

## Lifespan Respite Training Component

*NOTE: Including a Respite Message in Your Training*

*- Try to convey a lifespan perspective and a broad scope of conditions when presenting this section on respite, and avoid addressing any specific age group or disability group. This will help participants to think of others who are caregivers, or think of their own role as caregiver more broadly.*

*- The focus on caregivers, without mention of any specific task of care-giving, is meant to generalize the information, and make it appropriate to as wide an audience as possible. Include examples of care-giving that are drawn from other age groups and conditions other than the one specifically oriented to the audience or to the rest of the training materials, in order to again broaden the application of respite across the lifespan and for all disabling conditions.*

(Slide 1) Identifying Your Care-Giving Role:

Most caregivers would not recognize themselves as such. They are simply serving in the role as parent, grandparent, spouse, son or daughter, sibling, friend, or neighbor. When a need arises, they compassionately take on tasks for and in behalf of their loved ones as they expect anyone in a similar situation would willingly do. Temporarily, we may all be called upon to support others in times of need, and can make the adjustments to accommodate the increased stress of the situation. It can also be a gradual process, where the tasks and the amount of support needed increases over time.

*Optional Activity: Distribute Bingo Game Card, filled with roles they play, and the tasks they have done to assist others. Pass out a candy reward to those with the most spaces filled, or the ones who have BINGO'd a row or column.*

(Slide 2) Caregiver Stress

But when care-giving becomes the primary role, and/or the care-giving duties rise well above and beyond an easily accommodated range of support, and/or care-giving is constantly needed, and continuously provided without an end in sight, the demands of care-giving can become overwhelming, can damage the natural relationship that existed, and turn a care concern for one person into a health care risk for two people – the care receiver and the caregiver. Care-giving stress can quickly accelerate into anxiety attacks, depression and caregiver burnout, and cause significant mental and physical declines in the caregiver's health. And when a loved one is dependent on the continued ability of a caregiver to provide care, the sudden loss of that support can be devastating. *Review handout on 10 Tips for Caregivers/Warning Signs of Caregiver burnout (information is also included in the brochure).*

(Slide 3) Caregiver Needs

To prevent caregiver burnout and to protect precious relationships, caregivers are encouraged to find and use respite. Respite provides a temporary relief from the ongoing responsibilities of caring for loved ones in the home. Respite care services provide short term care to children and adults who have disabilities, or chronic or terminal illnesses, or

who are in danger of abuse or neglect, or who have experienced abuse or neglect. Respite is achieved when a caregiver allows others to temporarily take on some part or aspect of the caregiver's role. This provides a break to the caregiver, allowing for uninterrupted personal time, and encouraging the natural relationship that exists between the caregiver and the care recipient to return. Even if the natural relationships have had to change with the needs of a loved one, sharing the care-giving tasks with others allows some balance of normalcy to return and to be strengthened.

Because they don't identify themselves as caregivers, they don't know how to look for resources for themselves. The result is that caregivers try to "go it alone" without the information, resources, or support they deserve. When they can't do it all by themselves, a crisis or emergency might be the first time a respite service is used. Respite is not meant to only be used in case of emergency, although an emergency may convince a primary caregiver that he/she needs help and support to order to continue to provide care. Respite should be used regularly and be of sufficient duration to allow the caregiver to come back renewed and rejuvenated. Those who need respite use words and phrases, such as "needing to get out," "needing breathing space," or "needing a break." They may not recognize that they need respite to prevent caregiver burnout, and may not realize that when "life is hard" they are at great risk.

Getting caregivers to accept respite is surprisingly difficult. Caregivers sometimes push themselves too hard, and feel they have to do everything themselves. Mostly they don't have a lot of people they can find or trust to take such a critical role. Sometimes the loved one receiving support adds to the problem, by refusing to allow others to provide any care. Respite programs try to help caregivers address these concerns, even providing meet-and-greet opportunities between potential respite care providers and families needing care. But ultimately the best respite support is achieved when caregivers know and trust those who will be temporary caring for their loved one.

#### (Slide 4) Making New Friends

That may require caregivers to reach outside of their normal circle of friends and family, to bring others into that intimate circle of caring support. As difficult as this may seem, caregivers need to remember that some of their most intimate friends were once total strangers. *Review handout on Making New Friends.*

#### (Slide 5) Process to Accepting Respite

To accept respite, a caregiver may need to go through a lengthy preparatory process, which includes one or more of the following steps:

- 1) Understanding the care recipient's disease or disabling condition sufficiently so that differences are no longer shocking, unexpected, or unprepared for.

Caregivers may need to develop a certain skill level themselves before they can consider turning their care-giving role over to others. Care-giving skills and/or other resources that make it easier to provide care increases a caregiver's capacity to be effective in their role and may reduce their need for respite. This easily turns into the

skill and training they expect of a respite provider, and finding such a knowledgeable provider then becomes a barrier to respite. Caregivers need to remember that they too had to learn these care-giving skills and seek opportunities for potential respite providers to do the same.

- 2) Awareness of and exposure to other potential caregivers who understand these differences and are not put off by them, even if these differences are embarrassing or hard to manage.

Sometimes, caregivers need reassurance that care recipients will benefit from this exposure. Trying to avoid situations that expose these differences put caregivers at such a heightened risk for burnout. Caregivers need to recognize that “pretending that everything is normal” carries a significant stress load on them. While “having people know” might seem greatly embarrassing and demeaning, caregivers and care recipients actually report great relief when they are surrounded with people who know and understand.

(Slide 6) Accepting Respite, cont.

While greater awareness of how to support these differences in a variety of settings would ultimately be helpful to the care recipient, caregivers will tend to look at the natural supports of family and friends, or community connections, such as faith-based membership, for those who might already have some awareness of and exposure to the care needs of their loved one, or at least some sense of acceptance once those differences are known. This pool of people may be easier for the caregiver to consider as potential respite resources. Many respite programs are specifically designed to utilize providers selected by the caregiver. Respite providers who already have training or experience in working with others with similar care needs are also more likely to be allowed and accepted in sharing care-giving with the primary caregiver.

- 3) Allowing others to assist in care-giving by relinquishing momentary responsibility while caregiver builds comfort with and sees the competency of others as they try to provide care, respond to differences, and learn how to support care recipient.

Because care-giving routines can become ingrained in the tasks of daily living, caregivers cannot always see how to share those tasks with others. A pattern of eating together at mealtimes, for example, may seem disrupted by allowing someone else to assist with feeding tasks. Caregivers may need encouragement to allow this. Cultural norms may also make it difficult to allow this process, if the expectations of themselves and others make a caregiver reluctant to relinquish care duties or to allow someone outside of the family to come in to provide care.

Respite trials may be necessary before a caregiver achieves a respite experience, meaning that caregivers might need to gradually fade their support while allowing others to increase the level of support they provide. Caregivers can feel guilty for

wanting respite, and reluctant to leave a care recipient who doesn't want to be separated from them.

- 4) Fully entrusting care-giving to others, knowing that the care recipient is in good hands that will respond to needs, even if no one else provides care exactly as the caregiver would.

Caregivers may refuse respite because no one else can achieve the same level of care that the caregiver provides. A discussion of what level of care is “good enough” may help caregivers and care receivers accept temporary differences in care. Entrusting others with care may be easier if a respite provider starts with one or more tasks that are easiest for the caregiver to relinquish. This may allow the caregiver's experience with and trust in the respite provider to increase, and allow additional care-giving tasks to be shared in the future.

*Optional Activity: Top Ten Lists – have audience generate a group list of reasons why caregivers should use respite. Have an individual sheet for each participant to take home of their own Top Ten Reasons for Respite.*

**Conclusion:** Include information about how to find respite resources in their community (included in brochure).