

WHO
CARES

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SHARE EXPERIENCES
EXPLORE OPTIONS
GET SUPPORT



CAREGIVER CONVERSATION GUIDE

Background

Four in 10 American adults are family caregivers. They provide for the needs of parents, spouses, children with disabilities, and siblings. It's a labor of love that takes a toll physically, emotionally, and financially. Capital Public Radio's documentary team spent six months exploring this topic. The stories in *Who Cares* take listeners into the lives of three Sacramento families to explore the stress, struggles, and blessings of being a family caregiver.

Capital Public Radio produced *Who Cares* as part of the multimedia documentary series *The View From Here*. CapRadio is committed to raising the voices of everyday people responding to change in their lives, and the challenges of our times through public media and community engagement.

To achieve this goal, CapRadio collaborated with Del Oro Caregiver Resource Center on *Who Cares*. Together CapRadio and Del Oro set up a telephone hotline and a website to gather caregiver stories that were published as a community generated multimedia journal, *Caregivers Speak* (caregiversspeak.tumblr.com).

Now, the partnership is facilitating a series of community conversations to listen to the different stories, learn from one another's experiences, and strengthen community ties.

All stories and materials created through the project are available on the *Who Cares* website capradio.org/cares.



Getting Started

ABOUT

This guide is designed to help anyone who wants to bring caregivers together to have meaningful conversations about their needs and experiences. The conversations are designed to be approximately 60 minutes, though they can be altered to suit your needs.

MATERIALS AND EQUIPMENT

You may need the following items for your Caregiver Conversations:

- Snacks and drinks
- Internet connection
- Computer
- Projector (optional)
- Speakers
- Name tags if desired
- Sign in sheets, clipboard, pens as needed
- Flyer (customize and download)
- Discussion guide



Getting Started

BEFORE THE EVENT

Every dialogue is different. Facilitator(s) will want to consider:

- Who is your audience and what is motivating them to attend this conversation?
- How can this conversation support the group's needs?
- How much time do you have for the conversation?
- How can this conversation support your organization's goals?
- Look at the Caregiver Conversations webpage: capradio.org/cares
 - What themes do you want to explore?
 - Stories do you want to play?



TIPS

- Plan your conversation as part of a meeting, support group, or activity that is already scheduled through a local organization or caregiver support group.
- Reach out to community members you'd like to get more involved in talking about family caregiving. Customize and use the template flyer available for download on the Caregiver Conversations webpage.
- After a community conversation, participants tend to feel a variety of emotions. It's good to have suggestions about next steps, either through a local organization, support group or caregiver resource center (visit Deloro.org for a list of support groups and other resources).

Facilitation

Talking about caregiving can bring up a range of emotions. As the facilitator, you'll want to create a space in which people feel comfortable sharing and listening to each other's experiences.

PREPARE YOURSELF

It's a good idea to prepare in advance by listening to the stories you plan to share and reviewing the discussion questions posted on the Caregivers Conversations webpage. You may also want to gather basic information about the issues raised in stories you play. See page 9 for a list of audio clips, times, and short descriptions. You don't need to be an expert but it is useful to share your (or your organization's) connection to caregiving during the conversation and point people to where they can get more information about issues raised in the stories you play. Send them to the *Who Cares* website for more resources. Refer them to the Del Oro Caregiver Resource Center for additional services.

PREPARE THE GROUP

During group discussion, it's important that people feel safe to speak what is on their mind and in their heart. It can help to lay down some ground rules for the session. Here are some examples:

- We'll show each other mutual respect and empathy.
- We'll use "I" statements (I feel...I think...I hear...) to avoid saying something that might devalue someone else's perspective.
- If someone else's beliefs make us uncomfortable we'll say so, in a respectful way.
- We'll use "one mic" which means when one person is talking, give them your attention by not interrupting.
- We'll keep what's said in the room confidential to encourage honest discussion.



Facilitation

Remember to have fun and enjoy getting to know your neighbors. Sometimes people get wrapped up in emotion and the conversation can get heated, but that usually means someone cares deeply about the issue. Take a moment to acknowledge the experiences in the room that make this an important discussion for everyone and remind participants of the ground rules and goals (see page 7). Then, begin again.

TIPS

- Encourage everyone to participate. Factors like age, ethnicity, income levels, language, and familiarity with a topic can influence how comfortable people feel about sharing their experiences. Keep this in mind and actively engage everyone!
- Pay attention not only to what the speaker is saying but also to the emotions behind their words and to what may be most important for them.
- Sometimes the topics and conversations can bring up sadness and grief. Take a moment to acknowledge the experiences in the room.
- Stay neutral. Your job is to guide a group's conversation without taking sides.
- If you are asked something that you can't answer about the *Who Cares* project, tell people that they can email questions to theviewfromhere@capradio.org.
- If you are asked something that you can't answer about caregiving, tell people to contact Del Oro Caregiver Resource Center crc@deloro.org or (916) 728-9313.



Dialogue Session

Ok. Ready to go? Here is our suggested sequence of activities for conducting the conversations. We've listed a suggested time for each activity so that the session lasts about 60 minutes (not counting set up and clean up). Feel free to adapt wording, exercises, or timing.

SET UP

Arrive, set up chairs and tables, set out food and materials, test equipment, and do any other preparations for the conversation.

WELCOME & ICE BREAKER – 10 MINUTES

Welcome everyone to the Caregivers Conversation. Introduce yourself and what motivated you to organize this community discussion. Then lead a brief icebreaker exercise so people can get a sense of who is in the room (if this is an established group you may not need to do this). For example, have people go around the room and:

- Say their name and one word that describes what family caregiving means to them.
- Say their name and why family caregiving is an important topic to them.
- Say their name and what motivated them to come to this Caregiver Conversation.

GOALS & AGREEMENTS – 10 MINUTES

Tell people about the *Who Cares* documentary project (see beginning of this guide for ideas) and why you decided to lead a Caregiver Conversation. Then share the goals for the session. You may want to write them on a flipchart. Here are some possible goals:

- To discuss the stress, struggles, and blessings of being a family caregiver.
- To listen and learn from one another's experiences.
- To explore resources and get support.

After that, let the group know you'll be playing and discussing a series of audio clips to achieve the goals. Then engage the group in establishing some agreements for the group conversation so that it remains comfortable and respectful (see Prepare the Group on Page 5 for ideas).



Dialogue Session

PLAY AUDIO CLIPS & DISCUSS – 40 - 45 MINUTES

(15 minutes for 3 themes or 20 min. for 2)

Select the first topic you want to engage the group in discussing from the Caregiver Conversations webpage and introduce it. Play a couple of stories from that topic. Pick a few discussion questions from the Caregiver Conversations webpage that you think the group will find most interesting to get the conversation started. When appropriate, move on to the next topic you want to explore with the group—playing one or two stories and engaging them in discussion using the questions provided.

NEXT STEPS & THANKS – 10 MINUTES

Ask if a few people would share one thing they gained or learned from participating in this Caregiver Conversation. Thank the group for their time and attention and share why you think this conversation has made a difference. Invite people to share what they gained or learned on the feedback sheet provided. Share the results with theviewfromhere@capradio.org.

WRAP UP

Consider what went well and what you'd change for the next conversation. Rearrange chairs and tables as needed and clean the room.

CELEBRATE!



Themes & Stories

SELF CARE

No Respite	1:04	Laurel worries about her father who is her mother's caregiver.
Coping With Change	0:24	Rick says with change there's an upside and a downside.
Accept Help From Others	0:56	Loretta talks about the difficulty of accepting help but she realizes one must do it.
We're All Going To Need Care	0:27	Judy hopes there will be people to provide the care when we each need it.
Sleep Deprived	1:21	Judy talks about her chronic state of sleep deprivation.

DEMENTIA

Knowing How Everyday Day Goes	0:14	Loretta talks about the routine of her daily schedule.
It's Like Groundhog Day	0:25	Rick talks about the daily routine of caring for his wife.
Fibbing Keeps the Peace	0:32	Therapeutic fibbing helps Rick when his wife asks about seeing her parents.
Fibbing Settles Anxiety	0:46	Rick uses therapeutic fibbing with his wife when she struggles to find the right words.
Birds In The Window	0:22	Loretta helps her father bathe while he tells her what he sees through the window.

ISOLATION

The Lonely Life	2:03	Rick talks about being lonely and not having regular adult communication.
Nobody Asks "How Are You?"	1:06	People ask Rick about how his wife is doing, but less frequently ask how he's doing.
Friends Can Help	1:49	Rick says friends and relatives of caregivers should not take anything for granted.

CREDITS

AUTHORS jesikah maria ross
 Joanne Serrieh
 Catherine Stifter

REVIEWERS Michelle Nevins, Kate Gonzales

GRAPHIC DESIGNERS Veronika Nagy
 Melody Stone

PHOTOGRAPHY Andrew Nixon

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