

BETTER TOGETHER: COMMUNITY AS INTERVENTION IN END-OF-LIFE CARE



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<https://thepeacefulpresenceproject.org>



compassionate community care

We reimagine and transform the way communities talk about, plan for and experience serious and terminal illness.

Vision: A culture in which every community member receives compassionate, equitable support through the end of life.

SERVICES



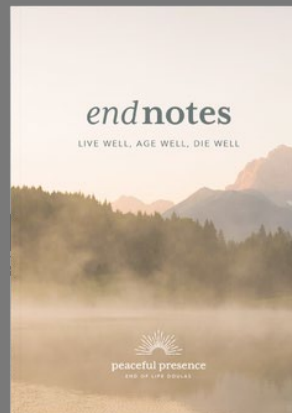
Education



Planning



Presence



95%

Compassionate Communities Model of Care

A Compassionate Community recognizes that caring for one another during times of crisis and loss is not simply a task for health and social services but is everyone's responsibility.



PUBLIC HEALTH PALLIATIVE CARE

Bereavement care as example

6.4% (10%)

High Risk – at risk of complex grief issues. May need referral to mental health professionals

35.2% (30%)

Moderate Risk – in need of some additional support e.g. peer support/ volunteer led group

58.4% (60%)

Low Risk – majority of individuals deal with grief with support of family & friends

Aoun et al. 2015, PLoS One



**What if our community came together
to support one another during times
of illness, loss and grief?**

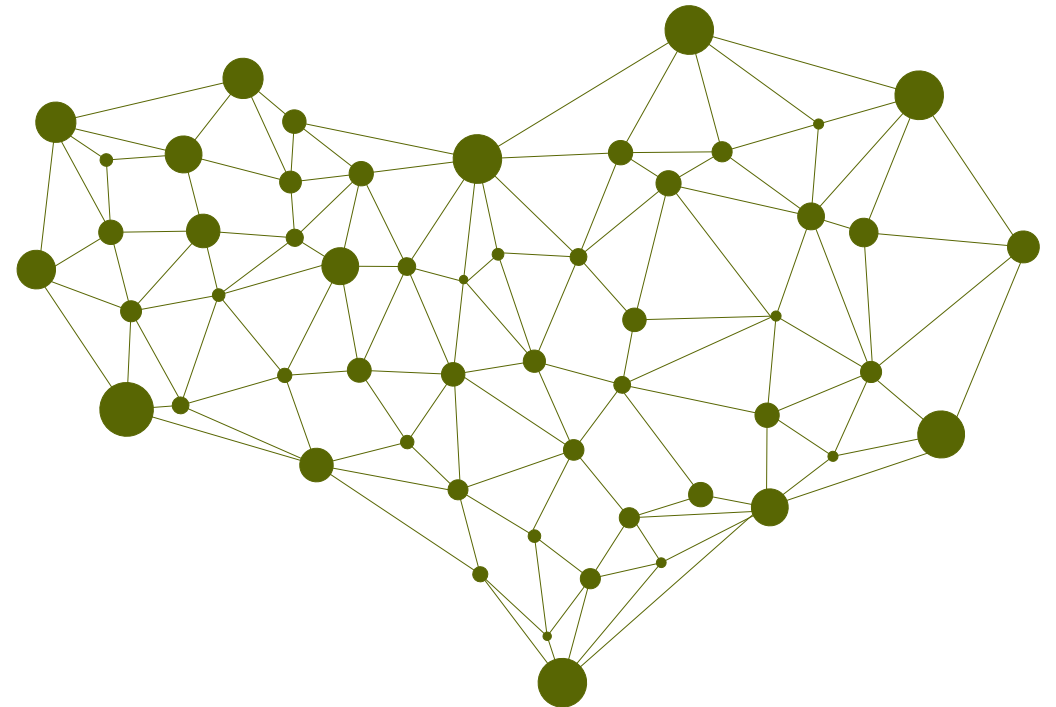
What would it feel like to know that your family,
your neighbors-- your patients-- were cared for?

Statewide Network for Serious Illness Care

- Peer to peer networks established in each county
- Ongoing mentorship and support to encourage best practices
- Referrals and online directory for EOL care practitioners

Education and training opportunities for:

- Community Health Workers
- Community Connector volunteers
- Professional end-of-life doulas



Oregon Network

FOR COMMUNITY-BASED SERIOUS ILLNESS SUPPORT



The ability to identify and strengthen cohesive networks of care increases community resilience and encourages higher quality, more equitable end-of-life experiences for all

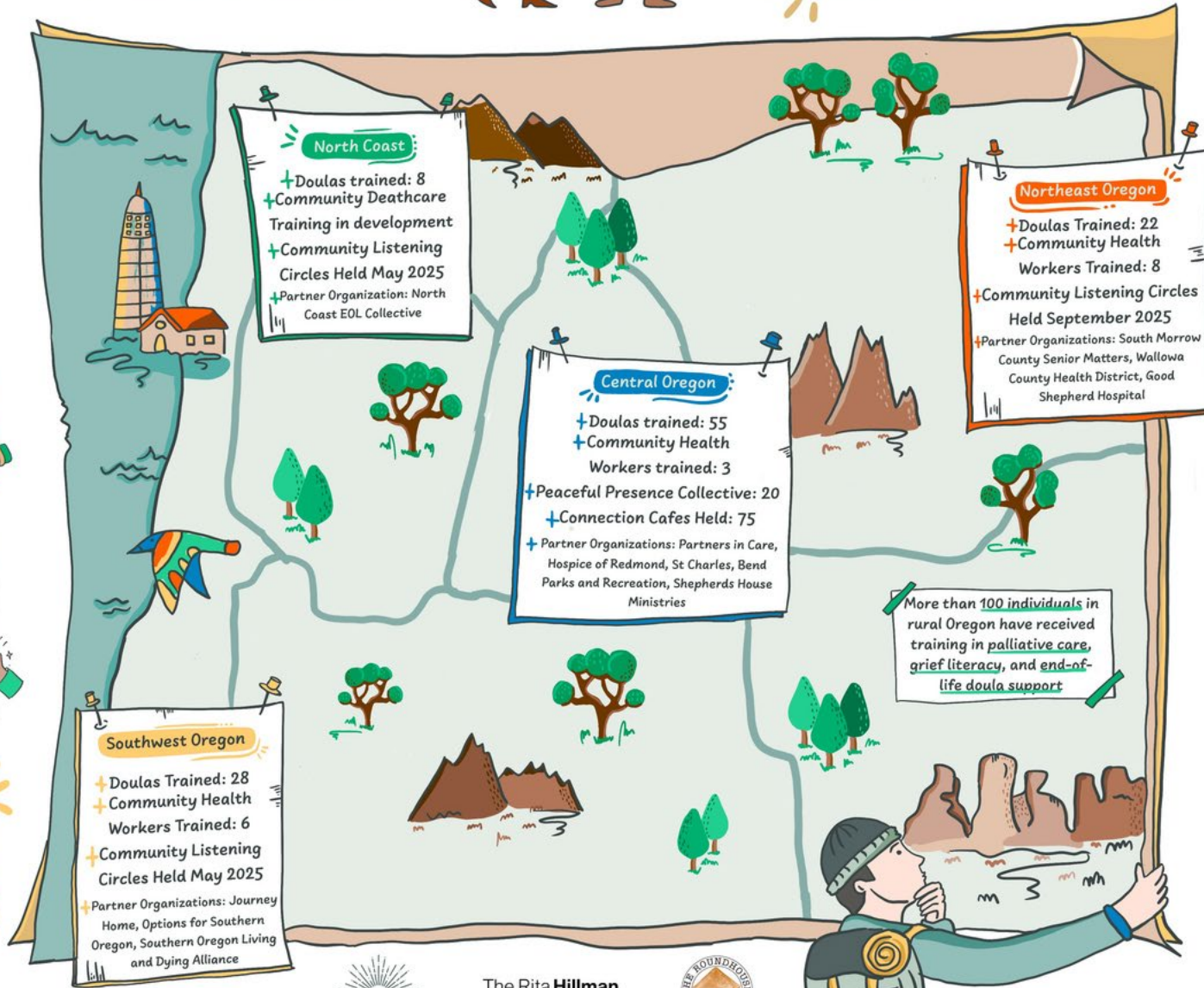
PROJECT GOALS

Widen the circle of caring for patients and caregivers

Identify roles of individuals who can embed the end of life care skill set in existing professions or capacities

Expand cohesive presence of informed community members who can support, especially in resource-limited settings

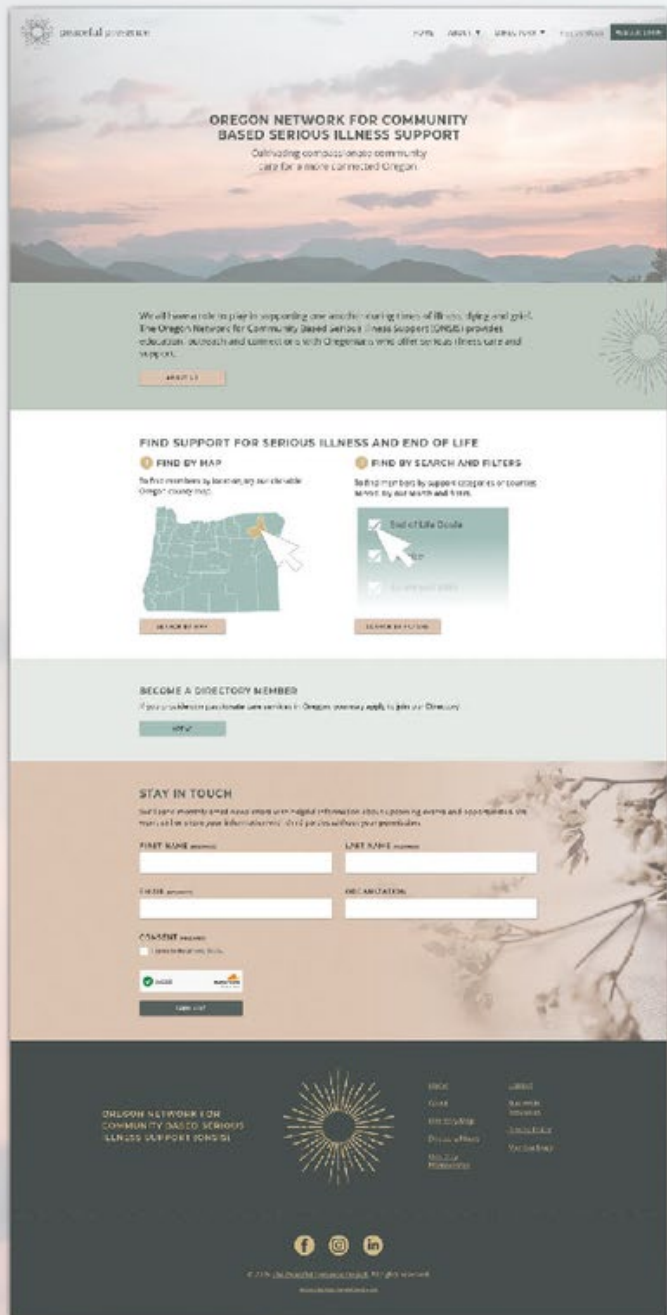
ULTIMATE GOAL
A more death literate Oregon



The Rita Hillman and Alex Foundation



illustration: mina yanci ibis | minadrawing.com



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ANNOUNCING NEW ONLINE END-OF-LIFE CARE DIRECTORY:

Oregon Network for Community Based Serious Illness Support

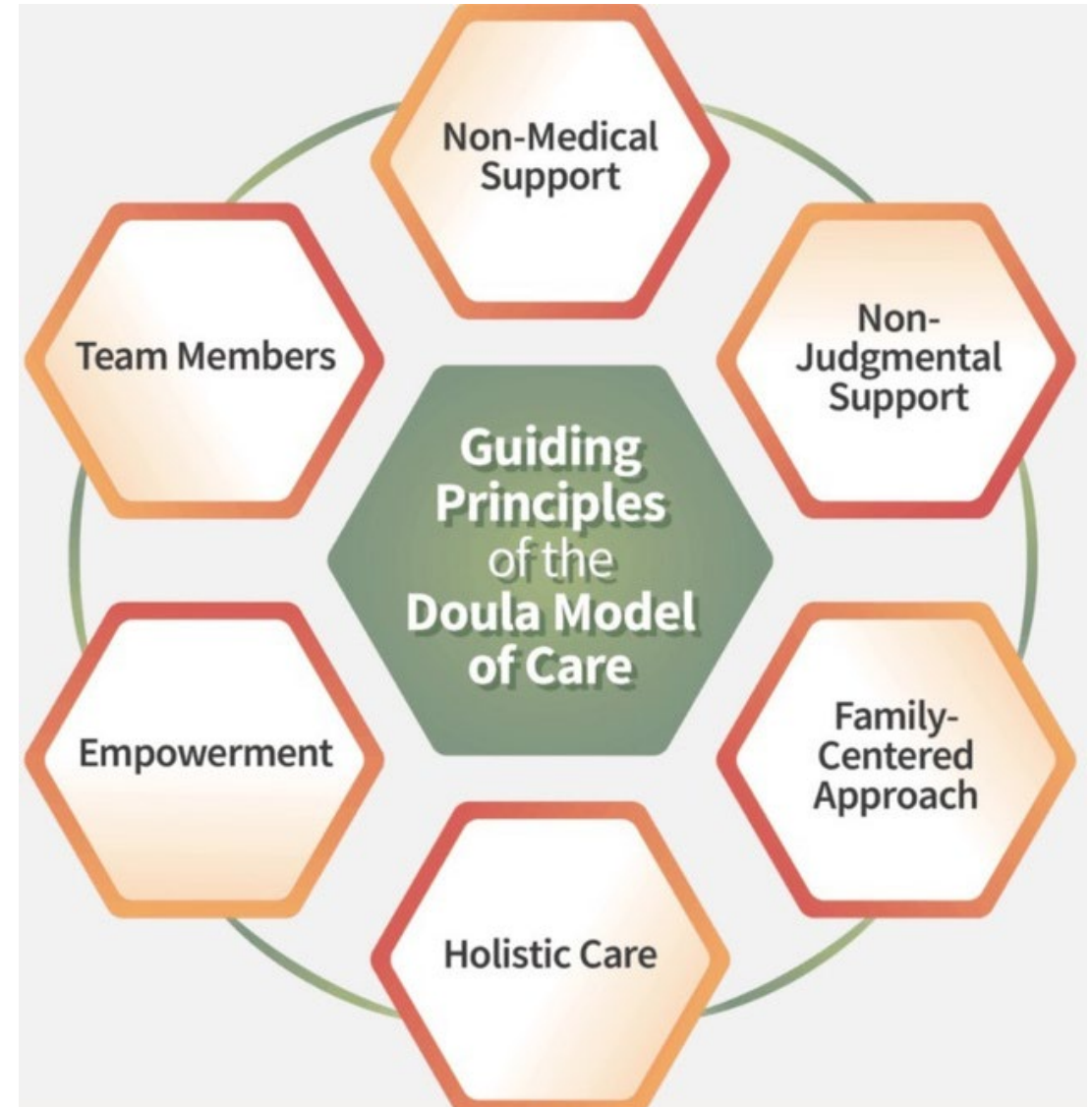
We all have a role to play in supporting one another during times of illness, dying and grief. The Oregon Network for Community Based Serious Illness Support (ONSIS) provides education, outreach and connections with Oregonians who offer serious illness care and support.

If you provide compassionate care services in Oregon, you may apply to join our Directory. If you are seeking a provider, you may search the Directory using a clickable Oregon county map, or by keywords and filters.

<https://onsis.org>

What is an end-of-life doula?

- End-of-Life Doulas [EOLDs] are non-medical companions to the dying and their families.
- EOLDs complement other services that a dying person and their family may be receiving, including hospice and/or palliative care.
- EOLDs provide a wide range of holistic life support services to address:
 - Physical
 - Emotional
 - Spiritual
 - Practical



Core competencies: what doulas do

NATIONAL END-OF-LIFE DOULA ALLIANCE CORE COMPETENCIES

COMMUNICATIONS

Patient and family advocacy
Cultivating key community relationships
Active listening/critical thinking
Conflict resolution/family dynamics
Creative problem solving

VALUES & ETHICS

Doula model of care
Biopsychosocial and spiritual dimensions
Cultural humility
Personal integrity
Accountability
Boundaries and legalities

End-of-Life Doula Competencies

KNOWLEDGE

Patient support
Caregiver support
Planning needs
Referrals and systems
Roles and responsibilities
Legal & medical knowledge

PROFESSIONALISM

Self-care
Scope of Practice
Confidentiality
Professional development
Business skills and tools
Medicare CoPs

Interdisciplinary team tasks doulas can support :

Emotional

- Active listening
- Legacy
- Calming presence

Practical :

- Coordinate caring circle in families/friends
- Arrange space in the home
- Household tasks/errands

Spiritual

- Guided imagery
- Meditation
- Readings

Physical :

- Non-medical symptom management
- Fresh-air
- Education about EOL
- Hands-on comfort, repositioning

A TIMELINE FOR EOLD SERVICES

Involves compassionate conversation, education and preparation with the client



Practice settings

- Hospice volunteers
- Hospital volunteers
- Community-based independent practice
(sliding scale/pro-bono)
- Hospice-embedded doulas
- Faith communities



Payment

- NOT currently covered by private or public insurance
- Grant funding
- Independent fee for service-- covered in bundle payment (acupuncture, massage)

Clinical Vignettes

- Richard: 93-y/o male, in assisted living with onset of Parkinson's disease and dementia, who is choosing to voluntarily stop eating and drinking (VSED).
- Leann: 52-y/o female with hereditary lung disease, living at home on continuous high-flow oxygen.
- Rachel: 50-y/o female lives alone. Metastatic ovarian cancer, on hospice.



Richard



- Wanted to choose Medical Aid in Dying, but did not qualify
- VSED option–wanted a team of support for son and daughter-in-law around the clock.
- Wanted to ensure wishes were followed.
- Doula team provided months of education, active listening, engaged palliative care, hospice team, ALF
- Died at home with doula support after 7 days.



Leann

- Living at home, alone for 12-14 hours/day
- On continuous high flow oxygen; unable to go outside of home due to COVID, wildfire smoke
- Didn't want hospice
- Twice-weekly visits with doulas for education, listening
- After 6 visits, ready for hospice, "it is less scary"
- Admitted to hospice and IPU within 2 days.



Rachel

- Lived independently, practicing Buddhist, member of cancer support group
- 80-year old parents came from coast to be caregivers
- Parents exhausted- vast community was chaotic
- Doula engaged: care coordination, respect for home vigil, caregiving (20-25 hours of support per week)
- Able to die at home, vigil at home, ease the workload on parents



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CHW in Primary Care Clinic:

“I am using the conversation starters to talk about illness and future choices”
“I am helping patients self-manage their symptoms in their home.”

“

”

CHW in Community Based Organization:

“I helped my patient verbalize her care preferences and then referred her back to her PCP to share them. We were able to get her on hospice and set up her home for visitors and goodbyes.”

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CHW in Federally Qualified Health Center:

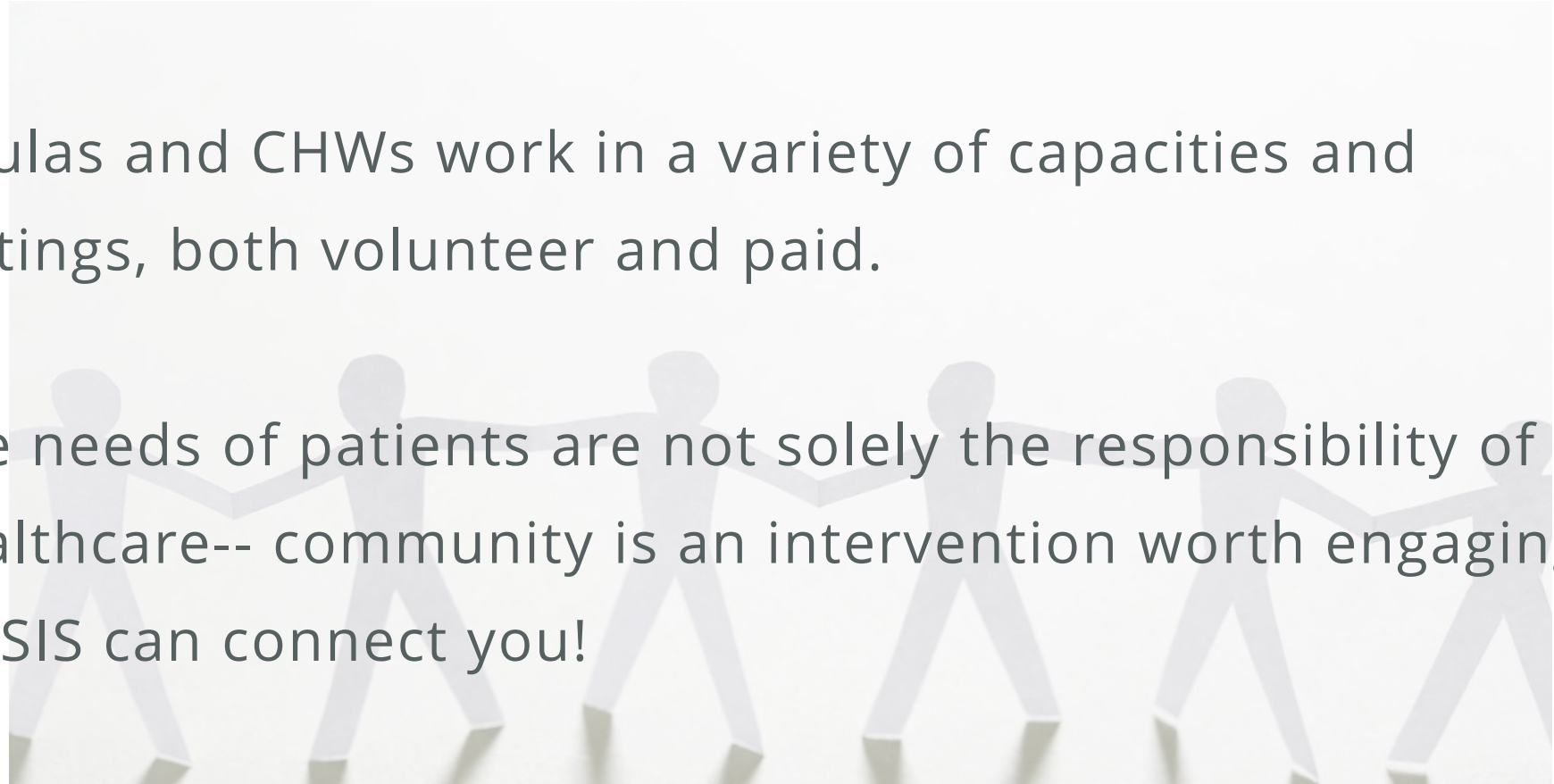
“I am educating and supporting caregivers with self-care and boundaries while they are taking care of a loved one who is ultimately going to be deceased soon.”

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Key Takeaways

- Trained community members provide collaborative support to families, patients and care teams.
- Doulas and CHWs work in a variety of capacities and settings, both volunteer and paid.
- The needs of patients are not solely the responsibility of healthcare-- community is an intervention worth engaging
- ONSIS can connect you!





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END OF LIFE DOULAS

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