Hell</li> <li>• Flowers, food, and donations are accepted ways of expressing condolences</li> <li>• Family and friends wear black or dark colors to mourn the deceased</li> </ul> | <ul style="list-style-type: none"> <li>• Students may want to spend more time at home with family during times of grief, and may struggle to focus in school</li> <li>• During times of grief students may feel more connected to their faith and may talk more openly about their faith in class. Others may feel more distanced from their faith and may feel more guilt or anger, which may manifest as isolation, sadness, or acting out in class</li> <li>• Students may miss class to attend wakes or burials</li> <li>• Students who believe their family member is going to paradise may have an easier time reaching a place of acceptance. Students who believe their family member is going to hell may struggle more with grief</li> <li>• Students may start to question their own life, faith, or mortality, and may seek guidance and support from you. Many Catholic churches have support groups</li> <li>• Wakes/funerals are typically held three days after death. A wake is a social gathering, usually held before a funeral. Traditionally, a wake takes place with the body present at the family home. Modern wakes are often performed at a funeral home</li> </ul> |

| Religious Group | How People Mourn or Honor the Deceased   | How this May Affect Your Student in Class   |
|-----------------|--|---|
| Jehovah Witness | <ul style="list-style-type: none"> <li>• Grief is considered a normal part of death</li> <li>• The dead are viewed as being unaware of their surroundings</li> <li>• Funerals and expressions of grief should be short and modest</li> <li>• Funerals may be attended by Non-Jehovah Witnesses at a Kingdom Hall</li> <li>• At the service a short talk may be given to comfort the family and explain beliefs on death and life after death. Stories of the loved one may be shared</li> <li>• There is a belief in resurrection of the dead</li> </ul> | <ul style="list-style-type: none"> <li>• Students may appear to be minimally expressive of the death. This is because showy expressions of grief are discouraged</li> </ul> |



| Religious Group | How People Mourn or Honor the Deceased  | How this May Affect Your Student in Class   |
|-----------------|---|---|
| Jewish          | <ul style="list-style-type: none"> <li>• People who are dying are never to be left alone</li> <li>• Death is seen as a part of the natural life cycle.</li> <li>• People who have passed away are believed to go to heaven to be with God</li> <li>• Autopsies, embalming, and viewing the corpse are prohibited</li> <li>• Funerals are not allowed on Saturdays or major religious holidays. Music and flowers discouraged during funerals</li> <li>• Some communities observe a 3 day period following the burial during which visitors are not received and time is devoted to lamentation</li> <li>• “Sitting Shiva” refers to the 7-day mourning period immediately following the burial. After the first 7 days, survivors are encouraged to rejoin society but still maintain mourning for 30 days. For others, mourning can last up to 1 year</li> <li>• Many mourners may wear a black pin with a torn ribbon, or a torn garment during the funeral and for the next week as a symbol of grief</li> </ul> | <ul style="list-style-type: none"> <li>• Students staying with an ill family member may have caregiving responsibilities that interfere with their school work</li> <li>• If the student did not get a chance to see the deceased after they died they may have greater difficulty accepting the death</li> <li>• Students may not want to receive flowers from their classmates, as it is not an accepted way of expressing condolences</li> <li>• Students may not be allowed to go to friend’s home to study or have classmates visit immediately after a burial, this may mean that they are more invested in talking with friends during class</li> <li>• Student’s grief may last up to a year if the family chooses to mourn for up to 1 year. This should not be seen as problematic if it is consistent with the student’s religious practice</li> </ul> |

| Religious Group   | How People Mourn or Honor the Deceased  | How this May Affect Your Student in Class  |
|---|---|--|
| Protestant<br>Includes:<br>Anglican<br>Baptist<br>Calvinism<br>Lutheran<br>Methodist<br>Pentecostal | <ul style="list-style-type: none"> <li>• Many families gather at home or at the funeral home to mourn the deceased and support the family</li> <li>• Some families may choose to bury the deceased. Others may choose to cremate the deceased and keep the ashes, or dispose of them in a ceremonial way</li> <li>• At the funeral, caskets may be open or closed. Some funeral services also include music and testimonials from those close to the deceased</li> <li>• Family and friends wear black as part of mourning</li> <li>• Protestants believe in an afterlife. They believe that the soul of those who followed God's will go to heaven, and those who commit sin go to hell</li> <li>• Flowers, food, and donations are accepted ways of expressing condolences</li> </ul> | <ul style="list-style-type: none"> <li>• Students may want to spend more time with family and may struggle to focus in school</li> <li>• Students may have strong reactions to the burial or cremation of their family member. Young children may also have questions about what happens to the physical body of the person who is deceased, and may come to you for information</li> <li>• Students who see an open casket may have strong reactions to seeing a cadaver, and may want to talk about their reactions in class</li> <li>• Students may wear more black during their mourning</li> <li>• Students may have different reactions to grief depending on whether they believe their family member went to heaven or hell, and these reactions (e.g., anger, fear, joy) may manifest in class</li> </ul> |

| Religious Group            | How People Mourn or Honor the Deceased   | How this May Affect Your Student in Class   |
|----------------------------|--|---|
| <p><b>Mormon (LDS)</b></p> | <ul style="list-style-type: none"> <li>• There are generally three services to honor the dead and console loved ones: The Visitation or Wake, the Funeral Service, and the Graveside Service.</li> <li>• Usually held in the same location as the funeral, the Visitation/Wake occurs prior to the funeral. It is often open casket and all who wish to pay respects to the dead are welcome. Family and friends may mourn privately at the end of the service and a Bishop may/may not be present.</li> <li>• Mormon funeral services generally take place in the local church building or ward and non-Mormon mourners are welcome in these buildings. Services can also be held in a family home or in the cemetery. Mourners dress in somber clothing (suits and ties for men). The service is typically conducted by a Bishop who shares thoughts and memories about the person who has died, hymns, prayers, and a sermon; often one or more family members deliver a eulogy. Hope and eternal life are typically the themes shared during the service; almost all services include evangelistic messages of atonement and the plan of salvation.</li> <li>• Funerals typically occur within one week of death are not generally held on Sundays.</li> <li>• The graveside service is usually held immediately after the funeral and is typically open to all mourners unless the family requests that it be limited to the family. Some families choose to only have a graveside service (i.e., no funeral). Graveside services are generally brief and conducted by a Melchizedek Priestholder who consecrates the site as the final resting place for the person who has died.</li> <li>• After the graveside service the family and mourners typically gather back at the church or ward and a “mercy meal” is provided by the Women’s Relief Society</li> </ul> | <ul style="list-style-type: none"> <li>• there is no set period of mourning or memorial activities for those of the Mormon faith.</li> <li>• Mormon youth are typically connected through their activities with their ward and may draw comfort from their Mormon peers.</li> <li>• Mormon’s are Christians, though they may not share the beliefs of other Christians (e.g, belief in the Trinity); this may make it difficult to share experiences with non-Mormon peers.</li> <li>• Many Mormons believe that the deceased immediately go to a spirit paradise or spirit prison upon their death and when Christ returns to earth, souls are judged again. Some youths may exhibit some anxiety if they believe that their loved one has not been admitted to paradise.</li> <li>• It is appropriate to send flowers to a Mormon family grieving the loss of a loved one.</li> </ul> |

| Religious Group | How People Mourn or Honor the Deceased  | How this May Affect Your Student in Class   |
|-----------------|---|---|
| Muslim          | <ul style="list-style-type: none"> <li>• Death is considered an act of God and is not questioned. Any expression of rebellion against God's decision to take a person away from a family is considered a sin</li> <li>• Muslims believe that the soul continues to exist after death and remains at the grave until judgment day when they will either go to heaven or hell</li> <li>• People in grief are encouraged to show their grief openly. They are encouraged to cry loudly as it is believed that crying cleans the soul</li> <li>• For 7 days, the family members are never left alone. Friends and neighbors bring food, as no cooking is supposed to be done in the family home or a funeral home during those 7 days</li> <li>• Friends visit the house of the deceased, talk with the family members, and encourage them to talk about how the death occurred and what they were doing at the time of death</li> <li>• Traditionally, there will be a prayer gathering in the home for 40 days. No television, radio, or any musical devices would be allowed for the 40 days (this practice is waning)</li> <li>• Women are not allowed to go to the graveyard. Male family members go to visit the grave daily or weekly for 40 days</li> <li>• There is religious prayer at the 40<sup>th</sup> and 52<sup>nd</sup> day after death</li> </ul> | <ul style="list-style-type: none"> <li>• Students may demonstrate greater commitment to achieve acceptance of the death of a loved one. This may be difficult for them if they are struggling with the loss</li> <li>• Male students may want to skip class to go visit the gravesites of their loved ones as a way of being close to them</li> <li>• Students may show their grief in class by crying or talking about the deceased</li> <li>• Students may have a lot of visitors during the first week after a funeral and this may make it harder for them to find a quiet place to do homework</li> <li>• Students may also want to stay at home where there is support, instead of coming to school</li> <li>• Students may want to spend more time on their phone while at school if they are not allowed to use technology at home during the 40 day mourning period</li> <li>• Male and female students may experience grief differently based on how they are allowed to mourn</li> </ul> |

## Other Forms of Grief and Loss

*Although we typically think of grief as our reaction from the death of a loved one, it actually involves a complicated set of emotions and behavior patterns. Additionally, grief can occur as a result of many different types of losses such as those detailed below. However, keep in mind, that the process of working through grief stemming from these different situations is often very similar.*

### Anticipatory Grief

Anticipatory Grief is a type of grief or bereavement that happens before the loss of a loved one occurs. In other words, it is the anticipation of loss that triggers grief. Anticipatory grief is most common among people who are caregivers or family members of people with terminal illness (e.g., cancer, Alzheimer's disease).

Anticipatory grief can begin as early as the moment a caregiver or family member learns that a loved one is diagnosed with a terminal illness, during the course of illness, or when there is notable decline in physical or cognitive health. Regardless of when it happens, anticipatory grief is common and normal. Anticipatory grief occurs because the caregiver or family member is emotionally preparing themselves for the death of a loved one.

Some people believe that anticipatory grief is the hardest part of being a caregiver. If any of your students are caregivers or have a family member with terminal illness, they may be experiencing anticipatory grief. This type of grief can also affect teachers who know students with terminal illness as well as students who have classmates with terminal illness. Students with terminal illness themselves can also experience anticipatory grief regarding their own loss.

### Complicated Grief

The stages of grief represent normal and common responses to grief. If, however, a person gets stuck in any one stage and is not able to move toward acceptance in a reasonable amount of time, they may be experiencing Complicated Grief, also known as Persistent Complex Bereavement.

Complicated grief is bereavement that is so severe it does not get better and/or worsens with time. It is often experienced as prolonged, constant, and debilitating emotional pain that interferes with a person's daily life. Often, one or more areas of a person's functioning (e.g., academic, social, day-to-day functioning) is significantly affected by their grief in a negative way.

### *Common Signs of Complicated Grief:*

- Extreme sorrow and longing for the deceased
- Intrusive thoughts or images of the individual's loved one
- Focus on little else other than the loved one's death
- Extreme denial of the loss
- Extreme avoidance or extreme focus on reminders of their loved one
- Extreme anger and bitterness over the loss
- Feeling life is empty or meaningless
- Extreme numbness or detachment from others
- Inability to enjoy life or recall positive memories of the loved one
- Difficulty carrying out normal routines
- Withdrawal and isolation
- Extreme, unwarranted self-blame
- Frequent bouts of crying
- Thoughts that they should have died instead or thoughts of suicide
- Repetitive and circular conversations around death or loss

### *Risk Factors for Complicated Grief*

While there is no known cause of complicated grief, there are specific factors that may increase the likelihood that someone will develop this type of severe bereavement. Below is a list and description of common factors that can increase a person's risk, but know that none of these guarantee that complicated grief will develop.

- **Suddenness of the death-** Those whose loved one died unexpectedly or suddenly are at greater risk of developing complicated grief
- **Violent deaths-** People whose loved one died in a violent or graphic way (e.g., with the use of weapons) are at greater risk
- **Self-blame-** People who blame themselves for their loss and have difficulty assessing their actual level of control and responsibility are at increased risk
- **Relationship to the deceased-** People who had a close relationship with the deceased are more likely to experience complicated grief
- **Gender-**Females are more susceptible to complicated grief than males
- **Vulnerability to mood and anxiety disorders-** People who are vulnerable or who have a history of depressive or anxiety disorders are at greater risk of developing complicated grief

***IMPORTANT NOTE:*** *If you notice any of these signs in your students or believe a student is at a heightened risk of developing complicated grief, take immediate action by talking to the student and their parents or guardians about complicated grief and consult with the counselor at your school to obtain a referral to a mental health expert in your area.*

## Other Events Causing Grief and Loss

It is important to note that loss is not only defined as the death of a loved one. Loss and therefore grief can be experienced from other life events in which a person experiences some significant change. The following is a brief but not exhaustive list of other possible type of loss:

- Loss of a friendship or relationship
- Loss of a pet
- Divorce
- Moving or relocation
- Deployment of a family member
- Incarceration of a family member
- Deportation of a friend or family member
- Natural disasters
- Developing a disability, diagnosis of serious or life-threatening illness

## Special Circumstances Surrounding Death

Many experiences with loss are a part of the natural life cycle; part of what it means to be human. Generally, we expect that death will occur due to old age or perhaps due to a prolonged terminal illness. There may even be some relief of suffering in these deaths. There are also circumstances that are more complicated where grief is layered with fear, confusion and shock. Below are some examples of these special circumstances:

### Suicide

Suicide creates a unique set of issues that complicate loss and produce strong emotions. Feelings of guilt, rejection and embarrassment are common. After a suicide has been confirmed, teachers should provide opportunities for grief support by helping students cope with their feelings and focus on simple tasks related to their education. Something else to keep in mind is suicide contagion: the process by which one suicide may contribute to another suicide or accident. Contagion accounts for between one and five percent of all suicide deaths annually. Adolescents are particularly susceptible to imitation because they tend to relate more strongly to their peers.

## **Violent Death**

A death that occurs due to unnatural circumstances or violence can have special complications. If the death involved a crime, expect some publicity, police involvement, and collecting of evidence. Furthermore, criminal investigations may continue on for many years afterward, especially if there is a court case pending. For the student and their family, there can also be an unconscious and illogical sense that once the investigation or court case is over, that the loved one will return. In addition, well-meaning members of the community may choose sides or promote vigilante justice. These actions only prolong the grief and distract from the real work of accepting death and letting healing begin. Whenever possible, be supportive and listen to the student if they should vent frustration with the process.

## **Death of a Classmate**

Death of a classmate is as upsetting for the students as it is for the teachers, parents, and administration. Regardless of the relationship of the classroom friendships, the loss of a peer brings in the possibility that the grieving child is also vulnerable to death. It is important to keep dialogues of grief open. Encourage students to share their memories and their experiences with grief. Be open to collaborating with the students on how to best honor their deceased classmate. A small ceremony of remembrance can be helpful to the students and school community.

## **Death of a Teacher or Other School Staff Person**

Death of a teacher can be a traumatic event for a child and can often be complicated by the shared grief of the educational support system around them. During this time, it is particularly important to keep daily routines as stable as possible but also flexible. Make sure to inform students, parents, and staff about the death as soon as possible with basic information. Hiding this information can create an atmosphere of rumor and speculation.

## **Death of a Military Service Member (Parent or Older Sibling)**

Death of a loved one who has served in the military is complicated. Feelings of grief or loss may already be present due to stressors related to deployment. Adjusting from the idea of a short time apart (months or years) to the idea that that family member will not return, may take a student some extra time to comprehend. In some incidents (i.e. classified missions), students may not know the circumstances around how their loved one died. Whenever possible, be supportive



and listen to the student if they should vent frustration in the process. It is very important that the student is connected with local military support systems.

## **Conclusion**

In closing, the best way to support your student's grief is to gain an understanding of grief yourself and to consider what your students may be experiencing and why. Hopefully, the material we have presented has added to your understanding of the different ways people grieve, the stages of grief, and the different types of losses we encounter. The charts that outline developmental and cultural factors should help you to respond to the various ways your students may show their grief. It is this curiosity and genuine interest in your students that will be the most powerful force in strengthening your connection and aiding with their grief.

## Grief Resources

*Below is a list of national and local resources for general issues related to grief. A complete description of each resource and contact information can be found in Module 6: Resources.*

### National Resources:

- Ambiguous Loss
- American Foundation for Suicide Prevention
- The Center for Complicated Grief
- Centre for Cultural Diversity and Ageing
- Children's Grief Education Association
- The Dougy Center
- Grief Speaks
- Kids Health: Helping Your Child Deal with Death
- Mayo Clinic
- National Alliance for Grieving Children
- National Center for School Crisis and Bereavement
- National Child Traumatic Stress Network
- New York Life Foundation
- PBS Parents; When Families Grieve
- Sesame Street Tool Kits for Parents and Caregivers
- Support After a Suicide
- VITAS Healthcare
- Youth.gov

### San Diego County Resources:

- Camp Erin San Diego
- Center for Compassionate Care of Elizabeth Hospice
- Chadwick Center for Children & Families
- Hope After Project
- Rady Children's Behavioral Health Urgent Care
- SOSL: Survivors of Suicide Loss
- USC Suzanne Dworak-Peck School of Social Work: National Center for School Crisis and Bereavement

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## Young Caregivers

*You may not know it, but you are likely to have young caregivers in your classroom or coming to your counseling offices. These are young people under the age of 18 who find themselves taking care of people who would typically be cared for by an adult. This includes impaired siblings, parents, grandparents or other adults in their lives. These caregiver responsibilities can be hard to manage – especially if teachers and counselors are not aware that their students are filling these roles.*

### Who are the Young Caregivers?

In 2005, a national report was published in which it was estimated that there were 1.3 to 1.4 million family caregivers under the age of 18 in the US (National Alliance for Caregiving and United Hospital Fund, 2005). These are young people who are providing assistance to family members – siblings, parents, and/or grandparents or other relatives – who need help because of a physical or mental illness/disability, or substance use. However, it is likely that this estimate is now a gross underestimation of the number of young people providing assistance to loved ones. Each day, 10,000 baby boomers reach age 65 in the US, and advancing age is a significant risk factor in the development of disease, resulting in more adults needing care. Additionally, greater numbers of older adults are raising their grandchildren, many of whom have health issues of their own. This increases the likelihood of young people being raised in an environment in which they need to provide care to the adults in their lives, often without anyone acknowledging that they are doing so. Yet, the burdens these young people carry are surely brought with them into the classroom where teachers and school counselors must navigate the behaviors and emotions associated with these stressors.

### Demographic Characteristics

The limited research on young caregivers in the US has focused on those who are between the ages of 8 and 18, but they can be younger. They are equally likely to be male or female, and although they include children and adolescents from all ethnic groups, they are more likely to come from ethnic minority backgrounds, living in lower income and single-parent households. But it is important to recognize that young caregivers exist because there is a family need – and that includes families from all walks of life.

### Caregiving Tasks

What kinds of tasks do young caregivers perform? We typically divide caregiving into two types of responsibilities: Activities of Daily Living (ADLs), which involve

intimate care such as bathing and feeding; and Instrumental Activities of Daily Living (IADLs), which consist of those activities that are necessary for independent living but not necessarily for fundamental functioning, such as meal preparation and household chores. Young caregivers can provide assistance with a wide range of tasks, even those that require skills that may be way beyond their years.

### Caregiving Tasks Include:

*Personal Care* – bathing, feeding, grooming; getting someone in/out of bed or walking from one place to another; transferring family members from beds to wheelchairs or other equipment

*Emotional Care* – listening empathetically, calming/soothing others, and watching over those in need of care

*Household Tasks* – laundry, dusting, vacuuming, cooking and shopping

*Financial Assistance* – paying bills, talking with bill collectors, making deposits at the bank-in some cases, young caregivers may contribute financially to the household

*Medical Assistance* – medication management; serving as a liaison to medical professionals and making medical appointments; navigating insurance; obtaining needed medical equipment

*Interpersonal* – translating information for family members who do not speak English

*Vigilance* – watching over an older adult to keep him/her safe. For example “keeping an eye on” a grandparent while a parent runs to the store

### Household Chores vs. Family Caregiving

How do we know the difference between a young person who is just “helping out” at home and a young person who has assumed the caregiver role? This is very difficult to do. Most young people have chores that they must complete to assist with the functioning of the family household. However, what starts out as assisting a family member now and again can evolve into more adult-like caregiving responsibilities for children or adults in the family. Young caregivers have been

shown to help with such intimate care as feeding, toileting, and grooming; more commonly, they provide much needed assistance with housekeeping, meal preparation, and running errands. Additionally, whereas it may be fairly easy to identify a caregiver when an abrupt health incident has occurred, such as a heart attack or stroke, it is more difficult to do when the transition is gradual. “Caregiving creep” occurs when a young person slowly takes on the caregiver role, making it exceedingly challenging for professionals to classify a young person as a caregiver. In both situations, the abrupt transition and the caregiving creep, it may be difficult for young people to recognize that they have become caregivers and need help.

### **Signs that a Student May Be a Young Caregiver**

Research conducted in the United Kingdom (Carers Trust, 2017) provides excellent information about the identification of young caregivers. Some of the behavioral signs include:

- Being late to class or missing days of school
- Tired, anxious or withdrawn
- Very mature for their age
- Isolated
- Not completing homework on time or submitting poor quality work
- Secretive about home life
- Anxious or concerned about an ill/disabled relative

A Word document containing a checklist for characteristics of Young Caregivers (called “carers” in the UK) is available from the Carers Trust at:

<https://carers.org/resources/all-resources/34-supporting-young-carers-in-schools-a-toolkit-for-initial-teacher-education-providers>

### **Why Don’t We Know More About Young Caregivers?**

Young caregivers have been called, “the forgotten generation.” Despite the large number of studies focused on adult caregivers, the US has not recognized the role that young people have played in family caregiving. This may be due to stigma about being a caregiver, reluctance of families to admit that they are relying on the assistance of a minor, fear of being reported to child protection authorities and having children taken away from the family, or just a failure to recognize the contributions that young people make to family caregiving.

## Impact of Caregiving on the Young

### Mental Health

How does caregiving impact their mental health? Young caregivers often report being stressed, worrying about family members, and feeling more mature than their non-caregiving peers. Because children and adolescents of various ages exhibit stress and depression in different ways, it is often challenging for teachers to recognize that both acting-out and internalizing behaviors may be the result of family caregiver burden.

### Physical Health

How does caregiving impact their physical health? When young people are performing tasks such as lifting an adult, it is possible to experience physical injuries. Young caregivers may be living in households that are relying on fast food because they don't have the time/energy to prepare healthy meals. These conditions can impact the physical health of young people. Additionally, recent research focusing on high school students who have assumed caregiver roles for siblings, parents, and/or grandparents shows that young caregivers are more likely to report recent drug or alcohol use than non-caregiving peers. Studies have just begun to examine how caregiving may compromise the physical health of young people.

### Education and Academic Achievement

How does caregiving impact education and academic achievement? Young caregivers have reported impacts of caregiving on their education in a variety of studies. The national report revealed that one in five young caregivers say their caregiving has made them miss a school activity or an after-school activity (20%), 15% say it has kept them from doing school work, and 8% say it has made them miss homework. In a large study of young caregivers in Florida, more than one third (37.7%) stated that it affects their academic performance by missing school or after school activities, being unable to complete their homework, and making it difficult to think or study due to interruptions.

The fact that caregiving is related to poorer mental and physical health, and can interfere with students' education, suggests that we must acknowledge young caregivers and strive to support these young people so they may grow to be resilient and successful. Research does show that there are some positive outcomes from family caregiving such as being more empathetic and having a greater sense of

commitment to others; we need to enhance these positive outcomes and find ways to help our students so that they, and their families, can enjoy the highest quality of life possible.

## Conclusion:

### What Can We Do To Help Young Caregivers?

The most common response that young caregivers give to this question is that they just want someone to know about their caregiver role, to listen, and to understand. They aren't asking for special treatment or using their caregiver role as a reason for not completing homework. But the truth is, teachers and counselors will likely need to find ways to make accommodations when necessary, such as when a family member is hospitalized. Young caregivers are like adult caregivers in this way; adults take on the caregiver role and all that it encompasses because that is what family members do, but still need support, compassion, and understanding.

Education is the key to helping young people to understand the caregiving challenges they are facing. This often requires some basic knowledge of health conditions; Module Three provides a quick guide to this type of information. However, it is important to recognize that the sharing of knowledge regarding family members' health conditions must be done in a developmentally appropriate way. Let the young person guide you. Never offer information (e.g, this type of cancer is usually terminal); rather, respond with clear, simple information and supportive language when a student asks you a question. Modules 4, entitled *Helping Grieving Students and Managing Classroom Behavior*, provides practical tips on how to provide a safe, welcoming, and supportive environment for young caregivers.

## Resources and Further Reading

*A complete description of each resource and contact information can be found in Module 6: Resources.*

### Activities and Materials to Support Young Caregivers

*Worksheets and more Resources for each of on the activities listed here can be found in Module 6: Resources.*

- I wish My Teacher Knew...
- Teacher/ Counselor Communication Form
- Art Heals Activities
- Gratitude Diaries and Lists for Positive Living
- Mindfulness activities and links to YouTube and insighttimer
- UCLA, YouTube video on the scientific evidence for mindfulness

### National and International Resources

- American Association of Caregiving Youth
- American Association of Retired Persons (resources for family caregivers)
- Carers Trust: Young Carers (for young caregivers)
- Carers Trust: Young Carers in School (for schools)
- Family Caregiver Alliance

### San Diego County Resources

- 211 San Diego
- Aging and Independence Services, San Diego: Family Caregiver Support Program
- Al-Anon and Alateen Programs
- Southern Caregiver Resource Center
- YMCA Kinship Program

### Web-based Tools for Young Caregivers

- Lotsahelpinghands – Caregiver Calendar
- National Caregiver Library: Tools for caregivers Plan Your Lifespan
- PACT Toolkit for Children of Parents with Cancer
- United Hospital Fund: Next Step in Care

## School Resources

- American Association of Caregiving Youth
- Carers Trust, United Kingdom

## Resources for Ill Adolescents

- The Clarity Project
- CureForward
- The Road Unpaved

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## Teachers and Counselors as Information Resources

*When students face illnesses or deaths in the family, they are dealing with many confusing, stressful, and sometimes frightening experiences. These students often turn to people they trust for information... and that most definitely includes teachers and counselors. In fact, teachers and counselors are often the first people that students confide in when they are facing significant challenges. As educators, we know knowledge is our most powerful weapon to help broken and confused hearts. This module provides much-needed information and insights into some of the difficult topics that may arise. The illness of a loved one is one of the most challenging events any of us face, and this certainly is the case with our students.*

### Acute versus Chronic Illness

It is first important to note the difference between illnesses of a short duration and those that last longer. **Acute** illnesses or injuries occur suddenly, last a short time but can be severe. Examples include getting strep throat, pneumonia, the flu, or breaking a bone. **Chronic** conditions develop over a longer period of time and can worsen as time goes on. They include such conditions as heart disease, diabetes, cancer, and osteo-arthritis. Coping techniques will vary with each type of condition and may make it necessary for a teacher to make a number of sudden, short term accommodations for a student (e.g., when a family member has been in a car accident) or develop a plan for longer-term coping strategies (e.g., when a family member is diagnosed with some types of cancer).

### Helping Students to Understand Diseases: Types of Illnesses

**Cancer** – This is a general term for a number of related diseases. All types of cancer involve the uncontrolled division of cells somewhere in the body. These cells then spread to surrounding tissue. There are a number of different kinds of cancer and the likely outcomes (i.e., prognosis) for patients will vary considerably. It is important to recognize that cancer is not always a death sentence for the patient. Some common types of cancer include breast cancer, leukemia (cancer of the blood), and skin cancer.

**Heart Disease and Stroke** – Heart disease is the general term for numerous heart and blood vessel problems. These problems are usually related to atherosclerosis, a build-up of plaque in the walls of the arteries. Plaque is a waxy substance that builds up in the arteries over time. When there is a lot of plaque in the arteries, it is difficult for blood to flow through; this condition can result in a heart attack or stroke.

***Cardiac Arrest*** – A malfunction in the heart’s electrical system. The heart suddenly stops working the way that it should. This may be caused by abnormal heart rhythms (see arrhythmia, below).

***Heart attack*** – This occurs when a blood clot blocks the blood flow to a particular part of the heart. When this happens, the heart muscle begins to die.

***Congestive Heart Failure*** – The heart is not pumping blood as well as it should. This means that the body is getting less blood and oxygen than it needs.

***Arrhythmia*** – This is an abnormal rhythm of the heart – it beats too fast or too slow.

***Ischemic stroke*** – This is the most common type of stroke. When a blood vessel that feeds the brain gets blocked, a blood clot forms and prevents the blood from reaching the brain. When this happens, the brain cells in that part of the brain die.

***Hemorrhagic stroke*** – This occurs when a blood vessel in the brain bursts. This type of stroke is most likely due to uncontrolled high blood pressure (hypertension).

***Dementia*** – This is the general term for a decline in mental ability that is severe enough that it interferes with our ability to carry out our daily lives. Some types of dementia that fall under this umbrella term are Alzheimer's disease, vascular dementia, dementia with Lewy bodies (DLB), Parkinson’s disease, frontotemporal dementia, Creutzfeldt-Jakob disease, Huntington’s disease, and Wernicke-Korsakoff Syndrome. The two most common forms of dementia are:

***Alzheimer’s Disease*** – This is the most common form of dementia (approximately 60-80% of all dementia cases). People who suffer from AD experience memory loss, difficulty with judgement, personality changes, and communication problems. They can also exhibit significant behavioral problems including becoming violent or displaying inappropriate sexual behavior. This disease is progressive and ultimately leads to the death of the patient. The onset of this disease is gradual and it gets worse over time.

***Vascular Dementia*** – This form of dementia occurs after a stroke and is the second most common form of dementia. Inadequate blood flow to areas affected by the stroke lead to brain cell death in those areas. Although these patients experience

many of the same symptoms as AD patients (e.g., memory loss, confusion and disorientation), the onset is sudden.

More information on the various forms of dementia can be found on the Alzheimer's Association's website (see Module 6: Resources).

**COPD** – Chronic obstructive pulmonary disease (COPD) is a progressive, chronic disease that makes it hard for a person to breathe. "Progressive" means the disease will get worse over time. Examples of COPD include emphysema (gradual damage to the air sacs in the lungs) and chronic bronchitis (inflammation of the bronchial tubes in the lungs).

**Diabetes** – Diabetes is a disease in which the body does not appropriately process sugar. Our diets contain different types of sugar that are necessary for good health. The pancreas produces a hormone called insulin, which helps the body to process the sugar. Diabetics do not produce enough insulin naturally so the sugar from food builds up in the blood. Diabetics take additional insulin to help their bodies process this sugar properly.

**Influenza** -- Influenza (i.e., the flu) is a highly contagious viral infection of the respiratory passages affecting the nose, throat, and lungs. It can cause fever, severe aches, and phlegm, and often occurs in epidemics. Influenza can lead to death in some populations including young children, the elderly, pregnant women, and people with certain chronic conditions (e.g., asthma).

**Pneumonia** – Pneumonia is an infection of the lungs that is caused by bacteria, viruses, or fungi. In this condition, the air sacs in the lungs become inflamed, fill with pus, and make it difficult to breathe. Inflammation may affect both lungs (*double pneumonia*), one lung (*single pneumonia*), or only certain lobes of the lungs (*lobar pneumonia*).

**Kidney Disease** -- Your kidneys filter extra water and wastes out of your blood, make urine, and help your body to control your blood pressure. When you have kidney disease the kidneys can't filter your blood like they should. This can cause wastes to build up in the body to dangerous levels. Kidney disease is often associated with other diseases such as diabetes and heart disease.

## Helping Students to Understand Medical Treatments

When a student or his/her family member has an illness, it is likely (though not always the case) that the family will pursue treatment. It is important for you to have some understanding of what kinds of treatments the student is dealing with when a loved one is ill.

**Radiation** – Radiation therapy uses x-rays or other types of radiation to kill or damage cells in the treatment of disease, especially cancer.

**Chemotherapy** – This is a type of cancer treatment that uses drugs to destroy the cancer. Chemotherapy works by slowing or stopping the growth of cancer cells, though it can also impact healthy tissue.

**Dialysis** – Dialysis is the artificial process of removing excess fluid, salt, and harmful waste from your body. A special machine is used to do what damaged kidneys cannot do. Patients typically undergo dialysis multiple times a week, a couple of hours each session, to remove these wastes from the blood.

**Oxygen Therapy** – Some diseases can prevent a person from getting enough air. Oxygen therapy provides a patient with extra oxygen. Oxygen therapy can be delivered through a tube put into the nose or a facial mask and attached to an oxygen tank. It can be administered in a hospital or at home for those with chronic conditions.

**Physical Therapy** – Physical therapy is used to preserve, treat, or restore physical movement that is compromised by disease, injury, or a disability. Physical therapists use specialized exercises, massage, and other kinds of treatments (e.g., heat) to help patients to improve or regain physical abilities.

**Occupational Therapy** – Occupational therapists work with people who have physical and/or mental limitations to develop ways to be able to take care of themselves. Whereas physical therapy treats the actual physical impairment that a patient is experiencing, occupational therapy takes a whole person approach and focuses on a person's ability to perform activities of daily living that allow us to function independently. These include activities like bathing, toileting, eating and walking as well as housekeeping and meal preparation.

## Helping Students to Understand How Health Care is Provided

Currently there are a number of efforts underway to help people understand their healthcare and make informed decisions about the kinds of care they do/do not want. This requires patients to have conversations with their doctors and their loved ones so they can make the decisions that are best for themselves. Students may speak with teachers or counselors about these documents, so it is important to understand what these documents address. It is also important that education professionals remain aware of the different approaches to healthcare delivery for the seriously ill, and the different kinds of settings in which their family members may be receiving healthcare. Each of these topics is addressed below.

### Documents that Ensure a Patient's Health Care Wishes are Honored

***Do Not Resuscitate*** – When a person is in poor health or is quite old, he/she may elect to have a “Do not resuscitate” order placed. The pre-hospital DNR form, signed by patients (or their legally recognized health care advocate if unable to do so themselves), and their doctor, indicates that the patient does not want to be resuscitated if the patient suffers a cardiopulmonary arrest (the heart stops beating or the patient stops breathing). Emergency personnel (e.g., paramedics) should not start cardiopulmonary resuscitation (CPR) on someone who has a signed, legal DNR form as long as the form is shown to them when they arrive. It is recommended that a DNR stay with the patient at all times. It should be kept in an easy-to-find location (e.g, the refrigerator door) so emergency personnel can find it, and a copy should be kept in their medical chart and local hospital. Even if a person has a DNR and emergency medical personnel do not start CPR, they will do everything they can to make the patient comfortable and may provide other kinds of treatment for conditions short of a cardiac arrest.

***Physicians' Orders for Life-Sustaining Treatment (POLST)*** – The POLST form is a medical order, signed by a physician, nurse practitioner or physician's assistant, which outlines the kinds of medical treatments a patient does/does not want. The top section of POLST is similar to a DNR, except that people can also say that they ***do*** want CPR. In addition to indicating whether CPR should be performed on the patient in the event of a full cardiac and respiratory arrest, it also includes goals of care ranging from full treatment to selective treatment (treating curable conditions but avoiding overly burdensome measures) to comfort-focused treatment.

POLST also includes decisions about artificial nutrition and hydration, such as feeding tubes or intravenous (IV) lines. POLST is most appropriate for people who are seriously ill, terminally ill, or of advanced age and who are, based on their health condition, expected to die within one year. Information on POLST can be found at the National POLST Paradigm website:

<http://polst.org>. POLST requirements, form names, and specific items considered, will differ by state. This website provides specific information on the State of California requirements.

## Advance Health Care Directives

This is a legal document that specifies what kind of health care a person wants/does not want and in the case that he/she cannot speak for him/herself, who should make those decisions on the patient's behalf. There are two parts to the document:

**Health Care Advocate** – (Also called the *Durable Power of Attorney for Health Care*) The patient designates who will be responsible for making health care decisions for the patient when he/she is unable to do so.

**Living Will** – In the second part of the document, the patient may specify the kinds of treatment he/she wants or doesn't want such as cardiopulmonary resuscitation, mechanical ventilation, transfusions, or tube feeding.

Versions of this document can be found on the internet and are free. You do not need a lawyer to complete this document and it becomes legally-binding when you have two witnesses sign the document. These documents do not expire and can be changed at any time. A person just needs to be sure that his/her physician and health care advocate have the most recent versions and that previous versions of the document are destroyed. For more information on Advance Directives, visit the Coalition for Compassionate Care of California (See Module 6: Resources).

## Physician-Assisted Dying

As of June 9, 2016, California state residents who are terminally ill (expected to die within six months) may elect to obtain a physician's help in ending their lives through the use of physician-prescribed drugs under the End-of-Life Option Act. This may be called by other names (e.g., Death with Dignity, Physician-Assisted Dying) and is still illegal in most states. In California, there are a number of legal requirements surrounding Physician Assisted Dying. The patient must consult with two physicians who agree that the patient is terminally ill and within 6 months of death, the patient



must have decision-making capacity and not be suffering from a mental disorder that impairs their ability to understand this decision, and must be able to administer the drug him/herself. No one can make the decision for another person to end his/her life. Students may experience situations in which a loved one has elected to die by taking medication prescribed by a physician. It is important that families receive clear information and support about this legal right as the impact of a loved one's Physician-Assisted Dying on the young has not yet been established. The physician can refer the student to an appropriate mental health professional, if necessary.

It is also important that education professionals be sensitive to moral and religious differences regarding this law when talking with students whose family members may elect to exercise their legal right to die. More information about the law can be found at the Coalition for Compassionate Care of California website: <http://coalitionccc.org/tools-resources/end-of-life-option-act/>. Whereas it is important for all education professionals to know about this law so that they can be informed should their students bring up this subject, it is important not to take a position on the law (i.e., remain neutral) in these conversations so as to respect the student and his/her family.

### **Refusal of Treatment**

An adult patient may refuse medical treatment. To do so, he/she must be well-informed to make the decision, have the decision-making ability to understand the consequences of refusing treatment, and make the decision without being manipulated or coerced by others. Dr. Steve Pantilat of the University of California, San Francisco has provided good information on a patient's right to refuse medical care: <https://www.the-hospitalist.org/hospitalist/article/123300/dying-wish>

## **Approaches to Health Care for Serious and Terminal Illness**

**Hospice** – Hospice is a specific type of care for patients who likely have 6 months or less to live. Patients do not seek a cure for their disease while on hospice; rather, the focus is on keeping the patient comfortable and addressing physical, emotional, psychosocial, and spiritual needs. Patients receive palliative care (see below) while on hospice so that symptoms are reduced and patients and their families enjoy the highest quality of life possible during this stressful time.

**Palliative Care** – Palliative care relieves suffering and improves quality of life for people of any age and at any stage in a serious illness. The illness does **not** have to be life-threatening. The focus is on reducing symptoms so that patients can enjoy the

highest quality of life possible. To accomplish this, health care professionals (doctors, nurses, social workers, chaplains, and other health care professionals) work as a team to provide an extra layer of support to patients by addressing their physical, emotional, psychosocial and spiritual well-being. Palliative care can include traditional medical therapies such as chemotherapy as well as alternative therapies such as aroma therapy, acupuncture, and pet therapy. This type of care takes a holistic approach and the patient's quality of life is at the heart of the treatment.

## **Facilities that Provide Health Care Outside of the Home**

**Hospitals** – Hospitals provide medical treatment for ill or injured people. Patients who are treated as “in-patients” are admitted to the hospital for treatment; those who get “out-patient” treatments get the treatment at the hospital without being admitted.

**Nursing Homes – Also called Skilled Nursing Facilities** (SNF pronounced “sniff”). These facilities provide nursing care for individuals outside of a hospital and are typically large, hospital-like settings where medical services are performed. Services include 24-hour nursing care, recreation, and help with daily activities. National averages are 109 beds per nursing home facility. Medicare pays for up to 100 days of care but the patient must be referred by a physician. SNFs are covered by Medicare/Medicaid and are regulated by the federal government. Nursing homes participating in Medicare or Medicaid must comply with federal regulations for long-term care facilities.

**Residential care for the elderly (RCFE)** – Often called board and care facilities or Senior Group Homes. RCFEs are non-medical facilities where elderly persons, age 60 or older, can get meals, a room, housekeeping, and assistance with personal care. There are usually up to 6 residents at the facility. These are not medical facilities and they are not covered by Medicare (though Medicaid or Social Security may be used for payments).

**Assisted Living Facilities** – Assisted Living Facilities are also known as Residential Care Facilities. They are designed for people who have difficulty living alone but do not need daily nursing care; occupancy generally ranges from 40 to 100 people. Services include meals, board, light housekeeping services, transportation to appointments, and social and recreational activities). Medicare does not pay for this but Medicaid may be used for services.

## Health and Illness Resources

### Activities and Materials

*Worksheets and more information on the activities listed here can be found in Module 6: Resources*

- I wish My Teacher Knew...
- I need information about...

### Resources

*A complete description of each resource and contact information can be found in Module 6: Resources.*

- Aging and Independence Services – San Diego County
- Alzheimer’s Association
- American Cancer Society
- American Diabetes Association
- American Lung Association
- American Heart Association
- California Coalition for Compassionate Care
- California Advance Directive form.
- End of Life Options Act: University of California Consortium on Law, Science and Health Policy.
- Get Palliative Care
- Influenza: Centers for Disease Control
- National Institute of Diabetes and Digestive and Kidney Diseases
- National Hospice and Palliative Care Organization
- Southern Caregiver Resource Center

### **IMPORTANT NOTE: Online Resources Regarding Health and Illness**

Although there are many great resources on health and illness available through the internet, we have to be careful that we are getting our information from trusted sources. Now that students often use on-line sources for healthcare information, they may not be savvy enough to determine whether the site is a legitimate source of healthcare information. The student should be told that any information they find is NOT a substitute for talking with a doctor and that they should share information they've found with their parents and doctors. These sites are respected sources of healthcare information; even so, the information from these sites should be shared with a doctor and not used as professional medical advice.

- Centers for Disease Control (CDC) <https://www.cdc.gov/>
- Familydoctor.org <https://familydoctor.org/>
- Mayo Clinic <http://www.mayoclinic.org/>

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## Helping Students and Managing Classroom Behavior

*It can be challenging to manage a classroom of students in the best of circumstances, but what do you do when there is a student in crisis? How can you help the student? How can you help your class as a whole? How can a counselor offer the best support, including knowing when is it time to seek outside assistance? The following provides an at-a-glance guide for these questions.*

*This module is divided into three sections: (1) How can I help an individual student? (2) How can I help my class? and (3) When is it time to get outside help?*

### How Can I Help An Individual Student?

#### Foundations for Providing Help

There are easy ways that you can help your students. These responses to their crises will help set the stage for positive interactions and building students' resiliency.

**Listen** – Many people will attempt to “fix” feelings of grief and quickly return to normal, but this can be counterproductive. Silence is our best tool. Answer questions as they come up, use the students' own words to reflect back, and acknowledge their feelings. Also, be a good role model by expressing your own emotions in healthy ways and practicing self-care.

**Use Creative Expression** – Art, writing, music, or creative play can be effective tools for creative expression. Craft materials like crayons and paper, paint, and tactile products like clay are terrific for creative expression. Older students may want to express themselves through writing or drawing, and this is a great way to deal with stress, grief, and loss. Allow for creativity to take over and get messy. Finding ways to use art as expression can be helpful in positively redirecting the emotions of grief.

**Encourage Movement and Play** – Physical activities like running, jumping, climbing, and team sports that use large muscle groups can also be a healthy use of extra energy putting the energy that fuels feelings associated with grief. For older students, encouraging them to “walk and talk” with a trusted adult can provide opportunities to exercise and talk about their challenges in a non-threatening way.

**Create routine** – Finding ways to create safety and predictability is helpful for children and adolescents, and can help stabilize feelings of instability.

*Be flexible and compassionate* – When the student returns to the classroom, give reasonable amounts of time to complete missed work. Whenever possible, allow the student to participate in a schedule for turning missed work.

## Your Response to Student Needs

### Empathy

Empathy, at its core, involves understanding a person's emotional experience from their perspective rather than your own perspective. By communicating and expressing your empathy, you offer support, validation, and respect for the student's own unique experiences of grief (see Wiseman, 1996). Based on the work of Wiseman, Brené Brown outlined the four main qualities of empathy in a useful video: <https://www.youtube.com/watch?v=1Evwgu369Jw>

1. Taking the perspective of another person
2. Staying out of judgement
3. Recognizing emotion in other people
4. Communicating that emotion to others

These qualities can be displayed through empathetic responses and non-judgement.

### Empathetic Responses

One of the most difficult instances teachers and counselors encounter is how to respond when a student discloses that someone is ill or has died. Examples of empathic responses to disclosures of terminal illness or loss include:

- I'm sorry for your loss ...
- I'm so glad you shared that with me ...
- How can I support you?...
- Loss can be difficult. You don't have to do this alone...
- Terminal illness can bring up a lot of difficult questions and emotions. Let me know how I can support you navigating those...
- Take the time you need ...
- I'm here for you...
- It's okay to feel what you feel...
- I may not have all the answers but I am here to hear you and support you in whatever ways I can...



## Empathetic Listening

When a student shares with you that someone they love was diagnosed with a terminal illness or has passed away, it is important that your first response is to listen. The kind of listening that is needed when someone has shared something very painful is active listening, which is different than the kind of listening that we do in typical conversation.

When listening actively or empathically, you should **be free of distractions** so that the student knows they have your full undivided attention. You should **listen patiently and quietly** as they share what has happened or what is happening with you. It is important that you give the student the time he/she needs to express him/herself fully before you respond. Demonstrate that you are listening and following along by using non-verbal behaviors like **making eye contact or nodding along**. Focus on the **words and the emotions** being communicated to you so that you understand and hear the student's full experience, rather than focusing on what you will say next.

After the student shares and you have understood what has been communicated, be sure your responses demonstrate empathy, non-judgement, and understanding. It can be helpful to share a similar experience of loss with your student, but keep the details brief and time spent on your experience short. Something like, "When my grandfather died, I felt very sad too" or "When I was your age, I lost an important person in my life too." Keep in mind, this is an important time to focus on the student's own experience of grief.

## Non-judgmental Acceptance

Holding a non-judgmental stance on your student's grief response is also important. Students may behave in various ways including reactions like denial, anger, and acceptance that may not make sense to you. Students may also demonstrate unique bereavement practices that are different than your own. Regardless of whether you fully understand your student's initial reactions to grief or their mourning practices, you can still offer support by embracing a non-judgmental and accepting understanding of them.

Non-judgement requires that you first must practice empathy. This will help you to understand that others may have different reactions than your own that are neither "good" nor "bad" – just different. It also acknowledges that students react in ways that make sense for them and that they are responding the way they are for specific reasons that may not be clear to you.

If you notice your student reacting in ways that are potentially harmful to them or problematic, it is better to talk about it in neutral terms or frame it as “unhelpful” rather than “bad.” For example, a student may want to scream and throw things. This could be framed as “unhelpful” but not bad. It is unhelpful but not bad because it still communicates something about what the student feels (anger) and needs (an outlet for anger). This can also provide teachers an opportunity to validate anger and offer an alternative outlet. Students may struggle to make sense of terminal illness or death, especially those who are younger, and this may be why they are responding to loss in ways that are not helpful (e.g., acting out in class). However, it is still important that you do not judge them so the students have the freedom to work through their grief in healthier ways without shame or fear.

### Support Students of Diverse Cultures

Perhaps one of the biggest challenges for teachers and counselors is how to respond to students’ grief or struggles when they come from very different cultural or religious traditions from our own. Here are some general recommendations for how to offer support that is both culturally sensitive and respectful.

#### Ask Questions

When you are unfamiliar with a student’s culture or religion and are not sure how a particular family will respond to death, you can start by asking the family general questions about what they might find most helpful from you. This is the best way to learn about what the family may need and how you may be able to support them. Here are some examples of general questions you can ask your student or the family:

- Can you help me understand how I can best help and support you and your family?
- Is there anything you would like me or the class to do to honor and support your family?

If you are also interested in learning about the family’s cultural or religious practices so that you can offer culturally specific support, you can ask questions that help you understand how they experience grief and how they mourn. At the core, we need to communicate 1) that we are asking these questions because we are trying to be sensitive to the family’s cultural background and 2) phrase these as invitations rather than demands for knowledge or demand to be taught about a family’s culture when the family is grieving. Here are some examples you could use:

- With the hope of offering [you or your family] the most culturally sensitive support, I'm curious about ... or I care about what has happened to you and would like to provide the kind of support that respects your family's traditions and cultural practices. With this in mind, I'm wondering... What emotions and behaviors are typical grief responses in [your] culture?
- What are [your family's] beliefs about death, and what happens after death?
- Are there ceremonies to attend? If so, who should attend, what is the mood and what is the appropriate attire?
- Are gifts or flowers accepted? Is it appropriate for the class to contribute?
- Are there any upcoming special days or dates that will be significant for [your] family?
- What types of condolences are okay to express?
- Are there ways that family members are expected to honor the deceased? If so, for how long?

### **Be careful of assumptions**

Even when we think we are familiar with a particular culture or religion, we may not know how each specific family practices that religion or endorses traditional cultural values. Many families blend cultural and religious practices, especially if there are people of different cultural or religious backgrounds in one family. So, be careful not to assume you know exactly how families will respond, even when you have a good understanding of the culture or religion. Be open to each family's unique variations in practice. If you find that you did make assumptions, the best way to respond is to apologize and commit yourself to learning more.

### **Be present and authentic**

Teachers and counselors are often people who are caring, empathic, and understanding. These qualities are your biggest assets during times of grief. Use those qualities to be present with your student and authentic about your concern and care. Even if you do not know what their cultural or religious background is, your care and concern can still shine through.

### **When to Check-in With a Student**

Many teachers worry that by checking-in with the student they may be bringing back painful memories or risk making the student sad again. Know that this is rarely the case. Most of the time, students and families are already thinking about

their loved one. It is more important that they know you care and are there to support them.

In general, if you work with the same students for at least one academic year, it is recommended that you check-in 3-4 times per year. If you work with your students on a semester basis, it is recommended that you check-in 2-3 times per semester. Here are additional guidelines about when it would be important to check-in with your student:

- You notice changes in their behavior (e.g., missing class, significantly less class participation, disruptive behavior)
- You notice changes in health or daily functioning (e.g., significant weight loss/gain, wetting themselves, self-harm, notable lack of sleep)
- The topics of illness (e.g., cancer), death, and dying come up in class
- Around anniversaries, birthdays, and holidays
- When there are significant school transitions (e.g., graduations)
- When important achievements are met (e.g., receiving an award) or unmet (e.g., failing a class)
- When there are family related school events that the student could have brought their loved one to (e.g., parent-teacher meeting, father-daughter dance)

## Classroom Behaviors of Caregiving and Grieving Students, and Your Responses to Them

### Problem Behaviors

Young people often have difficulty expressing emotions that are overwhelming them. Rather than calmly explaining what is bothering them, students' difficulties may come out in other ways. Students caring for others may exhibit any or all of the following behaviors:

***Acting Out Behaviors*** – Students who are stressed by caregiving responsibilities or grief may exhibit aggression directed at you, other adults, or classmates. This may take the form of overt aggression (hitting or yelling at others) or covert aggression (making snide remarks). Many students become sensitive to perceived slights by others and over-react to common classroom situations. They may “blow up” when there really wasn’t clear evidence of a behavior that provoked the outburst. You may also notice that there has been a change from the student’s prior behavior. A student who is typically easy going and adaptive may exhibit abrupt changes in behavior.

***Internalizing Behaviors*** – A student becomes withdrawn and appears to be unhappy. He/she has trouble concentrating or cannot see the point in doing his/her work or participating in class. The student may cry or show other outward signs of sadness. Alternatively, the student may lose interest in the things going on around him/her, withdrawing into a self-imposed shell.

***Victimized by Bullies*** – Research has shown that young caregivers are more likely to experience bullying than their peers. Not only are they dealing with the stressors that come along with caregiving, but they may also be victimized by other students because of their caregiver role. They may exhibit acting out or internalizing behaviors because of being mistreated.

***Exhaustion*** – You may notice that a student cannot stay awake in class. He/she is lethargic and has trouble concentrating and completing his/her classwork.

***Suspected drug/alcohol use*** – A student may come to class under the influence or exhibit behaviors consistent with hang-overs or drug withdrawal. This may stem from use of drugs that you can detect by smell or sight (e.g., marijuana or alcohol) or from drugs that are difficult to spot (e.g., opioids [also called opiates] such as Vicodin or Percocet).

Of course, the type of behaviors you will observe will be highly dependent on the age of the child or adolescent.

## **Actions to Address Problem Behaviors**

The first step in any of these situations is to establish a communication pathway with the student. Ask the student to talk with you privately. Begin by acknowledging the behavior that has led you to approach the student, and be sure to distinguish the behavior from the student him/herself. For example, “I’ve noticed that you seem angry these past couple of days. We all have things that upset us – and that can be hard to control at times. If we share our concerns with people who care about us, we can find a way through them. I care about you and I want to help. What can I do to help you?”

Ask the student, ***“What Do You Wish I knew?”***. Offer to let them write their answer. This can be less intimidating.

***Set Limits with the Student for his/her Behavior***– For example: “I understand that you are angry/sad/or tired. We all need some space or some

time, just so we can take a breath and calm ourselves down. Why don't you take the desk at the back of the room where you can have some privacy? Take a few minutes to compose yourself, and rejoin the group when you feel ready to do so.”

***Set Boundaries***– Under no circumstances should the student be allowed to hurt/interfere with the education of others. Make the boundaries very clear for the student's behavior.

***Self-Expression***– Provide opportunities for the student to express his/her emotions in appropriate ways. Allow them to retreat from the group to write about what is bothering them, draw pictures as a means of dealing with the emotions inside, or put their head down to rest. Allowing students to use an outlet for the emotions may help to reduce problem behaviors causing the emotions they can't control.

***Mindfulness-Based Stress Reduction***– Research shows that by training people to focus on the “here and now” through focused attention and deep breathing, stress can be minimized and control can be regained. There are many resources available to use in training entire groups of students to practice mindful breathing and relaxation. You might consider making this a part of your daily classroom warm-up as most people report positive outcomes from using these techniques.

***Check in with the Student Periodically***– You can show the student that you care by periodically checking in during a private moment. Preface it by saying, “I've been thinking about you and your family – how are things going?” Remind the student that you are available to listen if the student has concerns to share.

What do I say? Educators often have students who are dealing with extremely difficult family lives and may feel at a loss when it comes to what they can say to be supportive. Keep in mind that many times just letting the student know you care can go a long way toward relieving some stress. Examples of statements that convey caring:

- I have been thinking about you...
- I am sorry that you are dealing with such a difficult situation...
- How can I help you?...
- Would you like to talk about it? I'm here to listen...
- What do you need?...

## Providing Accommodations at School

- If you can, be flexible with homework. Grief or a caregiving crisis at home may make it difficult for a young caregiver to complete all assignments on time. Work with the student to design a reasonable plan for making up homework when they are facing a family crisis.
- Be sure that any messages from home to the school office are forwarded to the student immediately. Students worry that they will miss being notified of an issue with a loved one when they are away at school.
- Be proactive in terms of cell phone use. Allow them to check in at home when they are worried, but set reasonable limits to help the student stay focused on class work. For example, you might allow the student to use a phone during nutrition break to contact home. Reassure the student that if a message came from home to the school, it would be forwarded right away. Make sure that the office staff is aware of this arrangement.
- If a detention is warranted, find ways for the student to serve it during lunch time or nutrition/recess so that the student does not have to stay after school, limiting time away from home. In the case of young caregivers, many families depend on them to come home right after school to assist family members.
- Check-in with the student regarding test schedules (including tests for college such as AP exams) as the student may need accommodations during this time.
- Don't discuss student's family situations in front of peers. In particular, young caregivers often experience bullying to greater degrees than non-caregivers. Preserve the confidential nature of the young caregivers' family circumstances.
- Consider using a "caregiver identification" card at your school. This card, given to the student after consulting with a counselor, could serve as verification for teachers that the student is dealing with a significant caregiving situation or death at home. The student can share their status as a caregiver/grieving youth without having to get into details. It is **not** a card that would give students a "free pass" in terms of missing homework assignments or acting out in class. Rather, it would open the door for further private conversations with the student so that accommodations can be made for the student to be able to do the work that is

required of him/her. Most young people just want adults to understand what they are dealing with, and this card is a non-threatening way to do so.

It is important to recognize that there is a ‘roller coaster’ quality to the grieving or caregiving experience. Some days may be very good for the student and loved one, and other days may be very bad. This is particularly true of situations for young caregivers in which there is a long decline in functioning, such is the case with a chronic illness like Alzheimer’s Disease. Students who have experienced a death or are engaged in family caregiving will require a great deal of patience and may need weekly “check-ins” to monitor the situation. Most families adapt over time to these very volatile caregiving situations, but a young person will likely need emotional and informational support.

## **How Can I Help My Class?**

### **Talk to Your Class About Grief**

Opening the discussion of loss acknowledges that grief is normal. Explain about how grief affects people differently. Encourage students to share how they feel and how their family handles grief. Discuss what it might be like for their classmate to return to school. Discuss ideas for how they can help. In doing so, be very clear in letting the class know that teasing will not be tolerated. Instead, use the opportunity to teach about respect for the grieving process and encourage students to share different ways that grief is expressed in their cultures (see Grief Across Cultures section for some ideas). Also, prepare the class that this may be a long process.

### **Provide Opportunities for Grief Expression**

Provide a way for your class to express their grief and honor the grieving student. Students can participate in a short in-class ritual to acknowledge loss. For example, have each student write a short note or draw a picture and place it in a special box, hold a minute of silence, read a poem or light a candle in remembrance.

### **Create Rituals**

Honoring the loss that a student or a class has experienced can facilitate healing and can move students toward acceptance and closure. The types of activities or rituals that you can do may depend on the type of loss your student or class has experienced, the amount of time you have with your class, and your student’s readiness to engage in rituals that help them process their grief. Below is a list of classroom activities or ritual ideas that you can draw from to help your class honor and heal from loss.



***Write Goodbye Letters***—Invite your students to write a goodbye letter to the person that they have lost. The purpose of this exercise is to give students the opportunity to express how they feel about the person they lost and get a sense of closure. For young students, you can invite them to make a drawing as their goodbye letter.

***Condolence Cards***— Invite your students to create their own condolence cards for the student or family that experienced the loss. The purpose of this is to give students a chance to express how they feel and offer support to the family. Students can use art to express how they feel as well as write down messages of support for the family.

***Memory Quilt***— Ask each student to decorate or stitch a square of fabric. Stitch all the squares together to make a memory quilt that can be hung in the classroom or given to the family.

***Paper Flowers***— Invite your students to create paper flowers with messages of support to be delivered to the family who experienced the loss. The flowers can also be delivered at the funeral. The purpose of this is to allow students to show their support to the family in ways that allow them to express themselves creatively.

***Jars of Joy***— Invite students to write messages of support and condolences on strips of paper and fill a mason jar with them. Deliver the jar of messages to the family who has experienced the loss. An alternative option is to keep the jar available the whole school year or semester for students to write messages to the person they have lost throughout the year/semester. At the end of the year, the messages can be buried or delivered to the family who has experienced the loss.

***Cultural Rituals*** —You could also invite students to share the ways they mourn and honor people who have passed away, and then invite the class to participate in cultural mourning rituals. This could help students learn of different ways of mourning while also providing culturally consistent methods of grieving for students.

***Class Memory Tables***— You could invite your class to create a remembrance table for the student who was lost. The table could be in the classroom or on the deceased student's desk. Gifts and letters could also be saved in the student's locker. The remembrance table could have a picture of the student

and could be left open for students to leave gifts, cards, flowers, or whatever feels most consistent with their grief. At the end of the year, the gifts and cards could be given to the family who experienced the loss of their child.

***Plant a Plant/Tree***– Invite students to gather together and plant a tree or a plant in honor of the student at or near the school. Tending to something that has life can help students regain hope, understand the cycle of life, and provide a place for them to go to express their grief and mourning. An alternative of this exercise would be to invite students to paint a clay pot with images or messages of hope and assist them in re-potting a succulent into the pot. Students can then take the plants home. Plants can help students bring life back into their lives and can offer a helpful metaphor for the cycle of life.

***Community Project***– Start a fundraiser for the individual family or for a specific cause (cancer, victim’s rights, suicide awareness). Create a memorial event (5K run, celebration carnival, community picnic). Donate books, clothing, or food to a shelter or program in memory of the person who died. Create a community awareness program or start a group that helps others through paying it forward.

### **Talk to Your Class About Illness**

You can introduce the subject by noting that half of all American adults suffer from chronic diseases and dealing with illness is a fact of life. Explain that there are many options in healthcare to help us to understand and deal effectively with diseases, including terminal diseases (refer to Module 3, Health and Illness, for more information). Emphasize that there is no shame when a person suffers from a physical or mental illness; rather, our focus needs to be on helping that person and the people who care about him/her. You might encourage a classroom discussion about specific resources for different types of illnesses (such as cancer or Alzheimer’s Disease). You could include these discussions as part of a science module or another appropriate class section without drawing attention to the student(s) who are dealing with these illnesses.

### **Provide Opportunities to Learn About Illness**

There are a number of activities that you can do that will help to “normalize” the experience of illness in families:

***Health Communications***– You can include posters about health issues and successful behaviors for addressing those issues in your classroom. Rather than focusing solely on the negative aspects of behaviors (e.g., smoking and lung cancer), include information on new approaches to dealing with health problems and stories of those who have overcome significant health challenges.

***Expert Speakers***– Invite an expert on a particular health problem to the classroom to share with students. Many local healthcare agencies and colleges/universities have speakers who are willing to come to classrooms to speak for free. You can also integrate the topic into the specific subject for your class. For example, a speaker who is an expert on Alzheimer’s Disease would be appropriate for a Biology course, Health class, English class (there are many books that deal with AD), or even a statistics course (for a lesson on the epidemiology of the disease).

***Host a Health Fair***– You can create a wellness event such as a health fair in which agencies such as the American Cancer Society or the Diabetes Association are invited to your school campus to share information and resources with students. The “What Gives Your Life Meaning” campus campaign provides ideas about how to integrate health education into the curriculum as well as extra- curricular activities appropriate for students in grades K-12.

Collectively, these ideas will help you to address students’ reactions to illness or death in empathetic and constructive ways.

## **When is it Time to Get Outside Help?**

### **Guidance for Teachers**

Most of the typical behaviors can be dealt with in the classroom. Establishing positive relationships with students and acknowledging the challenges can result in positive outcomes for the student. However, at times, student’s behaviors may far exceed what is acceptable in the classroom and you may need additional help. Each student and situation is different, but it may help to have a plan in mind as to how you will increase the level of support or make a referral, based on the level of distress.

It is important to evaluate the level of distress and risk on a case by case basis. A student who gets upset in the classroom (e.g., crying, throwing a tantrum), may respond positively with a respite or time-out in the back of the room, if possible. If you can't calm them down, you may need to send them to the counselor. If the behavior is severe, you may need to call an administrator to come and retrieve the student. Each student and situation is different. Have a general plan in mind at the start of each school year as to how you will increase the support or make a referral based on the level of distress.

When you feel that you are not able to keep the student in the classroom, make sure that the appropriate school counseling personnel is made aware of the issue and follow-up if you don't get a timely communication back. In cases where there is an immediate safety concern, you should communicate via phone or email with the counseling staff telling them that you sent the student to the office, providing key information regarding the situation.

It is important to understand and know your limits as a teacher. In doing so, you are modeling healthy behavior for your student and respecting your other students. While it may initially feel like giving up or passing on the problem to someone else, you are really seeking to find the best care possible for the student.

### **Guidance for School Counselors**

In most cases, school counselors can provide a safe space for students while a temporary behavior problem dissipates. This "time-out" from extremely stressful circumstances can provide a brief respite for the student. Using active listening techniques is sometimes all that is needed to reassure and calm the student. Additionally, helping the student to generate alternative ways to express what they are feeling or identify other sources of help for the student to deal with his/her challenges (e.g., community resources) can go a long way.

There may be times, however, when it becomes clear that the student is in need of more help that you can provide. Sometimes, specialized training is necessary to help students who are clinically depressed, suicidal, or dealing with significant trauma. Typical signs that the student needs more serious intervention include depressive symptoms that last longer than 2 weeks, extreme outbursts of anger, or multiple school absences due to family crises. The key to this process is honest, timely, and regular communication between teachers and counseling staff. Knowing when to get additional help is an important part of your role as a counselor. What local agencies

comprise your “next steps” resources? You will find many of these resources described in the Resources Module of this toolkit.

It is also important to communicate with the teacher who has made the referral. This communication can take place face-to-face or can be shared by responding to the Teacher-Counselor Communication Form (see Materials Module) originally submitted by the teacher. The key to this process is honest, timely, and regular communication between teachers and counselors.

### **Questions to Guide Teacher/Counselor Actions**

Dealing with student distress in the classroom is challenging and can be so upsetting that it makes it difficult for us to make decisions "in the moment." It is often useful to have a set of questions developed ahead of time so we can use them to help us to discern what the appropriate course of action should be when we find ourselves facing a student crisis. These questions can help you to identify what you should do to help a student in crisis:

- What are the behaviors that are most concerning to you?
- Have you talked with the parents or guardians to discuss the behavior you are witnessing?
- Have you discussed these issues with the school counselor or school psychologist?
- Are there behaviors that need to be reported to appropriate agencies (e.g., Child Protective Services) or administrative personnel (i.e., what is your school’s reporting lines)?
- What community resources are available to provide to the student and/or his/her family?

### **Conclusion**

The above information is meant to provide some foundation for helping your student/class and helping you to know when the problem needs outside attention. While it is not possible to predict when problems will arise, it is imperative to have a plan for action when they do so that you feel prepared and can minimize the impact.

## Activities and Materials

*Worksheets and more information on the activities listed here can be found in Module 6: Resources*

- Teacher-Counselor Communication Form
- School Contact Information

## Resources

*A complete description of each resource and contact information can be found in Module 6: Resources.*

- 211 San Diego
- American Association of Caregiving Youth
- California Mandated Reporter Training
- Carers Trust, United Kingdom (Teacher Resources)
- Southern Caregiver Resource Center

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- Additional Information adapted from: <http://www.grievingstudents.org>





## Additional Support for Teachers and Counselors

*Teachers and counselors spend a great part of their days responding to the needs of others. As “high touch” professions, these activities can wear on you, creating significant physical and mental health issues if they aren’t addressed. We encourage you to assess your own support system and put into practice the resources and tips we’ve provided to enhance your own quality of life. Not only will you reap the benefits, you will be a good role model for healthy living and a source of comfort for your students.*

## Personal Well-being: How Can I Take Care of Myself?

### Understanding Self-Compassion

Self-compassion is a powerful tool toward building resilience and an important way to model loving self-care. According to the research of Dr. Kristen Neff, self-compassion is a combination of self-kindness, mindfulness, and common humanity. These three components in everyday life have strong links to overall health and well-being. Most importantly, self-compassion appears to be linked with higher levels of resilience which is especially important during a time of loss.

### Exercises for Self-Compassion

**Practice Self-Kindness** —This is the ability to practice loving-care with yourself; treating yourself similar to how you would treat a friend. This includes using words of encouragement, finding ways to soothe yourself with loving comfort, and practicing over all self-care. Here are some self-kindness ideas:

- Give yourself a hug
- Say words of kindness to yourself (think of kind words you might say to a friend)
- Put your hand on your heart, shoulder, or other soothing place and rub gently
- Start a gratitude journal. Write down a few things that you are grateful for every-day
- Write down a goal (small, manageable) everyday
- Place a small item that you make or has special meaning in your pocket for comfort
- Make time for play
- Donate your time. Help a neighbor. Volunteer. Find ways to give back to your community
- Get a pet or spend time at an animal shelter
- Stimulate your senses with things that are soothing (light a favorite scented candle, eat a favorite food, play soothing music, wrap yourself in a soft blanket)
- Take a slow deep breath to help center yourself
- Be outside. Connect with nature by taking a walk or hike
- Learn a new skill or craft
- Keep active. Exercise. Join an exercise group or team sport
- Practice yoga, mindfulness or set aside a few quiet moments
- Schedule time for friends. Socialize. Meet with friends. Talk. Share your life.
- Be creative. Start an art project. Draw. Paint. Build
- Sleep. Create a healthy sleep routine to prepare your body for rest

## **Mindfulness**

Mindfulness means to be intentionally present in the moment. Mindfulness practices can be used at any time and in many different situations. For example, mindful eating, mindful rest, mindful play, and mindful conversations are ways of incorporating intentional practice into everyday life.

There is a growing body of research on the positive impacts of these mindfulness based stress reduction practices. Mindfulness has been used in the medical field to help people cope with pain, illness, and stress. The primary goal is to use our brains to calm our bodies through breathing exercises, focusing attention on the present moment, and relaxing our muscles. The techniques are easy to learn and there are a large number of mindfulness resources available to help us to develop this skill.

### ***Exercises for Mindfulness***

- Download an app with guided meditations. Practice a few minutes a day
- When stressed, remind yourself to notice where your feet are at that moment. Shuffle them a little on the floor to ground yourself in the moment
- Go for a slow, silent walk. Pay special attention to the sights and sounds
- Imagine breathing in compassion for yourself and breathing out compassion for someone else
- Spend time listening to your surroundings
- Pay attention to your breath. Notice how your body moves with each inhale and each exhale

## **Common Humanity**

Common Humanity is the understanding that your pain, your struggles, your grief, while personal, are also shared common experiences and they are imperative to connecting with others. As adults we experience this through deep friendships, support groups and reaching out to others in need. We can connect too through shared stories from our ancestors or through books and the stories of others. We can use these practices to help ourselves and we can use them to help our students.

### ***Exercises Focusing on Common Humanity***

- Share your struggles with a trusted friend, one who can hold the weight of your story and also be an empathetic listener
- Share your story and struggle with someone else who is struggling or a younger person that may be at the beginning of a similar journey. Offer words of encouragement, hope, and lessons learned

- Join a support group for people who are sharing a similar experience
- In a writing exercise, write out a few sentences about the loss or feeling that you are experiencing in the moment. Read them back as if you were reading the words of a close friend. Then write a letter of support

## Respite

One of the best ways to care for ourselves is to take a break from the events/people that are causing us stress. This doesn't mean that we are uncaring, it just means that we need a break to recharge and replenish. Respite breaks can help to reduce stress whether those breaks are for extended periods or just an hour or so. The key is to make a commitment to release yourself from the stressor for a period of time so you aren't problem-solving, listening to others, or ruminating about the stressor. This "mental break" will help you to be a more effective teacher/counselor when you return from respite.

## Professional Well-being: Seeking Resources and Classroom Support from Your School Administrators and Staff

*While the first section of this module focused on self-care and how to deal with the many emotions that are evoked in "high touch" education professions, it is important to recognize that self-care can also include taking a "solution-focused" approach to student issues. This section is a reminder of the professional support you have around you. Sometimes the issues students face threaten to overwhelm teachers and counselors, and there is a need for more direct action to deal with the stressor. In these cases, helping yourself includes reaching out to other professionals who will help you to navigate problems.*

## Student Study Teams

When teachers or counselors have a concern about a student's school performance, they can call for a Student Study Team. It is not unusual for students who are dealing with family illnesses or death to experience a short-term decline in academic performance. However, if the student's declining academic performance is a concern, teachers, counselors, administrators, and other school support personnel may come together to discuss whether action is needed to assist the student. The purpose of the team is to examine a student's academic, behavioral and/or social-emotional performance. This approach can also help teachers and counselors to obtain needed support for assisting students in dealing with the stressors associated with family illness or death. By doing so, they may also reduce their own stressful reactions to their student's difficulties. Working together can also reduce the weight of

finding solutions independently and create space for sharing of ideas to best support the student.

### **Building a Supportive Network Among Colleagues**

It is often necessary to obtain additional information or seek out creative solutions in order to best serve a student's needs. Education professionals have a great local resource; their fellow teachers and counselors. Many of your colleagues have additional training or expertise in dealing with a variety of student issues. It may be useful for teachers to hold an ongoing "case conferencing" meeting at your school. A time when colleagues can bring student issues to the table anonymously. These confidential, scenario-based conversations can help generate solutions without directly naming the student. Consulting with a colleague(s) on an anonymous student case can also provide you with social support and help to reduce your own stress.

### **IMPORTANT NOTE: Confidentiality and FERPA**

*The sharing of personal student information should never be taken lightly. However, sometimes it is difficult to know when we must report what we've been told, when we may elect to share what we've been told, and when we must keep information confidential. There are a number of legal guidelines that teachers and counselors must adhere to with regard to confidentiality.*

### **Mandated Reporting**

Both teachers and counselors are mandated reporters. As such, they are legally bound to report cases of child abuse, neglect or maltreatment, or suspected child abuse to child protective services or law enforcement. The report must be made by the teacher/counselor him/herself immediately after receiving information about possible abuse and a written report should be submitted within 36 hours of receiving the information.

Mandated reporters such as teachers and counselors are required to take "appropriate action" if students engage in behavior that shows they are a clear and imminent danger to themselves and/or others. School Districts typically have information available for teachers and counselors to help them to determine what constitutes a clear and imminent danger and the actions they should take. School personnel should identify key individuals on their campus who can serve as a resource at the start of each school year, before any issues arise.

## Confidentiality

While there may be times when it seems appropriate for counselors and teachers to share information about a student if they determine that the information is relevant to a student's well-being or academic success, it is best to check with the school policy and counselor or teacher accrediting agencies for particulars about laws and ethics associated with protected communications for minors in a school setting in your state.

## Conclusion

Individuals in “high-touch” professions need to take extra steps to make sure that they keep their own mental and physical health as top priorities. We can't help others if we don't first take care of ourselves. We encourage you to use the techniques described in this manual to activate your emotion-focused and solution-focused coping behaviors. By doing so, you will not only help your students, but you will help yourselves.

## Activities

- Breathing GIF
- Mindful Teachers, Catharine Hannay
- New York Times, Well Guides, How to Meditate
- New York Times, Well Guides, Yoga for Everyone

## Resources

- New York Times, Well Guides, How to Get a Better Night's Sleep
- Self-Compassion Kristen Neff, Phd
- Self Care Wheel
- State of California Mandated Reporter Law

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## Materials

In this first part of the resource section are handouts that you are welcome to photocopy and utilize in your classroom.

*Note: For items 1-3, Teachers can make these forms available in class and provide a slotted shoe box so students may submit the forms privately.*

1. I wish my teacher knew... Adolescents
2. I wish my teacher knew... Elementary
3. I need information on...
4. Teacher– Counselor Communication Form

# College Student Caregivers – What We All Need to Know.

## Introduction

It is not uncommon to fail to recognize family caregivers – but this is especially true for college student caregivers. They often don't tell faculty or anyone at their institutions that they are caregivers and if they do, faculty and student services staff may feel ill-equipped to address the issues they are facing and may feel inadequate in their attempts to help. It is important that we understand that we can't "fix" the caregiving situation, nor should we try to. But we do need to acknowledge it – this is part of our "common humanity" – our shared experiences for which we can offer support and understanding. And importantly, we can help college student caregivers to navigate their classes while fulfilling their caregiving roles by making them aware of the supports available both on campus and in the community. We can also commit to developing more supportive services for our college student caregivers.

## General Statistics on College Student Caregivers.

A 2020 study by AARP, "Staying the Course: How Dual Responsibilities Create Challenges for Student Caregivers" provides a good look at the demographics of college student caregivers. It is estimated that 11% of college students, approximately 5 million individuals, are family caregivers. They have undertaken the daunting task of pursuing a college education while trying to manage caregiving responsibilities for a loved one. It is no surprise that 7 out of 10 say that caregiving has negatively impacted their academic ability with approximately 33% reporting that they have difficulty meeting deadlines or attendance requirements; this is compounded by the fact that the vast majority of them (86%) also work at least part-time.



Most of these students have been caregiving since before college (56%) but another 36% began providing care after enrolling in college. In fact, their caregiving status impacts the mode of instruction they choose with most of them taking their classes on-line or choosing to attend a fully online program.

Finances are a huge issue. Six out of 10 caregivers say that it has impacted their financial ability to pay for school and of those students who reported that caregiving has greatly impacted them financially, two-thirds (66%) are very concerned about their ability to continue with their education. Persistence toward a degree is constantly being threatened. Seventy percent of all college student caregivers reported concerns that their caregiving responsibilities would impact their ability to continue their education. In fact, 49% reported seriously considering halting their education and 14% of these students said that caregiving had such a significant financial impact that they actually did have to stop attending college. Yet they don't typically reach out for help because they believe that there is nothing to be done and that it is their own problem to face.

### **Interactions Faculty and Staff - The Great Silence**

Most don't tell anyone because they think they "should" be able to handle this on their own. Only about 1 in 3 family caregivers informed their instructor or another staff member about their caregiver status (AARP, 2020). When they did inform their instructors most caregivers reported they received support from their instructors however it was not very intense. Many students indicate that they are able to handle the student and caregiver roles simultaneously, but they would appreciate flexibility with attendance, deadlines, and more financial information. They are also open to tips on how to juggle responsibilities, information that most faculty and staff could provide as they do this in their own lives.

## What can faculty and student support staff “do”?

- **Acknowledgement.** Research shows that most of the time, caregivers just want to be acknowledged. They need to be validated in terms of the important family work that they are doing. Faculty could start their courses by surveying students ahead of time to see if there are any caregiving issues that might impact the student during the semester. This allows provides faculty the opportunity to acknowledge the family caregivers, and to offer support before any issues arise.– and may prompt them to seek additional information from advisors. Importantly,
- **Conversation.** Consider conducting a class survey in which information about all the roles that students have are documented, including those of employee or parent, and how those roles might impact them during the semester By surveying students at the same time that they are receiving syllabi, the students can also make a more informed decision regarding the limitations they may be working under and the workload that will be expected for the course. This opens the door to conversations with the professor about priorities and suggest ways to manage the workload. Students can have conversations with advisors, as well. They can discuss appropriate course selection and number of units that are reasonable to attempt in one term, given their family situations. If the student brings up leaving the institution, ask them to consider the possibility of slowing down by taking fewer units in a given semester, not stopping their educations.
- **Resources.** Help students to identify where the supports are available – for physical health, mental health, and support services for family caregivers. Most institutions provide services for physical and mental health through their student healthy and counseling centers. But also identify possible community supports for family caregiving. If you don’t know of any yourself, suggest that the student contact 211. Most communities in the US have access to 211, a service designed to help people find the supports they need in the community.

- **Flexibility** – Faculty members typically design courses so that all students are held to the same deadlines and expectations. Are there any places in your course where you are able to “flex” to provide opportunities for those with heavy family responsibilities to complete the work? For example, is it possible to provide more flexible due dates for assignments to provide greater flexibility for all students? If you take attendance, can you create a “lower stakes” point value for attending such that it rewards those who are there but does not severely impact those who might miss due to family caregiving responsibilities? When planning for schedules, are there opportunities to offer asynchronous versions of courses to encourage those who are family caregivers to participate? Each of these actions will allow more students to successfully engage in the course while still maintaining academic standards.
- **Campus Support.** It is also important for campuses to build resources for family caregivers. By acknowledging that many of their students have assumed this role, student services can be tailored to those caring for children, individuals with special needs, and/or aging family members.
- **Faculty Experts.** Utilize faculty experts to provide programming specific to family caregivers and those who are grieving. Many faculty members work with outside communities on topics related to family caregiving. Programs such as Psychology, Public Health, Social Work and Nursing are likely to have faculty members who conduct research and/or provide clinical services relevant for family caregivers. Campuses can also create partnerships between these faculty and colleagues from Student Affairs offices.

## Helping our College Student Caregivers

Awareness of college student caregivers is just the beginning. By educating ourselves about how we can support these family caregivers, we can encourage more of them to stay in school and complete their degrees. This has a life-long impact on these caregivers and their families. Consider exploring the supports we have at CSUSM and in San Diego County – and share this information with your students.

### Resources at CSUSM

- Youth Caregiver Website: [www.csusm.edu/youthcaregivers](http://www.csusm.edu/youthcaregivers) Provides information for young caregivers under age 18 as well as college student caregivers.
- Family Caregiving Matters podcast – This podcast is designed for family caregivers with a special focus on college student caregivers. It is available on most podcast platforms (e.g., spotify, itunes) and on the Youth Caregiver Website: <https://www.csusm.edu/youthcaregivers/fcm.html>
- Cougar Care Network – can help to get students connected to available supports on campus. <https://www.csusm.edu/ccn/index.html>

### Supports in the San Diego Community

- Southern Caregiver Resource Center – [www.caregivercenter.org](http://www.caregivercenter.org) Provides resources for caregivers of individuals aged 60+ with chronic or disabling disorders/diseases or those with Alzheimer's Disease or other cognitive impairing conditions.
- Aging and Independence Services -- Caregiver support programs for those helping adults age 60 and older. [https://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/caregiver\\_support.html](https://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/caregiver_support.html)
- (area code) 211 – or <https://www.211.org/> For help in locating support services in your area.

## Resources and Activities

### Healing Arts Activities

**Inside Out**— Have students fold a piece of paper in half (like a card). On the front of the “card” they create an image of how the world sees them. On the inside, they create an image of how they see themselves. If you have some funds available, you can purchase inexpensive papier-mache “masks” for students to decorate with paint, feathers, beads, etc.. Students decorate the outside to show how the world sees them and decorate the backside to reflect their own self-perceptions.

**Three Wishes**— Since young people often have difficulty projecting far into the future, you could instead ask them, “If they could be granted three wishes for today, what would you wish for?”. They could create an image of these three wishes. This is a somewhat future-oriented activity, but would probably also address difficulties/issues that they are currently struggling with and wish to eliminate.

**Finish My Thought**— Open-ended sentences are always good. “Lately, I’ve been feeling...”, “The biggest thing on my mind lately has been...”, “I can’t seem to stop worrying about...”. Invite students to write their responses on note cards, small white boards, or just a piece of paper. Then, ask those who feel comfortable to hold up their answers. You can tailor the open ended sentences to whatever it is you want them to talk about.

**Guided Imagery**— Take students on a journey where they will encounter certain things such as an island paradise. Ask them what they would take with them and who they would see on the journey. Then, have them create an image of the journey as a whole or a significant piece of it. The journey should be tailored to what would be relevant to a person of their age. An internet search will provide many examples of this kind of activity. Check out the Guided Imagery exercises from the Dartmouth Student Wellness Center:

<http://www.dartmouth.edu/~healthed/relaxdownloads.html#guided>

### Healing Arts Resources

**Healing Arts**— The internet has many websites that provide ideas for expressive arts projects. These include the following websites:

- Expressive Art Inspirations <http://intuitivecreativity.typepad.com/expressiveartinspirations/100-art-therapy-exercises.html>

- Pinterest Expressive Arts Ideas <https://www.pinterest.com/jaimecrispin/expressive-therapy-ideas/?lp=true>
- 25 Best Expressive Arts Ideas from Pinterest <https://www.pinterest.com/explore/expressive-art/?lp=true>

***Expressive Writing Websites*** — Great ideas for creative writing can be found on the following websites:

- Creative Writing Prompts <http://thinkwritten.com/365-creative-writing-prompts/>
- Writers Digest <http://www.writersdigest.com/prompts>
- Writing Forward <https://www.writingforward.com/writing-prompts/creative-writing-prompts/25-creative-writing-prompts>

***Create Music Online***— Some people find peace in creating or playing a musical instrument. If you don't play an instrument, you can still create music online.

- Clipsound and Music <https://bit.ly/36csQpU>
- Soundtrap <https://www.soundtrap.com/>

***Gratitude Diaries*** —Research shows that when we focus on positive aspects of our lives, we can improve our moods. One way to do this is to keep a Gratitude Diary where you can record things you are grateful for and why. Repeat the activity every day for three weeks. You should find that reflecting on these happy parts of your life will give you a more positive outlook. Examples of things you might be grateful for:

- Unconditional love
- A warm bed
- Food to eat
- A good friend

Your goal is to increase the amount of time you spend thinking about positive aspects of your life, every day.

- Favorite foods/books
- Favorite superheroes
- Happiest moments
- Kindnesses toward others
- Times you've showed strength
- Favorite movies or song

**Creating Lists**—Another positive journaling technique is to create a short, daily list on topics similar to these examples:

### ***Alphabetical Resource List***

*Below is an alphabetical list of resources for grief, caregiving, and healthcare issues.*

#### **211 San Diego**

Phone: 2-1-1

Website: <http://211sandiego.org/>

2-1-1 is a free, 24-hour confidential phone service and searchable online database.

This website is a great resource for services available in San Diego County including:

- Basic needs (food and shelter)
- Health and wellness
- Resources specific to seniors and families

#### **Advance Directives: Forms for the State of California**

Document Link: <https://oag.ca.gov/sites/all/files/agweb/pdfs/consumers/ProbateCodeAdvancedHealthCareDirectiveForm-fillable.pdf>

#### **Advance Directives: The Five Wishes Form**

Document Link: <https://agingwithdignity.org/docs/default-source/default-document-library/product-samples/fwsample.pdf?sfvrsn=2>.

#### **Coalition for Compassionate Care of California**

Phone: (916) 489-2222

Website: <http://coalitionccc.org/tools-resources/advance-care-planning-resources/frequently-asked-questions-faq-about-advance-health-care-directives/>.

*Mission Statement:* To promote high-quality, compassionate care for everyone who is seriously ill or nearing the end of life.

#### **Aging and Independence Services (AIS), County of San Diego Health and Human Service Agency: Family Caregiver Support Program**

Phone: 1(800) 510-2020

Website: [http://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/caregiver\\_support.html](http://www.sandiegocounty.gov/content/sdc/hhsa/programs/ais/caregiver_support.html)

*Mission Statement:* AIS provides services to older adults, people with disabilities, and their family members to help keep clients safely in their homes, promote healthy and vital living, and publicize positive contributions made by older adults and persons with disabilities. AIS supports Family Caregivers with the following:

- Contracted providers
- Care management
- Support groups
- Counseling
- Caregiver skills training
- Respite care
- Legal services
- Grandparent caregiver support
- Outreach/education

### **Al-Anon**

Provides support groups/counseling for recovering alcoholics and their loved ones.

Website: <https://www.alanonsandiego.org/>

*Mission Statement:* The Al-Anon Family Groups are a fellowship of relatives and friends of alcoholics who share their experience, strength, and hope in order to solve their common problems. We believe alcoholism is a family illness and that changed attitudes can aid recovery.

### **Alzheimer's Association**

Phone: 1(800) 272-3900

Website: <http://www.alz.org/>

The national Alzheimer's Association is the premier resource for information on Alzheimer's Disease and other dementias.

*Mission Statement:* To eliminate Alzheimer's Disease through the advancement of research; to provide and enhance care and support for all affected; and to reduce the risk of dementia through the promotion of brain health.

This website provides information on a range of topics including:

- An interactive brain tour
- Support services
- Links to clinical trials
- Links to caregiver support
- Videos to help children and adolescents understand the disease

### **Alzheimer's San Diego**

Phone: (858) 492-4400

website: <http://www.alzsd.org/>

*Mission Statement:* To provide San Diego families with care and support, while advancing critical local research for a cure.

This website is geared toward local San Diego families facing with Alzheimer's Disease. Information includes:

- Local resources for families with loved ones suffering from Alzheimer's
- Information about local education
- Information about local support groups



### **American Association of Caregiving Youth (AACY)**

Phone: (561) 391-7401 or (800) 508-9618

website: <https://www.aacy.org/>

The AACY website is the only website in the US that is geared directly toward young caregivers. *Mission Statement:* To increase awareness and provide support services for youth caregivers and their families by connecting them with Healthcare, education, and community resources. This website provides information on a range of topics including:

- Links to research on young caregivers
- Resources for caregivers (general)
- Information about the Caregiving Youth Project (CYP), Boca Raton, Florida

### **American Association of Retired Persons (AARP) Caregiving Toolkit**

Phone: 1(888) 687-2277

Website: <http://www.aarp.org/home-family/caregiving/caregiving-tools/>

Although this website is focused on adult caregivers, many of the tools they provide are relevant for young caregivers and their families. It provides:

- Links to a caregiving glossary
- Information about long-term care
- How to find care provider

### **American Diabetes Association (ADA)**

Phone: 1(800) 342-2383

website: [www.diabetes.org](http://www.diabetes.org)

*Mission Statement:* To prevent and cure diabetes and to improve the lives of all people affected by diabetes. This website provides information on a range of topics including:

- Diabetes basics
- Risk factors
- How to live with diabetes
- Diabetic meal plans and recipes (very informative)

### **American Diabetes Association: San Diego Office**

Phone: (619) 234-9897

Website: <https://www.diabetes.org/community/local-offices/southern-california-nevada>

This local website provides information on events in San Diego. Of particular note, for children who suffer from diabetes, is Camp Wana Kura for children age 5 to 12. The site also contains links to local support groups.

## American Lung Association (ALA)

Phone: 1(800) 548-8252

website: [www.lung.org](http://www.lung.org)

The ALA website is relevant for families dealing with various lung diseases including lung cancer, asthma, and cardiopulmonary obstructive disease (COPD). *Mission Statement:* To save lives by improving lung health and preventing lung disease.

This website contains useful information on:

- How the lungs work
- Available treatments for lung disease
- Effects of smoking
- How to help people quit smoking

## Ambiguous Loss

Pauline Boss, PhD

email: [pauline@ambiguousloss.com](mailto:pauline@ambiguousloss.com)

website: [http://www.ambiguousloss.com/four\\_questions.php](http://www.ambiguousloss.com/four_questions.php)

This site is a resource for information and workshops related to ambiguous loss. *Organization Statement:* Everyone experiences ambiguous loss if only from breaking up with someone, having aging parents, or kids leaving home. As we learn from the people who must cope with the more catastrophic situations of ambiguous loss, we learn how to tolerate the ambiguity in our more common losses in everyday life.

## American Cancer Society (ACS)

Phone: 1(800) 227-2345

Website: <http://www.cancer.org/about-us>

The ACS provides information and referrals for people suffering from cancer. The site is structured so that visitors can find information about:

- Various types of cancer/treatments (Cancer A-Z)
- How to reduce the risk of cancer (Stay Healthy)
- Treatments and Supports available (Treatment and Support)
- Special tab for children, for both when the child is the cancer patient and when the child is facing a loved one's cancer diagnosis
- Specific local support programs and services

## American Foundation for Suicide Prevention (AFSP)

Phone: 1(888) 333-2377 or 1(212) 363-3500

Email: [info@afsp.org](mailto:info@afsp.org)

Website: <https://afsp.org/about-afsp#contact-our-national-office>

*Organizational Mission:* Save lives and bring hope to those affected by suicide.

The AFSP can help with:

- Resources
- Statistics
- Facts
- Connections to local support

### **American Heart Association (AHA)**

Phone: 1(800) 242-8721

Website: <https://www.heart.org/en/>

*Organizational Statement:* To improve the lives of all Americans, we provide public health education in a variety of ways. We're the nation's leader in CPR education training. We help people understand the importance of healthy lifestyle choices. We provide science-based treatment guidelines to healthcare professionals to help them provide quality care to their patients. We educate lawmakers, policymakers and the public as we advocate for changes to protect and improve the health of our communities." This website provides important information on:

- Heart disease
- Stroke
- Heart attacks
- High blood pressure
- Tools for educators on teaching students about living healthy lifestyles
- Information and links to support caregivers

### **Breathing GIF**

Website: [https://31.media.tumblr.com/b1406ea40336dc68e5404b380c391d96/tumblr\\_nsj9tcMOgY1qkv5xlo1\\_500.gif](https://31.media.tumblr.com/b1406ea40336dc68e5404b380c391d96/tumblr_nsj9tcMOgY1qkv5xlo1_500.gif)

This is a link to a breathing GIF to help with meditation and breathing exercises.

### **Brene Brown on Empathy**

Video Link: <https://youtu.be/1Evwgu369Jw>

A clever video narrated by Brene' Brown and animated by RSA Shorts that describes the difference between empathy and sympathy and provides direction for a truly empathetic response.

### **California Mandated Reporter Training**

Website: <http://educators.mandatedreporterca.com/default.htm>

## Camp Erin San Diego

Phone: 1(800) 797-2050

Website: <https://elizabethhospice.org/services/counseling/camp-erin-san-diego>

*Organizational Statement:* Camp Erin San Diego is hosted by the Center for Compassionate Care of The Elizabeth Hospice and part of The Moyer Foundation network of free bereavement camps for children and teens ages 6 to 17 years of age who have experienced the death of someone close to them.

## Carers Trust, United Kingdom

website: <https://carers.org/how-your-school-can-support-young-carers/young-carers-in-schools>

The UK is the world-leader in the identification of young caregivers. This website is designed to help schools to set up programs to identify young caregivers. Although it was written for use in the UK, many of the ideas could be adapted to the US. Carers trust provides a Step-by-step Guide that outlines ten key steps to implementing effective identification and support for young caregivers in schools.

<https://youngcarersinschools.com/resources-cpd/step-by-step-guide/>

## Center for Compassionate Care of The Elizabeth Hospice

Phone: 1(800) 797-2050

Website: <https://elizabethhospice.org/services/counseling/center-for-compassionate-care>

This site offers online resources and support groups throughout San Diego Area.

*Organizational statement:* We support people of all ages through serious illness and grief to find and regain hope. The Center for Compassionate Care has been created to centralize programs and services offered to children, families, and individuals coping with the diagnosis of a serious illness or adjusting to the death of a loved one of any age.

## The Center for Complicated Grief

ph (212) 851-2107

Email: <http://info@complicatedgrief.columbia.edu>

Website: <https://complicatedgrief.columbia.edu>

This is an online resource for information regarding complicated grief. *Organizational Statement:* We use the term “complicated” to mean that something is getting in the way of coping with the death of a loved one. When grief is complicated, the pain can be unrelenting, and life seems empty of any possibility for happiness. We want to help lessen the pain. We want to make it possible to honor grief as a form of love.

### **Centre for Cultural Diversity and Ageing**

Email: [info@culturaldiversity.com.au](mailto:info@culturaldiversity.com.au)

Website: <http://www.culturaldiversity.com.au/news/94-news-and-events/225-resource-an-outline-of-different-cultural-beliefs-at-the-time-of-death>

*Organization Statement:* An Outline of Different Cultural Beliefs at the Time of Death Loddon Mallee Regional Palliative Care Consortium. This document is provided as a brief resource, which may assist healthcare workers to understand the different cultural or religious approaches to death and dying. This website includes extensive printable resource for different religious practices regarding bereavement. The cultural and religious groups covered in this resource are:

- Buddhist
- Catholic
- Christian
- Church of Jesus Christ of Latter-Day Saints (Mormon)
- Greek Orthodox
- Hindu
- Jehovah's Witness
- Jewish
- Maori
- Muslim (Islamic)
- Scientologist
- Seventh Day Adventist
- Sikh

### **Chadwick Center for Children & Families, San Diego**

Phone (858)-966-5803 or (858)-966-5992

Email: [ChadwickCenter@rchsd.org](mailto:ChadwickCenter@rchsd.org)

Website: <http://www.chadwickcenter.com/>

Helpful resource for services related to childhood trauma and abuse.

*Organization Mission:* To promote the health and well-being of abused and traumatized children and their families through excellence and leadership in evaluation, treatment, prevention, education, advocacy, and research.

### **Children's Grief Education Association**

Dr. Mary M. Lyles, MSW, LCSW

Phone: (832) 576-252

Website: <https://childrengrieve.org/>

Informational website with links and resources for military families, children and teens with lists of helpful phrases for communicating.

*Organizational Statement:* The CGEA is dedicated to serving the needs of grieving children and families and to providing education and support to those who serve them.

### **The Clarity Project**

Website: <https://www.youtube.com/user/ClairityProject>

Claire Wineland is a young woman who suffers from Cystic Fibrosis. This website contains videos Claire has posted regarding how she deals with her illness. Claire is an incredibly upbeat, funny, and intelligent young woman who provides a terrific model of how to face disease head-on while still finding the joy in everyday life.

### **Coalition for Compassionate Care of California**

Phone: (916) 489-2222

Website: <http://coalitionccc.org/>

*Mission Statement:* The Coalition for Compassionate Care of California (CCCC) promotes high-quality, compassionate care for everyone who is seriously ill or nearing the end of life. Our vision is to create a community where people explore their wishes for care towards the end of life, express these wishes, and have their wishes honored. Our goal is to transform healthcare so that medical care is aligned with individual patient's preferences—that people get the care they need and no less, and the care they want and no more. Resources include:

- Information on current health care policies
- Descriptions of POLST
- End of life issues
- Advance care planning for patients and their families.

## The Dougy Center

Phone: (866) 775-5683

Website: <http://www.dougy.org>

The Dougy Center offers a variety free online resources and activities for students.

*Organizational Mission:* The mission of The Dougy Center is to provide support in a safe place where children, teens, young adults, and their families grieving a death can share their experiences. Through our Pathways Program, we provide a safe place for families facing an advanced serious illness.

## End- of-Life Options Act

- University of California Consortium on Law, Science and Health Policy: website: <http://www.uconsortium.org/portfolio-view/end-of-life-care-act-fact-sheet/>
- Coalition for Compassionate Care of California: website: <http://coalitionccc.org/tools-resources/end-of-life-option-act/>

## Family Caregiver Alliance

Phone: 1(800) 445-8106

website: [www.caregiver.org](http://www.caregiver.org)

The Family Caregiver Alliance is the National Center on Caregiving.

*Mission Statement:* To improve the quality of life for caregivers and those they care for through information, services, and advocacy. Their website contains:

- Caregiver education (fact and tip sheets, webinars, classes)
- Policy and advocacy information
- Caregiver connections (information on how caregivers can connect with needed resources in their area). website: <https://www.caregiver.org/caregiver-connect>

## Grandparents Raising Grandchildren: YMCA Kinship Program

Phone: (858) 292 -9622

website: <http://www.ymca.org/yfs/programs/kinship-support-services.html>

Many young caregivers are living with a custodial grandparent. YMCA Kinship provides support services to relative caregivers, "Kinship Caregivers", who are raising a child of a family member. For most relatives, suddenly becoming a caregiver can be an overwhelming responsibility. YMCA Kinship strengthens

support systems by offering county-wide services to help caregivers preserve the family unit and avoid the entry/re-entry of children into the foster care system.

### **Grief Speaks**

Lisa Athan

Phone: (973) 985-4503

Email: [Lisa@Griefspeaks.com](mailto:Lisa@Griefspeaks.com)

Website: <http://www.griefspeaks.com/id90.html>

*Organizational Mission:* The mission of Grief Speaks is to normalize grief in our “Get Over It and Move On” society. The vision to give every child, teenager, and adult permission to grieve in his or her own way and time, through all different types of losses and transitions. Grief Speaks is an online resource containing useful information on:

- Different types of loss
- Helpful phrases and questions
- Stages of grief development
- Guidance for death of a classmate or teacher

### **Hope After Project**

Email: [info@hopeafterproject.com](mailto:info@hopeafterproject.com)

Website: <https://www.facebook.com/HopeAfterProject/>

*Organizational Statement:* We encourage building memorial community service projects to help those who are grieving find hope. Hope After Project provides:

- Online resources
- Local community service memorial ideas
- Volunteer projects
- Access for those interested in initiating a project

### **Kids Health: Helping Your Child Deal with Death**

Website: <http://kidshealth.org/en/parents/death.html>

*Organizational Statement:* When a loved one dies, children feel and show their grief in different ways. How kids cope with the loss depends on things like their age, how close they felt to the person who died, and the support they receive. This website offers tips for talking about death and other health and well-being concerns.

### **Lotsa Helping Hands Care Calendar**

website: <http://lotsahelpinghands.com/>

This tool provides a password-protected calendar for coordinating the care of a loved



one. Family members join as community members where they can post the needs of a loved one and family members can sign up to fill those needs. For example, if an ill loved one needs to be taken to a doctor's appointment, family members can login and sign up to take the loved one. The family can arrange for meal delivery, errands, and information about the loved one's health status to be posted in a secure web space.

### **Massachusetts General Hospital Cancer Center**

Phone: (617) 726-2361

Website: [www.mghpact.org/assets/media/documents/MGH-Cancer-Educator-Toolkit.pdf](http://www.mghpact.org/assets/media/documents/MGH-Cancer-Educator-Toolkit.pdf)

This toolkit provides in-depth information about how to help children whose parents are suffering from cancer. The toolkit is divided into information for the educator, parent, and child. The educator section contains specific information for teachers, administrators, counselors, and other school personnel, including what behaviors to look for, how to communicate with the parents, and how to adapt the classroom. The parent section provides a focus on communicating with the school and how to work with their children. The child section is designed to be used by children and adolescents. Korff, M.E. (2014). The toolkit helps educators support children of parents with serious illness. A component of the "Parenting at a Challenging Time Program."

### **Mayo Clinic**

Phone: (480) 301-8000

Website: <http://www.mayoclinic.org/healthy-lifestyle/end-of-life/in-depth/suicide/art-20044900>

*Organizational Statement:* Suicide grief: Healing after a loved one's suicide. A loved one's suicide can be emotionally devastating. Use healthy coping strategies such as seeking support to begin the journey to healing and acceptance. The Mayo Clinic provides online information and links for further education on grief specific to suicide.

### **Mindful Teachers**

Catharine Hannay

website: <http://www.mindfulteachers.org/p/self-care-resources.html>

The Mindful Teachers website provides teachers with specific information about how to incorporate mindfulness in the classroom and practice self-care.

### **National Alliance for Grieving Children**

Phone: (866) 432-1542

website: <https://childrengrieve.org>

Letter to Loved One link: [lausd.net](http://lausd.net)

*Organizational Statement:* The National Alliance for Grieving Children seeks to provide resource materials for professionals and volunteers working with grieving children, teens, families, and the communities where they live.

### **National Caregiver Library: Tools for Caregivers**

Phone: (804) 327-1111

website: <http://www.caregiverslibrary.org/quick-tools/tools-for-caregivers-and-employers.aspx>

This website contains useful tools for family caregivers. These tools include:

- Comprehensive caregiving needs assessment
- Driving assessment
- Home-safety tip sheet
- Caregiver self-assessment
- Information on care facilities
- Information on end of life issues
- Information on long-distance care

### **National Center for School Crisis and Bereavement**

Phone: (877) 53-NCSCB (877-536-2722)

Email: [info@grievingstudents.org](mailto:info@grievingstudents.org)

website: <https://sowkweb.usc.edu/about/centers-affiliations/national-center-school-crisis-and-bereavement>

*Organization Statement:* The National Center for School Crisis and Bereavement (NCSCB) aims to promote an appreciation of the role that schools can play in supporting students, staff, and families at times of crisis and loss. When children face situations such as a natural disaster or the death of a loved one, their learning, behavior, and development may be significantly impacted. The importance of schools to be prepared to assist students in the aftermath of these events remains an urgent and growing need. Through collaborations with various organizations and agencies, the center serves as a resource for information, training materials, consultation services, and technical assistance. The NCBCB provides online resources with link to information specific to teachers:

- Sample letters to parents
- Guidelines for types of loss
- Psychological first aid

### **National Child Traumatic Stress Network**

Phone: (310) 235-2633 or (919) 682-1552

Website: [www.NCTSN.org](http://www.NCTSN.org)

*Organizational Mission:* To raise the standard of care and improve access to services for traumatized children, their families, and communities throughout the United States. This network has online trauma-related resources from a cooperation between the Center for Mental Health Services, Substance Abuse and Mental Health Services Administration, US Department of Health and Human Services through a congressional initiative: the Donald J. Cohen National Child Traumatic Stress Initiative. These resources are coordinated with UCLA and Duke University.

*Organizational Statement:* You can play an important role in helping your children and teenagers recover from traumatic events. We have designed these pages for birth parents, adoptive parents, resource/foster parents, grandparents, caregivers, and all others who care for children and teens.

### **National Hospice and Palliative Care Organization**

Phone: (703) 837-1500

Website: <https://www.nhpco.org/about/hospice-care>

*Mission Statement:* To lead and mobilize social change for improved care at the end of life. Their vision is a world where individuals and families facing serious illness, death, and grief will experience the best that humankind can offer. This website provides excellent information on hospice care and is a great resource for students with a terminally ill family member in the home. It contains:

- “Basics of Hospice” video series
- Caregiving information
- End-of-life resources.

### **National Institute of Diabetes and Digestive and Kidney Diseases**

Phone: 1(800) 860-8747

Website: <https://www.niddk.nih.gov/>

*From the Website:* The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is part of the National Institutes of Health (NIH), the nation’s medical research agency. We conduct and support biomedical research, disseminating research findings, and health information to the public, and are part of the U.S. government under the Department of Health and Human Services.

### **National Kidney Foundation**

Website: <https://www.kidney.org/kidneydisease>

The website of the National Kidney Foundation provides useful information on prevention and treatment of kidney disease. There are a number of resources for patients including:

- Peer support
- Donor information
- Events that patients and their families can attend

### **New York Life Foundation**

Phone: (212) 576-7341

Email: [nylffoundation@newyorklife.com](mailto:nylffoundation@newyorklife.com)

Website: <http://www.newyorklifefoundation.org/>

Excellent selection of resources and links for grief and healing of families and young children.

*Organizational Mission: We Care.* The New York Life Foundation supports AChild-InGrief.com, a valuable collection of stories and resources that will help guide you and your family through the death of a loved one. New York Life is fully committed to providing those grieving with the tools necessary to cope with a loss.

### **New York Times, Well Guides**

‘How to Get A Better Night’s Sleep’ by Tara Parker-Pope

Website: <https://www.nytimes.com/well/guides/how-to-sleep>

This is a helpful guide and provides resources for a better night’s sleep.

*Well Guide Statement:* Most people know they need to eat right and exercise to be healthy. But what about sleep? We spend about one-third of our lives asleep, and sleep is essential to better health. Four out of five people say that they suffer from sleep problems. So how do you become a more successful sleeper?

### **New York Times, Well Guides**

‘How to Meditate’ by David Gelles

Website: <https://www.nytimes.com/well/guides/how-to-meditate>

This guide is very useful for beginning meditators and provides articles, videos, and links to helpful apps and resources.

*Well Guide Statement:* Meditation is a simple practice available to all, which can reduce stress, increase calmness and clarity, and promote happiness. Learning how to meditate is straightforward and the benefits can come quickly. Here, we offer basic tips to get you started on a path toward greater equanimity, acceptance, and joy. Take a deep breath and get ready to relax.

## New York Times, Well Guides

‘Yoga for Everyone’ by Kelly Couturier

Website: <https://www.nytimes.com/well/guides/beginner-yoga>

This guide is for yoga beginners and provides helpful information, links to online free resources and some beginning poses. *Well Guide Statement:* Whether you are young or old, overweight or fit, yoga has the power to calm the mind and strengthen the body. Don’t be intimidated by yoga terminology, fancy yoga studios and complicated poses. Yoga is for everyone.

## Parenting at a Challenging Time (PACT)

Phone: (617) 724-7272

Website: [mghpact.org](http://mghpact.org)

This website is focused on parents diagnosed with cancer. It provides information and resources to help parents navigate parenting their children when they are facing a cancer diagnosis and treatment. The website also links to their toolkit.

- Activities
- Videos
- Printouts for young children and grieving families
- Special section for military families

## PBS Parents; When Families Grieve

Email: [grief@sesameworkshop.org](mailto:grief@sesameworkshop.org)

Website: <https://www.pbs.org/national-memorial-day-concert/help-military-families/support-grieving-families/>

*Organizational Statement:* Find links to activities that help children deal with grief and get additional advice and support—from PBS KIDS, PBS Parents, and beyond:

## Physician’s Order for Life Sustaining Treatment (POLST):

Email: [info@polst.org](mailto:info@polst.org)

Website: [www.polst.org](http://www.polst.org)

This website provides information on the POLST form including copies of the form itself. This is a great resource for information on steps to take to ensure that loved ones get the kind of treatment we want and avoid treatments we don’t want.

## Plan Your Lifespan

Website: [www.Planyourlifespan.org](http://www.Planyourlifespan.org)

This website can help families plan for health events such as hospitalizations, falls, and memory loss. Users can plan for their health care and share these plans with family members.

### **Rachael Goldring: The Road Unpaved**

Website: <http://theroadunpaved.org/>

This is the personal blog of a young, adult woman who has dealt with significant health problems since birth. Rachael suffers from a severe congenital heart defect called Pulmonary Atresia and she only has one functioning lung. However, Rachael is determined to live her life to the fullest, her way. Her blog provides insights into what it is like to be an ill young adult. Her message is hopeful and useful for students who are facing similar health challenges.

### **Rady Children's Behavioral Health Urgent Care**

Phone: (858) 966-5484

website: <https://www.rchsd.org/programs-services/psychiatry/>

This is a San Diego behavioral mental health urgent care facility.

*Organizational Statement:* Behavioral health services are offered at Rady Children's Mid-City (San Diego) Urgent Care for children, teens, and their families struggling with urgent emotional and/or behavioral concerns that pose a risk to their safety or the safety of others, or that significantly impair their daily lives.

### **Sesame Street Tool Kits for Parents and Caregivers**

Website: <http://www.sesamestreet.org/toolkits/grief>

This is an outstanding collection of videos, games, and resources for engaging a child that is grieving.

*Organizational Statement:* Grief is complex; it encompasses a wide range of emotions that can come and go in waves. Use these tips, videos, children's story, and guide to help your family communicate with one another, express emotions, and begin the process of moving forward.

### **Self-Care Wheel**

Document Link: <http://www.olgaphoenix.com/wp-content/uploads/2015/05/SelfCare-Wheel-Final.pdf>

Website: [www.OlgaPhoenix.com](http://www.OlgaPhoenix.com)

This is a helpful visual tool for seeing how self-care is organized in your life.

*Organizational Statement:* This Self-Care Wheel was inspired by and adapted from the "Self-Care Assessment Worksheet" from Transforming the Pain: A Workbook on Vicarious Traumatization by Saakvitne, Pearlman & Staff of TSI/CAAP (Norton, 1996). Created by Olga Phoenix Project: Healing for Social Change (2013). Dedicated to all trauma professionals worldwide.

### **Self-Compassion, Kristen Neff, PhD**

Email: [selfcompassion.questions@gmail.com](mailto:selfcompassion.questions@gmail.com)

Website: <http://self-compassion.org>

Dr. Kristen Neff is a world recognized expert on self-compassion research. This website provides resources, assessments, self-compassion practices, and current research on self-compassion for those interested in more detailed information.

### **Southern Caregiver Resource Center (CRC Network)**

Phone: (858) 268-4432

website: [www.caregivercenter.org](http://www.caregivercenter.org)

This site is a great resource for caregiving information. It provides fact sheets, articles, and a variety of programs and services including education and training, family consultation, legal and financial consulting, and respite care.

*Eligibility for services (from the website):* To be eligible for services, an adult must be assisting/caring for an adult with a cognitive impairing condition that occurred after the age of 18 (for example: dementia, Alzheimer's disease, stroke, traumatic brain injury, Parkinson's disease) or someone age 60 years and older in need of assistance with daily living activities. Services are for residents of San Diego and Imperial counties. Many of the services provided by SCRC are free or offered at a reduced rate. Services are offered in English and Spanish. *Mission Statement:* The mission of SCRC is to help families and communities master the challenges of caring for adults with chronic and disabling conditions.

### **There are 11 non-profit Caregiver Resource Centers (CRCs) in California.**

To find one outside of San Diego or Imperial County, go to:

<https://www.caregiver.org/californias-caregiver-resource-centers>

### **Support After Suicide**

Email: [aftersuicide@jss.org.au](mailto:aftersuicide@jss.org.au)

Website: <http://www.supportaftersuicide.org.au>

This online organization has resources and opportunities to connect with other grieving families. *Organizational Statement:* The Support After Suicide Community brings together people who are bereaved by suicide.

### **SOSL: Survivors of Suicide Loss**

Support Line: (619) 482-0297

Email: <http://info@SOSLsd.org>

Website: <https://www.soslsd.org/>

This local San Diego area group offers meetings, services and online resources regarding suicide.

*Organizational Mission:* We provide support services that offer hope, comfort, and healing to those in grief from suicide loss and we promote suicide awareness and prevention.

### **United Hospital Fund: Next Step in Care**

Email: [nextstepincare@uhfnyc.org](mailto:nextstepincare@uhfnyc.org)

Website: <http://nextstepincare.org/caregivers>

This website provides useful information for family caregivers on the transitions that our loved ones make from one care setting (e.g., a hospital) to another (e.g., a skilled nursing facility). In the form of guides and checklists, it provides a quick resource for many tasks that caregivers have to complete. Topics include:

- Medication management
- ER visits
- Hospital stays
- Discharge plans
- Rehabilitation
- Home care

A really helpful resource is their *Family Caregiver Guide to Electronic Organizers, Monitors, Sensors and Apps*. These guides are available in English, Spanish, Chinese, and Russian. The guide helps families to determine whether electronics such as tablets and cell phones can help with some caregiving tasks, including staying connected with loved ones. This may be a perfect opportunity for technologically-savvy young caregivers to provide assistance to family members who aren't not comfortable with technology.

### **VITAS Healthcare**

Phone: (877) 228-8162

Website:

<https://www.vitas.com/resources/grief-and-bereavement/child-development-stages>

*Organizational Statement:* VITAS Healthcare serves people with serious illnesses. Our hospice care and palliative services provide comfort to patients and preserve dignity in the face of terminal illness. VITAS provides online resources and connections to local organizations and helpful information regarding:

- Stages of grief/Developmental Tasks of Grief
- Development issues
- Myths about grief



- Hospice
- End-of-life
- Alzheimer's disease
- Caregiving

### **Youth.Gov**

Phone: (877) 231-7843

Email: [youthgov@air.or](mailto:youthgov@air.or)

Website: <http://youth.gov>

*Organizational Statement:* This organization provides online information regarding incarcerated parents, homeless youth, and violence prevention.

*Organizational Mission:* youth.gov is the U.S. government website that helps you create, maintain, and strengthen effective youth programs. Included are youth facts, funding information, and tools to help you assess community assets, generate maps of local and federal resources, search for evidence-based youth programs, and keep up-to-date on the latest, youth-related news.

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