

# AIDS, HOSPICE AND VOLUNTEERS

## The Casey House Volunteer Program

### A Case Study

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#### INTRODUCTION

Casey House Hospice opened on March 1, 1988 and is Canada's only free standing hospice for people living with Acquired Immune Deficiency Syndrome (AIDS). Casey House is a thirteen bed facility nestled in a quiet residential neighborhood in downtown Toronto. The hospice is largely funded by the Ministry of Health but has a very supportive community which responds generously to fundraising efforts.

From the onset, Casey House has developed a multidisciplinary focus which incorporates volunteers as an essential ingredient. Volunteers participate in all aspects of hospice functioning such as assisting the nurses, welcoming visitors, administrative support, bereavement counseling, fundraising, and housekeeping. Casey House volunteers are fundamental to the compassionate, homelike atmosphere.

At Casey House, there are two types of volunteers, those on the Board of Directors and Board Committees, and those assisting with the provision of service. Volunteers who participate on the Board of Directors and Board Committees work directly with the Executive Director, while the front line service volunteers report to the Coordinator of Volunteers. This article will describe the volunteer program at Casey House, reviewing the ways in which it is unique and the challenges it faces.

#### VOLUNTEER ROLES AND STRUCTURE

Volunteers are involved in almost all aspects of Casey House Hospice. In 1990, volunteers contributed a total of 7374

hours at Casey House Hospice, which is a total of almost four full-time staff positions. Where possible, volunteers are divided into self-managing teams which meet on a monthly basis and take care of scheduling independent of the Coordinator of Volunteers. Many of the teams have volunteer team leaders who oversee scheduling and deal with daily issues. Each volunteer maintains a timesheet which is submitted monthly to the Coordinator of Volunteers. The timesheets provide both a measure of volunteer hours and a monitoring mechanism for the volunteer department to track volunteer activity.

Examples of volunteer teams are reception volunteers, volunteers who work directly with the nurses in all aspects of resident care (Support Care), grief and bereavement volunteers, volunteers who keep in touch with people on the waiting list (Outreach), volunteers who organize special events for the residents, housekeeping and maintenance volunteers ("dustbusters"), volunteers who manage the resource library and music library, volunteers who help with fundraising, a newsletter team, and many individuals who provide special services such as reading to residents, providing transportation, cutting hair, gardening, taking inventory, watering plants and bringing their pets to visit. The Coordinator of Volunteers delegates responsibilities to the volunteers in these roles, and counts on them to manage their teams.

#### VOLUNTEER RECRUITMENT

A policy of passive recruitment has been developed at Casey House due to

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the overwhelming number of potential volunteers who offer their services. Casey House receives an average of forty volunteer inquiries per month. Inquiries are responded to with an information package that explains the process, information about the Hospice, and an application form. When the application form is received, applicants are put on a waiting list for the next selection/orientation cycle.

New volunteers are incorporated into the program twice per year in order to maintain stability for the residents and staff and to maximize resident privacy. Each selection/orientation process incorporates thirty new volunteers into the program which satisfies the needs of the hospice without requiring active recruitment. At any given time there is a long waiting list of potential volunteers who have submitted an application. This surplus of volunteers is common within many AIDS service organizations in downtown Toronto but is not common to other hospices in the same community.

The passive recruitment strategy that results from this surplus of volunteers can be viewed in a positive light and may be interpreted as an outcome of a successful volunteer program. Passive recruitment saves staff time and advertising costs, allows for a very selective screening process, and indicates a favorable community response. It can, however, also be a potential drawback. The reality that Casey House is a popular place to volunteer creates a constant challenge in terms of recruitment and selection. The Coordinator of Volunteers must ensure that the selection process is objective and that everyone is given equal opportunity to participate. Potential volunteers are informed of the selection process, so that when they inquire they should expect to wait four or five months before an initial interview.

Moreover, by consciously adopting a passive recruitment policy the organization has unwittingly created a very homogenous group of volunteers, and is faced with the challenge of how to allow for diversification. At the time of writing there are 117 active volunteers, forty-nine (41.9%) women and sixty-eight men

(58.1%). Of the women, forty-four (89.7%) are heterosexual and five (10.3%) are lesbian. Of the men, nine (13.2%) are heterosexual and fifty-nine (86.8%) are gay. Given that most of our residents are gay/bisexual men, it is not surprising that a large proportion of Casey House volunteers come from the city's gay community.

Casey House volunteers are also a homogenous group with respect to race and ethnicity. Although there is some ethnic diversity, the volunteers are largely of European origin, and there are currently only two people of color who are Casey House volunteers. Since demographic information of the volunteers has only been documented in the past year, it is not possible to provide historical statistical information.

## VOLUNTEER SELECTION

Volunteers submitting completed questionnaires are invited to Casey House for an interview with the Coordinator of Volunteers. Potential volunteers are screened carefully and questioned about rigidity of their beliefs concerning spiritual issues, homosexuality and values in general. In addition to inquiries regarding their commitment and availability, individuals are asked about losses in their lives, how they deal with stress, the extent of their personal support systems, self awareness, their expectations, and their knowledge of Human Immunodeficiency Virus (HIV)/AIDS. From the shared experience in the last three and a half years it has become clear what type of people function most successfully as Casey House volunteers. Effective volunteers are those who are caring, nonjudgemental, flexible, self-directed, possess good communications skills, are gay/lesbian affirmative, and self aware. New volunteers should not be dealing with unresolved grief or other personal issues, should have a sense of humor, and have time and space in their lives to commit to Casey House for at least one year.

A few examples of volunteers who are not considered appropriate are people recently awakened to their homosexuality, and people who have recently experienced major losses or changes in their lives. Since twenty-five to fifty percent

more people are interviewed than can be accommodated, the challenge is to redirect those people who might be more appropriate in other agencies and to be clear and honest about why Casey House might not be the right place for them at this time. During the interview the Coordinator of Volunteers explores these issues with the potential volunteer, and together they make decisions about the appropriateness of the volunteer placement.

The issue of losses is much more difficult. At one point, Casey House had a strict policy that anyone who had lost someone close to them should have to wait fourteen months before volunteering. This was to allow people time for grieving around the one year anniversary date of their loss, and to encourage them to take care of themselves before they began taking care of others. In AIDS this presents a dilemma because so many people from the same communities are dying that many individuals have experienced multiple losses. In response to this dilemma, a less rigid approach has been taken. Since only half of the volunteers are involved directly in resident care, it is possible to involve people in hospice work with varying levels of resident contact. Now, people are encouraged to wait an appropriate amount of time, as agreed together with the Coordinator of Volunteers, before volunteering at Casey House. Each situation is evaluated on an individual basis.

One example of a situation where a potential volunteer was not deemed appropriate for volunteer work was a woman who was caregiving at home for her husband who was in the terminal stages of cancer. She wanted to be a Support Care volunteer at Casey House as a way of learning about palliative care and obtaining support for herself as a caregiver. Her needs were so great that she would be more appropriate as a client than as a volunteer. After some frank, supportive discussion she realized volunteering at Casey House was not the most appropriate way to work through her issues, and she was referred elsewhere.

Another example is of a gay man whose lover had died at Casey House two years ago, and who not only had AIDS

himself but had been caring for friends with AIDS. He applied to be a volunteer but made it clear he did not want resident contact but would prefer some administrative type of position. He wanted to volunteer at Casey House because of the contribution the hospice had made to his life and his community. During his interview with the Coordinator of Volunteers it was decided that he would be best suited to volunteer in a part of the building separate from the residential floor.

## ORIENTATION AND TRAINING

Volunteer Training is an ongoing process at Casey House. The initial orientation occurs only twice per year and involves twenty hours over a weekend period. Staff and experienced volunteers get to know each other and facilitate sessions on communication skills, bereavement issues, AIDS information, infection control, the history of Casey House, hospice philosophy, confidentiality, and the volunteer experience.

The orientation weekend is mandatory for volunteers in all departments of the Hospice and is only the first step. After the orientation weekend, volunteers attend practical skills sessions specific to the department they have been assigned to, and complete their first three shifts with the same experienced volunteer. This teaming of new volunteer and experienced volunteer helps to build the confidence of the new volunteers and serves as an informal buddy system. New volunteers are encouraged to contact their buddy if they have questions or need to discuss an issue surrounding their shift.

In the past there has been discussion about extending the volunteer orientation over a series of weeks as opposed to an intensive twenty hour weekend. An extended initial training period would give people more time to integrate the new information. However, when volunteers are asked to evaluate the orientation weekend the response is favorable. Comments have indicated that the orientation was very moving, concise, worthwhile, and reinforced their initial commitment. All of the sessions during the orientation weekend are of equal importance, and they build on each other. The weekend

serves as a team-building mechanism and is effective in screening out less committed volunteers. Thus, it is generally considered that those volunteers who cannot set aside one weekend as part of their commitment are unsuitable.

The training process at Casey House has evolved over the past three years to include suggestions made by the volunteers themselves. For example, the order in which the workshops are presented at the orientation weekend has changed. A panel of experienced volunteers who share their experiences with the new team has been included. There are also more communication exercises.

### VOLUNTEER SUPPORT

As a hospice, Casey House is committed to care for the caregiver, in addition to care for the resident. Support systems for staff members have been in place since the opening of Casey House, but support systems for volunteers were not immediately recognized as a priority. In recent years, however, support for volunteers has been identified as the number one ingredient that keeps volunteers involved in the Casey House volunteer program.

In January 1988, the very first Casey House volunteer orientation, twenty volunteers were trained, and three years later in January 1991, seven of those volunteers were still active. Of a group of twenty-four volunteers trained in October 1989, twelve (50%) are still active on their second anniversary. More recently, in June 1990 a group of twenty-one volunteers were trained and at the one year mark, June 1991, all twenty-one (100%) were still active. Finally in October 1990, twenty-four volunteers were trained and in October 1991, nineteen are still active. To date, there have been ten orientation weekends.

The key supports in place for volunteers are monthly meetings, Volunteer Days, a three month follow-up meeting after each initial orientation, yearly evaluations, an open door policy with the Coordinator of Volunteers, a Volunteer Appreciation Party, and a subsidy for six massages per year. Volunteers are also invited to access the Casey House counselling team, pastoral counselor, and bereavement program.

The volunteers are divided into teams and each team meets on a monthly basis. The meetings serve as a communication mechanism to keep in touch, problem solve and provide an opportunity for ongoing training. Minutes are kept and mailed out to all team members.

Another support in place for Casey House volunteers are Volunteer Days. Volunteer Days are held three or four times per year with an outside facilitator other than the Coordinator of Volunteers. They are full day sessions open to all volunteers as an opportunity to meet volunteers from other teams, share the experiences of working at the hospice, and solve common problems.

Three months after their initial orientation weekend, the new group of volunteers meets again with the Coordinator. At this meeting they share the excitement and disappointments of the first three months, reacquaint themselves, reflect, and set some goals for the rest of the year. This meeting typically takes the form of an informal potluck dinner with some structured activity and some informal social time.

At the one year anniversary of this orientation date, each volunteer meets formally with the Coordinator of Volunteers to review the year, such as the personal goals set at the three month follow-up meeting, renew their commitment to the hospice, reflect on their goals for the upcoming year, and to decide if there are any new areas of the hospice they would like to be involved in. At this point, they also receive their Casey House mugs, a very important tradition. Casey House mugs have become prized possessions and are only available to volunteers as an appreciation after one year of service. Staff are unable to purchase them, and they are unavailable to the public. The yearly meeting with the Coordinator and the receiving of the mug have fondly become known as "muggings," and are an important acknowledgment of the contribution of each volunteer.

Each year during Canada's Volunteer Recognition Week, a Volunteer Appreciation Party is held in honor of the Casey House volunteers. At this party are the annual presentation of the "Wacky

Awards," awards presented to volunteers on the basis of their endearing qualities or unusual events. Casey House does not present awards on the basis of the number of volunteer hours, or the "best" volunteers because the contributions of each volunteer are equally respected. For example, the volunteers themselves decided not to enter any individual Casey House volunteer into the provincial Volunteer Award competition. They believe strongly that each volunteer contributes what they are able and they do not want to create a competitive environment which may lead to burnout or less teamwork. The "Wacky Awards" are a way of honoring volunteers for their individuality, and the unique contributions they make to the hospice.

The most essential and important forms of support, however, are the open door policy of the Coordinator of Volunteers and the constant barrage of both written and verbal thank-yous. It is important that the Coordinator of Volunteers is accessible, and that all staff contribute to the positive feedback that volunteers receive on a continuing basis for their efforts.

### CHALLENGES IN THE VOLUNTEER PROGRAM

Ninety percent of people applying to volunteer at Casey House want to be Support Care volunteers. The number of volunteers who are placed in that department is limited for the sake of the residents' comfort and confidentiality, in addition to space limitations. As a result, some volunteers feel that being a Support Care volunteer is the number one position and all other positions are less important. Casey House does not foster this perception, in fact quite the opposite view is held. The staff at Casey House functions as an interdisciplinary team and knows from experience that sometimes a non-nursing staff person, such as someone working in housekeeping or security can be the person who connects most closely with a resident. Each member of the team is equally important.

There are some notable dynamics surrounding staff/volunteer relationships at Casey House. For example, the role of Support Care volunteer, allows individuals an opportunity to have a significant

involvement in resident care. They assist nurses in bathing, changing dressings, feeding, along with other aspects of resident care that are not legislated nursing responsibilities. At times it may be difficult for nurses, particularly those that have come directly from more traditional medical settings, to adjust to the role of the volunteer in hospice. They are uncomfortable about involving a volunteer in resident care, and may be willing to ask a volunteer to clean a tub or stock the linen cupboard but not to attend to an incontinent resident. This attitude can cause tensions between volunteers and staff.

Volunteers learn very quickly which nursing staff are open to their involvement, and which nursing staff are less comfortable using their services. They are trained that part of their role is to educate staff about the role of the volunteer, and to demonstrate their effectiveness through their work with the residents. Generally, however, nursing staff and Support Care volunteers develop strong relationships and work well together. The essence of successful staff/volunteer interactions are the personal relationships that develop. To ease potential tensions, there is a nursing/volunteer liaison staff person who meets with the Coordinator of Volunteers to facilitate smooth relations between the two groups.

In other cases, staff may feel guilty about asking volunteers to work. For example, housekeeping staff have not been comfortable assigning tasks to "dustbusting" volunteers, whose specific role is to assist in the upkeep of the hospice. As a result, "dustbusting" volunteers have tended to have a shorter retention rate at the hospice than other teams, and after interviewing a few of these volunteers it became apparent that they did not feel needed. Consequently, we have incorporated a volunteer team leader who works with the housekeeping staff to educate them about the role of volunteers and to ensure that "dustbusters" are well utilized by fostering good communication with housekeeping staff.

Nurses applying to volunteer in Support Care have always been an interesting consideration during screening. In one instance, Jane (not her real name) recently

graduated from nursing school, had just been hired in her first full-time nursing job and applied to be a Support Care volunteer. During the screening process she was questioned about how well she would be able to separate her role as a Registered Nurse who makes decisions all day long about patients' health care needs in a hospital, from her role as a volunteer where she would be somewhat restricted in terms of decision making in terms of resident care. She was sure that the separation would be very easy, and indeed would even be a welcome break from the responsibilities of her job.

After a few short months as a volunteer, however, Jane disappeared. Her name was not on the schedule and at the end of each month there was no time sheet from her. The Coordinator of Volunteers contacted her and when they met, Jane explained her feelings. At work she was very task oriented with patients, made decisions, and was the person in power. At Casey House she felt her "wheels spinning." She would come to do a Support Care shift, feel out of control, and not be able to take on the less task oriented role of a volunteer in palliative care. The role separation was simply not possible for her. After a follow-up phone call, Jane met with the Coordinator of Volunteers and was reassigned to another volunteer team at Casey House, where she found a much more satisfactory arrangement.

Another difficult situation occurs when the potential volunteer has been recently awakened to their homosexuality. In this instance it is not uncommon for individuals to view Casey House as an environment where they can gain support and assistance with the process of self acceptance. Leonard (not his real name) had recently moved to Toronto in an attempt to live an openly gay lifestyle. He wanted to be with people who would facilitate that process, and to whom he could talk to about the daily issues he was confronted with. During his interview, the Coordinator of Volunteers indicated that Casey House may not be the best environment to serve that purpose. Volunteers are most effective when they have a strong self image, and are not in the midst of significant personal issues.

More recently, a difficulty arose relating to resident confidentiality. During the volunteer orientation weekend, there is a session on confidentiality. Volunteers sign an oath of confidentiality and are informed that a breach of the oath can lead to their dismissal. Confidentiality extends to other volunteers as well as to resident care information. John (not his real name) called in to a radio talk show and identified himself as a Casey House volunteer. He then proceeded to tell the story of one of the Casey House residents. No names were mentioned, so he assumed he was not breaking any codes of confidentiality. The details of the story, however, were so specific that any member of the Casey House community or the residents' network who heard the story recognized the family immediately. John was asked to leave the program.

#### FUTURE INITIATIVES

Since there is a limit to the number of volunteers that can be incorporated into the volunteer program, there is little room for growth and expansion. It is possible that new areas could open up that would involve one or two volunteers, for example, art lessons for residents or other special resident-based services.

Currently, however, Casey House is exploring the possibility of offering a home hospice program, which would facilitate services to potential residents on the Casey House waiting list. Such an initiative would provide a new avenue for volunteer involvement at Casey House, and would require development of an appropriate orientation process and support mechanisms. Volunteers working in a person's home have very different needs than volunteers working within an organization where staff support is always available. Currently the Outreach volunteers maintain contact with potential residents on the Casey House waiting list. Over the last three years, the experiences of the Outreach volunteers and the fact that 150 people have died while waiting to be admitted to Casey House have emphasized the need for a home hospice program. Casey House could draw on the experiences of Outreach volunteers in addition to other AIDS service organizations in order to develop the new program.

Due to the fact that Casey House is a unique environment, the volunteer department is in the process of developing research methods to track cohorts of volunteers from the time of their application through to the time of their departure. One objective of this study is to learn about the motivations for involvement. Forms filled out at application, at the three month follow-up meeting, at the

yearly meeting and at departure ask volunteers to consider why they wanted to volunteer at Casey House, to reflect on their experience and think about what has kept them active as a volunteer. This information will prove invaluable for understanding volunteer motivations and responding to their needs in order to maintain a stable, effective volunteer program.

