Health IT Policy Committee
Certification/Adoption Workgroup

September 23, 2013

Paul Malley
President
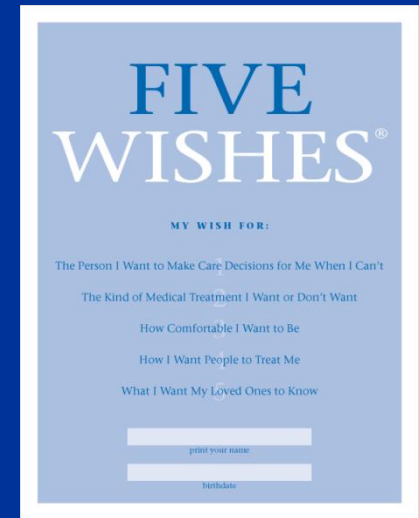Aging with Dignity

Aging with Dignity

National, non-profit organization founded in 1996

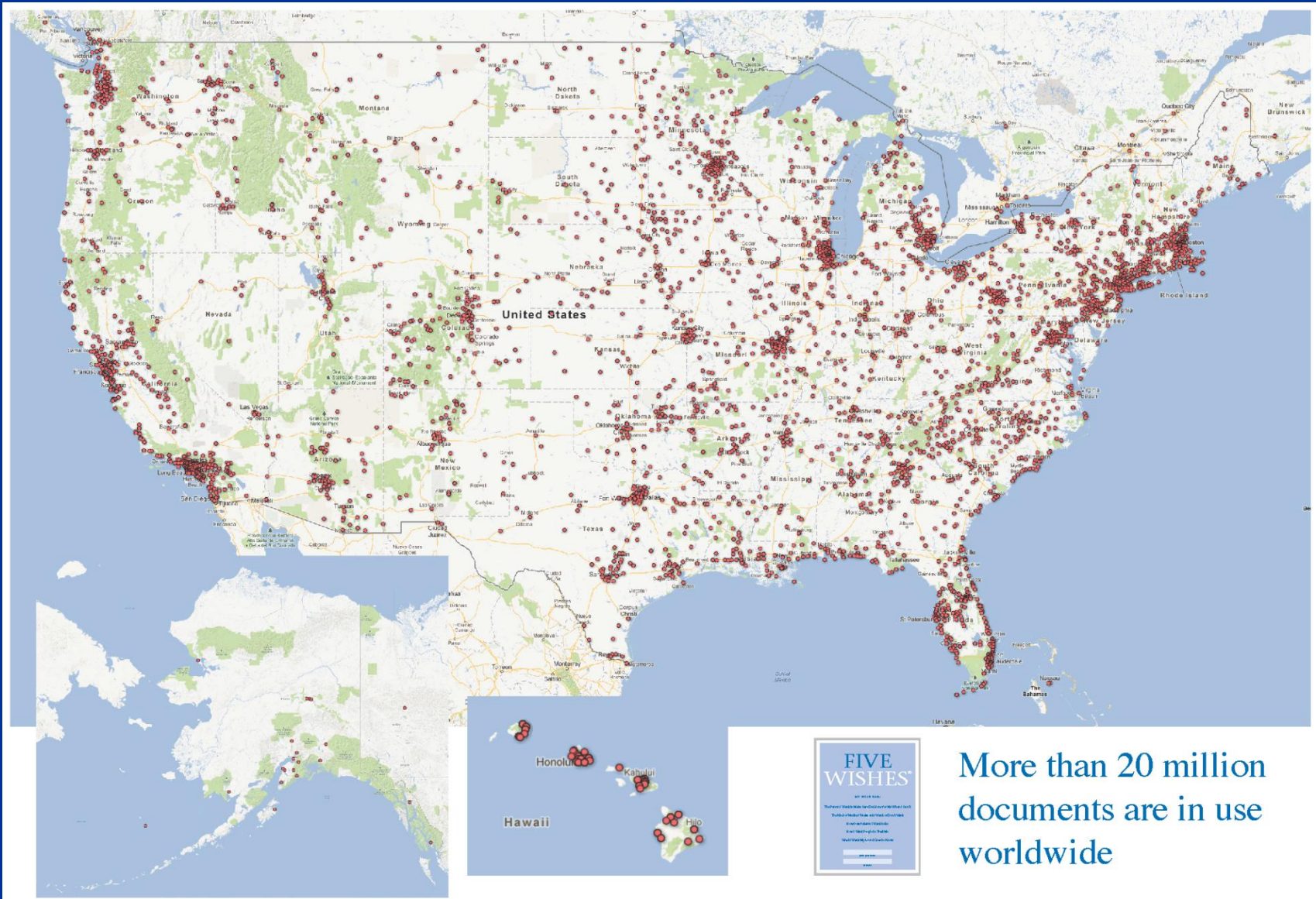Inspired by work of Mother Teresa of Calcutta
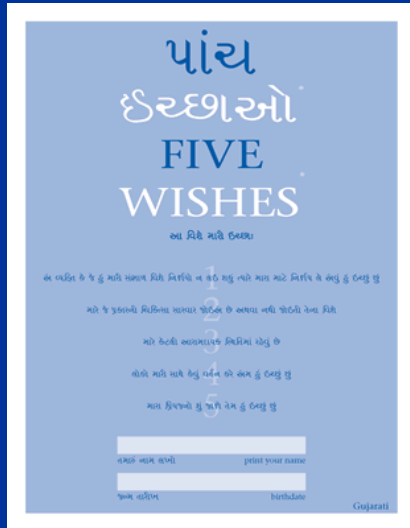
Action • Advocacy • Resources

- Written in everyday language

- Promotes peace of mind, helps avoid guessing and guilt

- A discussion tool for family and physician

- Includes:

  - Designation of health care agent

  - Preferences regarding life sustaining treatment, comfort, dignity, relationships, and spirituality

- National version introduced in 1998

- Meets legal requirements in 42 states, but helpful in all 50

- 20 Million distributed to date

- Distributed by network of 40,000 organizations

FIVE WISHES®

MY WISH FOR:

The Person I Want to Make Care Decisions for Me When I Can't

The Kind of Medical Treatment I Want or Don't Want

How Comfortable I Want to Be

How I Want People to Treat Me

What I Want My Loved Ones to Know

print your name

birthdate

Success through partnerships with 40,000+ organizations

FIVE WISHES

More than 20 million documents are in use worldwide

Bilingual FIVE WISHES

મને સંભાળ આપનાર તરીકે તમારે શું ધ્યાનમાં રાખવું જોઈએ

- હું પીડા સહન કરવા માંગતો / માંગતી નથી. હું ઇચ્છું છું કે ડૉક્ટર મને મારી પીડા દૂર કરવા માટે પૂરતી દવા આપે, ભલે પછી એના લીધે હું અર્ધસુપ્ત રહું કે એ ન લઉ ત્યારે લંઘું એના કરતા વધુ લંઘું.

- હું એવું ઇચ્છતો / ઇચ્છતી નથી કે મારા ડૉક્ટરો અને નર્સો મારો જીવ લેવાના ઇરાદાથી કશુંક કરે અથવા ન કરે.

- હું ઇચ્છું છું કે મને મોઢા વાટે ખોરાક અને પ્રવાહીઓ આપવામાં આવે અને સાફ અને ઉષ્માપૂર્ણ રાખવામાં આવે.

What You Should Keep In Mind As My Caregiver

- I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means that I will be drowsy or sleep more than I would otherwise.

- I do not want anything done or omitted by my doctors or nurses with the intention of taking my life.

- I want to be offered food and fluids by mouth, and kept clean and warm.

Albanian • Arabic • Bengali • Chinese simplified • Chinese traditional • Croatian • French German • Gujarati • Haitian Creole • Hebrew • Hindi • Hmong • Ilocano • Italian • Japanese Khmer • Korean • Polish • Portuguese • Russian • Somali • Spanish • Tagalog • Urdu • Vietnamese

Presence in diverse communities

Albanian	*gjuha shqipe*	Ilocano	Ti Pagsasao nga Iloco
Arabic	العربية	Italian	italiano
Bengali	বাংলা	Japanese	日本語
Chinese simplified	简体字	Khmer	▯▯▯▯▯▯▯
Chinese traditional	簡體字	Korean	한국어/조선말
Croatian	hrvatski jezik	Polish	język polski
French	*français*	Portuguese	português
German	Deutsch	Russian	русский язык
Gujarati	ગુજરાતી	Somali	Af Soomaali
Haitian Creole	kreyòl ayisyen	Spanish	español
Hebrew	עִבְרִית	Tagalog	Tagalog
Hindi	हिन्दी	Urdu	اردو
Hmong	Hmoob	Vietnamese	tiếng Việt

New Resource: *Five Wishes* Online

- Users can answer questions on-screen and print their completed *Five Wishes*, ready for signature

- OR, users can print a *Five Wishes* PDF in any of the 27 available languages and complete the document by hand

- Video tutorials provided in each section

- Not easily transferred to EHR because state statutes require signature of principal and two witnesses and/or notary

FIVE WISHES documented in Electronic Health Records:

- Documentation varies by location

- Lack of consistency in EHR methods = lack of consistency in advance directive documentation

- Best practice: document if patient has an advance directive AND include a copy of the full directive in the record (scanned image of a completed *Five Wishes*)

Bridging the worlds:
Clinical, Technical, Personal

- Best advance care planning is inherently personal. Involves discussion with family, close friends, caregivers, healthcare providers.

- Challenge 1: Translating the personal elements of advance care planning into clinical instruction or medical orders.

- Challenge 2: Translating the personal and clinical elements into data that can be effectively stored and accessed electronically.

The Elephant in the Room?

- Natural limits to what this information can tell clinicians.

- Unlike other clinical data stored in EHR, advance care planning is not binary (either/or). Not easily defined by a check-mark or data point.

- Personal preferences are static and often require interpretation.

- Be cautious of over-reliance on EHR data in determining care at the end-of-life.

- Advance directive information in EHR should inform, not dictate clinical decisions related to care at the end of life.

Enhanced or diminished role
for patients, families, caregivers?

- Decisions about care at the end of life should ALWAYS involve the patient or designated agent.

- Proceed with caution so EHR documentation is not perceived by clinicians to lessen the obligation to consult with patient and caregivers.

- Real concern that medical orders (POLST) and check-marks in EHR will de-personalize end-of-life decision making – creating a gap between clinicians and the patients and caregivers.

- Documentation of advance care planning in EHRs cannot be used to relieve clinicians of responsibility to involve patients and caregivers in end-of-life decisions.

Recommendations:

- Completed advance directives should be included in a patient's EHR. Noting that an individual has an advance directive is helpful, but it is best to have the full document easily accessible.

- Given the confusion between advance directives and medical orders (POLST), consider two distinct tracks for Meaningful Use measures:

    - Advance Directives: Record whether all patients over age 18 have an advance directive in the EHR.

    - Medical Order (POLST): Record whether a patient had an end-of-life medical order in the EHR at the time of death.

- Guiding principle: Use of technology to document end-of-life decisions should enhance – not diminish – the role of patients and caregivers.

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