

RECLAIMING JOY TOGETHER



Respite for All
FOUNDATION



THE RESPITE FOR ALL FOUNDATION

CREATING A VOLUNTEER-DRIVEN, FAITH-BASED SUPPORT
COMMUNITY FOR PEOPLE LIVING WITH ALZHEIMER'S AND
OTHER FORMS OF DEMENTIA



FROM THE FOUNDER DAPHNE JOHNSTON

Co-Founder & CEO
The Respite for All Foundation

I once heard Professor John Swinton say in a lecture given at Harvard that we need to see ourselves through other people for us to find our bearings. For instance, we need children to be a father, we need a husband to be a wife, and we need friends to be a friend. He goes on to suggest it is not the person living with dementia who forgets themselves but more the community who forgets them. Creating a loving alternative to this loss of connection is at the heart of Respite. We help our friends see themselves once again within a caring community.

Neurology offices provide testing, diagnosis, and behavior management. But where do people go to learn how to regroup, refocus and reclaim their joy? Respite communities provide education, friendship, growth, and the tools for families to help adapt to their new challenges. The faith-based, volunteer model is pioneering new ground for ordinary people to provide extraordinary care in regard to dementia.

If there was a quick fix to providing quality care for dementia, it would already be done. But we have a wonderful opportunity to gain new insight into new systems and begin to adapt and try new ideas. Through Respite, we reopen the doors to community engagement for our friends and provide renewed purpose for our volunteers. And in each interaction, we can see for ourselves that love never forgets.

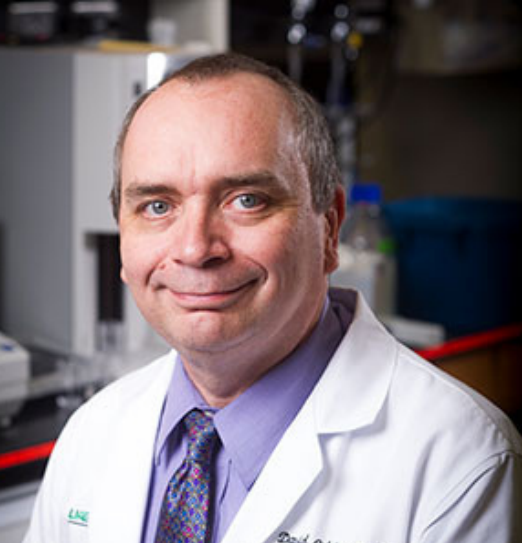
From 2012 - 2021, the original Respite Ministry volunteers served over

 **90,000** TOTAL HOURS

 **69,000** MEALS WITH A FRIEND



Reclaiming Joy Together



THE VALUE OF RFA PROGRAMMING FROM THE HEALTH CARE PROVIDER PERSPECTIVE

DAVID S. GELDMACHER, MD

Director of the Division of Memory Disorders and Behavioral Neurology at the University of Alabama at Birmingham, Dr. Geldmacher serves as Medical Director for Neurology at the University of Alabama (UAB) Hospital. He holds the Warren Family Endowed Chair in Neurology.

Community-based respite care provides a valuable asset to healthcare providers in supporting our patients and their families on the difficult journey through dementia. While platitudes like “You have to take care of yourself” are many, the actual opportunities for caregivers to do this are few. Many caregivers are acutely aware of the burdens imposed by providing care to a person with dementia but are unwilling to put another person in the place to shoulder that burden, even for a short time. This is especially true when the affected person experiences separation anxiety when away from the primary caregiver. The daycare model works for many, but often falls short of providing good levels of engagement and socialization for the person with dementia, especially those with milder impairments,

preserved social skills, and good mobility.

The model of respite care in faith-based communities has proved an effective way to address these problems. By being built as a ministry or community, the issue of shifting the burden of care from one person to another is transformed to care by many. The phrases “it takes a village” and “many hands make light work” come to mind here. The care is shared among a community of volunteers, each of whom knows what they’ve signed up for. Caregivers find great reassurance in that. Besides providing respite – and often a social outlet – to the caregiver, the community nature of respite programming provides a rare opportunity for judgment-free socialization and mental stimulation for the person with dementia.

“Beware of confusing programs with real life. Programs have their place, but life in the wild world is not programmable. Real life is not found in programs; real life is found in the give-and-take of relationships with other people. Life is filled with surprises, with hope as well as setbacks, with affirming as well as unsettling experiences. As shapers of a new culture, we must be very clear not to rest on programs but knowing each person and valuing what each person has to give and enabling each to make his or her contribution. Then we will be on the side of life.”

— CARTER CATLETT WILLIAMS

THE RFA CONCEPT

THE VOLUNTEER MODEL

Respite for All's (RFA) volunteer model supports people who are living with Alzheimer's and other forms of dementia by providing opportunities for joy, laughter, and relationship to coexist with this disease and its symptoms. Through this ministry, people who have been isolated, who are losing their identity, and who need connection are able to engage in a community of friends during weekday programs. Caregivers also get a much-needed break for personal errands or self-care while they leave their loved ones in the care of trained volunteers who lead participants through several hours of structured activity.

THE STRUCTURED DAY

Participants attending a four-hour day of respite enjoy the fun of interactive games and the fellowship of friends in an environment that supports independence. Each individual can contribute to decisions and choices made throughout the day, helping reinforce the human need for purpose and meaning, and the activities run by volunteers allow for the give and take of being needed and valued by another.

THE PROGRAM GOAL

RFA leads with the belief that the person is still whole, and volunteers look for ways to help participants recognize that in themselves. The atmosphere is one of a continuing-education class mixed with a cocktail party. The aim is to keep the mood light and fun, yet deep and lasting friendships are being made by the minute.





THE RFA THEORY

PURPOSE, MEANING, HOPE

The idea of building a program to provide participants with purpose, meaning, and hope stems from tenets found in Dr. Allen Power's book *Dementia Beyond Drugs*. His theory is that instead of filling those living with dementia with a heavy diet of powerful narcotics, anti-hallucinogens, antipsychotics, and anti-depressants, we need to be filling them with well-being.

THE HOLISTIC APPROACH

Dr. Power argues that once a person is diagnosed with dementia, we need to look at a holistic approach to taking care of their emotional and spiritual needs instead of relying solely on medicines that often make the symptoms worse. He believes we have to fill our loved ones up with the seven components

of well-being. Respite volunteers are trained to fill seven imaginary glasses each day full of:

- **Identity**
- **Connection**
- **Security**
- **Autonomy**
- **Meaning**
- **Growth**
- **Joy**



THE RESULT

By doing this, RFA volunteers are filling their friends with well-being. This is the core goal of Respite and, therefore, the essential duty of every volunteer and the motivation behind every activity and conversation.





ESTABLISHING THE RFA FOUNDATION



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ABOUT THE BARROWS

Warren Barrow was at the top of his game in 2014. As Executive Vice President of Caddell Construction Company, he had achieved national stature as one of the industry's top construction professionals. He oversaw all operations, estimating, and support for major construction projects all over the world. Most importantly, Warren and the love of his life, Dolores, had carefully planned for his coming retirement with dreams of travel, volunteering, and simply spending more precious time together.

HOW EVERYTHING CHANGED

Then suddenly, their world was shaken to its core and their plans rudely interrupted. The concept of "precious time together" was redefined by a change in Dolores' health. Warren's beloved wife began exhibiting strange symptoms that were finally diagnosed as Frontotemporal Lobe Dementia—a rare form of early-onset dementia that typically strikes people ages 45-65. His wife's diagnosis would prove to be the greatest challenge of Warren Barrow's life as he mobilized to support Dolores and manage her care. The Respite Ministry soon became Warren's anchor in ever-changing circumstances. The relationships developed with the Respite community were by far the most important source of support and fellowship as Warren and Dolores faced this staggering challenge together but not alone.

While living with FTD, Dolores' favorite pastime was to take carefree rides in Warren's antique '55 Chevy – a cherry-red hot rod. After her death, Warren sold the valuable car and used the proceeds to co-found the Respite for All Foundation with Respite Director Daphne Johnston in 2018. After a lifetime of overseeing major construction projects all around the world, Warren Barrow has made it his personal mission to spread the volunteer model of purpose and hope for those living with dementia. Warren's commitment to the Respite for All Foundation is the legacy of his devotion to his wife Dolores and a source of encouragement and real-time help for people who find themselves in similar deeply stressful situations. Like the people helped by the Respite for All Foundation, we, who serve at Respite, couldn't be more grateful for Warren Barrow's gifts and his leadership. The driving passion you find in all the RFA communities is steered by the power of two people and their undying love for one another.



RESPIRE: A FRIENDSHIP REVOLUTION

BY DAPHNE SIMPKINS

Since the birth of the Respite Ministry in 2012 at a Southern church in Montgomery, Alabama, their outreach to friends and neighbors living with dementia has been innovative and all welcoming. Though a faith-born ministry, Respite's place in the community, and now the world, has been an open-arms embrace—a great welcoming to friends, neighbors, and strangers of any ethnicity or faith who are living with dementia of any variety. Equally important, Respite also fearlessly welcomes and serves the people who are caring for people with dementia. The word caregiver is being revisited and redefined with many people attempting to find or redefine a word that best describes the people who are helping at Respite. That word is Volunteer, and it represents what the director Daphne Johnston calls “a friendship revolution.” Volunteer is a sweet, true word that emphasizes the helping hands needed to both serve and be served. For in the Respite care environment everyone is a volunteer. Everyone needs help. Everyone is needy because he or she needs to either receive help or give help during any season of his or her life. Volunteers help to make a Respite community serve and thrive in any locale. It is an adaptable model that can be tailored to your community and fit your resources and gifts.



RESPIRE'S HISTORY

From that early beginning of the Respite Ministry at First United Methodist Church in Montgomery, their model is now replicated in 20 other Respite programs with modifications for their own local neighborhood. Different names are chosen by each community, but the core values of volunteer Respite are all guided by one driving purpose: to come alongside others who need the help of neighbors and new friends. As a result of this commitment to loving and serving our neighbors, the story of dementia care is no longer one of dread and fear and assumed tragedy. More often, it is a story of trustworthy fellowship. Of jubilant and often, nostalgic, singing. Of being together. And after time with us, our sweet friends have not only reclaimed joy together. They sleep better. They have more peace and hope for the next day. That hope is priceless.



THE RFA MISSION

INCUBATE, INSPIRE, & SUPPORT

The mission of the Respite for All Foundation is to inspire, incubate, and support Respite Volunteer Ministries for communities seeking to minister to persons living with Alzheimer's and other dementia disorders through education, funding, and shared best practices.



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RFA communities create service opportunities (see flood kits below) for those living with dementia along with art, music, and innovative hand-eye coordination activities.



WHAT MAKES AN RFA COMMUNITY SUSTAINABLE?

- No Overhead
- Minimal Paid Staff
- Social Program
- No Meds Handed Out
- Daily Tuition
- Director Training



RFA TRAINING PROVIDES:

- Volunteer organization
- Standard group training
- Manual for implementing communities
- Cost-effective tools
- Quality standards and best practices
- Coaching for new directors
- Marketing approach



VOLUNTEER TESTIMONY

"Respite is like a breath of fresh air in lives that have gone stagnant. It is an anchor for lives that have been overwhelmed by a gulf of anxiety, unfamiliarity, and tremendous uncertainty. It provides an opportunity for people who have time in their lives to pour into others, but don't quite know how or where or what to do, which in turn provides the foundation for surprising relationships and comradery with those you come to serve.

"Respite is defined by the prefix 'inter,' as in interdenominational, intergenerational, interracial, intergender (if that is a word), and inter-acceptance (meaning you are accepted at whatever point you are in life with whatever you can or cannot bring to the table). Respite is where someone who is sinking can find solid ground. To borrow an old Charlie Brown phrase: Respite is a warm blanket."

- TRICIA SEAY, FUMC RESPITE VOLUNTEER



THE STRENGTHS AND ABILITIES OF OUR FRIENDS

“He’s just not himself” or “I miss who she was” are common feelings that are part of the grief of loving someone who is living with Alzheimer’s disease or other types of dementia. Yet despite the challenges they are facing, these precious friends will still retain many of the strengths and abilities they always had.

In his book *Alzheimer’s Disease and Dementia: What Everyone Needs to Know* (Oxford University Press, 2018), author Steven R. Sabat listed a number of strengths that continue to be part of an individual’s core identity, including the need to have purpose and the ability to experience fulfillment.

Respite Ministry is designed to foster purpose and fulfillment by providing caring interaction in a loving environment that supports growth for both participants and volunteers. One of the qualities on Sabat’s bullet list – “Can express themselves creatively via art, music, and dance and benefit from doing so” – could be considered a framework for many Respite activities. Volunteers work one on one with participants to engage in art projects that produce both a finished piece and a sense of accomplishment. The end results dually represent precious teamwork and moments shared with another, which are benefits that are commonly absent from the lives of those living with dementia. In addition, each Respite day wraps up with a group singalong, and Respite members enjoy familiar hymns and old-time folk classics.

Sabat also said that individuals living with dementia “can have spiritual experiences and retain religious perspectives.” This fact came home to the leaders of the Respite Ministry at First United Methodist Church during a chapel service where a friend said that he wanted to be able to pray for others because so many people had prayed for him.



ALZHEIMER'S DISEASE & DEMENTIA

WHAT EVERYONE NEEDS TO KNOW™



As Sabat said, individuals “can feel and show love for and gratitude for others.” And when this same kindhearted gentleman was given Christmas gifts from the ministry, he later took them home and put them in stockings for his own children.

Our friends also have a “need to be able to act independently and to have choices,” Sabat said. No one is pressured to join in activities. The volunteer model has created a rare environment of autonomy where those living with dementia are able to choose their own actions. In addition, volunteers are reminded to support participants in their activities—instead of rushing in to take over.

This volunteer model also embraces and supports a number of other qualities that Sabat says our friends retain, including:

- *Are sensitive to the emotions and vulnerability of others*
- *Can work to retain self-respect and dignity*
- *Can appreciate and yearn for the love and acceptance of others*
- *Need reassurance and compassion*
- *Can display and appreciate humor and other valued emotions*
- *Can act out of intention in meaningful ways in social situations*
- *Can recognize and remember the good intentions of others who try to understand, try to communicate, and show kindness*
- *Are aided by non-judgmental people and the non-anxious presence of others*



Reclaiming Joy Together

Finally, working purposefully and finding fulfillment helps our friends achieve another quality on the list: “Retain selfhood in a variety of ways.” After all, our friends are still who they are, and we love them just as they are.

PROGRAM SPOTLIGHT

ASBURY UNITED METHODIST CHURCH



Reclaiming Joy Together

HOW IT LAUNCHED

Anchor Community Respite Ministry was launched at Asbury United Methodist Church in Birmingham, Alabama, in October of 2019. The church's Director of Congregational Care, Maggie Dunaway, had been drawn to this ministry after serving as her own mother's caregiver following a diagnosis of vascular dementia. After she learned about respite ministry, Asbury put a program in place based on the RFA model.

THE ROAD TO RESPITE

The church's road to Respite included putting together a team of volunteers to establish the program, hiring a director to run the program, and making visits to other programs. The team was trained by RFA leader Daphne Johnston, and they spent time planning and marketing the program in the community and among local medical practices. The launch of the program was funded by member donations, mission committee donations, and a fundraiser. The program has since applied for and received two national grants and continues to receive donations from members and volunteers.





RFA'S REACH

1200 VOLUNTEERS
TRAINED

900 FRIENDS
ENGAGED

20 COMMUNITIES

900 CARE
PARTNERS
SERVED

A NOTE FROM THE SENIOR PASTOR

"As a pastor, it is a joy to watch a new ministry succeed in its mission and fulfill God's call for compassion and care of vulnerable members of our church and community. I encourage you to make respite care a part of the fabric of your congregation and community. Please do not hesitate to contact us should you have any questions."

- REV. DR. KIP LAXSON



PROGRAM SPOTLIGHT

SAINT LUKE'S EPISCOPAL CHURCH

The Founders Place at Saint Luke's operates on Tuesdays and Thursdays, following this typical schedule:

10:00 - 10:05 AM ARRIVAL/DROP OFF

Participants are dropped off and enthusiastically greeted by volunteers who will escort them inside and get them settled. Caregivers do not have to get out of their cars.

10:00 - 10:30 AM TABLE TIME

Coffee and visiting, puzzles, word associations, theme for the day, and singing.

10:30 - 10:45 AM OPENING THOUGHTS / DEVOTION

All faith traditions and non-traditions are welcome at Founders Place.

10:45 - 11:15 AM MOVEMENT TO MUSIC

Chair exercise incorporating cardiovascular activity, strength-building exercises, and flexibility training using props (weights, scarves, bouncy balls, rhythm sticks).

11:30 - 11:50 AM GROUP ACTIVITIES

After a brief break, participants engage in activities like brain fitness, service projects, hand-eye coordination games, small group discussion, and group short story writing.

12:30 - 1:00 PM GROUP ACTIVITIES

After lunch, participants have more group activities like balloon volleyball, bowling, and parachute games.

1:00 - 2:00 PM ART PROJECTS & SINGING

A NOTE FROM THE SENIOR PASTOR

REV. RICH WEBSTER

Rector of St. Luke's Episcopal Church in
Mountain Brook, Alabama



"When thinking about the 'success' of Founders Place, I first consider the impact that any Respite Care will have on the families involved. This is direct, unfiltered, hands-on love that meets a deep need, both in the life of the person needing a little joy for a few hours each week but in the caregiver who is often running out of options when it comes to filling each day with activity and routine and hope. Founders Place is a lifesaver, in that literal sense of the word.

"But there is still more. Love leaks out all over the place, and Founders Place is no exception. The impact on our church is hard to express, but I'll start by saying that the future of Senior Ministry is one of engagement, and that means giving our Senior Adults purpose and outreach opportunities. Founders Place has become, in effect, an 'activity' for our Seniors as they care for their friends and find new ways to love each other. Everyone wants to be needed, and a Respite Care ministry restores the dignity and worth of each participant.

"Finally, our Respite Care is a witness, a witness to beauty and joy and love in the face of pain, a reminder that we all matter before God. We are a better church, and our children are watching..."

– REV. RICH WEBSTER



Reclaiming Joy Together



THE HERB OF MEMORY

Rosemary has been linked to the concepts of enduring love, memory enhancement, and in the 14th Century, it was believed to restore vitality.

Our three rosemary sprigs represent people living with dementia, their care partners, and community volunteers, all in need of the spirit of Respite.

What better symbol to represent The Respite for All Foundation?



If you would like to make a tax-deductible donation, please make checks payable to:
The Respite for All Foundation.



Mail to:

RFA n/c Daphne Johnston
2622 Fernway Drive
Montgomery, AL 36111
Phone: 334-440-9911

Please contact Wealth Management Associate Caroline Warren
at caroline.warren@ubs.com or 334.260.3883, for information
about making a stock donation to Respite for All Foundation

Thank you for helping our participants and care partners in this meaningful way.