WALKING THEM HOME

Caregiving at the End of Life

Rhonda Osborn | Founder, This One Life

This One Life

End-of-Life Educator & Guide
Grief Coach | Caregiver Coach
Spiritual Director

BEFORE WE BEGIN

I am not a medical doctor, lawyer, or financial advisor. Everything in this presentation is generalized from my own experience and learning.

Please talk with your loved one's doctor or hospice team about their specific situation.

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QUESTIONS YOU MAY BE CARRYING

Am I doing this right?

What should I expect?

How do I stay present?

1. What is happening in the body
2. What to say and do
3. How to care for you

THREE UNIVERSAL TRUTHS

1

We die the way we've lived

Our personality shows up at the end. We meet this final challenge the way we've met others.

2

Being there — or not

If you're there, it's because they wanted you there. If you're not, it may be a gift of love: they were protecting you.

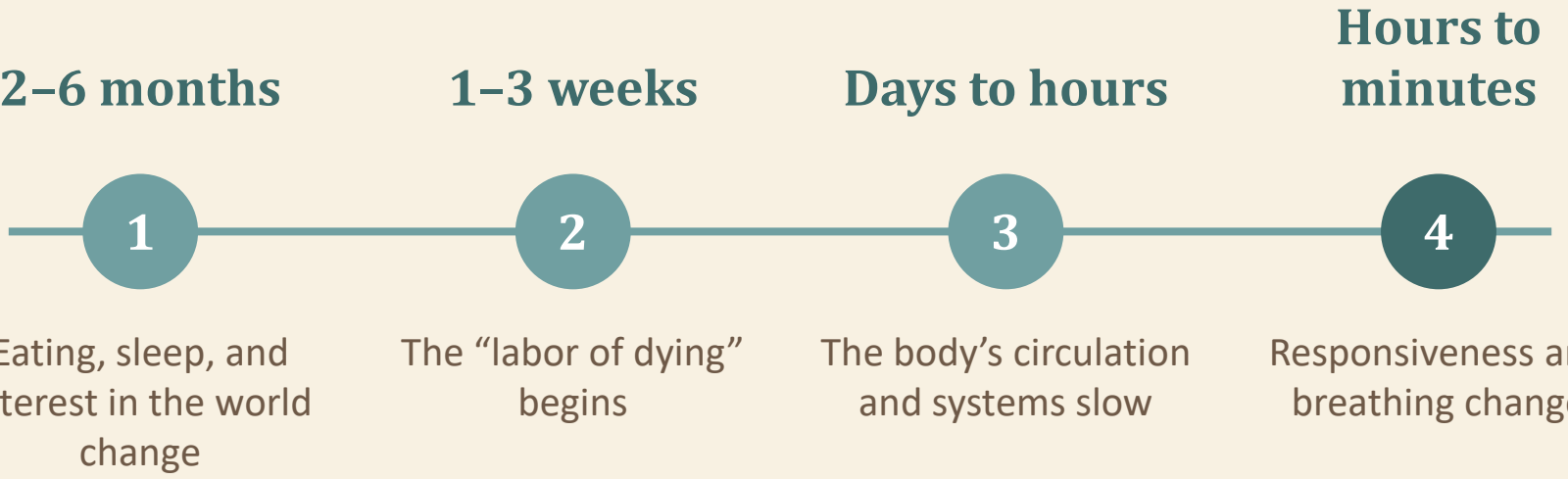
3

It's not like the movies

Real dying is slower, quieter, and more ordinary than what we've seen on screen.

THE BODY KNOWS HOW TO DIE

Just like it knows how to be born



FOOD & FLUIDS

2–6

months before death, eating begins to change

- Stop eating meat: beef, then chicken, then fish
- Stop fruits and vegetables
- Stop anything that takes energy to digest
- Want only soft foods: pudding, ice cream, soup
- Then only protein supplements, water, or Gatorade

The body doesn’t want or need the energy from food.

ALWAYS OFFER, NEVER FORCE

Offer. Never force.

Offer sips and small tastes. Accept “no” as an answer.

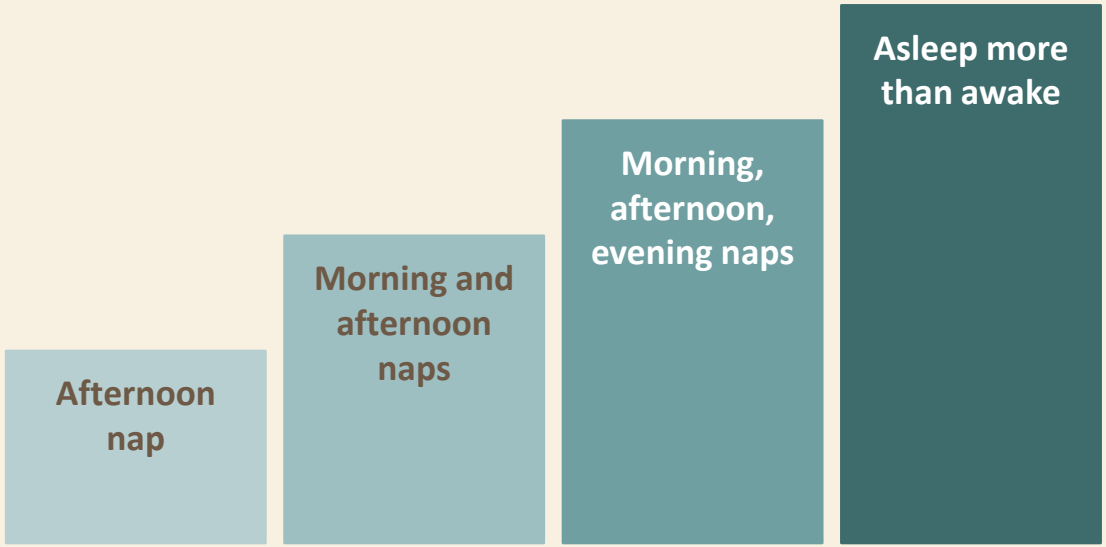
Food is how we say “I love you.” Other ways: sit close, hold a hand, play music, moisten dry lips.

Ask hospice first

Feeding tubes and IV fluids are rarely helpful at this stage and will likely add discomfort.

Talk with your loved one’s hospice team before deciding.

SLEEP



The dream world becomes their world.

Weeks before death, they may talk about people and places you can’t see.

WITHDRAWAL

Sorting out the “junk” of life

They are grieving their losses.

1. 2–4 months before death: no longer interested in the world, sports, or news
2. They are processing their life. Going within is hard work
3. They may push people away, or be hostile or aggressive

*Dementia

doesn’t play by the same rules

Sleep and withdrawal can last for years, so they don’t follow the usual timeline

Hospice may discharge someone after six months if decline is slow

Difficulty eating signals the dying process has begun, and hospice is appropriate again

THE LABOR OF DYING

1–3 weeks before death

- Asleep with eyelids partly open
- Puffing air; mouth open
- “Death rattle”
- Agitation
- Restlessness

Like a baby chick working its way out of its shell.

They look different from “fragile and weak.” They look like they are dying. Call hospice sooner rather than later.

WHAT AFFECTS THE LABOR

1

Pain

Tension locks us in the body. Treat pain until the last breath, even if unconscious. Hospice can help.

2

Fear

Letting go takes relaxing. Fear, including fear of what comes next, can make people hold on.

3

Unfinished business

If someone can’t be there, get them on the phone. The dying person can hear them.

DAYS TO MINUTES

Days to hours

- Mottling: bluish, dark patches on hands, feet, knees
- Passing urine and stool often

Hours to minutes

- Not responding to their surroundings
- “Fish out of water” breathing. Almost everyone does this

If they are working hard to breathe: hold their hand and match their breaths. Then calm your own. They often follow.

LANGUAGE TO LEAN ON

"Thank you"

"I forgive you"

"Please forgive me"

"I love you"

"Goodbye"

Instead of "It's OK for you to go"

"I understand you have to go when you're ready."

THIS IS SACRED SPACE



Hold a hand



Talk about everything, good and bad



Give people time alone in the room

ANTICIPATORY GRIEF

Grieving before the loss

You may feel

Guilt, anger, sadness, relief

Your body may show it

Tight shoulders, racing heart, shallow breathing

Whatever you are feeling is OK. Just notice it, and don't judge it.

DECISION FATIGUE

The quiet weight

- Dozens of small decisions a day
- Watching someone you love decline
- Being “on” for everyone else

What can lighten it

- Decide only what needs deciding today
- Let hospice and others carry some of it
- Let “good enough” be good enough

CARING FOR YOU

1

Your body

Attend to your health. Prioritize rest and nourishment.

2

A coping toolbox

Breathing, prayer, journaling, walking.

3

Small rituals

Light a candle. Pray. Journal.

4

Let others help

Say yes when someone offers. Be kind to yourself.

RESOURCES

Karnes, B. (2024). *Always Offer, Never Force.* Vancouver, WA: Barbara Karnes Books, Inc.

Karnes, B. (1986). *Gone From My Sight: The Dying Experience.* Vancouver, WA: Barbara Karnes Books, Inc.

O'Connor, M.-F. (2025). *The Grieving Body.* New York: HarperCollins.

QUESTIONS and COMMENTS



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Thank you

Rhonda Osborn | Founder, This One Life

(913) 954-8574

rhonda@this-one-life.com

www.this-one-life.com

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