A faith-based, communal approach to advance care planning
Community Engagement: A Vehicle for Culture Change around Advance Care Planning

Goals of Today’s Presentation

1. Gain awareness of an innovative, communal approach to advance care planning, What Matters, an initiative of the Jewish community of New York that is based upon the evidence-based model, Respecting Choices®

2. Understand how a community, faith-based approach to advance care planning can uniquely encourage individuals to have conversations about their goals, values and healthcare wishes and help to create wider culture change around end-of-life decision-making.

3. Present challenges and opportunities.
What Matters

Mission:
Guided by Jewish values, we envision a community that embraces advance care planning as a natural part of life, in which end of life decisions are known, respected and honored.

Vision:
We will engage New Yorkers in compassionate, value-driven conversations about advance care planning, so they may live with the comfort of knowing their choices will be honored by loved ones and health care professionals.

The What Matters Community – A Broad Collaboration

• **Funders** – a funeral home and a local philanthropy
• **Consortium Partners** – a community center, a theological seminary, and a nursing home
• **Steering Committee** – medical, religious, academic, and communal representation
• **Sites** – synagogues and communal organizations
• **Site Teams** – professional staff, clergy, lay volunteers
12 What Matters Sites to Date

- 8 synagogues
- 2 communal organizations
- 1 healthcare institutions and
- 1 rabbinic seminary
Why Now?
Source Survey of Californians by the California HealthCare Foundation (2012)

• 90% of people say talking with their loved ones about end-of-life care is important → 27% have actually done so

• 60% say making sure their family is not burdened by tough decisions is extremely important → 56% have not communicated their wishes

• 82% say it’s important to put wishes in writing → 23% have actually done it

Goals of What Matters

1. Invite people into conversations within safe, comfortable, familiar environment
2. Guide people through the ACP process with trained and certified facilitators
3. Help individuals reflect on their values and beliefs as a guide to healthcare decision-making
4. Refer to appropriate religious, medical, legal or communal resources
5. Emphasize the importance of designating and communicate one’s wishes to a healthcare agent
Goals of What Matters (continued)

6. Complete an advance directive / Health Care Proxy form
7. Encourage communication with loved ones, clergy, physicians, attorneys
8. Build community within and across Jewish denominations
9. Create culture change – destigmatizing and normalizing end of life conversation
Why Respecting Choices®?

What Matters has adapted the Respecting Choices® model of ACP because...

• RC is a reliable, evidence-based approach to ACP
• RC trains and certifies Advance Care Planning facilitators
• RC has a network of over 10,000 trained facilitators and has been replicated in diverse settings and communities
• RC’s approach to ACP honors an individual’s goals, beliefs and values for current and future healthcare
• RC has developed value-neutral and person-centered tools
• RC has created an accessible conversation roadmap
Understanding Advance Care Planning as a Jewish Process

Judaism teaches that studying and engaging in conversation about important issues is a way of clarifying values and deepening understanding.

Open-hearted dialogue strengthens individuals, relationships, and entire communities.

Honest and caring conversations about healthcare decisions participate in the tradition of sacred dialogue.

What Matters Strategies for Engaging, Educating, and Motivating Communities

• Materials
• Educational programs
• Voices from the field- Sage Voices
• Personalized facilitation – individual or group sessions
• Opportunities for multiple meetings with facilitators
A Sampling of What Matters Events

• Author Events - Lucy Kalanithi, Jessica Zitter, Roz Chast
• Films followed by discussion
• Book Groups
• Sermons on death and dying topics
• Lunch and Learn Conversations
• Panel Presentations (Legal, Religious & Medical experts)
• Death Over Dinner – Jewish Edition
• Adult Education Classes
• Group ACP workshops
• Interfaith conversations
• “Reimagine End of Life” – ACP track
Questions and Challenges

• Cultural aversion to talking about difficult topics related to Aging, Illness & End of Life
• Scaling Up while retaining Quality Control and Intimacy
• Making ACP relevant to specific populations including: younger adults, “unbefriended” adults, individuals with special needs
• Maintaining momentum and currency in sites
• How to replicate this community model in other non-healthcare communities
CONCLUSION

Throughout history, when people’s lives have been threatened—dissolving any pretense of invincibility—they have turned to their community, and often their community’s faith leaders, for support.

Today’s churches, synagogues, mosques, temples, and meeting houses remain places of comfort and caring, safe and supportive environments for discernment and discussion about the guidance our spiritual traditions can offer to those facing life’s most difficult passages.

Faith leaders and communities may be uniquely suited to convene conversations concerning matters of mortality.

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What Matters
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