The Electronic Dementia Guide for Excellence (EDGE)

An Internet-based Education Program for Care of Residents With Dementia in Nursing Homes

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The Electronic Dementia Guide for Excellence (EDGE) is an Internet-based education program designed to use person-centered care principles to improve the quality of care and life of persons with dementia in nursing homes and other settings. The process of developing, testing, modifying, rolling out, and adapting the EDGE Web site and program in various settings is described.

Key words: *dementia, Internet, person-centered care, staff education*

ORIGINS OF EDGE

In the late 1980s, nursing home operators, administrators, staff, and advocates were concerned about how the implementation of the Resource Utilization Groupings' (RUGs) reimbursement system in New York State (NYS) was influencing the quality of services for people with dementia. Among their concerns was that the RUGs system appeared to function as a barrier to admissions for ambulatory

persons with dementia who, while they required a great deal of care in the nursing home that the RUGs system did not recognize in its reimbursement algorithms, were awaiting admission in hospitals in large numbers. In response to these concerns, the NYS legislature created an initiative to address care of people with dementia living in nursing homes in a more realistic and comprehensive manner. The initiative included funds to supplement NYS nursing home reimbursement rates specific to the demands of caring for people with dementia. It was at this time that the NYS Dementia Grants Program was created under the administration of the NYS Department of Health (DOH) to improve quality of life and quality of care for people with dementia living in nursing homes.

To date, the NYS Health Department's Dementia Grants Program has funded more than 90 projects intended to improve quality of life and quality of care for people with dementia living in nursing homes. The projects have ranged widely in topic, scope, and sophistication. Examples of the types of projects funded include culture change projects, family "partnership" programs, spirituality, innovative staff-training programs, end-of-life and palliative care, sexual expression in dementia, depression in dementia, pain assessment and management, ethical issues, resident exercise programs, and many other topics.

The NYS DOH selected Eddy Alzheimer's Services located in Cohoes, NY, to manage and coordinate the Dementia Grants Program. Serving as coordinator for Dementia Grants, Eddy Alzheimer's Services' role included monitoring and oversight of projects, serving as a liaison between the projects and the DOH, and organizing statewide conferences to disseminate the results of the projects and best practices in dementia care.

By 1994, discussions had begun between staff at the DOH and Eddy Alzheimer's Services, searching for a mechanism to capture the positive findings and successful experiences of the NYS Dementia Grants Program to make them more readily available to NYS nursing homes. The discussions ranged widely and rapidly included identifying "state of the art," "best practices" for people with dementia living in nursing homes. We talked with providers, researchers, advocates, and academicians knowledgeable about dementia care, and determined that it was now possible to identify research-based care practices that demonstrably improved dementia care in nursing homes.

It was felt, naively it appears, that only if nursing homes had easy access to this information, best practices would be implemented and quality of care and quality of life for residents with dementia would thereby improve. Thus, our sights were limited to providing good practical information that was made easily accessible and could be easily used.

The original idea presented to Eddy Alzheimer's Services by our collaborators at DOH was to produce something in print that captured in an easy-to-apply way what was working and what was new in the nursing home to care for persons with dementia. Books, pamphlets, and even CD-ROMs were considered and rejected as media for this use because we feared that either they would be obsolete by the time they were distributed, or would languish on the administrator's or staff development department's bookshelf, or both. The most attractive option that avoided these presumed fates for our work was to develop an Internet-based product that would be continuously renewable and universally available.

At this time, in 1994, many nursing homes did not have or use computers, except for 1 or 2 machines in the comptroller's or the administrators' office. Many more nursing homes did not have access to the Internet. Indeed, the NYS DOH was still developing and refining its own Web site. Despite the lack of any appreciable Internet access and capability in most nursing homes at that time, we had confidence that nursing homes were rapidly moving in that direction. Consequently, the decision was made to use the Health Department's Web site and the Internet as a distribution vehicle for the product, as yet unnamed, to follow.

Once the Internet was selected as the distribution vehicle, the scope of what would come to be known as *The Electronic Dementia Guide for Excellence (EDGE)* broadened considerably. In these heady days, there was tremendous excitement about jumping into newly available technology. Now, in addition to reporting the results of the Dementia Grant Projects, we now committed to searching out research-based interventions and state-of-the-art care practices that did not necessarily proceed from the NYS Dementia Grants Program, but included information generated from journals, conferences, newsletters, and other sources.

An EDGE Advisory Committee was convened to provide feedback about the developing program. Nursing homes, large and small, for profit and not for profit, participated in a series of field tests providing valuable feedback about how new information and care practices, delivered via computer diskette at that time, were actually incorporated into everyday life in the nursing home.

What we discovered was that providing information was not enough, even if the information provided was recognized by nursing home staff as useful and likely to improve care. Nursing home staff, for multiple reasons, could not easily translate such information into improved and sustainable care

practices in their facilities. A sizable gap existed between the availability of information and the use of that information in practice to improve quality of care and quality of life.

Thus EDGE acquired another series of tasks: designing, developing, testing, and presenting an implementation system whereby current research-based information could be translated into improved care practices for nursing home residents with dementia. The original goal of providing information was now only part of a larger goal.

The task of making new dementia care information accessible to care staff in a way that would actually improve care proved to be a difficult one. Many modifications and adaptations were created through a process of clinical testing, consultations with experts in the field, and attention to the changing dynamics of the dementia care environments. Always, we went back to staff in dementia care settings and asked for their feedback, revised and modified accordingly, and retested.

This process proceeded by fits and starts, characterized by lack of resources in the technical arena, but was consistently supported by our colleagues at the DOH. We had caught a collective vision about EDGE and its potential to improve the lives of residents and staff of nursing homes. In the end, we developed a vision for EDGE that grew out of our experiences in this initial phase and was additionally informed by the valuable feedback we received along the way.

We determined that the primary goal of EDGE would be to improve quality of care and quality of life for people with dementia living in nursing homes. EDGE would have the following characteristics:

- have practical use in the long-term care setting;
- be extremely user-friendly;
- be of real help to improve quality of life for people with dementia living in nursing homes;
- reflect research-based, state-of-the-art techniques and care practices;
- delineate best living practices in a continuum format, without being overly prescriptive;
- cover the most relevant subject areas within a reasonable scope of information; and
- be subdivided under each subject area into approaches for residents in the different phases of dementia.

DEVELOPING AND TESTING EDGE

We wanted EDGE to be a practical tool-kit built on a biopsychosocial model to be used by all staff in an interdisciplinary team effort to help residents with dementia to achieve optimal quality of life in the facility. The practicality of EDGE was addressed by creating step-by-step guidelines for clinical practice, which adapted the most promising research-based interventions in the dementia care literature for effective use in long-term care. In the same vein, we chose to focus on the problems identified by nursing facility staff and frequently written about in peer-reviewed journals as the most difficult for staff to handle: physically aggressive, verbally disruptive, and socially inappropriate behavior; bathing; communication problems; and lack of meaningful activity.

Interventions were grouped initially along the lines of how resources are organized in long-term care facilities, ie, by departments such as activities, nursing, social service, etc. After the first presentation to our advisory board, we decided we wished to show staff that these interventions found to be successful with residents with dementia were not "special care" for the person with dementia, but *necessary* adaptive care to help them function at their highest capacity, just as eyeglasses and wheelchairs are for people with other types of challenging disabilities. We felt strongly that if we were to succeed in helping primary care staff view persons with dementia as "whole people" with many skills from their life experience still intact, and who possessed all the same needs that the staff themselves had instead of "residents with behavior problems that needed to be managed," we would need to organize the content along the lines of how people's needs are organized rather than on how facilities are, ie, by departments.

The BASICS* Hierarchy Model[1] (Table 1) provided the necessary "looking glass." Modeled on Maslow's hierarchic organization of needs model[2] and The Personalized Care Model,[3] it demonstrates the array of human needs from life sustaining (biological) to life meaning (symbolic) and how their satisfaction is predicated on an integrated, sequential system of interactions with the environment. It was adapted for EDGE and accompanied by everyday examples of the life-supporting activities that care providers furnished to demonstrate in familiar, practical terms that as each level of resident need is satisfied, all staff help the resident reach for and potentially succeed at the next level of need satisfaction. This proved to be an effective way to reframe the clinical responsibilities of all caregivers from merely attending to behavior problems to creating enhanced possibilities for successful adaptation on the basis of lifelong preferences and adaptation patterns for the person with dementia in the long-term care setting.

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*BASICS is an acronym formed by using the first letter of each need level of the model described in Table 1.

Table 1.

BASICS Hierarchy Model of Resident Needs in Long-term Care (EDGE Looks at All Levels of Need for Residents With Dementia)*	
Need satisfied	**Fosters**

Biological
  Basic needs for food, water, oxygen, safety, rest, and human stimulation.
	Self-preservation
	  Resident physically cared for and safe.

Activities of daily living
  Personal needs that support life style (eating, mobility, dressing, toileting, personal hygiene).
	Self-dependence
	  Environment provides supplies and assistance to foster self-performance.

Societal
  Need for unique personal identity, privacy (resident's place in society).
	Self-identity
	  Environment provides for privacy affiliation with groups, culture, family customs, education, resident selection of associations with individuals and groups.

Interpersonal
  Need for connection with others (love and belonging).
	Self-esteem
	  Environment fosters social role expression, supports interpersonal, and social abilities, promotes social confidence and an atmosphere of caring and being cared about.

Creative
  Need for personal expression, problem-solving opportunities, and meaningful activity.
  Need for the activity in the resident's life that brings joy (face lights up—"the spark of life" is there, if even for a fleeting moment).
	Self-expression
	  Environment supports independent activity, humor, creativity, and encourages use of talents and skills. Environment identifies and fosters the activity that brings that "spark of life" to the resident. It also supports the resident to continue to problem solve and make decisions in his/her everyday life.

Symbolic
  Need for expression of beliefs, hopes, dreams, values, and autonomy (ability to control important aspects of life). Sense of peace in the universe according to the individual resident's belief of the meaning of life.
	Self-actualization
	  Environment encourages hopefulness and self-fulfillment: ("Being all you can be")
	  Environment respects and encourages expression of the spiritual dimension of the resident and supports spiritual ministry from outside sources as requested by the resident or family.

*Adapted for EDGE from Vickers.[4] Originally modified with permission in Ronch.[1]

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Initial testing

The format of the interventions evolved through clinical testing and discussions with multiple disciplines in long-term care facilities and during presentations of the concepts to audiences composed of a wide variety of persons who provided care to persons with dementia. These included NYS DOH administrative personnel, surveyors, acute care staff, participants at dementia conferences statewide and nationally, home care staff, long-term care provider organizations, inpatient and outpatient geropsychiatric care providers and researchers, Alzheimer Association staff, community service providers, senior adult service providers, adult home staff, recreation/activity association members, and senior dementia day care staff. Each group's needs and suggestions were taken into

consideration as each stage of the program was being developed. The reaction was uniformly positive, especially as it became known that current research findings on what worked in long-term care settings for residents with dementia was being made available to primary care staff in an understandable language. The most frequent comment was: "Finally, someone who has been there and can understand what it is like and what we need."

It was decided that each intervention module would contain an implementation plan with step-by-step guidelines and all the information we believed was required to introduce and utilize it in the facility. The guidelines of each module contained the clinical purpose of the program, its rationale, resident selection criteria, a list of materials needed, and an evaluation sheet to track outcomes. In addition, each module came with an in-service education

script with formatted worksheets to teach the intervention, a sample interdisciplinary care plan listing resident problems and strengths to address and support with the intervention, a quality management tool to problem solve "what worked and what did not," and an environmental consideration worksheet tied to EDGE caregiver goals to support all needs as described in BASICS.

As part of our pilot testing of EDGE, we taught BASICS to primary care staff during orientation at the new Marjorie Doyle Rockwell Center in Cohoes, NY, a specialized Alzheimer's Disease Adult Care Facility in the Northeast Health System. We learned that staff were helped to visualize what to do if the goals of their actions were stated in familiar terms so as to help them apply the EDGE and its BASICS approach in their interactions with residents. EDGE caregiver goals to direct quality care were therefore adapted from Ryden and Feldt's Goal-Directed Care Model (see Table 2). Primary care staff could more easily relate to these goals to support quality of life under every level of BASICS than they could to more philosophical or abstract goals. Establishing relationships with residents that had as their goal for the resident to feel safe, physically comfortable, experience a sense of control, feel valued as a person, experience optimal stimulation and experience pleasure added clarity and focus to their daily work. Worksheets were developed to provide an exercise that staff could use to answer how *they* accomplished each of the caregiver goals to meet their own needs on every level of BASICS

brought the EDGE and this brought the BASICS philosophy home to them in a practical way.

Our first field test with the first 4 interventions to be developed, Big Band, Gentle Bathing, Tea Group, and Rocking Chair Therapy, was reported to improve dementia care in some noticeable ways in 9 of the 13 homes in the pilot phase. Tea Group and Gentle Bathing were the most frequently used interventions we found. The 4 facilities within Northeast Health used in the pilot phase received hands-on support by the EDGE director in implementing the interventions and were more successful. Seeing how it is done in person proved to be the key to success. Another group of facilities needed and responded well to telephone support as they attempted to use these first 4 EDGE approaches. We thus became aware of how crucial ongoing support, preferably on-site, would be in implementing EDGE.

Final testing

The program evolved to ultimately be composed of 10 interventions and a comprehensive 8-key implementation plan by the second field test. The final design contained our most successful concept: giving caregivers the tools to solve problems by "Being a detective and looking for that spark of life," a central component in the creative level of BASICS. (The term *spark of life* was coined in our discussions about what we wanted staff to look for, so that they knew they had achieved success. It is also used by Jane

Table 2.

EDGE Caregiver Goals for Residents With Dementia Under Every Level of BASICS*,†	
Goal	**Supports quality of life in resident by**
For the resident to feel safe	*Biological level:* meeting the need for the resident to feel protected and safe in his/her surroundings according to the resident's view of what makes him/her feel safe.
For the resident to feel physically comfortable	*Biological and ADLs level:* meeting the resident's personal needs, providing assistance and resources to support his/her physical comfort.
For the resident to experience a sense of control	*ADLs and societal level:* meeting the need for the resident to have some meaningful participation in fulfilling his/her personal needs according to the resident's unique view, and at the level of his/her functional ability.
For the resident to feel valued as a person	*Interpersonal level:* meeting the need for the resident to experience caring for others and being cared about as someone who is important to the community in which she/he lives.
For the resident to experience optimal stimulation	*Creative level:* meeting the need for the resident to express himself/herself using talents, skills, and remaining abilities to the highest degree possible.
For the resident to experience pleasure	*Symbolic level:* meeting the need for self-fulfillment and joy in celebrating his/her fundamental value as a human being at whatever level possible despite the loss of self experienced in dementia.

*ADLs indicates activities of daily living.
†EDGE caregiver goals adapted with permission from Ryden and Feldt.[5]

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Verity www.dementiacareaustralia.com). Staff were asked to observe their residents closely when they were with them to notice what makes their faces light up and brings that spark of life, even if only for a moment, and then to build on that. These instructions changed staff from passive observers of residents to active searchers for what worked to elicit a response many thought was gone from the behavioral repertoire of many residents with dementia in nursing homes.

The suggestion that staff look for the spark of life as a response to an experience provided staff with both programmatic, formal interventions to enjoy with residents as well as informal opportunities for individuals to experiment using the EDGE principles. One certified nurses aide (CNA) at one of the facilities in the field test had come to an in-service "looking for that spark of life" and decided to try it out with a particularly difficult resident back at her facility. She did not think it would work because she had tried everything she knew to make this former nurse who now had dementia happy without positive results. She began to notice that whenever this ex-nurse, who talked nicely only to professional staff, was with someone wearing a name tag, she would caress it and seem to admire it. The CNA asked her if she would like to wear a name tag with her title on it as she did when she was working. That was when she saw that spark of life that she had never seen before on this resident's face. She had a name tag made for her, found her a white nurse's jacket to wear, and asked her to help make beds on the unit. The resident, aide, and staff on the floor were much happier than they were before, a result that persisted 1 year later.

Implementation in facilities was slower than estimated because of lack of computer knowledge, other facility priorities emerging, such as the minimum data set (MDS) 2.0 rollout, and the need for more hands-on telephone and direct consultation. We were granted an 18-month extension when we were able to demonstrate through our documentation that facilities wanted to use it but needed more help and more time.

EDGE VIDEO

A survey of staff in long-term care was conducted by Marjorie Doyle Rockwell Center and the comments were clear that respondents wanted to hear about a successful intervention from someone who "had done it in their setting and see it implemented with actual residents in a facility." We accommodated this wish by making the EDGE video, which showed the implementation of the 8 keys of the EDGE program at the Eddy-Ford Nursing Home. The interventions, *Big Band, Tea Group,* and *Lunch Club,* were carried out and filmed with actual residents living in the facility. The results were quite surprising even for those of us who believed in EDGE very much. For example, in the *Lunch Club,* a woman who had not cooked in 5 years flipped a grilled cheese sandwich back from the edge of the grill as it was about to fall off. Her daughter did not believe that her mother had done this until she saw the film. Another resident, who rarely talked in groups on the unit, related a long story in *Tea Group* about how she was "a really good ice skater" when she was young, during a discussion facilitated in the film. When other staff in her facility saw the film, they were surprised and then began to talk to her about her ice skating when they cared for her, bringing many happy memories back to her and building new ones with her caregivers.

The video was an effective tool for demonstrating the actual EDGE approaches in action and for providing a quick program overview to potential users. We therefore decided to use it as part of the EDGE roll out process.

EDGE rollout

The film was shown at the 6 EDGE rollout workshops presented across NYS where the entire EDGE product was demonstrated to a total audience of about 600 employees, administrators, and managers of nursing facilities. The participants responded well to the workshop and EDGE, especially when they were able to see the positive changes in residents and staff during the EDGE video. They liked the candid comments that the staff from a number of disciplines made in the video about how the program had made them feel good about going to work. An MDS coordinator, a speech pathologist, a staff educator, and a social worker told poignant stories in the video about how much better they came to know their residents and assess their strengths and problems during one *Tea Group* or *Lunch Club*. Although the quality of the video was not of professional caliber, it moved staff that saw it in all venues because, in the words of one respondent, it allowed them "to see how it was done with real residents by someone who had done it successfully." The rollout workshops featured a demonstration of how to implement a Big Band program, complete with music and instruments, using the participants from the audience as "residents" in front of the workshop audience. This live demonstration of what they saw on tape received much praise and generated even more enthusiasm for the program.

The key to EDGE, we found, is that it provides step-by-step guidelines and tools for every facet of the program.

It allows staff a means to step out of their traditionally defined caregiver role and meet the dementia resident as a person capable of having a 2-way relationship with them. This supports both the resident's and staff's ability to find that spark of life in what they do every day. One social worker who facilitates *Tea Group* said it made her realize why she went into social work in the first place. An MDS coordinator and a staff educator both reported that it is the best time of their week, making them know why they stay in their difficult roles at the home: "To see the smiles on the residents' faces."

THE 8 KEYS TO DEMENTIA CARE

The 8 implementation keys of EDGE, seen in Table 3, provide entry to a complete dementia-training program for facilities that want to create a comprehensive new approach to care. The first key opens the door to the EDGE program as administration embraces EDGE as an institutional priority and commits leadership to the program publicly. It outlines meetings with staff on all levels to achieve this goal. The second key contains an inservice to foster building staff-resident relationships with Big Band and creates a way for residents and all staff to interact in extra-role relationships. The third key provides a means of looking at the quality of life of individual residents using BASICS, whereas the fourth key walks staff through understanding resident needs and behavior as communication when coping with disruptive behaviors. The fifth key guides staff through a special program for the "difficult resident" who provides them with a chance to be successful, the Tea Group. Communication with residents who need help to communicate is taught with Lunch Club in the sixth key. The seventh key helps staff achieve a practical overview about how to put all they have learned about quality dementia care principles into practice. The eighth and final key culminates in the ultimate goal of and mechanism for quality dementia care: Strengths-based care planning using BASICS.

Since each facility is encouraged to make EDGE a part of its facility approach to care of residents with dementia at its own pace, the modular composition of EDGE permits gradual utilization of the program while specific gains become visible during the adoption process with the use of each key. Some facilities alternatively chose to use one component of a key to begin their innovation process, and so were able to use the keys with interventions at their core or one of the interventions tied to every level of BASICS (see Table 3) supplied with the EDGE program as their starting point.

THE EDGE ONLINE

EDGE went online in 1998 and is currently available to anyone at www.dementiasolutions.com. Although access to computer terminals varies widely among nursing homes, a growing number of long-term care personnel have used EDGE either at work or using equipment available in their own homes. Having the EDGE online has provided us with a significant amount of valuable user feedback despite the limited availability of interactivity on the site. The EDGE product and Web site will be undergoing a significant upgrade to improve ease of use and expand the amount of material available.

We have seen that although the idea of having such a comprehensive program available on the web seemed timely when we began, there were significant logistical problems that limited our ability to realize our vision for EDGE. The upgrading is one way to address some of these. The major difficulty continues to be the lack of ready and convenient access to computer equipment or most potential users of EDGE—the hands-on caregivers and their clinical managers. As computers have become more available where staff reside, if not where they work, we are hopeful that the newly improved site will be accessed by staff more regularly and at least one terminal in each facility will become dedicated for use by the ID team for care planning and to investigate potential solutions for care givers to consider.

APPLICATIONS IN THE CONTINUUM OF CARE SETTINGS

Adult care facilities

In response to the increasing numbers of persons with dementia residing in adult care facilities in NYS, the NYS DOH elected to develop a version of EDGE especially for enriched housing, assisted living, and adult care facilities through a partnership of The Brookdale Center on Aging of Hunter College and The Eddy. The 4 keys selected by the development team led by 2 of the authors (J.R. and N.C.) and the DOH leadership on this project were BASICS, principles of quality dementia care, EDGE goals for every level of BASICS, and strengths-based care planning (using physically aggressive behavior as the illustration).

The Eddy adult care facilities were chosen with DOH's approval as beta sites because of their record of excellence and innovation, familiarity with EDGE on a corporate level (having served as pilot sites for the original EDGE nursing home version), their electronic communication system and IT capacity to speed communication and product

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Table 3.

Eight Keys to Dementia Care
First key—Meetings with staff on all levels
• Meetings held on all staff levels
• Identifies if care is meeting resident needs
• Implementation plan facility wide or on targeted resident units
• Appoint motivated EDGE coordinator
• Reviews progress monthly
• Looks at adapting environment in each department
• Quarterly and annual evaluation of EDGE Program Tool
• EDGE Performance Improvement Summary Tool
Second key—Inservice: Building staff-resident relationships/A Big Band musical program
• A program that engages residents who need cueing to become involved
• Promotes staff/resident interaction out of caregiver/patient role
• Provides ongoing teaching of preferred dementia care model
• Bridges the gap between interdisciplinary and primary care staff
• Increases number of staff interacting with residents
Third key—BASICS inservice: Looking at the quality of life of individual residents with dementia
• Explains using BASICS as a framework to plan care
• Staff looks at *own* needs using BASICS
• Staff looks at *resident* needs using BASICS
• Caregiver goals focus caregiver actions to individualize care
Fourth key—Inservice: Understanding resident needs when coping with physically aggressive behavior (PAB) and other disruptive behavior
• Discusses factors that may trigger PAB and other disruptive behaviors
• Teaches staff how to observe and describe disruptive behavior objectively
• All staff that interacts with the resident collaborate on the plan
• Team identifies unmet needs and strengths to develop interventions for care plan
Fifth key—Inservice: Tea Group—A special program for the "difficult resident" teaches staff
• To use a familiar ritual to help "difficult" residents succeed in a social setting
• To facilitate rediscovery of individual resident lifelong social skills and competencies
• To provide residents an opportunity to share and experience control
• How to reaffirm a resident's positive identity
• How Tea Group can provide residents a respite from negative feedback and failure
• To see "difficult" residents in a "new light"
• To relate to residents in a normalized social setting outside of their caregiver role
Sixth key—Communication inservice: breakfast (lunch or supper) club
• Communication techniques taught and demonstrated in a natural setting
• Teaches ways to improve the communication ability of residents with limited skills
• Staff enjoys interacting with residents outside their usual caregiver role
• Old competencies return as remaining functional abilities are supported
• Residents risk using more active communication methods after bonding with their peers and staff in the group
Seventh key—Inservice: Putting quality dementia care principles into practice
• Acknowledges principles, caregiver ethics, rights and BASICS needs used in participant's daily care of residents
• Teaches how to put more quality dementia care principles into practice
• Allows staff to become part of the process of improving care in the facility
Eighth key—Inservice: Strength-based care planning using BASICS
• Points out the advantages of strength-based care planning
• Teaches how to use the MDS to identify both resident problems and strengths
• Demonstrates how a resident problem can affect his needs on every level of BASICS
• Provides means for all staff to work as a team to plan effective care approaches for a resident

Source: The EDGE Project (www.dementiasolutions.com).

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modification, and because they had 2 new facilities that were set to begin operation in the last quarter of 2001 whose staff would need this training to achieve corporate standards of competency in care of persons with dementia. Initial feedback about usability, clinical value, and outcomes was positive. Staff educators reported that this was a useful platform to provide needed training for staff at all levels in this setting. Statewide introduction of this EDGE/adult care facilities version to a sample of providers and regulators took place in late 2003.

Hospital settings

A unique application of the principles of quality dementia care used in EDGE took place at the Cabrini Medical Center (CMC) in New York City, beginning in 2000. CMC was awarded a United Hospital Fund grant to develop a family caregiver oriented acute care medical unit for persons with Alzheimer's disease and related dementias that was part of the their family caregiver initiative. The goal of this 8-bed unit, named "Windows to the Heart" by those who work on it, was to improve the quality of medical care and family experience during the patient's hospitalization, and to prevent the functional deterioration that typically accompanies hospitalization of people with dementia by building care partnerships between family members and hospital staff using a person-centered care philosophy.

Prior to the opening of the unit, the entire staff and family representatives, some of whom were also employees, participated in developing the unit's policies, procedures, and practices, and participated in training using an adaptation of the EDGE model that focused on how to achieve optimum outcomes at every level of BASICS. The goal was to use the family members of patients as informants and adjuncts in personalizing care while the patient was in the hospital, and interdisciplinary staff was taught to use the approaches to difficult behavior contained in EDGE. The unit received a physical refurbishing at modest cost to support its programmatic and clinical components and related goals. Patients admitted from the emergency department and transferred from other units because of behavioral or other difficulties have demonstrated a significant positive response to this specialized care, notably by requiring few or no psychotropic medications and by exhibiting fewer behavioral problems when cared for on the Windows unit.

The Windows to the Heart unit has become a model that has stimulated much media and public interest and earned a great deal of recognition for its innovative approach and positive outcomes.

Nursing homes

The Eddy Ford Nursing Home's Lunch Club and Big Band continue 5 years later. Two residents who were in the original group remain in both groups and have maintained their abilities to participate in them. Over the 5 years, many of the participants had intercurrent illnesses, but, typical of many of the residents in our pilot sample, regained their former function on recovery and returned to the 2 groups. Eddy Ford continues to have 2 Tea Groups, Lunch Club, and Big Band once a week with some of the same facilitators as well as new ones who have been trained by the veterans. Although formats have been adapted in some cases, the programs continue to be successful. They reported recently that the most motivating concepts for staff in teaching EDGE remain using BASICS and "looking for the spark of life."

Three special EDGE projects were conducted by graduate students at MDRC and Eddy Ford Nursing Home with staff on all 3 shifts to further refine the EDGE program. This resulted in their creating together a new teaching model using the EDGE Physically Aggressive Behavior module and Resident Assessment Protocol (RAP) activity worksheets to solve behavior problems by looking for that spark of life and using feedback from all shifts to individualize the resident's care plan. This modification enabled the interdisciplinary care planning team and the primary care staff together to recognize each other's expertise and value as teammates, who together could promote a better quality of life for residents and staff. The evening and night shift staff, who frequently are seen in a secondary role to the day shift staff, appreciated that their suggestions were taken seriously by the interdisciplinary care planning team. Their meetings became quality improvement forums on each shift as staff learned from each other what worked best with each resident when difficult behavior occurred. This project became the basis for *Behavior Rounds,* which was honored by the NYS DOH with a Best Practice Award.

After 5 years, the EDGE concept has evolved into new interventions, which fit tight schedules and low staffing levels. Seven of the original pilot nursing facilities, are using EDGE interventions, either in the original or adapted versions. For some facilities, it remains a component of orientation programs to teach newly hired staff how to see residents with dementia as unique persons, whereas in others where EDGE had been the basic teaching tool, it has since been replaced with effective programs using concepts learned from EDGE. Some facilities report that they still go back to using EDGE guidelines for new staff, whereas others continue programs as they began, but

report enthusiasm from some employees has diminished because of staffing issues and decreased resources, making time unavailable.

The EDGE and culture change activity

EDGE has come to be utilized as an effective framework for teaching staff to provide "person-centered care" to residents with and without dementia that reflects the growing interest in changing the culture of care in long-term care settings. Laurel Woods and Talmadge Park Care Center (Connecticut), Rowan Court (Vermont), Isabella Geriatric Center, Cabrini Center for Nursing and Rehabilitation (New York City), St Cabrini Nursing Home, and The Sarah Neuman Center for Nursing and Rehabilitation (Westchester, NY), and The Meadows (Cooperstown, NY) have all used the EDGE program as a central component of staff education in dementia care or as the blueprint for changing the nature of resident-staff relationships to reframe the way care is provided. The Sarah Neuman Center is currently conducting a large scale research project (funded by the NYS DOH Dementia Grants Program) using the EDGE as one component of their "tool kit" to implement and perform a multifaceted evaluation of a corporate (The Jewish Home and Hospital Lifecare System) sponsored, facility-wide program of culture change.

THE FUTURE OF EDGE

The EDGE Web site presentations and publication describing the approach in action[6] opened EDGE concepts to a wider audience. The Web site is undergoing significant upgrading and calls are still asking for referrals to the online program. We continue to suggest that facilities foster staff interaction using "BASICS—looking for that spark of life" concept and encourage them to use the EDGE format to write their own guidelines for effective programs that are working in their facility, so that they may be continued despite staff turnover.

In its original version, EDGE was difficult to navigate, dense with text and forms, and hard to use. As of this writing, we are preparing significant modifications to the structure and format of the EDGE site to enhance its effectiveness as an educational resource portal. These upgrades include changes in the visual architecture and navigational structure of the site to feature more user-friendly tools such as site maps, tool bars, drop down form menus, intervention problem searching, and layering of information to speed user access to the information they most need at each use.

We are also currently researching new online Web technologies that could be implemented into the next version of the EDGE online that will be easy to use by novices and yet have a greater impact on caring for persons with dementia in nursing homes. For example, a chat room or discussion board would provide a great communication vehicle among all caretakers so that they might be able to discuss their findings, thoughts, and/or ideas.

Our goal for the next step in EDGE's development is to have an easy to use yet comprehensive portal packed with information about how to care for persons with dementia that all nursing homes and other interested persons can log onto and use from virtually any Web-connected computer at any time. This would allow us to be up to speed with and make optimal use of current technology. The content of EDGE will continue to embody the principles of person-centered care and will keep providing the "how to," so as to help practitioners make the difficult transition from research to practice.

As a result of a strong commitment from the NYS DOH in EDGE, it will be reintroduced to the long-term care provider community over the next 3 years through a multi-pronged approach. This will include presentations and demonstrations at regional and national meetings and conferences, encouraging its use by the nursing homes awarded grants through the NYS Dementia Grants Program, and working with other stakeholders in long-term care to provide education about its benefits and inviting feedback about its use on the Web site.

Most challenging will be identifying a method to ensure the long-term upkeep, maintenance, and updating of EDGE over time. We plan to install EDGE on the NYS DOH Web site, where it will continue to be available for use by all nursing home staff and anyone wishing to learn about helping persons with dementia residing in nursing homes.

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