

Schedule

4:00PM EST	Parkinson's Foundation Introduction (Crista Ellis)
4:05PM EST	Part 1 – Veterans & Parkinson's: Planning for the Future (Emily Hall) <ul style="list-style-type: none">• Have a better understanding of how treatment plans may change with disease progression• Learn how to discuss advancing symptoms with the care team to best address needs/concerns
4:35PM EST	Q&A Session #1 (Moderated by Crista Ellis)
4:50PM EST	Part 2 – Veterans & Parkinson's: Planning for the Future (Emily Hall) <ul style="list-style-type: none">• Discuss various care options available and when to seek outside assistance for care needs• Understand the role of Palliative Care in long-term planning
5:15PM EST	Q&A Session #2 (Moderated by Crista Ellis)
5:30PM EST	Closing Remarks & Conclusion of Webinar (Crista Ellis)

What is Palliative Care?




- Chronic Symptom Management
- Supportive Care for the Whole System
- Improving Quality of Life
- Support for Care Partners
- Provide Anticipatory Guidance
- Goals of Care
- Advance Care Planning
- Complementing, but NOT replacing other treatments

Myths of Palliative Care

- It is only for people who are imminently dying
- It is only for people with terminal cancer
- If you receive palliative care, you cannot get any other treatments like chemotherapy, surgery, or kidney dialysis
- It makes the person die sooner
- It is only available in hospitals
- It means my provider has given up on me
- It is only for pain management
- It will cost a lot of money
- I will stop seeing my other doctors once enrolled

The 3 C's of Palliative Care

- **Comfort**
 - Pain, nausea, constipation, shortness of breath, and more. Sometimes more than friends/family can manage on their own and need professional assistance.
- **Communication**
 - Open discussion of diagnosis, prognosis, treatment options, and informed decision making. Having someone to help coordinate can alleviate a challenging step (mPOA, decision-maker, advance care planning)
- **Coordination**
 - Ensure all parties understand patient's goals and objectives then direct care based on these goals. Focus on "what really matters" in these difficult conversations.



The Three C's of Palliative Care

- 1 Comfort
- 2 Communication
- 3 Coordination

Benefits of Palliative Care

- Less pain and other symptoms like constipation
- Better communication between PWP, provider, and family member(s)
- Alignment of care with the wishes of the PWP that meets their emotional & spiritual needs
- Results from the 1st randomized clinical trial comparing Palliative Care to “usual care” for PD & related disorders found that palliative care significantly improved QoL, symptom burden, and grief, while reducing caregiver stress at 6 months ((Kluger et al., 2019).
- Telehealth options!
 - Telehealth has been found to increase access to Palliative Care for those who live in more rural/remote areas or are homebound due to their advancing PD (Katz, 2019).
 - In 2017, 2 randomized controlled clinical trials showed that outpatient care for people with PD provided via telemedicine was equivalent to the care provided in-person, but telemedicine was significantly preferred to in-person visits, saving a median of 88 minutes and 28 miles per visit (Beck et al., 2017; Korn et al., 2017).

Caregiver Burden

- Perception of strain and stress resulting from a perceived obligation to provide care for their loved one with Parkinson’s Disease (Machi et al., 2020).
- Characteristics related to higher rates of burden:
 - Disease Severity, Presence of Non-Motor Symptoms (i.e., Psychosis), Self-reported QoL, Higher rates of Self-reported depression in PWP
- Available Supports (Lum & Kluger, 2020)
 - Educational materials, Home Health, Respite Care, Advocacy Organizations, Local/Online Support Groups
- D

Anticipatory Guidance

- Open, ongoing conversations about choices related to the medical impact on employment, living situation, finances, and safety concerns (Lum & Kluger, 2020).
- Creating safe spaces for conversations about PWP's wishes/preferences
- Providing the Care Partners with guidance that may inform future decisions
 - Offer strategies, ideas, and solutions
- Questions:
 - Is it okay for us to talk about...?
 - Are there specific things you are wondering about the future?
 - Some patients I work with worry about _____. Are these things you've worried about?
 - Have you thought about how you will adjust when...?
 - Is there something you're worried might change? Can I offer ideas of how I've seen other families handle that?
 - Can I offer something I've seen other PWP or Care Partners do when they experience a similar situation?
- Offer Guidance – Normalize – Goal to Alleviate Anxiety/Worries



<https://www.ariadnelabs.org/2021/11/16/what-matters-to-me-workbook/>

What Matters to Me

A Workbook for People with Serious Illness

NAME

DATE

ARIADNE LABS the conversation project

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My Health

1 What is your understanding of your current health situation?

2 How much information about what might be ahead with your illness would you like from your health care team?

About Me

3 MY GOOD DAYS - What does a good day look like for you?
Here are some things I like to do on a good day:

EXAMPLES
Get up and dressed • Play with my cat • Make a phone call • Watch TV • Have coffee with a friend

4 MY HARD DAYS - What does a hard day look like for you?
These are the toughest things for me to deal with on a hard day:

EXAMPLES
Can't get out of bed • In a lot of discomfort • No appetite • Don't feel like talking to anyone

5 MY GOALS - What are your most important goals if your health situation worsens?
These are some things I would like to be able to do in the future:

EXAMPLES
Take my dog for a walk • Attend my child's wedding • Feel well enough to go to church • Talk to my grandchildren when they come to visit

My Care

Everyone has their own preferences about the kind of care they do and don't want to receive. Use the scales below to think about what you want at this time.
Note: These scales represent a range of feelings; there are no right or wrong answers.

• Answer where you are right now. For each scale below, think about what you want now. Revisit your answers in the future, as they may change over time.

• Use your answers as conversation starters. Your answers can be a good starting point to talk with others about why you answered the way you did.

6 As a patient, I'd like to know...
Only the basics about my condition and my treatment All the details about my condition and my treatment

7 When there is a medical decision to be made, I would like...
My health care team to make all the decisions To have a say in decisions whenever possible

8 What are your concerns about medical treatments?
I worry that I won't get enough care I worry that I'll get too much care

9 How much medical treatment are you willing to go through for the possibility of gaining more time?
Nothing. I don't want any more medical treatments Everything. I want to try any medical treatments possible

10 If your health situation worsens, where do you want to be?
I strongly prefer to be in a health care facility I strongly prefer to be at home, if possible

11 When it comes to sharing information about my illness with others...
I don't want those close to me to know all the details I do want those close to me to know all the details

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1 MY FEARS AND WORRIES - What are your biggest fears and worries about the future with your health?
These are the main things I worry about:

EXAMPLES
 I don't want to be in pain - I'm worried that I won't be able to get the care I want - I don't want to feel stuck somewhere where no one will visit me - I worry about the cost of my care - What if I need more care than my caregivers can provide?

2 MY STRENGTHS - As you think about the future with your illness, what gives you strength?
These are my main sources of strength in difficult times:

EXAMPLES
 My friends - My family - My faith - My garden - Myself ("I just do it")

3 MY ABILITIES - What abilities are so critical to your life that you can't imagine living without them?
 I want to keep going as long as I can...

EXAMPLES
 As long as I can at least sit up on the bed and occasionally talk to my grandchildren - As long as I can eat ice cream and watch the football game on TV - As long as I can recognize my loved ones - As long as my heart is beating, even though I'm not conscious

If you become sicker, which matters more to you: the possibility of a longer life, or the possibility of a better quality of life? Please explain.

4 MY WISHES AND PREFERENCES - What wishes and preferences do you have for your care?
If my health situation worsens, here's what I want to make sure DOES happen:

EXAMPLES
 I want to stay as independent as possible - I want to get back home - I want my doctors to do absolutely everything they can to keep me alive - I want everybody to respect my wishes if I say I want to switch to comfort care only

And here's what I want to make sure DOES NOT happen:

EXAMPLES
 I don't want to become a burden on my family - I don't want to be alone - I don't want to end up in the ICU on a lot of machines - I don't want to be in pain

Is there anything else you want to make sure your family, friends, and health care team know about you and your wishes and preferences for care if you get sicker?

5 MY QUESTIONS - What questions do you want to ask your health care team?

EXAMPLES
 How will you work with me over the coming months? - What treatment options are available for me at this point - and what are the chances they'll work? - What can I expect if I decide I don't want more curative treatment? - If I get sicker, what can you do to help me stay comfortable? - What are the best-case and worst-case scenarios?

My People

1 Are there key people who will be involved in your care (family members, friends, faith leaders, others)? For each person you list, be sure to include their phone number and relationship to you.

2 How much do they know about your wishes and preferences? What role do you want them to have in decision making? When might you be able to talk to them about your wishes?

3 Which person would you want to make medical decisions on your behalf if you're not able to? This person is often called your health care proxy, agent, or surrogate. See the [Guide to Choosing a Health Care Proxy](#) for help.

Name, phone number, relationship to me Yes No
 I have talked with this person about what matters most to me. Yes No
 I have filled out an official form naming this person as my health care proxy. Yes No
 I have checked to make sure my health care team has a copy of the official proxy form. Yes No

My Health Care Team

Who are the key clinicians involved in your care?

1 My primary care provider Name Phone number

2 My social worker Name Phone number

3 My main specialist Name Phone number

4 Other Name Phone number

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Advance Care Planning

- Goals and preferences for life-sustaining treatment and care
 - *If done with an attorney – be sure this is addressed!
- Designating a healthcare proxy (medical power of attorney, decision-maker)
- American Academy of Neurology Parkinson Disease Quality Measurement Set recommends annual review of advance directives and designated healthcare surrogates.
- 94% of patients preferred early information on prognosis and treatment and 68.5% reported having some kind of ACP document, only about HALF of the PWP wanted to discuss ACP documentation early on. A smaller portion wanted early discussions about end-of-life care planning (27%) or end of life care options such as hospice (21%) and a very small number felt end of life issues should never be discussed (Tuck et al., 2015)
- For those with PD who die in the hospital, 97% have never had an ACP discussion documented (Walker et al., 2014).
- Social Workers** can provide additional education, support, and assistance with completion of documentation. They are also key to ensuring this is scanned properly into your VA records!



<h2>Five Myths About Advance Care Planning</h2> <p>Get the facts about these common advance care planning myths.</p>	<p>Myth My loved ones will know what I want when the time comes.</p> 	<p>Myth I need a lawyer to create an advance care plan.</p> 
	<p>Fact Not necessarily. In one study, nearly 1 in 3 people guessed wrong when asked to predict which end-of-life decisions their loved one would make.</p>	<p>Fact Most states offer free advance directive forms online, and you do not have to involve a lawyer.</p>
<p>Myth I only need a plan if I'm very old or ill.</p> 	<p>Myth An advance care plan only matters if I put it in writing.</p> 	<p>Myth Once I put my plans in writing, I can't change them.</p> 
<p>Fact It's impossible to predict the future. An emergency can happen at any age. Creating a plan now helps ensure that someone you trust can make decisions that reflect your wishes.</p>	<p>Fact The most important part of planning is discussing your wishes with your loved ones. It can save them from worrying about whether they made the right decisions for you.</p>	<p>Fact Your advance directives can be changed at any time. In fact, you should review your plans at least once a year and after any major life event like a move, divorce, or change in your health.</p>
<p>Ready to get started? Visit www.nia.nih.gov/acp</p> 		

Advance Care Planning Resources

- Five Wishes: <https://fivewishes.org/>
- VA Form 10-0137A (What You Should Know About Advance Directive)
 - <https://www.va.gov/vaforms/medical/pdf/10-0137A.pdf>
- VA Form 10-0137 (VA Advance Directive Durable Power of Attorney For Health Care and Living Will)
 - https://www.va.gov/vaforms/medical/pdf/va_form_10-0137_fill.pdf
- VA Advance Care Planning Coordinators & Group Visit Options:
 - https://www.socialwork.va.gov/ACP-GV_Site_Leads.asp
 - https://www.socialwork.va.gov/ACP_GV.asp

https://www.va.gov/geriatrics/pages/advance_care_planning_topics.asp

ASK YOUR PROVIDER FOR A PALLIATIVE CARE REFERRAL!

Palliative Care is NOT just for people with advanced PD...
it can be benefit at any stage!

Build Your Team!

Patient	Care Partner, Family Member(s), & Support Persons	Movement Disorder Specialist	RN/Educator	Social Worker	Physical Therapist
Occupational Therapist	Speech Language Pathologist	Palliative Care NP	Dietician	Sleep Neurologist	Blind Rehab Outpatient Specialist & NVI Optometrist
Chaplain	Pelvic Floor Physical Therapist	Neuropsychologist	Music Therapist	Mental Health Provider	Recreational Therapist

Richmond PADRECC IDT Clinic

Clinical Team Members of Richmond PADRECC

- MD/DO/NP
- Clinic RN
- RN Clinical Educator
- SW (Me!)
- Sleep MD
- Palliative Care NP
- PT
- OT
- SLP
- AT
- BROS/Vision Therapy
- Dietician
- Chaplain
- Music Therapy
- Neuropsychology
- PT – Pelvic Floor
- Recreational Therapy

IDT Clinic – Thursdays

- Started June 2022
- Originally 2 Patients – Recently expanded to 3 Patients (looking to do 4 soon!)
- Offer F2F or VVC for 3 hours (i.e., 9:00AM-12:00PM) with some flexibility
- Typically includes – PT, OT, AT, SLP, SW, RN, BROS/Vision (PRN: Music Therapy, Sleep MD, Dietician, Chaplain)
- Providers are added via Consults
- Plan for Follow-up IDT Clinic every 12 months
- PADRECC IDT Meeting 12:15-1:00PM
 - Veteran & family NOT present
- SW/RN follow-up to provide treatment plan to veteran/care partner
 - Provide copy of treatment plan
 - Place referrals/orders accordingly

Support Groups & Education

- Philadelphia & Richmond PADRECC *Virtual - 1st Monday @ 1:00-2:00PM EST
 - Email Jessica.Kaplan@va.gov or Gretchen.Glenn@va.gov for Microsoft Teams info
- San Francisco PADRECC *Virtual - 3rd Tuesday @ 4:00-5:30PM PST
 - Email Annie.LiWong@va.gov for video links
- Houston PADRECC *Virtual – 1st Thursday @ 12:30-1:30PM CST
 - Call Sally Samuel, RN (713-794-8410) for Microsoft Teams link
- West Los Angeles PADRECC *Virtual – 2nd Tuesday @ 10:00-11:00AM PST
 - Call Patricia Pittman (310-478-3711 ext: 48001) for link
- VA Long Beach *Virtual via VVC – Every other Friday @ 1:00-2:30PM PST
 - Call Megan Gomez, PhD (562-706-0740)
- Northwest/Portland PADRECC *Virtual – 2nd Friday @ 10:00-11:30AM PST
 - Call 503-220-8262 ext: 58593 to register
- Early Onset Support Group *Virtual (PWP diagnosed before age of 50) - 2nd Wednesday @ 5:30 EST
 - Email Jessica.Kaplan@va.gov or 804-675-5931
- Parkinson's Disease Caregiver Support Group *Virtual – 3rd Monday @ 10:00-11:00AM EST
 - Email Jessica.Kaplan@va.gov or 804-675-5931

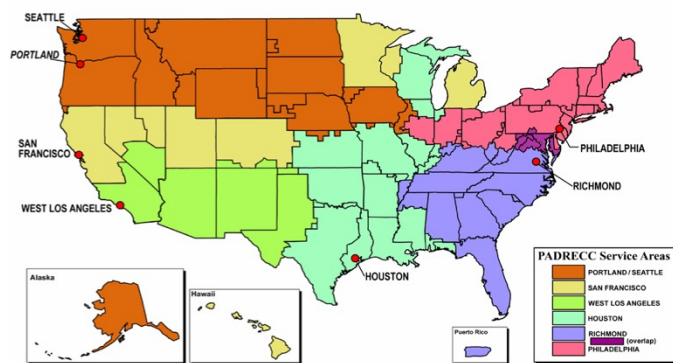


The VA Parkinson Report (Fall 2023) https://www.parkinsons.va.gov/Consortium/VAParkinsonReport_2023_final.pdf
<https://www.parkinsons.va.gov/patients.asp>

Check Your Eligibility for Care!

- Call the Veterans Affairs Toll Free Hotline (877-222-8387)
 - <https://www.va.gov/health-care/eligibility/>
- Contact Your State Veteran's Agency
 - <https://department.va.gov/about/state-departments-of-veterans-affairs-office-locations/>
- Find a Local Accredited VSO
 - <https://www.va.gov/ogc/apps/accreditation/index.asp>
 - Disabled American Veterans (DAV), Veterans of Foreign Wars (VFW), American Legion
- Call Your Local VA Facility – Ask for Central Registration (Phone or In-Person)
 - Need: VA Form 1010EZ, DD214, Insurance Cards including Income and Social Security information
- Need to Get a Copy of DD-214?
 - <https://www.va.gov/records/get-military-service-records/>
 - SF-180 Form

Service Areas for PADRECCs



Veterans Health Administration

<https://www.parkinsons.va.gov/Consortium/index.asp>

<https://www.parkinsons.va.gov/Care.asp>

PADRECC Consortium Hotline 1-800-949-1001 ext: 205769

Eligibility & Care at a PADRECC or Consortium Center

- Veteran must be enrolled in VA Health Care System to receive care
 - <https://www.va.gov/health-care/eligibility/>
- Choose a PADRECC or Consortium Center to receive care:
 - <https://www.parkinsons.va.gov/care.asp>
- VA Primary Care Provider or Neurologist makes a referral to PADRECC or Consortium Center using an Inter-Facility Consult (IFC), or the Veteran can self-refer by calling the PADRECC or Consortium Center directly:
 - PADRECC Consortium Hotline 1-800-949-1001 x205769

Resources for Veterans & Benefits

Out of the Interest of Time....

Please Revisit the Following Webinar:

"Resources for Veterans with Parkinson's" (Gretchen Glen, LCSW)

<https://www.parkinson.org/library/videos/resources-for-veterans>

National Average Costs for Care

- In-Home Personal Care: \$30/hour
 - 7 hr/wk - \$840/mo, 15 hr/wk - \$1800/mo, 30 hr/wk - \$3600/mo, 44 hr/wk - \$5280/mo
- Assisted Living: \$4,807/month
- Memory Care: \$5,995/month
 - Typically an additional \$1,000+ Monthly to Assisted Living Cost
- Long-Term Care in Nursing Home: \$9,584/month (private room)
 - *Semi Private – cheaper option - \$7,756/month

<https://www.aplaceformom.com/caregiver-resources/articles/in-home-care-costs>
<https://www.aplaceformom.com/caregiver-resources/articles/cost-of-memory-care>

Planning & Saving for the Future

- **Genworth:** Financial Solutions for Long Term Care – “Cost of Care Survey”
 - <https://www.genworth.com/aging-and-you/finances/cost-of-care.html/>
 - Each year since 2004, they survey medical providers to gather a database of average regional costs for common LTC expenses
- According to a Forbes (2022) Article, they recommend saving ~3.1 years of the annual cost of a semi-private room for your area by age of 85.



<https://www.forbes.com/sites/davidmarotta/2022/05/31/how-to-self-insure-for-long-term-care-health-expenses-2022/?sh=1fbo6443b538>

Paying for Long-term Care Services

- Long-term Care Insurance
 - *The longer you wait – the more it will cost!
- Apply for State Medicaid (Local County/City Department of Social Services)
- Private Pay
- Eligible for VA Contract Nursing Home Placement
 - 70-100% SC Overall; 60% SC + Unemployability; Some special considerations
 - Must check with local VA Geriatrics CNH Team for evaluation of eligibility
- Eligible for State Veterans Home (Medicaid, Private Pay, Service-Connected 70-100%)

If you are Non-Service Connected or 0% Service-Connected, you will need to complete an updated 1010EC and 1010EZR Form to be considered for any Geriatrics & Extended Care Service

Home Accessibility

- Occupational Therapy Consult/Referral
 - Assessment for Home Safety, Durable Medical Equipment Needs, & Education
 - Floors? Stairs? Carpet/Rugs? Bathroom Size? Shower/Tub? Doorway Width? Split Level?
- Prosthetics Department
 - All equipment is covered if medically justified
 - Ramps, vertical platform lifts, and stair glides/lifts
 - Home Modification Grants <https://www.prosthetics.va.gov/psas/HISA2.asp>
- Assistive Technology <https://www.rehab.va.gov/AssistiveTechnology/index.asp>
 - Wireless Call Bells, Automatic Door Openers, Home Automation Systems (lights, thermostats, TV's)
- VBA Benefits (*recommend speaking with VSO)
 - Disability Housing Grants for Veterans <https://www.va.gov/housing-assistance/disability-housing-grants/>



Modular Front Ramp Installation



Vertical Platform Lift



Stair Glide/Chair Lift

Assess Your Support System

- Do I have a care partner?
 - Do I have a back-up care partner?
 - If I don't have anybody – do I have a plan if you need assistance?
- How many supportive family members/friends do I have?
 - Do they live nearby?
 - Do they work full-time?
 - Do they have their own health issues or limitations?
- If I needed more help...
 - Who would help me?
 - Who would move in with me?
 - Would someone let me move in with them?



Transportation

- VA Beneficiary Travel
 - Based on Income (1010EZ Form)
 - 70-100% Service Connected
- Medicaid
- Some Insurance Plans
 - Humana, Anthem Healthkeepers Plus, etc.
- Local Agencies on Aging
- Local City/County Transit – Senior/Wheelchair Options
- VBA Auto Grant (*recommend speaking with VSO)
 - VA Automobile Allowance & Adaptive Equipment
<https://www.va.gov/disability/eligibility/special-claims/automobile-allowance-adaptive-equipment/>



Telehealth Options



- VA Video Connect Application
- VA-Loaned Device for Appointment Use (if eligible)
- *Fantastic option for connecting with PADRECC providers including your Rehab Therapists!
- If you are having difficulty with you technology before, during, or after appointments – you can contact the Office of Connected Care Help Desk (866-651-3180) for assistance

<https://telehealth.va.gov/>

Home-Based Primary Care

- Provide comprehensive, interdisciplinary, primary care in the homes of veterans with complex medical, social, and behavioral conditions for whom routine clinic-based care is not effective.
- Team includes:
 - Primary Care, Nurse, Social Work, Rehab (OT), Psychology, Nutrition, & Pharmacy
- *Check with Your Local VA or CBOC! (limited to certain mile radius from facility/clinic)
 - Some non-VA medical groups also offer home-based primary care as well



https://www.va.gov/geriatrics/pages/Home_Based_Primary_Care.asp

Skilled Home Health Therapies

- PT, OT, SLP, Nursing, Wound Care, or IV Antibiotics provided by a community-based agency that has a contract with the VA.
- They will bill your Medicare first, unless you specify/request for them to use VA-pay
- Designed to be short-term

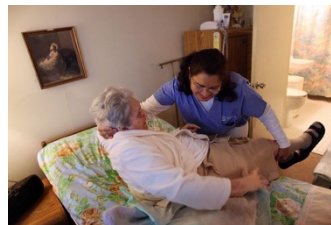


Consults may be requested through your local VA Primary Care Provider, especially if you receive specialty PADRECC care out of the area

https://www.va.gov/GERIATRICS/pages/Skilled_Home_Health_Care.asp

Homemaker/Home Health Aide Program

- Provided by an External Agency, setup by VA (consider potential staffing shortages)
- Personal Care or Assistance With:
 - Eating
 - Dressing
 - Grooming
 - Bathing
 - Toileting
 - Moving from one place to another (mobility)
 - Grocery Shopping
- Ongoing assessment/reassessment completed by your local VA facility.



Consults may be requested through your local VA Primary Care Provider, especially if you receive specialty PADRECC care out of the area

https://www.va.gov/GERIATRICS/pages/Homemaker_and_Home_Health_Aide_Care.asp

Vet-Direct Program

- Not available at all VA's – confirm with your site!
- Personal Care or Assistance With:
 - Eating
 - Dressing
 - Grooming
 - Bathing
 - Toileting
 - Moving from one place to another (mobility)
 - Grocery Shopping
- Eligibility may differ from H/HHA Program (above)
- Hire Aides/Workers through spending plan – requires more coordination on your end, but more autonomy to hand-select caregivers you'd prefer for veteran.



Consults may be requested through your local VA Primary Care Provider, especially if you receive specialty PADRECC care out of the area

https://www.va.gov/GERIATRICS/pages/Veteran-Directed_Care.asp

Palliative & Hospice Care

- **Palliative Care**

- *Our PADRECC has a Palliative NP embedded within our Clinic
- ALL enrolled veterans are eligible if they meet clinical need for service
- IDT – MD/NP, SW, Nurse, Chaplain, Psychology, Other Staff PRN
- Address physical symptoms, family coping, emotional or spiritual distress, and access to needed resources.
- In-Person, Phone, or Virtual Appointments

- **Hospice Care**

- Terminal condition with less than 6 months to live
- ALL enrolled veterans are eligible if they meet clinical need for service
- There are NO copayments for Hospice Care, whether it is provided by VA or an agency contracted with VA
- Provided at Home (VA-Pay vs. Medicare by Community Agency), CNH placement, or CLC Hospice Unit (depending on local VA facility)

https://www.va.gov/GERIATRICS/pages/Palliative_Care.asp

https://www.va.gov/GERIATRICS/pages/Hospice_Care.asp

Respite Care



- For veterans who need help with activities of daily living, isolated, or caregiver is experiencing caregiver burden.
- Can be used in combination with other Home & Community Based Services
- **In-Home Respite**
 - Needs help with ADL's, veteran is isolated, caregiver is experiencing burden
 - Usually in addition to H/HHA Program Hours (add on to provide relief)
 - Weekly benefit
- **Nursing Home Respite**
 - Available for maximum of 30 days per calendar year and subject to availability
 - Contract Nursing Home vs. Community Living Center @ VA (will need to verify with local VA facility if CLC is available)

https://www.va.gov/geriatrics/pages/Respite_Care.asp

Community Adult Day Health Care

- Provide elderly or disabled veterans therapeutically-focused care during daytime hours that include:
 - Meals, ADL-care, safety supervision, individual & group activities, medical monitoring, and [socialization](#).
- Goal to age in place and avoid nursing home placement
- Good option for respite care for caregivers
- *Please contact your local VA for a list of current Adult Day Health Care facilities, please note some of these include roundtrip transportation

https://www.va.gov/geriatrics/pages/Adult_Day_Health_Care.asp

Program of General Caregiver Support

- Provides training, education, respite care, and mental health services
- Open to all eras
- Caregivers must provide unpaid personal care to any veteran with at least 1 ADL or requires supervision/protection due to cognitive impairment
- No application required
- Intake/assessments are completed to ensure eligibility

https://www.caregiver.va.gov/Care_Caregivers.asp



VA Caregiver Support Line
1-855-260-3274 (toll-free)

Monday – Friday, 8 a.m. – 10 p.m. ET
Saturday, 8 a.m. – 5 p.m. ET

Program of Comprehensive Assistance for Family Caregivers (PCAFC)

- Provides education, training, enhanced respite care, mental health counseling, travel for veteran's appointments, monthly stipend, access to healthcare through CHAMPVA if eligible, and financial planning and legal resources for primary family caregivers.
 - Must have 70% SC rating or higher (single or combined).
- Veteran must need in-person personal care for minimum of 6 continuous months based on any one of the following:
 - An inability to perform an activity of daily living;
 - A need for supervision/protection based on symptoms or residuals of neurological or other impairment/injury; or
 - A need for regular or extensive instruction or supervision without which the ability of the Veteran to function in daily life would be seriously impaired

*For the FASTEST route, complete application online <http://www.caregiver.va.gov>

*Otherwise, complete VA 1010CG Form (<https://www.va.gov/vaforms/medical/pdf/10-10CG.pdf>) and submit to local VA facility's Caregiver Support Program Office. If you have trouble locating them, you can call the Helpline # located on previous slide

*Please Note – Enrollment in PCAFC will impact H/HHA and Vet-Direct Program hours/enrollment

Community Residential Care (CRC)

- For veterans who do not need hospital or NH care, but cannot live alone due to medical or psychiatric conditions and have no support person who can provide monitoring, supervision or help with activities of daily living.
- Settings include:
 - Assisted Living facilities, Personal Care Homes, Family Care Homes, Group Living Homes, and Psychiatric Community Residential Care Homes. Inspected/Approved by local VA staff, but are chosen by the veteran.
- VA does NOT provide financial assistance, veteran is responsible for covering the cost of housing (VA compensation, VA pension, Social Security, other retirement/income sources).
- Provides room, board, limited personal care, and supervision – may also include psychiatric care, primary care, medication supervision, and self-care supervision.

https://www.va.gov/geriatrics/docs/Community_Residential

Medical Foster Homes (MFH)

- Affordable private-pay care alternative in an intimate residential setting with familiar caregivers at less than half the cost of nursing home care.
- Safe, clean, and supportive care residence with home-cooked nutritious meals, leisure activities programming, ADL-care, medication dispensing
- VA-Team support:
 - Monitoring, case management, home medical care, and oversight including inspections and unannounced visits
- Level of functioning is AT or NEAR requiring nursing home level of care
- Stable monthly income of at least \$2400/month – Not paid for by VA
- *Many VA facilities are in various stages of development of their own programs, please contact your local VA facility to inquire if you are interested

https://www.va.gov/GERIATRICS/pages/Medical_Foster_Homes.asp

Adult Family Homes

- Private homes where residents (6 or less) rent rooms
- Shared common spaces, possible shared bedrooms/bathrooms
- Trained caregiver on duty 24/7 to help with daily activities
 - If care needs exceed what home can provide, may request Homemaker/Home Health Aide Consult for additional personal care support
- VA does NOT pay for veteran's rent
- Good option for veterans with limited support system or limited support system in the immediate area that can provide physical support/supervision
- *Please contact your local VA for a list of updated VA Adult Group/Family Homes

https://www.va.gov/GERIATRICS/pages/Adult_Family_Homes.asp

Assisted Living & Memory Care

- Assisted Living
 - Rented room/apartment with shared living spaces (dining area), some apartments have their own kitchen.
 - Trained caregiver on duty 24/7 – staff can help with daily activities (bathing, dressing), medications, some nursing assistance, meals, and planned recreational/social activities.
 - If veteran requires more care than facility can provide, they may request a Personal Care Aide or for veteran to be transferred to higher level of care.
 - VA does NOT pay for veteran's rent
- Memory Care
 - Some, but not all Assisted Living's may include a Memory Care unit
 - Locked units for improved safety – dementia, wandering, sundowning, confusion
 - Typically ore expensive than Assisted Living (approximately an extra \$1,000/month)

https://www.va.gov/GERIATRICS/pages/Assisted_Living.asp

*A Place For Mom: Free Service <https://www.aplaceformom.com/>

Continuing Care Retirement Communities (CCRC's)

- *Not available through VA – but another option to consider
- Big investment with access to future higher levels of care if needed
- Typically includes:
 - Independent Living – Assisted Living – Memory Care – Health Care (Rehab & Long-Term)
- Opportunity to still age in place with a sense of stability, familiarity, and socialization

<https://www.care.com/c/continuing-care-retirement-community-cost/>

[Continuing Care Retirement Community Costs | Vi Living](#)

[Learn About Continuing Care Retirement Communities \(aarp.org\)](#)



Contract Nursing Homes (CNH)

- Local VA Contract Nursing Home (CNH) Team provides oversight to CNH facilities to ensure veterans receive care and services they are entitled to for Short-Term Rehab or Long-term Care Placement.
- Administrative Eligibility:
 - 70-100% Service-Connected
 - 60% Service Connected + Unemployability
 - Some veterans may be eligible for placement if they require placement due to a Service-Connected Condition that is less than 70%, but would need to be evaluated/verified/approved by the CNH team at their local facility.
 - All veterans are entitled to Inpatient Hospice with/without meeting administrative criteria (above).
- Clinical Eligibility:
 - Need assistance with 3+ activities of daily living (cannot be independent in need of housing)
- *Please contact your local VA for a list of updated CNH placements, as these update frequently

https://www.va.gov/GERIATRICAL/pages/Community_Nursing_Homes.asp

State Veterans Homes

- Nursing facilities that are owned, operated, and managed by State Governments
- Payor Sources for Long-Term Care
 - Service-Connected Rating of 70-100% or 60% + Unemployability
 - Medicaid
 - Private Pay
- Short-Term Skilled Rehab (SNF) typically available, check with your local facility



Sitter & Barfoot State Veterans Home
(Richmond, VA)

Roanoke, VA
Virginia Beach, VA (coming soon)
Fauquier County, VA (under construction)

https://www.va.gov/geriatrics/pages/State_Veterans_Homes.asp

Nursing Homes



- Accepts Medicaid, Private Pay, or LTC Insurance Policy
- Facility is NOT restricted to list of contracted facilities with the VA
- Recommend searching on Medicare Website to start your search, then schedule tours in-person, speak with admissions staff, and speak with other individuals you know about experiences with other facilities.
- <https://www.medicare.gov/care-compare/?providerType=NursingHome>

VA Forms

- If you are **Non-Service Connected** or **0% Service-Connected**, you will need to complete an updated 1010EC and 1010EZR Form to be considered for any **Geriatrics & Extended Care Services** including:
 - Homemaker/Home Health Aide
 - Vet-Direct Program
 - Contract Adult Day Health (CADHC)
 - Community Residential Care (CRC)
 - Medical Foster Home (MFH)
 - Respite
 - Contract Nursing Home (CNH)
- VA 1010EZR <https://www.va.gov/vaforms/medical/pdf/va%20form%2010-10ezr.pdf>
- VA 1010EC https://va.gov/vaforms/medical/pdf/VA_Form_10-10EC.pdf

Contact Your Local VA

- Ask Your Primary Care Clinic for the Social Worker's Name/Contact Information – or a Referral!
- Ask Your Movement Disorder Specialist or Neurologist for the Social Worker's Name/Contact Information – or a Referral!



Take-Away Points

- Be honest with your provider – the Good & the Bad!
 - If things aren't work – treatment plans may change, time to explore other options and THAT IS OKAY!
- What does Quality of Life mean to you? What Matters most to you?
- Palliative Care is not the same as Hospice Care
- Palliative Care aims to discuss goals of care, advance care planning, assess motor/non-motor symptoms, address psychosocial concerns, caregiver burden, anticipatory guidance, chronic symptom management, and COMPLEMENTS but does not replace your team of providers.
- Palliative Care is for ALL disease stages in PD – please consider requesting a referral from your Movement Disorder Specialist to start the conversation!
- Advance Care Planning is for everyone!
- Start assessing your resources, supports, and long-term plans (back-up plans)
- Speak with a VSO/Veterans Services to see:
 - If you are eligible for care
 - To file a Service Connected Disability Compensation Claim
 - To explore any other benefits

Emily Hall, LCSW

Southeast PADRECC

Central Virginia Veterans Affairs Healthcare System

Richmond, Virginia

Clinic: 804-675-5931

Emily.hall6@va.gov

Work Cell: 804-924-4663

VA



U.S. Department of Veterans Affairs

Veterans Health Administration
Parkinson's Disease Research,
Education & Clinical Centers

Resources (1)

- <https://www.parkinson.org/living-with-parkinsons/care-programs/palliative-care#:~:text=Also%20known%20as%20supportive%20care%2C%20is%20a%20care%20approach%20that,social%2C%20spiritual%20and%20other%20challenges>
- <https://www.palliativecareservices.org/three-c-palliative.php>
- <https://www.verywellhealth.com/advanced-parkinsons-disease-5200544>
- Parkinson's Disease and Related Disorders. Education in Palliative and End-of-Life Care – Neurology (EPEC-N) and the International Neuropalliative Care Society (INPCS). <https://www.inpcs.org/i4a/pages/index.cfm?pageid=3332>. Published 2022. Accessed September 30, 2022.
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- 1. Kam-Mei Lau MPhil & Alma Au PhD (2011) Correlates of Informal Caregiver Distress in Parkinson's Disease: A Meta-Analysis, *Clinical Gerontologist*, 34(2), 117-131, DOI:
- 2. Saleem, T. Z., Higginson, I. J., Chaudhuri, K. R., Martin, A., Burman, R., & Leigh, P. N. (2013). Symptom prevalence, severity and palliative care needs assessment using the Palliative Outcome Scale: a cross-sectional study of patients with Parkinson's disease and related neurological conditions. *Palliative medicine*, 27(8), 722–731.
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Resources (2)

- <https://medicinetoday.com.au/mt/2023/january/feature-article/advanced-parkinsons-disease-clinical-challenge#subscribe>
- <https://www.ariadnelabs.org/2021/11/16/what-matters-to-me-workbook/>
- <https://www.samaritannj.org/hospice-blog-and-events/hospice-palliative-care-blog/palliative-care-myths-misconceptions/>
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Resources (3)

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- <https://www.forbes.com/sites/davidmarotta/2022/05/31/how-to-self-insure-for-long-term-care-health-expenses-2022/?sh=1fbo6443b538>
- <https://www.genworth.com/aging-and-you/finances/cost-of-care.html/>

Q & A #2

5:15-5:30PM EST



Upcoming Veterans Webinars			
June 29	August 31	October 26	December 14
 Resources for Veterans with Parkinson's	 Veterans & Parkinson's: Managing Anxiety, Depression, & Apathy	 Veterans & Parkinson's: Planning for the Future	Environmental Exposures in Veterans with Parkinson's
Learn more and register to attend at: www.Parkinson.org/Veterans			
Better Lives. Together.			

Care Partner Summits



Conversations & Connections For Caregiving

5 Regional In-person Events

Saturday, November 4th

- Northeast: Cherry Hill, NJ
- Southeast: Atlanta, GA
- Great Plains: Dallas, TX
- Midwest: Twin Cities, MN
- West: Bay Area, CA

National Webinar

Saturday, November 11th

- Streamed live and recorded
- Nearly 2,000 registrations

Register at Parkinson.org/Summit

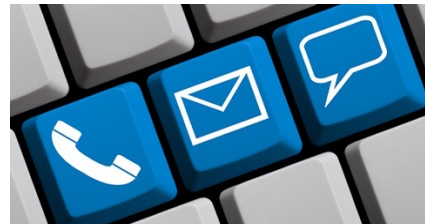


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