

# Strategies for Developing New Dementia Advocates in Families Affected by Genetic FTD

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## Introduction

Patient voices are critical inputs for dementia research and therapy development. While many patient-contacting institutions solicit and act on patient feedback, the perspectives of affected people and families remain under-represented in institutional discourse on dementia.

Individuals from families affected by familial FTD face serious barriers to sharing their personal stories and participating in public advocacy. Stigma around neurological health prevents many from speaking about their experiences with familial disease. The demands of caretaking for a family member with dementia can further limit access to public advocacy.

What are effective strategies for developing people into skilled dementia advocates?

## Sub-population Characteristics

Different identities carry a wide range of strengths, limitations, and orientations to advocacy work.

**Asymptomatic Carriers**

- Sense of urgency
- Desire for connection with other carriers
- Compartmentalization of fear and mourning

**Caregivers**

- Intimate experience with disease progression
- Limited time, money and energy
- Social isolation related to caregiving role

**Symptomatic Individuals**

- Navigating changes in relationships, employment, housing
- Anosognosia
- Limited ability to travel

**Untested Family Members**

- Denial and avoidance
- Perceived pointlessness of testing when no treatment exists

**Variant-Negative Family Members**

- Survivor's guilt
- Planning and supporting care for variant-positive family members

**Spouses and In-Laws**

- Witnesses of symptom onset
- Parents of at-risk children

## Strategy #1: Personal Storytelling

Effective storytelling creates a model for trainees to put their own experiences into words. Facilitated spaces (personal conversations, discussion groups) allow trainees to express complex experiences without fear of alienating others or harming family relationships.

With practice and support, some trainees will feel able to tell their personal story in more public ways.



Autobiographical comic, Ansel Dow, 2026



FTD Writing Group, 2026

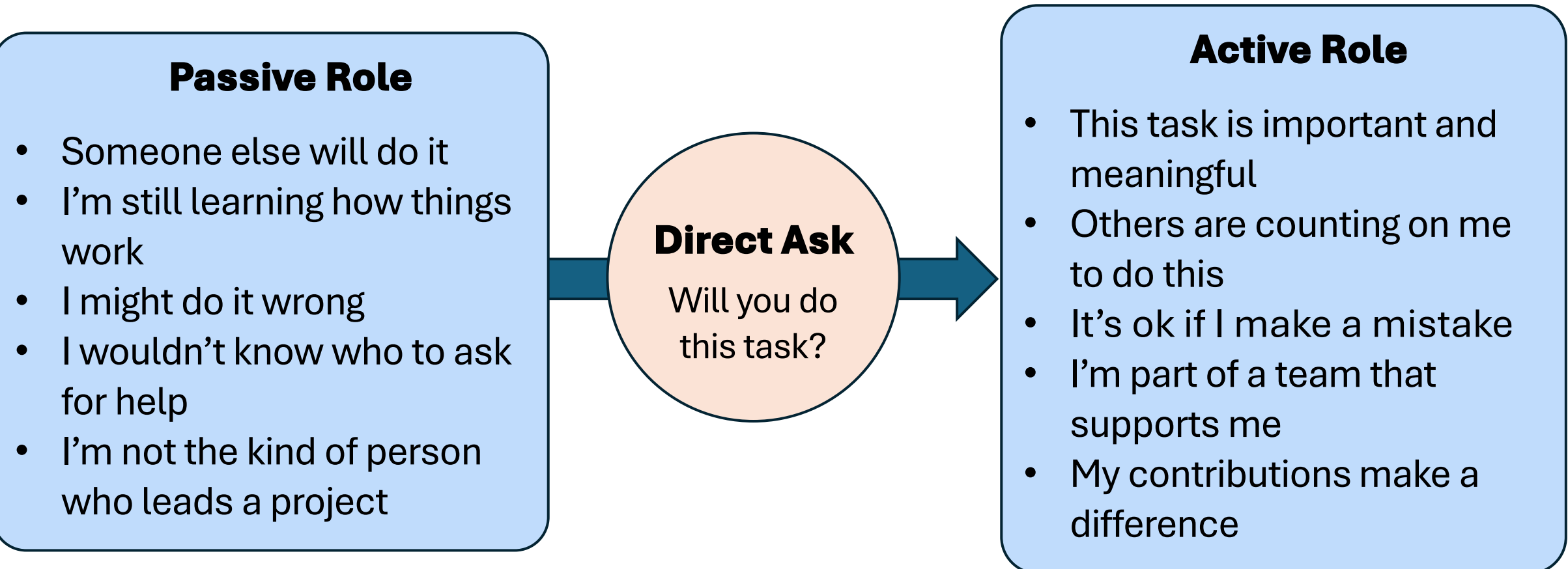
### Writing Group Prompts

- How has FTD changed your experience of the winter holidays?
- What's a piece of art hanging on your wall that has a special meaning?
- If you could deliver a letter to yourself 20 years ago, what would you write?

## Strategy #2: Escalating Responsibilities

An advocate trainer must create the conditions for trainees to take on new responsibilities of escalating complexity. The trainer should provide helpful models for the trainee to observe, assess the trainee's strengths and interests, and encourage the trainee to ask questions. The trainer must then make a **direct ask** of the trainee.

A direct ask is a request for the trainee to take on a specific task. If done well, it will create a change in the trainee's understanding of their own role, from **passive** to **active**. The task should be proportional to the trainee's experience, big enough to require focused effort but not so big that success seems unachievable.



**✗**

Will someone do this?

Let me know when you've finished.

Will you invite people to the meeting?

It's ok if you don't have time to do this.

**What makes a good Direct Ask?**

**Specific person**

Jessica, will you do this?

**Specific time period**

Will you do this by this Friday?

**Well-defined task**

Will you text all the team members and ask if they'll attend?

**Meaningful task**

I'm counting on you to do this.

**✓**

## Strategy #3: Collaborative Projects

A collaborative advocacy project can be a classroom where trainees learn to find creative solutions and work effectively with their colleagues. Split the work into sections assigned to trainer and trainee; the trainer will model behavior on how to address roadblocks that the trainee can learn from. Ask for the trainee's input and take their answers seriously: "Let's try it your way and see how it goes!"

**Collaborative Problem-Solving**

- "Who do you think we should contact first?"
- "Based on what she said, do you think we should follow up again?"

**Technical Skills**

- "If they don't reply to the email, try sending them a text"
- "Here's a list of genetic counselors who work on FTD; start with them"

**Build Network of Relationships**

- "Sarah is joining us today, she's a great person to ask if you have questions about graphic design"

**Modeling Values**

- "Our first priority is that attendees feel welcome"
- "If you have a family conflict and can't attend the meeting, that's ok!"

## Strategy #4: In-Person Meetings

In-person meetings allow new advocates to develop meaningful personal relationships with others much faster than online-only contact. Although these meetings are often expensive and difficult to organize, they can accelerate the growth and commitment of trainees.

- 1-on-1 conversations
- Conferences
- Lawmaker advocacy
- Family reunions

In-person events are great opportunities to introduce family members who otherwise would not participate in advocacy work. The friendships that form in person can be the anchor that transforms someone into a dedicated advocate.

Cure MAPT FTD at the AFTD Education Conference, 2026