

# the **conversation** project



April 16, 2024  
Seacoast Village Project

the **conversation** project



Who are the people in your life you're accountable to or support?

What brings you here today?



the **conversation** project

Helping people share  
their wishes for care  
through the end of life

# Why talking matters

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We can't plan for everything. But we *can* share what matters to us with the people who matter most to us.

Talking creates the foundation of a care plan built on our values—a plan that will be available when the need arises.



# All in the approach

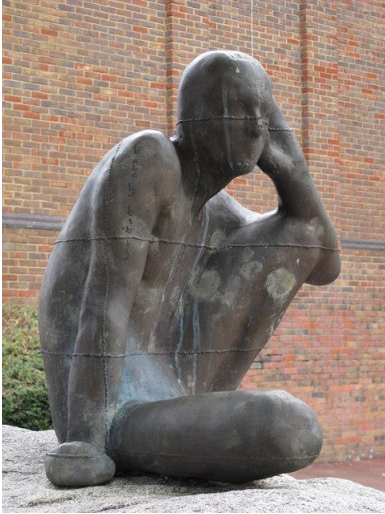
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Shifting from	...to
Death and dying	Life and living
What's the matter <u>with</u> you	What matters <u>to</u> you
Clinical model	Values-based model
Telling	Listening



# Listening matters too

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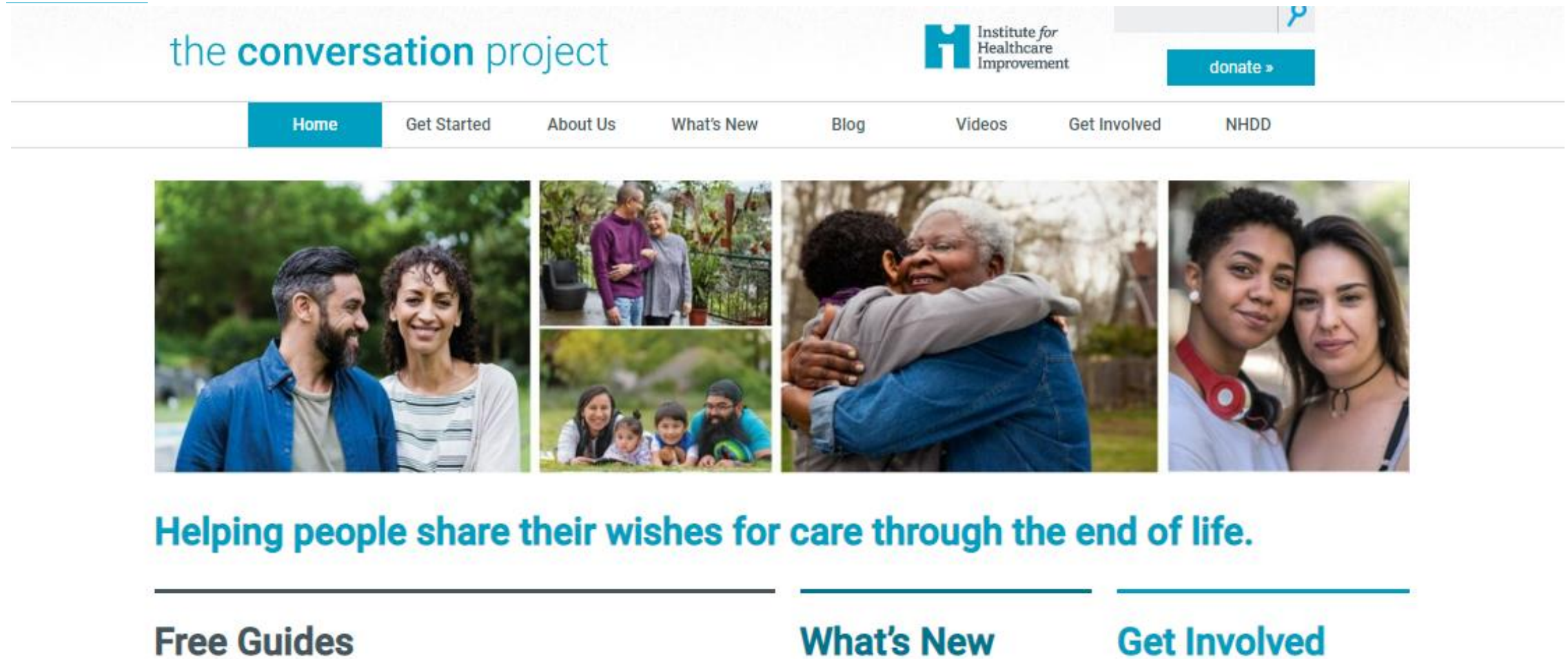
“It is often **through the quality of our listening** and not the wisdom of **our** words that we are able to effect the most profound changes in the people around us. When we **listen**, we offer with our attention an opportunity for wholeness”

– Rachel Naomi Remen, MD

“Our ultimate goal, after all,  
is not a good death but a  
good life to the very end.”

~ Dr. Atul Gawande

# Our website







Who will make health  
decisions for me if I

Mandy

Ella

Peter

Rachel

Martin

Donna

# Personal stories

## Blog

### With Dementia, More is Needed than a Boilerplate Advance Directive

By Katy Butler, 02/25/2019



## Blog

### Breaking Down the Barriers Between Medicine and Spirituality

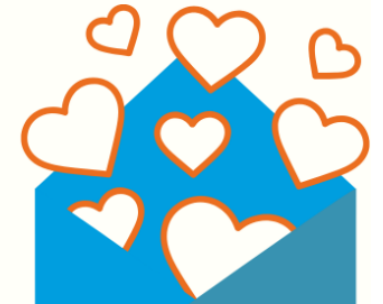
Posted on 05/30/2017



## Blog

### Dear Loved Ones: Trim My Chin and Upper Lip Hairs!

By Anna Wacławiczek, 06/07/2019



## Blog

### A Matter of Heart: A Father's Reflections on Advance Care Planning

By Ira Byock, MD, 06/10/2019





# Free tools (in multiple languages and audio)

Starting a Conversation

Choosing a Health Care Proxy

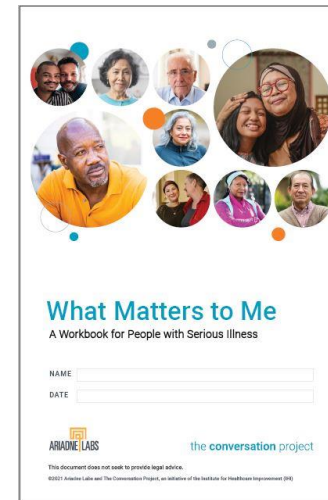
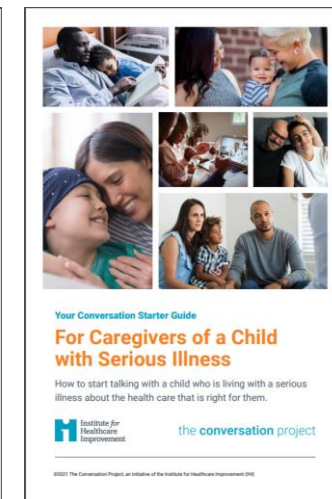
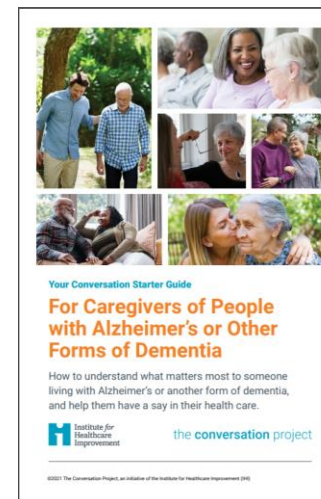
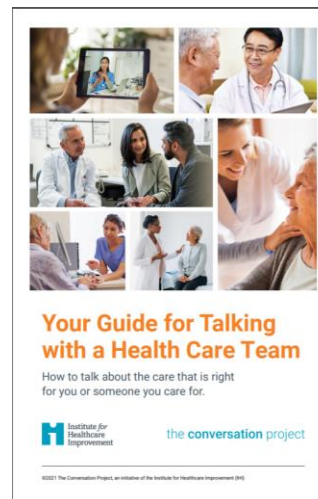
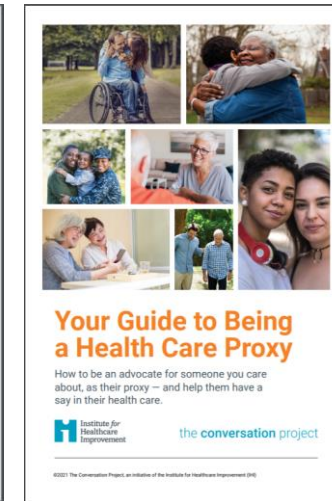
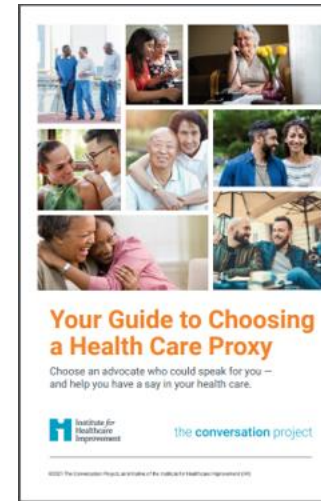
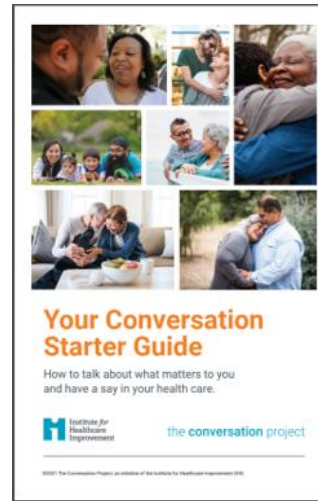
Being a Health Care Proxy

Talking with a Health Care Team

Caregivers of People with Alzheimer's or Other Forms of Dementia

Caregivers of a Child with Serious Illness

People with a Serious Illness



# Exemplify - taking this to your community

## Live

- Local leaders promoting TCP (retirees!)
- Presentations (invited and hosted)
- Train the trainer

## Work

- Health care organizations
- General employers – mailings, brown bag lunches, HR process

## Pray

- Shared sermons and materials – guest preaching
- Hosted events at houses of worship
- Integration of TCP into pastoral care and seminary education
- Collaboration with regional interfaith organizations

## Learn

- Medical and nursing school courses
- Undergraduate courses/lectures in ethics, bioethics, and humanities
- Faith-based educational institutions
- Health care systems partnering with local university/high schools
- OLLI courses



# How to bring up your end of life wishes?



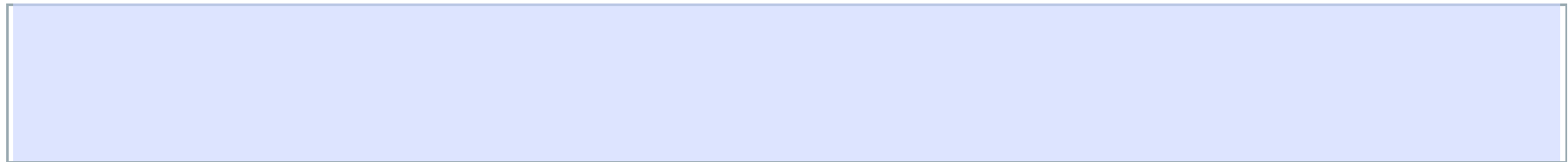
# The Starter Guide: Preparation

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## STEP 1

### Think About What Matters to You

- › Try finishing this sentence:  
What matters to me through the end of my life is...



**SOME IDEAS** Being able to recognize my children; being independent;  
being able to spend time with the ones I love

That's your "what matters to me" statement.

# What matters to me...

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*“I want to say goodbye to everyone I love, have one last look at the ocean, listen to some 90’s music, and go.”*

*“Having my sheets untucked around my feet!”*

*“Peaceful, pain-free, with nothing left unsaid.”*

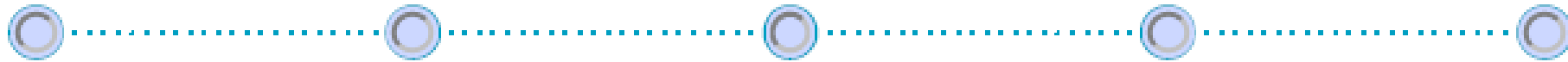
*“In the hospital, with excellent nursing care.”*



## STEP 2

# Plan Your Talk

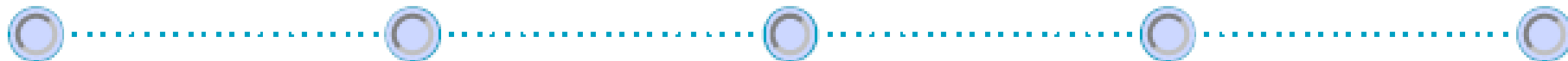
► **When there is a medical decision to be made, I would like...**



My health care  
team to do what  
they think is best

To have a say  
in every health  
care decision

► **What are your concerns about medical treatments?**



I worry that  
I won't get  
enough care

I worry that  
I'll get too  
much care



# Who and How to Bring up your Wishes

## › Who needs to know what matters to you in your health care?

Check all that apply:

- |   |  |
|---|--|
| <input type="checkbox"/> Parent(s)  | <input type="checkbox"/> Trusted friend(s)           |
| <input type="checkbox"/> Spouse/partner(s)                                  | <input type="checkbox"/> Doctor(s)                   |
| <input type="checkbox"/> Chosen family member(s)                            | <input type="checkbox"/> Nurse practitioner/nurse(s) |
| <input type="checkbox"/> Adult child/children                               | <input type="checkbox"/> Social worker               |
| <input type="checkbox"/> Faith leader (minister, priest, rabbi, imam, etc.) | <input type="checkbox"/> Other: <input type="text"/> |

## › Where would you feel comfortable talking?

- |   |  |
|---|--|
| <input type="checkbox"/> At the kitchen table     | <input type="checkbox"/> Video chat or phone call    |
| <input type="checkbox"/> At a favorite restaurant | <input type="checkbox"/> At my place of worship      |
| <input type="checkbox"/> In the car               | <input type="checkbox"/> Other: <input type="text"/> |
| <input type="checkbox"/> On a walk                |  |

## › The Conversation Project uses the saying, "It always seems too soon, until it's too late."

**When will you start this conversation?**



# When to have a conversation

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## Early

Coming of age – 18 & 21

## Often

Before a medical crisis – 30, 40, 50, 60, 70

## Major life event

College, marriage, children, divorce, Medicare, death in the family

## Major trip

## Newly diagnosed with a serious illness



# How to start

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“I need your help with something”

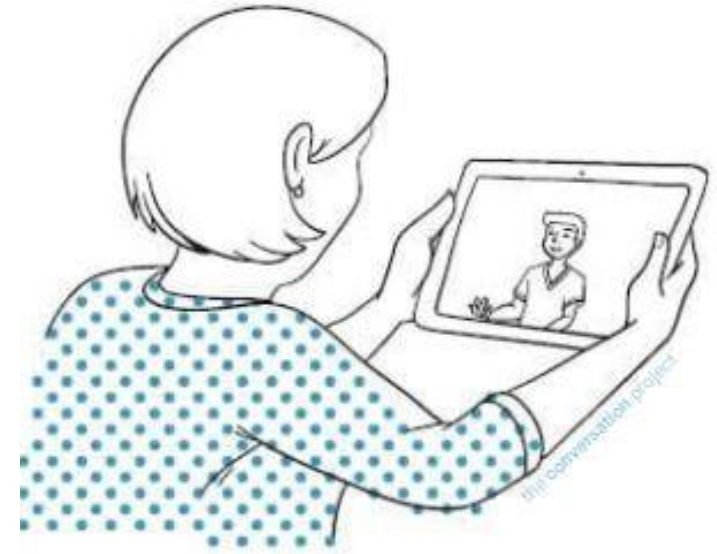
“Will you help me think about my future?”

“I was thinking about what happened to \_\_\_\_\_ and it made me realize \_\_\_\_\_.”

“Even though I’m OK right now, I’m worried that \_\_\_\_\_ and I want to be prepared.

Can we talk about some things that matter to me?”

“I heard about the Conversation Project and answered some of their questions about things that matter to me when it comes to my care through the end of life. I’d like to talk to you about it.”



# Other Tools To Ensure Wishes are Understood/Carried Out


- The Conversation Project Conversation Starter Guides/What Matters to Me Workbook
- Prepare for Your Care
- 5 Wishes™
- CaringInfo.org

I received a tough diagnosis. How do I think and talk about what's important in my care?

Posted on 08/02/2022



If you are dealing with a serious illness, you may want some ideas for how to talk about what matters to you and ways to find support. Here are a few suggestions for getting started.



**How to tell someone your wishes when they don't want to listen**  
Posted on 07/05/2022

So you've decided to think about and share your wishes for medical care... and the person who you want to talk to doesn't want to hear it. What do you do? Here are some ideas:...

[more »](#)

## Three Ideas for Solo Agers to Keep in Mind

Posted on 03/28/2022



Planning for your future is important for everyone. For solo agers, documenting what matters to you is even more important to make sure your wishes are honored. *Your goals and preferences matter and you are valuable.* Read about the different options [here](#).

# Areas to consider/watch for

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## The role someone wants to have

Autonomy

## Type of care

Current answers

Home

“Whole enchiladas” and “plug pulling”

“If I can parent our children...”

## The role others will play

Finding a proxy who will/can honor wishes

Solo agers

Telling more than one person

Eeyore example

Avoiding family or caregiver “bullying”



# Conversations clarify

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**Sent:** Monday, March 29, 2021 9:39 AM

**To:** Info <[info@IHI.org](mailto:info@IHI.org)>

**Subject:** Thank you so much

I have elderly grandparents who live alone in another state, with nobody nearby to take care of them. I have suggested assisted living or having an aide come to their home for years but they always refuse. They have dementia and other health problems but have always been fiercely independent and mistrustful of others. I viewed your Conversation Project guides on my flight to Colorado and when I got here, I decided to change my usual approach to the issue. I started asking questions instead of telling them how worried I was. The questions I asked came straight out of your materials. Your guide was very helpful to start a 2 way conversation and I am so grateful for your initiative. Not only are they open to me being their healthcare proxy, they also have agreed to move to assisted living. I am so relieved, and so grateful for the information you made available at no cost to people. Thank you!



# Hope....giving up vs letting go

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“There's always hope...[T]he question is what we are hoping for?”

“Early on, we hope for a cure...[A]nd when that is impossible, we hope for as much good time as possible. And then, at a later point, we hope for relief from suffering. And then, in everyone's life, we reach a time when we are hoping for a death with dignity.”



# Don't Panic – It's OK: A letter to my family

If you are faced with a decision that you're not ready for,

It's ok

I'll try to let you know what I would want for various circumstances,

But if you come to something we haven't anticipated,

It's ok

And if you come to a decision point and what you decide results in my death,

It's ok.

You don't need to worry that you've caused my death – you haven't –

I will die because of my illness or my body failing or whatever.

You don't need to feel responsible.

Forgiveness is not required,

But if you feel bad / responsible / guilty,

First of all don't and second of all,

You are loved and forgiven.

If you're faced with a snap decision, don't panic --

Choose comfort,

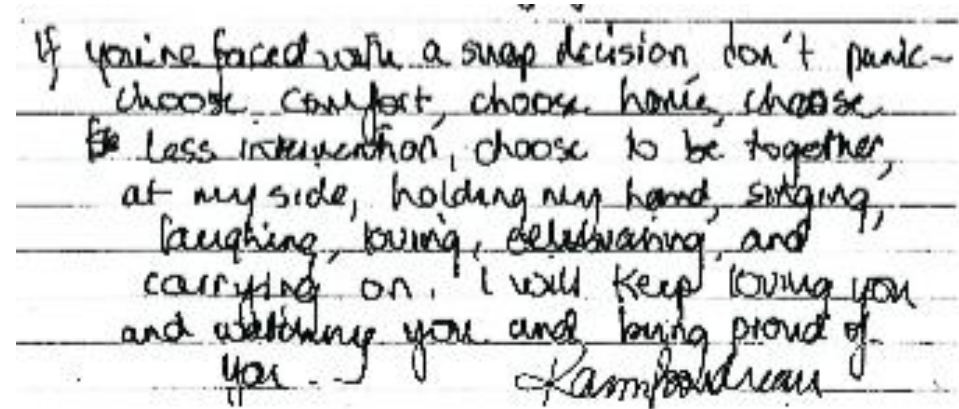
Choose home,

Choose less intervention,

Choose to be together, at my side, holding my hand,

Singing, laughing, loving, celebrating, and carrying on.

I will keep loving you and watching you and being proud of you.



If you're faced with a snap decision, don't panic -  
choose comfort, choose home, choose  
less intervention, choose to be together,  
at my side, holding my hand, singing,  
laughing, loving, celebrating, and  
carrying on. I will keep loving you  
and watching you and being proud of  
you. - Kamryn

# Leaving in action

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Complete the Conversation Starter Guide

Pick your person, start the conversation with someone who may speak on your behalf

Document your proxy and wishes

Bring **What Matters to Me** concept back to your circles

Send a text to someone right now

# Questions?

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[theconversationproject.org](http://theconversationproject.org)

 Twitter/X: @convoproject  
 Facebook: @TheConversationProject  
 Instagram: @convoproject

the **conversation** project

