

COPING WITH
Chronic Illness

An afternoon of learning from local experts about living with chronic illness and caring for those with chronic illness.

Meet Our Speakers



CHERYL BLANCHARD LCSW, CCM

Cheryl Blanchard, LCSW, is a Certified Dementia Care Specialist and Certified Case Manager. She has worked with seniors throughout TN for several years in a variety of roles and has focused most of her training on caring for those with Alzheimer's Disease for over 10 years. She joined Alzheimer's TN as the regional director for the middle TN area in 2021.



DR. CYNTHIA PEARMAN MD, FAAFP, FAAHPM, HMDC

Dr. Pearman is a native of Knoxville, graduated in 1981 from UTK and 1986 from UT College of Medicine in Memphis. She did residency in Family Medicine in Greenville, SC and worked in urgent care, university health, and in faculty teaching positions in SC, NC, and at UTMCK in Knoxville. Dr. Pearman is board certified in Family Medicine and in Hospice and Palliative Medicine. She has practiced palliative care and hospice full-time since 2016.

REV. CATHERINE NANCE

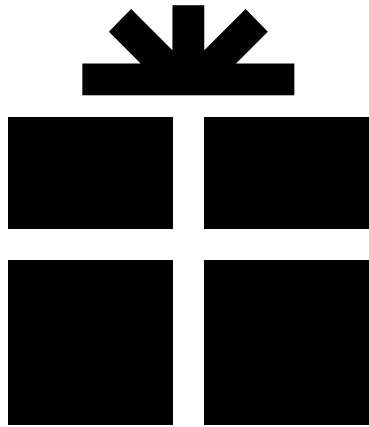
Catherine is the 42nd Senior Pastor at Church Street United Methodist Church in Knoxville, TN. She earned a B.S. in Political Science from the UT Chattanooga and her M.Div. from Duke Divinity School.

REV. PAT CLENDENEN

Pat is a retired elder of the United Methodist Church. She serves as the Stephen Ministry Pastor at CSUMC.

MEGAN DUNAWAY

Emcee and host for this event, Megan is the Community Relations Director at Morning Pointe Assisted Living and Memory Care in Hardin Valley. She is a member of CSUMC.



Did you receive a
door prize ticket?

THANK YOU TO THE MANY DOOR PRIZE
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Thank you to our
goody bag
sponsors!

BE SURE TO CHECK YOUR BAG FOR TREATS AND
HELPFUL INFORMATION FROM AREA SERVICE
PROVIDERS.

Did you know that CSUMC has a monthly caregiver support group?

Join us!

Meetings are the 3rd Tuesday of each month at 10:00am in the CLC with time for education and sharing. Purposeful activities and programming takes place for care recipients at the time of the meeting.

November 21st *Preparing for the Holidays* with Gabrielle Blake, LCSW

December 19th Music Therapist Erica Davidson joins us for our Christmas party

January 16th *Organization, "Right-sizing," and Moves* with Joanna Lankford, Caring Senior Move

And now some helpful information
while you wait for our presentations to
begin.



*“I know God will not give
me anything
I can't handle. I just wish
that He didn't trust me so
much.”
~ Mother Teresa*



You've received a difficult diagnosis- now what?

- Allow yourself to feel what you are feeling.
- Be kind to yourself. It is easy to “shoulda, woulda, coulda” and find blame.
- Review medical options with your treatment team. If a second opinion is desired, seek one early in the process.
- When you are ready, share the news with trusted people in your life.
- Take time for rest.



Gather
information from
trusted sources

Alzheimer's Tennessee
Parkinson's Foundation
American Cancer Society

Avoid information
overload and
misinformation through
general web searches
(AKA "Dr. Google")

Gathering Support

Categorize your support system—

- Who might help with medical appointments?
- Who might watch my loved one while I go to the grocery?
- Who is a good listener?

Have a spokesperson—

- Designate one person to update family/friends.
- Ask this person to make requests on your behalf (send out Meal Train info).



Caregiving

“There are only four kinds of people in the world.
Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers.
And those who will need caregivers.”
~Rosalyn Carter



“I’m a caregiver, and I need help”

Build your support system

Use tools like a Family Calendar

How might seasons and celebrations be different this year?

What needs may be different during school holidays?

Use caregiver resources through support groups, education, or call line.

Spiritual Support (Stephen Ministry, Parish Health, Pastoral Support), and Therapy



*Carry each other's burdens,
and in this way, you will fulfill the law of
Christ.*

Galatians 6:2

Ways to help others- Tangible Offers

Instead of

“Let me know when I can help.”

“You sure have your hands full. Wish I could help somehow.”

“I’d love to help. Call me if there is anything I can do.”

“Let us know if there is something we can do to help.”

Try

“When is your next doctor’s appointment? Can I help you on that day?”

“I make really great chicken soup. Can I bring some by on Tuesday or Friday?”

“I’m going to be wrapping presents on Saturday. I can pick up your stash and wrap them for you.”

“I’m going to Kroger this afternoon. Can I pick up your shopping list?”

Ways to help others— Be Mindful of your words



- God has a plan
- Jesus is watching over you
- You'll see him in Heaven
- There is a purpose in all of this
- Be grateful for...
- I'm praying for you

Instead

- Meet the person where they are.
- Mirror language when possible.
- Do what you say you are going to do.
- Your actions mean more than your words
- ***How can I purposefully pray for you?***

Not sure what to say?

Presence over Perfection

“When someone is broken, don’t try to fix them.
You can’t.

When someone is hurting, don’t try to take away
their pain.
You can’t.

Instead, love them by walking beside them in the
hurt.
You can.

Because sometimes, what people need is simply
to know
They are not alone.”



Dr. David Servan-Schreiber *Anti-Cancer, A New Way of Life:*

*Serious illness can be a terribly lonely journey...Our Western values, with their worship of concrete results, may blind us to our profound animal need for presence when facing danger and uncertainty. **Gentle, constant, reliable presence is often the most beautiful gift our dear ones can give us.***




Ways to help others— Remember other members of the family




- Spouses and children are going through a similar emotional whirlwind as the care recipient.
- Set a reminder on your calendar to check in regularly about new needs, or simply be a shoulder to cry on or a bended ear to listen.


“You really should take better care of yourself.”




“You should speak with a therapist.”



“You should keep him at home because of covid.”



“You should try herbal remedies.”



“You should.....”

Ways to help others-
Avoid
“Shoulding”

Ways to help others— Don't offer unsolicited advice

- Remember that everyone's experience is different and within the same diagnosis there are many variations.
- Avoid sending random articles from the Internet about the diagnosis.
- Instead try an approach like this: *"I know you must have people giving you lots of information right now, and I don't want to overwhelm you further. If you do want me to research anything or look for resources for you, though, I am happy to do that."*



More tools and tips

Keep a Legacy Drawer or File with Important Papers

Be mindful of private or protected information that should not fall into the wrong hands.

Consider including:

- Names of accounts and institutions, a recent bank statement
- If you have them, your investment advisor's and accountant's contact information
- Discharge papers, birth certificates, marriage certificate
- Copies of your estate planning documents other than the will and where to find your will
- Copy of your Long-Term Care Policy, life insurance



Pack a “Go Bag”

Change of clothes

Toiletries

Copies of
Healthcare and
\$ POA (and a POST
form if applicable)

Medication List

Copies of
Insurance Cards

General Health
History



Person Centered Care

- Do you have any strongly held values or beliefs that would influence how medical decisions would be made?
- Who are you close with and who do you not want involved in your care?

Teepa Snow, Positive Approach to Care

Teepa Snow and the PAC Team share about dementia so that everyone can understand why this is happening and how to support those living with brain change in a more positive and respectful way.

"Rewiring our own perceptions, attitudes, communication strategies, actions, and responses, provides the shift that promotes change for the others around us." ~Teepa Snow

Watch helpful videos and podcasts on her Facebook and Instagram



What is important to you?

It is not only important to know IF you want treatment interventions, but also under what circumstances would you want those interventions.

What does good care look like to you now and how would that change as your illness progresses?

The Conversation Project Website offers helpful prompts for having these conversations with loved ones.

Hospital Discharge Planning

Leave a voicemail or speak with the discharge planner as soon as possible.

List your top 3 skilled rehabilitation/nursing home selections.

Address medication barriers

- How expensive is this medicine?
- Is there a generic option?
- What are side effects?



COST OF CARE



Personal Care Attendants

- Non-medical in-home care
- Cost around \$30-\$35/hour

Assisted Living Communities

- Medical and non-medical assistance
- Shared or private rooms, amenities vary greatly
- **Starting** costs around \$3800/mo for shared rooms, \$4000/mo for private rooms, for memory care \$5000/mo

Nursing Homes

- Medical assistance
 - Usually, shared rooms
 - Pricing varies, but usually around \$300/day
-

Care Community Considerations

- Proximity to family and friends
- Cost
- Room size and features
- Safety in the environment—railing, safe entry procedures, walk in showers, grab bars
- Culture and “feel” of the community
- Amenities
- Ratio of male to female
- What does the average day look like?





When choosing assisted living

- Drop in unannounced but do not be upset if unable to tour.
- Try the food.
- Ask about additional fees-levels of care, deposits, community fees, cable/phone.
- Ask others about their experiences with that community.
- Check them out on social media.



When choosing nursing home care

- Check state survey records.
- Learn what job positions are open.
- Ask if they are using agency staff for floor staff coverage.
- Ask to briefly meet the executive director or director of nursing.
- Watch how staff interact with residents when they do not know they are being observed.



Advocating for loved ones

- Be present and get to know staff
- Learn “who does what” to better know whom to contact with problems.
- Never underestimate the value of a dozen donuts dropped by the nurses’ station.
- Advocate for the resident’s involvement in care decisions.
- Respect staff members’ time constraints—be brief, make appointments, schedule a care plan meeting.

What does Medicare Pay for?

Skilled Rehabilitative Care-

Part A pays for all covered services for the first 20 days of skilled nursing care.

For days 21 through 100, Part A pays for all covered services except for the applicable co-pay, which is usually covered by a Medicare supplemental policy a.k.a. Medigap policy.

Hospice Care

Home health and Medical Care-

Part B covers doctors' bills and some other medical services and supplies.

***Medicare is not a long-term care insurance



Financial Programs

Office on Aging Savings
Check Up
865-524-2786

Patient Assistance
Programs
& GoodRx

Access to durable
medical equipment—
(SPARK, Scottish Rite)

Link to food
assistance—Food
pantries, SNAP Benefits,
Caring Plate, Mobile
Meals

Nurse Case Managers
(Insurance Companies,
Medical Systems)

What else?—Senior
Information and
Referral out of Office on
Aging

Safety Tools



- TN Yellow DOT—A safety form for your car
<https://www.tn.gov/tdot/traffic-operations-division/transportation-management-office/yellow-dot-program.html>
- Silver Alert Kit--Prevent and prepare for wandering
<https://www.alztennessee.org/help/community-programs/silver-alert>
- Medic Alert Found—Medic Alert ID
<https://www.alztennessee.org/help/living-with-alzheimers/medicalert-found>
- Personal Response System—Fall and medical event assistance
<https://www.knoxseniors.org/pers/>

Helpful resources

25 Common Nursing Home Problems and How to Resolve them.

Found at

<https://justiceinaging.org/25-common-nursing-home-problems-how-to-resolve-them/>

Ombudsman

<https://www.tn.gov/aging/our-programs/long-term-care-ombudsman.html>

**25 Common Nursing Home Problems—
& How to Resolve Them**



Helpful websites



The Dementia Directive found at
dementia-directive.org

End of Life Care forms and information at
endoflifecaretn.org

Conversation Ready Kit found at
conversationproject.org

Thank you!

A special thanks to Valerie Nicholson for her leadership of the event planning committee.

Thanks to the many volunteers who helped with today's event!

Presented By:

