BY DANIELLE ARENDS, MSN, RN, APN
SUSAN FRICK, MSW

Without Warning™

Lessons Learned in the Development and Implementation of an Early-Onset Alzheimer's Disease Program

Few programs have been developed to meet the needs of those living with early-onset Alzheimer's disease. In 2004, we began Without Warning™ and have since led a daylong seminar, 57 family meetings, 3 events for children younger than 18 years, 3 events for adult children, and numerous social events for the whole family. We have studied the impact of this disease on the entire family and the importance of a strong, organized program. More work is desperately needed to continue to address the needs of this population and to fill the huge gap in services our country currently faces.

Key words: Alzheimer's disease, dementia, early-onset Alzheimer's disease, family, program development

"Aren't I too young to have Alzheimer's disease (AD)?" When we envision a person living with AD, what comes to mind is the image of an elderly person. However, it is estimated that as many as 10% of those diagnosed with AD are younger than 65 years and have what is called early-onset Alzheimer's disease (EOAD). Although EOAD is defined as AD diagnosed before the age of 65, it can affect people much younger. In fact, most individuals with EOAD are in their 40s and 50s when symptoms begin. Because of their youth, the experience of AD is profoundly different for those with early onset. As noted by Harris et al in their article "Living With Early Onset Alzheimer's Disease: Exploring the Experience and Developing Evidence-based Guidelines for Practice,"

> People diagnosed with early onset dementia appear to have added additional stressors because of their age and stage in the family life cycle. These added stressors, we believe, have more of an overwhelming impact upon the whole family system. These challenges are related to obtaining a diagnosis, changing family roles and relationships, workforce and retirement issues, and feelings of social isolation.[1(p119)]

Alzheimer's disease is a devastating illness at any age, but when it strikes during midlife, it is often shocking and overwhelming. Many patients do not feel prepared for the abrupt changes in lifestyle and family dynamics that typically accompany an EOAD diagnosis.

Nationally, most programs are designed to support families living with late-onset AD (diagnosis after the age of 65). Few programs have been developed that are specific to the needs of people with EOAD, although they are experiencing issues that are not common to those who are older when diagnosed (Table 1). Because living with EOAD is different, these individuals need the opportunity to meet others who share their experiences. As professionals, we must first acknowledge that journeying with EOAD is unique, and then begin to fill the gap in services for this subset of individuals with AD who are younger at the time of diagnosis.

Throughout this article, we share our experiences in running a support group that is specific to the needs of those journeying with EOAD. Over time, we have learned

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TABLE 1.

Group Discussion Topics Unique to Individuals With Early-Onset Alzheimer's Disease

- Getting a diagnosis
  - Doctor not thinking AD since so young; longer time to get a diagnosis
  - Often mistaken for depression and referred to a psychiatrist
  - How many doctors they had to see before getting a diagnosis
- Employment
  - Most still working at time of diagnosis
  - Relationship with coworkers was strained
  - Anxiety around when is the right time to stop working
  - Exit from work often awkward, stressful, and embarrassing
- Financial
  - No income at an age when not expecting it
  - Loss of current income and lifestyle
  - Possible loss of lifestyle and retirement
  - Financial planning may be not yet in place
  - Spouse now responsible
  - Difficulty accessing services because of age
  - Health insurance
  - Medicare gap
  - Social Security Disability Insurance
- Individuals
  - Lower self-esteem
  - Few peers who share the experience
  - Loss of role in household
  - Loss of employment
  - Loss of purpose
  - Difficulty in social situations
- For spouse
  - Loss of partner and is "working alone" (runs household, manages finances, raises children, social coordinator)
  - Always in charge; always responsible
  - Rarely alone
  - Becomes the breadwinner
  - Loss of intimacy
- Children
  - Will this happen to me? Fear of the future
  - Did I do something wrong?
  - Life is more restricted (parents focus is elsewhere; parents not able to bring kids places)
  - Impacts social life (changes in peer relationships; do not want to have friends over)

(*continues*)

TABLE 1. (*Continued*)

Group Discussion Topics Unique to Individuals With Early-Onset Alzheimer's Disease

  - Emotional issues (helplessness, depression, loss of control, embarrassed)
  - Having troubles in school—anger issues
  - Loss of parents as a couple
  - Loss of "mom and dad" role models
  - Loss of childhood/innocence
  - Taking care of younger siblings
  - Taking care of both unaffected and affected parents
  - For the person with AD—more chaos in the house

Abbreviation: AD, Alzheimer's disease.

much about providing a comprehensive program that offers education and support to the entire family unit. We describe the mission of the group and provide practical advice for those who want to start their own group. We discuss how to determine a meeting location, the benefits of providing a program that meets the needs of both individuals with EOAD and their family members, how to structure the meeting and groups, and the specifics of running a large program.

HISTORY OF THE GROUP

Our early-onset program, Without Warning™, started in 2003 when Marty became a patient of the Rush Alzheimer's Disease Center (RADC). He had been diagnosed with EOAD several years earlier at the age of 49 and was determined to find help as he journeyed with the illness. However, he became very frustrated on learning that programs for individuals his age simply did not exist. He attended early-stage groups that supported people dealing with the early stages of AD but felt that he did not fit into those groups because he was an average of 20 years younger than the other participants. The types of issues he was dealing with such as having to stop working and dealing with his young children were not the topics of discussion in typical AD support groups. He inquired at many Chicagoland organizations and received the same news—programming specific to early-onset disease was not available. With Marty's encouragement, the staff at Rush began a task force to look at the needs of our early-onset patients. Marty was a key member of the task force, along with another individual with EOAD and her spouse. Other task

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force members included 2 nurse practitioners, a social worker, an education coordinator, a music therapist, and representatives from the Greater Illinois Chapter of the Alzheimer's Association.

The first thing the task force did was to gather data about how many of the RADC patients were younger than 65 years at the time of diagnosis and where these individuals lived. A survey was mailed to these families to determine needs and how to best meet them. Feedback from the survey encouraged us to host an educational seminar for individuals with EOAD and their families. In response to this request, a seminar was held in April of 2004, with 12 families in attendance. The topics in the seminar included (1) "Early Onset: What's It All About?" led by a neurologist from the RADC; (2) 2 facilitated discussion groups running concurrently, 1 for individuals with EOAD and 1 for family members; (3) "Planning for the Future" led by an elder law attorney; and (4) "Participating in Volunteer Opportunities" led by a nurse practitioner and a music therapist. Seminar evaluations were very positive and revealed that families wanted ongoing support in the form of monthly gatherings. In response to this request, our group has met monthly since June of 2004.

MISSION OF THE GROUP

The mission of our group is guided by 2 key principles: (1) to support the entire family unit through the journey of EOAD and (2) to allow the program to be individual and family driven. Our mission statement is

> Inspired by someone affected by early onset Alzheimer's disease, Without Warning™ supports and empowers individuals and their families who face Alzheimer's disease early in life. Designed to enhance vitality and quality of life, Without Warning™'s specifically tailored programs offer individuals and their families opportunities for education and support. By realizing that "we are not alone," we hope individuals and their family members will find purpose, dignity, and the opportunity to live each day with meaning and grace.

When developing a program, it is important to consider meeting the needs of the entire family unit. Because AD affects the entire family, it is beneficial to have a program that supports everyone involved. We have seen the benefits of providing multiple ways to support the entire family, including greater communication within the family about the disease, the opportunity for social interaction between families, and a chance for younger children to talk with kids their own age and realize that they are not alone.

Throughout the development of the Without Warning™ program, the individuals with EOAD and their family members have been the driving force. Through committees, questionnaires, and group meetings, members are encouraged to voice their desires and interests for the group. They have provided guidance on how the meetings should be structured, additional groups that would be beneficial, and what discussion topics would be of interest. In fact, one of them named the group Without Warning™. As staff members, we were considering names, but they were "dry" and did not convey the reality experienced by persons with EOAD. One of our task force members who has EOAD said that the name of the group should be "Without Warning" because that is how the illness came on for her. Without Warning™ is far more expressive because we listened to someone experiencing the illness.

By having the individuals with EOAD and their family members drive the development, the Without Warning™ program has been far more successful in meeting their needs. In some cases, what we as professionals thought would be a good program for these individuals and families was not of interest to them. For example, as staff, we were thinking about offering Web-based services. The group members, however, pushed to meet on a regular basis, and, as a result, deep friendships have developed. These friendships might not have flourished through a Web page.

Practical issues to consider

Meeting location

During the initial development of the Without Warning™ program, we put much thought into where we should meet. Selecting a comfortable and inviting setting is important. We wanted a place where people could sit, visit, and feel relaxed. We could have easily met at Rush University Medical Center in downtown Chicago. But we rejected the medical center campus, which is large and not always easy to navigate and which would be a constant reminder of their illness. Also, driving or taking public transportation into downtown Chicago can be an intimidating experience. Another option was to meet at a continuing care community in the Chicagoland area. We had collaborated with many of these communities for more than 10 years as we recruited participants into our longitudinal studies about memory and aging. Thus, many of them would have been willing to share their space with our group. However, we decided that continuing care communities would again focus on the illness.

We investigated meeting at a library but found that the meeting space was not conducive to the structure and atmosphere we had intended for our meetings. In the end, we decided that a church could provide this environment. For the past 4 years, we have met at St Peter's United Church of Christ in Elmhurst, Illinois, which is in a suburb west of Chicago. Our initial needs assessment had shown that many of our respondents lived in the western suburbs, so this was an ideal location. We are fortunate that the church believes in our program and donates the space to us. To express our thanks, we make a modest yearly donation.

When selecting a space for an EOAD program, consider how the group might grow over time. We have been lucky that the space we use is large enough to grow with us. In the 4 years since we started, the average attendance at Without Warning™ has increased from 10 people to 40. To keep group sizes small, we now have 4 to 5 separate groups meeting concurrently. The church we use has enough rooms to accommodate this arrangement.

We also wanted a location that was easily accessible, both in travel to the location and within the building. To make travel to the meetings easier, we picked a location that was near several expressways. Because there are few early-onset programs in the country, we have people who drive several hours to our group, and we have found that it is vital to choose an accessible location.

Within the building, we wanted a location that was relatively easy for people to navigate. We have seen that some of our people have perception problems. They favor well-lit rooms, hallways, and stairs, plus access to an elevator.

Meeting schedule

Our Without Warning™ program has always been structured to meet the needs of both the individuals with EOAD and their family members. So, we weighed carefully both the time of the meetings and the structure of the group. We meet once a month. The time of the meetings is from 10:00 AM to noon because morning hours are typically better for individuals with EOAD. About the structure of the group, we wanted time for the individuals and the families to meet in separate groups to discuss their own unique issues and time for everyone to be together. To meet both of these needs, we developed the following structure:

Most individuals with EOAD are in their 40s and 50s when symptoms begin. Because of their youth, the experience of AD is profoundly different for those with early onset.

10:00–10:30 AM Announcements and social time—coffee/rolls provided
10:30–11:30 AM Separate EOAD and family group sessions
11:30 AM –noon Social time

This structure has worked well for us over the past 4 years. Having the meeting in the same location and with the same food items provides a sense of consistency that is beneficial. Social time in the beginning of the meeting allows for individuals to familiarize themselves with the space and relax before breaking into groups. It is also an opportunity for members to ease into the meetings. When living with an individual who has EOAD, it is common to struggle to arrive to a destination on time, so this flexible first half hour provides a practical transition period.

There is benefit in providing an environment where couples and families can interact together. Many of our individuals with EOAD report difficulty socializing with peers who might not understand the communication limitations they are experiencing. In this setting, everyone is able to feel comfortable and safe, and many friendships have developed. Many individuals with EOAD have said that, since living with this illness, coming to Without Warning™ is the only place where they feel normal. They can socialize without fear and they appreciate being with a group where they do not have to explain their problems with memory or social interactions. Giving this time when couples or family members can be in a group and feel normal is an important part of the structure of an early-onset program.

After the 30-minute social time, announcements and introductions are made. This is when we share our progress on the many projects we do as a group. Our projects include public speaking, writing, social events, and coordinating a fund-raising gala. We also take this time to introduce any new members. Because the group has grown so large, the introductions are made by the staff and individuals have a chance for more detailed introductions in the smaller group settings.

At this point, we break into smaller, separate groups for individuals with EOAD and family members. This part of the morning typically lasts 60 to 85 minutes. We have kept the group meetings to 85 minutes or less because it can be difficult for some individuals with EOAD to sit in a group structure much longer.

Staff group facilitators

Because we run 4 groups at each Without Warning™ meeting, we require at least 6 staff members. For each group of individuals with EOAD, it is best to have at least 2 staff members. If an affected individual wants to get more food or coffee or go to the bathroom, it is wise to have one staff member available to monitor the situation while the second staff member remains with the group. When this situation arises, staff quietly check on individuals with EOAD and make sure they arrive back into the group safely. Although most individuals with EOAD are early in the disease process, in a new environment, there is always a chance someone could get turned around and lost. Each of the 2 family groups has at least 1 staff member to help guide the conversation.

Name tags

We have learned that name tags are extremely helpful. When arriving at each meeting, all members are given a permanent name tag that is preprinted. We use tags that are encased in a plastic sleeve. As members arrive, we randomly assign each family member to a group by placing either a yellow or green piece of paper in the sleeve behind their name. The color tells the person which family group to go to that day. For the individuals with EOAD, we use blue to indicate the "verbal" group and red to indicate the "music" group. Facilitators decide who goes into the blue group and who goes into the red group. This color assignment strategy is a discreet way to assign the groups, and in the end, we have 4 sessions running concurrently: yellow, green, red, and blue. At the end of each meeting, the name tags are collected for use at the next meeting.

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On 1 occasion, an individual with EOAD joined the family group by mistake. As a result, family members now receive a name tag with a subtle underline beneath their name. Individuals with EOAD receive a tag without an underline. This way, staff can quickly identify who belongs to which type of group.

Ending on time

One hour does not seem to be long enough for the family groups, and it is often difficult to end these sessions. But a timely wrap-up of the family sessions is important because it is a hardship for staff when the family sessions linger longer than the individual sessions. Early in our group development, on the completion of his group, an individual with EOAD went into the parking lot looking for his wife who was still in the family group. He was quickly located, but to prevent this type of problem, it is imperative that the family groups end in a timely fashion. We have found that a 5-minute warning before the end of the family session is helpful so that family members can begin to wrap up their thoughts. In addition, the group facilitator must leave the group at the completion time, even if the conversation is still in full swing. It is important that all staff members are accessible to the individuals with EOAD as soon as their session finishes. Prompt endings greatly reduce the risk of wandering and help provide companionship to those who may begin to feel anxious once their structured session has ended.

When these smaller group meetings are completed, we gather back in our original room for a 30-minute period of informal socialization. The social time at the end offers families a chance for goodbyes and to connect with those who may not have been in their group that day. It also offers time for members to ask questions of the staff and to get clarification on issues that came up in the sessions.

Group visitors

We are occasionally approached by media, students, or healthcare professionals who are seeking the opportunity to observe a meeting. Our policy is to never allow this type of observation, and we are very strict with this rule. Our goal is to provide a safe and confidential place for individuals and families to share. If media is interested in speaking with our members, we give the family the reporter's number and leave it up to the family to call the reporter if they so choose. Several of our families have participated in media projects including newspaper, radio, and television. In 1 case, a special meeting was set up specifically so that a reporter could interview a group of Without Warning™ members. If someone is looking to recruit for a research study, we ask that he or she provide a written flyer about the study, which includes a contact name and a number; we are happy to make this information available to all members.

Group dynamics

Groups for individuals with EOAD

When we began Without Warning™, we broke into 2 groups, 1 for individuals with EOAD and 1 for the family members. As we have grown and the needs of some of our members have changed, we further developed these smaller groups. We now break into 2 groups for individuals with EOAD. One is for people who are more verbal and have insight into their memory problems. They talk about life with EOAD and they brainstorm strategies for coping. Examples of group discussion topics that are unique to individuals with EOAD are given in Table 1. The other is a music therapy group for individuals who are less verbal. This group, which is led by a certified music therapist, incorporates music into the session while providing time to discuss feelings.

By having both groups available, we are able to better match the specific needs of individuals with EOAD. Staff regularly observes how the individuals are responding to their group. Staff communicates with each other and with the family to help decide which group is the best fit. Because AD is a progressive illness with good and bad days, these group assignments should be fluid and adaptable, responding to each individual's needs at the time. Furthermore, when planning groups for individuals with EOAD, it is important to consider how to break into groups, consistency within the group, session format, and how to handle decline in the individual.

Over our 4 years, we have learned the importance of handling a transition well. For any person, *transitions*, which are moments of change, can be stressful. For individuals with EOAD, transitions can be a time of great uncertainty. When individuals transitioned from social time of large groups to that of separate, smaller groups, we learned several things. Some people with Alzheimer's will follow their family members. Also, as people are moving into different groups, this can be a time when individuals with EOAD get lost. They can move into the wrong location or try to leave the building. We learned the importance of making this transition time move smoothly. We now ask family members to go to their groups (green or yellow) first. During this time, all staff members remain with the individuals with EOAD and help accompany each of them to their appropriate group (verbal "blue" or music "red"). As our group continues to grow, we will need to reevaluate this system. Recently, while helping the individuals with EOAD into their group, we did have a woman fall. Although she was unhurt, we would not want this to occur again. With more people at each meeting, we might need to have the families walk their individuals to the proper room before heading to their own group.

Consistency within the groups needs to be considered. It increases the sense of routine and comfort for the group members. We have worked to be consistent with regard to staff, format of the group, and techniques used within the meeting.

We find it important to have consistent lead facilitators in the individual groups. The additional staff members often rotate, but by having 1 consistent person, the members have a sense of routine and can develop a relationship with the leader.

To help structure the group, we have developed a binder filled with quotes from books written by people with EOAD. They are grouped into topics such as communication, identity, purpose, sharing the diagnosis, and self-esteem. The facilitator reads a quote, and then asks the members to comment on it. Using the quotes helps spark discussion and leads to more in-depth conversations. It has proven to be a good way to encourage people with EOAD to share their thoughts and feelings. The group also benefits from allowing time for introductions, time to share stories, and time to support each other.

There are a couple of facilitator techniques we have found to be very helpful in making the individuals with EOAD successful in a support group setting. The first is cueing. When we go around the circle or encourage a person to join the conversation, the person might need reminders of what the topic is or what he or she is expected to comment on. The facilitator might need to repeat information that provides a context or a framework for the discussion. A facilitator might also need to rephrase what the individual said. This helps the individual to comment further on his or her thought. It also helps others to understand what was said and respond to it. Such phrases that help with rephrasing are, "So it sounds like you are saying . . ." or "Let me see if I have this right. . . ." Rephrasing helps the person feel that he or she was heard and understood. It also allows the other participants to join in the conversation.

As with any early-stage group, what to do once an individual progresses to the moderate stage of the illness is a challenge. We are fortunate enough to have a music therapist for our meetings, which makes it possible for moderately impaired individuals to keep coming to the group as long as they are engaged in the music sessions. However, owing to limitations in staff, we are unable to accommodate individuals who require 1-on-1 companionship. At 1 time, a gentleman who had progressed in the illness experienced difficulties using the bathroom independently. In 1 situation, he urinated on the bathroom floor. In such situations, we have asked families to be responsible for providing companionship. In our experience, once this stage is reached, the family self-selects out of the meetings or the family member comes without his or her loved one.

Groups for family members

The family group sessions are run in a traditional support group format. We used to begin each session with introductions but received feedback from members that this took too much time. We now introduce new members only. We ask new members to share with us their name and who they are with at the meeting, as well as how old the individual with EOAD is. Our experience is that with little prompting, the families drive the conversation themselves. The facilitator serves as a resource, prompts conversation when needed, and asks probing questions when appropriate.

Each facilitator tends to have his or her own style. Some facilitators like to begin the session with an inspirational poem, quote, or thought. Jump-starting the group session in this manner is a great option, and families seem to respond well to it.

Our family groups have grown over time as well, and at one point, we had an average of 20 people in the family group with 2 facilitators. Within these large family groups, close friendships and support systems developed; however, we quickly learned that the group size was not ideal. Although we were able to address many different topics during the family session, owing to the large group size, we were often not able to delve very deeply into any one topic. In addition, it was difficult for the facilitator to ensure that everyone had a chance to talk. Some individuals felt comfortable sharing in such a large venue and others did not, and some members simply never had the chance due to time constraints. On the basis of our own experience and that of other support groups, the optimal group size is 8 to 12 members.

To address this concern about group size, we conducted a survey that gave family members a chance to voice their opinions about the large group size and its effectiveness or lack of effectiveness. We were curious to know whether family members preferred smaller groups, and if they did, how they wanted us to divide up. Brainstorming for the survey yielded several ideas: randomly divide up at each and every meeting, divide alphabetically, divide on the basis of stage of the illness their individual is experiencing, have members split themselves into 2 groups, offer 2 topics of interest each month so that members can choose which group to go to that day, split by gender, or alternate each month between the large group and 2 smaller groups. Overall, the survey revealed that family members wanted smaller groups and preferred that the division of groups be random. Although we were unable to accommodate each individual request, feedback from the survey helped us understand what most family members wanted.

To achieve this goal of responding to family requests, we randomly divide family members into 2 groups of approximately 10 to 12 participants each. This format has made it possible to keep the groups closer to the recommended size and still let members participate in group sessions with a variety of people. On occasion, we offer a special topic for the family members. They can choose to participate in the special topic or not. A non–topic-specific group is always running concurrently. For example, a chaplain ran a group highlighting spirituality, with the more traditional group running simultaneously. A key factor for families is learning and gaining support from their peers. Our format of random division and occasionally offering special topics seems to maximize opportunity for connection and works well for our members. However, the group continues to grow and members change, so it is important that we continue to request feedback.

Through 4 pioneering years of coordinating our Without Warning™ program, we have learned how to put together a comprehensive program for those journeying with EOAD. We have learned how being young with AD has unique issues. We have learned the importance of listening to the group members and allowing their wishes to be the driving force to the group. We have learned how to structure and facilitate the larger group and smaller group sessions. Finally, we have learned the wonderful benefits of providing an opportunity where people living with EOAD can meet others on the same journey.

It is our hope that more people with EOAD can benefit from the development of similar programs throughout the country. These benefits can best be expressed by those individuals with EOAD themselves. Bob, who is 65, said, "I had always been in an organization where I valued colleagueship and so it was wonderful to discover that I had colleagues on this journey too." Ron, who is 58, said, "You go from a work place and you have another place to go. I can't wait for those every-month meetings. I don't know what I'd be doing if I didn't have that." Susie, who is 55, stated, "I came here and realized that I'm not alone. We are able to laugh about what is happening to us." Finally, Ted who is 55, said,

> It is nice to be back because last month I really missed not being at this group because the group is very helpful. And having not been here last month it was a void. It feels good to be back with this group. It is like a replenishment each month. It might not seem like that, but it really does provide that—a refreshment. Because it really does get you, the weeks when things can be frustrating or that kind of thing. It is an uplifting and positive experience. It is just a great group and I'm happy to be here.

Danielle Arends, MSN, RN, APN*, is Certified Advanced Practice Nurse, Rush Alzheimer's Disease Center, Rush University Medical Center, Chicago, Illinois. She has 10 years of experience working with older adults with dementia.*

Susan Frick, MSW*, is Social Worker, Rush Alzheimer's Disease Center, Rush University Medical Center, Chicago, Illinois. She has 21 years of experience working with older adults with dementia.*

Address correspondence to: Susan Frick, MSW, Rush Alzheimer's Disease Center, Rush University Medical Center, 600 S Paulina, Suite 1027, Chicago, IL 60612 (susan_frick@rush.edu).

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