



## **MEDIA RELEASE**

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### **NEW CHARITY RAISES ALARM OVER DEMENTIA**

A new charity has been launched to raise public awareness and provide desperately needed help to Bermuda's growing number of dementia patients and their families.

Action on Alzheimer's & Dementia (AAD), a registered non-profit, was founded by Bermudian Elizabeth Stewart, who recognised the dire need for the island to more effectively tackle issues related to dementia after her mother was diagnosed with Alzheimer's disease eight years ago at the age of 67.

"I discovered Bermuda had little to nothing to offer in terms of information, support and practical help," says Stewart, 40, whose mother Judith died in May this year. "It was a devastating diagnosis for everyone—especially for my mother, who felt very isolated and alone in her disease. I was on the web every day learning what I could about Alzheimer's, what treatment my mother should be having to preserve her memory as long as possible, and what we could do on a daily basis to help her. It was steep, emotionally-taxing learning curve that our family meandered through."

Now Stewart hopes AAD will be able to help other families trying to cope with the disease, and also educate medical professionals, caregivers, nursing homes and other health services in Bermuda about the best care and treatment practices for surging numbers of dementia patients. Alzheimer's is one of numerous types of dementia, and one of the most common. A progressive disease that destroys areas of the brain, it causes memory loss, confusion, and eventual loss of speech, understanding and movement. While most cases of Alzheimer's develop after age 65, so-called 'early-onset' Alzheimer's can be diagnosed in people as young as 30. The disease has no cure, but studies indicate drugs can help slow its progression.

"I had this overwhelming feeling that more *had* to be done to help those with dementia and their family, and that public awareness of this global problem needs to be raised," says Stewart.

As the international community marks World Alzheimer's Day on September 21, Stewart is speaking out to raise public awareness about the disease and other dementias. "I stress the word *disease* because it doesn't seem to get recognised like cancer, heart disease and

diabetes,” she says. “Yet, every four seconds, someone worldwide is diagnosed with dementia. Thirteen percent of individuals age 65 and older have Alzheimer's disease and after age 65, the odds of a person having Alzheimer's double approximately every five years—to 50 percent when an individual reaches the age of 85.”

High healthcare costs are also an alarming factor. The cost of caring for a person with dementia is four times that of looking after a patient with cancer or heart disease. Despite this, dementia research is desperately underfunded, she says. More than seven in 10 people with Alzheimer's disease live at home, where family and friends provide almost 75 percent of their care.

“Alzheimer's disease and others dementias are rarely talked about in Bermuda—yet it is a big problem that is only getting worse as our population ages,” says Stewart. “It needs to be understood, treated and get the same recognition and support as other diseases on this island. We have to think about who is going to care for individuals with dementia, where they are going to live, who is going to finance their care? The reality we need to face is that one in four of us *will* have dementia by the time we are 80 and these are important questions that need answers.”

AAD's goals include:

- Increasing public awareness about Alzheimer's disease (the most common form of dementia) and other dementias through written materials, website ([www.alzbermuda.com](http://www.alzbermuda.com)) & public forum participation;
- Providing information and dementia-specific training for those working in healthcare settings;
- Providing information, emotional support and financial assistance to those caring for dementia patients, including payment for medications, medical equipment and respite care for family caregivers;
- Helping to identify and help those in the community who are living alone with no identifiable caregiver or advocate;
- Hosting support group meetings for family members and those with dementia on the first Saturday of each month.

The first major initiative organized by AAD will be a series of training sessions and seminars for individuals working with dementia patients. AAD is bringing two representatives from the national charity Dementia UK to Bermuda at the end of November to conduct a full day of training on Tuesday, November 27 at the Fairmont Hamilton Princess Hotel. There will be a small charge to attendees.

“Anyone who works with, or encounters individuals should attend,” urges Stewart. “This includes those who work at care homes in Bermuda, those working as private caregivers, family members who are caring for someone at home, nurses, doctors, or anyone who is genuinely interested. As far as I know, this is the first time there has been any dementia training by an outside organisation. I really hope it will not only provide valuable

information and tools but also motivate and inspire everyone who attends to improve the lives of those suffering dementia in Bermuda.”

The visiting Dementia UK trainers will also hold a question-and-answer session for families, a lunch-and-learn for GPs at the King Edward VII Memorial Hospital, special training for staff and an audit of the ARDU/CCU facilities at KEMH, plus audits of two participating care homes in Bermuda.

“What I have discovered is that there is little to no dementia-specific training for those working with individuals with Alzheimer’s disease and other dementias,” Stewart says. “This has to change. It can be a very challenging and emotionally-draining job to care for someone with dementia and it is really important that we inspire our care workers and give them the knowledge and tools to care for those with dementia on a daily basis to the best of their ability.

“There are so many things that can be done to improve the daily lives of all people with dementia and we need to find out what these are and implement them.”

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