

Dementia at End of Life

What **All** Post-Acute Providers
Should Know



with
Barbara Karnes, RN
Award Winning End of Life Educator
& Hospice Pioneer



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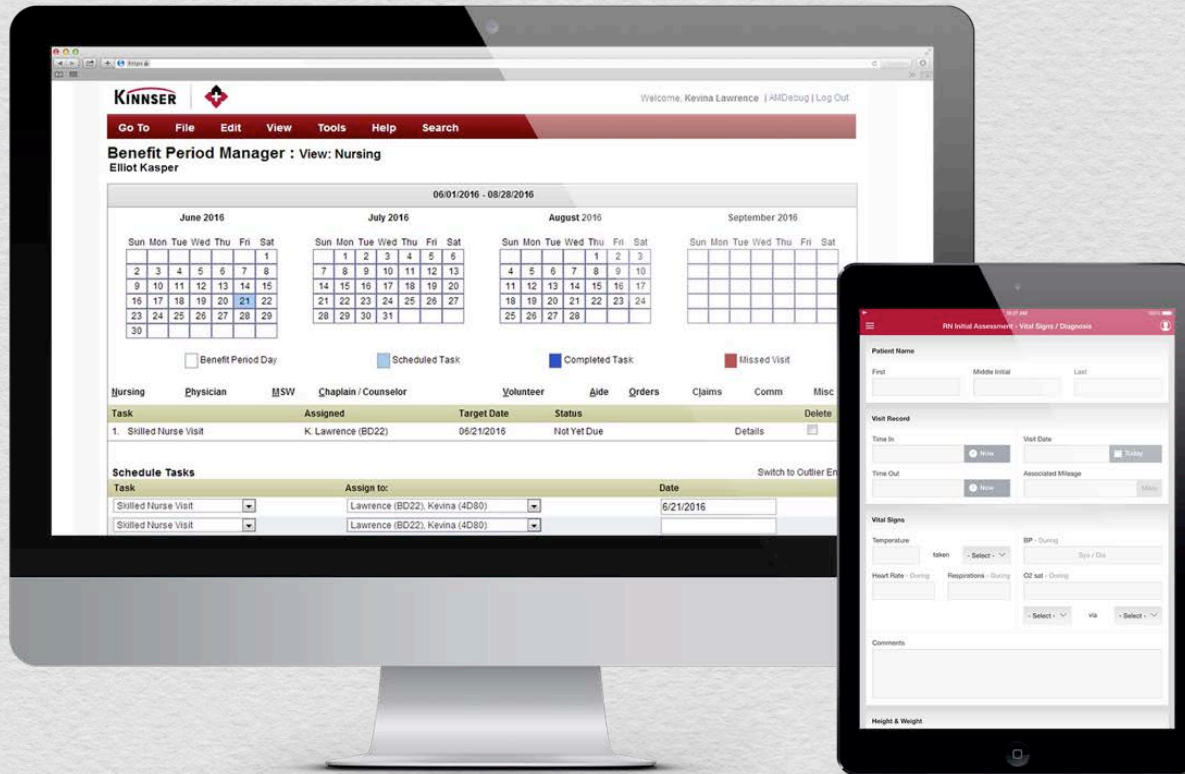
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More than
5 million Americans
currently have Alzheimer's disease or
other forms of dementia



Diseases involving dementia cost

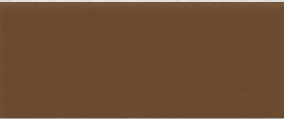
\$236 billion

in 2016



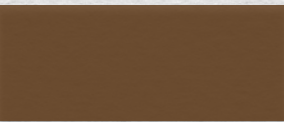
One in three

American seniors dies with Alzheimer's disease or other form of dementia



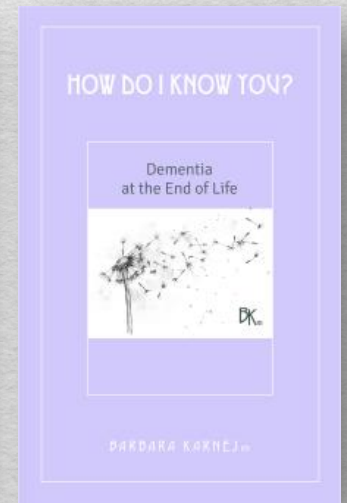
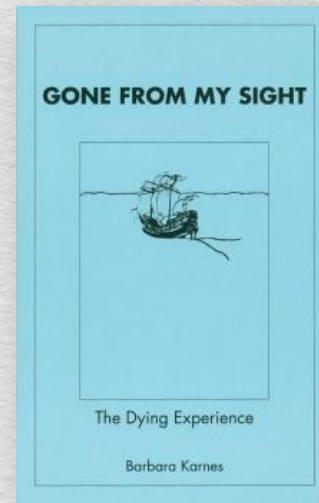
Thirty years ago, there was no information available for families about the dying process.

One woman changed that.



Barbara Karnes, RN

End of Life Educator & Hospice Pioneer



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Is dementia a disease
or **a symptom?**



Is dementia a disease
or **a symptom?**

- Dementia is not a specific disease



Is dementia a disease or a **symptom**?

- Dementia is a group of symptoms that affect memory, thinking and social abilities

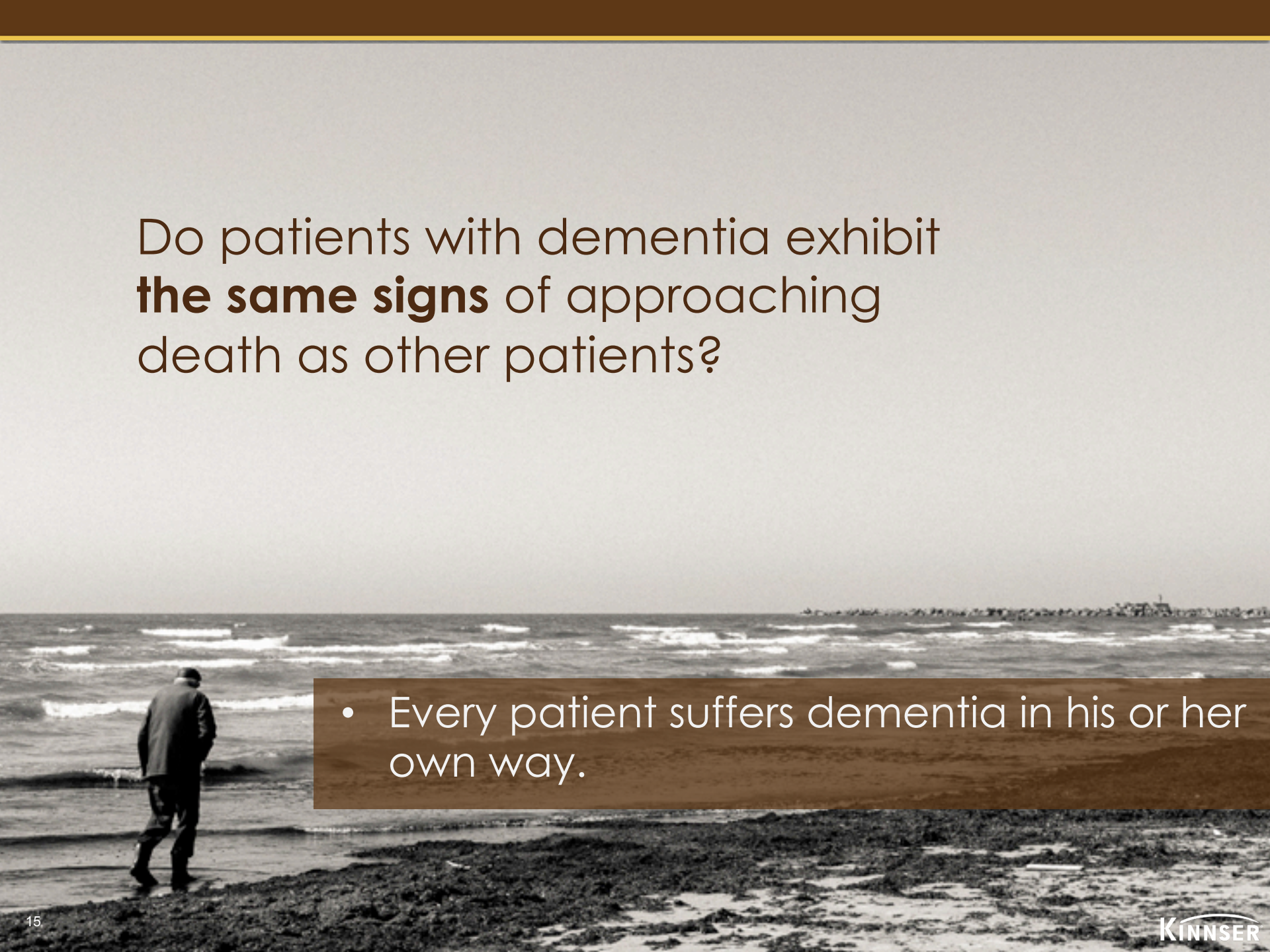


Is dementia a disease or a **symptom**?

- Alzheimer's disease is the most common cause.

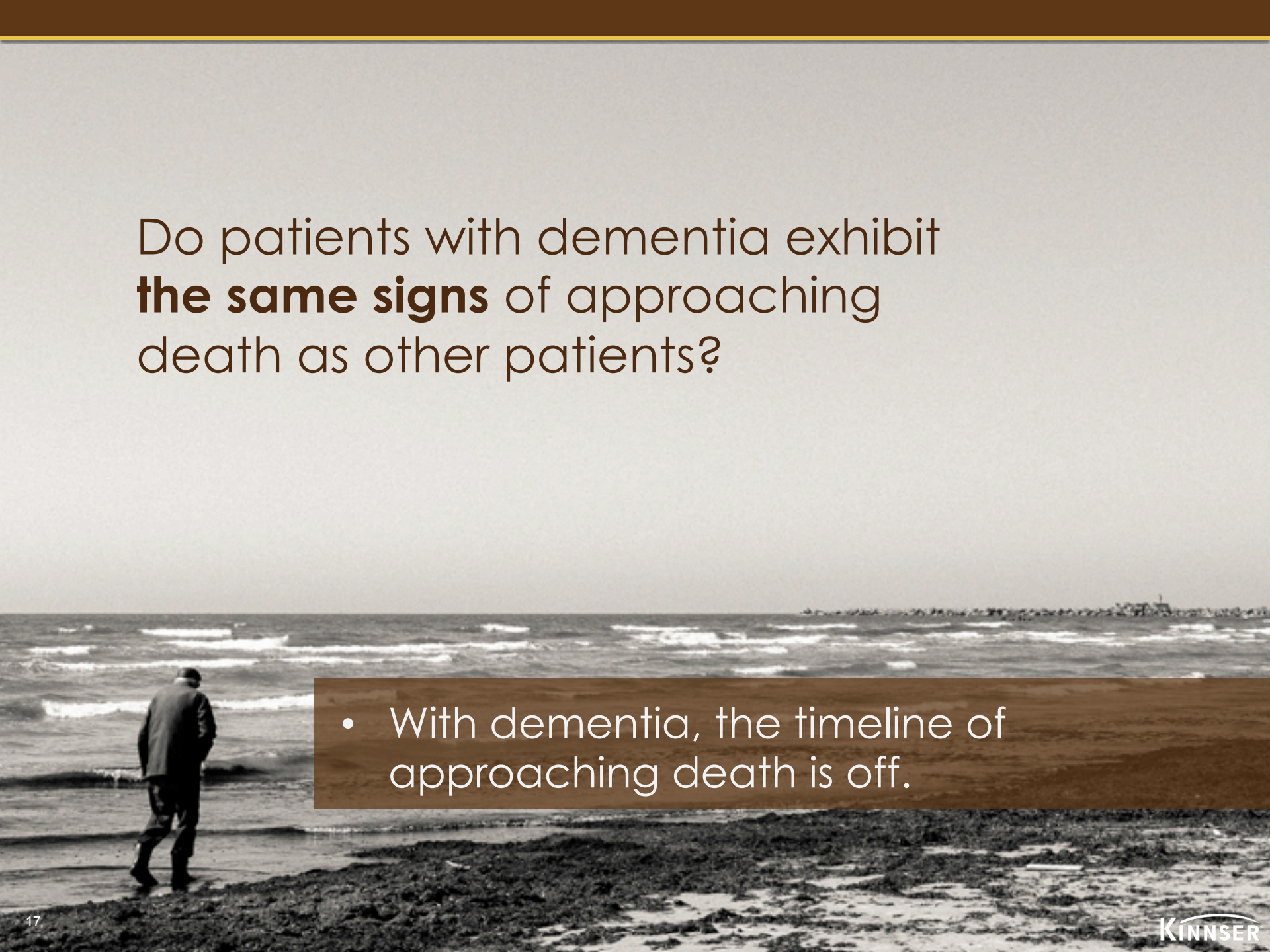
Do patients with dementia exhibit **the same signs** of approaching death as other patients?



A person in a dark coat stands on a rocky beach, looking out at the ocean under a grey sky. The waves are breaking on the shore. In the distance, a rocky pier or breakwater is visible.

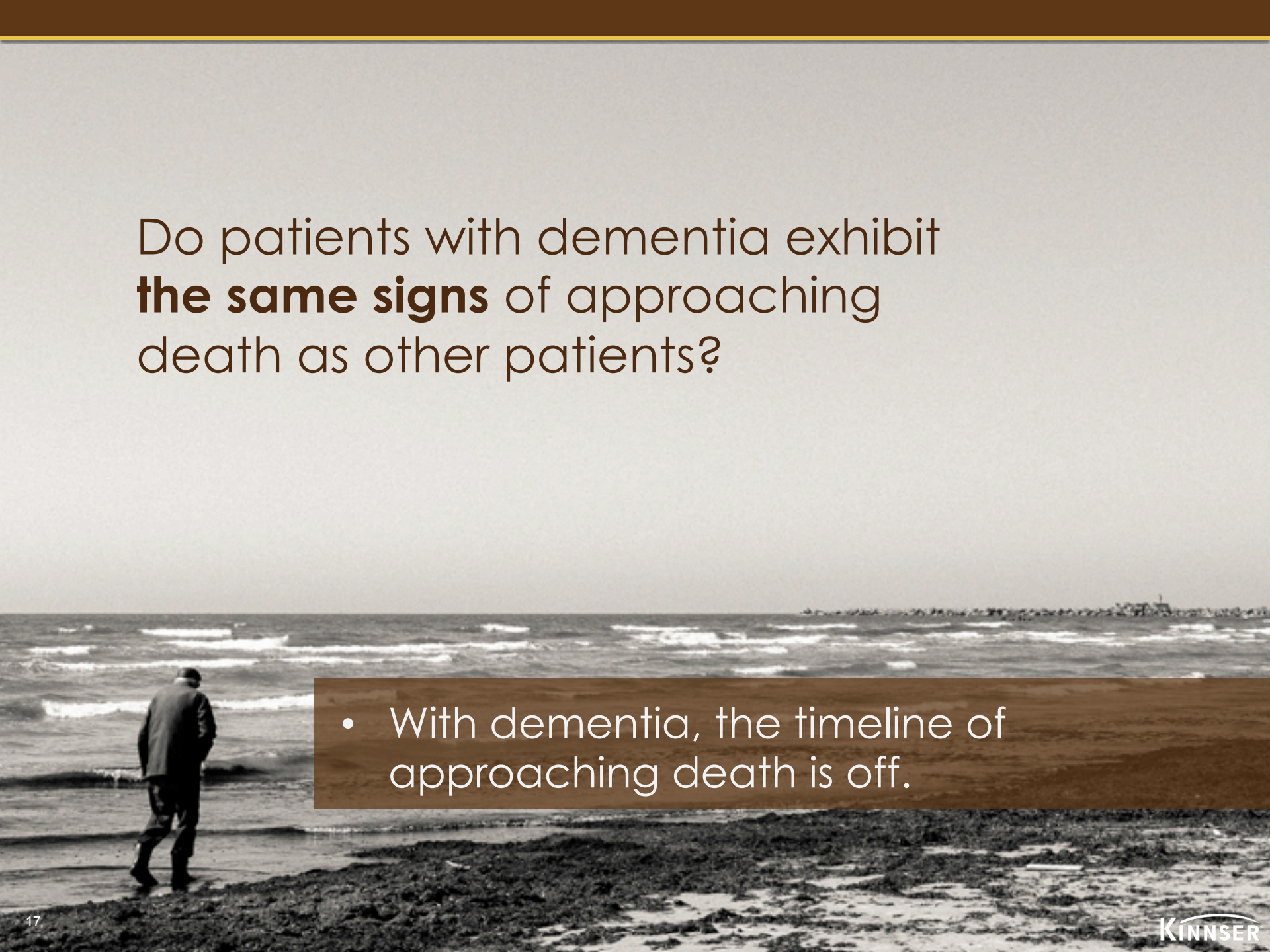
Do patients with dementia exhibit **the same signs** of approaching death as other patients?

- Every patient suffers dementia in his or her own way.

A person in a dark coat stands on a rocky beach, looking out at the ocean under a grey sky. The waves are breaking on the shore. In the distance, a rocky pier or breakwater is visible.

Do patients with dementia exhibit **the same signs** of approaching death as other patients?

- Dementia doesn't play by the rules.

A person in a dark coat stands on a rocky beach, looking out at the ocean under a grey sky. The scene is somber and contemplative.

Do patients with dementia exhibit **the same signs** of approaching death as other patients?

- With dementia, the timeline of approaching death is off.

A person in a dark coat stands on a dark, pebbly beach, looking out at the ocean. The waves are breaking in the distance under a grey, overcast sky. The overall mood is somber and reflective.

Do patients with dementia exhibit **the same signs** of approaching death as other patients?

- The person with dementia may eat less, sleep more, and withdraw into their own reality, but those occurrences may not relate to approaching death.

A person in a dark coat stands on a dark, pebbly beach, looking out at the ocean. The waves are breaking in the distance under a grey, overcast sky. The overall mood is somber and reflective.

Do patients with dementia exhibit **the same signs** of approaching death as other patients?

- Not until not eating becomes a big issue can we consider that a person with dementia has entered the dying process.

Why is a change in **eating** so important?





Why is a change in **eating** so important?

- If we don't eat, we won't live.



Why is a change in **eating** so important?

- The question becomes do you insert a feeding tube, or not?

Why is a change in **eating** so important?

- Offer food. Do not force.

What is the **typical**
dying process?



What is the **typical** dying process?

- The typical dying process involves three things: eating, sleeping & withdrawing from the world

What is the **typical** dying process?

- The person gradually stops eating.

What is the **typical** dying process?

- The person begins sleeping more until they don't get out of bed and are asleep more than awake.

What is the **typical** dying process?


- The person begins withdrawing from the world.

What is the **typical** dying process?

- With dementia, there are no such points of reference to guide us as to when death may occur.


Why is dementia,
especially
Alzheimer's disease,
called **“the long
goodbye?”**






Why is dementia,
especially
Alzheimer's disease,
called **“the long
goodbye?”**

- With dementia, we lose our loved one long before their body actually leaves us.




Why is dementia,
especially
Alzheimer's disease,
called **“the long
goodbye?”**

- From diagnosis until death is generally a very long time, often years.



Why is dementia,
especially
Alzheimer's disease,
called **“the long
goodbye?”**

- It is years of gradually watching a loved one decline and become less and less able to function.



Why is dementia,
especially
Alzheimer's disease,
called **“the long
goodbye?”**

- There are no reliable points of reference to guide us as to when death may occur with dementia.



What are some of
the challenges
faced by families &
professionals?



What are some of
the challenges
faced by families &
professionals?

- We must continuously adjust our interactions and reactions to whatever aspect of dementia is showing itself at any given time.



What are some of
the challenges
faced by families &
professionals?

- Put more simply, the challenge is to be in the present, in the moment, in all exchanges.

Is there a special role for
professional caregivers?





Is there a special role for **professional caregivers**?

- The role of professional caregivers is important because of their experience and perspective.

What are some of the considerations when a patient **stops eating**?



What are some of the considerations when a patient **stops eating**?

- Not until eating becomes a big problem, can we consider that a patient with dementia has begun to die.

What are some of the considerations when a patient **stops eating**?

- Food, water, and artificial feeding are hard choices.

What are some of the considerations when a patient **stops eating**?

- Advanced Directives help avoid a lot of anguish regarding artificial feeding.

What are some of the considerations when a patient **stops eating**?

- There are no right or wrong answers about feeding or not feeding.

What are some of the considerations when a patient **stops eating**?

- The natural way we all die from disease or from old age is by gradually not eating and not drinking.

What are some of the considerations when a patient **stops eating**?

- Not artificially feeding a person with Alzheimer's or dementia allows that person to approach death in a normal way.

What signs indicate that a person with dementia should be admitted to **hospice**?



What signs indicate that a person with dementia should be admitted to **hospice**?

- It is very hard to determine if a patient with dementia has six months or less to live.

What signs indicate that a person with dementia should be admitted to **hospice**?

- Problems with eating become key to admitting a person who has only dementia.

What signs indicate that a person with dementia should be admitted to **hospice**?

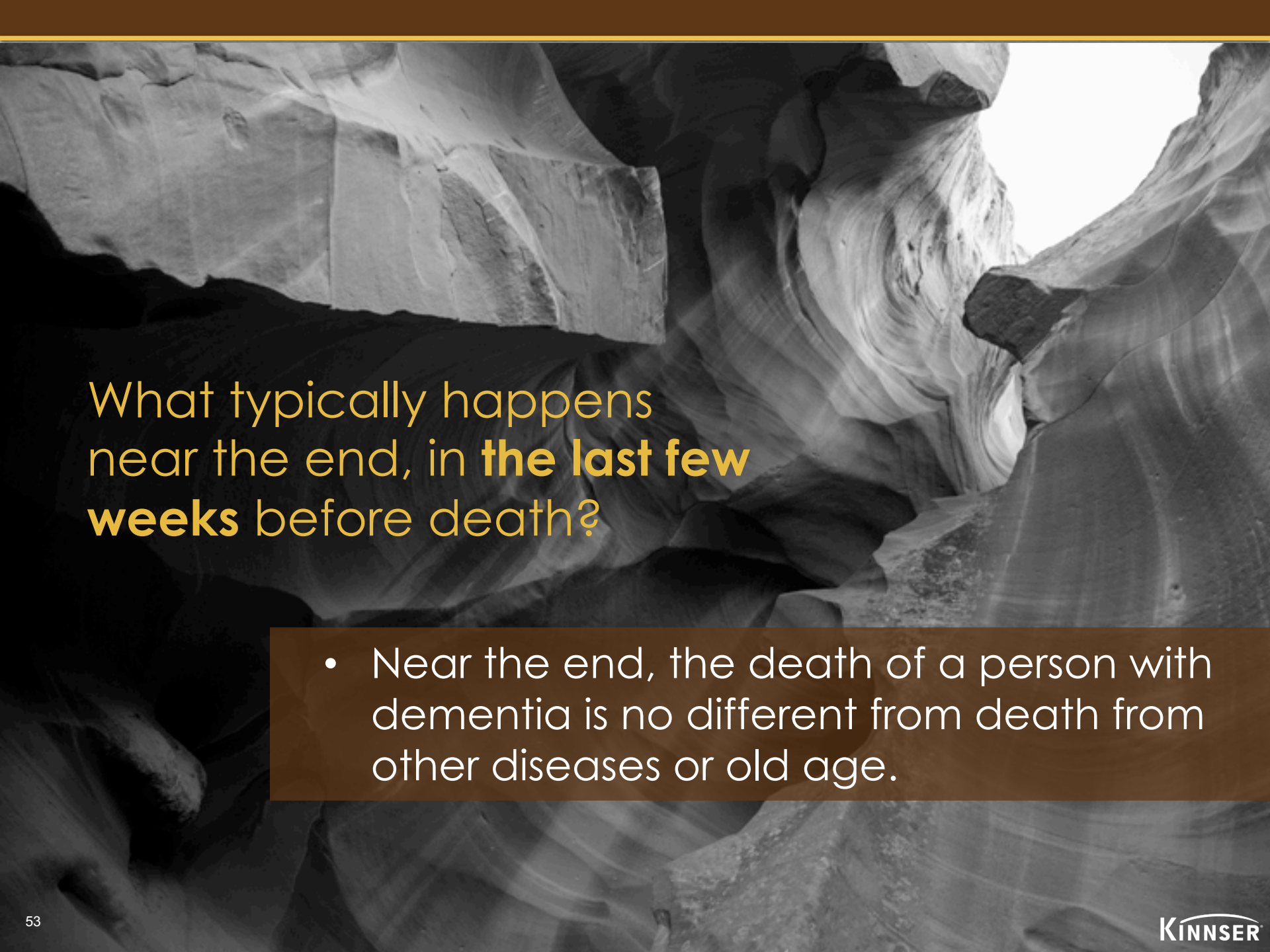
- When swallowing is impaired to the point a feeding tube is being considered – that is the time hospice can be considered.

What signs indicate that a person with dementia should be admitted to **hospice**?

- Document inability to swallow, choking, and aspiration with the choice of no artificial feeding.



What typically happens near the end, in **the last few weeks** before death?



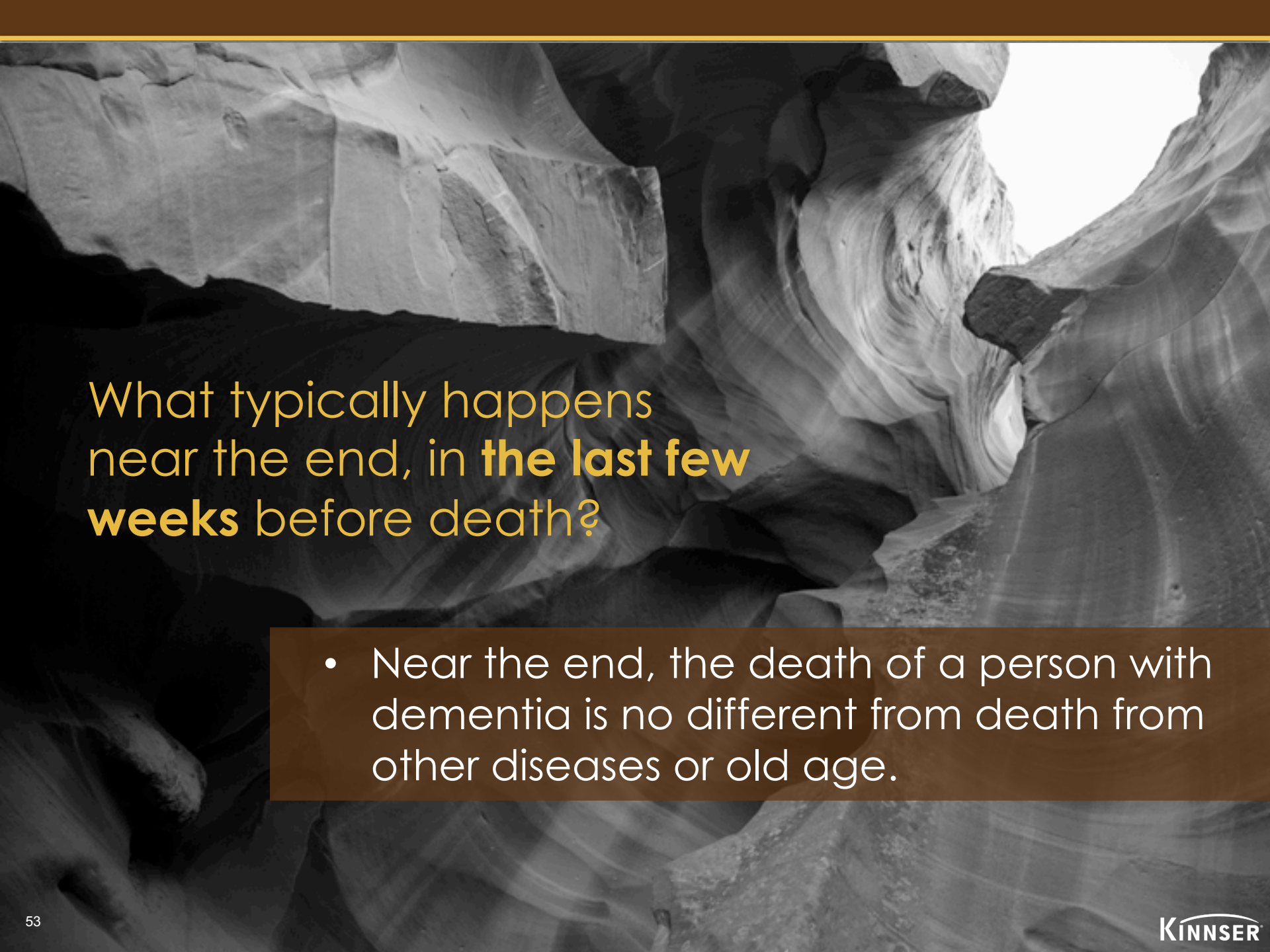
What typically happens near the end, in **the last few weeks** before death?

- Near the end, the death of a person with dementia is no different from death from other diseases or old age.



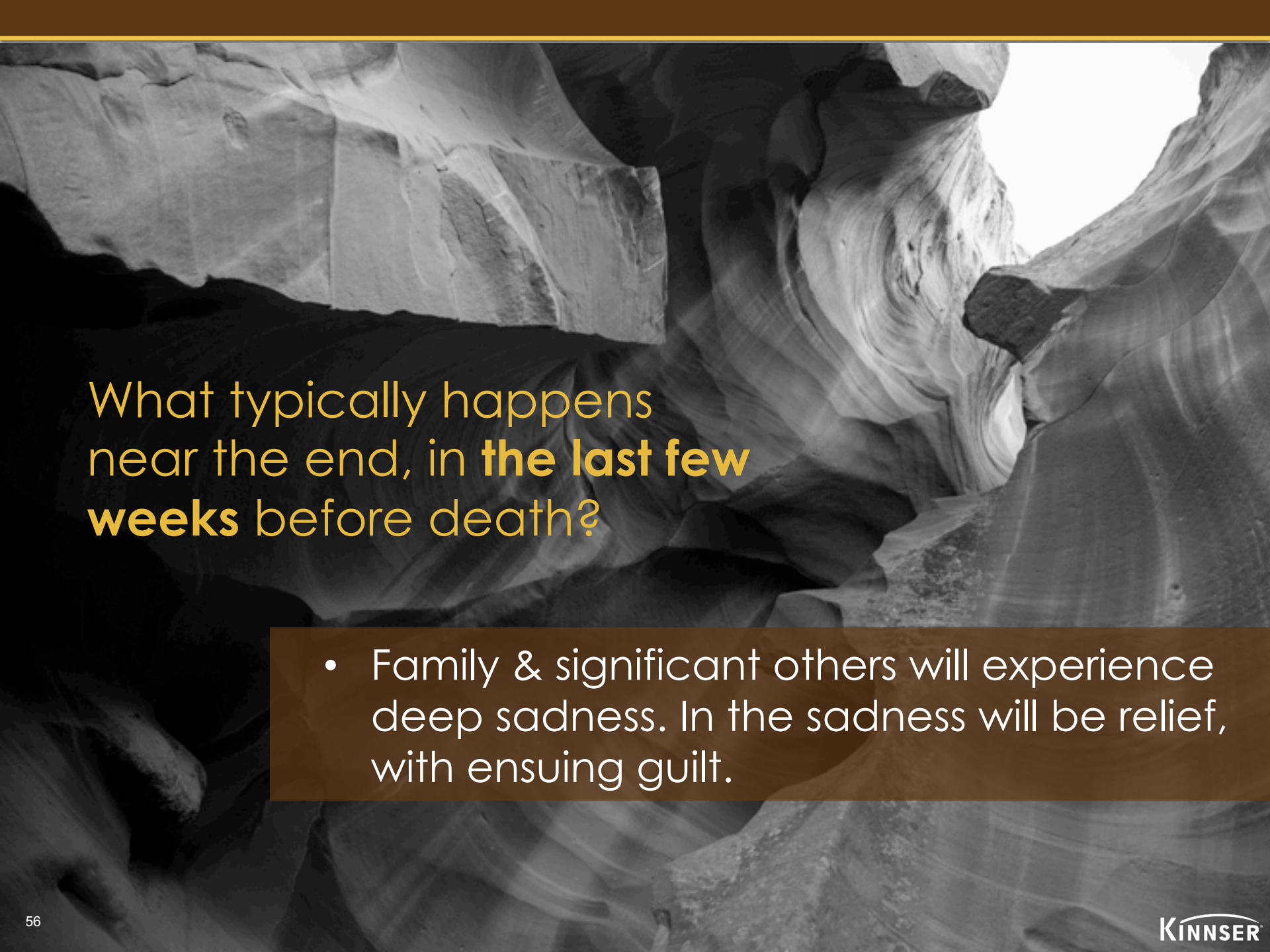
What typically happens near the end, in **the last few weeks** before death?

- Weeks before death, breathing changes, becoming rapid and congested.



What typically happens near the end, in **the last few weeks** before death?

- In the final hours and minutes, most people are non-responsive. We generally sleep through our final experience.



What typically happens near the end, in **the last few weeks** before death?

- Family & significant others will experience deep sadness. In the sadness will be relief, with ensuing guilt.



What typically happens near the end, in **the last few weeks** before death?

- Be gentle with yourself and encourage others to do the same. Hold on to the good and let go of everything else.

What about **advanced directives** for patients with dementia?



What about **advanced directives** for patients with dementia?

- Advanced Directives made when the patient is still able to make rational decisions can save a great deal of anguish.

What about **advanced directives** for patients with dementia?

- There are no right or wrong answers about feeding or not feeding.

What about **advanced directives** for patients with dementia?

- The natural way we all die from disease or from old age is by gradually not eating and not drinking.

What about **advanced directives** for patients with dementia?

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