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**INDEPENDENT
LIVING**

A GUIDE FOR CARE PARTNERS OF
PEOPLE LIVING WITH SCHIZOPHRENIA



HELP YOUR LOVED ONE TAKE STEPS TOWARD INDEPENDENCE

Caring for someone living with schizophrenia can be demanding, especially when you're working toward helping them live more independently. That's why we're here—to help you help them.

Independent living means something different for everyone. What's important is setting achievable goals and working toward them. Whether it's housing independence or managing daily routines, remember to celebrate every little win as you and your loved one build confidence and get closer to your goals.

Finding a balance that helps you and your loved one feel safe, confident, and in charge can help keep things manageable. Be sure to take advantage of tools, routines, and support strategies. Together, you'll find the kind of independent living that's right for you both.

QUICK TIPS

Keep it simple. Frequent check-ins can give both you and your loved one peace of mind. Giving your loved one support and building confidence goes a long way.

- Notice what makes your loved one's day (and yours) run more smoothly
- Establish a steady routine, phone reminders, or a pillbox to help your loved one remember things
- Have one of their friends text your loved one regularly
- Encourage your loved one to keep notes on basic information such as their moods, sleep patterns, any stress and what brings it on, as well as how they're feeling at different times of the day

Check-ins can help you spot what's working well and whether your loved one may need help making changes to their routine.

RESOURCES

This guide gathers trustworthy resources to help build independence on your loved one's own terms. Whether they're just getting started or building on strengths they already have, these materials can encourage independence.

PAGE **Caregiver Toolkit**

5 Living independently means being able to communicate. This toolkit can help you get clearer answers about your loved one on a range of topics, from emotions to future plans and goals—all of which are big steps to independence.

PAGE **Housing Toolkit at a Glance**

8 Making housing decisions starts with understanding your loved one's situation. Whatever it is, chances are you'll find inspiring solutions and support with this housing toolkit. A thorough four-part structure can help you assess your needs.

PAGE **Circle of Care—A Guidebook for Mental Health Caregivers**

15 Caring for your loved one may seem overwhelming at times. There are community resources you may not be aware of that can make a world of difference.

LOOKING FOR EVEN MORE?
Visit HomeGroundSCZ.com
to find a variety of helpful tools.



TOGETHER IN COMMUNITY

This resource guide was developed by Teva Pharmaceuticals as part of our commitment to supporting the hardworking community that is dedicated to caring for people living with schizophrenia.

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nami.org



sczaction.org



Schizophrenia[®]
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Caregiver Toolkit

Talking with your Loved One: Questions to Ask



Communicating with a loved one affected by schizophrenia can be a challenging journey. It's crucial to engage with your loved one from a place of empathy, actively striving to understand their viewpoint without judgment, regardless of whether their perspective aligns with yours. This approach supports understanding and reinforces trust and respect, which increases the likelihood that you can make decisions together to improve their quality of life.

Emotional wellbeing

1. How are you feeling today?
2. Is there anything specific that's bothering you or causing distress right now?
3. Are you experiencing any symptoms or thoughts that are troubling you?
4. How can I best support you today?
5. Can you tell me more about what your mood has been like recently?
6. Have you noticed any changes in your thoughts or feelings this week?

Treatment and medication management

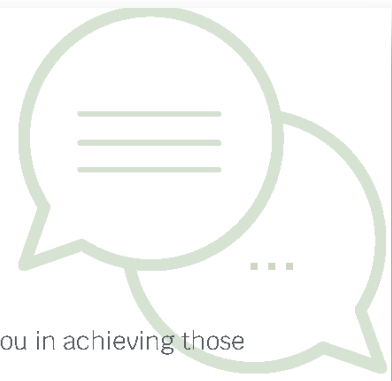
1. Have you taken your medication as it was prescribed?
2. Do you have any questions or concerns about your condition or treatment plan?
3. Are you experiencing any side effects from your medication?
4. Is there anything we need to discuss with your doctor at your next appointment?

Daily living and comfort

1. How can we make your living environment more comfortable for you?
2. Are you interested in any activities or hobbies today?
3. Would you like some company, or would you prefer some time alone right now?
4. What part of your daily routine do you enjoy the most?
5. Are there any tasks or chores that are becoming difficult for you?

Social engagement and support

1. Have you talked to your therapist (or other mental health professional) recently?
2. How can we work together to manage your stress and reduce triggers?
3. Would you like to involve other family members or friends in your support network?
4. Who in your life has been the most supportive recently?
5. Are there any social situations you're feeling anxious about?



Future planning and goals

1. What would you like to accomplish in the next few months? How can I support you in achieving those goals?
2. How do you feel about your progress in your personal goals?
3. Are there any concerns or worries you have about your future?
4. How can we plan for potential challenges or crises in advance?

Personal strengths and health routine

1. How can we maintain a healthy routine together, including healthy eating, exercising and getting a good sleep?
2. What do you feel are your strengths and talents, and how can we nurture them?
3. What new healthy habits would you like to develop?
4. What skills or hobbies make you feel most fulfilled?

Open dialogue

1. Is there anything else you'd like to talk about or share with me today?
2. What has brought you joy or comfort this week?
3. Are there any recent experiences or feelings you'd like to discuss further?





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We Need Housing! Now What?

Housing Toolkit at a Glance

The right home begins with knowing where you are, where you want to be, and who can help you get there. The Housing Toolkit provides step-by-step guidance.

HOUSING TOOLKIT AT A GLANCE



Housing Toolkit Structure

The housing toolkit is structured to allow you to easily access the information that's most important to you. Each section includes worksheets to help you reflect, plan, and take concrete next steps. You can figure out what type of housing supports your loved one's safety, recovery, and stability by considering their personal situation, what they can afford, and what is available in their state.

There are four main parts to the toolkit:



**Introduction
Using The
Housing Toolkit**



**1
Understanding
Your Loved One's
Situation**
Identify the personal considerations that will guide your housing plan



**2
Assessing
Housing
In Your State**
Obtain practical guidance to understand local housing options



**3
Understanding
Financial
Considerations**
Analyze how your financial resources shape your housing plan



**4
Putting it All
Together: Build
Your Plan**
Create an actionable roadmap to finding the best housing solution for your loved one.





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Housing Toolkit at a Glance

- Part 1: Understanding Loved One's Situation**
 - Part 2: Assessing Housing In Your State**
 - Part 3: Understanding Financial Considerations**
 - Part 4: Putting It All Together: Build Your Plan**
-



Part One

Understanding Your Loved One's Situation

Before making any housing decisions, it is essential to understand your loved one's current situation. Part One is a foundation for everything that follows in the toolkit — it helps you assess key personal and clinical factors, like age, daily living skills, symptoms, treatment needs, and home environment. Read [Assessing Your Loved Ones Situation](#) as a first step to determining your loved one's housing needs.

Since schizophrenia and psychosis-related disorders often emerge during college years, we have provided a supplemental overview of college housing options: College Related Housing.

Using Worksheets for Part One

Housing decisions can feel overwhelming at times. The five worksheets guide you to finding and selecting the right housing options for your loved one based on five assessments

- 1. Stability Assessment:** This worksheet helps you assess your loved one's symptom management, impact on family life, willingness to seek or accept help, and the capacity to be treated.
- 2. Environment Needs Assessment** This worksheet guides you in evaluating access to surrounding supports your loved one may need, such as support services (e.g. treatment, medication, therapy), safety needs (e.g. consistent services, routines), transportation options, social support, hobbies, personal goals and preferences, and nearby features.
- 3. Activities of Daily Living (ADLs) Assessment:** This worksheet helps you determine their daily ability to manage hygiene, meals, dressing, finances, and household tasks
- 4. Symptoms Severity Assessment** This worksheet will help you understand how symptoms may influence your loved one's housing requirements, through rating the frequency and intensity of positive, negative, cognitive, other symptoms, and co-occurring conditions.
- 5. Treatment Management:** This worksheet helps you evaluate how well your loved one can manage their treatment, like taking medications, attending appointments, understanding side-effects, and coordinating care.



Prioritizing Your Concerns for Part One

Begin by listing your main concerns in the table below to help you identify which sections of the “Understanding your Loved One’s Needs” toolkit are most relevant to your needs. Then rate how concerning it is (high, medium, no concern) and use your assessment as a guide on where to focus in Part One.

Worksheets	What are your top concerns?	High Concern	Medium Concern	No Concern
Stability Assessment		Round-the-clock care facilities with qualified staff and therapeutic options	More supported housing with some community integration	Living at home with additional medical supports in nearby community
Environment Needs		More integrated housing supports to learn basic life skills and personal goals	Facilities with optional structured training to address life skills, needs, and desires	Exploring add-on community features that meet various needs and preferences
Symptom Severity		Structured 24/7 environment with symptom-specific therapies, treatments, and interventions	Facilities with tailored medical supports as needed when symptoms are challenging	Community-based therapies, sessions, and/or medication management near living arrangement
Treatment Management		Medication and treatment are all overseen in the housing facility	Housing has supports that address and/or administer treatment and meds as needed	Housing environment providing flexibility to get medication/treatment with caregiver help
Activities of Daily Living (ADLs)		Facilities provide daily structure, programs, and routine care to fulfill everyday basic living needs	Freedom of movement in structured living environments balanced with added supports	Varying personal independence to manage daily living needs, receiving help if needed or requested.

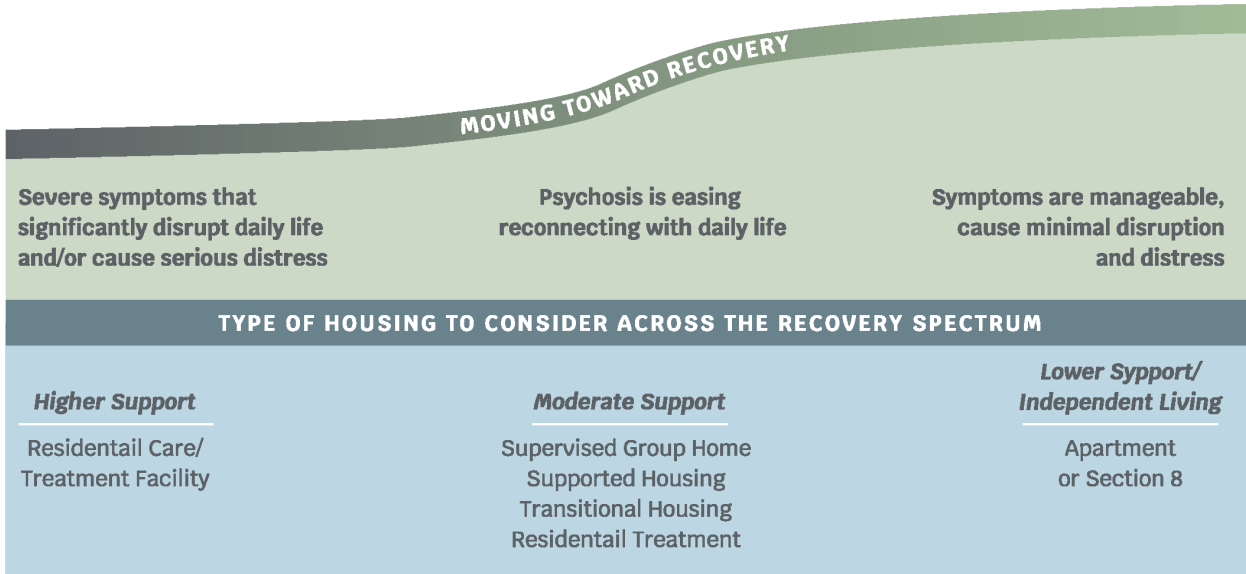


Part Two

Assessing Housing in Your State

Part Two helps you explore available housing options, understand key terms, and make informed decisions: [Assessing Housing in Your State](#).

The graphic below helps you reflect on your loved one’s recovery journey and identify the types of housing that might help the most. The toolkit’s main content will provide more details about various housing types along the recovery spectrum.





Part Three

Understanding Financial Considerations

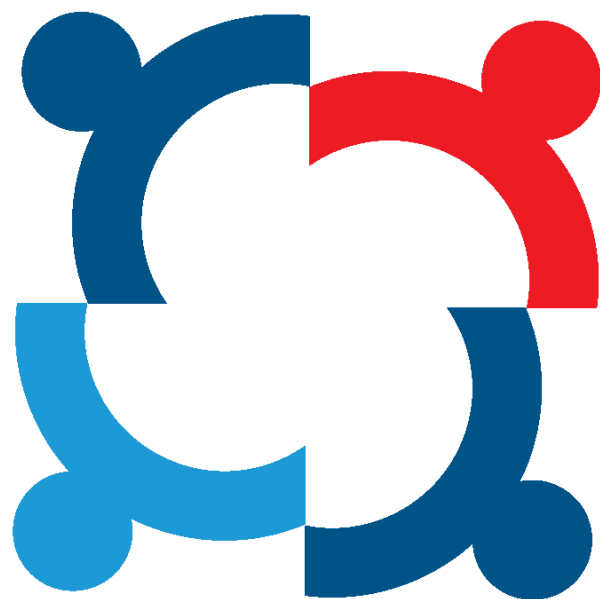
This document helps you understand what financial resources can be used, such as Supplemental Security Income (SSI), Social Security Disability Insurance (SSDI), Medicaid, Medicare, or housing vouchers. It also reviews the pros and cons of different housing options: Financial Considerations. The companion worksheet will help you map out your loved one's financial situation: [Finances for Housing Worksheet](#).

Finally, Put It All Together

Build Your Plan

Now that you've explored your loved one's needs, housing types, and financial factors, the [Build Your Housing Plan & Build Your Plan Worksheet](#) will help you pull it all together into a clear, personalized strategy. You'll evaluate local housing options, assess their suitability, schedule tours, and make informed decisions.





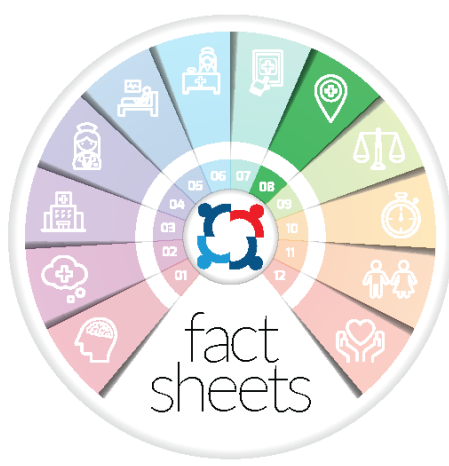
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FOR MENTAL
HEALTH
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08: Community Services

Introduction

As a caregiver, it is challenging to help the care recipient. The person you care for may need help finding mental health services in addition to practical help such as personal care, cooking, shopping, transportation, finances, and paperwork. It is often difficult to find the time and energy to make it all happen, and still attend to the other parts of your life. Learning how to access the available support in your community can relieve some of the pressure.

Background: Mental Health Caregivers and Community Services

In a recent study, mental health caregivers reported dissatisfaction with the number (51%) and quality (46%) of mental health community services in their care recipient's area. The problem was most acute in rural areas where services were sparse and remote. Studies of caregivers of adults with mental illness have found that:

- One in four caregivers say they have difficulty finding services.
- Caregivers experienced trouble in finding or arranging the following:

- day or treatment programs (64%);
- peer support (58%);
- case management (49%);
- in-patient treatment (48%); and,
- substance abuse treatment (45%).

Often it is the caregiver who becomes the advocate and has the most knowledge about the care recipient's situation, but this can come at the price of personal sacrifice and lack of work-life balance. One in three caregivers (34%) reported barriers to talking with providers about their own needs for self-care. More than a third wanted, but could not get, respite services (39%).²⁸

Finding Needed Services

Services for the care recipient: If you are a caregiver looking for services, there are mental health advocacy organizations such as the National Alliance on Mental Illness (NAMI) and Mental Health America (MHA) that can help. Advocacy organizations often have staff and volunteers who also happen to be caregivers. They may know the local resources and be able to help you open doors. It can be comforting to have someone standing with you who understands the system and has provided care.

²⁸ National Alliance for Caregiving (2015) *On Pins & Needles: Caregivers of Adults with Mental Illness*.

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Many caregivers rely on their family doctor or other health care providers to find services and support. Health care providers, however, may not be versed in the range and quality of specific community mental health programs available in your community. They may not have any information about services that would support caregivers and families. Because of our fragmented health and social service system, care recipients and caregivers often fall through the cracks.

In a recent study, mental health caregivers indicated the need for policy support to help make services available and easy to navigate. Specifically, they asked for mental health coverage parity (31%) and care navigator services (30%).²⁹

Mental Health Services and Supports

Mild to moderate symptoms of mental illness may be treated by one main provider, although more serious conditions often require a multidisciplinary approach. If your care recipient lives in an area short on mental health professionals, routine treatment can be delivered through a local health clinic, with additional expert care as needed through tele-health or psychiatric consultation. Mental health care may involve the following:

- **Assessment and diagnosis:** Effective mental health care requires ongoing assessment, care planning, and diagnosis as the care recipient's needs change and the underlying condition(s) become clear.
- **Psychotherapy:** A range of individual, group and family therapies are effective to help people with mental health conditions change their patterns of thinking, feeling, and behavior. Once the person you care

for has a diagnosis, consider researching therapies found to be effective for the specific condition. When searching for a therapist, examine their credentials in providing those specific therapies. Living in a rural area does not need to be a barrier to a given therapy because therapists are often available through tele-health. (A word of caution: check with the care recipient's health insurer to find out whether tele-health is a covered benefit.)

- **Medication:** Psychiatric medication may be an important part of stabilization and recovery. Some people with mental health conditions require continued medication while, for others, medication is only needed at certain points or not at all. Effective prescribing practices achieve a balance between managing symptoms and minimizing side effects. Be patient as it can take weeks to determine whether the medication is working.
- **Service brokering and system navigation:** Obtaining the services and support the care recipient needs can be a daunting task. If the person you care for goes to a mental health agency or health clinic, a service broker (which can be a case manager, care coordinator, or social worker) may be assigned to arrange care, health coverage, income support, and other needs. If you feel the care recipient needs help communicating their needs to the service broker, ask to be included in a visit. If the person you care for is willing to involve you, he/she may need to complete a 'consent to release information' form.

²⁹ Ibid.



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- **Emotional support:** The road to recovery can be hard. People with mental health conditions often need someone they can turn to as a sounding board or for encouragement. Mental health professionals should provide emotional support as needed. Peer support specialists are particularly helpful because they have personal experience with the recovery process. They know how hard it can be, but they also know that it gets better. Peer support specialists are often employed by mental health agencies or independent organizations.
- **Life skills and socialization:** Common symptoms of mental illness include confusion, self-doubt, loneliness, and anger. Training in social skills and stress reduction helps a person with a mental health condition build good relationships. Instruction in practical skills like budgeting and cooking can improve quality of life. Mental health agencies and peer support centers offer opportunities to help the care recipient meet others, learn healthy social interaction skills, and reduce isolation.
- **Housing support:** Decent, safe, affordable housing lays a foundation for recovery, yet without financial assistance, independent housing is out of reach for many people on a fixed income.³⁰ A recent study of mental health caregivers found that 45% of the care recipients lived with the caregiver.³¹ Although there are advantages to living as an extended family, the situation can also be stressful. Mental health agencies often employ housing specialists to help with subsidized housing. In some communities, the waiting lists are long, but signing up is still worthwhile.
- **Supported employment:** Most people with mental health conditions want to work, and would work, given effective employment and vocational support.³² Studies show that work promotes recovery³³ by offering financial independence, a sense of purpose, social interaction, and hope.³⁴ The two most effective models of supported employment for people with mental health conditions are Individual Placement and Support (IPS), and the Psychosocial Clubhouse. Community mental health centers may offer these programs, although Clubhouses are often independent agencies.
- **Crisis intervention:** Crisis services intervene at the breaking point. Crisis counselors stabilize, help prevent further crises, refer to professional help, and follow-up to ensure long-term recovery. A crisis response system can include 24/7 telephone counseling, mobile crisis response teams, walk-in clinics, short-term crisis stabilization units, respite services, and transportation. If the person you care for is in crisis and an immediate threat to him/herself or to others, call 911 and ask for a Crisis Intervention Team (CIT), or get to the nearest hospital emergency room as soon as possible. If your care recipient is suicidal, The National Suicide Prevention Lifeline has trained counselors who can speak with you or your care recipient 24/7 and can be reached at 1-800-273-8255.
- **Hospital and residential treatment:** In-patient care may be necessary if the person you care for is in psychiatric crisis, is at risk of harm to self or others, or requires complex intervention.

³⁰ Cooper E, Knott L, Schaak G, Sloane L, Zovistoski A (2015). *Priced Out in 2014: The Housing Crisis for People with Disabilities*. Technical Assistance Collaborative. <http://www.tacinc.org/knowledge-resources/priced-out-findings/>

³¹ Hunt et al (2015). *On Pins & Needles: Caregivers of Adults with Mental Illness*. p. 20.

³² McQuilken M, Zahriser JH, Novak J, Starks RD, Olmos A, Bond GR (2003). *The Work Project Survey: Consumer perspectives on work*. *Journal of Vocational Rehabilitation* 18: pp. 59-68.

³³ Burns T, Catty J, White S, et al (2009). "The impact of supported employment and working on clinical and social functioning: Results of an international study of Individual Placement and Support." *Schizophrenia Bulletin* 35: pp. 949-958.

³⁴ Douglas D, Diehl S, and Honberg R (2014). *The Road to Recovery: Employment and Mental Illness*. National Alliance on Mental Illness. p. 3 <https://www.nami.org/About-NAMI/Publications-Reports/Public-Policy-Reports/RoadtoRecovery.pdf>

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- Most psychiatric hospital stays are brief, no more than a week or two, with specific treatment goals. In-patient mental health care may be received in the psychiatric unit of a general hospital, a privately operated psychiatric hospital, or a state psychiatric facility. It is best if the care recipient enters into in-patient care of their own accord, but when the care recipient or others are at immediate risk, involuntary commitment may be necessary. Today, many hospitals ask patients to name a caregiver to be involved in discharge planning. Designated caregivers receive information to support aftercare, which can improve outcomes.
- Residential mental health treatment is a step-down, or hospital diversion, strategy usually consisting of two to eight weeks of intensive treatment in a home-like setting. Goals include reducing symptoms, learning healthy coping mechanisms and living skills, rebuilding relationships, and preventing relapse. (A note of caution: residential treatment is expensive, and health insurance coverage can be difficult to obtain).

Helpful Resources

There are various online tools to access services through national organizations. One resource is your local municipality. Many people don't think of the public sector as being an access point for mental illness but in fact there are many programs that may assist you. Examine the information and referral systems that can provide you with phone numbers and other information on available services. The following includes examples of services and assistance that may be of interest:

- **Eldercare Locator** provides assistance to families who are seeking programs and services in their local communities. www.eldercare.gov/Eldercare.NET/Public/Index.aspx
- **The National Institute of Mental Health (NIMH)** offers information on topics by condition, population, and prevention. www.nimh.nih.gov/news/science-news/2011/support-program-can-help-caregivers-cope-with-relatives-mental-illness.shtml
- **The Substance Abuse and Mental Health Services Administration (SAMHSA)**, a federal agency, offers a confidential nationwide mental health and substance abuse services locator. Locator services are available either online or by telephone: findtreatment.samhsa.gov/
- **The National Alliance on Mental Illness (NAMI)** offers various education and support programs for people with mental illness and their families. To learn more about specific programs, visit www.nami.org/programs. To find a NAMI organization in your area, visit www.nami.org/local.
- **Mental Health America (MHA)** offers information and programs including the Peer Support Program housed within the Peer Support Center. www.mentalhealthamerica.net/center-peer-support
- **National Family Caregiver Support Program (NFCSP)** was established in 2000 to provide support to caregivers and since that time has expanded to include a variety of caregiving situations including mental health. Through the NFCSP, money is distributed to states and territories in the form of grants to provide support to caregivers. www.acl.gov/programs/support-

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caregivers/national-family-caregiver-support-program

- **Lifespan Respite Program** is a community-based system of care for family caregivers providing care to family members of all ages. www.acl.gov/programs/support-caregivers/lifespan-respite-care-program
- **Aging and Disability Resource Centers** are considered 'single points of entry,' 'no wrong door,' or 'access points' to resources related to Long-Term Services and

Support (LTSS). Through person-centered counseling (PCC), individuals are assisted through the process and learn about the resources available to them. www.n4a.org/adrcs

- **The National Association of Area Agencies on Aging** provides a wealth of information for caregivers related to housing, home and community-based services, transportation, elder law, and much more. www.n4a.org/agingservices

Helpful Websites

AARP-Caregiving www.aarp.org/home-family/caregiving/

Caregiver Action Network caregiveraction.org

Family Caregiver Alliance www.caregiver.org

Mental Health.Gov www.mentalhealth.gov

National Alliance for Caregiving www.caregiving.org

National Alliance on Mental Illness www.nami.org/Find-Support/NAMI-Programs

U.S. Department of Health and Human Services (HHS)

www.mentalhealth.gov/talk/community-conversation/services/index.html

www.caregiving.org/circleofcare