Bearing Witness: Robert Coley-Donohue

User's Guide

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Introduction

This guide is primarily intended for teachers, health care professionals and community workers. Because the video is 90 minutes long, it may not be suitable for screening in one sitting. This guide will enable you to use discrete segments of "Robert's" story in a classroom or community setting.

Starting

Many people have little knowledge of ALS. Before using the video you may want to solicit responses from your group about their understanding of ALS. This will allow you to correct false assumptions as well as build upon the group's overall knowledge of the disease. Here are the facts: *

- ALS stands for Amyotrophic Lateral Sclerosis.
- ALS is also known as Lou Gehrig's Disease.
- ALS is a progressive neuromuscular disease that causes nerve cells to die.
- Muscles eventually become weak and paralyzed while the senses remain unaffected.
- A person's intellect is usually not impaired.
- ALS can afflict anyone at any age, although onset is usually in middle age.
- 90% die within three to five years of diagnosis. Some die in a few months others live longer than five years.
- ALS is not contagious.
- Less than 10% of cases are hereditary.
- About 3,000 Canadians are currently living with ALS.
- ALS is the most common cause of neurological death in Canada.

* Information the ALS Society of Canada

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Segment One: Thirteen minutes
Starts 00:00 at beginning of NFB logo. **Ends** 12:45 Robert turning off the light in his bedroom.
View a clip: 56k | 200k

Synopsis: *Introduction to Robert and his three adult children. Robert's diagnosis of ALS. Wife Barbara and her subsequent death from the same disease. A Modified Barium Swallow tests Robert's ability to swallow. Robert describes his positive approach to life.*

Questions before screening:

What do you know about ALS? Why do you think there isn't more public awareness of ALS?

Questions after screening:

How would you respond to news that a loved one had ALS? How will Robert's view of life help him? Hinder him? What are the visible signs of Robert's disease?

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Segment Two: Seven minutes

Starts 12:45 with title card: *Like Barbara, Robert registered with the Victoria Hospice.* **Ends** 20:05 Robert hammering at a spoon in his workshop.
View a clip: 56k | 200k

Synopsis: *Robert talks to a hospice counsellor about not wanting to be a burden. He goes for coffee with his old friend Ian. As Robert weakens he requires the help of Home Care workers. A visit by an Occupational Therapist.*

Questions before screening:

What is palliative care? How would you feel about losing your independence? What kind of professional support would be helpful to someone with ALS?

Questions after screening:

How can friends be of help? What are the advantages to dying at home? Disadvantages? How does "life go on" in spite of the ALS?

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Segment Three: Eleven minutes

Starts 20:07 Robert on the deck of the Ferry to Vancouver. **Ends** 31:47 Kelvin watching over his father in the living room.
View a clip: 56k | 200k

Synopsis: *Son Kelvin talks about role reversal. Lisa describes Robert as "not a philosopher" but a doer. Robert hopes when his time comes it is quick but fears it will not be so. Robert has a G-tube inserted into his stomach. Kelvin assists dad with the tube feeding.*

Questions before screening:

How would you feel about caring for a parent? What fears do you have around a slow death?

Questions after screening:

In what ways has Robert's condition deteriorated? How does Kelvin demonstrate good care practices? Would you use a G-tube to prolong your life?

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Segment Four: Ten minutes

Starts 31:47 at title card: *As Robert's ALS progressed, he required more Home Care assistance.*
Ends 41:00 Robert in his wheelchair by the sea in the autumn.
View a clip: 56k | 200k

Synopsis: *Robert requires more Home Care assistance to help with bathing and meals. A hospice counsellor pays a visit. Robert's view: "Be better to be remembered as a person than as a bag-of-bones lying in bed with no hope of enjoying life." A transition to autumn and Robert struggles to put on his coat. He takes a trip to the beach in his electric wheelchair.*

Questions before screening:

How would you feel about a stranger bathing and dressing you? What would it be like if you could no longer carry on a conversation because people couldn't understand what you're saying? How would you know when your quality of life had reached a point where life no longer seemed worth living?

Questions after screening:

How does Robert continue to exercise his independence in spite of his disability? How does the hospice counsellor help Robert with his dream? What personal qualities does Robert demonstrate in this segment?

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Segment Five: Thirteen minutes

Starts 41:00 Kelvin and Robert at the cemetery in winter. **Ends** 54:40 Lisa on camera "...a lot more respectful of that."

View a clip: 56k | 200k

Synopsis: *Kelvin expresses dread at seeing his father suffer. Ken helps his dad with eating. They joke and Ken points out the value of humour. Robert tells his hospice counsellor that there's no use fighting his need for help. Robert enters Hospice for a week's respite care. Ken hopes that his father doesn't linger once his condition worsens. Lisa helps her dad with his feeding and stresses the need for Robert to have control over what people do to him.*

Questions before screening:

How can humour play a role in helping ease the suffering of both caregiver and patient? How easy is it for you to ask for help? What steps can be taken to ensure that disabled people still exercise control over their lives?

Questions after screening:

What are your views on the right of terminally ill patients to end their lives? What control does Robert still have over his life?

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Segment Six: 15 minutes

Start 54:48 Ken and Kelvin on a speakerphone. **Ends** 1:10:21 Kelvin on camera ".... my dad didn't feel safe."

View a clip: 56k | 200k

Synopsis: *Ken and Kelvin meet with a Case Manager to explore options for further Home Care. Robert wants to remain at home. Six months later Robert requires 24-hour home care. The cost is $7,500/month of which a B.C. provincial plan provides $3,000. Friend Ian visits Robert and gives him a shave. Robert now uses an alphabet board to communicate with some humorous* *results. Ken talks about the challenges of managing his dad's care. Robert becomes increasingly frustrated. Eventually, for safety reasons Robert and his family consider placement in a facility.*

Questions before screening:

What would you imagine the cost to be of providing 24-hour home care? What are some ways to be involved with someone even though their ability to communicate has been severely restricted?

Questions after screening:

How could family caregivers be given more support in looking after a family member? What factors would make it difficult for a severely disabled ALS patient to remain at home?

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Segment Seven: 7 minutes

Starts 1:10:25 Robert's living room. **Ends** 1:16:44 van drives away

View a clip: 56k | 200k

Synopsis: *Support workers and family meet at Robert's to discuss his moving to a facility. Two weeks later Robert's son Ken and wife Alison have the hard and sad task of moving Robert to an extended care hospital.*

Questions before screening:

If you were terminally ill, at what point would you opt to move to a care facility?
How would you feel leaving your home never to return to it again?

Questions after screening:

What kind of care does Ken show in helping his father move?
What, if anything, would have made it possible for Robert to remain at home?

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Segment Eight: 14 minutes

Starts 1:16:48 exterior Gorge Road Hospital. **Ends** 1:29:38 at title card: *Dedicated to....*

View a clip: 56k | 200k

Synopsis: *Kelvin and wife Leslie visit Robert at the Gorge Road Hospital. Kelvin speaks of his dad's strength by example. Lisa and Ken visit their dad. Lisa hopes he dies peacefully and that she is by his side. Ken and wife Alison arrive with their first baby. A tender moment as Robert gazes down and smiles at the sleeping baby. Nine months later Robert develops severe respiratory problems and chooses to discontinue his G-tube feeding. He dies four days later with his family by his side. A closing montage of photos covering the span of Robert's life.*

Questions before screening:

How do you feel about visiting people in the hospital? How comfortable would you be with someone who is close to death? If you were terminally ill, at what point would you no longer wish to be kept alive?

Questions after screening:

What are your thoughts on the removal of feeding as a means of ending one's life?
How would you like to be remembered? What will be your legacy?

Resources

Websites and Newsletters

ALS Society of Canada: www.als.ca
ALS Survival Guide: www.alssurvivalguide.com
ALS Newsletter: www.mdausa.org/publications/als

Books

Tuesdays with Morrie by Mitch Albom

Amyotrophic Lateral Sclerosis: A Guide for Patients and Families, 2nd Edition
by Hiroshi Mitsumoto Theodore L. Munsat

A Manual for People Living with ALS, published by the ALS Society of Canada