

# 10 Ways to Move Beyond the Tragedy Narrative of Dementia

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A reflection on dignity, connection, and living well with dementia.

## Introduction

Public understanding of dementia has long been dominated by images of loss, decline, and hopelessness – a tragedy narrative.

While dementia does bring real challenges, an exclusively tragic narrative can contribute to inaccurate assumptions, social withdrawal, and reduced quality of life for those diagnosed. It can bring real harm.

There is another way to understand dementia; a better way. One that provides space for dignity, connection, growth, and continued well-being in life. Research and lived experience both show that people with dementia continue to experience emotion, creativity, and meaning. Changing the tragedy narrative helps communities respond with inclusion and support rather than fear.

Here are ten approaches that offer practical ways individuals, families, professionals, and communities can help change the narrative.

## **1. Separate the Person from the Condition**

A diagnosis describes a medical condition — it does not define the person. Talk about the person's history, interests, personality, values, and relationships before focusing on cognitive changes.

Narrative shift: From “What’s wrong with them?” to “Who are they?”

Practical step: When introducing someone, share something about who they are (interests, career, family) before mentioning dementia, if it is relevant at all.

Why it matters: a diagnosis is information — not identity.

## 2. Change the Language We Use

Language shapes perception and belief. Terms that reduce individuals to a diagnosis can unintentionally reinforce a tragedy narrative.

Person-directed language acknowledges the individual first.

Avoid language that defines people by loss or burden. Use person-directed, respectful terms that emphasize humanity and presence.

Narrative shift: From labels to people

Instead of: “dementia patient,” or “demented”

Use: “person living with dementia”

Why it matters: Person-directed language reinforces identity, dignity, and individuality.

### **3. Focus on Abilities, Not Only Challenges**

Dementia changes certain cognitive functions, yet many abilities remain. People living with dementia or other brain health conditions continue to create, enjoy relationships, express opinions, and participate in daily life.

Narrative shift: From deficits to strengths

Practical steps: Ask, “Are there workarounds that can be put in place to support a person’s autonomy and joy when taking part in favorite activities?” rather than communicating to a person that they should give up favorite activities.

Practical Steps: Ask, “What can this person still do and enjoy?” rather than focusing only on what has changed.

Why it matters: Promotes well-being and provides space for growth and joy.

## **4. Encourage Creative and Sensory Expression**

Art, music, movement, photography, poetry, storytelling, and nature experiences allow expression even when verbal communication becomes more challenging. Creative and sensory expressions allow identity to be preserved and expressed beyond words.

Narrative shift: From silence to having a voice, in new forms

Why it matters: Creative engagement supports mood, identity, and connection beyond memory-based interaction.

## 5. Recognize That Meaning Doesn't Disappear

Meaning and purpose can come through small roles, shared rituals, creative expression, or simply being part of a community.

Examples:

Helping set the table

Watering plants

Sharing stories with children

Participating in creative groups

Narrative shift: From “nothing left to contribute” to “still has a place, still can create, still can contribute.”

Why it matters: Having a role supports self-worth and identity.

## **6. Share Stories of Living Well**

Media and public conversations often highlight only late-stage or crisis situations – worst case scenarios.

Elevating and sharing real stories of connection, creativity, lived experience and adaptation brings balance and hope.

Narrative shift: From fear-based images to human stories

Practical step: Include voices of people living with dementia in events, articles, panels, and decision-making spaces.

Why it matters: Sharing stories of people living well with dementia provides a more complete and accurate picture.

## **7. Support Relationships, Not Just Care Tasks**

Care is more than managing needs. It includes laughter, conversation, music, arts, shared meals, and time together.

Care is often framed around physical or medical needs, but relationships are equally important for quality of life.

Narrative shift: From task-focused care to relationship and person-directed care

Practical step: Make time for conversation, shared activities, and simply being together — not only task completion.

Why it matters: Care leads to connectedness.

## **8. Value Emotional Truth**

Feelings remain deeply present. Comfort, joy, fear, frustration, love — all are real and meaningful, even when memories fade.

Emotional experience remains strong throughout the course of dementia.

Narrative shift: From memory-only identity to emotional identity

Practical step: Prioritize environments and interactions that promote comfort, safety, and connection — not just memory support.

Why it matters: Demonstrates that people living with dementia are more than memory.

## 9. Include, Don't Isolate

Promote inclusion in community life. Isolation reinforces the tragedy narrative. Inclusion reinforces belonging.

People living with dementia belong in community spaces — social gatherings, creative programs, faith communities, advocacy groups.

Narrative shift: From withdrawal to belonging

Practical step: Encourage and facilitate participation in:

Faith communities

Arts programs (including visual, written, spoken, and performance arts)

Social gatherings

Advocacy efforts

Why it matters: Individuals and communities benefit when people living with dementia remain visible and engaged.

## **10. Talk About Dementia as a Life Experience, Not Just a Medical Condition**

Dementia is both a medical reality and a human experience. It is only part of someone's life story. When we speak about it with nuance, respect, and humanity, we help others see the full picture.

Narrative shift: From clinical problems to human experience

Narrative shift: From "a life defined by decline" to "a life adapting to change."

Why it matters: Focusing only on pathology overlooks social, emotional, relational, and creative dimensions of life.

## Closing Reflection

Changing the tragedy narrative does not ignore the real difficulties dementia can bring. It simply tells the whole truth — that life with dementia still includes love, meaning, resilience, beauty, and connection.

When we change the narrative, we change how people are treated, how they see themselves, and how they live.

When communities adopt this broader view:

Stigma decreases

Support improves

Inclusion grows

Quality of life increases

A more accurate and humane story leads to more compassionate responses — and better lives for people living with dementia and those who care about them.