

Caregiving 101

Exploring the Complexities of Family Caregiving

Staff Development Series

The Technical Assistance Centers for
Caregiver Programs & Lifespan Respite

National Center on Caregiving at Family Caregiver Alliance



Presenter

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Training Goal

The goal of this training is to provide participants with an understanding of the potential impacts care providing has on family caregivers

Participants will understand

- Overview of Family Caregivers
- Challenges of Caregiving
- Barriers Faced by Caregivers
- Emerging Issues
- Caregiving Rewards
- Resources

Overview of Family Caregivers

- **What is Caregiving**
- **Who are the Caregivers**
- **Definitions**
- **Self Identity**
- **Statistics**

Overview: What is Caregiving

- Caregiving takes many forms
- Helping older, chronically ill or disabled family member and friends in everyday ways
- Many of these helpers do not think of themselves as caregivers:
 - **Buying groceries, cooking, cleaning house, doing the laundry**
 - **Spending time making plans to help someone (e.g making MD appts., driving to the doctor, re-ordering meds, coordinating care)**
 - **Helping someone to get dressed, take a shower or give medicines**

Overview: Who are the Caregivers

- Partner / spouse
- Adult child
- Parent
- Other relative (e.g. sibling)
- Friend
- Anyone who provides care
(e.g. shopping, personal care, medical management, etc.)

Overview: Definitions

Family Caregiver (CG)

Any relative, partner, friend or neighbor who has a significant personal relationship with, and provides a broad range of assistance for, an older person or an adult with a chronic or disabling condition

Care Recipient (CR)

An adult with a chronic illness or disabling condition or an older person who needs ongoing assistance with everyday tasks to function on a daily basis (frail elder)

Overview: Self Identity

- Recognize family caregivers and name what they do as being a “caregiver”
- Family / friends think of themselves in terms of relationships (e.g. spouse / partner, adult child rather than as a caregiver)
- If family members do not know they are “caregivers,” then they do not know to look for resources
- Professionals are in the position of helping family members identify this role and what it means to each individual

Overview: Selected Caregiver Statistics

- **29 %** of households in the US provide care to an elderly person in a 12-month period
National Alliance for Caregiving, AARP 2009
- **73 %** of workers report that they are currently providing or have recently provided care to someone over 18
National Alliance for Caregiving, AARP 2009
- **62 %** report having to rearrange work schedules, decrease their hours or had to take leave
MetLife, 2010

Overview: Selected Caregiver Statistics

- An estimated **10.9 million** family members and friends provide unpaid care for a person with Alzheimer's disease or another dementia. Providing **12.5 billion** hours of care, representing an average of **21.9 hours** per week. **21%** of caregivers live in the same household as the person for whom they provide care

Alzheimer's Association, 2010

- The value of those services provided by informal caregivers (family or friends of seriously ill loved ones) is estimated at **\$375 billion** annually which is more than the total Medicaid spending in 2007

Public Policy Institute, National Alliance for Caregiving w/Evercare, 2009

Challenges of Caregiving

- Direct Care
- Caregiver Stress
- Common Stressors
- IRS of Caregiving
- Caregiver Needs
- Caregiver Self Care
- Ongoing Issues

Challenges: Direct Care

- **Pain is undertreated leading to behavioral issues**
- **Communication skills important in dealing with dementia, as it is counter intuitive**
- **Skills can be taught and resources are available**
- **Caregivers hurt themselves**
(e.g. back problems, due to lack of training)
- **Caregivers are hurting the CR by not knowing how to provide care appropriately**
- **Caregivers are “making it up”**
(e.g. often need OT/PT evaluations)

Challenges: Caregiver Stress

- **14%** of caregivers rate the **physical strain of caregiving high**

Caregiving in the US, 2009

- **31%** rate the **emotional stress of caregiving high**

Caregiving in the US, 2009

- **23 %** of family caregivers caring **for five years or more reported their health is fair or poor**

National Alliance for Caregiving, 2009

Challenges: Caregiver Stress

- **Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as**

10 years off a family caregiver's life

Epel, S., et al. (2004) Proceedings of the National Academy of Sciences, 101, 49.

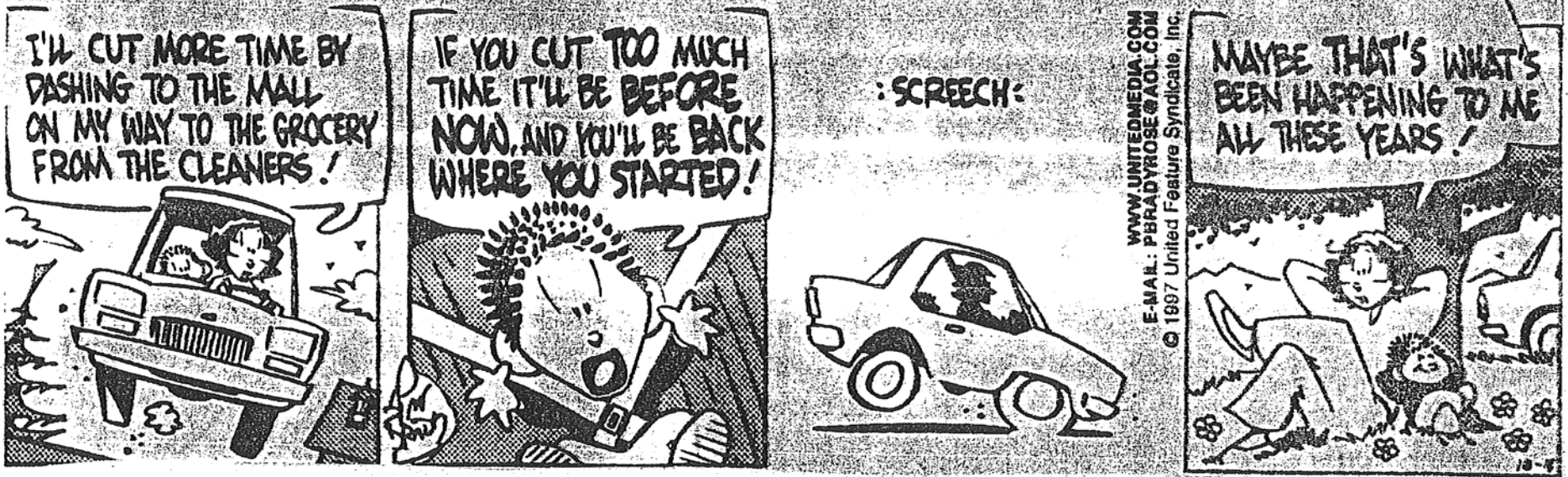
- **More than 1 in 10 (11%) family caregivers report that caregiving has caused their physical health to deteriorate**

Center on Aging. (2005) How do family caregivers fare? A closer look at their experience. Washington, DC: Georgetown University.

Challenges: Common Stressors

- **Resistant, Angry CR**
- **Long Distance Caregiving**
- **Family Disagreement(s)**
- **Physical Care Needs**
- **Change**
- **Uncertainty**
- **Poor / Ineffective Medical Care**
- **Money, Money, Money**
(not enough)
- **Legal Matters**
- **A Need for a Move to More Supportive Housing**
- **Care Supervision Needs**
 - **Memory Problems**
- **Life, Health, Safety Concerns**
 - **Driving**
 - **Refusal of Medical Assessment/Tx**
- **Difficult Caregiver Feelings**
 - **Frustration/Anger**
 - **Guilt**
 - **Depression**

ROSE IS ROSE Pat Brady



Challenges: IRS of Caregiving

- All caregivers need three things:
 - I**nformation
 - R**espite
 - S**upport
- Responsibilities change as condition changes
- First stages are the most demanding as caregivers are least informed of what is needed or expected, leading to insecurity and uncertainty

Challenges: Caregiver Needs

- **Respite/breaks from caregiving are essential**
 - **Maintain a life outside of caregiving**
- **Caregivers need to know their needs/feelings count**
 - **They have a right to say “I can’t do it”**
 - **Their feelings are important**
 - **They must take care of their own health**
- **They have a right to ask questions and be listened to**
 - **Get information about community resources**
 - **Get medical systems to pay attention to them / their concerns**
- **They have a right to not be abused or ignored**
- **They can’t do it alone**
 - **Help them identify sources of support**
 - **Help them say “YES” to offers of help**
 - **Help with where to find assistive supplies (e.g. incontinence, DME, adaptive clothing)**

Challenges: Caregiver Self Care

- **Higher morbidity and mortality**
- **Physical injury (e.g back strain)**
- **Don't do their own preventive health care**
- **Juggling many roles (e.g. working cgr., sandwich cgr.)**
- **Intervention has been shown to ameliorate some of the consequences**
 - **Teach coping strategies**
 - **Address issues of alcohol/substance/prescription abuse**
- **Sleep deprivation**

Challenges: Caregiver Self Care

- **40% to 70%** of family caregivers have clinically significant symptoms of depression (approximately a quarter to half of these caregivers meet the diagnostic criteria for major depression)
Zarit, S. (2006). Assessment of family caregivers: A research perspective. Caregiver Assessment: Voices and Views from the Field, 2, 12-37.
- Nearly three quarters (**72%**) of family caregivers report not going to the doctor as often as they should while **55%** say they skip doctor appointments for themselves. **63%** of caregivers report having poorer eating habits than noncaregivers
National Alliance for Caregiving and Evercare, 2006



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Challenges: Ongoing Issues

- **Caregivers' input not taken into consideration**
 - Caregiver and care receiver may have different perceptions
 - Rehab emphasis on physical functioning
 - Senior services have concentrated on poor isolated seniors
- **Lack of social support**
 - Decreases caregiver's sense of well being
 - Those with neurobehavioral problems receive the least support
- **Cost of long term care**
 - Discharge due to financial considerations
 - Caregivers not know what to expect, how to care for patient
 - Needs of caregiver not taken into consideration
- **Strain on marital relationships / families**
- **Appropriate knowledge of medical care tasks**
(e.g wound care)

Barriers Faced by Caregivers

- Education
- Formal System
- Isolation
- Informal Supports
- Trust
- Finances/
Legal Concerns
- Self Care Barriers
- Guilt
- Grief & Loss

Barriers: Education

Information on the illness

- **Communication skills**
- **Honest information on prognosis / long term care needs**
- **Care strategies**
 - **Back care**
 - **Bathing, dressing, toileting, etc.**
 - **Communication skills**
- **Understanding behavioral issues**

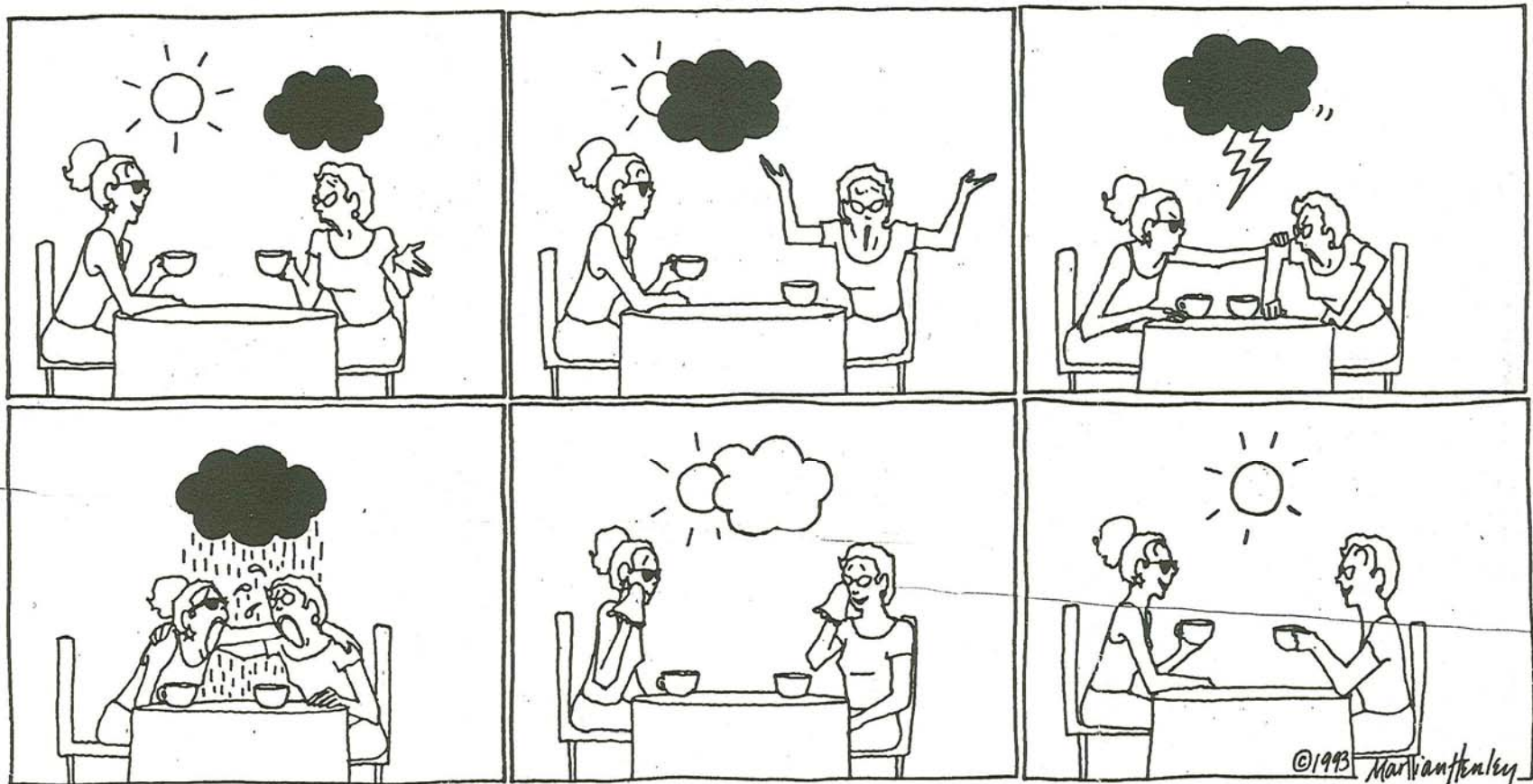
Barriers: Formal Systems

- **Talking to MD / other professionals**
- **Learning the system**
- **Accessing services**
- **Information about community resources**

Barriers: Isolation

- **Feelings of abandonment**
- **Not knowing how / who to ask for help**
- **Family conflict**
- **Loss of social supports**
- **Physical limitations**
 - **Chronic illness of caregiver**
 - **Depression**
 - **Substance use / prescription abuse**

MAXINE



Barriers: Informal Supports

- **Feeling isolated and alone, increases with length of time as a caregiver**
- **78% of caregivers feel they need more help or information**
Epel, S., et al. (2004) Proceedings of the National Academy of Sciences, 101, 49.
- **Family conflict often prevents getting help**
- **One person in family usually does the majority of the caregiving**
- **Using support helps caregivers to take better care of themselves and CR**

Barriers: Trust

- **Ethnic/cultural issues**
- **Filial obligation**
 - **Willingness to give and accept care**
- **Fear of strangers**
- **Paranoia inherent in dementia**
- **Embarrassment**
- **Fear of being robbed**
- **“We’re not like that”**
 - **Never had to ask for help**
 - **Never accessed systems**
 - **Stigma of “welfare”**



Barriers: Finances

- **Cost of hiring**
- **Too rich to be poor / too poor to be rich**
- **Assets in the house—don't want to touch**
- **Overwhelmed with bills / who is paying them?**
- **Nest egg**
 - **Afraid of running out of money**
 - **Want children to inherit**
 - **Depression mentality**



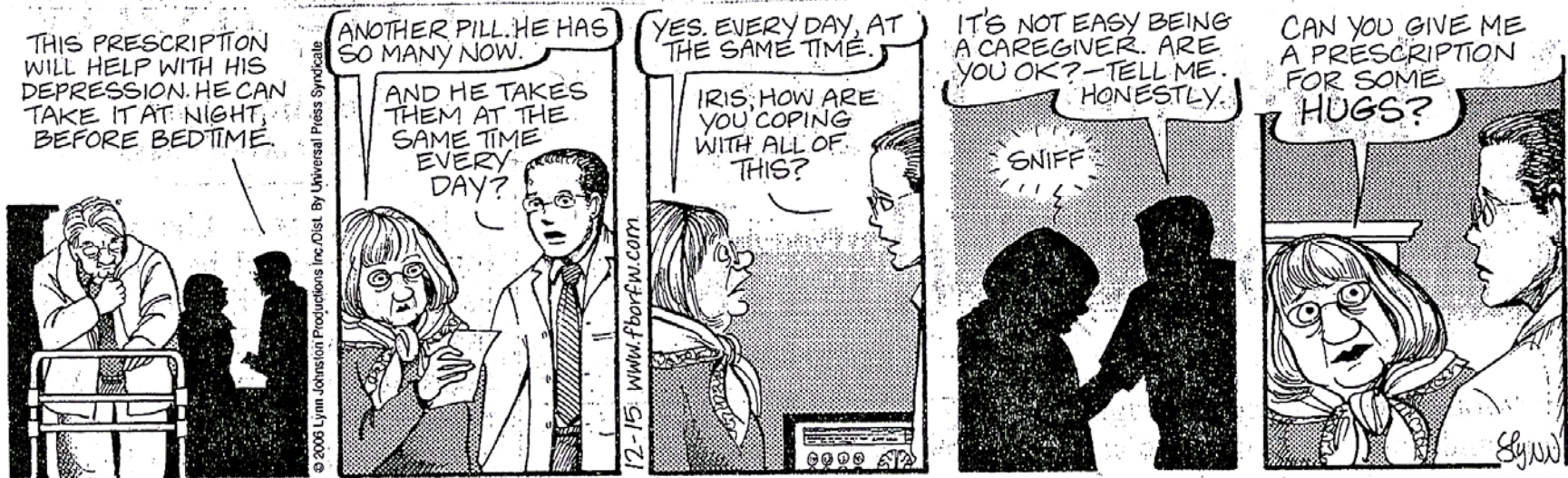
"Now read me the part again where I disinherit everybody."

Barriers: Legal

- **Powers of attorney for health care and finance**
- **Who handles the money / has signatory power on checking accounts**
- **Release of information for medical conversations**

Barriers: Self Care

- **Getting systems to pay attention to them**
- **Don't admit to own needs**
 - **Own medical care, risks due to caregiving**
 - **Respite**
- **Not knowing how to receive offers of help**
- **Dealing with other family members**
- **Depression / stress**



Barriers: Guilt

- **“I should”**
 - **No one will do as good a job as I do**
 - **Fear something will happen if you are away**
 - **Can I place my loved one in a facility?**
- **Guilt vs Regret**
- **Being “Perfect” is a set up for failure**
 - **I am not in perfect control of my emotions**
- **Do I deserve to have a good time if my loved one is suffering?**
- **Thinking about my needs is selfish**
- **Ambivalence**

Barriers: Grief & Loss

- **Ambiguous loss**
 - Loss of future
 - Loss of who the person was
 - Loss of chance to “make it right”
 - Loss of role
- **Guilt**
- **Being selfish**

Emerging Issues

- Why is Caregiving Important
- Recognize Family Caregiving
- Research to Practice
- Emerging Issues - Why Now
- Paradigm Shift

Emerging Issues: Why is Caregiving Important?

- **Families are usually the first choice for how and by whom an adult with disabilities would like to have assistance**
- **That care comes at a cost to the family, both economically and emotionally**
 - **Financial impact to families can be devastating**
 - **Recognizes that the emotional impact for families can be debilitating-need for mental health services and other caregiver support services**

Emerging Issues: Professionals Need to Recognize Family Caregiving

- See the unit of care is the CR and CG
- CG assessment and support needed to improve outcomes and continuity of care for the CR
- CG confidence and competence leads to better outcomes for the CR
- Understand the caregiving situation – including service needs, unresolved problems, and potential risks – in order to meet the needs of the CG
 - To identify services available for the CG & provide appropriate and timely referral for services
 - Resource referrals need to be specific and targeted, so as not to overwhelm the caregiver



Emerging Issues: Research to Practice

- **High amount of research activity in past 30 years on intervention for caregivers to improve:**
 - **Stress**
 - **Burden**
 - **Health & Depression**
 - **Competency & Coping**
- **Growing body of research results for evidence and best practice approaches to replicate in states and local communities**
- **Growing body of consumer information, online training resources and community service databases that make access to information easier**



"Nonsense, Mother, You'll probably outlive us all"

Emerging Issues: Why Now

- **Caregivers are being served through VA, national and state programs**
- **Need for caregiver assessment across service areas**
- **Chronic illness demands caregiving**
- **Policy issues**
 - **Healthcare reform act**
 - **Medicare billing**
 - **Title III E**

Emerging Issues: Changing the Paradigm: From Passive Patients to Person & Family Centered Care

- Caregivers have been mostly overlooked as a health and care partner by the formal system
- Visibility of informal caregivers as a major part of the LTC workforce and for whom services and supports should be provided is growing as a policy issue
- Caregivers are being woven into evidence and best practices as major components of programs managing chronic care conditions
(e.g. care transitions; care coordination)
- Caregivers were mentioned **16 times** in the *Patient Protection and Affordable Care Act* (Health Care Reform)

Caregiving Rewards: Family Insights

- Opportunity to create positive memories
- Improved my relationship / chance to heal the past
- Learned to put someone else first / made me a better person
- Patience / learning to listen
- Gratefulness / my chance to pay my parents back for their caring
- Increased my compassion and tolerance
- Get to experience love and joy through caring
- No regrets / peace of mind / closure / completion / time to say goodbye
- Spiritual fulfillment
- Role model for the next generation of how to care for family / reap what sow
- My parent is my best friend / still alive for me to appreciate / way to honor her
- Changed my priorities - I learned what's important
- Developing new skills and competencies / feel more self confident
- Satisfaction in a job well done / fulfillment

Conclusion

Professionals can facilitate caregivers dealing with someone with chronic illness or disability by:

- **Understanding the complexities faced by family caregivers**
 - **Helping them identify as a caregiver**
 - **Listening to their concerns/experience**
 - **Acknowledging their feelings**
 - **Encourage them to seek assistance**

Resources

- Technical Assistance Center
- Family Caregiver Navigator
- Family Caregiver Alliance's Fact Sheets

Resources: Technical Assistance Center

The screenshot displays the Family Caregiver Alliance website. At the top, the logo and name 'FCA FAMILY CAREGIVER ALLIANCE National Center on Caregiving' are visible. A search bar is located in the top right corner. Below the header, a navigation menu includes 'Public Policy & Research', 'Caregiving Info & Advice', 'Fact Sheets & Publications', 'Newsletters', 'Groups', 'Press Room', and 'About FCA'. The main content area is titled 'Home > Innovations Clearinghouse > Technical Assistance Centers'. It features a sidebar on the left with a tree view of the site's structure, including sections like 'Clearinghouse Home', 'Understanding the Clearinghouse', 'Browse By Category', and 'Technical Assistance Centers'. The main content area has a breadcrumb trail, social media links, and a large heading 'Technical Assistance Center for Caregiver Programs'. Below this, there is a welcome message, a paragraph describing the center's purpose, and a call to action for feedback. A section titled 'The Newsletter of the Technical Assistance Centers' follows, with links for the current issue, archives, and subscription.

FCA FAMILY CAREGIVER ALLIANCE
National Center on Caregiving

Public Policy & Research | Caregiving Info & Advice | Fact Sheets & Publications | Newsletters | Groups | Press Room | About FCA

Home > Innovations Clearinghouse > **Technical Assistance Centers**

@Family Caregiver Alliance | [E-mail to a Friend](#) | [Printable Version](#)

Technical Assistance Center for Caregiver Programs

Welcome to our online Technical Assistance Center!

It is dedicated to providing you, your staff and your agency with the tools needed for the efficient development and delivery of caregiver support services. Explore this site to find upcoming and archived [training events](#), [news](#) from the Lifespan Respite and Aging networks and the TA Centers' [newsletter](#).

Additionally, you can [search](#) this entire Clearinghouse to identify best practices, [specific tools](#) and [policy & advocacy efforts](#); [connect](#) with fellow professionals from the aging networks; and [request](#) specialized technical assistance.

We invite you to take the opportunity and provide feedback to further shape the activities of the Technical Assistance Centers to more closely meet your Caregiver Programming needs. Give us your feedback [here](#).

The Technical Assistance Centers resulted from a partnership between the National Center on Caregiving at Family Caregiver Alliance and [ARCH National Respite Network and Resource Center](#), with the support of the [US Administration on Aging](#). To read more about the partnership click [here](#).

To access the Technical Assistance Center for Lifespan Respite click [here](#).

The Newsletter of the Technical Assistance Centers

The [Newsletter](#) of the Technical Assistance Centers brings timely information to the aging and lifespan respite networks about best practices, key research findings, and policy trends related to family caregiving and lifespan respite.

[Current Issue](#)

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Search the Clearinghouse: [search](#)

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Resources: Family Caregiver Navigator

The screenshot shows the homepage of the Family Care Navigator website. At the top, there is a navigation bar with the FCA logo and the text 'FAMILY CAREGIVER ALLIANCE National Center on Caregiving'. Below the navigation bar are several menu items: 'Public Policy & Research', 'Caregiving Info & Advice', 'Fact Sheets & Publications', 'Newsletters', 'Groups', 'Press Room', and 'About FCA'. A search bar is located on the right side of the navigation bar.

The main content area features a large heading 'Family Care Navigator' with the subtitle 'State-by-State Help for Family Caregivers'. Below this, there is a welcome message: 'Welcome! If you are providing care to an **older or disabled family member or friend**, you know that navigating the long-term care system can be difficult. This state-by-state resource is intended to help you locate government, nonprofit, and private programs in your area. It includes services for family caregivers, as well as resources for older or disabled adults living at home or in a residential facility. It also includes information on government health and disability programs, legal resources, disease-specific organizations and much more.'

Below the welcome message, there is a section titled 'What Resources are Available in My State?' with a map of the United States. The map is color-coded by state, and a legend below it indicates 'NATIONAL'. To the right of the map, there is a section titled 'I Have a Question' with a list of seven questions:

1. Can I get paid to care for a family member?
2. How can I find someone to help care for my family member at home?
3. Help! I need a break! How can I find respite care?
4. How can I help my family member if I don't live nearby?
5. How can I take time off work to care for a family member?
6. How can I deal with my family member's challenging behaviors without losing my patience?
7. Where can I get more information on assisted...

On the left side of the page, there is a sidebar with a navigation menu. The menu items are: 'Family Care Navigator', 'Resources by State', 'General Information & Assistance', 'Services for Family Caregivers', 'Services for Care Recipients Living at Home', 'Resources on Living Arrangements for Care Recipients', 'Government Health & Disability Programs', 'Legal Help & Advocacy', 'Disease-Specific Organizations', 'Family Caregiver Organizations', 'Frequently Asked Questions', 'Glossary', 'What's Included?', 'Fact Sheets & Publications', 'Federal & State Legislation', and 'Give Us Your Feedback'. Below the menu, there is a button that says 'Make a Donation to FCA' and a note that says 'Funded in part by a grant from the Jacob and Valeria Lapech Foundation'.

Resources: Family Caregiver Alliance Fact Sheets



- Caregiving & Ambiguous Loss
- Caregiving & Depression
- Community Care Options
- Dementia, Caregiving & Controlling Frustration
- Grief & Loss
- Helping Families Make Everyday Care Choices (for Providers)
- LGBT Caregiving: FAQ
- Making Choices About Everyday Care (for Families)
- Taking Care of YOU: Self-Care for Family Caregivers

and much more ...

Questions?

***Please feel free to
submit your questions***

**Unanswered questions will be archived on
the Family Caregiver Alliance's website
at www.caregiver.org**

**Thank you for participating
in today's webinar!**

For information on resources and additional
Staff Development Series webinars
please visit us at www.caregiver.org

National Center on Caregiving

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