

This Is Us Conversation Starter Guide

How to have the hard but important conversations.



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Right now, 1 in 5 Americans are providing unpaid care to an adult loved one.

Caring for others is one of the most fundamentally human things we do. And yet, people who are providing care in the United States, especially those caring for older adults and people with disabilities, aren't valued by our society. It's time our culture talks about care and aging to help shift how our society values care.

Care takes many forms: it can be preparing meals and providing transportation, as well as managing medication or assisting with moving around their home, providing emotional support, companionship, and so much more. Whether you are a family member, parent, friend or neighbor, if you provide care for a loved one - you are a caregiver. Currently, 65 million Americans are caring for a loved one and 11 million are sandwich generation caregivers, providing unpaid care for adult members of their family (i.e. parents or siblings) while also raising their own children. While often joyful, being a caregiver can also be more demanding than a full-time job and incredibly isolating. Having a care team or a care squad can be a beneficial way to tap into a supportive community in order to sustainably provide care for a loved one. This provides support for both the primary caregiver and care recipients, allowing them to share care responsibilities as needed.

Despite care being a concern in most of our lives, there are few cultural models for us to look at for how to have difficult conversations with family about care and end-of-life plans. We rarely, if ever, see conversations about preparing for caregiving on network TV, especially ones with detail, nuance, and relatability.

This conversation starter guide, inspired by *This Is Us: The Final Chapter* and real life experiences of family caregivers in our network, can be used as a tool when you begin talking with your loved ones about disease, care, and death or to plan for this crucial phase in your lives. While this guide is not entirely inclusive of all you may want to discuss, it's intended to help you begin thinking about how you can prepare for the future. Each section includes examples from the series to demonstrate how difficult conversations may be modeled and adapted.



Before gathering to have an important conversation about care, here are some things to consider:

When and where do we need to have this conversation?

Typically we have difficult conversations when a crisis hits and we are forced to face our current reality. While it's understandable that topics of health, aging, care, and death can be intimidating, having ongoing discussions and asking tough questions throughout the lifespan can help us to prepare for the future. Taking time to talk in a comfortable and safe environment can empower our loved ones to exercise their agency and express their wants and reduce feelings of isolation or fear.

Who needs to be a part of this conversation?

So often family care planning is led by the children of the person receiving care and can be one of the first instances that care recipients lose agency in their daily life and decision making. Be sure to remember to involve care recipients and their partners in important conversations and decision making.

Who is in your care squad?

Caring for a loved one can be more work than a full-time job and is most often unpaid. It's important to consider who will be involved in managing daily routines, providing support, and making big decisions. Paid care workers can be a phenomenal help but aren't always accessible to every family. Taking time to determine matters such as who makes final decisions, handles family communications, manages financial, legal, and medical matters are all crucial points to discuss.

What types of care are needed, now and in the future?

Care needs vary by person, age, ability, illness, culture, and family. It's important to consider what levels of support will be needed and what must be done to achieve the best quality of care. Care can include medication management, doctors appointments, meal preparation, as well as hands-on physical care. Taking time to consider the breadth of these needs, resources or access needed, and planning ahead for future needs can help you to prepare as a family.

What cultural factors need to be considered?

Aging and care needs can often conflict with cultural beliefs and practices that families follow. Considerations such as: the role of elders, family leaders, religious practices, privacy and communication, independence/agency, hands-on care, medication, information sharing, language, end of life care and decisions, finances, legality, and matters of ethics and morals are all areas where changes may need to be made. With changes in health or aging, what was once unspoken and understood often requires reconsideration and assessment. Encourage your care squad to dig into previous traditions to see if changes need to be made.

What is your plan for a crisis or end-of-life care?

At some point in our lives we will all need to provide or receive care in some way. Care is universal and end-of-life planning is something we all will need to consider. Taking time to communicate your own needs/wants

as well as understanding those of your loved one are some of the most important conversations we can have. When crisis strikes, family tensions are more likely and conflict, sibling politics, or unnecessary transfer of power can all become challenging parts of our reality. Creating clear, agreed-upon plans for the future can help serve as a “north star” when the time comes for tough decisions to be made.

Difficult conversations can be overwhelming. Here are some questions to prompt discussion with examples from This Is Us on how these subjects were addressed and can be adapted:

Communication

- Who is the primary point of contact for care recipients?
- Who is the person responsible for communicating care or health updates to others?
- What communication methods are needed for care?
- What communication methods are most effective for your care squad?

Example: In the episode [“Taboo”](#) Rebecca gathers her family to directly communicate her wants and needs for care in advance of her Alzheimer’s worsening.

Legality & Finances

- What legal matters need to be considered?
- Who will assume medical and financial power of attorney?
- Is there an updated advanced directive or living will?
- How does illness/aging impact your loved one’s ability to represent themselves?
- What financial matters need to be managed?
- What costs will be needed for care?

Example: Kevin’s career as a successful actor enables him to [provide a robust amount of financial support and resources](#) towards his mother’s care that most American families do not have access to. While his ability to provide housing for his mother is not representative of many of our realities, this conversation demonstrates the importance of considering financial and legal matters ahead of time.

Medical Needs & Medicines

- Who is responsible for managing communication with medical and/or care workers?
- What, if any, medication management is needed?
- What medical decisions need to be made? What is the process for this? How might this change?

Example: Miguel is the primary caregiver for Rebecca while also having the support of a care worker, Laila. Miguel wakes up every morning ahead of Rebecca to ensure her medications are prepared along with his own.

Daily Care & Hands-on Support

- How often is support needed? When may this become daily care?
- What physical, mental, cognitive, and emotional support is needed?

- How will hands-on care be managed? Who will do this?
 - What access and physical needs ought to be considered?
 - Additional considerations: physical needs (hair/skin/body), dress and appearance, religious or cultural symbols artifacts, dietary needs, prayer practices, gender preferences of care/medical workers, use of medicine, etc.

Example: Relationships with partners evolve as care becomes a part of daily life. [Rebecca and Miguel have a conversation](#) about these changes and their future together as they discuss Rebecca's Alzheimer's diagnosis. [The Big Three also discuss](#) the emotional complexities and challenges of hands-on caregiving.

Caregivers

- Who is responsible for primary and secondary caregiving? Where will they live?
- Do the primary caregivers work? Do they have access to paid leave?
- Will you need to hire a care worker? Who is paying for these services?
- What resources is the care-recipient eligible for (i.e. Veterans benefits, Social Security Disability Insurance, Medicaid waivers, etc.) and how do they access them?
- What mental and emotional health resources are available to the primary caregiver?
- Who will support the primary caregiver? When will they have time to tend to themselves, their careers, their families?
- What time commitments and life changes may be needed for the primary caregiver?
- Who will step in if the primary caregiver is no longer available? Who is part of your care squad?

Example: After insisting on managing Rebecca's care alone, [Miguel agrees to accept help from The Big Three, his care squad](#), to ensure everyone is able to support one another sustainably.

Housing

- Where will your loved one be living? Will this change in the future?
- Where does your loved one want to live, now and in the future?
- How accessible is your current home? Will changes need to be made?
- Is your loved one's community safe?
- Is there easy access to grocery stores, green spaces, hospitals, and their doctors?
- Who lives with your loved one? Will this change?
- Will your loved one need to move for additional care now or in the future?
- Will you need additional lodging for a care worker?

Example: During Thanksgiving, [Rebecca explains](#) to her children that with time her illness will require her to receive full time care and in order to have this, she needs to prepare for where she and her care worker will live.

Cultural & Religious Considerations

- What religious practices and rituals are most important?
- Where is "home" for your loved one? Do they want to return home?
- How will religion/culture guide you through care or end-of-life planning?
- How does age play a role in decision making? Do elders typically lead decisions?
- How does culture/religion play a role in medical or care needs?

- How does community play a role in care decision making?
- How does intergenerational care play a role?
- How may hierarchy or gender roles play a part in care and decision making?

Example: As we age, what is important to us as individuals becomes increasingly important and valuable. When [Rebecca visits the Metropolitan Museum of Art with her sons](#), she uses her agency and power as a mother to share how she wants to live her life moving forward- on her own terms. While this is empowering, it is one of the first examples of us seeing her children struggle to determine who gets to make the decisions at this stage as their mother, who they have been raised to respect, is now becoming increasingly unwell.

End of life Care

- What does your loved one want for end-of-life care? What are their wishes?
- Who and when will decisions be made to transition to end-of-life care?
- What end-of-life care planning and decisions need to be made?
- What will happen after your loved one passes away, both short-term and long-term?
- Who will provide care during this period?
- Who will be present for end-of-life care?

Example: [The Big Three and their partners discuss](#) how to provide Rebecca with the best quality of life during her end of life care.

Language & Accessibility

- How will language and accessibility play a role in care?
- What language/access needs will a care squad or care worker need to consider?
- What support will be needed to communicate effectively with your loved one?
- What language and access needs to be considered when with care or medical staff?
- Could an independent interpreter or translator be needed at any point?

Example: As a sandwich caregiver, Kate spends a lot of time prioritizing how she can care for her mother and children, this includes how she considers Jack's care needs and how living in a familiar environment is important for him because he is blind. This later also becomes an important factor in Kate considering how she can care for her mother long-term..

Decision Making & Conflict Resolution

- Who will be the primary and secondary decision maker when disagreements occur?
- How can your care recipient maintain and utilize their agency as much as possible?
- Who has historically made decisions in your family/community? How may this change?
- What conflicts may arise? What conflict resolution plans or agreements can be made in advance?

Example: Rebecca's care squad [gathers to discuss her long term care](#) after Miguel's passing, and Kate, as Rebecca's previously chosen decision maker, leads the conversation and decision making.

Morals & Ethics

- How does illness, disease or aging impact ethics or morals around how approach care is practiced?
- What considerations need to be made around cognitive ability and decision making?
- What values are most important to your loved one and family? How can these best be upheld?

Example: Prior to Rebecca's diagnosis, [Randall is challenged](#) with whether or not to encourage his mother to see a doctor about her health concerns. This conversation becomes emotionally charged as he struggles with what he is witnessing versus his mother's wishes.

Privacy & Information Sharing

- What matters of privacy or information sharing need to be considered?
- What information does your loved one want shared/not shared?
- Who will have access to passwords, PINs, and security codes?
- Who will receive and communicate information about diagnosis and/or care?
- Who has decision making power about what information is shared?
- With what frequency and means will communication occur?
- What happens to your loved one's digital footprint (i.e. social media, email accounts, etc.)?

Example: [The Big Three sit down together](#) and Randall explains to Kevin that their mother has been diagnosed with cognitive impairment, or early stages of Alzheimer's.

For more information and resources, visit caringacross.org.