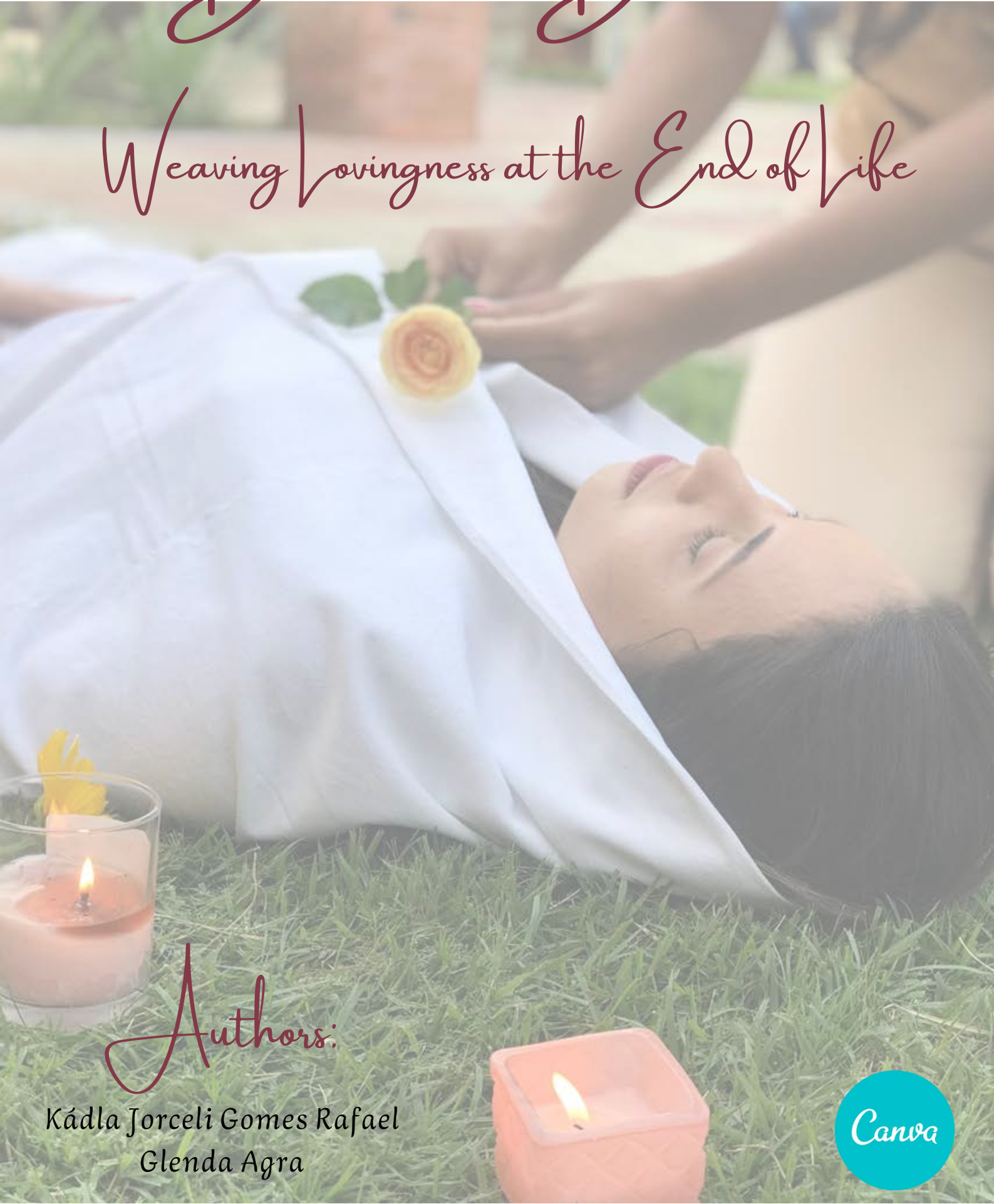


Death Doulas

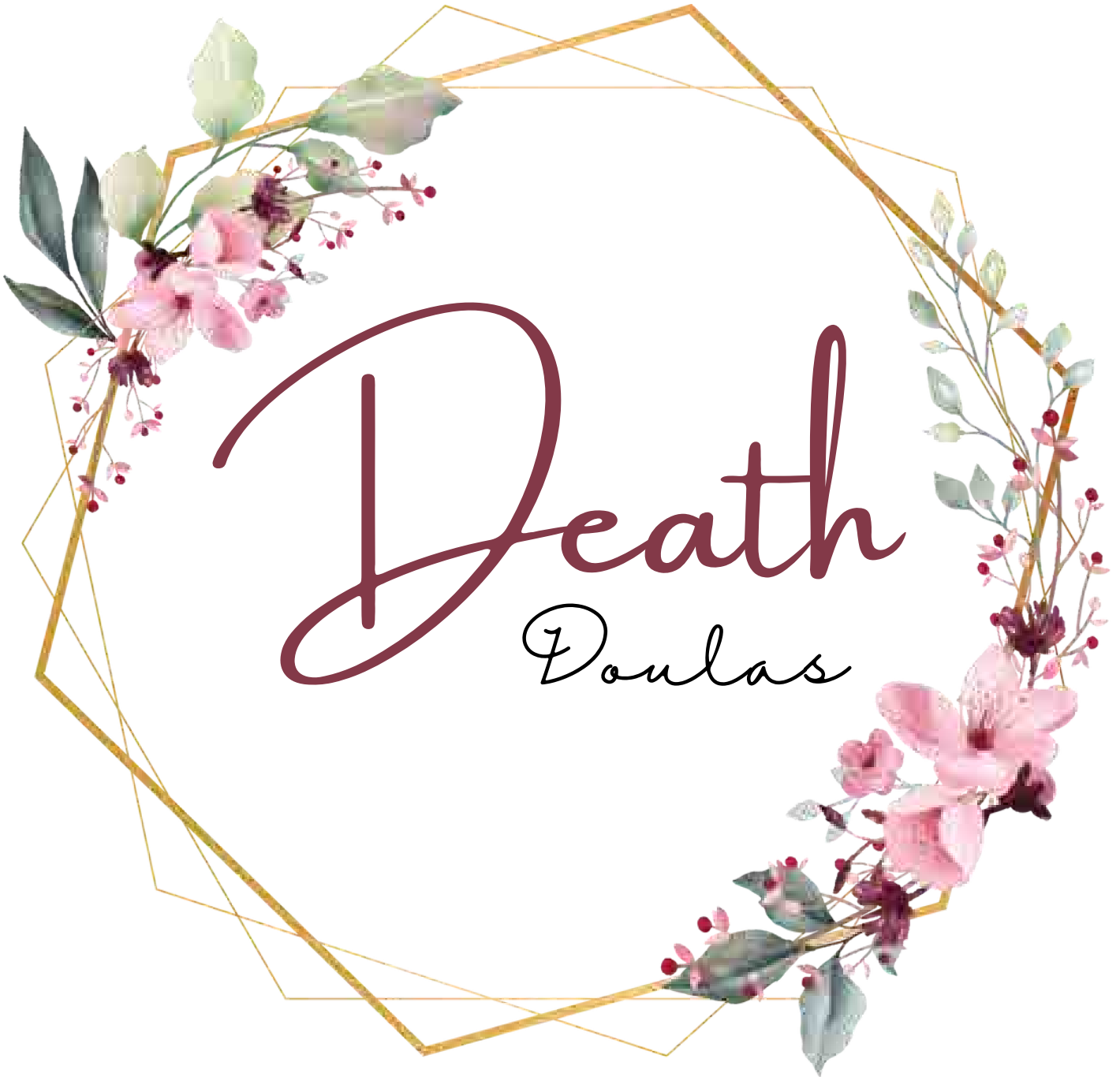
Weaving Lovingness at the End of Life



Authors:

Kádla Jorceli Gomes Rafael
Glenda Agra

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Weaving Lovingness at the End of Life

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Crislayne Silva de Macêdo

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Characters:

Patient - Maria Aparecida Freire de Avelar

Death Doula - Kádla Jorceli Gomes Rafael

Relative - Maria Heloyse de Lima Monteiro

PET: Charry

Graphic Designer:

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Maria Tereza Baptista Oliveira

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Presentation



The booklet "Death Doula: weaving Lovingness at the end of life" is the result of a scientific research carried out by the Center for Studies and Research in Palliative Care of the Federal University of Campina Grande-PB and it aims to help healthcare professionals, patients, family members as well as society in general to understand the role, importance and services of death doulas.

To the judges who evaluated the booklet, our eternal gratitude!

The people who will read the booklet, we hope you will like it!
It was prepared with scientific rigor and with great affection!

“In all cultures, despite different beliefs and traditions, death has always been seen as a transition and a sacred moment. Watching people die was a normal experience until the second half of the last century. But, as Medicine evolved, our experience with illness and the end of life changed completely. The sick were no longer sent home when it was perceived that they were going to die soon, or they began to be taken to the hospital at the slightest warning indicating their end of life. We ceased to watch over, to be an attentive presence, to lend a hand to those who are leaving. And with that we lose some of our humanity and the possibility of connecting with each other. It is from this context that death doulas propose to rescue the ancestral tradition of caring for people who are in the process of the end of life, providing lightness, patience, affection, presence and a sacred space for welcoming and lovingness during the process of death and dying”.

Ana Catarina Infante - Death Doula - (A Passagem, 2022).

Summary:



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Death Douglas

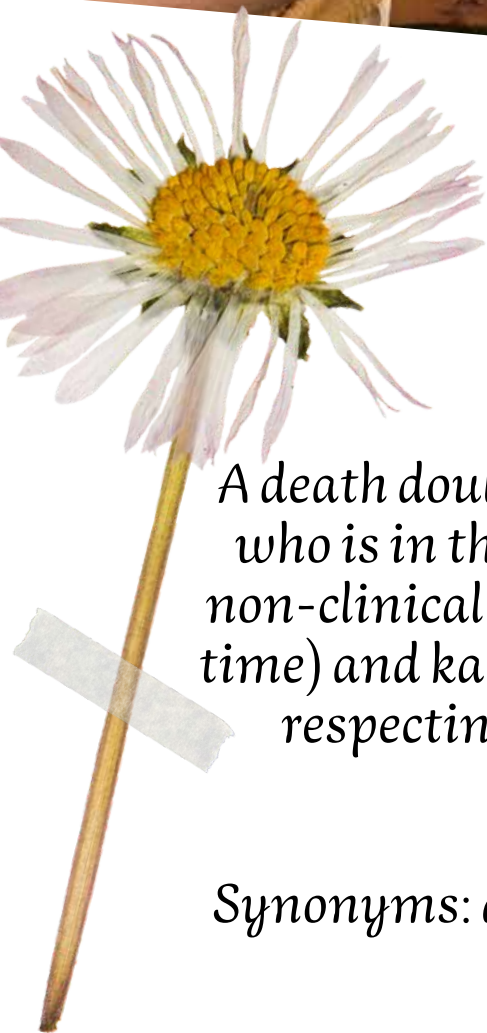
Historical Aspects



Doula

The term 'doula' has Greek origins and means 'woman who serves' and was first used in the 1970s to designate women who offered physical, emotional and cognitive support to pregnant women during childbirth and puerperium. They can be called 'life doulas'; 'birth doulas' and 'childbirth doulas'.

From the model of the birth doula, other areas began to be considered for the development of the training of specialized doulas, and among them, the death doulas.



Death Doula

A death doula is a collaborator who accompanies the person who is in the process of end of life, providing practical and non-clinical care, based on orthothanasia (death at the right time) and kalothanasia (the beautiful death; the good death), respecting biopsychosocial and spiritual dimensions.

Synonyms: doula end of life, midwife of the soul, midwife of death, thanadoula.



Emergence and Objectives

Death doulas first emerged as caregivers and companions of end-of-life patients in the United States, United Kingdom, Canada, and Australia. In Brazil, there are companies that have been offering training courses for death doulas since 2018.

The death doula collaborator offers to:

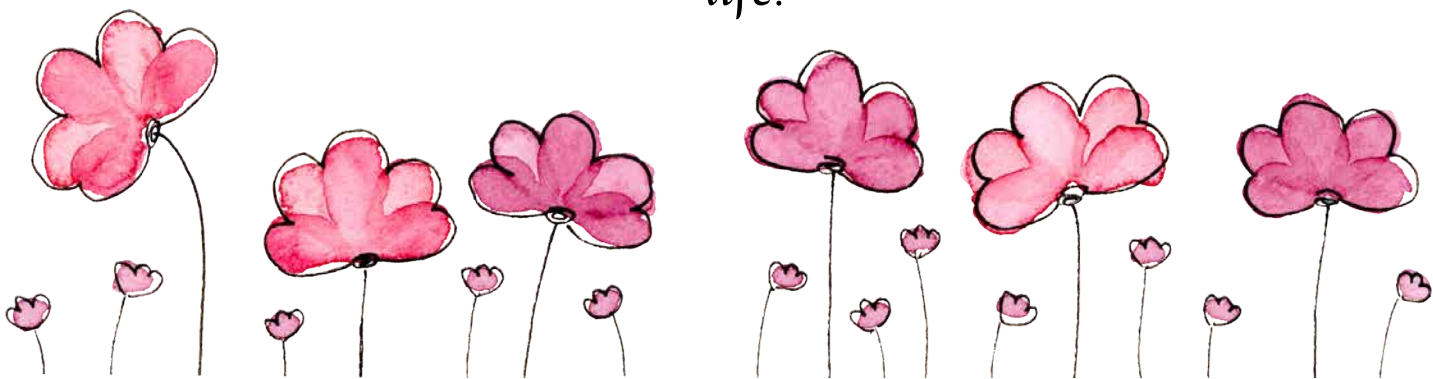
- recognize the moments of death in life as opportunities for transformation and connection to the impermanence of life;
- contribute to socially deconstruct the meaning of the sickness, the suffering, the aging, the vulnerability and death, to see them all as part of the natural process of life;
- accompany people with life-limiting and/or life-threatening illnesses and their families before, during, and after their death.



Good Death

The work of death doulas has become more evident and growing due to the advocacy of the "good death" movement, in the sense of changing the attitudes and behavior of society at large, in relation to the process of death and dying, as well as the end-of-life care.

In this sense, the death doula helps conversations with people who want to talk, to deepen and connect with their life cycles, their griefs, their transition process and rites of passage in order to live a more conscious life.





Areas of expertise:

The death doula collaborator is someone who provides his/her services - as a caregiver, supporter and advocate for the patient - in the three phases of the death and dying process:

pre-mortem phase: the one that begins with the diagnosis of the disease or with aging itself;

death phase: characterized by the active process of death and death itself;

post-mortem phase: the one that goes from death to the mourning of family members.



Roles of Death Doulas

The main roles of Death Doulas are:

- caregiver (practical and non-clinical) of the person who is in the process of end of life;
- mediator between the person who is in the process of end of life, his/her family and the multidisciplinary team;
- facilitator of the daily routine of the person who is in the process of end of life.





Legislation

In Brazil, Bill 3,946/2021 - which deals with the professional practice of Doula - was approved in the Senate on March 23, 2022 and was sent for deliberation to the House of Representatives.

This Bill contains the attributions of the birth doula and code 3221-35 of the Brazilian Classification of Occupations for the professional Doula.



Death
Douglas

Tasks and Services

Tasks and services of death doulas according to the

Physical Dimension:

Dear Reader,

Some services can only be provided if the death doula has specific professional training for that.

In these cases, we will point out those services with this marker (🌈)



They know and understand the physiology of the end-of-life and death process;

They recognize and assess the signs and symptoms of the active dying process;

They help make the environment more peaceful, welcoming, loving, and sacred;

Tasks and services of death doulas according to the


Physical Dimension:



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They provide comfort, well-being and quality of life measures, appropriate to the patient's stage of life and needs:

massages;

 thermotherapy;

 cryotherapy;



They help the person:

in their eating;

in the change of decubitus;

In oral, bodily and intimate hygiene;

In skin hydration;

in ambulation and excretory needs;



Tasks and services of death doulas according to the

Physical Dimension :


They organize the Vigil ;

They remain by the patient's side during the active process of death, stimulating therapeutic touch, providing a light environment, according to previously expressed wishes;



Tasks and services of death doulas according to the Physical Dimension :



 They perform post-mortem body care at home (for example: sanitize, buffer, dress and prepare the body for the wake) if the family wishes so;



Tasks and services of death doulas according to the

Emotional/Psychic Dimension:

They Provide emotional support to the patient and their family;

They Perform active and empathetic listening;

They provide a compassionate presence;

They carry out empathetic communication strategies such as:



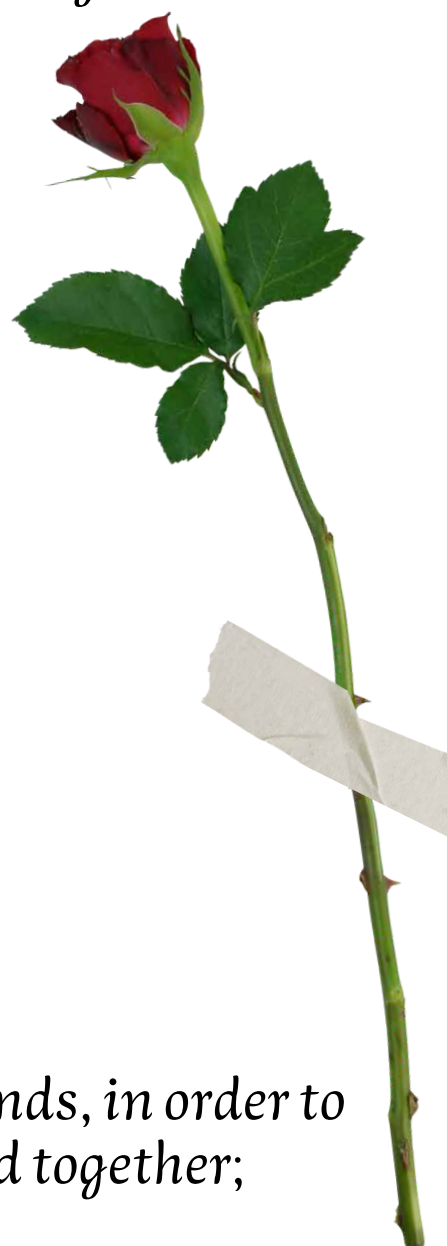
- They support the multidisciplinary team and family in the communication of the patient's diagnosis;

- Listen to complaints, concerns, anxieties and fears of the patient and their families;

Tasks and services of death doulas according to the

Emotional/ Psychic Dimension:

They welcome emotions and feelings of the patient and their family members during the diagnosis, the active process of death, the post-death and mourning;



They stimulate conversation circles with friends, in order to share stories and life experiences they had together;

They stimulate the participation of family members and friends during all the death process, in order to provide dignity to the last days of life of the patient;

Tasks and services of death doulas according to the

Emotional/ Psychic Dimension :

They keep company;

They support decision-making;

They respect the patient's wishes;

They defend the interests of the patient and their family members during the process of death and dying;



Tasks and services of death doulas according to the

Emotional / Psychic Dimension :

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They carry out activities together with the patient:

they read books;

they listen to and sing songs;

they play an instrument;

they watch movies and TV shows;

they say prayers together;



Tasks and services of death doulas according to the

Emotional/ Psychic Dimension:



 They carry out Integrative and Complementary Health Practices:

music therapy;

animal-assisted therapy;

massage therapy;

foot reflexology;

art therapy;

aromatherapy;

meditation;

Reiki;



Tasks and services of death doulas according to the

Emotional/ Psychic Dimension:

They help the patient remember moments of life, in order to rescue the meaning and significance for the current moment;

They offer genuine presence, mindfulness, and therapeutic touches;

They Assist in the referral of the patient to specific care with a Psychologist, Chaplain, Social Worker;



Tasks and services of death doulas according to the

Social Dimension :

They organize and plan the weekly schedule together with the patient and family members;

They accompany the patient to medical appointments;


They transmit to the medical team the verbal complaints and non-verbal attitudes adopted by the patient;

They keep company to patients who do not have family support; who feel lonely or abandoned, or whose caregivers feel exhausted and need rest;



Tasks and services of death doulas according to the

Social Dimension :



They keep close contact with the multidisciplinary team in order to facilitate communication between the family and the person who is dying;

They keep the patient and family members informed about medical issues, disease progression and active death process;

They assist the patient in administrative activities: they type and send e-mails, collect mail;

Tasks and services of death doulas according to the

Social Dimension :

They accompany and/or provide moments of leisure to patients;

They facilitate the fulfillment of end-of-life wishes: birthday and wedding parties;



Tasks and services of death doulas according to the Informative/Educational Dimensión:



They guide family members about the care and needs of the patient at each stage of the death and dying process;

They explain medical terms to the patient, family, and friends;

They guide the family about the premonitory signs of end of life;

They guide and facilitate the moments that can be carried out by family and friends in the active process of death and in the last hours of life (e.g.: staying as close as possible; saying goodbye);

They support the patient in communicating intentions and wishes regarding the place of death (e.g. dying at home) as well as farewell rituals (e.g. being buried; being cremated) to family members;



Tasks and services of death doulas according to the

Informative/ Educational Dimension:

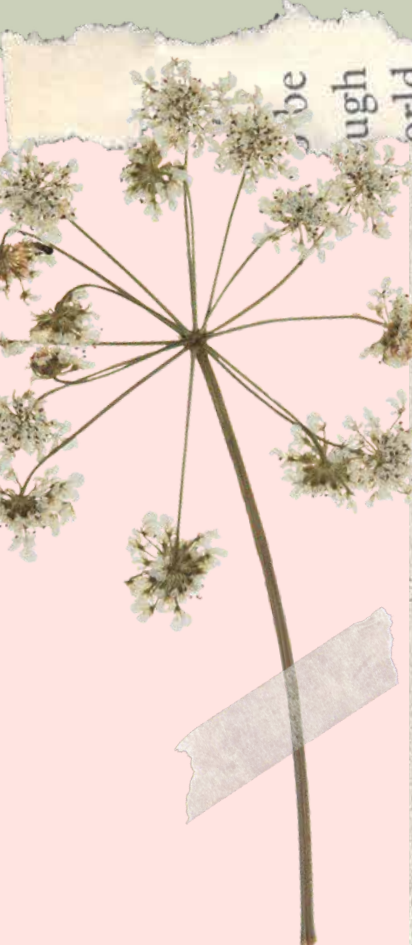
They assist the patient in the preparation of Advance Healthcare Directives (information about anticipated intentions, such as: not being tube fed; not being intubated; not being resuscitated; desire for organ donation or not; where and with whom they want to experience the death process);

They explain about the Living Will (document written with the patient's anticipated wills authenticated by a notary);



Tasks and services of death doulas according to the

Informative/Educational: Dimension



They promote education for death (e.g., lectures, courses, workshops, seminars, webinars at public events, universities, communities and training programs);

They manage Death Cafes (meetings and conversation circles with people who like to discuss topics related to death and dying);



Tasks and services of death doulas according to the

Spiritual Dimension :

They provide spiritual support to the patient and their family, respecting religious and spiritual beliefs and values;

They encourage the client to talk about religious/spiritual beliefs, trying to rescue their beliefs;

They help, within their possibilities, the patient and the family to understand and/or accept death;



Tasks and services of death doulas according to the

Spiritual Dimension:

They encourage the client to elaborate on their life legacy, such as:

- writing letters;
- organizing a photo album;
- recording videos;
- writing their biography;
- recording their last messages of life;
- creating a memorial with photos of birthdays, anniversaries and special commemorative dates with family and friends, including messages of affection;

They assist the client in solving pending issues, such as:

- forgive him/herself;
- ask for forgiveness;
- find someone they want to say goodbye to;
- help identify how they want to be remembered;

They help the patient find peace;



Tasks and services of death doulas according to the

Spiritual Dimension :

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They provide support to those who will be by the patient's side during the last hours of life;

They plan vigil with family members;

They facilitate final conversations and goodbyes;



They prepare rituals at the bedside, according to beliefs and religious/spiritual traditions of the patient;



They accompany the patient and the family with more attention, care and lovingness at the final moment of their lives;



They provide grief support to family, friends and relatives after the patient's death.



Death
Douglas

Scenarios and Professionals

Scenarios and Professionals



Performance:

The first death doulas were nurses with extensive experience, however anyone - healthcare professional or not - can perform the tasks and services of death doulas, as long as they are trained to do so.

Job Scenarios:

In the context of caregiving, the death doula worker can work in homes, outpatient clinics, hospitals, clinics, long-term care institutions, support and rest homes, long-term care and palliative care units, compassionate communities, indigenous and quilombola communities, prisons and funeral homes, as well as in other social settings.

In the field of education, the death doula collaborator can teach classes, lectures, free courses, short and long-term courses, workshops, manage Death Cafes and conduct research.



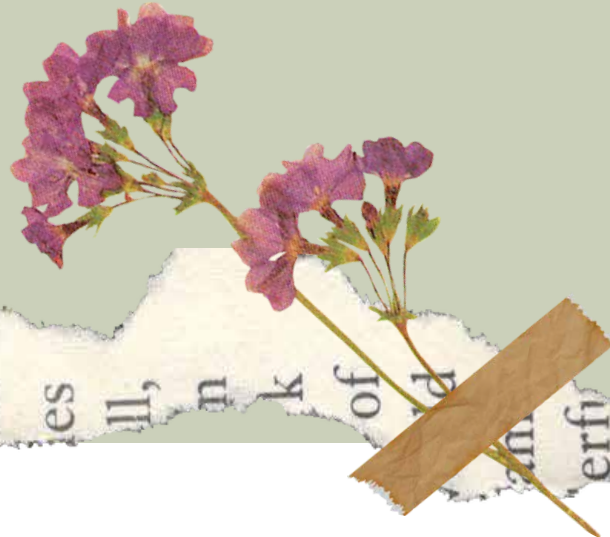
Compassionate community - is a community development initiative, associated with Palliative Care, where groups of neighbors come together to organize ways to help people in their residential area.



Death
Douglas

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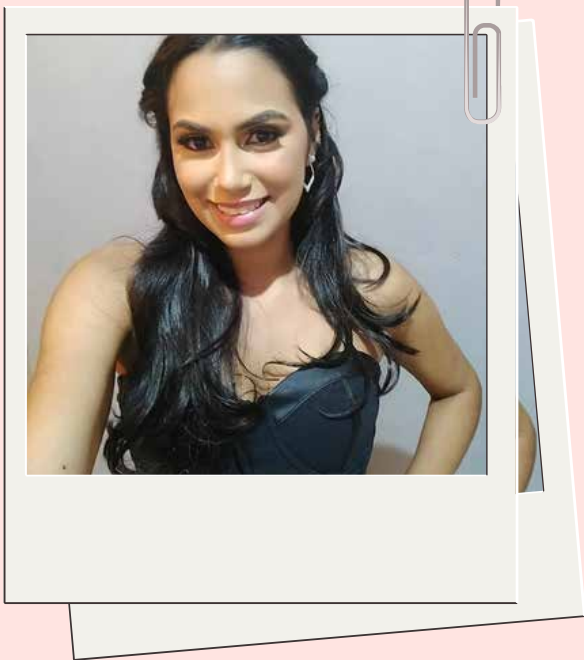
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