



The Fundamentals of Respite Care

What is the Illinois Respite Coalition?



- The Illinois Respite Coalition (IRC) is a non profit organization that provides in-home respite care through a DHS funded grant that allows us to provide respite in 16+ counties in southern Illinois
 - Bond, Champaign, Clark, Clinton, Crawford, Cumberland, Dewitt, Edgar, Effingham, Jasper, Macon, Marion, Mason, Moultrie, Richland, Washington
- The IRC provides respite information & referral services statewide
- The IRC is also dedicated to increasing awareness of the importance of “Lifespan Respite” and promoting education and training for families and providers of respite services
- When funded, we provide statewide emergency respite assistance across the lifespan

What is Respite Care?

- Respite is a short time of rest or relief, it is a break for the caregiver
 - The caregiver has downtime while the person with special needs receives care from qualified individuals
- An individual can receive respite care:
 - At home, a community organization or residential care center
 - From paid staff, volunteers, family or friends
 - For part of the day, evening or overnight
 - Occasionally or on a regular basis
- Respite is important because approximately 67.5 million Americans serve as family caregivers for an ill or Disabled relative. According to the National Alliance for Caregiving during the past year.



Benefits of Respite Care

- Respite care helps:
 - Relieve stress
 - Make time for other family members
 - Boost personal health
 - Caregivers catch up on responsibilities
 - Offer a new perspective
 - Reduce hospital costs/ delay more costly care options
 - Avoid or delay placement in out-of-home facility
 - Reduce risk of abuse and neglect
 - Loved one/ care recipient break up monotony of day, increase stimulation and socialization

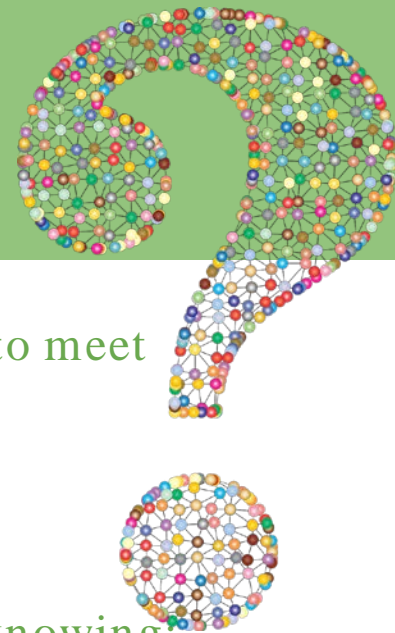


Brief History of Respite



- Respite is a relatively new service
 - Although there were some programs in the 1960s, it wasn't until the 1980s that respite began to flourish
- To date, there's still a shortage of respite programs and providers nationwide & insufficient funding and resources to serve all in need
- Lifespan Respite Care Act was enacted in 2006 to create a program to assist family caregivers in accessing affordable and high quality respite care
- Illinois received Lifespan Respite Care funding in 2009 as a 3 yr grant
 - Funding through primarily 3 agencies: DHS, DCFS, DOA
 - Emergency Respite Care Program created

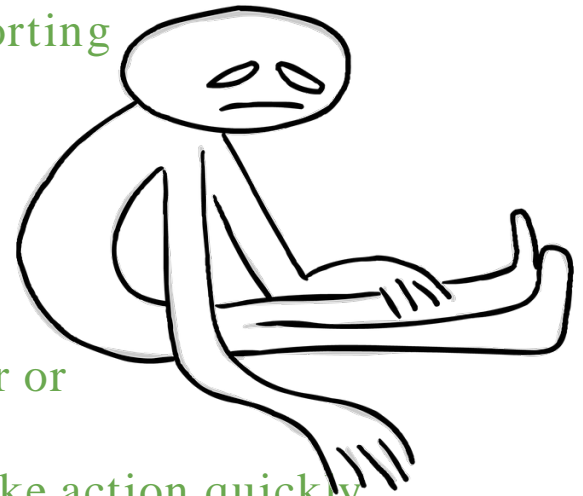
Why use Respite Care Services?



- Respite can give a caregiver the time and assistance required to meet personal needs
 - Errands: shopping, exercising, doctors visits
 - Sleep
 - Socialize
- Respite provides comfort and peace of mind to the caregiver knowing:
 - Their loved one is spending time with another caring individual, receiving appropriate care, and following family preferences
 - With respite, interaction with others is possible and can be a welcome change of routine.

Caregiver Burnout

- Caregiver burnout is the mental, emotional and physical exhaustion that can develop through the responsibilities of supporting and caring for another individual
- Causes:
 - When busy caring for a loved one, the caregiver neglects their own emotional, physical and spiritual health
- Caregiver burnout is not healthy for the caregiver or care recipient
 - Make sure to watch for warning signs and take action quickly



Signs of Caregiver Burnout

● Warning signs include

- Lack of energy
- Sleep problems
- Changes in eating habits, weight loss or gain
- A feeling of hopelessness
- Withdrawing from/ losing interest in activities you once enjoyed
- Neglecting your own physical and emotional needs
- Feeling like caregiving is controlling your life
- Becoming unusually impatient, irritable or argumentative
- Anxiety about the future
- Depression, mood swings
- Difficulty coping with everyday things
- Headaches, stomach aches and other physical problems



Managing and Preventing Caregiver Burnout

- Encourage caregiver to:
 - Accept help
 - Focus on what they are able to provide
 - Set realistic goals
 - Get connected
 - Join a support group
 - Seek social support
 - Take time for themselves
 - Focus on their health needs
 - See their doctor



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What are different Kinds of Respite?

- There's a number of ways that respite can be provided, but there are five common types (dependent on eligibility)
 - In-home respite care
 - Day centers & Recreational centers
 - Informal Respite Care
 - Residential Respite Care
 - Respite for emergency situations
- The varying types of respite are essential so families can have the respite that fits their schedule and needs

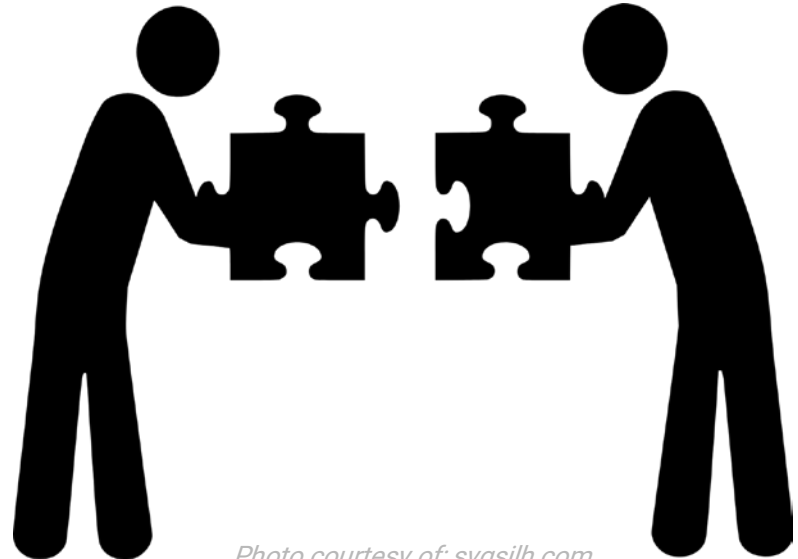


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In-Home Respite Care

- In-home respite care is a type of respite care service provided in the home to assist the caregiver and person with a disability or special needs
- In-home respite services vary and can include:
 - Companion services
 - Help with supervision, recreational activities and visiting
 - Personal care services
 - Help with bathing, dressing, toileting, exercising and other daily activities
 - Homemaker services
 - Help with housekeeping, shopping and meals
 - Skilled care services
 - Help with certain medical services or care



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In-Home Continued

- In-home respite workers can be employed privately, through an agency or as a part of a government program
- Make sure the services are appropriate for your needs
 - Cost, level of training and services provided vary among different agencies, programs and people
- Medicare – limited based on eligibility
- Medicaid – administered by individual states, respite provided through waiver funding.
- When working with your respite worker, it is always important to go over the unique, individualistic needs of the respite care recipient
 - Everyone is different, so get the care that matches their needs



Day Programs/Recreational Programs (Group)

- Provides care outside the home and is designed to meet individual needs while supporting strengths, abilities and independence
 - Care recipients interact with others in a structured environment
- Day programs provide many activities
 - Music, recreation, discussion, support
- Staffing varies across programs, so ask if staff provides medical assistance should it become necessary
- This option is extremely helpful for caregivers who work during the day



Informal Respite Care

- Informal respite care is respite care that is more sporadic
 - Many times this could be help from a family member, close friend, neighbor or volunteer that's willing to occasionally help out
- When thinking about respite care, it's important to remember the people who have offered to help in the past
 - Put together a mini schedule or list of people to contact based on what they can help with/ when they are available
- Informal respite care can allow the caregiver some down time while the care recipient is spending time with someone you both already trust



Residential Respite Care

- Residential respite care is support in a residential facility overnight, for a few days, or even for a few weeks depending on the program
- Allows caregivers to take an extended break or vacation while their loved one is in a supervised, safe setting that is designed to meet personal needs
- Enrollment in the program is needed because programs' availability and eligibility vary
- It may be difficult for the respite care recipient to adjust to the new environment
 - Visiting beforehand is an option
 - Regular stays allow the overall adjustment to be easier, and increases staff's familiarity with a caregiver's loved one



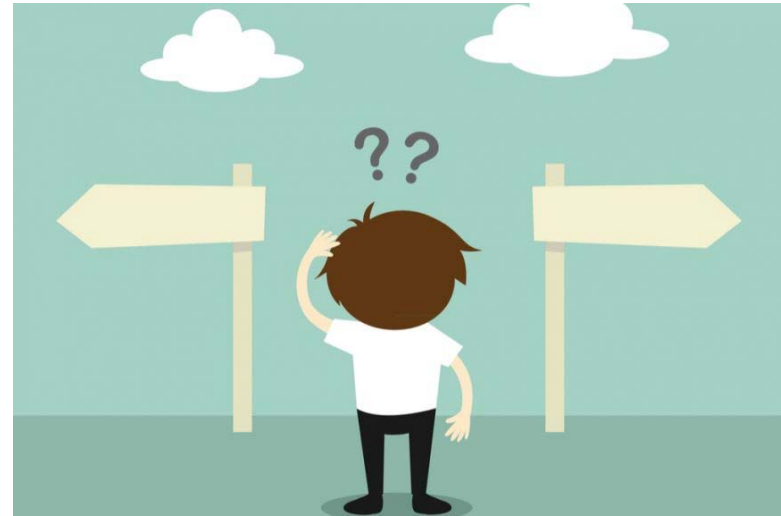
Respite Care for Emergency Situations

- Accidents, surgery or unexpected trips can create a need for emergency respite care
- Doing research and planning before an emergency happens can give families knowledge of resources to contact, should the need arise
 - Using a resource during a non-emergency time, if possible
 - Talking with family, friends and neighbors to see who could help in an emergency situation
- Emergency care respite services can result from (but are not limited to) any of the following circumstances:
 - Caregiver illness (physical, mental or emotional), caregiver hospitalization or doctor appointment, illness of a loved one, funeral/wake, drug/ alcohol abuse, counseling/ support, risk of loss of employment, preparation for care recipient to transition between living arrangements, other family emergency or need

How to choose the Respite that's right for You

- Assess your needs for the type of respite care that would best suit your schedule
 - Consider type of care, skills, location and frequency
- In some areas, respite care options are limited
 - Work with social service agencies and talk with people in the community
- When working on acquiring respite
 - Describe current caregiving situation, explain what's hoped to be gained from respite care service
 - Ask questions about qualifications, types of service offered, cost and hours of availability

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Selecting your Respite Care Service

- Considering individual needs is the best way to hone in on the right type of respite
 - Each person is different, has unique needs and wants
 - Respite can/ should be individualistic
 - Families and respite providers should work together and maintain open communication
- When finding the respite care worker, if possible, it is a good idea for both the care recipient and caregiver to participate in the interview process
- Make sure that the respite chosen has staff that will adequately meet all needs
 - Meet with the respite worker, plan to visit a day program, plan to visit a residential facility



Overcoming Respite Concerns

- It's normal for caregivers to be apprehensive about trying new things:
- Cost
 - Ability to pay/ afford respite care services
 - Financial assistance such as scholarships, sliding scale fees or government programs/ grants/ church groups/ charities
- Reliability
 - Dependability of support worker or service
 - Agency staff should be trained and reliable and are often certified, but you can ask agencies about qualifications
- Guilt
 - Caregivers may feel like they should be able to do it all/ cultural influence
 - It's okay to seek help, asking is a sign of strength not failure
 - Remember that respite benefits both the care recipient and the caregiver



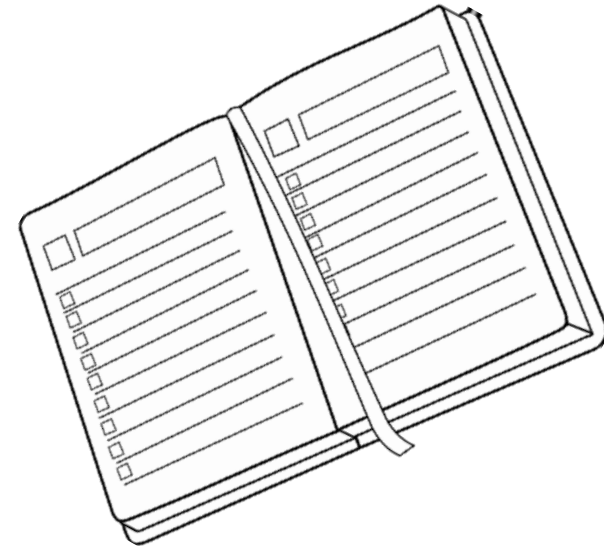
Preparing for Respite



- The care recipient will need time to adjust to a new caregiver
 - Make sure the recipient knows as much as possible
 - Make sure they still feel in control of their decisions and outcomes
- As a respite care provider, make sure you familiarize yourself with the care recipient
 - Be honest in all discussions/ learn from each other
 - Obtaining a written care plan and asking questions is important to ensure you know as much as you can
 - Info on care recipient: What do you like and admire about me? What are things important to me? How to best support me?

Ways to make Respite Care Effective

- Begin using respite early on in the “caregiving career”
- Use respite regularly (i.e. on a more scheduled basis)
- Use respite in sufficient amounts (dosage- don’t give yourself too little)
- Use respite along with other services
 - What else is out there?
 - Eligible for more?
- Tailor the respite to each family’s unique needs
- Make a plan ahead of time about what to do during Respite
- Enjoy your time, this should be guilt free!



Sources: 1) *Examining What Caregivers Do During Respite Time to Make Respite More Effective*. (2008). Lund, D.A., Utz, R., Caserta, M.S., & Wright, S.D. 2) *Making Respite More Effective* [Webinar]. (2011). Lund, Dale.

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Evaluating Your Respite Care

- Caregivers should periodically evaluate the services they are given
 - Sometimes a worker or program is no longer suitable
 - Change of needs
 - Suggestions of things to improve
- When evaluating your respite service, consider:
 - What do you need that respite isn't offering?
 - Is the service meeting my needs?
 - What works best?
 - What can be improved?
 - Where can I find what I need?



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Things to Consider

- Here is a list that has an overview of things to consider when looking for help in the home or from a home care provider
- Provider is:
 - Able to communicate in the preferred language
 - Trained in First Aid & CPR
 - Trained in specific care needed
 - With an agency (if important)
 - Able to provide references
 - Available when you need them
 - Able to provide a back-up if necessary
 - Able to manage your specific health and behavioral care needs



Quick Tips

- Good respite care includes ensuring safety and meeting basic needs, but it also means involving the care recipient as much as possible
 - Making sure they are comfortable/ responding well to the care they are receiving
- Ask about special training from care provider, if needed for your loved one
- Respite support should aim to care for the whole person, not like a patient
- Find out how care providers are supervised/ supported
- At the end of the day, it's most important that the care recipient feels supported and gets the care they need
 - Remember to thank your respite care provider for Their work and support!



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