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# Home-Based Primary Care: An Essential Lifeline for Caregivers of Home-Limited, Medically Complex Patients

## Do you have a loved one who – due to serious illness or complex medical condition(s) – rarely or never leaves their home? Or if they do leave their home on occasion, can only do so with considerable assistance?

It's estimated that more than 7 million older adults in the U.S. are homebound or home-limited (nearly homebound), relying on in-home caregivers (usually family members) to assist with their day-to-day needs and general care. In these cases, it's often extremely difficult – if not impossible – for these medically complex patients to access primary care services in a traditional office or clinic setting, which only adds to their caregiver's burden.

## In-Home Caregivers: The Unsung Heroes

- The demands on in-home caregivers can be significant, as homebound, frail elders require a high level of care – everything from changing and maintaining feeding and tracheostomy tubes, monitoring vital signs, and administering medications – to basics such as skin and wound care, and ordering supplies.
- The role of an in-home caregiver for a medically complex patient blends high-level nursing-type care and administrative skills with personal, intimate knowledge of the patient and their holistic needs.
- Whether a caregiver is a paid worker or a family member, their availability to provide safe, compassionate in-home care is what makes it possible for many older adults to age in place and maintain some degree of independence in the place they call "home."

## Home-Based Primary Care (HBPC) Supports Patients and Caregivers

### What is HBPC?

- HBPC provides in-home primary medical care, typically ongoing, to medically complex patients for whom office visits are either difficult or impossible.
- Also known as the "modern-day house call," HBPC is exactly what it sounds like – physicians, nurse practitioners, and physician assistants travel to a patient's home, or place they call "home," to deliver primary care services.
- HBPC providers typically function as part of an interdisciplinary team to manage both medical and non-medical needs (e.g., social factors, environmental needs).

### How does HBPC help?

- HBPC has been proven to improve health outcomes, enhance the quality of life for patients and caregivers, and reduce the total cost of care by preventing unnecessary emergency room visits and hospitalizations.
- HBPC can also help caregivers by eliminating the stress and time involved with transporting the patient for primary care visits while still receiving support and guidance on managing the patient's complex medical and social needs.


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### What types of services does HBPC provide?

- By providing medically complex patients the same services they would receive in a primary care office, HBPC is different from other types of in-home care, such as home health care. HBPC visits can include:
  - Routine medical care and management of chronic diseases
  - Annual wellness visits
  - Addressing urgent medical needs
  - Vaccinations
  - Management of cognitive and neurological disorders
  - Advance care planning (e.g., goals of care conversations, end-of-life preferences)
  - Wound care and other procedures
  - Care coordination with community services and other healthcare providers, including specialists in psychiatry, podiatry, optometry, dentistry, and more
  - Coordination of diagnostic testing (e.g., blood tests, EKGs, ultrasounds, x-rays)
  - Medical visits at assisted living facilities, group homes, foster care homes, and similar settings
  - Caregiver support and guidance on managing the patient's complex medical and social needs

### Is HBPC covered by insurance?

- For Medicare beneficiaries, services delivered by the HBPC provider are covered under the same Medicare benefits that apply when seeing a provider for an office visit, i.e., Medicare covers 80% while the remaining 20% is subject to deductibles and copays.
- Certain Managed Care or Health Maintenance Organization (HMO) health insurance plans may require a referral or for the HBPC provider to be selected as the primary care provider. An HBPC Practice in your area can answer specific questions regarding coverage.

## Consider if Home-Based Primary Care (HBPC) is the Right Solution for Your Loved One(s)

### Is HBPC right for someone you care for?

- Patients do not need to be formally considered "homebound" to qualify for HBPC.
- Some examples of when HBPC might be in a patient's best interests:
  - The patient has difficulty leaving the home due to medical conditions such as dementia or physical mobility limitations
  - The patient requires medical devices or special assistance/transportation accommodations to leave the home
  - Leaving the home can adversely affect the patient's physical and/or mental health
  - Caregivers and/or other family members are not available or able to transport the patient
  - Patients transitioning from one healthcare setting to another need assistance with "bridging a primary care gap"

### Where should you start?

- If HBPC seems like a good fit for someone you care for, you can discuss it with the patient's primary healthcare provider or healthcare system. They may be able to refer you to an HBPC provider.
- The following "conversation starters" may help during that discussion:
  - *Leaving the home is very difficult for the person I care for and prevents them from coming to see you as often as needed. What are the options for their receiving primary medical care at home?*


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- *The patient's medication refills are out. It's been more than a year since they last visited the clinic, and I am unable to get them there due to their medical condition(s).*
- *Can you recommend or refer me to a home-based primary care provider so that I can help the person I care for receive the primary medical care they need at home?*

### What other in-home services are available besides HBPC?

- *Skilled home health services* provide in-home nursing, physical therapy, occupational therapy, or other support services under the direction of a primary care provider. These services are covered by Medicare when the patient is deemed "homebound" and is certified to have a skilled need by a provider.
- *Concierge healthcare* is a subscription-based program that guarantees access to medical professionals 24/7.
- *Hospital at Home*® provides safe, high-quality, hospital-level care to older adults in the comfort of their own homes. Contact your local hospital/health system or health plan to inquire about availability. Learn more at https://www.hospitalathome.org/
- *Palliative care* is team-based consultative care focused on symptom management and advance care planning.
- *Hospice care* is non-curative support focused on providing comfort and end-of-life care when a patient is diagnosed with a terminal illness.

## What You Can Expect with Home-Based Primary Care (HBPC)

### Caregivers are an essential part of the care team.

- The HBPC provider (together with an HBPC practice team, if applicable) is typically the primary resource for the caregiver and patient, including planning and coordinating care with specialists, home health, and other community resources.
- Caregivers serve as patient advocates; they are often in the best position to describe the patient and their needs, and the daily challenges the patient may be facing in their home environment. Therefore, they need to remain in close communication with the HBPC team and play a key role in determining a care plan best aligned with the patient's wishes.
- In addition to providing medical care and answering clinical questions, your HBPC provider and practice team can provide patient and caregiver education, conduct regular checkups, coordinate bloodwork and other labs, and so forth.
- Your HBPC practice team can also help with obtaining insurance approvals or providing guidance on available coverage options, as well as connecting the caregiver to other providers, as needed.

### Help is available for navigating Durable Medical Equipment (DME).

- Home-limited and homebound patients often need medical equipment and supplies known as "Durable Medical Equipment" or "DME" from different suppliers (e.g., wheelchairs or motorized scooters, hospital beds, walkers, home oxygen).
- Your HBPC practice team will explain which DME will be covered through insurance and/or which DME will require purchase as an out-of-pocket expense.
- Ordering DME can be a complex process, and caregivers are encouraged to advocate on behalf of the patient as needed, and keep track of company names, phone numbers, order status and anticipated delivery.


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### Connecting with community services is worthwhile.

- In addition to addressing the patient's primary medical needs, you may need community resources or social support. Check out the following resources to locate community programs and social services in your area:
  - *Eldercare locator* to find your local Area Agency on Aging – https://eldercare.acl.gov/Public/About/Aging_Network/AAA.aspx
  - *The Aunt Bertha network* connects people seeking help and verified social care providers – https://company.auntbertha.com
  - *The National Care Planning Council* helps families recognize the need for, and implement, long-term care planning – https://www.longtermcarelink.net/eldercare/ref_state_aging_services.htm
  - *The U.S. Department of Health and Human Services (HHS)* provides a collection of resources by state for older adults and caregivers – https://www.hhs.gov/aging/state-resources/index.html
- If you or someone you care for is receiving skilled home health or hospice services, you can also ask your home health or hospice agency social worker about additional community resources.

## Important Tips for Caregivers

- The level of care required by the patient will dictate how much of your time and energy will be needed on an ongoing basis. Taking care of someone confined to a bed is typically more time- and energy-consuming than caring for someone more mobile.
- You learn by doing. When you first begin caregiving, there will be many things you need to learn. Be easy on yourself. Ask for help and ask as many questions as necessary so you feel comfortable.
- Have individual calendars for the patient and yourself to make it easier to remember if someone is coming over, when to order supplies, when appointments are (both the patient's and yours), and so on.
- Reach out for counseling/mental health support for the patient and, as needed, yourself – to help with issues like anxiety, depression, loneliness and stress.
- Arrange for support from family members, friends, and other caregivers. If you do rely on someone else, document all the processes/schedules you follow for the patient and make sure the person supporting you knows how to do it all. You can also let them know they can call you with questions and in an emergency. This will allow you to confidently take a much-needed break from caregiving.
- Remember to practice self-care. If you don't take time for yourself, you won't be able to provide the best care for the person you are caring for. Know there are options available such as respite care, to give you a break when needed. Learn more at https://www.nia.nih.gov/health/what-respite-care.
- Stay in regular contact with family and friends by phone, online and, when possible, in person. Consider joining caregiver support groups online and in-person. Having a pet in the home can also provide companionship for you and the patient.
- Reenergize and refresh by taking part in physical activities (e.g., walking outside, using a treadmill or indoor bike) or going on small trips (while ensuring that another caregiver is available).

### *Be sure to check out the government programs available for caregivers.*

- Many government programs allow family members of veterans and people with disabilities to get paid for caring for them. The Medicaid Self-Directed Care program lets qualified people manage their own health services. It also lets them hire family members as caregivers in some states. For more information on getting paid as a caregiver for a family member, go here: http://bit.ly/USA_caregiver_support.
- A Federal Savings Account (FSA) for dependents is available for adult dependents and children. It is a pre-tax saving account (usually offered through an employer) that may also be available for family members caring for adult dependents to help with costs such as adult day programs. More information on dependent care FSAs is available at https://fsastore.com/learn/eligibility/elderly-dependent-care-fsa.


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**From a caregiver**

*"Home-based primary care is a very personal experience. It makes the patient feel special and the patient and caregiver more comfortable. It's so much easier to have the provider come to you, where you don't have to get the patient out of bed and arrange for transportation. Plus, it helps you remember that, though the patient may be diminished in their capacities, that does not mean you only need to see the loss in the situation. There are still many joys to be found."*

– Long-time caregiver for a homebound patient

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The Home Centered Care Institute is a national nonprofit organization focused on scaling home-based primary care and bringing it into the healthcare mainstream.

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