

hospitalized in CAMH and that she had taken along gifts and spent time with the patient. Staff praised her for her kindness and told her that an empty person would not be able to give as she was giving. But there is such fragility there.

What we count success comes in unexpected ways, not always planned. One resident is often in another world, not engaging with anyone because the furious activity in her head is totally absorbing her attention. Distressed at seeing a once very active achiever spend hours sitting motionless staring off into space, her family wanted to find some activity that would engage her and bring her some enjoyment. Her mother would visit and mention an activity that they might do together. If there was a little spark of interest, she would gently fan the flame as they planned the activity together. Date and time would be set but when it came time to participate, the daughter had completely lost interest and refused to have anything to do with the activity. Her disappointed but persevering mother would propose another activity, hoping that she would find one that would give her daughter pleasure. They would plan another outing together but again, when it came time to go, her daughter was apathetic. Finally, when mother told her son of the frustration she was feeling because she couldn't find just the right activity to engage her daughter and bring her some enjoyment, he had an insightful comment, "But mom, it is the planning that brings her the most enjoyment."

There are other stories which clearly illustrate why our residents require a lot of high level support. There are stories that expose much fragility. There are stories that reveal staff members to be knowledgeable and understanding, insightful and sometimes ingenious in response. There are also stories of fun times, peaceful times and of happy moments breaking through stress and anxiety. Staff will tell you that House of Compassion is a good place to work and that our residents are courageous people that we are privileged to support. Our residents manage to live in the community and stay out of hospital for long periods, and that fulfill our expectations wonderfully.

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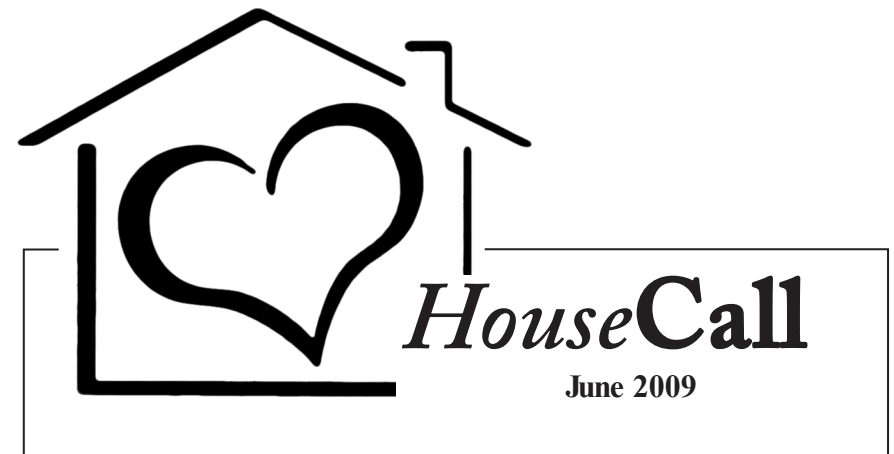


HouseCall is the newsletter of the HOUSE OF COMPASSION of Toronto, a ministry founded on Christian values, providing high level supportive housing to residents with severe mental illness in need of a caring and secure home.

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**“For God alone my soul waits in silence for my hope [expectation] is from him.” Psalm 62:5**

## EXPECTATIONS

“Expectations” is a term used by case managers who are trying to find suitable housing and programs for their clients with mental illness. When we ask why case managers or families choose to apply to House of Compassion for their clients, the answer is because “your expectations are low” and “your compassion is high”. These two are tightly bound together at House of Compassion. Too high expectations can be harmful in that they set people up for failure. Expectations that are imposed become rules. We prefer to adjust our expectations in order to work with our residents helping them achieve their “personal best” in wellness. Staff at House of Compassion try to be accepting, not judgmental.

“Recovery” is the explicit goal of every funded mental health program. Recovery embraces hope, not hopelessness, in the acceptance of mental illness. But recovery is also individually defined. For those with severe and persistent mental illness recovery may mean adjusting to community living after a long stay in hospital and requiring a high level of support to do so. High supports are needed for the resident to stay in the community and out of hospital.

“High level supportive housing” refers to dedicated housing for people with severe and persistent mental illness. High supports by definition includes trained staff present on a 24/7 basis, support for medical regimens, particularly taking medications regularly, and support for the activities of daily living. While these supports consume a fair bit of time, staff trained in psychosocial rehabilitation spend hours devoted to counseling, listening, encouraging and reassuring. House of Compassion provides high level supportive housing for twenty-one residents. There is a very long waiting list for any vacancy because there are far more people requiring housing with high supports than there are units in the GTA.

It is important to understand that, while our expectations are adjusted to match the gravity of the illness, our program is rooted in hope and a positive attitude. Together with our residents, our aim is to keep our residents in the community and out of hospital. Overall, we succeed in achieving this shared goal.

One resident has lived with us for nearly twenty years, another for eighteen. We want our residents to consider their place in HOC to be a home in every sense of that rich word. These two residents, along with one or two others, have now reached that age that officially defines them as seniors. Our program is adapting to fit in with the new Aging In Place strategy, through which seniors are provided with extra supports to enable them to remain in their homes rather than moving into long term care.

Along with realistic expectations, we do encourage achieving more personal goals. One of our long term residents did “move on” to a more independent-living environment. But, without high level supports the independence was too stressful and the resident returned to HOC. The resident blamed the setback on the lack of company, on being alone. Two factors that need to be considered are that mental illness is not improved through the changes aging imposes and that isolation is not conducive to mental health.

Some programs stress training or retraining with a goal of employment, but it is not always a lack of training that prevents our residents being employable. Some of our residents are highly trained, university graduates. One is a university graduate in commerce, a chartered accountant, who once held a prestigious job with a major bank until the illness became so severe that it was no longer possible to function. Another resident has a university degree and was a group leader on campus. After graduation, this resident with many skills started a business which flourished. But the illness manifested itself and progressed to the point where it was impossible to continue working or living independently, and finally the entrepreneur was placed under guardianship. Several other residents have impressive resumés and work histories. Their inability to pursue a career now is not a matter of training; it is directly related to the severity of the illness.

For some residents the illness interrupted education and training when they were in their teens and they are unprepared for skilled work. Currently, only one of our residents is gainfully employed, working in a sheltered workplace. But stress takes its toll and the resident frequently returns home agitated, taking frustration out on doors and furniture. Another resident, formerly living in housing which required each resident to be out of the house during working hours, left the house each day and returned home each night at the appointed time. However, instead of attending the program, the resident was walking the streets in all kinds of weather for hours on end, endangering health and risking personal safety. Some residents are engaged in programs which take up the hours of a normal work day. Several are involved in peer support clubhouses.

Residents know working earns wages and they certainly need spending money as none has much left over after living expenses are covered. One resident, who has the least pocket money, was glad of our offer to pay to have the garbage taken out regularly. He did it once. When asked a second time, he walked away sadly saying he just “couldn’t” do it. It isn’t a question of willingness to work; some mourn the loss of the working life they once had.

Similarly our program supports the activities of daily living, such as regular meals. Again, it isn’t that residents do not know how to cook, clean house, manage personal care, maintain a schedule – many were homemakers in their earlier life and some were caregivers, looking after a family member. But illness has interfered with these skills. More than one resident has been referred by case managers to our program because they “forget” to eat regularly, “forget” to take medications and “forget” to care for themselves. Again expectations have to be adjusted to meet reality.

Each resident is different with very different needs, although the official diagnosis is similar. One is very chatty, a compulsive attention grabber, argumentative and picking fights with everybody; it takes an enormous amount of time to deal with this resident, to calm and to halt the compulsive non-stop talking and the constant changing of direction. Another is extremely anxious and needs much reassurance that she can continue to live with us. Another obsesses about a diabetes diagnosis, certain that the outcome will be amputation of feet, and that the diabetes is “stalking him to kill him”. Staff have to beg him to eat as his health is compromised.

Several residents are delusional. One, who can present as very poised and has beautiful manners making her a delight to chat with for a few minutes, has the delusion that a friend who was in the army and who recently died, has passed on to her the responsibility of being a peacekeeper, and that she is supposed to be a peacekeeper in Toronto’s streets. However, this means she must “fight” in the streets to fulfill her duties as peacekeeper and she “can’t do that” and that is her dilemma. Another spends almost all of his pin money on flowers to lessen his guilt for causing the deaths of two major figures in the public domain, deaths he firmly believes he is responsible for.

We have a resident whose illness manifests itself in an inability to move from one place to another. He takes ten steps forward, then must return and start all over from the starting place. It takes him several tries to come downstairs from his bedroom every morning and sometimes he gets stuck in the middle. Occasionally he is found in the middle of a room unable to move out of the way for some time. One time he was heard on the porch outside the front door, cursing at the door, saying, “Why do you do this to me? You know you’re blocking my way.” Staff opened the screened door which he couldn’t do for himself.

Our residents tell us in their own words what it is like some days coping with mental illness. One resident came down one day late in the morning in a dressing gown. She looked very sad and drained. A sympathetic staff member initiated a conversation. The resident had got up out of bed and drawn a bath. But at that point all energy left her. She couldn’t muster enough to take the bath and dress. Her own words are evocative. She described herself as “empty inside” and “hollow” as if there was “nothing there”. She “felt like she had been murdered and her soul sucked out of her”. She despaired that she couldn’t even manage to take a bath. After some comforting time spent with a staff member, she acknowledged that at least she had been able to get out of bed and that was an accomplishment. She said “it was God who had helped her to get up”. This thought was therapeutic and she was able to return to her bedroom and get dressed.

Another time when she spoke again of her emptiness and having nothing in herself to give, staff reminded her that she had recently visited a relative who was