



Advocacy: From “Private Speaking” to Public Advocacy

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Life Before Caregiving

- Clear(er) Relationship Roles and Relationships
 - Parent
 - Child
 - Spouse/Partner
 - Sibling
 - Employee



Caregiving: The Invisible Life Transformation

Disorientation is what happens to you when you are being transformed from loved one to caregiver

During caregiving, roles and relationships require revising our roles in ways not anticipated, nor desired

- Parent---Caregiver
- Spouse--Caregiver
- Child--Caregiver
- Sibling--Caregiver
- Employee—Caregiver

No Recognized “Caregiver Script” to Lean on

Ambiguity about
care “beginnings”
and “endings”

"Always on" role

Increased
uncertainty and
relationship
boundaries

No benchmarks
of “success”

Limited feedback

Insider-Outsider
Differences



Caregiver Disorientation

Who can I turn to for support and mutual understanding?

How do I figure out what kind of help I might need when I'm not sure I even know?

Why is it so difficult to advocate for myself and/or my loved one?



Caregiving Changes You and Your Values—**Making it More Difficult to Advocate**

(Un)Predictability

(Im)Patience

(Un)Certainty & (Hyper)Vigilance

(Inter)Dependence

Power(less)

(In)Competence & Self Doubt

Challenges of Advocating for Yourself, a Loved One, Your Family

It's so difficult to untangle the emotions of what you are experiencing from the experience itself.

Others Can't Separate **You** From What You are Sharing

People Want to **Change** Your Stories

Relational Stakes Are Always **High**

Benefits of Advocating for Yourself, a Loved One, Your Family

Your insights and experiences are needed and vital

Only you/your loved one can provide the experiences and insights from your perspective

Advocating Within the Circle of Care



Kleinman's Eight Questions

Read Kleinman's eight questions below. Click on the (+) symbols to learn more.

What do you call the problem?

What do you think causes the problem?

Why do you think it started when it did?

What do you think the sickness does?

How severe is the sickness?

What kind of treatment do you think the patient will receive?

What are the chief problems the sickness has caused?

What do you fear most about the sickness?

Click to learn about the source:

Off Stage- Private Advocacy Work

Spend time exploring the problem or challenge with your loved one/family

What beliefs/values/expectations make this so important to you/your family?

Focus on what your lived experiences help you/your loved one/ family know or understand about this problem that others might not be aware of.

Off Stage- Private Advocacy Work

What can you/your family do to help address the problem?

What might you/your loved one/family need to better understand to creatively address the problem that they may not be aware of?

How would you/your family benefit from addressing the problem?

Who else might benefit from addressing this problem?

Constructive Conflict

- Constructive conflicts allow us to focus on task-related aspects, allowing for exploration of opposing perspectives and a more complete analysis of what is happening.
- Dysfunctional conflicts means participants can't move beyond interpersonal and emotional aspects.
- Constructive conflict facilitates innovation by encouraging discussion.
- Constructive conflict allows people to focus on the best ideas and solutions (rather than focusing on being against another).

Translating From Private to Public Advocacy

- What is it that others (your designated audience) most need to know to understand the situation?
- What might be most challenging or difficult for others to understand?
- What emotions might be misunderstood?
- What kinds of personalization might get in the way of helping others see or understand the depth and severity of the problem?
- How might *your* problem be explained in a way that is not reducible to *your* problem?

Ask Questions in Order to Understand and Influence Outcomes & Create Shared Realities



Questions for Big Issue Advocacy

- What do I need to know about this issue /program to understand the organization's approach?
- What are the key elements of organizational "realities" or constraints that will affect and guide my line of questioning?
- Who is involved in decision-making regarding the subject of my inquiry?
- What are relevant timeframes?
- Who else should I be talking with?
- **Action: Always send a follow-up thank you message if speaking with staff**



Next Level Questions for Developing a Strategic Plan and Consensus Building (Big Ideas)

- Who in the organization will champion my idea?
 - Do they have the power to implement it or just support it? (A strategic plan needs both)
 - Does everyone I've spoken with agree that this is a good, workable idea?
 - What is missing from the strategic plan?
 - Do you have any other advice for me?
- **ACTION: Refine your 'ask' & execute.**

