

COMMUNICATIONS QUESTIONNAIRE

The Louisiana Lifespan Respite Coalition distributed a descriptive survey to the March 2013 Summit to solicit information about how to communicate to the caregiver in Louisiana.

Twenty surveys were returned, representing about 10 percent of attendees. Most of the respondents felt they were somewhat familiar with care-giving services in their area, they received occasional questions about care-giving supports, and they were most likely to find out about available services from an organization familiar with this type of help and most often one that served the elderly.

When the respondents received a call for help, it was nearly always from the actual caregiver, a person they perceived as already in a crisis, wherein the request for help was a personal “emergency” for one on the verge of “losing their mind”. In fact, respondents felt that the biggest obstacle to reaching the caregiver was their state of crisis, which inhibited the caregiver’s ability to plan. Additionally, respondents were aware of a lack of actual respite resources in the state and no central source of information to find respite resources.

Respondents felt the best way to reach the family caregiver was through social media, church bulletins, a news story, a doctor’s office or an organization dealing with the elderly.

Respondents felt it was important for the Coalition to define respite as a service that offers “relief” and support for the caregiver, so they can step away from the daily stress of providing care. The actual definitions provided to relevant questions are below:

HOW DO YOU DEFINE RESPITE?

Planned or emergency **care** provided to a person to **relieve** their primary caregiver of natural or familial **support**

Emergency or periodic **care**, providing **relief** or a **break** for the caregiver that allows him or her to continue providing care to parents or delays out of home placement

Sitter **services** for “down” time

Caregiver **relief**

Temporary **relief** from some strenuous or **stressful** situation or responsibility

Getting a **break**

A **service** that will allow the family to **support** needed to avoid **stress** and burn out while offering safe and competent **care**

The take a step back philosophy of caregiving, that everyone can be their best self (patient, caregiver) with some degree of **rest** from caregiving

System of **care** providers, the **support** network and the **services** provided to children and adults in need of **care** to improve their daily lives

Care for the caregiver

Relief for a family caregiver

Care for me and others

Services and **supports** designed to give relief to a caregiver in their caregiving duties for a set period of time

Temporary **break** from the ongoing **care** of a person with a disability

Planned or unplanned **break** for short duration to provide **services** to a individual while giving the caregiver a **break**

WHAT, IN YOUR OPINION, IS THE RIGHT WAY TO DESCRIBE RESPITE CARE TO A FAMILY CAREGIVER WHO HAS NOT YET SOUGHT HELP?

An ability to do what needs to be done for “you”

Period of **relief** or giving them a **break** so they can continue to **provide care** when they return from that break

Someone to help give you a **break**

Caregiver **relief**

Giving yourself permission to enjoy some time away from the responsibility of caregiving to **rejuvenate**, which allows for better caregiving

Let me help you

Relief..to care for you're loved one in their own home assist them with social and recreational activities

Help so you can take a **break**

It's okay to ask for **help**

Relief

Support

an opportunity to **take care** of yourself

enjoy the simple things again

take care of yourself too

An opportunity to receive support for caregiving needs, that will allow some personal time to **take care** of their personal needs

That to best serve their loved one they need **self care**

Respite will be support to assist you with caring for your loved one and free some of your time to **take care** of yourself, household, other family members

Time off

Renew energy

Respite is an opportunity to **help you** be healthy so you can give the **care** your family needs.

Helps prevent burnout

WHAT WORDS ARE “HELPFUL”?

Break

Support

ARE THERE ANY HELPFUL IMAGES THAT COME TO MIND IN DESCRIBING RESPITE? hugs/nurture

Respondents were very concerned that communications not be negative, demoralizing or judgmental. They also believed language should not sound like you were replacing the caregiver due to personal failure, guilt or feeling overwhelmed.

WHAT WORDS WOULD YOU AVOID?

Burden, planned stay, relief of responsibility
Don't use any language that sounds like we're replacing you or implies you failed
Get away from
Don't feel guilty
Crazy
You're upset
Sitter, baby sitter, worker, always use people/person, first centered language
Guilty, burnout, overwhelmed, broken, selfish
Anything negative
It's a person not a disability
Demoralizing words that would lead to notion that things cannot be better
Only in emergency
Break for you
You deserve it