



Planning for Emergency Respite

Emergency respite, also known as crisis care respite, is often needed when the caregiver experiences illness, job loss, death in the family, domestic violence, homelessness, or another emergency. Emergency respite is short term care that may last from one hour to several weeks depending on the needs of the primary caregiver and may take place in-home or out-of-home.

When a crisis occurs you may be especially stressed and anxious about the incident that caused the crisis as well as the fate of your loved one if and when you have to leave. The care recipient will likely pick up on the anxiety and perhaps become agitated and anxious themselves. It is important to not only consider this, but to be prepared for it. It's important that all transitions are made as comfortable and anxiety-free as possible.

Do Advance Planning. Searching for emergency respite in advance of an emergency situation will help alleviate fears about having to leave the care recipient suddenly. The search will involve as much advance planning as possible.

Questions to consider when developing an emergency respite plan are:

- ***Who are the respite providers in close enough proximity to provide assistance at any hour?***

Well in advance of any emergency or crisis situation, family caregivers should make every attempt to identify in-home providers or out-of-home programs in the immediate area that will provide emergency respite. If possible, using these providers for planned respite experiences will help familiarize the care recipient to the program or provider and will also ensure that the provider is familiar with the care recipient's special needs. Make sure that the provider or program has all necessary medical and personal information about the care recipient in advance of the emergency.

- ***Can the emergency respite accommodate individuals who are dependent on medications or other 'invasive' procedures for their survival?***

"My husband is an insulin-dependent diabetic. Can the program measure his blood sugar and administer the correct amount of insulin?" "My child can take no food or liquids by mouth and requires gastric tube feedings. Can the respite program legally and safely administer the feedings?" These are very real concerns for caregivers and may also be a liability issue for respite providers. All respite programs should have a risk management plan in place to protect

the care recipients and those who are providing the care. Read more in [ARCH National Respite Guidelines](#).

Many programs are not equipped to provide care to someone who is ventilator dependent or has other serious medically related needs and it is important for caregivers and care recipients to have this information in advance.

• Is the emergency respite program equipped to handle behavioral challenges imposed by the care recipient and do they have policies and procedures in place for doing so?

Consider an individual with serious mental health issues who may have a history of repeated suicide attempts, a child with autism, or an adult with dementia, who is adept at escaping his or her surroundings and running away. When the family is already in crisis due to the situation that warranted emergency respite, they need to feel confident that their loved one will be cared for in a safe, responsible and supportive manner.

Not all respite programs can offer that degree of care. It is therefore up to the professionals who are assisting families in crisis, to assist them in finding appropriate accommodations for their loved one with extensive special needs. While these are concerns that everyone who seeks planned respite must consider, for those in a crisis situation there may not be time for the caregiver to research whether or not these concerns will be appropriately addressed.

Accessing Services. If a family member is anticipating an emergency situation, like an impending trial date or a planned medical procedure, they have time to prepare for care that is out of the realm of their traditional planned respite. Even for a family who does not receive planned respite services, advanced warning provides them with an opportunity to find safe shelter for the family members in their care. These situations allow caregivers to plan for short term ‘emergency’ respite care.

Planning for a possible emergency is somewhat easier for families who regularly use planned respite or are involved in other family caregiver support services. They already have a relationship with a provider and can more easily broach the subject of planning in the event of an emergency.

Not all families have additional family, friends and respite providers who they can call upon in an emergency. For those families who are isolated and lack family or a social network of potential helpers, they may want to contact their health care provider, hospital social worker, public health nurse, law enforcement or other professional helpers who can direct them quickly to the services they may need.

There are always some emergencies that do not allow for a caregiver to thoughtfully turn over the care to someone else. Again, planning in advance is critical.

Funding for Emergency Respite. Most Home and Community-based Medicaid waivers include provisions for emergency as well as planned respite. Each state's eligibility criteria and funding for waivers are different; check with your state's Medicaid office. Your local Area Agency on Aging may also set aside funds for emergency respite through its Family Caregiver Support Program, but you must meet certain eligibility requirements as well. Many State lifespan Respite Programs have developed respite vouchers to help pay for respite in emergency situations. Check with your state [Lifespan Respite Program or a State Respite Coalition](#) if there is one.

Recommendations for Family Caregivers preparing for respite during an emergency:

1. Before an emergency occurs, check with your physician or case manager (if you have one) for possible emergency respite providers in your locality. Reach out to community or faith based agencies for recommendations of respite programs or volunteers who might be available in an emergency.
2. Research options and funding sources for emergency respite before an emergency occurs. Contact your state Lifespan Respite Program, state respite coalition, Medicaid agency, or Aging and Disability Resource Center for a list of possible services, funding possibilities and other resources for emergency care or search your state's resources in the [ARCH National Respite Locator Service](#).
3. Once you have identified possible providers in closest proximity to you, reach out to potential providers to find out about their criteria and process for accessing care in an emergency and do as much advance planning as possible. If necessary, pre-certify the care recipient in more than one program or with more than one home care agency. Before an emergency occurs, utilize these providers for planned respite so that the provider and the care recipient will be prepared and comfortable with the respite arrangement in an emergency situation.
4. Prepare a list of questions to ask potential providers. Questions to consider include whether the program can legally and safely administer medication, gastric tube feedings or other special medical procedures, and if the program has a risk management plan to protect care recipients.
5. Inquire about the credentials and work experience of the staff/volunteers who will be providing care. If required, find out if providers are trained to deal with behavioral issues or dementia.

For more information and resources, see the ARCH Fact Sheet on [Emergency Respite: Help for Family Caregivers in Critical Times of Need](#).

Prepared by ARCH National Respite Network.