

# ARC TALKS

WEBINAR SERIES

## Caring for the Caregiver

November 20, 2024 | 12:00pm - 1:00pm ET



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# ABOUT ARC



**Our vision is to make a significant impact on the curability of amyloidosis**

The Amyloidosis Research Consortium (ARC) was founded in 2015. ARC harnesses the power of collaboration and innovation to advance science, and both improve and extend the lives of those with amyloidosis.

As a **patient-founded, patient-focused non-profit organization**, ARC is determined to shift this paradigm.

# Amyloidosis Research Consortium

## OUR FOCUS

**IMPROVING**  
the speed and  
accuracy of  
diagnosis

**INCREASING**  
our understanding  
of the genetics,  
biology and  
natural history  
of amyloidosis  
to identify new  
treatments

**ACCELERATING**  
regulatory  
approval and  
reimbursement  
of effective  
treatments for  
patients

**ENHANCING**  
care and quality  
of life of patients  
and caregivers  
throughout their  
amyloidosis  
journey

# ARC Talks Supported By

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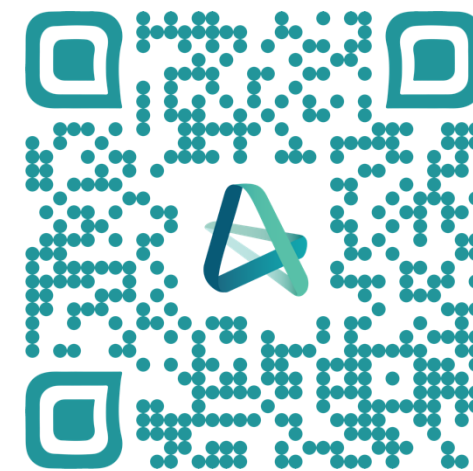
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# 2024 Community Survey



## Take the 2024 Amyloidosis Community Survey

Share your voice. Shape the future.



[arci.org/survey2024](https://arci.org/survey2024)



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# National Family Caregivers Month

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## The Diagnosis

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Shock, fear, a new world of learning about the disease.  
It will be different for everyone.

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You're in for a marathon, not a sprint.  
And you don't know how long this race will be.





- Practical
- Medical
- Legal & Financial
- Emotional

# Practical Aspects of Caregiving



You Can't Do It Alone

# Asking for Help

<p>Who to ask?</p>	<ul style="list-style-type: none"><li>• Family</li><li>• Friends</li><li>• Religious and community groups</li><li>• Professionals</li></ul>
<p>How to ask?</p>	<ul style="list-style-type: none"><li>• Be direct and specific</li><li>• Be honest</li><li>• Use websites to communicate and organize requests</li></ul>
<p>What to ask for?</p>	<ul style="list-style-type: none"><li>• Meals and groceries</li><li>• Equipment/supplies/needed items</li><li>• Transportation</li><li>• Companionship/regular visits</li><li>• Outings (for you and/or your loved one)</li><li>• Check-in calls</li><li>• Inclusion in life events via videos and photos</li></ul>

# Tips & Tricks

- Don't be afraid to ask. People want to help; it makes them feel good too.
- Keep a list of people who offered to help at the beginning so you can call on them later.
- Use your helper's unique skills.
- Work with your helper's schedule and be flexible with your requests (e.g. grocery brands).
- People who live far away can send articles and books for discussion or provide supportive calls.
- Be ready with answers up your sleeve for "well meaning" people.
- Ask for concrete needs – you never know who might have a shower chair in their attic.
- Check with realtors for stair lifts that are being removed from homes they are selling.
- Check Goodwill, churches, firehouses, libraries for needed items.

# Practical Resources

- CaringBridge: <http://www.caringbridge.org>
- Lotsa Helping Hands: <https://lotsahelpinghands.com>
- Caring Village: <http://www.caringvillage.com>
- [Postagram](#)
- Home Instead Article: [How to Ask Others for Help](#)



# Medical Aspects of Caregiving



Be Your Own Advocate

# Be Prepared

- Pack a medical go-bag
  - Notebook and pen
  - Books and magazines
  - Knitting and puzzles
  - Blanket or sweater
  - Chargers
  - Medications
- Pack an overnight bag for hospital stays
- Create a “clinic closet” at home
  - Pill organizers
  - Medical supplies



## Take Notes!

- Date
- Doctor and specialty
- Location
- Questions
- Discussion notes
- Recap and next steps
- Pocket for cards

**Don't Forget Your Own Medical Care!**

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- Don't be afraid to ask questions.
- Write down your questions ahead of time so you won't forget during the stress of the appointment.
- Write down the answers!
- Bring medication lists and copies of your insurance cards to every appointment.
- Learn what care you can do and say no to the rest. Opening a port or changing a catheter may be something you can learn and are comfortable doing. But perhaps not. It's ok to leave it to professionals.

- National Institute on Aging Worksheets:
  - [Managing Medications and Supplements](#)
  - [Coordinating Caregiving Responsibilities](#)
  - [Questions to Ask Before Hiring a Care Provider](#)
  - [Home Safety Checklist](#)
- Caregiver Log Book: <https://familycaregiversonline.net/free-caregiver-log-book/>
- Medisafe Digital Health Platform: <https://www.medisafe.com/>

# Legal & Financial Aspects of Caregiving



Be Prepared



# Documents You'll Need to Manage Your Care Recipient's Finances:

Family caregivers are often called on to manage a loved-one's finances and/or adjust to reduced income and increased expenses in their own household. One of the most important things you can do once you've taken on this role is to get organized and make sure you have access to the following important documents.

**Checklist**

**Important legal documents**

- Power of attorney
- Living will
- Will
- Trust documents

**Important financial documents**

- Bills
  - Utilities
  - Household maintenance payments
  - Medical fees
  - Other recurring expenses

## Documents You'll Need to Manage Your Care Recipient's Finances: *Continued*

- Deeds
- Mortgage papers and ownership statements
- Loan agreements
- Stock and bond certificates and statements
- Pension, 401(k) and other retirement benefit statements
- Bank and brokerage account information
- Insurance policies
  - Long-term disability
  - Healthcare
  - Home
  - Auto, etc.
- Social Security payment information if Social Security or Social Security disability already has been secured
- Pay stubs if the individual was working prior to the impairment
- State and federal income tax returns
- Medical records

- Upload important documents to My Chart and keep a copy in your medical bag.
- Change accounts to your name.
- Have a discussion with your loved one to determine what they want.
- Find an advocate. Don't expect to do this alone. Social services at hospitals, ARC, other groups have people who can help you navigate appointments, questions, billing and insurance.

## Legal & Financial Documentation:

- NFCA Document List
  - <https://nfca.typepad.com/files/checklist.pdf>
- National Institute on Aging Worksheet
  - [Important Documents and Paperwork](#)
- Nokbox: <http://www.thenokbox.com>

## Financial Assistance Programs:

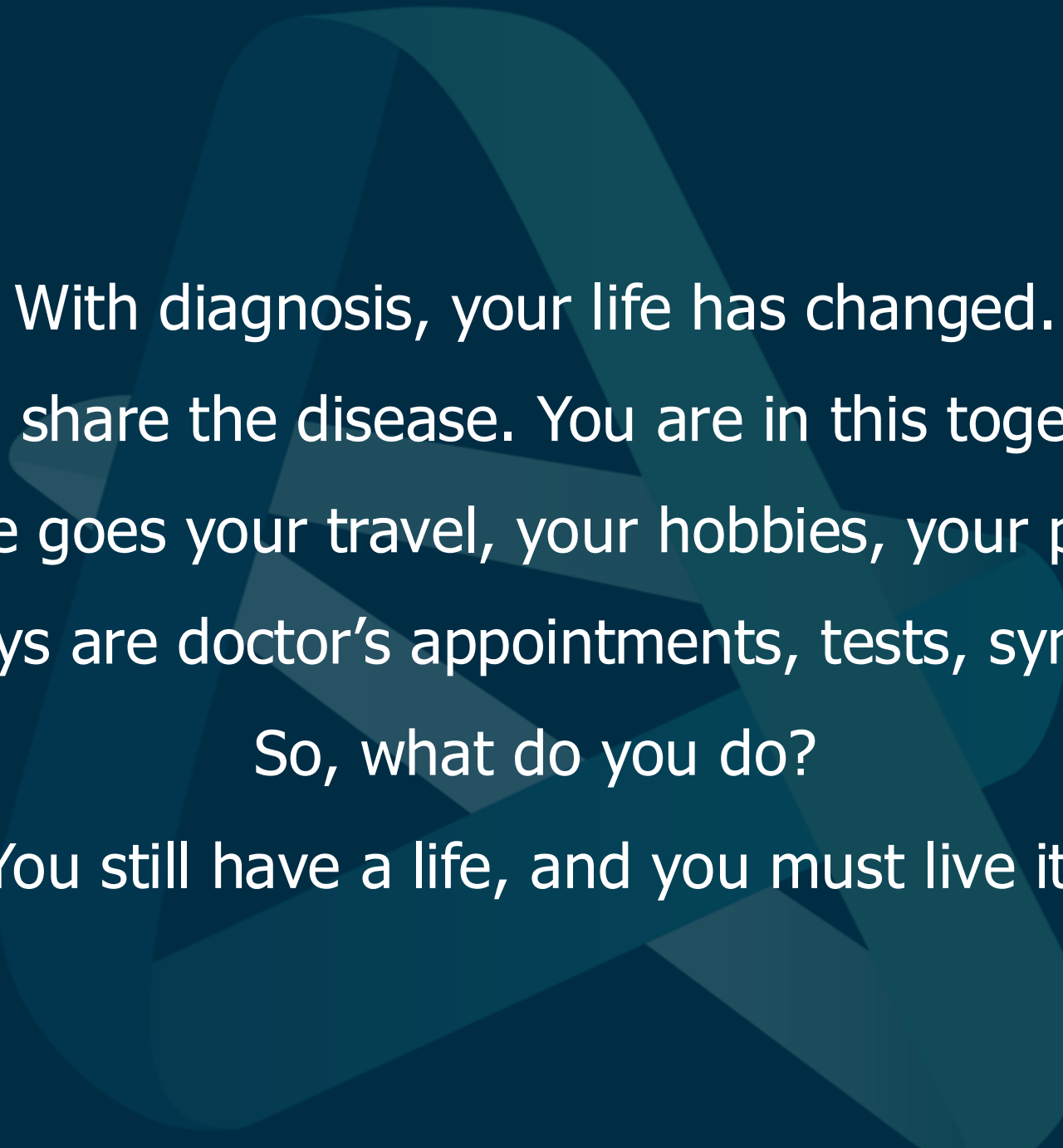
- National Family Caregiver Support Program: <https://acl.gov/programs/support-caregivers/national-family-caregiver-support-program>
- NORD Caregiver Respite Fund: <https://rarediseases.org/living-with-a-rare-disease/caregiver-resources/>
- VA Caregiver Support Program: <https://www.caregiver.va.gov/>



# Emotional Aspects of Caregiving



With Diagnosis, Your Life Has Changed



With diagnosis, your life has changed.  
You share the disease. You are in this together.  
There goes your travel, your hobbies, your plans.  
Your days are doctor's appointments, tests, symptoms.  
So, what do you do?  
You still have a life, and you must live it.



- **Managing Expectations**
  - They can change by the hour.
- **Preserving Pride and Dignity**
  - Try not to speak for your loved one. Encourage people to talk directly.
  - How much should you tell people? It can be hard to find the balance between maintaining privacy for the patient and getting support for the caregiver.
- **Experiencing Grief, Guilt, and Resentment**
  - It's normal to feel grief for your loved one and grief for life as you knew it. It's normal to feel sorry for yourself and wish the struggle was over.
- **Dealing with Anxiety and Depression**
  - Counseling can be helpful for both patient and caregiver. Recognize when you or your loved one needs professional help.
- **Navigating Conflict**
  - Pick your battles. Let someone else be the bad guy.
- **Coping with Burnout**
  - You will lose it sometimes. And that's ok. Burnout is real. You need a break.

When there's nothing  
else to do, accept those  
thoughts and prayers.  
Each one is a way of  
saying, "I love you."

# Tips & Tricks

- Talk to someone – a friend, a support group, a professional.
- Be careful what you commit to. But stay involved when you can.
- Find things to do to get a break. But also find things to do together.
- Always have a Plan B.
- Do what you can and let it go.
- Treat yourself to a massage, manicure, spa service.
- Try meditation or exercise.
- Be honest with yourself and others about what you're feeling.

# Emotional Resources

- ARC Support Services: [support@arci.org](mailto:support@arci.org)
- Amyloidosis Support Groups: [Caregivers Facebook Page](#)
- Cleveland Clinic: [Caregiver Burnout Symptoms and Prevention](#)
- Mayo Clinic: [Caregiver Stress – Tips for Taking Care of Yourself](#)
- Mental Health America: [When is it Depression? 5 Red Flags](#)
- Psychology Today: [Find a Therapist](#)
- [988 Suicide and Crisis Lifeline](#)

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What Keeps Us Going?

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# General Caregiving Resources

- Caregiver Action Network: <https://www.caregiveraction.org/>
- Family Caregiver Alliance: <https://www.caregiver.org/>
- National Alliance for Caregiving: <https://www.caregiving.org/>
- AARP Family Caregiving: <https://www.aarp.org/caregiving/>
- Area Agency on Aging: <https://www.usaging.org/>
- National Institute on Aging: <https://www.nia.nih.gov/>
- ARC Support Services: [support@arci.org](mailto:support@arci.org)

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# Caring for the Caregiver

Thank you for joining us today.  
Please take a few minutes to fill  
out the post webinar survey.