

COMMUNITY RESOURCES FOR PATIENTS AND CAREGIVERS

Yes, it is your job to supply patients and caregivers with resources, even if they are assigned a Case Manager. Be sure to document any resources provided in the medical record. Keep this on your computer for easy access and printing.

******REMEMBER******

Some of the references on this page lead you to the American Association of Retired Persons (AARP). **HOWEVER, our clients often fit into the resources for older adults, even if not over 50** due to the mental illness itself or developmental condition. This includes low-income housing, senior housing, and other entitlements.

Some Things You Might Not Know: But Should

--Did you know that Medicare alone does NOT cover nursing home care? It covers some but not room and board, which may be about \$5,000 a month.

--Did you know that Hospice usually doesn't cover room and board, which can be about \$7,000-\$8,000 a month?

--Did you know that Medicaid covers nursing home and hospice care?

--Did you know that your patient usually has to have, a three-day hospital stay, before going to a nursing home? You cannot just send someone to a nursing home. If the person is sent to the ER, or admitted to the hospital, you have to work with the medical provider and “**hospital discharge planner**” to facilitate nursing home placement **or** short-term care for rehabilitation, until able to return home. If you work with patients who go to the ER and cannot take care of him or herself at home, you might have to intervene. Otherwise, the person will be sent home. Home Healthcare doesn't provide 24/7 care. **Please protect your patients from going to the ER, and being sent home while still ill, and not able to care for**

him or herself. A nursing home stay for rehabilitation post-hospitalization, allows an assessment to take place to get services in the home, allows the person to get stronger and healthier to return home or, proof of the need to remain in a nursing home.

Medicare Home Health Benefits: What Caregiving Costs Are Covered: Financial and Legal <https://www.aarp.org/caregiving/financial-legal/info-2019/medicare-home-health-care-benefits.html?intcmp=AE-CAR-LEG-EOA1>

Medic Alert Proof of Hardship Form:

20150227-Sponsored_Form.pdf (medicalert.org) **I recommend that your clients who are homeless, have diabetes/seizures, or are cognitively impaired get a medic alert. This is the proof of hardship form for low-income people.**

Caption Call: “CaptionCall phones are optimized for individuals with hearing loss. The unit uses voice-to-text technology, assisted by captioning agents and automated speech recognition, to transcribe your conversation so that other speakers’ words appear on your CaptionCall screen. CaptionCall is federally funded as part of Title IV of the Americans with Disabilities Act (ADA), so there’s no cost for qualifying individuals.” FREE!!!!!!
<https://captioncall.com>

AARP Resources for Caregivers and their Families This website can help guide you on a multitude of issues to consider when a loved one needs care.

AARP Resource line: 1-877-333-5885

YOUR KINDESS IS APPRECIATED: Medicaid Only

I always ask caregivers, if he or she is getting paid to help my patient who has a mental illness or developmental condition. If not, then I take action. So many people are thankful and could have used the caregiving money years ago. **It is sad that other mental health staff didn’t know about this program, or failed to initiate it.**

I fill out a DHS form from my state's Department of Health and Human Services, that I keep on my computer, should a loved one be caring for a severely mentally ill patient of mine. I have the person take the form to the local DHS office and they will assign a caregiver **or** pay the loved one to do it (if the family member in Michigan is disabled, they cannot be a caregiver for someone in the home who is disabled). The form may be called, "chore provider" or have other similar names. You MAY want to get a Release of Information for the DHS office, in case they need information faxed to them, elaborating on the mental illness and severity of such.

I also fill out the form for the MEDICAL PROVIDER if a **medical condition** is a reason, as opposed to the mental illness. This way the caregiver can take the form to the MEDICAL PROVIDER, and have them sign it. Then, take it to the DHS office. If proof of a bad back, need of insulin, etc., is needed, then the medical provider just has to sign the paper. If I can justify for psychiatric reasons, I do the form myself and sign it. **More information below:**

For Medicaid recipients How to Receive Pay when Becoming a Family Caregiver (aarp.org)

"All 50 states and the District of Columbia offer self-directed Medicaid services for long-term care. These programs let states grant waivers that allow qualified individuals to manage their own long-term home-care services, as an alternative to the traditional model where services are managed by an agency. In some states, that can include hiring a family member to provide care.

Benefits, coverage, eligibility, and rules differ from state to state. Some programs pay family caregivers but exclude spouses and legal guardians. Others will pay care providers only if they do not live in the same house as the care recipient.

Program names also vary. What is called Consumer Directed Care in one state might be called Participant-Directed Services, In-Home Supportive Services, or Cash and Counseling in another. Contact your state Medicaid program to ask about its options or to start the sign-up process.

Enrolling in self-directed care involves the following steps:

- Assessment.** *Your loved one—with assistance if desired or needed—is assessed for capacities, need, preferences, risks, and strength as the Centers for Medicare & Medicaid Services requires.*
- Planning.** *Your family member and any chosen representatives create a written service plan detailing the daily living assistance required. Areas may include bathing, dressing, feeding, helping with light housekeeping and laundry, managing medications, moving from bed to wheelchair, preparing meals, shopping, supervising activities, and transporting to appointments. Contingency plans should be available for coverage when the care provider is off and instructions for fill-in caregivers should address risks.*
- Budgeting.** *If the assessment shows need, a budget for goods and services will be provided.*
- Selection.** *When the care plan is set, the care recipient, or a surrogate if needed, chooses a caregiver.”*

Caregiver.com:

6 Things to Remember as You Start to Care for Your Parents, Bathroom Safety, Caregiver 101, to name a few of the helpful and supportive information provided on this website.

Caregiver Rush Initiative: <https://aging.rush.edu/caregiverinitiative/>
Family Caregiver Alliance: <https://www.caregiver.org/caregiver-resources/all-resources/>

National Alliance for Caregiving at www.caregiving.org

Caregiver Action Network at www.caregiveraction.org

Well Spouse Association at www.wellspouse.org

“The Well Spouse® Association, a nonprofit 501(c)(3) membership organization, advocates for and addresses the needs of individuals caring for a chronically ill and/or disabled spouse or partner. We offer peer support and educate health care professionals and the general public about the special challenges and unique issues "well" spouses face every day.”

ARCH National Respite Network and Resource Center at www.arch-respite.org/home

National Alliance on Mental Illness (NAMI) What We Do: This site provides resources for people with mental illness and caregivers.
<https://www.nami.org>

National Family Caregiver Support Program

<https://www.acl.gov/programs/support-caregivers/national-family-caregiver-support-program>

“The National Family Caregiver Support Program (NFCSP), established in 2000, provides grants to states and territories based on their share of the population aged 70 and over to fund a range of supports that assist family and informal caregivers to care for their loved ones at home for as long as possible.”

Eldercare Locator

www.eldercare.acl.gov

“Are you a family caregiver in need of information or assistance? Are you interested in learning more about the programs and services that may be of assistance to you or your loved one? The Eldercare Locator, a public service of the US Administration on Aging, is the first step to finding resources for older adults in any US community. Just one phone call or website visit provides an instant connection to resources that enable older persons to live independently in their communities. The service links those who need assistance with state and local area agencies on aging and community-based organizations that serve older adults and their caregivers.”

Caregiver Action Network

<http://www.caregiveraction.org/>

“Resources from the Caregiver Action Network, including a Peer Forum, a Story Sharing platform, the Family Caregiver Tool Box and

more. CAN also provides support for rare disease caregivers at”:
<http://www.rarecaregivers.org>

US Food and Drug Administration, Office of Women’s Health Tips for Caregivers

“FDA Office of Women’s Health understands caring for someone can be rewarding, but challenging. FDA’s Tips for Caregivers website provides tools to help caregivers manage the care of their loved ones. The website provides tips for caregivers of older adults, young children, teens, and people with special needs. The website also highlights seven tips for all caregivers to know. FDA Office of Women’s Health also provides information on women and clinical trials.” To learn more, visit: fda.gov/womeninclinicaltrials

Next Step in Care <http://www.nextstepincare.org>

“Next Step in Care provides easy-to-use guides to help family caregivers and health care providers work closely together to plan and implement safe and smooth transitions for chronically or seriously ill patients.”

Financial Steps for Caregivers

WISER (Women’s Institute for a Secure Retirement)

“Financial Steps for Caregivers: What You Need to Know About Money and Retirement is designed to help you identify financial decisions you may face as a caregiver. The decision to become a caregiver can affect both your short-term and long-term financial security, including your own retirement.” For more information on planning for a secure retirement, please visit <http://www.wiserwomen.org>.

Alzheimer’s & Dementia Caregiving Alzheimer’s Association

“The Alzheimer’s Association works on a global, national, and local level to provide care and support for all those affected by Alzheimer’s and other dementias. They offer help through a professionally staffed 24/7 Helpline (1.800.272.3900), face-to-face support groups and educational sessions in communities nationwide, and comprehensive online resources and information through the Alzheimer’s and Dementia Caregiver Center.”

Alzheimer's Foundation of America

"The Alzheimer's Foundation of America offers a national, toll-free helpline (866-232-8484) staffed by licensed social workers, educational materials, a free quarterly magazine for caregivers and "AFA Partners in Care" dementia care training for healthcare professionals." For more information about AFA, call 866-232-8484, visit www.alzfdn.org.

The Association for Frontotemporal Degeneration (AFTD)

"AFTD promotes and funds research into finding the cause, therapies, and cures for frontotemporal degeneration. They also offer information, education, and support to persons diagnosed with an FTD disorder, and for their families and caregivers." To learn more about AFTD, visit www.theaftd.org.

The Lewy Body Dementia Association (LBDA)

"LBDA works to raise awareness of Lewy body dementias (LBD), promoting scientific advances, and supporting people with LBD, their families, and caregivers. LBD is a complex disease that can present a range of physical, cognitive, and behavioral symptoms. It dramatically affects an estimated 1.4 million individuals and their families in the United States." To learn more, visit www.lbda.org.

Alzheimers.gov – For the People Helping People with Alzheimer's

"Resources from the Administration for Community Living on Alzheimer's disease and other forms of dementia" www.alzheimers.gov

National Institute on Aging: Alzheimer's Disease Education and Referral Center at <https://www.nia.nih.gov/health/alzheimers>

"Resources from the National Institutes of Health on Alzheimer's disease and other forms of dementia, including information on clinical trials and current advances in scientific research."

US Department of Veterans Affairs: Dementia Care (including Alzheimer's)

"For those caring for a Veteran, resources on dementia care through the

VA and information on new research on dementia in Veterans.”

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

Cancer Caregiving

National Cancer Institute

<https://www.cancer.gov/about-cancer/coping/family-friends/family-caregivers-pdq>

“Family caregivers may be spouses, partners, children, relatives, or friends who help the patient with activities of daily living and health care needs at home. Many cancer patients today receive part of their care at home. Hospital stays are shorter than they used to be, and there are now more treatments that don’t need an overnight hospital stay or can be given outside of the hospital. People with cancer are living longer and many patients want to be cared for at home as much as possible. It is important that the family caregiver is a part of the team right from the start. These resources are about adult family caregivers in cancer.”

Cancer Experience Registry – Caregiver

“The Cancer Experience Registry is a unique online community that allows people facing cancer to share their experiences, identify the issues that impact their lives, take surveys, access resources, and learn from each other. It is free, confidential, and open to anyone who has been diagnosed with cancer or provides care to a cancer patient.”

Cancer Support Community Helpline: 1-888-793-9355 or to chat live at www.cancersupportcommunity.org

“The Cancer Support Community Helpline provides emotional and educational services for all people affected by cancer and their family caregivers.”

Cancer Support Community Affiliates & Support Groups for Caregivers

“The Cancer Support Community Affiliate Network consists of 44 licensed affiliates, 170 locations and a growing number of healthcare partnerships.”

<https://www.cancersupportcommunity.org/find-location-near-you>

American Cancer Society – Caregivers Page

“A cancer diagnosis affects close friends and family too. Find out what to expect if you become a caregiver for a person with cancer, and get tips for making sure that you take care of yourself as well. Resources available include information and support on How to Care for Someone with Cancer, Taking Care of Yourself as a Caregiver, How to Be Supportive to Someone with Cancer, When Your Child has Cancer, and a list of American Cancer Society Support Services and Programs for families who are managing cancer.”

<https://www.cancer.org/treatment/caregivers.html>

Help for Cancer Caregivers

<https://www.helpforcancercaregivers.org/>

“A collaboration of Anthem, Inc., CancerCare, Caregiver Action Network, Indiana University and Michigan State University, this website provides resources and news on caregiver caregiving.”

Caregiving for Persons with Disabilities, Rare Disease

- ALS (Amyotrophic Lateral Sclerosis) Association
- Autism Society of America
- Autism Speaks
- Brain Injury Association of America
- Easter Seals
- Epilepsy Foundation
- Global Genes
- Muscular Dystrophy Association
- ALS (Amyotrophic Lateral Sclerosis) Association
- National Alliance on Mental Illness (NAMI)
- National Down Syndrome Society
- National MS Society
- National Organization for Rare Disorders (NORD)
- The Arc
- United Cerebral Palsy
- http://webstl.alsa.org/site/PageNavigator/STL_8b_caregivers.html.

Yes, it is your job to help people with the above information, even if you are not a Case Manager.

Keep this page on your computer so you can download it easily for your patients, other mental health professionals, family members and caregivers.

Dr. Kelly Gardiner PhD, PMHNP, CNS, BC

Go to www.drkellygardiner.com for more information and free handouts.