

The First Decade of the John Gordon Home: Learning how to House HIV and AIDS

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Without realizing they would set precedents and shape early responses to AIDS, in the early 1990s the AIDS Committee of London Ontario did a needs assessment of the gay male community, focusing on the conditions of those living with HIV and AIDS.¹ At the time, it was clear that some people living with the virus were ostracized by the larger community. As a result, The John Gordon Home was established as a community living space for those dying of HIV and AIDS. The home was named in memory of the first man in Southwestern Ontario to publicly declare that he had the virus. The Board of Directors of the AIDS Committee of London (ACOL) wanted the home to be a space void of judgment, where tenants could be themselves, and die with dignity.²

Outlining the Home's first decade shows key changes. The John Gordon Home opened in June 1992 in a Victorian dwelling on Dufferin Street in London, Ontario. The home was remodeled, furnished, and paid for by volunteers.³ Julie Johnston was the home coordinator and only paid staff for the first few years. Acting for ACOL and with help from the John Gordon Home Board of Directors, she organized the running of the home, which had room for eight palliative men and women with HIV. Tenants were cared for by a team of 30 volunteers, while continuing to maintain their relationships with their regular physicians, HIV specialists, and visiting

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1. Julie Johnston interview, St Thomas, Ont., Feb. 16, 2000. Julie Johnston, a staff member at the John Gordon Home, was among the five people interviewed in the preparation of this article during January and February 2000.
 2. *London Free Press*, Oct. 10, 1992.
 3. *Ibid.*

nurses. The mandate of the John Gordon Home was to supplement, rather than to replace existing health services.

Two years after the home's opening, in 1994 the Ontario Health Ministry gave funding for paid staff, which precipitated a restructuring of the institution. The care provided by staff continued to be supplemented by a strong volunteer component.⁴ The funding and restructuring was done primarily through the work of Sam Conti, who temporarily became home coordinator when Johnston took a maternity leave. In his new position, Conti came to realize that the John Gordon Home was too large to be run as a subsection of ACOL. The home and the AIDS Committee had diverged in their reactions to the virus; the home attempted to provide support for those with HIV, while the Committee had developed a mandate of education and prevention.⁵ Furthermore, the rent and upkeep was very expensive at the Dufferin location. It was becoming clear that the John Gordon Home should revisit structure, funding and volunteer staffing.

Conti proposed to ACOL that the home be run by an Executive Director who would be accountable to the John Gordon Home Board of Directors rather than to ACOL. Conti was later appointed Executive Director. This transition took place in order to make the home into a viable institution eligible for core funding. The Ministry of Housing was given a proposal for a new John Gordon Home to be built on Pall Mall Street. The response was affirmative.

When tenants and staff moved to the new home in 1997, it was a groundbreaking event. The John Gordon Home was the first facility in Canada to be built specifically for people living with HIV and AIDS.⁶ The new home, with eight apartments, was based on a supportive living model, while the old home had used a communal/hospice model. Next, amid a second restructuring of staffing and volunteer support systems, even more complex than that of 1994, Sam Conti died in January 1998 of complications while undergoing surgery.⁷ Subsequent evolution gave the Home a blend of new and old.

This evolution rewards careful study. This article is based on five interviews conducted in 2000 with current and former staff members and

4. *London Free Press*, Sept. 1, 1994.

5. Lisa Poultney, *London, Ont.*, Feb. 23, 2000.

6. *London Free Press*, Jan. 13, 1998.

7. *London Free Press*, Jan. 14, 1998.

tenants of the John Gordon Home. The staff included June Sarteretto, a Health Care Attendant who had worked there since the old home opened. Julie Johnston, also interviewed, was the original home coordinator and later co-acting Executive Director. (Johnston left the home in 1998.) Another former member interviewed was Lisa Poultney, one of the original volunteers who became the Manager of Finance and Administration during the first restructuring, and was co-acting Executive Director, with Johnston. The tenants interviewed included Norman Shearing, who lived for a short time in the old John Gordon Home before moving to the new location. Norman acted as a tenant representative on the Board of Directors. The other tenant interviewed was Danny McKeegan who moved in soon after the new John Gordon Home opened and was also a tenant representative on the Board of Directors. These interviews helped to elaborate the early history of the John Gordon Home. As one of the earliest such efforts, the Home's first decade merits close attention. Three key elements in its history will be explored: the dream which lay beneath the original home and the reality of communal living, the move to the new home and the changes in the care needs of people with the disease, and the crisis that volunteers and staff experienced because of the recurring changes in expectations.

The old John Gordon Home on Dufferin Street was a turn of the century, 8 000 square foot home rented from Joe Swan, then a London City Councilor.⁸ It was a communal living space with a shared porch, living room, kitchen, dining room, and bathrooms but separate bedrooms. Staff, volunteers, and residents shared meals together⁹ and used the front porch, kitchen, and living room as spaces for communication and community building. Julie Johnston remembered the old home with fondness. She was particularly proud of the family atmosphere that communal housing generated. Johnston acted as a benevolent authority, advice giver, and member of the family. Johnston explains the importance of the communal spaces for the family atmosphere of the old home:

In the summer I would meet up with tenants on the front porch. I would get the report of the day, what happened last night, just to let me know if things were going all right or not. I could always tell [from the] people who were sitting on the front porch who was in trouble.

8. *London Free Press*, June 23, 1992.

9. *London Free Press*, Feb. 26, 1993.

The common kitchen was the big draw for activities. Like any house, you sit around the dining room table, or you stand around in the kitchen. It was a kitchen party ... I would go in and have a coffee and whoever was at the table was there for a reason ... and that was an hour I would just spend and talk to whoever was there.

We also had a big living room ... I remember that the most. When it was really really sad there, when someone had died or someone was dying, ... the staff and volunteers would go and we would just flop. And I remember one afternoon we just told jokes, for an hour ... tenants were there, staff, volunteers ... it was a good healing thing, there was at least a place to be able to go and just be together ... It was really good for the families [of the tenants] that were there ... It gave them a sense of family ... They never felt that they were in anyone's way, or intruding on anyone ... It was like a home.¹⁰

As a resident of both the old and new houses, Norman Shearing remembered that there was more of a sense of family in the old house. Tenants, staff and volunteers participated in traditional family activities. Residents were asked to let others know if they were leaving the house, and they would call if they were staying out later than expected.¹¹ Dinner was at a set time and "Sundays we always, always, always had a roast."¹² This traditional sense of family living was very important to the residents who sometimes found themselves without the support of a biological family.

It's a chosen family ... with the gay community, a lot of us don't have families, because a lot of families reject us for being gay, so a lot of gays would chose their family. Some people may not get along ... but most of the time we get along pretty good.¹³

The AIDS Committee had been correct in their assessment of the importance of a supportive community for people living with HIV and AIDS. Some of the tenants who lived in the home had long been isolated from their families; some had been isolated economically, still others were isolated emotionally. Lisa Poultney remembers,

One fellow who was a cross dresser in a small town ... was absolutely terrified that someone would find out that he was gay and that he dressed up in women's clothes. So sometimes he did not go out for weeks at a

10. Johnston, St Thomas, Ont., Feb. 16, 2000.

11. *Ibid.*

12. Norman Shearing, London, Ont., Feb. 2, 2000.

13. Shearing, London, Ont., Feb. 2, 2000.

*time. So [in the Home] he was relaxed, for the first time in his life ... They made friends ... They got to be gay men alone ... with nothing else hampering them for the first time in their lives and for some of them, I really do believe it was the happiest time in their lives.*¹⁴

The gay male atmosphere at the old home served as a place where men felt a sense of community, belonging, and family. As Johnston stated, the community living spaces also allowed for the families who visited their sons to feel a part of the John Gordon Home family.

On the other hand, the old home was not problem free. For example, family members who felt more secure in a straight atmosphere felt discomfort in the gay male community of the home. Poultney recalls the mixed blessing that such an atmosphere sometimes provided:

*[One] family ... wanted to be ... with their ... gay son, but had never come to terms with his homosexuality, may not, in fact, have even known about his homosexuality before he became really sick. So they were very uncomfortable with maybe being around him, or even maybe being around the other residents. If you [as a family] were spending a fair amount of time there, you may have been exposed to people that ... you normally in the course of your life you would not be. There was discomfort. There were people who just refused to even come and visit their family. Some of that was homophobia. Some of that was fear of contracting HIV and AIDS. And it's always hard to tell where one starts and the other ends.*¹⁵

There were other unfortunate aspects of the communal atmosphere that affected the tenants themselves. For example, the two bedrooms on the ground floor were used for palliative tenants. This meant that gatherings in the kitchen might disturb the people dying in the rooms next to them.¹⁶ Furthermore, a number of tenants who lived at the John Gordon Home were schizophrenic. Many schizophrenics have difficulty interacting with others. For tenants afflicted with this type of problem, supportive housing rather than communal living is preferable. Poultney explains the difficulties that these tenants experienced in the old home:

Schizophrenia often put them on the streets, which then, further, put them at risk of contracting HIV ... Over-stimulation is very disturbing to

14. Poultney, London, Ont., Feb. 23, 2000.

15. *Ibid.*

16. Johnston, St Thomas, Ont., Feb. 16, 2000.

[schizophrenics] *and they really need the quiet and the privacy so that they can focus and filter the voices if they are having auditory hallucinations, for example. So a group setting as the old home had was very difficult for people who were schizophrenic. They would always have to retreat to a relatively small room.*¹⁷

At the time that the old house became operational, those admitted were expected to live for a few months and then die in the home.¹⁸ In terms of the physical layout of the old home, palliative care sometimes became quite difficult. There were only two bedrooms on the first floor. Tenants who had total mobility loss were assigned to these rooms, while those tenants who could walk up stairs had rooms on the second floor. However, sometimes people who lived on the second floor would become immobile when there was no space available on the main floor. This meant they were trapped in their rooms, and could not participate in the atmosphere of the home. Even those who lived on the second floor could not walk all the way up the stairs without resting. Shearing remembers, "I was upstairs, and when I first moved into the John Gordon, stairs were a little bit of a problem for me because [I was] getting out of breath by the time I got up there".¹⁹

In the early to mid 1990s the home catered to individuals who were dying of the HIV virus. June Sarteretto recalls that the division of tenants onto two floors was impractical for palliative care, "People were just too sick; we needed to get to people faster and better."²⁰ Johnston explains the rudimentary devices that the volunteers and staff developed in order to monitor the tenants:

*At any given time we would have four palliative people. So if you were on shift you had to go between the two levels. If someone needed your help upstairs, communication became a problem. We worked around that. We had phones [on] ... the meridian system, so that we could check on people. We developed our own unique communication tools to use for people when they needed us ... There was a feature that you could press ... and it would buzz in a room, and you could talk back and forth. Rather than them having to pick up the system ... they could answer you back without having to lift a finger ... You could activate to listen in on a room at night if you needed to ... so it would act like a baby monitor.*²¹

17. Poultney, London, Ont., Feb. 23, 2000.

18. Danny McKeegan, London, Ont., Jan. 12, 2000.

19. Shearing, London, Ont., Feb. 2, 2000.

20. June Sarteretto, London Ont., Jan. 5, 2002.

21. Johnston, St Thomas, Ont., Feb. 16, 2000.

In 1997 the grand move to a new building began as four residents who were living at the old John Gordon Home moved into the Pall Mall Street location. The new home had eight full apartments, each containing kitchens, washrooms, bedrooms, and living rooms. Communication devices were installed in the form of a 'panic button' in the front hall of each apartment for emergencies, and telephones were connected both to the in-house lines and to the residential and long distance network. In order to rectify the mobility problems, an elevator large enough for a hospital stretcher was installed.²² There continued to be a communal kitchen and living room as well as a healing garden available to all residents. Whereas the old John Gordon Home was run on a hospice/communal model, the new home was designed for supportive living. The Ministry of Housing insisted upon separate apartments, which reduced the communal living that had existed in the old home and changed the overall atmosphere.²³ Since the new house was built specifically for people who were living with the HIV virus, there were many improvements from the old house to physically accommodate people who had HIV and AIDS.

The new home was built at an important time during the history of the disease itself, a time when researchers were finding new drug cocktails that enabled people with the virus to live a longer and healthier life. The supportive living model was more practical for the late 1990s because tenants were relatively healthy and able to participate in activities outside the home, including paid employment, attending conferences, gardening, and volunteering in the community.²⁴ Since, the home was "not a place to die any more [but] a place to live,"²⁵ it has become important to provide tenants with increased independence. The traditional family atmosphere, with roasts on Sundays and people calling in if they stay out late, was no longer in effect in the new home. Furthermore, the new house helped to bring in tenants that may not have chosen to live in the communal style housing. Danny recalls:

I went up to the old house for the interview and my idea was 'No, I'm not moving into a house like this because it's just rooms.' I'm 43 years old, I've had a lot of privacy in my life and I said 'No, I don't want to do

22. Shearing, London, Ont., Feb. 2, 2000.

23. Poultney, London, Ont., Feb. 23, 2000.

24. Shearing, London, Ont., Feb. 2, 2000. & McKeegan, London, Ont., Jan. 12, 2000.

25. McKeegan, London, Ont., Jan. 12, 2000.

that. ' And then they showed me [the new house] and I said 'Okay, this is what I want'.²⁶

Other benefits of the new home accrued to the schizophrenics who moved in. They gained a quiet place to themselves for working out their internal struggles. Families who less familiar with gay male culture could be entertained by tenants in their separate apartments. Tenants were able to carry on their intimate life in ways that would not be possible in a communal setting. In communal living spaces, one has to interact with everyone even if personalities may be in conflict. Shearing believes that this is less of an issue in the new house because the structure affords a more independent lifestyle:

Some guys don't want a relationship [with others.] They're just here because they have to be here ... Sometimes it depends on how the illness is affecting you at that time. Because sometimes you can get cranky and nasty because of this illness.²⁷

Poultney concurs with Shearing on this point. In the old house she saw conflict because of communal living that could be avoided in the new apartment style living space:

The fact of the matter is, while people did get along very well, there was also a lot of conflict. You were throwing eight people together that all have a disease that is terminal. That manifests in a lot of different ways [such as attitudes like] 'The only reason I have to sit across from you at the diner table is that you have the same disease as I do, when I would not have paid you any mind in my other life.' ... While I was in the new home, I saw deep friendships start to come between tenants that had not existed in the old place. I think that [independent living] facilitated real friendships to happen, and not just 'getting along'.²⁸

The transition from one house to the other marked a change in the atmosphere that was connected to the ways in which the new medications created healthy individuals. The changed climate had profound effects. Some staff left the institution because they continued to feel a strong connection to the old home as a structure, the old ways of dealing with the disease, and the old atmosphere of the home. Johnston reminisces about the Dufferin street location using the Pall Mall house as an opposition:

26. McKeegan, London, Ont., Jan. 12, 2000.

27. Shearing, London, Ont., Feb. 2, 2000.

28. Poultney, London, Ont., Feb. 23, 2000.

The common room is there [in the new home] and it's nice, but I don't know how much it is used. It's not like a home. I think a lot of us have to get rid of that idea. It's not the same disease, it's not the old John Gordon Home, and I think a lot of people are stuck back there. We loved it so much that we can't even compare the two.²⁹

Poultney makes a similar statement of reminiscence, recognizing its idealization:

The people who created John Gordon Home and its initial dream have felt that there is that loss of hominess. Some of the comments have been that 'You used to walk into the old John Gordon Home and there was the smell of cookies cooking in the oven' ... I am not sure that some of those things were not just a symbol that pointed to ... a kind of living together that may not have actually existed. I think it was a bit of a dream.³⁰

Many of the staff and volunteers of the 'initial dream' found the transition to the new house with the new manifestations of wellness in the tenants to be a difficult adjustment. Furthermore, the move to the new house marked a second restructuring in staff and volunteer roles. For example, Sarteretto recalls that "in the old John Gordon Home, without the volunteers we would never have made it. They could do almost anything. They were right in the nitty gritty work with [the staff]."³¹ In the old home Johnston had the volunteers doing "everything from helping with meds, to changing beds, to changing [diapers], to cleaning, to cooking."³²

In the new home, policies were implemented that restricted the roles of the volunteers. They were no longer required to be trained in and to administer intravenous treatments, and were denied access to the 'care binders' of the tenants which documented the aspects of the disease that each resident experienced.³³ These administrative changes as well as the new manifestations of the disease sparked volunteer and staff turnover.

For some people, they were very clear about what they had come to do, which was to provide palliative care and care for the dying. For those people, when people weren't dying any more, it was time to go.³⁴

29. Johnston, St Thomas, Ont., Feb. 16, 2000.

30. Poultney, London, Ont., Feb. 23, 2000.

31. Sarteretto, London Ont., Jan. 5, 2000.

32. Johnston, St Thomas, Ont., Feb. 16, 2000.

33. Poultney, London, Ont., Feb. 23, 2000.

34. *Ibid.*

Other staff and volunteers struggled with the shift from palliative care to other forms of care. Johnston gave a revealing statement about how it felt for the team to adjust to the new situation:

Staff's reaction, whether they would admit it or not, is they feel useless, they feel like they don't have a purpose any longer. People who are in palliative care are a strange breed. They are there because they want to be, they know that they are good at it. It takes a special person to do it ... When people are caring for those who are dying, you feel like you're doing something, you feel like you're needed. And when that trend stopped, you had the same people in the same role performing different jobs. It was a very different switch ... If you're not feeling like you're being useful you may have frustration, you may have boredom. And from boredom you get bitchiness, you bicker back and forth, you find fault in the little things ... On top of the multiple loss that you experience, ... the loss of the tenants in the house, ... you're losing your role ... so you've got a lot of grief.³⁵

The new staff and volunteers who came into the home brought very different job expectations than had the older members of the team. They are more prepared to do administrative work, and have different understandings of the systems of interaction between staff and tenants.³⁶ For example, the team that interacted with terminally ill tenants, Poultney said,

were used to having a six to eight hour shift there. They were quite busy and they were providing care to a number of different people. And then they were coming to the home ... and tenants were all out, or they did not want to see you, or you certainly did not have a requirement to provide care. For many volunteers, that's not what they wanted to volunteer their time doing ... Some shifted and decided to take tenants for groceries, or go on outings.³⁷

Occasionally former volunteers found it difficult now to deal with some aspects of the tenants such as schizophrenia. This manifested itself in more obvious ways when tenants became healthy:

I remember one person saying 'I came to provide palliative care, I didn't come to provide mental health care' ... That psycho-social component was growing. It was always present, but when someone is actively dying, there is bigger things to focus on, whereas when they're trying to figure

35. Johnston, St Thomas, Ont., Feb. 16, 2000.

36. Sarteretto, London Ont., Jan. 5, 2000.

37. Poultney, London, Ont., Feb. 23, 2000.

*out how they are going to live their twenty-four hour regular day life, the psycho-social issues manifest more. Some of the staff said "I'm not going to do this. I'm going to leave." Others struggled with the change, trying to understand, trying to learn new skills, trying to stay because they were very committed to the organization, or the people.*³⁸

On the heels of the change in location, change in tenant health, administrative changes, and volunteer and staff turnover, in 1998 the Executive Director, Sam Conti, died of complications during surgery.³⁹ Many of the tenants and staff thus lost someone very close to them and they experienced an immense amount of grief.⁴⁰ Shearing remembers the feeling of paralysis that the tenants in the home felt when the Executive Director passed away so suddenly, "When Sam died it was just -- stop! Nobody knew what to do and nobody wanted to take that step ... when Sam died it was a major shock to everyone."⁴¹

Johnston and Poultney took over as co-acting Executive Directors. This created further stress on staff and tenants because two of the integral administrators were working overtime. Johnston and Poultney were stretched to their limits at a time when the tenants and staff needed their active support. Poultney remembers that the Board of Directors was very concerned about the upheaval that Conti's death was causing in the home:

*The Board, being one step out, knew that they wanted things to function in a particular way and they wanted to make sure that things continued to function. When they saw the staff grieving as emotively as they were, some of them wanted [to] ... 'Tell them to get better, to get over it, and move on' ... I [had] staff saying 'How do I function, I've just lost ... one of [my] best friends' ... And so you were balancing between two very different understandings of the situation.*⁴²

Johnston recalls the stress that she felt, having so many responsibilities:

*I had very little time for staff, very little time for tenants ... I was pulled in too many directions. I did not have the time I needed to support the staff and the tenants.*⁴³

38. Poultney, London, Ont., Feb. 23, 2000.

39. *London Free Press*, Feb. 17, 1998.

40. Johnston, St Thomas, Ont., Feb. 16, 2000.

41. Shearing, London, Ont., Feb. 2, 2000.

42. Poultney, London, Ont., Feb. 23, 2000.

43. Johnston, St Thomas, Ont., Feb. 16, 2000.

Eight months after she became co-acting Executive Director, in 1998 Johnston left the John Gordon Home for a job with the Victorian Order of Nurses. The home was reorganized administratively. This integrated Poultney's job as Manager of Finance and Administration and Johnston's job as Home Coordinator into other positions. Poultney stayed on as acting Executive Director until Eric Dow was hired as the new Director. Since Poultney could no longer return to her original position, she moved on to pursue new directions.

This history of the John Gordon Home delineates some of the changing aspects of living with HIV and AIDS and how those infected are being dealt with on a practical level. Over the years between 1992 and 2000, the change from palliative to healthy tenants precipitated a change in the physical setting needed to accommodate different levels of care of those living with HIV, and created a disjuncture for care givers when the parameters of care began to change. Canada now has experienced some twenty years of response to HIV and AIDS. For the last ten years, the John Gordon Home has been an integral part of making the loss more bearable to those afflicted and the people who support them. To this day, homosexuals who are affected by the disease may be ostracized by their families and the outside community. The John Gordon Home continues to provide a sense of family, dignity, and comfort to men and women who are living with, and dying of the virus. Documenting this work by means of oral history enables us to understand the complex and varied layers of experience which comprise the changing responses to this illness.