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A Focus On Hope Over Hardship

Adults with physical disabilities find hope, spiritual guidance, and self-discovery by participating in an award-winning Wellness/Spirituality Program.

TEACH ME TO LIVE WITH REAL hope, and I will give you my trust," says Mikala, a resident at The Boston Home (TBH) in Dorchester, Mass. "Here one can only be honest and live with real hope, not just a false substitute."

TBH, a not-for-profit nursing care facility for adults with physical disabilities—primarily multiple sclerosis (MS) and other progressive neurological diseases—helps residents like Mikala to find hope through a holistic process of self-discovery and spiritual awakening known formally as the Wellness/Spirituality Program.

Initiated by TBH in 1999, the program received the Hope Award from the Consortium of MS Centers in 2002 for inspiring hope, promoting healthy behaviors, and exemplifying a spirit of optimism in the area of clinical practice, research, and education.

Seeking Fulfillment

TBH is the only facility of its type in New England and one of the few in the United States. With an average age of 53, most residents have active and searching hearts. They desire to discover that their lives make a difference, to find support in coping with their dependence and failing bodies, and to find meaning in their lives. They hunger for spirituality: the deep-seated

passion to live well. To fulfill these desires, the first goal of the Wellness/Spirituality Program is to address both emotional and spiritual healing so that the residents can face

in turn, improves the quality of life for all at TBH. The Wellness/Spirituality Program at TBH is guided by an interdisciplinary team of professionals, who consult closely with the residents. The

team currently consists of the program director, two social workers, the facility's director of admissions and outreach, and a minister from a local church. But certified nurse assistants and other staff are also being trained to contribute to the process as part of career ladder programs.

With members of the Jewish, Hindu, Muslim, Quaker, and Christian faiths in residence at the 96-bed facility, every effort is made to keep the program all-inclusive, multicultural, and nondenominational.

Elements Of The Program

The components of the Wellness/Spirituality Program have evolved over the years through a series of team meetings, resident input, and individual program evaluations. Grass-roots involvement of the residents is considered crucial to the program's success and meaning.

While a number of ideas are on the drawing board or awaiting funding, the current program is stocked with semi-



their physical challenges and create for themselves a richer experience of life. In essence, the program aspires to create a climate of hope over hardship.

The second goal of the program is to encourage each resident as well as each staff member to discover the strength that resides within the human spirit. By so doing, a climate of mutual respect and acceptance is created. This,

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nars, presentations, and group and individual activities—all geared toward improving the spiritual well-being and quality of life for residents and staff. Among the selections are:

- *Life questions seminars.* During this series of six seminars, which meet once each month, small groups of residents discuss major life themes and approaches in terms of specific topics. Subjects have ranged from “tending our life’s garden” to “fires of love in our lives.” Residents are required to make a six-month commitment.

- *Death and dying seminars.* Residents and caregivers tackle the difficult subject of accepting mortality as a part of the normal cycle of life. Discussions range from memories of those loved, to thoughts of individual death, to the legacies of each one’s life.

- *Far away places.* This series of 17 or so short videos from the series “Field Afar” by the Maryknoll Association follows the exploits of groups of volunteers who travel the world helping people in need to improve their lives through teamwork and brotherhood. Each 25-minute presentation features people of a different culture.

The videos are followed by group discussions during which residents compare and contrast their own life circumstances with those of the people depicted.

- *Remember-when groups.* These sessions offer time for residents who are limited in speech or have cognitive issues to recall memories of childhood and experiences of family. The groups are especially helpful in enabling residents with impaired short-term memory to express remembrances from the past.

- *Sensory groups.* These gatherings provide sensory experiences for residents who are unable to communicate verbally but can respond, for example, to the smell of lilacs, the taste of apple cider, or the touch of leaves.

- *Writing groups.* Residents, who might otherwise be unable to compose a letter, are given the opportunity to express themselves in writing on events and experiences that they wish to record as keepsakes or share with family. A staff member does the writing but does not edit.

- *Memorial services.* These encounters provide closure to every death as well as an occasion for residents to honor and share memories of the deceased as a valued member of the community. Several residents have indicated the music and reading they hope to have at their service.

- *Shared spiritual experiences.* The staff and resident blessing-of-hands ceremony is perhaps the best example of a “shared spiritual experience.” In this ceremonial activity, all individuals wishing to have their hands blessed may participate. As each pair of hands is oiled and blessed by the leader, the

group reflects that theirs “are the hands of God on earth.”

- *Days of spiritual retreat.* These sessions allow a group of residents to bond and have several hours of shared discussion and prayer.



■ **One-on-one spiritual counseling affords each interested resident personal time to explore issues of spirituality.**

Other Activities

Some activities in TBH’s Wellness/Spirituality Program require the help of trained facilitators, experts, or instructors and are offered only when such individuals are available.

Examples include:

- *Relaxation response, autogenic training, conscious and mindful breathing techniques.* These sessions are alternately led by a staff member, resident, or caregiver who has been trained in the methods.

- *Adaptive yoga.* Sessions are led by a professional yoga instructor who will tailor the program for participants in wheelchairs.

- *Speakers’ bureau for religious holidays and national celebrations.* Recent guests have included a Buddhist monk and a lecturer on the meaning of Passover.

In addition, the program provides religious services for all denominations; bible-study groups, which allow residents of diverse religious backgrounds to come together in study and reflection; resident-led ecumenical prayer groups; discussion groups, which are designed to open up the world of religious dialogue; and one-on-one spiritual counseling, which affords each interested resident personal time to explore issues of spirituality.

The program also offers activities for TBH’s clinical staff, including individual consultations for staff in spiritual or material need and training classes in TBH’s Wellness/Spirituality Program.

The wellness-spirituality team is in the process of refining its own assessment tool, which will fit the unique character of the program. It will

include subjective feedback, specific evaluation tools, and statistical attendance analysis. But the team also realizes that improved quality of life for all at TBH cannot be fully measured.

Thus, any assessment tool may necessarily fall short. For the team, the criteria for measurement come from the residents’ personal interviews, evaluations, and shared comments. These measure tangible results and become a source for future development.

Resident Response

Margaret has found that participation in the Wellness/Spirituality Program has helped her interact more deeply with other residents with whom she had previously shared only on a social basis. She came to understand that she is not alone and has far more in common with others than she ever thought. The small discussions on a host of topics encouraged her to clarify and express her feelings, thoughts, and experiences. She has learned to ask for spiritual guidance and has discovered God to be more real and active in her life.

Jeanine notes that a great burden has been lifted from her shoulders and that she is free to express both her bouts of interior anger and fears of further inevitable degeneration. She is learning how to cope with the challenges of the present moment and of an unknown future.

Albert says he has learned how to communicate with those who are unable to speak and often seem to be out of touch with the reality around them. He notes how mischief can be glimpsed, restlessness sensed, and peace felt. This opens up a different way of seeing meaning in others’ lives and renews again the richness and power of simple human presence. But, as Albert cautions, your heart has to learn how to look. The Wellness/Spirituality Program taught him how.

It is not easy living with a progressive neurological disease. The residents at TBH want to live each day with the passion of the abundant life, experiencing meaning in their lives, knowing that they make a difference. They want to maintain interest in life and to be active participants in their own health, both exterior and interior. In short, they want to cultivate a life that accepts what is given and looks forward to tomorrow. They want to cultivate hope over hardship. The Wellness/Spirituality Program aims to be part of both their challenges and their victories. ■

For More Information

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- For additional information on The Boston Home, visit www.thebostonhome.org or www.wisdomwonder.com.